GENETIC PRIVACY
A LEGAL PERSPECTIVE

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I declare that this work is my own.

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CONTENTS

CONTENTS

CHAPTER ONE
HEALTH CARE, PATIENT RIGHTS AND PRIVACY

CHAPTER TWO
HUMAN GENETICS AND GENETIC PRIVACY

CHAPTER THREE
AUTONOMY AND GENETIC INFORMATION

CHAPTER FOUR
CONFIDENTIALITY AND GENETIC INFORMATION

CHAPTER FIVE
PRIVACY AND GENETIC INFORMATION

CHAPTER SIX
CONCLUSION

INTRODUCTION

GENETIC PRIVACY: A LEGAL PERSPECTIVE

INTRODUCTION

This thesis examines the concept of 'genetic privacy'; that is, the privacy interests which surround genetic information. The work is set in the context of the wider debate about the function and value of privacy *in se.* The application of privacy to the field of genetics reveals a plethora of interests which are currently under-protected by the law. An argument is made herein for the legal recognition and protection of such privacy interests. The thesis proceeds in the following manner.

- Chapter one establishes the parameters for the work and gives a brief account of the rise in concern about privacy protection in western states. It is argued that with the establishment of the so-called western liberal tradition one can see the beginnings of a role for privacy in society. As that tradition has grown and developed so too has the need and function of privacy. In this chapter a further parallel is drawn between the role of privacy generally and the role which it plays in the health care context. At this stage a tentative definition of privacy is offered which consists of two elements: (i) *informational privacy,* which concerns issues of access and control surrounding personal health information, and (ii) *spatial privacy* which concerns issues of access to the 'person' or 'self' and control of one's own personal sphere of life. To illustrate these two senses of privacy examples are drawn from the discipline of medical law, and in particular from the problem of the patient in persistent vegetative state (PVS).

- Chapter two involves a discussion of the current knowledge concerning genetic information and the current uses to which genetic information can be put. An account is also given of the nature of genetic disease. The focus of this chapter is the identification of the range of interests which individuals, families, employers, insurers and the state might have in genetic information. Also, as a means of providing a useful mechanism for discussing the problematic issues which surround this topic, this chapter outlines four case scenarios which will be used in subsequent chapters to examine the efficacy of various legal means which could be used to protect privacy interests in genetic information.

- Chapter three concerns the principle of respect for autonomy and considers this principle from both the ethical and legal perspective. The current legal position on the protection of patient autonomy in the United Kingdom is examined and the principle as so understood is applied to the genetic information case scenarios to test the efficacy of this area of law in addressing the issues raised.

- Chapter four adopts the same approach as chapter three, this time using the concept of confidentiality, as it is understood in professional, ethical and legal terms. Again, this chapter concludes with an application of the concept under scrutiny to the case scenarios.

- Chapter five draws together the prior arguments and seeks to mount a defence of the view of privacy advanced in this work. The chapter begins with an account of the public/private distinction - which is crucial to an understanding of the privacy debate - and goes on to review the current literature on the nature, value and scope of privacy as a social construct in western culture. Examples are drawn from the United States where legal protection of privacy has been accorded both at the level of the common law and the Constitution. In keeping with the overall structure of the thesis, the chapter culminates in an assessment of the success with which privacy as defined can address the problems raised by the case scenarios.

- Finally, in chapter six the thesis is brought to a conclusion. It is argued that the law could be used to protect the range of interests which have been discussed by recognising and developing a right to (genetic) privacy. An account is given of the various means by which such a right could be introduced and comment is made on the possible efficacy of such an approach. The chapter also considers a less interventionist role for the law in establishing an appropriate 'care ethic' for professionals who deal in personal genetic information.

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CHAPTER ONE

HEALTH CARE, PATIENT RIGHTS AND PRIVACY

1.1 - INTRODUCTION

Privacy is a problem. Or rather, privacy causes problems. It causes problems for sociologists[1], psychologists[2], anthropologists[3], philosophers[4], politicians[5], doctors[6], lawyers[7], governments[8], states[9], communities[10], groups[11] and individuals[12]. The problems

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[1] Benn, S.I. and Gaus, G.F. (eds.); "Public and Private in Social Life" , London, Crook Helm and St. Martin's Press, 1983.

[2] See, Goffman, E.; 'The Presentation of Self in Everyday Life', London, Pelican Books, 1971, Ingham, R.; 'Privacy and Psychology', in Young, J.D. (ed.); 'Privacy', Chichester, Wiley & Sons, 1979, chapter 2, Jouard, S.M.; 'Some Psychological Aspects of Privacy', 31, *Law and Contemporary Problems*, 307, 1966, Kelvin, P.A.; 'Social Psychological Examination of Privacy', 12, *British Journal of Social and Clinical Psychology*, 248, 1973, Margulis, S.T. (ed.); 'Privacy as a Behavioural Phenomenon', 33, *Journal of Social Issues*, No.3, 1977.

[3] See, Moore, B. Jr.; 'Privacy', New York, M.E. Sharpe Inc., 1984, Murphy, R.F.; 'Social Distance and the Veil', 6(1), *American Anthropologist*, 1257, 1964, and Westin, A.; 'The Origins of Modern Claims to Privacy', in Schoeman, F. D.; 'Philospohical Dimensions of Privacy', Cambridge, Cambridge University Press, 1984, at pp. 56 - 74, Arendt, H.; 'The Human Condition', Chicago, University of Chicago Press, 1958.

[4] Kupfer, J.; 'Privacy, Autonomy and Self Concept', 24, *American Philosophical Quarterly*, 81, 1987, Negley, G.; 'Philosophical Views on the Value of Privacy', 31, 2, *Law and Contemporary Problems*, 319, 1966, Reiman, J.H.; 'Privacy, Intimacy and Personhood', 6, *Philosophy and Public Affairs*, 26, 1976, and generally, Schoeman, F. (ed.); 'Philosophical Dimensions of Privacy : An Anthology', Cambridge, Cambridge University Press, 1984.

[5] See, Ames, J.; 'Privacy Law Forced Back on the Agenda', 89(6), *Law Society's Gazette*, 8, 1992.

[6] Berg, K.; 'Confidentiality Issues in Medical Genetics: The Need for Laws, Rules and Good Practices to Secure Optimal Disease Control', Second Symposium of the Council of Europe on Bioethics, Strasbourg, 30 November - 2 December 1993, CDBI-SY-SP (93) 3, Boyd, K.M.; 'HIV Infection and AIDS: The Ethics of Medical Confidentiality', 18, *Journal of Medical Ethics*, 173, 1992, Wertz, D.C. and Fletcher, J.C.; 'Privacy and Disclosure in Medical Genetics Examined in an Ethics of Care', 5(3), *Bioethics*, 212, 1991, Dworkin, G.; 'Access to Medical Records: Discovery, Confidentiality and Privacy',42, *Modern Law Review*, 88, 1979, and Cantrell, T.; 'Privacy: The Medical Problems', in Young, *op. cit.*, chapter 9.

[7] For example, Dworkin, G.; 'Privacy and the Law', in Young, J.B. (ed.); 'Privacy', Chichester, Wiley & Sons, 1979, chapter 5, Gavison, R.; 'Privacy and the Limits of the Law', 89(3), *Yale Law Review*, 421, 1980, Markesinis, B.S.; 'Our Patchy Law of Privacy - Time to do Something about it', 53(6), *Modern Law Review*, 802, 1990, Parent, W.A.; 'A New Definition for Privacy for the Law', 2, *Law and Philosophy*, 305, 1983, Prosser, W.L.; 'Privacy : A Legal Analysis', 48, *California Law Review*, 338, 1960, Wacks, R.; 'Personal Information, Privacy and the Law', Oxford, Clarendon Press, 1989, Warren S.D. and Brandeis, L.D.; 'The Right to Privacy', 4, *Harvard Law Review*, 193, 1890-91.

[8] See, Hixson, R.F.; 'Privacy in a Public Society', New York, Oxford University Press, 1987, Gould, J.P.; 'Privacy and the Economics of Information', 9, *Journal of Legal Studies*, 827, 1980, Mellors, C.; 'Governments and the Individual : Their Secrecy and his Privacy', in Young, J.B. (ed.); 'Privacy', Chichester, Wiley & Sons, 1979, at p.87, Handler, J.F. and Rosenheim, M.K.; 'Privacy in Welfare: Public Assistance and Juvenile Justice', 31(2), *Law and Contemporary Problems*, 377, 1966 and Creech, W.A.; 'The Privacy of Government Employees', 31(2), *Law and Contemporary Problems*, 413, 1966.

[9] See, for example, Article 8 of the European Convention for the Protection of Human Rights and Article 12 of the Universal Declaration of Human Rights, both of which provide for the protection of personal privacy. For comment on the former see, Loucaides, L.G.; 'Personality and Privacy Under the European Convention on Human Rights', 61, *British Yearbook of International Law*, 175, 1990.

[10] As Westin has commented, '[n]eeds for individual and group privacy and resulting social norms are present in virtually every society. Encompassing a vast range of activities. these needs affect basic ares of life for the individual, the intimate family group, and the community as a whole.', see Westin, A.; 'Privacy and Freedom', London, The Bodley Head, 1967, at 13.

which it causes relate to its definition[13], its function[14], its nature[15], its utility[16], its value[17] and its protection[18].

In this work some of these problems will be addressed. The subject matter will be approached from the perspective of the law, and therefore the focus of the work will be on the protection of privacy by legal means. However, because the scope of privacy is so wide-ranging no attempt can be made to analyse the concept in all of its many facets and guises. Considerable narrowing of focus is required. The focus which has been chosen for this thesis is the role of privacy in a health care setting: it will examine patient privacy and the

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[11] Schoeman, F.D.; 'Adolescent Confidentiality and Family Privacy', in Graham, G. and LaFollette, H., (eds.); 'Person to Person', Philadelphia, Temple University Press, 1989, at 213 - 234, Walden, I.N. and Savage, R.N.; 'Data Protection and Privacy Laws: Should Organisations Be Protected?' , 37, *International and Comparative Law Quarterly,* 337, 1988, Creech, *loc. cit.*

[12] Blom-Cooper, L.; 'The Right to be Let Alone', 10(2), *Journal of Media Law and Practice*, 53, 1989, Kupfer, J.; 'Privacy, Autonomy and Self Concept', 24, *American Philosophical Quarterly,* 81, 1987, Benn, S.I.; 'Privacy, Freedom and Respect for Persons' in Schoeman, 'Philosophical Dimensions of Privacy', *op. cit.*, Gavison, 'Privacy and the Limits of Law', loc. cit., Gross, H.; 'Privacy and Autonomy', in Feinberg, J. and Gross, H.; 'Philosophy of Law', Second Edition, USA, Wadsworth Inc., 1980, Henkin, L.; 'Privacy and Autonomy', 74, *Columbia Law Review*, 1410, 1974, Fried, 'Privacy', 77, *Yale Law Journal*, 475, 1968.

[13] Parent, W.A.; 'A New Definition for Privacy for the Law', 2, *Law and Philosophy*, 305, 1983, Parent, W.A.; 'Recent Work on the Concept of Privacy', 20(4), *American Philosophical Quarterly,* 341, 1993, Gavison, Privacy and the Limits of Law', *loc. cit.*, Posner, R.A.; 'The Right to Privacy', 12, *Georgia Law Review*, 393, 1978, McCormick, D.N.; 'Privacy: A Problem of Definition', 1, *British Journal of Law and Society*, 75, 1974, Fried, 'Privacy', *loc. cit.*

[14] Innes, J.C.; 'Privacy, Intimacy and Isolation', New York, Oxford University Press, 1992, Benn, S.I.; 'Privacy, Freedom and Respect for Persons' in Schoeman, 'Philosophical Dimensions of Privacy', *op. cit.*, Gavison, Privacy and the Limits of Law', *loc. cit.*, Fried, 'Privacy', *loc. cit.*, Murphy, 'Social Distance and the Veil', *loc. cit.*

[15] Much debate centres around the philosophical nature of privacy. Is it a right, a claim, an interest, and issue of control or a state of being? For a discussion of the possibilities and a review of the literature, see Schoeman, 'Philosophical Dimensions of Privacy: An Anthology', *op. cit.*, chapter one.

[16] Reiman, J.H.; 'Privacy, Intimacy and Personhood', 6, *Philosophy and Public Affairs*, 26, 1976, Rachels, J.; 'Why Privacy Is Important', 4, *Philosophy and Public Affairs*, 323, 1975, Thomson, J.J.; 'The Right to Privacy', 4, *Philosophy and Public Affairs*, 295, 1975, Scanlon, T.; 'Thomson on Privacy', 4, *Philosophy and Public Affairs*, 315, 1975.

[17] Wacks, 'Personal Information, Privacy and the Law', *op. cit.*, Hixson, *op. cit.*, Thomson, ibid, Scanlon, ibid, and Negley, 'Philosophical Views on the Value of Privacy', *loc. cit.*

[18] This issue has given rise to much concern recently in the United Kingdom. Over the past thirty years there have been six attempts to introduce some form of legislation to protect privacy. None has succeeded. Furthermore, several committees have been established to examine the matter and report: in 1972 the Younger Committee (*Report of the Committee on Privacy, Cmnd 5012*), in 1990 the Calcutt Committee (*Report of the Committee on Privacy and Related Matters, Cm 1102*) and in 1993, Calcutt re-examined the question of privacy legislation and recommmended Parliamentary intervention (*Review of Press Regulation, Cm 2135).* As a direct result of the latter, the Lord Chancellor's Department, in association with the Scottish Office, produced a consultation paper entitled *Infringement of Privacy* in July 1993 inviting comment on the possible nature and content of a civil remedy for infringement of privacy in the UK. To date, no further action has been taken.

interface between medicine and law in the protection of individual rights in the provision of health care. More particularly, this work concentrates on the privacy issues raised by what has been termed the 'New Genetics'. The advent of genetics and genetic testing has given rise to unique problems in the health care setting. The discovery of a predisposition to a genetic condition in one individual also reveals information about the genetic make-up and potential risks to family members. There is, therefore, potential for conflict over access to and control of such information. Traditionally, the duty of confidentiality owed by a health care professional to a patient has provided an appropriate means by which personal health information has been secured. It is not clear, however, that the problems which surround genetic information in the familial milieu can be adequately dealt with using confidentiality. Furthermore, the principle of respect for patient autonomy - which has been described as the guiding ethical principle in health care and which has more recently received legal sanction by the UK and US courts - is similarly ill-equipped to provided a satisfactory solution to the problems posed by family genetic information. This thesis examines these problems and argues for the value of an appeal to the concept of privacy in seeking to resolve some of the more intractable issues.

1.2 - Establishing Parameters

It is necessary in this first chapter to establish parameters within which this work will be set. In particular, it is necessary to establish a context for the discussion of privacy and a justification for its treatment from the legal perspective.

It is submitted that the search for the essential character of the concept of privacy centres around the search for a means to establish an identifiable and sustainable interface between the public and private spheres of human life[19]. Furthermore, because human life does not exist in a vacuum but in a human society, it is submitted that privacy is also concerned with

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[19] See generally, Benn and Gaus, Public and Private in Social Life, *op. cit.*

regulation of the relationship between an individual and the society in which s/he lives[20]. Indeed, the two concepts of 'individual' and 'society' are inextricably linked - the definition of one provides, almost by analogy, the definition of the other. For example, Giddens defines a *society* as,

> '...a cluster, or system, of institutionalised modes of conduct. To speak of 'institutionalised' forms of social conduct is to refer to modes of belief and behaviour that occur and recur - or, as the terminology of modern social theory would have it, are socially *reproduced* - across long spans of time and space.'[21]

Yet, he is of the opinion that,

> 'societies only exist in so far as they are created and re-created in our actions as human beings. In social theory we cannot treat human activities as though they were determined by causes in the same way as natural events are. We have to grasp what I would call the *double involvement* of individuals and institutions: we create society as we are created by it.'[22]

For the purposes of this thesis, the treatment of the concept of privacy will be conducted in the context of the individual/society relationship in a western liberal democracy. It is necessary to make a choice about a particular contextual setting because privacy *per se* is simply an abstract concept. It requires a context in order to give it meaning because its function changes according to how we define the notions of 'individual' and 'society'[23]. A

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[20] See, Wacks, R.; 'Personal Information, Privacy and the Law', *op. cit.*, at 7, and Tomlinson, P.J.; 'Privacy and Law Enforcement', in Young, 'Privacy', *op. cit.*, chapter 6.

[21] Giddens, A.; 'Sociology : A Brief But Critical Introduction', Second Edition, London, MacMillan Press, 1986, at 8. Social systems he defines as, '[involving] patterns of relationships among individuals and groups.' at 12.

[22] *ibid*, at 11.

[23] For a study of the role of privacy in a range of different societies such as Classical Athens, the times of the Old Testament and Ancient China, see. Moore, B.; 'Privacy: Studies in Social and Cultural History', *op. cit.* It has been claimed that today in China the concept of privacy is an anathema to the populous: '[w]hen Victor Sidel, a physician well known for his national and international work in public health, visited the People's Republic of China some years ago, he encountered common public-health practices that required people to reveal highly personal information, which was then posted in a public place. Sidel asked, "Don't people consider this an invasion of their privacy?" and his Chinese interpreter could not translate the question. The Chinese language apparently lacked a concept of privacy in the sense that makes it an ethical value in Western society.', see, Macklin, R.; 'Privacy and Control of Genetic Information', in Annas, G.J. and Elias, S.; 'Gene Mapping: Using Law and Ethics as Guides', New York, Oxford University Press, 1992, chapter 9, at 157. Similarly, Ketcham notes that, '...while in the West there is great value placed on [the] lonely sense of

desire for privacy is a bi-product of our social organisation. It is necessary therefore to choose a particular conception of 'society' or the 'individual', each with its corresponding adjunct, in order to analyse privacy in a meaningful way. The reasons why the model chosen is that of the western liberal democracy are outlined below[24].

2.1 - PRIVACY AND THE WESTERN LIBERAL TRADITION

The western liberal tradition - with its central tenets of democracy and a commitment to individualism - is a phenomenon which is unprecedented in human history. Its origins can be traced to events which took place only a few centuries ago, yet the effects which its ethos has had on human beings and human societies is remarkable. This is especially true of the effect on the function and perceived value of privacy. The origins of modern claims to privacy are found in the same epoch as the origins of this liberal tradition[25] and with the rise of individualism can be witnessed a rise in concern for personal privacy[26]. Thus, to a certain extent, the development of the western liberal democracy has been parallelled by the increase in importance of the role of privacy in the lives of those individuals who, together, constitute such a society. To set this thesis in such a context, therefore, provides valuable insight both into the concept of privacy as well as aspects of liberal societies[27].

"private space," it is a concept uncherished and scarcely even recognised as existent by Japanese.', see Ketcham. R. 'Individualism and Public Life', New York, Basil Blackwell, 1987, at 113. Moore, *ibid*, posits that 'a desire for privacy [is] a panhuman trait', at 276. He notes, however, that, '...privacy is minimal where technology and social organization are minimal.', *ibid*.

[24] Benn, 'A Theory of Freedom', New York, Cambridge University Press, 1988, notes, '[t]he judgements we make about our privacy arrangements must take the rest of our cultural ideals largely as we find them. Individuals like ourselves in our kind of culture [western liberal democracy], then, do have an interest in privacy in the management of the internal economy of their own personalities and of their personal relations with others', at 287.

[25] See, for example, Westin, 'Privacy and Freedom', *op. cit.*, chapter one. This is reproduced in Schoeman, F.D. (ed.); 'Philosophical Dimensions of Privacy: An Anthology', *op. cit.*, at 56 - 74.

[26] See Vincent, G.; 'A History of Secrets?', in Prost, A. and Vincent, G. (eds.); 'A History of Private Life', Volume 5, London, Belknap Press, 1991, at 147 - 149, wherein he discusses the totalitarian regime and its view of privacy. As he states, 'In a totalitarian regime all barriers between private life and public life seem to be broken down.' He rejects the view, however, that there is no room for, or desire for, privacy in such a society.

[27] For a discussion of privacy in primitive societies, see Westin, A.F.; 'Privacy and Freedom', *op. cit.*, at 11 - 22.

2.2 - The History of Privacy and the Western Liberal Tradition

The eighteenth and nineteenth centuries represented a time of great turmoil and great change in human history. In particular, two events proved to be instrumental in the establishment of the liberal tradition which is now so prevalent in the modern world. These two events were two revolutions : the French Revolution which brought sweeping political change and the Industrial Revolution which acted as the catalyst for world-wide socio-economic change. Together they altered incontrovertibly the course of humankind.

2.2.1 - *The Renaissance, The Reformation and the 'Age of Reason' - the Fomenters of 1789*

The French Revolution of 1789 resulted from the culmination of many factors borne out of an era of which the Revolution signals the end point[28]. That period of history, which can loosely be referred to as the late Middle Ages, saw the advent of the Renaissance and the Reformation; in themselves periods of considerable turmoil and declension. The Renaissance was a time of challenge and change when originality of thought became prevalent and old traditions and institutions began to be questioned. In particular, religious dogma was openly disputed and intellectual freedom actively encouraged. This laid the way for the Europe-wide rejection of Catholic idolatry by the Protestant Reformation[29]. At that time, the influence of the churches both in relation to matters of the state and the lives of

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[28] See Kelly, J.M.; 'A Short History of Western Legal Theory', Oxford, Clarendon Press, 1992, who traces the development of western legal and political thought from the times of the Greeks and Romans, through the Middle Ages (1100-1350), the Renaissance and Reformation (1350 - 1600) and beyond to the later Twentieth century. See also, Goodman, E.; 'The Origins of the Western Legal Tradition: From Thales to the Tudors', Sydney, The Federation Press, 1995.

[29] Kelly, *ibid.*, states, 'It is worth...noting...that the general psychological and social connection between the ethos of Protestantism, with its emphasis on the individual's direct relationship and answerability to God, and the rise modern capitalist enterprise, is thought to be well established; the link, roughly speaking, is supposed to lie in the idea that God's favour, the outward mark of his "election" of an individual for salvation, will be visible in material prosperity here on earth; this transmutes subtly into the idea that God's favour attaches to whatever efforts the individual will make to bring prosperity about: God helps those who help themselves.', at 167 - 168. He cites, Weber, M.; 'The Protestant Ethic and the Spirit of Capitalism', translation Parsons, T. (London 1976), and Tawney, R.H.; 'Religion and the Rise of Capitalism', (London, 1926).

individuals were far greater than they are today[30]. Transformation in the churches therefore meant direct transformation of many aspects of social life; religious *and* secular. Stone, for example, argues that the collapse of Puritanism in England in the late seventeenth century left a number of essential - if unintended - legacies for the more secular society that succeeded it[31]. He contends that,

> 'respect for the individual conscience directed by God was one element of Puritanism...that survived to help create not only the desire to provide religious toleration for 'tender consciences', but also to induce a respect for personal autonomy in other aspects of life.'[32]

Of the development of this 'toleration' he says,

> 'It was the reaction to the excesses of Puritanism, however, which provided other important contributions to the trend towards individual autonomy. One was the eighteenth century hostility to 'enthusiasm' of all kinds and the consequent growth of a willingness to tolerate most forms of Christian sectarianism provided they did not disturb the public peace. When toleration at last became a positive virtue, a great step had been taken in the direction of autonomy.'[33]

This is but one example of how, in conjunction, the Reformation and the Renaissance provided an 'openness of spirit', both in intellectual and ecclesiastical terms, which proved to be wholly conducive to the changes to come. As Barber has noted,

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[30] Kelly comments, however, that about the year 1100, the concepts of state and church began to emerge as separate entities, with separate, although connected, spheres of operation. No longer were they viewed as 'simply two aspects' of the same unity, *ibid*, at 123 - 128. The result of this was that a need arose for philosophical and spiritual justification of the state as a separate entity. The first 'decisive step' towards providing this came from St Thomas Aquinas who, arguably, came to be one of the forefathers of modern legal and political theory, at 124 - 126. St Thomas 'fused' Aristotle's doctrine about man's civic nature with Christian doctrine about God's role in the creation that nature and thereby 'legitimized' the state itself 'as a part of God's design'. *ibid*. The book *Defensor pacis* (Defender of the Peace), by Marsilius (Marsiglio) of Padua which was published in 1324, went further than this because of its claims that the entities of state and church were wholly separate and that the latter should be subordinated to the former in matters temporal. Kelly observes of the work that '[it laid] like an unexploded mine among Europe's intellectual furniture, to be detonated two centuries later in the age of the Reformation', at 127. He is of the opinion that the work of Marsilius 'is a milestone in the history of constitutional freedom', at 130.

[31] Stone, L.; 'The Family, Sex and Marriage in England 1500-1800', London, Penguin Books, 1977, at 176-177.

[32] *ibid.*

[33] *ibid.*

> '...the largely pejorative meaning that the classical and early Christian periods gave to such terms as *individual* and *privacy* was transformed during the Renaissance in a fashion that eventually produced the Protestant Reformation and the ethics of commerical society.'[34]

The Enlightenment period, or the 'Age of Reason', which followed from the Renaissance and the time of the Reformation, saw an even greater willingness among the intellectual elite to challenge and to question traditions and to seek personal and social betterment[35]. This period saw a marked increase in popularity for 'individual' pursuits, and thinkers of the time turned their attentions towards notions of 'the self' and the underlying value of such[36]. In particular, in the late seventeenth and early eighteenth centuries a view developed which today forms one of the cornerstones of western civilisation and epitomises the very essence of liberalism. This view is commonly known as *individualism*[37,38]. It is an idea which embodies a moral notion about what it is to be a human being. It is the foundation for a belief system which holds that all human beings are unique, that they possess basic rights and that such rights should be respected[39].

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[34] Barber, B.; 'Strong Democracy', Berkeley, University of California Press, 1984, at 195.

[35] Kelly, *op. cit.*, at 249 - 250, describes the Enlightenment thus, '...to call the Enlightenment a 'movement' may be misleading; it was more a shared mood or temper, or attitude to the world, in which the dominant note was one of profound scepticism towards traditional systems of authority or orthodoxy (especially those of religion), and a strong faith in the power of the human reason and intelligence to make unlimited advances in the sciences and techniques conducive to human welfare.'

[36] Sennett, R.; 'The Fall of Public Man', London, Faber and Faber, 1989, chapter five.

[37] See, generally, Lukes, S.; 'Individualism', Oxford, Blackwell, 1973. For an account of the rise of individualism in western culture see, Ketcham, *op. cit.*, esp. chapter two. For comment on and criticism of individualism, see Avineri, S. and de-Shalit, A., (eds.); 'Communitarianism and Individualism', Oxford, Oxford University Press, 1992.

[38] Benn, 'A Theory of Freedom', *op. cit.*, at 215ff, discusses various 'individualistic models of social collaboration'.

[39] Kelly, *op. cit.*, at 228, maintains that Grotius was the first proponent of this view. Citing Tuck, he notes that Grotius' work, *Inleidinghe tot de Hollandsche Rechts-gheleerdtheydt* was, 'the first reconstruction of an actual legal system in terms of rights rather than laws', see Tuck, R.; 'Natural Rights Theories', Cambridge, 1979, at 66.

Commenting on the phenomenon of individualism, Walton has noted,

> 'Fundamental to individualism is the claim in respect of the logical priority of the individual as opposed to society. A society is taken to be the aggregate of individuals contrasting with the organicist's claim that the whole is in some sense greater than the parts.'[40,41]

Shils has argued that a commitment to individualism is the *sine qua non* of a humane and liberal society. He says,

> 'A society that claims to be both humane and civil is committed to their [humanity and civility] respect. When its practice departs from that respect, it also departs to that degree from humanity and civility.'[42]

2.2.2. - *The Emergence of a 'Need' for Privacy*

The changes brought about in the periods leading up to the French Revolution were common throughout Europe and paved the way for an increasingly important role for privacy in society. For example, the connection between the rise of individualism and privacy is made by Benn,

> '...the importance attached to the privacy of the person is one aspect of the Western European, post-Renaissance liberal stress on individuality, on moral responsibility of the normally rational individual, and his responsibility for what he is and does.'[43]

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[40] See, Walton, A.S.; 'Public and Private Interests: Hegel on Civil Society and the State', in Benn and Gaus, 'Public and Private in Social Life' , *op. cit.*, chapter 10.

[41] Compare the views of Michael Sandel as commented on by Benn, 'A Theory of Freedom', *op. cit.*, at 256 - 258: 'a person is not prior to to community but constituted by it'. For a range of views on this, and related points, see Avineri and de-Shalit, 'Communitarianism and Individualism', *op. cit.*

[42] Shils, E.; 'Privacy: Its Constitution and Vicissitudes', 31(2), *Law and Contemporary Problems*, 281, 1966, at 306.

[43] Benn, S.I.; 'The Protection and Limitation of Privacy', 52 (11,12), *Australian Law Journal*, 601, 686, (1978), at 604 - 605.

This point has been noted by other commentators[44]. As an example, the work of Lawrence Stone provides valuable insight into the changing patterns of behaviour *vis* family life prior to and beyond this turbulent time. His approach is essentially three-fold in that he identifies stages of evolution of family life over the three centuries from 1500-1800[45]. He discusses the 'open linear family' which he asserts existed from 1450-1630, the 'restricted patriarchal nuclear family' from 1550-1700, and the 'closed domesticated nuclear family' from 1640-1800. Stone equates the development of the latter phase of family life - which is that which is most familiar to those living in family units in contemporary society - with the rise of individualism and the Renaissance Humanist stress on 'civility'[46]. He argues that the rise of individualism and liberalism, and their success, are due to a combination of the following factors: secularism, the pursuit of happiness, humanitarianism, physical and bodily privacy and the development of the market economy[47]. Of particular interest is the integral part which privacy has played. He notes that with increasing stress on 'civility' came increasing emphasis on the need and desire for privacy[48]. The sum and substance of this 'civility' involved the identification of behaviour considered to be worthy of 'civilised' persons and its cultivation. The corollary of this involved the labelling of certain other forms of behaviour as uncivilised. The result was not necessarily that uncivilised behaviour was discouraged (for this was not always possible), but that it was hidden from view : it became *private*. As he comments,

> 'One of the features of this new 'civility' was the physical withdrawal of the individual body and its waste products from contact with others.'[49]

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[44] See, for example, Moore, 'Privacy: Studies in Social and Cultural History', *op. cit.* at 283, Lukes, *op. cit.*, at 59 - 66 argues that privacy is a central tenet of individualism, also O'Donovan, K.; 'Sexual Divisions in Law', London, Weidenfeld and Nicolson, 1985, chapter one.

[45] Stone, L.; 'The Family, Sex and Marriage in England 1500-1800', *op. cit.*

[46] *ibid*, at 171. Stone states that 'civility' is, 'defined as a set of external behaviour traits which distinguished the civilised from the uncivilised.' *ibid*.

[47] *ibid*, at 179.

[48] *ibid*, at 169 - 172.

[49] *ibid*, at 171.

The development of a 'need' for spatial privacy during this time also came about because of changes in the types of person who constituted society. It is thought that human beings have not always had a need, or an ability, to form close relationships with other human beings[54]. This is particularly true of the middle ages when life was brutal and brief, and in the words of one commentator,

> 'The expectation of life was so low that it was imprudent to become too emotionally dependent upon any other human being.'[55]

This was not, however, simply a question of prudent advice or misplaced self-preservation. There would seem to be two reasons why individuals in the past did not need to, or could not, form close personal relationships.

First, prior to the eighteenth century the standard view of individuals was very functionalist. Individuals were perceived to be merely a part of a greater whole, bound together in the 'Great Chain of Being'[56]; insignificant as a separate entity, non-deserving of recognition as something unique. In those times people were valued because of their utility rather than their personal qualities or attributes. Thus, as Stone says,

> 'One wife or child could substitute for another, like soldiers in an army.'[57]

The implications of this were, it is thought, that no deep, emotional bonds developed between individuals to any recognisable extent compared with contemporary human relations. Since individuals were not seen to be of any particular worth *in se* there was

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[54] For an interesting discussion of how relationships are formed in modern society, see Duck, S.; 'What Are We Trying to Develop When We Develop A Relationship?', in Giddens, A. (ed.); 'Human Societies: A Reader', Cambridge, Polity Press, 1992, at 23 - 25.

[55] See, Prost, *op. cit.*, at 5.

[56] Stone, *op. cit.*, at 172.

[57] *ibid.*

In his opinion the motive for this was as follows,

> 'It was a desire to separate one's body and its juices and odours from contact with other people, to achieve privacy in many aspects of one's personal activites, and generally to avoid giving offence to the 'delicacy' of others. The essence of this movement was to create a culture in which the elite, the gentleman and the lady, were clearly distinguished by a whole set of immediately recognisable external behaviour traits.'[50]

This behaviour is immediately recognisable today but it is no longer indicative of one's membership of an *elite*. Current cultural mores surrounding such behaviour make it necessary to carry out the practices in a state of privacy in order to avoid the culturally-engendered response of embarrassment[51]. In this context, what can be called *spatial privacy* has gone from being a privilege of the ruling classes to an everyday necessity. The behaviour remains the same. The need for and function of privacy, however, have changed.

The development of a 'need' for spatial privacy among the upper classes can be observed in various other aspects of seventeenth and eighteenth century life. For example, unlike trends in the fifteenth and sixteenth centuries when upper-class houses were built with a series of interconnecting suites and no corridors, seventeenth and eighteenth century architects began to design grand houses which were made up of separate rooms connected by an independent corridor, arguably to allow privacy to be respected[52]. This view is substantiated by Aries,

> '...[not until the eighteenth century did the family begin] to hold society at a distance, to push it back beyond a steadily extending zone of private life.'[53]

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[50] *ibid.*

[51] Benn, 'A Theory of Freedom', *op. cit.*, at 281, is of the opinion that, '[e]mbarassment is the culturally appropriate response in a society with the concept of *prudenda*; anyone not displaying it may be censured as brazen or insensitive.'

[52] Stone, *op. cit.*, at 169, comments that 'the motive was partly to obtain privacy for individual members of the family, but more especially to provide the family itself with some escape from the prying eyes and ears of the ubiquitous domestic servants, who were a necessary evil in every middle and upper-class household.' See also pp.245 - 246.

[53] Aries, P.; 'Centuries of Childhood', Harmondsworth, Penguin, 1979, at 386.

nothing to be gained by forging emotional ties. This attitude extended even to those who today are regarded unquestioningly as intimates; that is, spouses, life partners and children[58]. It would seem that persons could function quite easily without the need to establish and maintain intimacies with others.

According to Stone, the second reason why close personal relationships were not formed to any great extent prior to the eighteenth century was because of the psychological make-up of people of that time. He says,

> 'In the sixteenth and seventeenth centuries there predominated a personality type with "low gradient" affect, whose capacity for warm relationships was generally limited, and who diffused what there was of it widely among family, kin, and neighbours.'[59]

Thus it would seem that not only did individuals have no perception of any need to form intimate relationships, but also they were incapable of doing so.

Stone argues, however, that a change has taken place in the last few hundred years in relation to both of the above[60]. Regarding the generally-held attitude towards individuals, he talks of the change which took place which he calls an 'abandonment of the principle of human interchangeability'[61]. That is, people began to value each individual as unique and of worth and not as a wholly replaceable entity[62]. This was a direct result of the general change throughout society which took place at that time which gave increasing importance to an egocentric view of society and the individual at the expense of the prevailing

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[58] See Aries, *op. cit.*

[59] Stone, *op. cit.*, at 180.

[60] *ibid.*

[61] *ibid.*

[62] Furthermore, Stone also notes a change from the sixteenth and seventeeth centuries in certain sections of society in terms of personality types: 'In the eighteenth century there predominated among the upper bourgeoisie and squirarchy a personality type with "steep gradient" affect, whose general capacity for intimate personal relationships was much greater, and whose emotional ties were now far more closely concentrated on spouse and children.', *ibid.*

functionalist view[63]. The conjunction of changes in personality types and changes in value systems was instrumental in the evolution of a view of the world which places the individual at its centre and which focuses considerable attention on individual acts and individual responsibility. In turn, the development of a 'need' to form intimate relationships gave rise to a corresponding 'need' for the appropriate circumstances in which such relationships can be formed: the desire to escape scrutiny and interference from others. Spatial privacy therefore became essential. As Benn has noted,

> 'Post-Renaissance individualism provided the ideological ground for the interest in privacy, and growing social complexity generated the need for it, but not until relative affluence enabled people to enjoy exclusive places - personal bedrooms, personal studies - were interests in privacy as such articulated.'[64]

Seventeenth and eighteenth century Europe was composed predominantly of oppressive oligarchies where the minority elite enjoyed tremendous wealth and privilege at the expense of the majority poor. Thus, as this quote indicates, the changes which occurred in the period leading up to the French Revolution, and in particular, the effect which these changes had on desires for privacy, were only felt by the upper classes of European society, for only they had the 'relative affluence' spoken of by Benn[65]. Stone observes that,

> 'As for the poor, who constituted the majority of the population, they continued well into the nineteenth century to live in one- or two-roomed houses. Under these conditions, privacy was neither a practical possibility nor, one imagines, even a theoretical aspiration.'[66]

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[63] Although Stone admits that the actual cause of such a 'mass-personality change' is not precisely known, he nevertheless cogently concludes that this was as a result of the political and social changes occuring at the time: '...it seems plausible to suggest that [the change] may have been associated not only with the broad social and intellectual changes of the period, but also with a series of changes in child rearing, which created among adults a sense of trust instead of mistrust.' This latter element is discussed by him in much more depth in chapter 9.

[64] Benn, 'A Theory of Freedom', *op. cit.*, at 295.

[65] *ibid.* At p.285 Benn remarks, '...writers have criticised preoccupations with privacy, particularly the privacy of family relations, as part of the pathology of post-Renaissance bourgeois society.' See, Leach, E.; 'A Runaway World?', London, Oxford Univeristy Press,1968, (1967 Reith Lectures), and Halmos, P.; 'Solitude and Privacy: A Study of Social Isolation, its Causes and Therapy', London, Routledge and Kegan Paul, 1952.

[66] Stone, *op. cit.*, at 170.

Certainly, from the historical perspective,

> 'the possibility of having a private life was a class privilege limited to those who lived, often on private incomes, in relatively sumptuous splendor.'[67]

Yet, the movements of the Renaissance, the Reformation and the Enlightenment set in motion events which were to change incontrovertibly European society and, ultimately, western civilization. As we know, the culmination of the changes which had swept Europe was the French Revolution.

2.2.3. - *The French Revolution*

The French Revolution was one like no other because it embodied a desire for political and social change on a much grander scale than had ever before been contemplated. Previously, revolutions had been aimed at a particular group in control, a superior or a monarch. No institutional reform was intended or envisaged. The unique character of the French Revolution is found in the fact that it was instigated and carried out because of a desire to bring about such institutional reform. The embodiment of the change that was brought about, and which remains today at the heart of the French Constitution[68], is contained in the Declaration of the Rights of Man and of Citizens adopted by the French National Assembly in 1789. This document represented the culmination of changes and the shift in fundamental values which had occurred in the recent past and provided a physical embodiment of the ideas and ideals which sprang from that time and which continue to epitomise the (modern) liberal democracy: freely-elected representative government, the

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[67] Prost, *op. cit.*, at 7. It is ironic that today the 'upper classes/social elite' have less means of protecting privacy because there are more threats to it from tabloid journalism. Celebrities and royalty (and to a lesser extent public officials) experience threats to their privacy which most 'average' individuals do not.

[68] The French Constitution was adopted in 1791 by the National Assembly formed after the Revolution. Even today, this Constitution represents an exemplary charter for liberal democracies.

separation of legislative, executive and judicial powers, the notion of inalienable human rights, and the ideal of human equality[69].

Although the French Revolution did not in itself do anything for privacy or its protection, it concretised the values and the changes which had given rise to increased interest in, and concern for, privacy. Further, it secured the way forward for 'democratized' societies and, thereby, paved the way for an increasingly important role for privacy in such societies[70].

2.2.4. - *The Industrial Revolution*

The Industrial Revolution, which took place throughout Western Europe and the United States in the late eighteenth century and nineteenth century, proved to be the link between notions of democracy and individual freedoms which had developed from the French Revolution and the notion of market economy and capitalism which evolved as a result of industrial innovations[71]. This brought about great social changes on a variety of different levels.

The advent of industrialisation allowed geographical mobility on a scale never before possible or imaginable. With this came, inevitably, mass migration of people to those places

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[69] The idea that all human beings are equal is not one which was novel at that time. It was a theory which has existed from the times of the Greeks and Romans and which had been sustained among theological, political and legal writers throughout the ages. However as Kelly, *op. cit.*, notes, 'The general notion of human equality, the presumption against privilege, of course had very ancient roots, but...[was]...stated most stridently at, and since, the French Revolution.' Kelly traces western legal theory through human history and comments on the attitude of the writers towards the notion of equality and notes than, in almost every period, the majority favoured some view that 'all are worthy of equal treatment'. The justifications for this vary. For example, the Greeks considered alien the notion that 'one man is as good as another' but considered that, in the eyes of the law, equality existed between men (at 29 - 30). In the Middle Ages, it was creation of all humanity by God which bestowed the quality of equality (at 104 - 107 and 146 - 148). That is not to say, however, that in practice the theory was applied. Slavery was still common in Europe in the late Middle Ages, and political subordination was also commonplace (at 146). It was not until the French Revolution that theory and practice began to coincide.

[70] Westin discusses the 'origins of modern claims to privacy' in his acclaimed work Privacy and Freedom, *op. cit.* He makes particular note of the role of privacy in the modern democratic state, ibid., chapters one and two.

[71] Capitalism has existed since the sixteenth century, industrial capitalism since the late eighteenth century, ie- with the Industrial Revolution.

where there was work, namely; towns and cities[72]. Industrialised countries therefore experienced a period of rapid urbanisation. The growth of towns and cities meant that there was an urgent demand for the provision of basic services such as adequate housing, water and health care. The latter became a particularly pressing need[73] because, with the rise in concentrated populations, came a rise in the incidence of infectious disease and a substantial increase in the mortality rate[74]. However, in the early part of the industrial revolution such basic services were not always available and life for the working classes in towns and cities was, 'toil and wretchedness, rich in suffering and poor in enjoyment.'[75]

Not surprisingly, these conditions put increased strain on the personal lives of individuals[76]. The relocation of the population from the country into towns led to a substantial impingement on living space[77]. Where industrialists built dwellings for their workers in close proximity to their place of work there was no sharp division between the working and the non-working lives of individuals. Very often individuals found themselves living

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[72] It should also be noted that additional factors contributed to the movement of people from the country to the towns and cities. As the eighteenth century progressed land became a valuable commodity and 'private' ownership as a concept took hold. The result was that customs of access and use were denied to those who had previously worked the land: depriving them of their main means of subsistence. Given this, little choice remained: become destitute or find employment in the new industries.

[73] For an excellent critique of the whole social order of that time, see Engels, F.; 'The Condition of the Working Class in England', edited by Kiernan, V., London, Penguin Books, 1987. This book was initially published in 1844 and includes some interesting statistics. For example, Engels notes that scarlet fever, rickets and scrofula were largely confined to the working class, in whose streets the mortality was twice as high compared to the middle class streets. He also observes that the death rate in the cities was higher that in the countryside: 1 in 30 compared to 1 in 40.

[74] Note, however, that after the middle of the nineteenth century mortality rates began to drop dramatically and the major causes of death were no longer infectious disease but rather other conditions such as heart disease and cancer. See McKeown, T.; 'The Modern Rise of Population', London, Edward Arnold, 1976, esp. at 80 - 82. There is much controversy about the causes of this change. The main factors would seem to be improvements in nutrition and standards of livings, environmental improvements through public health legislation and administration and the effects of medical interventions for certain conditions. The importance of the role of the latter has, however, been disputed, see McKeown, ibid, at 150, '..on balance the effects of hospital work in this period were probably harmful...any patient faced the risk of contracting a lethal infection up to the second half of the nineteenth century...and it was not until much later that hospital patients could be reasonably certain of dying from the diseases with which they were admitted.' *Cf* - Winter, J.M.; 'The Decline of Mortality in Britain, 1870 - 1950', in Barker, T. and Drake, M., (eds.); 'Population and Society in Britain, 1850 - 1950', Batsford Academic and Educational, 1982.

[75] Engels, *op. cit.* at 69.

[76] See Prost and Vincent, (eds.), *op. cit.*, which outlines social changes which had influences on the lives of the poorer classes which eventually led them to demand more private space, especially Prost, 'The Transition from Neighbourhood to Metropolis', at 103ff.

[77] See Giddens, 'Sociology : A Brief But Critical Introduction', *op. cit.*, at 6.

next to, or in very close proximity to, co-workers in cramped and less than ideal conditions. Such conditions heightened individuals' awareness of personal space - or rather the lack thereof - and contributed directly to the development of a desire for spatial privacy among the poor. Thus, although for different reasons, the desires of the poor began to mirror those of the elite concerning a 'need' for spatial privacy.

2.2.5. - *Informational Privacy*

The living conditions created by industrialised society had another profound effect on the lives of individuals. People saw a marked increase in the speed with which information about themselves was disseminated. By this period of history human psychology had changed and individuals now had a sense of the intimate: personal relationships were formed as a matter of emotional need. Yet, one's range of 'intimates' in industrial society was greatly extended. Not only did one share one's life with family and friends but also with many hundreds or thousands of other persons who lived or worked in the same place or who frequented the same establishments. Strangers therefore became pseudo-intimates : vast tracts of one's life could be shared with persons for whom one could feel very little, yet about whom one could know a great deal. However, because individuals did not choose these 'intimates' and because they could not control the flow of information about themselves between such 'intimates' (and others), people began to experience an increasing sense of loss in relation to a side of their lives which had also come to be associated with the private sphere: personal information[78]. Just as the 'need' for privacy had manifested itself in a desire for spaces where individuals could ensure limited access to their person, so too then developed a 'need' for feelings of control over personal information[79].

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[78] *Cf*, Shils, 'Privacy: Its Constitution and Vicissitudes', *loc. cit.*, at 288 - 292.

[79] See, for example, Jouard, *loc. cit.* One might make the point that the likelihood of neighbours knowing one's 'personal' details is higher in a village than in a town, and this is certainly true. However, the likelihood is also higher that a eighteenth/nineteenth century village the populus constituted a community - akin to an extended family - where the lives of all were so intimately connected than intimacies were willingly and necessarily shared. The same is not true of a city where personal information can be disseminated to complete strangers and no control can be exercised over its use thereafter. Reporting in 1972 the Younger Committee commented, '...the apparent loss of privacy through physical proximity may be more than offset by

2.3. - Privacy : A Definition

It is submitted that the notions of privacy considered above continue to reflect the privacy needs of persons today. These 'needs' embodies two conceptions of privacy. First, privacy as a state of non-access to the individual's physical body or 'person' - what has been called here *spatial privacy.* Second, privacy as a state in which the individual has control over personal information - what has been termed *informational privacy*[80]. From these two conceptions of privacy one can deduce one unifying definition: privacy as a state of separateness from others. This includes physical (body) separateness from others (*spatial privacy*) as well as separateness of parts of our lives which are so intimately connected to our idea of 'self' that they equate with physical separateness. Included in this is personal information (*informational privacy*). This is the definition of privacy which is adopted in this work. In chapter five the reasons for this choice of definition will be more fully considered and properly justified. For the moment, privacy should be taken to refer to a state in which an individual is separate from others, either in a bodily sense or by reference to the inaccessibility of certain intimate adjuncts to their individuality, such as personal information.

2.3.1. - *Why Protect Privacy?*

It has been argued that with the rise of the western liberal democracy there arose a need for individual privacy. It has also been shown that the privacy interests which individuals have

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anonymity in modern crowded communities...[t]he significant change affecting privacy is the growth in numbers and sizes of communities and the creation of conurbations which contain an increasingly high proportion of the whole population.', at 23 - 24.

[80] This view of privacy corresponds largely with a lay view of the concept. The Younger Committee on privacy found that the responses of individuals to questions in a commissioned survey about what constituted invasions of privacy tended to place the notion of privacy into one or both of two groups: freedom from intrusion or privacy of information, see Younger Committee, 1972, *op. cit.*, at 32.

are of two distinct kinds. What has not been explained is why individuals need privacy. Several arguments can be made.

First, as has been shown, a state of physical separateness from others is necessary in order to allow personal relationships to begin and to grow. The levels of intimacy which typify the modern personal relationship can only be achieved by ensuring and securing separateness from others. Trust, which is essential to the establishment and maintainance of all relationships, requires not only a degree of intimacy to develop but also a currency in which to deal. An important part of that currency is personal information. Individuals trade private information both as a sign of trust and on the basis of trust. The security of the information is guaranteed by the tacit undertaking that it will not be noised abroad. In this way personal and professional relationships flourish and an important part of the fabric of society is woven more tightly[81]. As Fried has said,

> Love and Friendship...involve the initial respect for the rights of others which morality requires of everyone. They further involve the voluntary and spontaneous relinquishment of something between friend and friend, lover and lover. The title to information about oneself conferred by privacy provides the necessary something. To be friends or lovers persons must be intimate to some degree with each other. Intimacy is the sharing of information about one's actions, beliefs, or emotions which one does not share with all, and which one has the right not to share with anyone.[82]

Second, a degree of separateness - that is, being alone with no company or selected company - allows the individual personality to reflect on experiences and learn from them. Constant company, and so constant interaction, deprives the individual of time to assimilate life experiences and to get in touch with one's own individuality[83].

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[81] See Fried, 'Privacy', *loc. cit.*

[82] Fried, C.; 'An Anatomy of Values : Problems of Personal and Social Choice', Cambridge (Massachussettes), Harvard University Press, 1970, at 142.

[83] Jouard, *loc. cit.*

Third, it has been argued that the modern psychological make-up of individuals is such that a degree of separateness is required to ensure that individuals retain a degree of mental stability. Jouard has put a forceful argument that (western) public life puts considerable strain on individuals who must assume certain personae to integrate with others[84]. These personae, not being full and true reflections of the personality of the individual, cannot be maintained indefintely without serious psychological consequences. A state of privacy allows the 'masks' to be dropped and a degree of release to be obtained.

Fourth, tangible harm can come to an individual who is not granted a degree of privacy. As regards spatial privacy, invasion on the body which is unauthorised is disrespectful of the individual and may cause physical harm. The criminal and civil laws of assault recognise and protect to a degree the inviolability of the human body. Perhaps less obvious, but no less valid however, is the mental harm which can arise if one's spatial privacy is not respected. For example, clandestine observation can produce profound feelings of violation in individuals even although no actual physical contact occurs and/or no personal information is gathered[85]. Similarly, unauthorised use or disclosure of personal information can lead to harm to individuals. Information about one's personal condition, behaviour or habits which others find distateful can lead to individuals being ostracised from communities or becoming the object of violence and discrimination. As Greenawalt puts it,

> 'One reason why information control seems so important is precisely because society is as intolerant as it is, precisely because there are so many kinds of activity that are subject to overt government regulation or to the informal sanctions of loss of job or reputation.'[86]

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[84] *ibid*, and see generally, note 2 above.

[85] See Benn, S.I.;'Privacy, Freedom and Respect for Persons', in Schoeman, F.D.; 'Philosophical Dimensions of Privacy', *op. cit.*, chapter 8, at 230 - 231.

[86] Greenawalt, K., 'Privacy and its Legal Protections', 2(3), *Hastings Center Studies*, 45, 1974.

The hysterical reaction to AIDS which lasted for most of the 1980s, and the intolerance and discrimination which continue to flow from that time - and which have in part been institutionalised[87] - are recent reminders of how 'intolerant' society can be[88].

There is one final argument in support of the protection of privacy. The above arguments concentrate on individual interests. Arguably, however, there are also *public* interests in privacy protection. For example, it can be argued that it is in the public (society) interest to have a community inhabited by 'complete' individuals as opposed to two-dimensional characters[89]. Similarly, for a society which holds the individual in esteem and seeks to accord him or her respect, it is surely in the public interest to reduce to a minimum all potential harm to individuals. Moreover, it should not be overlooked that harm can come to society itself if privacy is not respected. If the element of trust which is so crucial to the development of relationships is lost because individuals cannot seek and receive guarantees about the security of information, important and valuable information will not be communicated. This can render important social organs powerless to deal with a variety of social conditions. A powerful example of this can be seen in the medical confidentiality case of *X v Y*[90]. In this case a newspaper gained access to the medical files of two doctors who had AIDS and who were continuing to work in general practice. The newspaper sought to disclose this information and argued that it was justified in doing so because the public had a right to know that doctors were continuing to treat patients when they were afflicted by such a condition. The court, however, rejected this argument and in issuing an injunction

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[87] For examples of the ways in which discrimination and bias have been included in certain UK laws applying to those afflicted by AIDS see generally, Haigh, R. and Harris, D., (eds.); 'AIDS: A Guide to the Law', Second Edition, London, Routledge, 1995. Examples include the continuing practice of insurance companies of requiring supplementary information from those in so-called 'high-risk groups' as opposed to those who engage in 'high-risk practices', and the governmental policy which prevents same sex partners from 'inheriting' a tenancy from a deceased partner, as is possible with spouses.

[88] This is also discussed by Benn, 'A Theory of Freedom', *op. cit.*, chapter 10 and p.282.

[89] Benn notes that, '...the children of the kibbutz have been found by some observers defective as persons, precisely because their emotional stability has been purchased at the cost of an incapacity to establish deep personal relations. Perhaps we have to choose between the sensitive, human understanding that we achieve only by the cultivation of our relations within a confined circle and the extrovert assurance and adjustment that a *Gemeinschaft* can offer. However this may be, to the extent that we value the former, we shall be committed to valuing the right of privacy.', in 'Privacy, Freedom and Respect for Persons', *op.cit.*, at 237.

[90] *X v Y* [1988] 2 All ER 648.

held that there was a *public interest* in maintaining the confidence of people such as the two doctors. Rose J. summed up his reasoning as follows,

> ...[i]n the long run, preservation of confidentiality is the only way of securing public health; otherwise doctors will be discredited as a source of information, for future patients "will not come forward if doctors are going to squeal on them".[91]

All of these reasons will be considered in more depth in future chapters. For the present, it is sufficient to note that the definition of privacy advanced in this thesis is two-pronged : it relates both to spatial and informational privacy. And, there are strong reasons for recognising and protecting both kinds of individual privacy - reasons which are grounded in both private and public interests.

2.3.2. - *Privacy : A Role for the Law?*

The public/private distinction is central to the western liberal tradition and arises from the commitment of the latter to individualism. A sphere of the 'private' embodies areas of life in which individuals are not subject to scrutiny, restraint or interference by society. The boundary between the two areas of public and private requires careful policing for the division is in a constant state of flux. Crucial to this role of 'policing' and, arguably, the existence of the division between public and private itself, is the law[92]. The question of the existence of the public/private distinction in western life and the problem of the sustainability of a division between the two spheres is, in essence, a debate about the limits of law. If the private sphere represents non-intereference, non-intrusion and non-action by others, there is little role for the law to play *in that sphere*. However, in maintaining a delimitation around that sphere of life, arguably, the law has a significant role as the prime motivator and regulator of human action in society. Morever, to examine the tension

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[91] *ibid*, at 653.

[92] See, O'Donovan, 'Sexual Divisions in Law', London, *op. cit.*, at 2 - 3.

between public and private life from the legal perspective provides insight into the concept of law, its function and its limitations.

In addition, it is submitted that the role of the law in protecting interests and finding acceptable solutions is crucial. The history of privacy has been beleaguered by obscurantism and imprecision[93]. Clarity of function and scope is essential to the development of a workable concept and, in the opinion of the present writer, this is attainable only by legal means. It will be contended that, in light of the submissions about privacy and related matters with which this thesis will detail, there should be a role for the law to play in seeking protection of the concept as it has been defined. This is because of the value it has and because of the primacy of the role of the law as a means to balance interests which conflict and to resolve disputes as they arise in relation to matters of value to our society and the individuals in it. Given the fact that privacy is currently accorded no direct legal protection in the UK, the ultimate aim will be to evaluate proposals for introducing patient privacy protection in this country .

3.1. - THE INTERVENTIONIST STATE AS TENET OF THE WESTERN LIBERAL TRADITION

A further justification for the choice of the western liberal democracy as a context for this discussion of privacy is the phenomenon of the expanding role of the state in western communities. In the course of the twentieth century western society has witnessed increasing interest of states in a whole range of matters concerning the lives of citizens[94]. As Stromholm has indicated,

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[93] *Infra*, chapter five.

[94] For example, in the last century western society has witnessed the state taking responsibility for the provision of many basic services such as housing and utilities, subsistence benefits, education and child welfare. Of primary importance among these is the provision of health care, discussed infra. On another level, western societies are epitomised by an excess of legislation stemming from paternalistic attitudes of the state towards its citizens. Thus, we find legislation prohibiting or severely restricting sales of alcohol and other drugs, promoting health and safety at work, requiring the wearing of seat belts or safety helmets, etc.

> ...prevailing democratic ideologies stress the need for continuous debate on matters of public interest...the complexity of modern society and the subtle interwovenness of facts and interests within its framework have led to the feeling that almost everything concerns everyone in one sense or another. Thus, any unimportant event may touch upon matters in which the public may claim a legitimate interest.[95]

Hence, what the ideology giveth with one hand it taketh away with the other. Individual interests are given more importance in democratic communities but at the same time public interests are also afforded greater weight. This increases tension at the interface between the public and private areas of life and requires that we define, with as much clarity as possible, where the boundaries between the two areas lie. Arguably, it is the function of privacy to provide a mechanism to ensure that such boundaries are well constituted. A legally protected right to privacy ensures that such boundaries are ultimately respected. It also provides recognition of the fact that at times certain areas of life can, and should, be kept separate. As Schoeman states,

> ...respect for privacy signifies our recognition that not all dimensions of persons or relationships need to serve some independently valid social purpose.[96]

4.1. - CURRENT THREATS TO PRIVACY

The justification for examining privacy *at the present time* can be linked with the above. Western democracies have evolved and progressed over the last two hundred years but never before has there been the potential for as many different forms of invasion of privacy as exist today. Various explanations have been put forward as to why there seems to have been a rise in concern, especially in the twentieth century[97].

Such legislation comes in a variety of forms ranging from prohibition with the threat of criminal sanction, through civil liability to the use of fiscal means to control behaviour.

[95] Strömholm, S.; 'Rights of Privacy and Rights of the Personality : A Comparative Study', Stockholm, P.A. Norstedt and Söners Forlag, 1967, at 17.

[96] See, Schoeman, F.D.; 'Privacy and Intimate Information', in Schoeman, 'Philosophical Dimensions of Privacy: An Anthology', *op. cit.*, chapter 17, at 413.

[97] For a somewhat dated but neverthless interesting survey of UK attitudes see, Younger Committee, Cmnd 5012, 1972. The Committee at that time found that privacy rated highly in the concerns of the UK public,

4.2. - The Twentieth Century and the Continuing Process of Democratisation

Antoine Prost has posited that one significant change which has occurred in the twentieth century has been a greater division between home and work life. This has resulted because more people have begun to work in someone else's space rather than their own. He argues that this physical division between the workplace and the home has led to a greater separation in the minds of people between the two spheres of life[98]. This in turn has led to an increased reluctance to allow one to encroach on the other[99]. One might view this as part of a continuing process. In the 19th century living conditions required individuals to live and work closely with one another and this resulted in increased desire for both spatial and informational privacy. Today, the *de facto* division which exists for most people between their work and home life provides them with a clearer division between the two spheres of life and therefore provides them with more privacy. However, this has in turn led to a greater division between the two spheres in the individuals' minds which has led to a greater desire to maintain such a division, that is, a greater desire for privacy. This

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ranking in importance only after concerns about crime prevention, unemployment and educational standards. On a wider level, Benn, 'A Theory of Freedom', *op. cit.*, at 294ff, considers that the rise in interest concerning privacy rights in western states can be attributed to social changes of two kinds: cultural and technological. Posner, who has offered an economic analysis of privacy, argues that the increase in personal income over time has led to greater likelihood of invasions of privacy and correspondingly more desire for privacy. As he notes, '[t]here is apparently very little privacy in poor societies, where, consequently, people can readily observe at first hand the intimate lives of others. Personal surveillance is costlier in wealthier societies, both because people live in conditions that give them greater privacy and because the value (and hence the opportunity cost) of time is greater - too great, in fact, to make the expenditure of a lot of it in watching the neighbours a worthwhile pursuit. An alternative method of informing oneself about how others live was sought by the people and provided by the press. A legitimate and important function of the press is to provide specialization in prying in societies where the cost of obtaining information have become too great for the Nozy Parker.', see Posner, R.A.; 'An Economic Theory of Privacy', in Schoeman, 'Philosophical Dimensions of Privacy: An Anthology', *op. cit.*, chapter 15, at 335.

[98] See, Prost, A.; 'Public and Private Spheres in France', in Prost, A. and Vincent, G. (eds); 'A History of Private Life', *op. cit.*, at 9 - 49. At 27 he comments, 'The contrast between private life and work life is nowadays embedded in the very structure of modern cities and scedules. People no longer work where they live or live where they work. This principle applies not just to apartments and workshops but the whole neighbourhoods. Every day huge populations migrate between home and workplace by automobile and mass transportation.'

[99] *ibid.*

phenomenon demonstrates the voracious appetite of privacy - the more it is fed the more it requires feeding[100].

Prost has noted the spread of privacy concerns through all strata of society in the twentieth century. As he says,

> ...the twentieth century may be seen as a period during which the differentiation of public and private, at first limited to the bourgeoisie, slowly spread throughout the population. Thus, in one sense the history of private life is a history of democratization.[101,102]

If one accepts that with the progress of 'democratization' has come a rise in the 'need' for privacy and, therefore, a growth in the importance of privacy, the continued progress of 'democratization' around the world provides a further justification for examining privacy and the nature of its role in such a process. Certainly, the western liberal tradition would seem to have been vindicated by its apparent 'success' as a blueprint for a 'good society'. The recent demise of the USSR and the soviet-block communist countries and their replacement by 'democratic' systems says more about the world-wide perception of the values and accomplishments of liberalist capitalism than it does about the effectiveness of communism. As one commentator has said,

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[100] There is some empirical evidence to support this. In 1972 the Younger Committee on Privacy commissioned a survey which aimed to established public attitudes towards privacy. Among it conclusions it stated the following : '[e]ven if there is today more real privacy for some than hitherto, our survey of public attitudes to privacy shows that people who have become accustomed to privacy prize it the more highly.', see Younger Committee, 1972, at 24. A summary of the survey is found at Appendix E in the report.

[101] Prost, A.; 'Introduction', in Prost and Vincent, *op. cit.*, at 7.

[102] Other 'twentieth century developments' of pertinence to privacy, are also observed by Prost. For example, he notes, '[a] half-century ago the family took precedence over the individual; now the individual takes precedence over the family. The individual was once an intrinsic part of his or her family. Private life was secondary, subordinate and in many cases secret or marginal. Now the relation of individual to family has been reversed. Today, exept for maternity, the family is nothing more than a temporary meeting place for its individual members. Each individual lives his or her own life and in doing so expects support from a now informal family. A person who considers his or her family suffocating is free to seek rewarding contacts elsewhere. Private life used to coincide with family life; now the family is judged by the contribution it makes to the individual private lives of its members.', see Prost, 'Public and Private Spheres in France', *loc. cit.*, pp. 67 - 102, at 84.

> There are few states in the world today that are not proclaimed by their rulers to be 'democracies', whatever their actual political complexion may be.[103]

Moreover, the heightened role of privacy within such a 'democratic' state or system has not gone unnoticed[104]. As Barth has put it,

> It is [a respect for privacy] as much as in any other single characteristic that the free society differs from the totalitarian state.[105]

A similar view is expressed by Bryant,

> Totalitarians are, in principle, unwilling to tolerate reserves of privacy. Lenin told the young communists in 1920, "We recognise nothing private. Our morality is entirely subordinate to the interests of the class struggle of the proletariat".[106]

The apparent connectedness between democracy (or democratisation) and privacy indicates clearly the appropriateness of the choice of the western liberal democracy as a context within which to study privacy.

4.3. - The Technology Society: New Threats to Spatial and Informational Privacy

In all spheres of life sophistication in computers, photographic equipment, bugging and recording devices has increased dramatically the likelihood of a breakdown in the

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[103] See Fukuyama, F.; 'The End of History?', 16, *The National Interest*, 3, 1989, and Fukuyama, F.; 'Reply to My Critics', 18, *The National Interest*, 21, 1989. See also, Kryl, M.; 'Are We Facing the Triumph of Liberalism and the End of History?', in Brecher, B. and Fleischmann, O., (eds.); 'Liberalism and the New Europe', Aldershot, Avebury, 1993, at 49 - 58.

[104] See, for example, Westin, 'Privacy and Freedom', *op. cit.*, especially chapter two, Benn, 'A Theory of Freedom', *op. cit.*, at 289 - 297, Kupfer, J.; 'Privacy, Autonomy and Self-Concept', *loc. cit.*, Hallborg, R.G.; 'Principles of Liberty and the Right to Privacy', 5, *Law and Philosophy*, 175, 1986, and Hirschleifer, J.; 'Privacy: Its Origin, Function and Future', 9. *Journal of Legal Studies*, 649, 1980.

[105] Barth, A.; 'The Price of Liberty', New York, The Viking Press, 1961, at 12.

[106] Bryant, C.G.A.; 'Privacy, Privatisation and Self-Determination', in Young, J.B. (ed.); 'Privacy', *op. cit.*, at 70 - 71.

distinction between public and private life in the twentieth century[107]. This has, understandably, been accompanied by a corresponding rise in the degree of concern which individuals feel about their personal privacy. For example, in 1972 the Younger Committee on Privacy published the results of a survey which it had conducted to determine the attitudes of members of the public towards various forms of 'invasion of privacy'[108]. Individuals were asked, *inter alia*, to consider whether, in general, people had less privacy than before. It was found that 58% of those interviewed thought that this was so. Only 19% thought that people had more privacy. The remaining 23% did not think the situation had changed. As the Report states,

> This view of the general decline of privacy was held by every sub-group formed by analysis on several dimensions such as age, and socio-economic grouping, except the small group (3%) who rated "protecting people's privacy as not at all important".[109]

The main reason given by respondents for their feelings that privacy had declined was the increase in the number of forms one must fill in which led to a feeling that too much was known about individuals by a wide variety of organisations[110]. The second most common reason advanced was that privacy decline was due to housing being more crowded together with neighbours overlooking one's house and garden[111]. It is submitted that although this survey was commissioned and carried out over two decades ago there is nothing which has changed so radically in contemporary society which might lead us to expect that the results

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[107] For an interesting examination of the US state cases on privacy concerns surrounding compiuters, see Karasik, E.H.; 'A Normative Analysis of Disclosure, Privacy, and Computers : The State Cases', 10, *Computer/Law Journal*, 603, 1990.

[108] Younger, *The Report of the Committee on Privacy*, Cmnd. 5012, July 1972. A shortened version of the survey report is contained in Appendix E of the Committee's report. The Committee discusses its conclusions about the survey in chapter six, particulary paragraphs 98 - 102. 236, Table F; 239, Table J.

[109] *ibid*, Appendix E, at 232.

[110] *id.*

[111] These responses were to a question which asked about feelings of the decline of privacy *in gerenal*. This should be compared with the resposne obtained when people were asked if they felt their their personal privacy had been eroded in the last five years of their life. Here the opinion was almost equally balanced. A paradox? Perhaps, but the Report explains this apparent disparity thus, '[t]he explanation lies partly in the connection between privacy and age, since younger people were more likely to have increased their privacy by gaining independence from their family, and partly in a general feeling of anxiety about the extent to which the general deterioration in privacy might might affect the individual in the future.', *ibid* at 242.

would be very different if the same survey were conducted today[112]. That said, and the age of the Younger survey aside, a problem exists concerning the value of this survey and the kinds of conclusions which one can draw from its findings. This has been articulated by Wacks,

> ...an attitudinal survey, of the kind conducted by the Younger Committee,...can, at best, illustrate only that a certain proportion of those questioned regard their 'privacy' invaded by certain forms of conduct or that they have experienced particular forms of such invasions to a greater or, lesser extent. And, though such research may reveal interesting attitudes, they do not directly address the question of whether there is a social 'problem' of sufficient gravity to warrant legal control or regulation.[113]

Writing in 1989, Wack's solution was another survey[114]. His, however, targeted solicitors in metropolitan England, Wales and Northern Ireland[115] rather than members of the general public. His aim was to establish the degree to which individuals are subjected to assaults on their privacy of a sufficiently serious nature for them to take action, legal or otherwise, to prevent their recurrence or to seek to remedy their loss of "privacy."[116] His findings are revealing. First, 43.4% of the total number of actual complaints received concerned the alleged misuse of confidential information (computerised or otherwise). This represented the largest group of reported claims and mirrors the finding of the Younger Committee. Second, Wacks discovered what he calls 'an unexpectedly high number' of complaints in respect of 'intrusion'. By this he means telephone-tapping, bugging, spying, photographing or electronic surveillance of private activities. 30.9% of the total number of

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[112] It should also be noted that of a category of seven civil and social rights (which included improving race relations, protecting the freedom of the press and giving equal rights for women) protecting people's privacy was ranked the most important. In this context it is submitted that a different outcome might well result today. This does not mean however that privacy concerns in se have diminished any, but simply that other concerns, such as accepting racial and sexual equality, have taken on increased importance compared to 1972.

[113] Wacks, R.; 'Personal Information, Privacy and the Law', op. cit., at 135 - 136.

[114] See generally, Wacks, 'Private Information, Privacy and the Law', *op. cit.*, chapter four.

[115] This included law centres and the National Council for Civil Liberties.

[116] *ibid*, at 138.

actual complaints received concerned intrusion. Once again, this reflects the results of the Younger Committee which found that intrusion was of particular concern to individuals.

What can we conclude from these surveys? It can be seen that both show a high degree of concern for informational privacy, as demonstrated both by a section of the general public chosen at random (Younger) and from a sample of those who have sought professional advice on their legal position (Wacks). By contrast, Wacks' survey does not seem to ask about invasions of spatial privacy[117]. This is not surprising since his thesis argues that privacy should be seen solely in terms of protection and control of personal information[118]. Nevertheless, both surveys show a heightened awareness of the special nature of a private sphere and record considerable abhorrence among individuals when this sphere is felt to be invaded. Both Younger and Wacks reflect a view of the world which divides our existence into separate spheres. In one sphere - the public shere - we can be observed, listened to and interacted with by others and no feelings of invasion or intrusion arise. By contrast, in the private sphere - often represented by the home and the family unit - similar acts by others meet with considerable hostility and induce strong feelings of violation and intrusion. We have seen that the Younger survey recorded the second highest response for feelings of intrusion through close-proximity living. It should also be noted that Wacks observed a very high number of persons experiencing feelings of intrusion because of alleged surveillance of private activities. Now, it might be argued that such concerns as noted by Wacks relate solely to informational privacy rather than spatial privacy - the concern of the individuals in question being the obtaining of information by surreptitious means. Whereas this is no doubt part of the concern, it is submitted that it does not accurately reflect the reality of the situation. It is unfortunate that Wack's survey does not provide us with more

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[117] The questionnaire was presented as follows. "In the last five years, approximately how many persons have sought advice in respect of possible legal action they might pursue from : a) the alleged 'tapping' of their phone?, b) the alleged 'bugging' of their home or office?, c) the alleged spying upon, photographing or electronic surveillance of their private activities?, d) the publication without their consent of private facts by the news media?, e) the use without their consent of their name or picture for advertising or other commercial purposes?, f) the alleged misuse of confidential information (computerised or otherwise) e.g. by credit rating agencies or the National Health Service?". See Wacks, *op. cit.*, at 142.

[118] See further *infra*, chapter five.

detail on the precise nature of the concerns of individuals who sought legal advice. In particular, we do not know whether their complaints arose because certain information had been obtained by clandestine surveillance. The relevant questions asked simply, 'In the last five years, approximately how many persons have sought advice in respect of possible legal action they might pursue arising from : a) the alleged 'tapping' of their phone?, b) the alleged 'bugging' of their home or office?, c) the alleged spying upon, photographing or electronic surveillance of their private activities?'[119] These questions tend to suggest that it is the act of surveillance, rather than the obtaining of any personal information therefrom, which has been the concern of individuals. Furthermore, given that Wacks later asks specifically about complaints concerning, 'the alleged misuse of confidential information (computerized or otherwise)'[120], it is suggested here that his survey shows indirectly that feelings of invasion are experienced *even if* no information is gathered. One could be engaged in perfectly innocuous activities such as reading or watching television, yet many of us will maintain that an invasion of privacy has occurred if we are subjected to clandestine observation. It is suggested that these feelings correspond to the construct of spatial privacy: a sphere which can be invaded by mere observation and need not be connected to informational privacy. In this respect, it can be concluded that the surveys of both Younger and Wacks reveal a high degree of concern for the protection of such a conception of privacy. Thus, both surveys reveal not only that individuals perceive privacy as a construct which embodies two concepts (spatial and informational separateness), but also that there is serious concern about the protection of such spheres of life.

4.4. - Privacy and the Press

Personal privacy has been put under increased threat in recent years by the vagaries of the media, and in particular the press. Sir David Calcutt has been the central figure in a long

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[119] Wacks, *op. cit.*, at 142.
[120] *id.*

drawn out saga in the United Kingdom concerning the need for tighter controls on the press and the protection of individual privacy.

In the UK there is no direct legal protection of personal privacy (informational, spatial or otherwise), although certain privacy interests are protected in an ancillary manner through other legal rights and rights of action. For example, the law of breach of confidence protects confidential information - an important subset of personal information. Similarly, the law of trespass protects property interests which can in turn protect personal spatial interests by ensuring limited access to property and therefore limited access to persons on the property. However, towards the end of the 1980s there was a growing concern about the activities of the press in intruding on the lives of individuals coupled with a growing realisation that existing laws could not protect adequately all of the privacy interests which individuals would like to enjoy. In April 1989 it was announced that a Committee would be set up under the Chairmanship of David Calcutt QC with the following terms of reference:

> In the light of the recent public concern about intrusions into the private lives of individuals by certain sections of the press, to consider what measures (whether legislative or otherwise) are needed to give further protection to individual privacy from the activities of the press and improve recourse against the press for the individual citizen, taking account of existing remedies, including the law of defamation and breach of confidence; and to make recommendations[121].

Like the Younger Committee before it, however, the Calcutt Committee declined to recommend the introduction of a statutory right of privacy in the UK[122]. Instead, the focus of the Committee fell on the establishment of the Press Complaints Commission (PCC) which was designed to replace the Press Council as the self-regulatory body of the press. The PCC was given 18 months to prove that it could adequately police the press and

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[121] Home Office, *Report of the Committee on Privacy and Related Matters* (The Calcutt Report), Cm 1102, HMSO, June 1990, at 1.

[122] *ibid*, paragraph 12.5.

provide effective means of redress for complaints by individuals concerning intrusive journalistic practices. Recommendations regarding legal measures to tighten individual privacy protection were confined to the establishment of certain criminal offences in England and Wales and the right to complain to the PCC and seek redress for any privacy invasions. During its investigations the Committee found that although a wide range of complaints had been received about press activity, the nature of the complaints could be arranged into two distinct categories of intrusion into privacy:

- physical intrusion by reporters and/or photographers; and
- publication of intrusive material.

The Committee made reference to a recent survey which had been conducted by MORI for the News of the World on 28 - 30 November 1989[123]. This showed that 73% of those sampled considered that the press intruded too much into the lives of public figures. That said, only 29% of the sample thought that tighter laws for privacy protection were required. The Committee commented that,

> We have found no reliable evidence to show whether unwarranted intrusion into individual privacy has or has not risen over the last twenty years[124].

This of course is restricted to invasion by the press. Yet, despite the above comment, the Committee felt that there existed a need for legislation to address the problem of intrusion into the lives of individuals by the use of surveillance technologies. It proposed criminal offences along the following lines[125]:

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[123] *ibid*, paragraph 4.6.

[124] *ibid*, paragrpah 4.8.

[125] *ibid*, paragraph 6.33. Defences were outlines as follows : 'It should be a defence to any of these proposed offences that the act was done - a. for the purposes of preventing, detecting or exposing the commission of any crime, or other seriously anti-social conduct; or b. for the protection of public health or safety; or c. under any lawful authority.', see paragraph 6.35.

- *The following acts should be criminal offences in England and Wales:*

  a. entering private property, without the consent of the lawful occupant, with the intent to obtain personal information with a view to its publication;

  b. placing a surveillance device on private property, without the consent of the lawful occupant, with the intent to obtain personal information with a view to its publication;

  c. taking a photograph, or recording the voice, of an individual who is on private property, without his consent, with a view to its publication and with the intent that the individual shall be identified.

It is submitted that these criminal offences are premised on a view of spatial privacy which bears out that argued for above. It can be seen that although entry onto private property is necessary in the case of (a) and (b), the same is not true of offence (c). Thus, actual physical intrusion is not always necessary for an invasion of privacy. Furthermore, in the case of (a) and (b) no actual personal information need be obtained to constitute an invasion of privacy. It is sufficient that the private sphere has been penetrated and there is an intention to seek out such information for publication. That is, it is the invasion of the private space rather than the taking of private information which is thought to constitute the offensive behaviour. Similarly, as regards offence (c) it is not the obtaining of information in the guise of a photograph or a voice sample which is necessarily the invasion of privacy - for this could occur when the person was in public - but rather it is the obtaining of this information when the person is in the private sphere. It is important to note that there is no qualification that the information be 'personal' or 'private'. This suggests that the focus of the offence, as with (a) and (b), is the invasion of the private sphere rather than the obtaining of personal information. Together these suggested offences suggest not only a loophole in the existing law, but also a perceived need for greater protection in the field of spatial privacy.

In July 1992 David Calcutt was again asked to report on the issue of privacy and press regulation. This came about because of a failure on the part of the press to implement successfully the recommendations of Calcutt I and because no action had been taken regarding the introduction of the criminal offences outlined above. In an amazing turnaround, the Report of Calcutt II recommended that further consideration should be given by the Government to the introduction of a statutory right of privacy in the UK[126]. It was also recommended that the criminal offences be enacted (with minor changes)[127]. In response a Consultation Paper was produced by the Lord Chancellor's Department in association with the Scottish Office[128]. In the end, however, Calcutt's recommendations concerning a statutory right to privacy were rejected[129]. Moreover, no steps have, to date, been taken to implement the criminal provisions protecting spatial privacy. It is undeniable, however, that there remain considerable concerns about this form of personal privacy. The inaction of the UK Government will serve only to exacerbate such concerns.

4.5. -The European and International Dimension

The rise in concern for personal privacy can also be witnessed on the International and European level[130]. In particular, the need to protect informational privacy has been advocated by a number of bodies over the last few decades. As long ago as 1980 the Council of the OECD issued guidelines on the protection of privacy and cross-border flows of personal data[131]. In 1981, the Council of Europe issued a Convention for the Protection of

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[126] Department of National Heritage, Review of Press Self-Regulation, Cm 2135, HMSO, January 1993, paragraphs 7.33 - 7.42.

[127] *ibid*, paragraphs 7.1 - 7.31. The changes proposed do not affect the essential nature of the offences, as discussed above. It should be noted that because the Report recommended the introduction of a statutory complaints tribunal, an alternative approach that was offered was to incorporate the substance of the criminal offences into a statutory code which the tribunal would admisiter. This proposal was endorsed by the National Heritage Select Committee, see - HC 294-1, 1993.

[128] Lord Chancellor's Department/Scottish Office, Infringement of Privacy, July 1993.

[129] This occurred in the summer of 1995, see debate at 263 H.C.Deb. c.1323, following the announcement of the response of the Government to the recommendations for a privacy law - Cm.2918, 1995.

[130] For comment see, Brennan, T.J. and MacAuley, M.K.; 'Remote Sensing Satellites and Privacy: A Framework for Policy Assessment', 4(3), *Law,Computers and Artificial Intelligence*, 233, (1995); Tupman, W.A.; 'Cross-national Criminal Databases: The Ongoing Search for Safeguards', 4(3), *Law, Computer and Artificial Intelligence*, 261, (1995); Slee, D.; 'Privacy and the European Union : An Examination of the Provenance and Content of the Forthcoming Data Protection Directive and its Likely Impact on UK Data Protection Law', 4(3), *Law, Computers and Artificial Intelligence*, 277, (1995), and Reidenberg, J.R.; 'Privacy in the Information Economy: A Fortress or Frontier for Individual Rights?', 44, *Federal Communications Law Journal*, 195, 1992.

[131] 23 September 1980.

Individuals with regard to Automatic Processing of Personal Data. To date this is the only international legal instrument in this field[132].

The European Community has long been aware of the problems and concerns relating to cross-border personal data exchanges and in a number of resolutions dating back as far as 1976 the European Parliament has expressed considerable disquiet about the lack of harmonisation in this area within the Community. Several calls have been made to the Commission to prepare draft legislation aimed at remedying the situation[133]. In 1981 the Commission issued a recommendation which made it clear that it considered protection in this area to be of fundamental importance, and recommended that member states ratify the Council of Europe Convention before the end of 1982. The failure of many member states to do so and the diversity of national approaches to the protection of personal data eventually led the Commission to produce, not one, but two draft directives aimed at harmonisation of Community laws. COM (90) 314 final - SYN 287 was issued on 13 September 1990 and contained a proposal for a Council Directive concerning the Protection of Individuals in relation to the Processing of Personal Data[134]. On the same day and in the same document[135], the Commission also proposed a Council Directive on the Protection of Personal Data and Privacy in the context of Public Digital Telecommunications Networks, in particular the Integrated Services Digital Network (ISDN) and Public Digital Mobile Networks. It was felt that this second directive was necessary to supplement the general directive by applying the general principles of data protection to the specific requirements of the new telecommunications networks. The Council and the European Parliament had stressed on many occasions the need to protect

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[132] Note, however, the Convention leaves open a large number of options for the implementation of basic principles which it upholds.

[133] OJ No C100, 3/5/1976, p.27; OJ No C140, 5/6/1979, p.34; OJ No C87, 5/4/1982, p.39.

[134] A lacuna in UK Data Protection law is thought to have been exposed by the House of Lords decision in *R v Brown* [1996] 1 ALL ER 545. For comment see, Morton, J.; 'Data Protection and Privacy', 10, *European Intellectual Property Review*, 558, 1996.

[135] COM (90) 314 final - SYN 288.

personal privacy in light of developing technologies[136]. The general directive was eventually adopted in its final form on 24 October 1995[137]. In response the UK Government produced a consultation paper inviting views on how it might best implement the provisions of the directive[138]. This must be done before 24 October 1998[139]. The telecommunications network directive remains in a draft form. For the purposes of this chapter the production of these directives reinforces the argument already advanced that to an unprecendented degree the potential threat to informational privacy is greater now than it has ever been. The arguments concerning spatial privacy have already been made. Thus we see that for both conceptions of privacy advanced in this work - spatial privacy and informational privacy - there are very good reasons for seeking at the present time to study the desirability and efficacy of legal protection of personal privacy. Historical and sociological events have conspired to produce a society which values individuals yet which threatens their privacy interests almost as a matter of course. It is therefore submitted that it is a valuable and worthwhile exercise to examine the concept of privacy along the lines outlined herein. It has already been stated that the focus of this work is privacy in the health care setting. The next section explains why this context was chosen.

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[136] OJ No C257, 4/19/1988, p.1; OJ No C196, 1/8/1989, p.4; OJ No C7, 12/1/1987, p.334; OJ No C12, 16/1/1989, p.66; OJ No C12, 16/1/1989, p.69.

[137] Dir 95/46, OJ L281/31, 23 November 1995.

[138] Home Office, Consultation Paper on the EC Data Protection Directive (95/46/EC), HMSO, March 1996.

[139] For comment on how the Directive will affect rights in the UK see, Hogg, M.; 'Privacy and European Data Protection Rights', 1996 *Scots Law Times* 127.

5.1. - PRIVACY IN CONTEXT: THE HEALTH CARE SETTING

As has already been stated, privacy has found a role to play in very many areas of life. And, for the large number of areas where privacy has found a role, there is a corresponding large number of *different* roles which privacy plays. To attempt a discussion of privacy in all such areas would be foolhardy. It is submitted that it is necessary to focus on one area of life - one aspect of the interface between the individual and society - in order to carry out a worthwhile and sufficiently in-depth study of privacy. This means, therefore, that what is said in this work must be seen as context specific. The definition of privacy which is offered, the function it is perceived as having, and the role which it is argued it should play, are limited by the setting in which the discussion is carried out. This is not to say that what is argued in this work will not be of some relevance to privacy in other contexts, it is simply to state that no warranty is given as the applicability of what is said outside the chosen context for this discussion. The chosen context is that of health care. The focus of this work is, therefore, patient privacy.

5.2. - Privacy : A Concept in Search of a Context

To a great extent, the reasons for choosing the health care setting as a context for this discussion of privacy mirror the reasons for setting the entire work within the broad context of the western liberal tradition. The need to choose a context is dictated by the nature of the concept of privacy. Privacy is exceptionally difficult to define. One can offer a variety of different definitions of privacy, some of which can conflict, and some of which are antithetical to each other, yet almost all of which can be justified and are plausible[140]. This thesis is not intended to involve a philosophical discussion of the range of possible meanings of privacy. Nor, is it intended to provide a definitive account of privacy. Rather, it is intended to argue for a particular conception of privacy which will be of practical use

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[140] This will be discussed further in chapter five, *infra*.

in helping us to understand the kinds of individual interests which are at stake in the health care context and in appreciating the role which the law might have in recognising and protecting such interests. For such a particular conception is required a particular setting, the limits of which are relatively certain and the function of privacy therein relatively clear. The reasons for choosing as that context the health care setting are outlined below.

5.3. - Health Promotion & the 'Cult of the Body'

Axiomatically, the rise of western liberal democracy has spawned a very egocentric society. For the majority, one's private life takes considerable precedence over social or community matters. Moreover, Prost has argued that,

> [t]here is no more telling sign of the primacy of individual life than the modern cult of the body.[141]

This is a reference to the near-obsessional interest displayed by many in the western world concerning personal appearance and body management. Prost cites increases in concern with personal hygiene, physical fitness and healthy eating as evidence of the development of such a cult[142]. The consequence of all of this, he notes, is that the body has become the focal point of personal identity,

> [t]o be ashamed of one's body is to be ashamed of oneself.[143]

With the increased interest in the body has come an increased concern with threats to the body. Arguably, the most consistent and persistent threat to the body is illness. Not surprisingly, therefore, concerns about ill health have taken a sharp rise in recent times[144]. Indeed, the promotion of health and well-being has become of paramount importance to

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[141] Prost, A.; 'The Family and the Individual', in Prost and Vincent, 'The History of Private Life', *op. cit.*, at 93.

[142] *ibid.*, at 87 - 101.

[143] *ibid.*, at 93.

[144] Prost discusses this at 95 - 98.

western society. Of course, the health of individuals is of importance to all societies, but it is with unwaiverable conviction that western states place the pursuit of health as primary among the prerequisites of a 'good life'. Further, in such states health has come to mean, not just the absence of illness, but the attainment of a state of well-being which includes an entire range of desirable features and characteristics, including physical fitness, attractiveness to others, correctness of proportions and psychological stability[145]. Often the attainment of this state is achieved with the help of modern medicine. Technological advances have allowed the boundaries of medicine to be pushed ever further forward, making the treatment of actual *ill* health but one option in a range of possible options offered to patients. As more can be done for the 'health' of the populus, so more interest is taken by the populus in its 'health'[146]. This helps to explain the importance of health promotion - and therefore health care - in western societies. It is submitted that it is valid to choose the health care setting as a context for a discussion of privacy because of the important place which health care has in our society and because of the strong connection which exists between concerns about health promotion and concerns about privacy protection.

5.4. - Body, Self and Privacy

The link between the self and the body is an obvious one for various reasons, not least of which is the fact that the body is seen to 'house' the self and be governed by it. Furthermore, the body is a tangible and real manifestation of the abstract we call 'the self' which makes the latter easier to conceptualize. Body and self are inextricably linked, and often - and quite naturally - the two are perceived as being one and the same. Protection of the body therefore becomes synonymous with protection of the self. So, in circumstances

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[145] The World Health Organisation defined 'health' in its Constitution of 1946 as '...state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity.', WHO; 'Constitution', New York, WHO, 1946.

[146] The habit of turning to medicine for the promotion of health has been called the 'medicalization of health' and it is not always perceived as appropriate or desireable, see, for example, Downie, R.S., Fyfe, C. and Tannahill, A.; 'Health Promotion: Models and Values', Oxford, Oxford University Press, 1990, at 1.

where the body is under threat, for example by disease or illness, individuals can experience feelings of deep violation of their inner self and invasion of a sphere of their life over which they thought they had exclusive control. As the Danish Council of Ethics has put it,

> Disease - especially severe disease - is a personal matter in the sense that it concerns fundamental aspects of a human being's person: the potentiality for physical development, pain, suffering and, ultimately, death. A person's outlook on his own disease is therefore a decisive part of his relationship with himself. To a very great degree, this relationship is instrumental in determining an individual's personal sphere, that part of life which a person is entitled to keep to himself.[147]

Moreover, if individuals subject themselves to health care in an attempt to remove the immediate threat to their body, in the process this might exacerbate the feelings of violation and invasion which have been experienced. For example, in order to assist in the betterment of health, very often aspects of the self have to be revealed to health care providers. Thus, the body must be exposed to detailed examination, intimate and personal details have to be disclosed, family histories must be recounted, and humiliating procedures must be braved. The end result of all of this may, or may not, be an improvement in health. The ultimate goal of health care, therefore, may, or may not, have been achieved. But in the process, the individual has revealed his or her inner self to others, has given away personal information and knowledge and has been exposed to invasive incursions on the body. Of course, this is not to say that health care is *necessarily* a threat to that private sphere of an individual's life, but it does highlight how the provision of health care is intimately connected with the private life of individuals and also how health care provides the means for potentially serious invasions of privacy.

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[147] See, Danish Council of Ethics, 'Ethics and Mapping the Human Genome', 1993, at 52.

5.5. - Threats to Patient Privacy in the Health Care Setting

There are many ways in which the provision of modern health care and the machine of modern medicine pose potential threats to patient privacy. An example is found in the use of wards to care for patients. Some of the most personal moments of one's life are lived out in hospitals, yet easy access to persons is afforded by a system which places groups of patients together in the same room with no separation between them save a flimsy curtain. Conversations about diagnosis, prognosis and treatment can be overheard, notes are left at the end of patients' beds which can easily be read, and generally, the practice of everyday medicine is conducted before an audience consisting not only of other patients, but also families and friends of such patients and other visitors to the institution. Even when patients have private rooms the position is not much improved. Access to their person and information about their condition is freely available to a range of hospital staff: both clinical and ancillary. Doctors, nurses, auxilliaries, support staff, cleaners, and administrators can all gain such access. Even unauthorised visitors can easily breach the security of hospitals to invade the privacy of patients[148]. Indeed, one of the most celebrated privacy cases to be heard in the UK courts in recent times involved just such a scenario.

5.5.1. - *The case of Kaye v Robertson*

In *Kaye v Robertson*[149] a British television actor, Gorden Kaye, had been seriously injured during the winter storms of 1990 and underwent brain surgery at Charing Cross Hospital in London. While he was in a private room recovering, two reporters from the Sunday Sport newspaper gained access to his room, carried out an interview and took some photographs. Their intention was to publish these in a subsequent issue of the newspaper.

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[148] This may sound like a plea for greater security in hospitals, but it is not. It is an example of how patients are placed in an extremely vulnerable setting when in the hands of health care providers. The nature of the institutions of medical care is such that tight security is a scarce and ill-affordable luxury. This is a fact of life. But, it should nevertheless be recognised that this feature of modern health care serves to heighten the privacy concerns of the incumbents of such institutions.

[149] [1991] FSR 62. This case is discussed in more detail, *infra*.

Mr Kaye, however, had no recollection of the interview minutes after it had taken place and, in any event, was in no state to give valid consent to its publication. Yet, on seeking a remedy to prevent publication, he was, in effect, unsuccessful[150]. The extent of his remedy was to have a statement published along with the story and photographs which made it clear that they had been obtained without the plaintiff's consent. In his judgment Leggatt L.J. made the following comments,

> [the] right [of privacy] has so long been disregarded here that it can be recognised now only by the legislature....it is to be hoped that the making good of this signal shortcoming in our law will not be long delayed.[151]

This case, perhaps more than any other, has highlighted the woeful inadequacy of English law in relation to the legal protection of personal privacy. No better protection has been recognised or accorded by the Scottish courts[152]. That the circumstances which gave rise to this case took place in a health care setting is significant. As Bingham L.J. said,

> If ever a person has a right to be let alone by strangers with no public interest to pursue it must surely be when he lies in hospital recovering from brain surgery and in no more than partial command of his faculties.[153]

The vulnerable position in which persons find themselves in the health care setting makes all the more pressing the need for adequate and effective protection of their interests, including those of privacy. Moreover, this case provides a good example of how the privacy interests which patients have in the health care setting are of two distinct, yet related,

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[150] In the absence of specific legal protection of privacy in the UK, Mr. Kaye had to try four different existing forms of action in an attempt to secure a satisfactory remedy. These were: Libel, Malicious Falsehood, Trespass to the person, and Passing Off. Only malicious falsehood was considered to be of any relevance, but no damages were awarded and the injuction granted was limited to publishing anything with the interview and photographs which, 'could be reasonably understood or convey to any person reading or looking at the Defendant's *Sunday Sport* newspaper that Plaintiff had voluntarily permitted any photographs to be taken for publication in that newspaper or had voluntarily permitted representatives of the Defendants to interview him while a patient in the Charing Cross hospital undergoing treatment.', *ibid* at 66. In other words, Kaye could not prevent publication of the story or photograph, merely publication of his consent.

[151] *ibid*, at 71.

[152] These matters will be discussed further in chapter six, *infra*.

[153] *ibid*, at 70.

kinds: informational privacy and spatial privacy. The invasion of Gorden Kaye's privacy occurred at two levels: the invasion of personal space by uninvited third parties and the invasion of his privacy interests in personal information by the publication of photographs of him and details about his condition in a public newspaper. The plaintiff's failure to secure adequate legal protection of either of these interests is lamentable and requires that the situation be redressed.

5.6. - PRIVACY, STATE INTEREST AND HEALTH CARE PROVISION

A further justification for this choice of context is the role of state interest in health care provision. Just as it has already been observed that one sign of a democratic system is the extent to which the state takes an interest in the lives of individuals, it is clear that one of the primary ways in which this occurs is in relation to health care. As Prost comments,

> ...sickness, a central concern of private life, has become the focus of much public policy. Nothing is as private as health, yet nothing is so readily made the responsibility of the public authorities. Health is now a public as well as private affair.[154]

The interest of the state in health matters has consequences for patient privacy in at least two ways. First, in those countries which provide state-run health care, the public nature of the enterprise takes away from the individual patient control of their environment. Whereas such a public system might facilitate the chances of every individual of gaining access to medical care, it does little to address concerns with individual privacy which flow from this. For example, scarcity of resources means that ward systems have to be used with the resultant threat to privacy outlined above.

Second, under the mantle of public health, states take it upon themselves to intervene in the lives of individuals in circumstances where interference is thought to be justified on health

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[154] *ibid*, at 98.

grounds (usually invoking a 'best interests' argument) or when the individual is perceived to be a threat to the health of the community at large (usually invoking a 'public health' argument)[155].

5.6.1. - *Notifiable Diseases*

As an example of state intervention consider the concept of notifiable disease. *All* states pass legislation requiring the notification to public authorities of cases of specified contagious diseases[156]. The most common 'notifiable' diseases include typhoid, smallpox, cholera, plague and relapsing fever[157]. In such circumstances, it is argued that the threat to privacy which such notification poses is justifiable because of the threat of disease in the wider community. In many cases this is undoubtedly true. However, the choice of which diseases are notifiable is sometimes open to question. For example, in some states AIDS has been made a notifiable disease[158]. Yet AIDS[159] - or rather its antecedent HIV[160] - cannot be transmitted by casual contact. Individuals must engage in 'high risk behaviour' before

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[155] See, for example, the US Supreme Court decision in *Jacobson v Massachusetts* 197 US 11, 24 - 30, 49 L Ed 643, 25 S Ct 358 (1905), in which it was held that the court could balance the interests of the individual in refusing smallpox vaccine (protected under the Constitution) against the state's interest in preventing disease. The conclusion of the court was that the state interest was sufficiently compelling not to render unconstitutional a law requiring compulsory vaccination against smallpox save in circumstances where the individual could show significant disadvantage or threat to life.

[156] For a critical account of infectious disease control legislation in Germany, Switzerland, England, Sweden and the Netherlands, see Dute, J.; 'Affected By The Tooth of Time : Legislation on Infectious Diseases Control in Five European Countries', 12, *Medicine and Law*, 101, 1993.

[157] In England and Wales the law governing this matter is found in Public Health (Control of Disease) Act 1984. Other relevant legislation includes the Public Health (Infectious Diseases) Regulations 1968 and 1985. In Scotland the law is to be found in a number of statutes dating back to the Infectious Disease (notification)act 1889 and the Public Heath (Scotland) Act 1897.

[158] For comment on this issue and various other legislative responses to HIV/AIDS, see Keown, J.; 'AIDS: Should It Be Made a Notifiable Disease?', July/August, *Professional Negligence*, 121, 1989, Fluss, S.; 'What Can Legislators Do to Combat AIDS?', January, *Commonwealth Law Bulletin*, 283, 1988, and Kirby, M.D.; 'AIDS Legislation - Turning Up the Heat?', 12, *Journal of Medical Ethics*, 187, 1986. States in which AIDS is notifiable include, Denmark, Norway, Sweden, and most U.S. states. Neither HIV nor AIDS is notifiable in the U.K.

[159] AIDS is a nemonic for Acquired Immune Deficiency Syndrome. The condition was first discovered in 1981.

[160] HIV refers to Human Immunodeficency Virus. The virus was first discovered in 1983. A test became available in 1985. It is thought that HIV leads to AIDS. AIDS, as a syndrome, cannot be transmitted from one individual to another.

transmission is possible[161]. In fact, this disease has been labelled by American clinicians as 'the least infectious disease we have every come across'[162]. To some this suggests that the 'balance' between public interests in public health and private interests in personal privacy is not being struck in an acceptable manner[163].

Moreover, if notifiable diseases legislation is not supported by additional provisions designed to ensure that individual rights are protected, the continued existence of such legislation becomes questionable. A recent survey of the legislative provisions of five European countries concluded,

> In many respects current legislation on infectious diseases control appears to be outdated. For at least two reasons legal provisions need modernization: First, there has been a considerable increase in medical knowledge of disease transmission and as a consequence the methods of interrupting the spread of disease are today much more refined than they were in the past; second, in current legal analysis greater emphasis is placed on the protection of individual rights, especially the right to privacy and the right to physical integrity.[164]

Other examples of state interest in health matters include: the regulation of abortion[165], compulsory vaccination programmes[166], the requirement of blood tests before marriage[167],

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[161] There are only three methods of transmission of HIV. These were identified in 1982. They are: unprotected anal or vaginal sex, the sharing of needles in intravenous drug abuse and the infection by a mother of her unborn child. No other verified method of transmission has been identified.

[162] Jeffries, D.; 'AIDS - The New Black Death?', *Medico-Legal Journal*, 158, 1986, at 158.

[163] This is especially true given the consequences of making a disease notifiable. Not only does this mean that all clinicians are legally obliged to pass patient information onto authorities, but also it means that the same authorities have considerable powers to collect further information through compulsory examination and contact tracing. Furthermore, in the name of disease control, such authorities can exercise strong control powers over individuals including quarantine and isolation. See, Dute, *loc. cit.*, at 101. See also, Guttmacher, S.; 'HIV Infection: Individual Rights v. Disease Control', 17(1), *Journal of Law and Society*, 66, 1990.

[164] Dute, *loc. cit.*, at 107 - 108.

[165] In the US these are considered to matter of the constitutionally protected right of privacy, see chapter three, infra.

[166] Most western states require, or strongly encourage, parents to have children inoculated against a range of diseases including tuberculosis, polio, rubella and measles.

[167] In many U.S. states prospective spouses are required to submit to a blood test before the marriage ceremony. Tests can be done for a range of matters including HIV, STD's (sexually transmitted diseases) and some genetic disorders.

the denial of property rights in one's own body[168] and the prohibition of assisted suicide/euthanasia[169].

It is not argued here that all of these examples necessarily relate exclusively to an invasion of personal privacy, but they do all concern a blurring of the division between public and private spheres of life. In this thesis an attempt will be made to provide greater clarity for this division in the health care setting using the concept of privacy.

5.7. - CURRENT THREATS TO PATIENT PRIVACY

Finally, the justification for studying privacy in the health care setting *at the present time* is found in the increased threat which technological *medical* advances pose to patient privacy. Just as it has been argued above that technological advances have given rise to more concerns about privacy generally, so too it can be seen that medical advances are likely to heighten patient concern for privacy in a clinical setting. There are two ways in which this is likely to happen.

5.7.1. - *Advances in Medical Technology and the Threat to Patient Informational Privacy*

As medical science pushes ever onwards it reveals new and seemingly never-ending knowledge about our species, *homo sapiens*. Better than ever before we understand how as an organism we reproduce, grow, develop and die. In particular, scientific advances now

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[168] See, *Moore v The Regents of the University of California* 793 P 2d 479, 271 Cal Rptr. 146 (1990). For comment, see Nuffield Council on Bioethics, 'Human Tissue: Ethical and Legal Issues', April 1995, at pp.2, 5, 10 - 12, 55, 67, 72 - 73, 123, 139 - 140, Annas, G.J., 'Outrageous Fortune: Selling Other Peoples Cells', *Hastings Center Report*, November/December, 36, 1990.

[169] Most western states expressly forbid assistance in the taking of one's own life. Generally the criminal law acts as the sanction, see, in the UK, *R v Cox* (1992) 12 B.M.L.R 38, but *cf R v Arthur* (1981) 12 BMLR 1. Attempts to alter this in Oregon and the Northern Territory in Australia have not been successful. In the Netherlands no legislation exists to legalise euthanasia. Assistance in taking one's life is accepted but only within narrowly defined guidelines. For comment on this latter, see Keown, I.J.; 'The Law and Practice of Euthanasia in the Netherlands', 108, *Law Quarterly Review*, 51, 1992. In January 1994 the Report of the House of Lords' Select Committee on Medical Ethics (H.L. Paper 21, 3 volumes, 1993/1994) expressly rejected reform in the UK along the lines of introducing legislation allowing voluntary euthanasia. On the subject of reform in this area see, Otlowski, M.; 'Active Voluntary Euthanasia: Options for Reform', 2, *Medical Law Review*, 161, 1994.

allow us to examine ourselves at the microscopic level. It is now possible to examine the human genome and to understand the workings of deoxyribonucleic acid (DNA) : the so-called blueprint of life. For the community such advances are clearly in the interests of the collective good. For the individual, however, the ability to gain knowledge about *one's own* genome could be a frightening prospect. Such information could reveal an underlying disease or dysfunction, or could indicate a predisposition to such disease. Moreover, it could have implications for one's relatives given the common genetic heritage which family members share. Also, once such information is discovered a question mark arises over its use and possible misuse. Family members, the state, insurers and employers could all claim an interest in 'knowing' the genetic information of individuals. The basis and legitimacy of such interests will be discussed in chapter two. That such information exists, however, means that potential invasions of privacy can occur. Before scientific advances provided us with the means to gather such information there was no such concept as 'genetic privacy'. Now, arguably, such possibilities require that we address questions of privacy which arise from the discovery of genetic information.

A related point concerns the use of electronic medical records which facilitates considerably the use of personal health data. Such systems open up many potential uses of health data beyond the immediate care and treatment of the patient from whom the data were collected. In ways which are unprecedented, personal information about individual patients can be disseminated and used on a much wider scale than ever before. For example, Dierks has argued that compiled medical data can be assigned to four main uses: therapy, administration, financing and research[170]. Databanks of health information have been proposed in various jurisdictions[171], not least the United Kingdom where a National Health Service super database has been established providing multiple access points throughout the

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[170] Dierks, C.; 'Medical Confidentiality and Data Protection as Influenced by Modern Technology', 12, *Medicine and Law*, 547, 1993.

[171] See Gostin, L.; 'Genetic Privacy', 23, *Journal of Law, Medicine and Ethics*, 320, 1995 in which he discusses the US position.

country[172]. Genetic registers and DNA fingerprint banks have also been proposed for a variety of reasons including medical research and crime detection and prevention. In the US the exceptionally ambitious National Health and Nutrition Examination Survey (NHANES) is underway to collect both genetic and non-genetic information. Already the project has collected non-anonymous health data from over 40,000 Americans in 26 states. The data collected range over 500 separate issues concerning, *inter alia*, the individual's diet, bone density, blood pressure, risk status, drug use and history of sexually transmitted disease. NHANES also tests and stores biological samples for long-term follow-up and statistical research[173]. Yet, although such moves might make the administration of hospitals easier, or the balancing of national health care budgets more accurate, or the catching of criminals less time consuming, or even the search for further medical advances a little less difficult, without adequate legal safeguards for the rights of individual patients, unauthorised uses of personal medical data could be construed as harmful and offensive invasions of privacy. Dierks argues that medical confidentiality, as the traditional means used to ensure that patient privacy is protected, can no longer adequately protect patient rights. From the perspective of German laws, he argues for a greater role for data protection provisions both to protect patient rights and,

> ...to let the enormous chances presented by new methods of data processing be fully exploited in research.[174]

Writing from within a system which has made the right to 'informational self-determination' a constitutional right[175], he argues for an acceptable balance to be struck between 'optimized data exploitation and maximum protection of the individual's rights'[176]. However, in systems with a less developed sense of individual patient rights such as the UK, to talk of balance is meaningless. A balance cannot be struck if patients are

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[172] See, Tonks, A.; 'Information Management and Patient Privacy in the NHS', 307, *British Medical Journal*, 1227, 1993.
[173] Gostin, *loc. cit.*, at 322.
[174] *ibid*, at 550.
[175] *ibid*, at 548.
[176] *ibid*, at 549.

denied recognition of the fundamental rights related to being a patient. It is far from clear that such rights are adequately defined and/or recognised in this country[177]. As paramount among them, the right of privacy requires clear definition and recognition. As will be shown in chapter four, the law of confidentiality is in an unsophisticated and confused state in the United Kingdom. Whereas it is not denied that it helps to protect some privacy interests of medical patients, it will be argued that it cannot adequately do so when faced with new problems posed by medical advance. As an alternative, a particular view of the concept of privacy will be outlined which will form the basis of a legally protected right which *can* protect the interests of patients.

5.7.2. - *Advances in Medical Technology and the Threat to Patient Spatial Privacy*

Another problem has arisen in recent years because of developments in life-prolonging techniques. *Inter alia*, privacy arguments have been advanced to challenge the application of such techniques to patients. This can be seen most readily in the cases of patients in persistent vegetative state (PVS) which have come before the courts of the United States, the United Kingdom and the Republic of Ireland (Eire).

5.7.2.1. - *What is PVS?*

It is notoriously difficult to articulate a satisfactory definition of Persistent Vegetative State[178]. Common features include an irregular but cyclical state of circadian sleep and wakefulness, yet which is not accompanied by any evidence of self-consciousness or awareness, specific recognition of external stimuli, or consistent evidence of attention or

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[177] The Data Protection Registrar has, for example, urged the British medical profession to adopt a 'culture of data privacy'. Speaking at a conference on healthcare computing in April 1997, Ms Elizabeth France argued that the use of 'pseudonymised data' could go a long way to addressing the problems of privacy and confidentiality which surround the NHS's medical data networks, see Carnell, D.; 'Data Protection Registrar Calls for Culture of Privacy', 314, *British Medical Journal*, 922, 1997.

[178] For comment on the legal positions in the British isles, see, Mason, J.K. and Laurie, G.T.; 'The Management of the Persistent Vegetative State in the British Isles', *Juridical Review*, 263, 1996.

inattention or learned responses. Patients generally retain cranial-nerve and spinal reflexes, including those related to visual and auditory stimuli. Such patients are, however, wholly insensate. The condition of PVS is furthermore degenerative: the grey matter of the brain dissolves and in correctly diagnosed patients there is no hope of recovery of consciousness. In contrast, the brain stem remains intact and there is therefore no need for artificial ventilation. The same is not true of feeding and hydration. The feeding and hydration of patients in PVS is done either by naso-gastric intubation or gastrostomy tube.

5.7.2.2. - *PVS: The Legal Issues*

In each PVS case to be heard by a court of law the question for the court has been the legitimacy of removal of invasive artificial feeding techniques done with a view to allowing the patient to die[179]. The legal issues which arise from such a proposed course of action are, in the main, two-fold : first, on what civil law authority might such a decision be taken (and by whom)? and second, what is the position of the criminal law, given that the patient will die as a direct result of the removal of feeding? For the purposes of this thesis it is interesting to note that privacy arguments have been advanced in many of these cases justifying the removal of artificial nutrition and hydration. Basically, the argument which has been put is as follows : to continue to 'feed' an individual when there is no evidence that the individual consents to the procedure and there is no 'benefit' to be gained from the procedure (medical or otherwise) is an invasion of the patient's fundamental rights. Most particularly, it is argued that it is an invasion of the patient's privacy. This argument is seen most clearly in the cases which have come before courts in jurisdictions which have a written consitution, in particular, the United States and the Republic of Ireland (Eire).

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[179] Normally, this would happen within two to three weeks from dehydration.

5.7.2.3. - *PVS in the United States*

The nature of the United States Constitutional Right to Privacy will be discussed in detail in chapter five. This is a very wide-ranging right of US citizens which protects many areas of personal life such as the abortion decision, access to contraception and to reproductive services, and home and family life. This now also includes cases involving PVS patients. In *Re Daniel Joseph Fiori* - a recent decision of the Superior Court of Pennsylvania concerning PVS - the judge helpfully carried out a very comprehensive survey of all of the US cases to address the problem[180]. They number over fifty[181]. In his judgment he considers all of the methods used by the US courts in dealing with PVS cases,

> Absent the existence of a statute on the subject, the various legal precepts relied upon to authorise the withdrawal of sustenance from a person in persistent vegetative state have been reduced to a "best interests" analysis, "substituted judgment" criterion or a "clear and convincing" evidence standard of proof which draw their strengths from the federal or state constitutional *rights of privacy*. Equally applicable to the right of an individual to forego life-sustaining treatment is the common law right to freedom from unwanted interference with bodily integrity ("self-determination").
> [emphasis added, citations omitted][182]

One of the most celebrated examples of this is the case of *In re Quinlan*[183]. Karen Ann Quinlan was admitted to hospital on the evening of April 15 1975 after experiencing two 15 minute periods of respiratory failure for reasons which have never been made clear. Three days after her admission the attending physician found evidence of decortication and partial brain stem death requiring that Karen be placed on a respirator to assist her breathing.

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[180] Superior Court of Pennsylvania. Opinions filed January 17th, 1995; 438 Pa. Super. 610; 652 A. 2d 1350 (1995).

[181] This case is discussed by O'Flaherty J. in the Irish case *In the Matter of a Ward*, to be discussed *infra*.

[182] *Fiori*, at 650. The Superior Court decision was later upheld by the Supreme Court of Pennsylvania: *In re Fiori* 543 Pa. 592; 673 A. 2d. 905 (1996).

[183] *In re Quinlan* 70 NJ 10 (1976), 355 A 2d 647.

Although initially in a coma[184], Karen soon developed 'sleep-wake' cycles. This led the expert physicians attending her to conclude unanimously that she was in a "chronic persistent vegetative state". An application was lodged by her father who sought judicial authority to withdraw the life-sustaining measures temporarily preserving his daughter's life, and his appointment as guardian of her person to that end. His request was opposed by Karen's doctors, the hospital, the County Prosecutor, the State of New Jersey and Karen's guardian *ad litem*.

The Supreme Court of New Jersey granted Karen Quinlan's father's wish and appointed him guardian. It held that Karen had a fundamental right of privacy under the US Constitution which did *not* disappear simply because Karen could not exercise it personally. Moreover, the court held that the right of privacy enjoyed by Karen (and all other US citizens) is broad enough to encompass the decision to refuse life-sustaining measures[185]. It was recognised that the State has a constitutional interest in the preservation and sanctity of human life, but in dealing with this challenge to the plaintiff's arguments the court made the following statement:

> We think that the State's interest contra weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims. Ultimately there comes a point at which the individual's right overcomes the State interest. It is for that reason that we believe Karen's choice, if she were competent to make it, would be vindicated by the law. Her prognosis is extremely poor...she will never resume cognitive life. And the bodily invasion is very great...she requires 24 hour intensive nursing care, antibiotics, the assistance of a respirator, a catheter and a feeding tube[186].

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[184] It is important to distinguish between coma and PVS. Coma is typified by a state in which patients can make no verbal response, cannot obey commands and do not open their eyes either spontaneously or to any stimulus. In such a state the patient's respiratory function can be depressed or varied, unlike the PVS patient whose respiratory function is normal. Also, unlike PVS, coma carries with it a chance of recovery depending on the severity of the condition, its cause and treatment, see, 'The Permanent Vegetative State : A Review by the Working Group Convened by the Royal College of Physicians and Endorsed by the Conference of Medical Royal Colleges and their Faculties of the United Kingdom', 30, *Journal of the Royal College of Physicians of London*, March/April 1996, 119, at 121.

[185] *Quinlan*, at 39.

[186] *ibid*, at 40.

Of course, Karen could not exercise the right for herself but the court held that her father as guardian could do so. In this way the civil law authority for the decision to terminate can be seen to be grounded in the patient's right to privacy - a right which protects, *inter alia*, bodily integrity. This, it is submitted, is akin to the notion of spatial privacy argued for above.

It should be noted that the US courts' protection of 'spatial privacy' in the case of PVS patients has not always been articulated in privacy terms. In cases decided subsequent to *Quinlan* some courts have preferred to rely on the common law rather than the Constitution. For example, in *In re Eichner*[187] an 83 year-old man in PVS was held to have expressed sufficiently clearly prior views about not wishing to be maintained in such a state to allow the court to authorise removal of his artificial sustenance. This was done by reference to his common law right to informed consent, the corollary of which is the right to refuse[188]. Similarly, in *In re Conroy* - a case dealing with refusal of treatment albeit not by a PVS patient - it was held that whereas constitutional privacy might be relevant, it was not necessary because the common law was adequate[189].

In the three companion cases of *In re Peter*[190], *In re Farrell*[191] and *In re Jobes*[192] the New Jersey Supreme Court formulated guidelines and procedures under which life-sustaining medical treatment (including artifical feeding) may be withdrawn[193]. In justifying the right of patients to seek withdrawal of treatment the court "reaffirmed the principles established in *Quinlan* and *Conroy*"; namely, the consitutional privacy protection accorded to

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[187] *In re Eichner* 52 NY2d 380, 420 NE2d 72.

[188] See also the companion case decided at the same time which applies the same reasoning, *In re Storar* 52 NY2d 363, 420 NE2d 64.

[189] *In the Matter of Claire Conroy* 486 A 2d 1209 (NJ SC) (1987).

[190] 108 NJ 365, 529 A. 2d 419 (1987).

[191] 108 NJ 335, 529 A. 2d 404 (1987).

[192] 108 NJ 394, 529 A. 2d 434 (1987).

[193] Two of these cases concerned paitents in PVS (Peters and Jobes).

individuals' decisions to refuse treatment and the common law right of self-determination. This latter right encompasses,

> [T]he right of a person to control his own body. [It] is a basic societal concept, long recognised in common law[194].

A fair conclusion to draw from the above would be that the concept of spatial privacy - a physical sphere in which the individual's interests and person are considered to be inviolate except with due cause[195] - is an important and recognised interest in the US. Indeed, it receives protection at two levels. Of course, the common law right of self-determination and the constitutional right of privacy are not applicable solely to patients in PVS[196]. But as has been explained, the unrelenting progress of medicine produces new problems for the law with unnerving regularity and the case of PVS illustrates how, in the US at least, the law has adapted to ensure adequate protection for individual interests, particularly those concerning spatial privacy. Indeed, the problem of PVS has even received Supreme Court attention. However, the terms which the court has used in protecting the PVS patients rights add some confusion to the question of the nature of the protection afforded.

5.7.2.4. - *Cruzan v Director, Missouri Department of Health et al.*

The US Supreme Court dealt with the question of PVS, and more generally the issue of refusal of medical treatment, in 1990 in the case of *Cruzan v Director, Missouri Department of Health et al*[197]. Nancy Cruzan was involved in a car accident in January 1983 which left her hospitalised and in persistent vegetative state. After it became apparent that nothing

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[194] This was stated in *Farrell*, *ibid* at 347, quoting *In re Conroy* 98 NJ at 346.

[195] In the case of *In re Peters*, supra,the New Jersey Supreme Court said the following : 'We find it difficult to conceive of a case in which the State could have an interest strong enough to subordinate a patient's right to choose not to be sustained in PVS.', 108 NJ at 380.

[196] For an example of how the case of *Conroy* has, in fact, substantially expanded the common law right to self-determination in the context of consent to medical treatment see, Schultz; M. M.; 'From Informed Consent to Patient Choice : A New Protected Interest', 95, *Yale Law Journal*, 219, 1985.

[197] 497 US 261, 111 L Ed 2d 224, 110 S Ct 2841, decided June 25 1990.

more could be done for their daughter, Nancy's parents, as co-guardians, asked the employees of the hospital to terminate artificial feeding and hydration. The employees refused to do so without court approval. The trial judge ordered that the parents request should be carried out, but this was overturned on appeal in the Missouri Supreme Court. The parents in turn sought leave to appeal to the US Supreme Court which was granted. The appeal was, however, unsuccessful.

The objection voiced by the parents of Nancy Cruzan against the decision of the Missouri Supreme Court concerned only one aspect of the ruling. The court had held that a patient *has* a right to refuse treatment, including artificial sustenance and that this was based either on the constitutional right of privacy or the common law right to self-determination. Furthermore, the court had held that the decision to refuse treatment *could* be taken on behalf of a patient if the patient was unable to do so him or herself. However, in so holding, the court added that no person could assume the choice of terminating medical treatment for an incompetent person in the absence of "clear and convincing, inherently reliable evidence" that the patient would have so wished. It was held that such was absent in the case at hand[198].

In essence the Supreme Court upheld this view relying on the state interest in the preservation of human life. This interest entitled the state to impose a heightened evidentiary burden on those seeking to terminate life and further entitled the state to take measures to guard against potential abuses of the law to the detriment (death) of incapax

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[198] 'The testimony adduced at trial consisted primarily of Nancy Cruzan's statements made to a housemate about a year before her accident that she would not want to live should she face life as a "vegetable", and other observations to the same effect. The observations did not deal in terms of withdrawal of medical treatment or of hydration and nutrition.' *ibid*, at 246. It should not be thought, however, that the result of the case was that Nancy Cruzan was maintained indefinitely. Several months after the Supreme Court decision another hearing was held before the original trial judge who again ordered that the feeding be removed. This time the state did not object. New evidence had been brought to the trial about Nancy's wishes. Despite the attempts of various groups to prevent the removal of feeding, and after thwarting a group of protesters who tried to enter the patient's room to reconnect her feeding tube, the tube was eventually removed on December 26 1990 and Nancy died 11 days later.

patients. Of interest to this thesis however is the nature of the classification of the right protected.

Having noted the position of state courts regarding PVS cases and the role given to both the right of privacy and the right to self-determination, the Supreme Court took a different approach in grounding the right of the individual to refuse treatment,

> Although many state courts have held a right to refuse treatment is encompassed by a generalised constitutional right of privacy, we have never so held. We believe this issue is more properly analysed in terms of the Fourtennth Amendment liberty interest[199].

The Fourteenth Amendment provides that no State shall "deprive any person of, life, liberty or property, without due process of law." Citing its own prior decisions, the Supreme Court argued that the basis for the right of individuals to refuse medical treatment lies in the constitutionally protected liberty interest[200]. The outcome of this decision was the same as that of the Missouri Supreme Court : individuals have the right to refuse invasive treatments which interfere with the personal physical sphere of their being[201]. The terminology used is, however, different. This terminological disparity - which some would call a conceptual confusion[202] - is an on-going problem for the those seeking to interpret the American Constitution. It has wide-ranging implications for the constitutionally protected privacy right and we shall return to this issue in later chapters. It is sufficient to note at this

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[199] *ibid*, at 242, note 7.

[200] See, *Jacobson v Massachussetts*, 197 US 11, 24 -30 , 49 L Ed 643, 25 S Ct 358 (1905), [in this case the Court balanced the recognised liberty interest of the individual in refusing invasive vaccination with the state interest in protecting public health]; *Washington v Harper*, 494 US 210, 108 L Ed 2d 178, 110 S Ct 1028 (1990), [in this case the Court held that the forcible injection of medication into a non-consenting person's body represents a substanital interference with the person's liberty]; *Vitek v Jones* 445 US 480, 63 L Ed 2d 552, 100 S Ct 1254 (1980), [in which the Court held that the transfer of a patient to a mental hospital coupled with mandatory behaviour modification treatment implicated liberty interests]; and Parham v J.R., 442 US 584, 61 L Ed 2d 101, 99 S Ct 2493 (1979), [here the Court held that a child, in common with adults, has a substantial liberty interest in not being confined unnecessarily for medical treatment].

[201] For analysis of the *Cruzan* decision and its implications for US citizens and states see, Capron, A.M. (ed.); 'Medical Decision-Making and the "Right to Die" after *Cruzan*', 19(1-2), *Law, Medicine and Health Care*, 1991.

[202] See, for example,Wagner DeCew, J.; 'The Scope of Privacy in Law and Ethics', 5, *Law and Philosophy*, 145, 1986.

time that the interest which the courts seek to protect - be it labelled a privacy interest or otherwise[203] - corresponds to the interest which has been identified as spatial privacy in this thesis[204].

5.7.2.5. - *The Republic of Ireland : In the Matter of a Ward*

In July 1995 the Irish Supreme Court heard its first PVS case[205]. The subject of the case, W, was born in 1950 and suffered irreversible brain damage after experiencing three cardiac arrests during a minor gynaecological operation on 26 April 1972. On 14 October 1974 the President of the Irish High Court declared W to be of unsound mind and incapable of managing her own affairs. Initially the father of the ward, then her sister, and then her mother, was appointed committee of her person. In 1992 W was fitted with a gastrostomy tube under general anaesthetic[206]. Finally, in March 1995, an application was made by the committee and the family of the Ward to the High Court in the following terms : (a) that all artificial nutrition and hydration cease; (b) that the Court should give such directions to care having regard to the order of the Court as are appropriate. The High Court assumed jurisdiction in the case under its *parens patriae* jurisidiction derived successively from the prerogative of the British Crown to the Lord Chief Justice of Ireland[207] and finally to the President of the High Court or his assignee[208]. This allows the court to take decisions on behalf of all incapable persons - adult or minor - in respect of both personal and financial

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[203] As Annas has pointed out, '...it should be noted...that both rights [privacy and liberty] derive from the same source, and their content in this context is unlikely to be different.', see, Annas, G. J.; 'The Long Dying of Nancy Cruzan', 19(1-2), *Law, Medicine and Health Care*, 52, 1991.

[204] Writing two years after the *Cruzan* decision, Meisel notes that, 'The Court's shift from a privacy analysis to a Fourteenth Amendment analysis is unlikely to have any impact in state courts on common-law or state constitutional grounds, as well as federal constitutional right of privacy. This has been brone out in subsequent state court decisions, in which they have continued to rely on state constitutions, state statutes, and the common-law right to be free from unwanted intereference with bodily integrity to provide the basis for the right to refuse medical treatment, the refusal of which will reuslt in death.' see Meisel, A.; 'A Retrospective on *Cruzan*', 20(4), *Law, Medicine and Health Care*, 340, 1992.

[205] *In the Matter of a Ward* (1995) 2 I.L.R.M. 401

[206] It should be noted that the Ward was not a case of 'full PVS', but as the trial judge said, 'although the Ward is not fully PVS, she is nearly so and such cognitive capacity as she possesses is extremely minimal.' For comment on this see, Mason and Laurie, *loc. cit.*

[207] By the Government of Ireland Act 1920.

[208] By the Courts of Justice Act 1936.

aspects of their lives. In all cases the paramount interest must be the best interests of the ward. On 10 May 1995 the High Court issued an Order stating that it consented on behalf of the Ward to the withdrawal and termination of abnormal and artificial means of nourishment and declared such withdrawal lawful. Furthermore, the court consented on W's behalf to the non-treatment of infections or other pathological conditions save in a palliative way and declared such non-treatment legal. The Attorney General, the Institution in which the Ward was cared for and the Solicitor General as Guardian *ad litem* appealed to the Supreme Court against the decision. The family also sought to vary the order[209].

The decision of the Supreme Court was delivered on 27 July 1995. In delivering their judgments the majority of justices relied on the privacy rights of the Ward as justification for granting authority to allow her to die.

Chief Justice Hamilton focused on the primacy of the right to life protected under the Irish Constitution (Bunreacht na hEireann, Article 40.3.2.). He noted that the right necessarily implies various other ancillary rights not individually or specifically set forth in he Constitution: the right to live life in the fullest content, to enjoy the support and comfort of one's family, to social contact with one's peers, to education, to the practice of religion, to work, to marry and have children, to bodily integrity, to self-determination and to privacy[210]. More specifically, he argued that the right includes the right to die a natural death and not to have life artificially maintained merely to prolong life. Of the treatment of the Ward he said, '[it] is intrusive, constitutes an interference with the integrity of the body and cannot be regarded as normal means of nourishment.'[211]. Acknowledging that the right to individual privacy and bodily integrity are examples of those unenumerated right

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[209] In essence this concerned a very similar issue to that central to *Cruzan*. The High Court stated that the standard of proof required clear and convincing evidence before medical treatment would be discontinued. The family submitted that the correct standard is balance of probabilities. Second, the family has the right (as opposed to the court) under the Irish Constitution Article 41.1. to require that medical treatment (feeding) be discontinued.

[210] Transcript of Hamilton C.J.'s decision, at 49.

[211] *ibid*, at 51.

recognised by Article 40.3 of the Constitution, he quoted with approval the following passage of his own judgment in *Kennedy v Ireland*,

> ...though not specifically guaranteed by the Constitution, the right to privacy is one of the fundamental personal rights of the citizen which flow from the Christian and democratic nature of the State. It is not an unqualified right. Its exercise may be restricted by the constitutional rights of others or by the requirements of the common good and is subject to the requirements of public order and morality.[212]

Similarly, he referred with approval to an article written by the President of the High Court in which it was stated,

> ...there are very powerful arguments to suggest that the dignity and autonomy of the human person (as constitutionally predicated) require the State to recognise that decisions relating to life and death are, generally speaking, ones which a competent adult should be free to make without outside restraint, and that this freedom should be regarded as an aspect of the right to privacy which should be protected as a "personal" right by Article 40.3.1.[213]

From this he concluded that, if mentally competent, W would have the right to forego the feeding and medical treatment. He went on to argue, moreover, that W's incapacity did *not* deprive her of her right under Article 40.1 of the Constitution to be treated equally before the law[214]. He concluded that the responsibility for the exercise of any of the rights of the Ward rested with the President of the High Court, Lynch, J. by virtue of his *parens patriae* jurisdiction[215]. In the exercise of this jurisdiction the first and paramount consideration must be the well-being, welfare or interests of the Ward. Applying this, Hamilton held that the best interests of the Ward lay in removal of the feeding from her and denial of all

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[212] *ibid*, at 52. *Kennedy v Ireland* 1987 I.R. 587.

[213] *id*.

[214] *ibid*, at 55 - 56.

[215] *ibid*, at 56 - 57.

further medical treatment, save palliative care. This required clear and convincing proof of all relevant matters, which he was satisfied Lynch J. had adduced at trial.

In like manner, O'Flaherty, J.[216], Denham, J.[217], and Blayney J.[218] used privacy as the basis of their respective decisions in this case. The only dissent in the case, that of Egan J., was based on the fact that W was not fully in PVS and therefore the judge in question did not feel that he could make the orders requested. The majority did, however, dismiss the appeals and ordered that artificial feeding and hydration be removed from the Ward. The common basis for the right which justified such a decision was the patient's right to privacy: a right to die with dignity and not be subjected to invasive and unnatural medical procedures. Once again, it is submitted that the recognition and protection of such a right is akin to protecting the spatial privacy interests identified in this work.

5.7.2.6. - *Guillain-Barre Syndrome: the Canadian and New Zealand Experience*

Guillain-Barre Syndrome (GBS) is a disease which affects the nervous system. It destroys the connections between brain and body leaving the afflicted person with a useless body, unable to breathe, eat, move or communicate. The brain, however, is not dead in the conventional medical sense[219]. In many ways the victims of this condition resemble patients in PVS. First, the condition is hopeless and irreversible. Second, conscious functional brain control over the body is absent requiring medical intervention to feed, and in the case of GBS, to breathe. Third, the 'problem' of patients suffering from such conditions is new and arises as a direct result of medical advances. A few years ago such patients would have died soon after developing their respective conditions. Fourth, given

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[216] Transcript, at 5ff.

[217] Transcript, at 34ff. Denham gives a good acount of the content of the Irish privacy right at 34 - 36.

[218] Blaney J. did not make specific reference to the right of privacy, but he did not make specific reference to any other right either. The essence of his judgment was to endorse fully the decision of the President of the High Court. This means clearly that he accepted the privacy argument which formed the basis of the latter judgment. See the comments of Hamilton, C.J., *supra*.

[219] That is, the patient is not brain-stem dead. In fact, in many cases patients retain intellectual capacity and mental competence, yet have no control over their body whatsoever.

that medical assistance is provided, sooner or later the question of withdrawal of invasive support procedures will raise its head. For these reasons it is valuable to consider judicial pronouncements of the question of withdrawal of support from GBS patients. Of particular note are decisions of the New Zealand and Quebecois courts.

5.7.2.7. - *Nancy B v Hotel-Dieu de Quebec*

The decision in the case of *Nancy B v Hotel-Dieu de Quebec*[220] was handed down in 1992. It concerned a patient suffering from GBS who, although completely unable to move, had retained her mental capacity and intellectual competency. An action was brought requesting that her artificial support be discontinued and an injunction was granted forbidding any further medical intervention and permitting the medical person in charge of Nancy's case to stop respiratory support[221]. The Superior Court of the Province of Quebec held that to keep a patient on a respirator without her consent constituted an intrusion and intereference which violated her person[222]. The language used was that of autonomy and the right to self-determination, but the interest which the court sought to respect was the inviolability of person by unwarranted and unwanted medical treatment.

5.7.2.8. - *Auckland Area Health Board v Attorney-General*

The leading case to deal with withdrawal of life-sustaining treatment in New Zealand is *Auckland Area Health Board v Attorney-General*[223]. This case concerned an application made by doctors for a declaration clarifying the criminal law position if life-sustaining measures were removed from a GBS patient. In authorising withdrawal of support the High Court referred with approval to *Nancy B*. It was stated,

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[220] *Nancy B v Hotel-Dieu de Quebec et al.* (1992) 86 DLR (4th) 385.
[221] *ibid*, at 395.
[222] *ibid*, at 391.
[223] *Auckland Area Health Board v Attorney-General* [1993] 1 New Zealand Law Reports 235.

> The *Nancy B* case...serves to highlight...a set of values which are central to our concept of life; values of human dignity and personal privacy...Human dignity and personal privacy belong to every person, whether living or dying. Yet, the sheer invasiveness of the treatment and the manipulation of the human body which it entails, the pitiful and humiliating helplessness of the patient's state, and the degradation and dissolution of all bodily functions invoke these values.[224]

Clearly, the spatial privacy interests of the patient suffering from Guillain-Barre Syndrome are the same as those of the patient in PVS in this regard. These decisions show how the Quebecois and New Zeland courts have recognised the importance of these interests and have sought to protect them by authorising the removal of unjustified life support systems.

5.7.2.9. - *PVS Cases in the United Kingdom*

There have been numerous decisions in England and Wales concerning the withdrawal of feeding and hydration from patients in PVS[225]. All have applied the reasoning in the seminal case of *Airedale NHS Trust v Bland*[226]. Anthony Bland was crushed in the Hillsborough stadium tragedy in April 1989 and suffered serious brain anoxia. He was subsequently diagnosed as being in PVS. Three and a half years later his medical carers, with the full support of his family, sought to discontinue artificial feeding and allow him to die. Yet, because no *parens patriae* jurisdiction remains in England[227], the English courts faced a dilemma. No one, not even the court, could consent on behalf of the incapacitated patient to withdrawal of the invasive feeding. The course left to the courts was to make an anticipatory declaration about the lawfulness of any proposed course of action. The

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[224] *ibid* at 245.

[225] For comment see Mason and Laurie, *loc. cit.*

[226] *Airedale NHS Trust v Bland* [1993] AC 789.

[227] It having been removed, (perhaps accidentally), by the Mental Health Act 1959 and the revocation of the Warrant under the Sign Manual under which the jurisdiction of the Crown was conferred. See *Re F (mental patient : sterilisation)* [1990] 2 AC 1 *per* Lord Brandon at 57. See also Lord Browne-Wilkinson in *Bland* at [1993] AC 789, at 883.

uniqueness of this case and its inherent controversial nature ensured that it received a hearing by the highest court in the land: the House of Lords.

Their Lordships approached this case in a manner very different to the other jurisdictions which have been examined. Rather than taking the opportunity to vindicate patient rights (of privacy or otherwise), the court placed exclusive emphasis on the futility of the treatment and the test of patient best interests. Lord Mustill's argument, which was typical of the arguments advanced, can be explained as follows,

- treatment of the incompetent is governed by necessity and necessity is, in turn, defined in terms of the patient's best interests;
- once it is determined that there is no hope of recovery, any interest in being kept alive disappears and, with it also disappears the justification for invasive therapy;
- in the absence of necessity, there can be no duty to act, and in the absence of a duty to act, there can be no criminality in an omission.

This line of reasoning takes a very physician-oriented approach. This is compounded by the fact that the determination of the patient's best interests is, in the final analysis, to be carried out by the clinicians responsible for the management of the patient[228]. Thus it is for the doctors to decide whether further treatment is futile, it is then for them to decide whether removal of feeding is in the patient's best interests (as established by reference to medical opinion), and if they so decide then they are absolved of any possible future criminal liability because they no longer have a duty to treat the patient[229].

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[228] *ibid*, at 870, *per* Lord Goff. In determining 'best interests' the House referred to the Bolam principle (normally used in negligence actions): would a responsible body of medical opinion do as the practioner intends to do?, see *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582; (1957) 1 BMLR 1.

[229] This reasoning has been followed in other cases, including, *Frenchay Healthcare NHS Trust v S* [1994] 2 All ER 403, *Re C*, reported as a news item only (Ford, R.; 'Patient in Coma May Die with Dignity', (1995), *The Times*, 18 November, p.1), *Re G* [1995] 3 Med.L.R. 80, and *Swindon and Marlborough NHS Trust v S* [1995] 3 Med.L.R.84.

The requirement to seek court approval for withdrawal of feeding was maintained by the House of Lords[230] but in subsequent cases the main function of the court has been reduced to declaring that the diagnosis of PVS is correct. Once that is done it automatically follows that it is in the patient's best interests not to receive feeding and hydration. In addition, the Official Solicitor has declare that no case will be opposed once the diagnosis is confirmed. This means that cases are decided routinely at first instance with appeals increasingly unlikely. As Mason and Laurie have commented,

> [c]omplete medicalisation of non-treatment decisions in the condition is only a short step away; further involvement of the English courts is likely to be confined to those cases in which there is serious dispute between or within the health caring and family groups.[231]

There is no mention of the patient's right to privacy in the judgments of their Lordships in *Bland*. This is interesting because privacy arguments *were* advanced[232]. Anthony Lester QC and Pushpinder Saini as *amici curiae* put forceful privacy arguments advancing Anthony Bland's *right* to have artifical feeding withdrawn. As they put it,

> Although there is no enforceable general right to personal privacy in English law...the common law ensures respect for personal privacy by means, *inter alia*, of the principle of self-determination according to which a doctor must not invade the bodily integrity of his patient so as to treat him against his wishes...Human dignity in the context of the present case is not an abstract metaphysical notion; it is an established and orthodox legal concept which can be judged objectively by a court or tribunal, whether by our courts or by the European Court of Human Rights. There is a social duty to respect the patient's right to, and interest in, personal privacy and human dignity during what remains of his life. [233]

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[230] Practice Note [1994] 2 All ER 413; (1994) 18 BMLR 159., and recently, Practice Note [1996] 2 FLR 375.
[231] Mason and Laurie, *loc. cit.*, at 269.
[232] See, for example, the arguments by the *amici curiae* at [1993] AC at 848.
[233] *ibid.*

They continue:

> It would be a fallacy to suppose that if the appeal were allowed this would mean that the courts would be respecting the patient's privacy, bodily integrity and human dignity. The current invasive measures artificially maintaining his life would then continue without his consent...it cannot have been intended, when the *parens patriae* jurisdiction over incompetent adult patients was removed, to authorise such a gross form of discriminatory treatment against such individuals on the grounds of their mental disability...The House must decide whether patients in the present patient's condition are to be allowed to die with dignity, or whether they should continue involuntarily to be what was described as "passive prisoners of medical technology" because they are "symbols of life" whose "bodily integrity" must be maintained...In some cases the artificial prolongation of corporeal existence must degrade and demean the very humanity which it is meant to serve. Highly invasive medical treatment may perpetuate human existence without hope of consciousness, through a combination of body and feeding tubes that many of whatever religious belief or philosophical conviction might reasonably regard as an insult to life rather than as a proper respect for its sanctity.[234]

All of these sentiments are ones with which the present writer agrees, and we have seen them articulated by others in other jurisdictions in cases very similar to this, but virtually none of them received support or saw repetition in the judgements of their Lordships. Passing reference is made to the 'interest' of the patient in personal autonomy[235], but each time the relevance of this is dismissed because the patient is not capable of exercising his autonomy to make a choice about treatment. All agree that any such choice should be respected if it could be made, but faced with the impossibility of this each judge falls back on the best interests test. This, as has been shown, is then defined by reference to clinical judgment and medical criteria.

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[234] *ibid*, at 849, 850.

[235] See, for example, Lord Mustill, 891, 892 and 893

One might ask, what difference does this make? The outcome appears to be the same as all other cases in all other jurisdictions examined, so why focus on the different nature of the tests applied? The answer is that the outcome is not the same. The case of *Bland* demonstrates that the rights of the individual are very dependent on medical judgments and objectively determined tests of best interests which refer almost exclusively to medical opinion. There is no recognition as such of personal rights, least of all the right of privacy. This is a cause for concern. The nature and scope of patient rights are very vaguely defined in the United Kingdom. Moreover, in a country where there is no constitutional protection of rights, and arguably a tendency to defer to the medical profession on matters of patient care, there is a very genuine fear that the rights which do exist might be compromised or eroded over time. It is reasonable to argue that the *Bland* decision does much more to strenthen the position of medical staff and to add to their degree of power over patients than it does to clarify or fortify the rights of patients themselves. In such a climate a clearer statement of the rights of patients is needed and primary among such rights should be the right of patients to privacy.

5.7.2.10. - *Scotland's Contribution: Law Hospital NHS Trust v Lord Advocate and Others*

Finally, brief mention should be made of the legal standing of PVS patients in Scotland. After much debate the position was eventually settled by a bench of five Court of Session judges in *Law Hospital NHS Trust v Lord Advocate*[236]. Janet Johnstone was a middle-aged woman who fell into PVS as a result of a failed suicide attempt. The case for withdrawal of feeding and hydration was made by the hospital treating her and a guardian *ad litem* was appointed to argue on her behalf. Because of the complexity of the issues involved and the unprecedented nature of the case, the Lord Advocate also appeared. The solution of the Inner House of the Court of Session to Mrs Johnstone's condition can be seen as something of a half-way house between the English position and that of other jurisdictions. Unlike

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[236] *Law Hospital NHS Trust v Lord Advocate and Others* 1996 SLT 848; 1996 SLT 869.

England, the Court of Session was able to claim a continuing *parens patriae* jurisdiction and therefore sought to deal with the case as one of consent. This has been the approach of the American, Canadian and Irish courts. Unlike these courts, however, the Court of Session did not apply a rights-based analysis, but preferred to follow the English lead and apply a best interests test dominated by reference to medical opinion[237]. Furthermore, the court held that there was no obligation to apply to the court in every future case : a decision as to whether or not to do so would rest on those responsible for the care of the patient. For future cases, it remains to be seen how the *parens patriae* jurisdiction of the Court of Session will be administered. In *Law Hospital NHS Trust v Lord Advocate and Others*, where the only decision to be taken was whether or not it was in the patient's best interests not to receive further feeding, the Inner House of the Court of Session felt that it alone had authority to 'consent' to the withdrawal. That is, there was no need to appoint a tutor dative; the traditional appointee of the Scottish courts for welfare matters of incompetents. This departs from the position in the US where a guardian can seek authority to consent on behalf of the incompetent. It is not clear whether the Inner House envisages that future tutors dative - appointed before the 'withdrawal' decision has to be taken - will have the authority to do so, or whether the court, or the medical carers, must have the last word.

5.7.3. - *Spatial Privacy: A Conclusion*

The above cases demonstrate the privacy interests which PVS patients have[238]. It has already been argued that these interests are not confined solely to such patients but extend to all patients in the health care setting. Yet, the decisions to date in PVS cases demonstrate several things about legal protection of spatial privacy: first, although the interest which patients have is common to all cases, the language and means used to protect this interest vary between jurisdictions. Although the interest has most commonly been referred to as a

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[237] *ibid*, at 859 *per* Lord President Hope.

[238] For speculation on the position in Australia (where the courts are yet to hear such a case) see, Mendelson, D.; 'Jurisprudential Aspects of Withdrawal of Life Support Systems from Incompetent Patients in Australia', 69, *The Australian Law Journal*, 259.

privacy interest, this is not always the case, and this begs questions of accuracy of terminology. This will be dealt with in chapter five. Second, from the UK perspective it is not clear that the interest which an individual patient has in spatial privacy is adequately protected. The UK courts have approached the problem in PVS cases from a medical perspective and have failed to frame their decisions in terms of individual rights, preferring instead to hand responsibility and power to the medical profession. This, it is submitted, will only lead to further erosion of patient rights and possibly a failure to protect adequately their interests. Third, these cases are a striking example of how medical advances pose increasingly complex problems for patients and practitioners and give rise to difficult questions and issues about the sanctity of human life and the protection of the bodies and personalities of patients. It is submitted that the progress of medical science indicates that such invasions are likely to continue rather than abate in the future. The fact that privacy arguments have been advanced in such cases demonstrates the importance of a particular conception of privacy as applied to patients; namely, spatial privacy. In addition, it supports the amenability of privacy arguments to protect patient interests in their person.

6.1. - SPATIAL & INFORMATIONAL PRIVACY: NEW GENETICS & NEW PROBLEMS

So far, two separate conceptions of privacy have been advanced in this thesis: informational privacy and spatial privacy. It has been argued that the privacy of patients in the health care setting is composed of *both* of these forms of privacy. It has also been argued that medical advances increase concerns about possible privacy invasions and reveal a need to ensure proper protection of the rights and interests of patients. The concern of this thesis is, as has been stated, the *legal* protection of patient rights and interests in the United Kingdom. To date, what legal protection has been accorded to the spatial and informational interests in the UK has been of two distinct forms.

First, concerns about security of information have been considered as part of the domain of the law of confidentiality. Confidential information is imparted from patient to doctor and the doctor is under an ethical and legal duty to refrain from disclosing such information to others without due cause. The appropriate legal remedy is an action for breach of confidence. In the medical sphere, however, it is arguably the relationship which is the focus of the protection rather than the information itself. Moreover, it is difficult to determine when and to what extent the rights and interests of third parties external to the confidential relationship, are protected. These factors, in combination with others, have caused problems in the past and have led some to argue that this action of breach of confidence is ill-equipped to deal with the kinds of problems which arise for patient privacy from the so-called 'doctor/patient relationship'[239].

Second, the ethical principle of respect for patient autonomy has recently received legal recognition in the UK. A series of cases has protected the interest of patients in exercising their autonomy to prevent unwarranted interference with their bodily integrity[240]. Such an interest corresponds in large part to the concept of spatial privacy. The notion of patient autonomy which emerges from these cases in one of patient choice : the patient has the right to choose whether or not to receive treatment and can refuse treatment even if this has serious and/or fatal consequences. This, however, is dependent on the patient being able to exercise choice, which in turn is dependent on numerous conditions which are designed to ensure that the patient can understand options, comprehend consequences and evaluate risks and benefits. If this cannot happen, as, for example, in the case of patients in PVS, then a best interest approach is adopted which, as has been shown, places heavy reliance on medical opinions and evaluations.

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[239] See, for example, Wacks, R.; 'Privacy and Press Freedom', London, Blackstone Press Ltd., 1995, at 56.

[240] See, *Re T (adult : refusal of medical treatment)* [1992] 4 All ER 649; [1992] 3 WLR 782, *Re C (refusal of medical treatment)* [1994] 1 All ER 819; [1994] 1 FLR 31 and most recently *Re MB*, Court of Appeal, 26 March 1997, unreported. *Cf - Re S (adult : refusal of medical treatment)* [1992] 4 All ER 671. For a discussion of these cases see chapter three, *infra*.

Of course, this brief account of confidentiality and autonomy cannot lead to any concrete conclusions. It is designed to show simply two things: first, that forms of legal protection already exist in the UK for the interests identified in this thesis as informational and spatial privacy interests. Second, these means of protection have proved to be flawed in protecting patient interests. Arguably, this alone should be the cause of some concern. However, the focus of this thesis will show how these concepts are wholly inadequate to deal with privacy problems in one specific area; namely, human genetics. This area of scientific development has given rise to unique problems for both individuals and families and is the paradigm example of how technical advances can pose a threat to personal privacy. It will be shown that the nature of the interests which individuals have in their genetic constitution relate both to informational *and* spatial privacy and it will be argued that what is required is recognition of a patient privacy right *per se*. Only in this way can we provide a proper basis for adequate legal protection of such interests.

Thus the remainder of this work will proceed as follows. Chapter two will consider the nature of human genetics and the kinds of problems which have arisen for both informational and spatial privacy. Chapter three will examine the role of patient autonomy in protecting patient rights and interests in the UK. Chapter four will consider the same role of the law of confidence. Chapter five will involve an analysis of the concept of privacy as seen by other commentators and will include a defence of the definition of privacy advocated in this work. It will also demonstrate how the view of privacy adopted here can help to address the privacy issues surrounding familial genetic information and can help to formulate a legally recognised privacy right. Finally, chapter six will consider proposals for reform and possible legal remedies.

CHAPTER TWO

HUMAN GENETICS AND GENETIC PRIVACY

1.1. - INTRODUCTION

This chapter will consider the current state of knowledge about human genetics and will outline the available options regarding possible uses of such knowledge. The claims of persons and institutions with an interest in genetic information will also be examined and the potential conflicts explained. The chapter will conclude with a discussion of various scenarios which highlight the unique problems posed by genetics for society and the law. These will be used in chapters three and four when considering the utility of appeals to autonomy and confidentiality as a means of addressing such problems. We shall return to these scenarios again in chapter five where it will be argued that the concept of privacy, as defined in this work, is the proper means for resolving these problems.

2.1. - THE HUMAN GENOME PROJECT

The Human Genome Project was established in 1988 with the ambitious aim of mapping and sequencing the entire chain of human DNA[1]: the human genome[2]. A double helical string of DNA is contained in the nucleus of every cell in every human being. DNA dictates the nature and function of all such cells[3]. For this reason the human genome is often referred to as 'the master blueprint of us all'[4]. It is estimated that the work of the Human Genome Project will be completed by the

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[1] Deoxyribonucleic acid.

[2] For general comment on the project and its aims see, Watson, J.D.; 'The Human Genome Project : Past, Present and Future', 248, *Science*, 44, 1990.

[3] It is estimated that a human being is composed of ten million million cells.

[4] See, US Department of Energy and National Institues of Health, 'The Human Genome 1991-92 Program Report', 1992, at iii.

turn of the century[5]. International coordination of the project is undertaken by the Human Genome Organisation (HUGO)[6].

Already, the project has proved to be a source of invaluable knowledge regarding the make-up, nature and function of the so-called double helix of life[7]. The benefits which will accrue from this work are extensive. In July 1995 the House of Commons Science and Technology Committee produced a report on Human Genetics[8] within which the Committee outlined the potential benefits of human genomic research[9]. These include:

- Better understanding of human illness and the role of the 'genetic component' in a great many conditions including psychiatric, mental and neurological disorders;

- Quicker and cheaper diagnoses of common diseases;

- Better understanding of the "biochemical or physiological mechanisms" involved in genetic disease: 'focusing on the mechanism involved may bring about cures.'[10];

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[5] See, for example, Wilkie, T. 'Perilous Knowledge : The Human Genome Project and its Implications', London, Faber and Faber, 1993.

[6] For an accessible and comprehensive account of the work of the Human Genome Project and its consequences see, Bodmer, W. and McKie, R.; 'The Book of Man : The Quest to Discover Our Genetic Heritage', Little, Brown & Company, 1994.

[7] The expressed aim of the Project is to acquire, '...complete knowledge of the organization, structure and function of the human genome...', see, 'Human Genome 1991-92 Program Report', United States Department of Energy, Office of Energy Research Office of Environmental research, Washington DC, 1992, at iii.

[8] House of Common Science and Technology Committee, 'Human Genetics: The Science and its Consequences', Third Report, HMSO, 6 July 1995.

[9] *ibid*, at 33 - 51, paragraphs 65 - 124.

[10] *ibid*, at 36, paragraph 69.

- Improved techniques in the design of drugs to produce chemicals which can fit precisely with molecules implicated in disease;

- Gene Therapy;

- Germ-line Therapy.

However, as the Committee pointed out,

> While genetics is likely eventually to transform medicine, it may take some while before treatments based on genetic knowledge become available...[i]n the short term, the most widespread use of medical genetics will be, as now, in diagnosis and screening.[11]

Thus the first real and tangible benefits to emerge from this work have been tests kits for genetic diseases and conditions[12]. These make the identification and analysis of defective genes relatively inexpensive and, increasingly, a common-place occurrence[13]. Tests can be used to detect an individual's genetic predisposition to a particular genetic disorder or his or her status as a carrier of a genetic condition

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[11] *ibid*, at 36 - 37, paragraphs 71, 72. As the Report makes clear, '*Diagnosis* is aimed at individuals; genetic *screening* is routine screening of populations, or identifiable subsets of populations (for example, men or women only, or ethnic groups at increased risk for particular diseases).', *id*.

[12] As the Gene Therapy Advisory Committee noted in its First Annual Report (November 1993 - December 1994), 'The application of gene therapy in any routine sense for health care is a long way off. A prolonged period of research lies ahead and it would be wrong to expect immediate returns or instant cures in view of the time and effort that must be expended.', see House of Commons Science and Technology Committee Report, *ibid.*, at 47, para. 111. The NHS Central Research and Development Committee on the New Genetics produced its first report in May 1995 (Department of Health, *Report of the Genetics Research Advisory Group*, May 1995) in which it opined that '[c]orrective gene therapy...is still a long way off.', *ibid* at 17. It also laid down the following requirements before it would consider acceptable the widespread implementation of gene therapy : (a) has safety been established?, (b) is treatment possible?, (c) is effectiveness proven?, *id*.

[13] It has been estimated that there are over 3,500 'established' and 2,500 'suspected' genetic disorders. Disorders are 'suspected' to exist principally because of a lack of familial data to substantiate the existence of more rare conditions, see McKusick, V.A.; Mendelian Inheritance in Man: Catalogs of Autosomal Dominant, Autosomal Recessive and X-linked Disorders, Eleventh Edition, (John Hopkins University Press 1993). 95% of the most common diseases can be tested for as well as about one hundred of the rarer diseases.

which might afflict progeny. Already 95% of the most common genetic diseases can be tested for as well as about one hundred of the rarer diseases. And, as one commentator has noted,

> This is likely to rise to a thousand or more over the next decade as the human genome project bears fruit.[14]

Yet, as the Science and Technology Committee has indicated, the development of therapies from the work of the Project is not commonplace. Some successes have, however, already occurred. For example, in 1990 the first attempt was made to treat a human being with an inherited genetic disorder through the use of genetic engineering techniques[15]. The success of this procedure led to other attempts using similar techniques[16] and in 1994 specialists at the Jones Institute for Reproductive Medicine at the Eastern Virginia Medical School, USA successfully completed the first genetic testing for Tay-Sachs disease[17] to be carried out on an embryo prior to its implantation in the womb of its mother[18].

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[14] See Vines, G.; 'Gene Tests: The Parent's Dilemma', November, *New Scientist*, 40, 1994, at 42.

[15] The technique was carried out by a team from the National Institutes of Health in Bethesda, Maryland USA, on a young girl suffering from SCID (Sever Combined Immune Deficiency). In this case, the condition was caused by an inherited inability to produce an enzyme (adenosine deaminase) essential to the proper functioning of the immune system. Most persons afflicted with the condition die in early childhood; normally by succumbing to a minor infection. The technique employed by the Bethesda team was as follows. A sample of the most affected cells (white blood cells or 'T' cells) was extracted from the patient's body and subjected to genetic modification techniques which allowed the missing enzyme to be 'inserted' into the genetic make-up of each of the cells in the sample. Thereafter, the cells were allowed to divide and multiply until a sufficient quantity of the 'treated' sample was produced. This was then transfused back into the girl in the same way as an ordinary blood transfusion. Although apparently simple, this was the first time such genetically-modified material had been used in the treatment of a human being with a genetic disorder. For a fuller account of events see, Wilkie, 'Perilous Knowledge : The Human Genome Projects and its Implications', *op. cit.*, at 16 - 23.

[16] *ibid.*

[17] Tay-Sachs disease is caused by the absence of an enzyme which breaks down fatty substances in neurons. It is a fatal disorder of the nervous system which invariably results in a slow, painful death within the first five years of life.

[18] This resulted in the birth of a healthy baby girl in January 1994. See, Rennie, J.; 'Grading the Gene Tests', *Scientific American*, 270(6), 66, 1994.

Clearly, these advances have far-reaching implications for the future of medicine and the provision of health care. It is undeniable that they bring considerable benefits to humanity. However, it is also undeniable that they will change incontrovertibly the way we consider the human species and the way in which we consider ourselves. In the preamble to the World Medical Association Declaration on the Human Genome Project, it was stated that,

> [t]his area of scientific progress will profoundly affect the lives of present and future members of society, bringing into question the very identity of the human individual and intruding upon the snail's pace of evolution in a decisive and probably irreversible manner.[19]

Moreover, the implications which these advances have for personal privacy are profound. Whereas few would deny that the availability of genetic knowledge can be beneficial, it must also be recognised that such tests can be the source of problems. Information concerning one's genetic make-up is of a highly personal and sensitive nature. To discover that one is likely to develop a debilitating condition in later life or that one will pass on such a condition to one's children can be a devastating and profound experience. Exposure to such knowledge can alter considerably one's self-perception and can challenge notions of self-identity[20]. Furthermore, such knowledge can affect an individual in his or her social, professional and familial milieux with adverse results. The mere availability of genetic information serves to heighten concerns about the uses to which such information might be put; uses which might compromise the interests of the person who has been tested (the proband). For example, by revealing the information to employers or insurers or other interested third parties, the

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[19] This declaration was adopted at the World Medical Association's 44th assembly in 1992.

[20] This point is made by the Danish Council of Ethics, Ethics and Mapping the Human Genome, 1993, at 52.

information might lead to judgements being made which adversely affect or even discriminate against the individual. More uniquely, genetic tests also reveal information about relatives of the proband, with, arguably, a corresponding threat to *their* interests and *their* privacy. Family members might be loath to learn of a relative's predisposition to a particular genetic condition given the likelihood that they carry a similar risk. Finally, the state itself could put genetic information to many uses given the ability of such information to identify with high degrees of accuracy individuals and their current or future traits.

For all of these reasons, the existence and availability of genetic information gives rise to legitimate concerns on the part of the individuals to whom it relates regarding its use or possible misuse. The next section outlines the current state of knowledge about human genetics and the current possibilities regarding testing and screening. Given the existence of such knowledge and its potential uses, the parties who might have an interest in such knowledge will then be discussed. Finally, the problems of reconciling the various interests will be highlighted in a series of case studies.

3.1. - HUMAN GENETICS AND GENETIC DISEASES

It is the function of this section to explain terminology, to outline the facts concerning genetic information and to examine the nature and efficacy of genetic testing.

Genetic disorders are caused by mutations in genes. Genes are responsible for the functioning and operation of every cell in the human body[21]. It is thought that

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[21] It is estimated that between 50,000 and 100,000 human genes exist each of a length of a few thousand base pairs.

every individual carries several 'defective' genes within their genome[22]. However, not every individual suffers from, or will suffer from, a genetic disorder. This is so because of two important influences which dictate the pathology of genetic 'diseases': inheritance and the operation of external factors.

The genetic constitution of all human beings is contained in their chromosomes. Every individual has twenty three pairs of chromosomes: half inherited from their mother and half from their father[23]. Some genetic diseases - *recessive disorders* - only manifest themselves in individuals whose parents both pass on the same gene defect. The parents themselves are asymptomatic and only carry the recessive gene : hence the term 'carrier'. Any individual who inherits only one copy of such a recessive gene will also be asymptomatic but may be a carrier. The presence of one copy of the healthy gene is sufficient to override the deleterious effects of the unhealthy gene. The conjunction of two defective genes, however, results in disease. Examples of such disorders include cystic fibrosis, thalassaemia and sickle cell anaemia. On average, the chances of being affected by such a recessive disorder when both parents are carriers is 25%[24].

In contrast, *dominant disorders* require both copies of a gene inherited from parents to be healthy in order to avoid disease. Examples of such conditions include Huntington's Disease and certain forms of Alzheimer's disease. The chances of

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[22] See Suter, S.M.; 'Whose Genes Are These Anyway?: Familial Conflicts over Access to Genetic Information', 91, *Michigan Law Review*, 1854, 1993, at 1858: '[e]veryone probably carries between three and nine deleterious or disease genes, most of which are recessive.'

[23] Genetic diseases are generally of one of three kinds: (1) Chromosomal disorders, which involve the 'lack, excess or abnormal arrangement of one or more chromosomes, producing excessive or deficient genetic material', (2) Mendelian or simply inherited disorders which are determined by a single gene mutant, and (3) Multifactorial disorders which are 'caused by an interaction of mutliple genes and multiple exogenous or environmental factors', see, Wilson, J.D., Braunwald, E., Isselbacher, K.J., Petersdorf, R.G., Martin, J.B., Fauci, A.S., and Root, R.K.; Principles of Internal Medicine, Twelfth Edition, (McGraw-Hill Inc. 1991) at 24.

[24] On a purely statistical analysis, another 25% will not carry the gene defect at all. 50% of the offspring will, however, be carriers. Furthermore, it should be noted that if an affected person marries a carrier of the condition 50% of their progeny will be affected, *ibid*.

being affected by such a condition are 50% in each case. Such dominant disorders differ from recessive disorders in two important respects. First, many dominant disorders do not usually manifest themselves until later in life[25]. This means that a family can be complete before there is any sign that a genetic trait has been inherited. Second, when manifestation does occur it is characterised by extreme variation in the symptoms experienced by family members[26]. This can further delay the recognition of a pattern of inheritance in a particular family[27].

Both of the above kinds of disorders are called monogenic disorders[28]. They carry a relatively high risk of transmission to first degree relatives of an affected person. Polygenic disorders relate to conditions which result from the interaction of two or more defective genes. Examples include ischaemic heart disease, congenital cancer and diabetes[29]. Only 5% to 10% of first degree relatives are affected by such conditions because of the need for many genes to interact to cause disease[30]. Such

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[25] Around 50% of dominant disorders are 'late-onset' disorders.

[26] An additional complicating factor is that of non-penetrance: that is, although defective genes have been passed onto progeny the progeny remain unaffected by the condition.

[27] Additional differences between recessive and dominant disorders include the fact that parents of a sufferer from a recessive condition will in general be entirely free of the disease. At least one parent of a person afflicted with a dominant condition will also be affected (although it is possible in a small number of cases for an individual to suffer from the condition because of a mutation which has occurred). Further, recessive conditions do not in general pass through generations vertically. Only siblings are affected. With few exceptions, the incidences of such disorders are rare because of the need for the conjunction of two individuals both of whom carry the defective gene and transmit it to their children. Dominant disorders transmit vertically through generations and are more likely to result in disease.

[28] The other form of single inherited disorders which is common involves the so-called 'X-linked' disorders. These affect the sex chromosome. The sex of any individual is determined by the arrangement of the X and Y chromosomes. Woman have two X chromosomes (XX). Men have one X chromosome and one Y chromosome (XY). X-linked genetic disorder therefore afflict men (in the vast majority of cases) because, if their X chromosome is damaged or defective, they do not have another healthy copy of the chromosome which will override the deleterious effects of the unhealthy X chromosome. Clearly, this is not the case for women. Common X-linked disorders include colour-blindness, haemophilia, ocular albinism and Duchenne Muscular Dystrophy. Women act as carriers of the gene defect and it is they who pass it onto their sons. Men cannot pass the defective X chromosome onto their sons because the male always contributes his Y chromosome to his sons; the X chromosome is transmitted to his daughters. All female offspring of an affected male are carriers. Wilson *et al, op. cit.* at 28.

[29] Other common conditions include asthma, epilepsy, hypertension, multiple sclerosis and schizophrenia.

[30] Wilson *et al, op. cit.* at 30. The precise number of genes responsible for polygenic traits is unknown, *ibid.*

polygenic disorders are an example of the general class of multifactorial conditions which forms the other common classification of genetic dysfunction[31]. Polygenic disorders can work alone or in tandem with environmental conditions to result in human disease. Common external environmental factors which influence the manifestation and/or progression of genetic disease include; diet, exercise, stress, alcohol and drugs, and exposure to toxic chemicals or radiation[32]. As with purely polygenic conditions, however, the predictability of the occurrence of multifactorial genetic conditions is very low compared to monogenic disorders[33]. For this reason the majority of research which has been carried out to date on genetic conditions and diseases relates to the latter rather than the former. That said, by far the most common disorders experienced by individuals are due to multifactorial, as opposed to a monogenic, dysfunction[34]. Indeed, it is thought that in the future it will be possible to detect a genetic component in a great many disorders and conditions which today are seen as purely organic or as resulting from social and not physiological dysfunction; for example, schizophrenia, manic depression, and drug or alcohol abuse.

These facts allow us to draw certain conclusions about the nature of genetics and genetic information. Any information which becomes known about a particular individual's genetic constitution also reveals, with varying degrees of certainty, information about the genetic constitution of members of both their immediate and extended family. For relatives, this can reveal the possibility that one already has a particular condition or that one is at increased risk from developing such a condition or that one is a carrier. However, the chances of this being the case can

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[31] For a general discussion of such conditions see, Williamson, R. and Kessling, A.M.; 'The Problem of Polygenic Disease' in Ciba Foundation Symposium 149, 'Human Genetic Information : Science, Law and Ethics', Chichester, John Wiley & Sons, 1990, at 63 - 80.

[32] The study of such conditions has been coined *Ecogenetics*, see Pence, G.E.; 'Classic Cases in Medical Ethics', Second Edition, New York, McGraw-Hill, Inc. 1995 at 407 - 408.

[33] *ibid.*

[34] Indeed, it is thought that, '...only three percent of all human diseases are caused by defects in a single gene...', see Rennie, 'Grading the Gene Tests' , *loc. cit.*, at 96.

rarely be accurately predicted simply on the basis of test results of a relative[35]. Although some conditions carry a straightforward statistical probability of affliction, increasingly it is becoming clear that many variable factors influence one's genetic constitution. This precludes the drawing of any concrete conclusions based simply on information from others[36]. As the Danish Council of Ethics has noted,

> [i]n many - possibly even most - cases, great uncertainty still attaches to ascertaining whether or not a disease is hereditarily conditioned. A long string of illnesses such as cancer and cardiovascular disease cannot be categorically classified as being hereditarily or environmentally conditioned, but must be assumed to be due to the - as yet only partly clarified - interaction of hereditary and environmental factors.[37]

The degree of uncertainty which accompanies such information might lead to considerable unease and concern among relatives about their own genetic status. For those who choose not to be tested themselves the prospect of living with such uncertainty is a daunting one. Yet, even for those who choose to be tested, the benefits are neither immediate nor guaranteed.

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[35] The technical term for a person who has been tested is the *proband* or the *index case*, see Wilson *et al*, *op. cit.*, at 24.

[36] Gostin points out that the sensitivity of testing is limited by the known mutations in a target population. As he states, '[S]creening can detect only 75 percent of CF chromosomes in the U.S. population. Approximately one in every two couples from the general population identified by CF screening as "at-risk" will be falsely labeled. Predicting the nature, severity, and course of disease based on a genetic marker is an additional difficulty. For most genetic diseases, the onset date, severity of symptoms and efficacy of treatment and management vary greatly.', see Gostin, L.O.; 'Genetic Privacy', 23, *Journal of Law, Medicine and Ethics*, 320, 1995 at 323 quoting Fost, N.; 'The Cystic Fibrosis Gene : Medical and Social Implication for Heterozygote Detection', 263, *Journal of the American Medical Association*, 2777, 1990.

[37] *Op. cit.*, at 10. See also, Cavoukian, A.; 'Confidentiality Issues in Genetics : The Need for Privacy' in Second Symposium of the Council of Europe on Bioethics, Strasbourg, 30 November - 2 December 1993, CDBI-SY-SP (93) 5 at 4.

3.2. - Genetic Information and Testing

A wide range of genetic tests are now available[38]. In contrast, few cures for genetic disorders currently exist[39]. In this respect the usefulness of testing is limited. Since the knowledge to which tests give rise can only be used to avoid the onset of disease in a very small number of cases, the value of such tests must be sought elsewhere. Indeed, several arguments have been advanced about the value of testing in the absence of cure. For instance, concerning multifactorial conditions which are heavily influenced by an environmental component, it has been argued that such knowledge can be used to inform individuals fully of possible risks to health which can possibly be minimised by a change in lifestyle[40]. Similarly, the discovery of one's status as a carrier for a particular condition means that any decision which will be taken thereafter regarding reproduction will be an informed decision. Also, it has been argued that one can better prepare for hardship to come, both mentally and in other ways, if one is aware of the risk of developing a disease at a later stage in life[41]. Such early prediction allows appropriate support mechanisms - such as counselling - to be set in place in advance of the onset of any disease[42].

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[38] Vines notes, '[a]ll Britain's health regions have genetic testing and counselling centres, which can test for about 20 of the commonest inherited disease, which together account for 95 per cent of all cases', *loc. cit.*, at 42.

[39] As one commentator has said, '[f]orced analysis of the human genome will cause the gap between diagnostic ability and therapeutic failure to widen more than ever. We shall detect diseases with greater and greater precision, we shall learn to predict at the preclinical or prenatal stage without being able to do anything about the cause.', see Schmidtke, J.; 'Who Owns the Human Genome? Ethical and Legal Aspects',44(1), *J. Pharm. Pharmacol.*, 205, 1992, at 209.

[40] See, for example, Ryan, M.P., *et al.*; 'An Ethical Debate : Genetic Testing for Familial Hypertrophic Cardiomyopathy in Newborn Infants', 310, *British Medical Journal*, 856, 1995, in which a view is put that early detection of this inherited weakness of the heart can mean that, '[t]he child can be raised with an emphasis on avoidance of energetic activities rather than be suddenly banned from an established sporting pursuit during adolescence, when the disease is diagnosed clinically', at 857. See also, Reilly, P.; 'Rights, Privacy, and Genetic Screening', 64, *Yale Journal of Biology and Medicine*, 43, 1991. However, with the whole range of multifactorial conditions the problem comes in knowing which aspects of one's lifestyle are causal in the onset of disease.

[41] See Ball, D., Tyler, A. and Harper, P.; 'Predictive Testing of Adults and Children' in Clarke, A. (ed.), 'Genetic Counselling : Practice and Principles', London, Routledge, 1994, at 63 - 94, especially 71. Also see, Pelias, M.Z.; 'Duty to Disclose in Medical Genetics : A Legal Perspective', 39, *American Journal of Medical Genetics*, 347, 1991.

[42] This of course presupposes that such support mechanisms exist.

It must be borne in mind, however, that even in this context the efficacy of genetic tests is limited. Tests can neither predict the particular likelihood of the onset of a condition, nor the date when disease will develop nor the severity of the condition which any one individual is likely to experience[43]. Further, mutations in disease-causing genes can themselves be responsible for disease. To be truly effective a test must be capable of detecting all such mutations[44]. Yet, because longer genes are more likely to carry mutations, the difficulty of this task increases with the genetically more complex conditions. The recently discovered BRCA1 gene[45] - thought to be responsible for five percent of all breast cancers[46] - is unusually long[47]. It has been estimated that even once a test is developed its efficacy will be limited: '...a negative result would be indeterminate and could be expressed only as a probability'[48].

In certain circumstances the cooperation of family members is required to provide an accurate test result for the existence of a genetic condition. Tests fall into one of two categories: linkage tests and genetic tests. The latter detect the 'defective' gene itself and can be carried out without familial cooperation. Linkage tests, however, merely detect 'markers' which accompany genes and for accurate results blood samples are required both from affected and unaffected members of one's family.

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[43] See, Berg, K.; 'Confidentiality Issues in Medical Genetics: The Need for Laws, Rules and Good Practices to Secure Optimal Disease Control', Second Symposium of the Council of Europe on Bioethics, Strasbourg, 30 November - 2 December 1993, CDBI-SY-SP (93) 3 at 4 - 5. Also, Gostin, 'Genetic Privacy', *loc. cit.*, at 323.

[44] A recent example of this has been the test for hypertrophic cardiomyopathy. Initial screening proved to be inaccurate until the discovery of a mutation of the cardial beta-myosin heavy chain gene MYH7, see, Ryan *et al*, *loc. cit.*, at 856.

[45] The discovery of the gene was announced on 15 September 1994 by a team at the University of Utah.

[46] For a statistical breakdown and comment see, Eeles, R.; 'Testing for the Breast Cancer Predisposition BRCA1', 313, *British Medical Journal*, 572, 1996.

[47] The gene consists of 100,000 base pairs of nucleotides, which is ten times longer than the average gene.

[48] See, Pence, *op. cit.*, at 411 - 412. The same problem occurs with all 'long' genes, for example, the gene for cystic fibrosis.

Without these, test results are inconclusive[49]. The full informed consent of all relatives might, however, be difficult to obtain[50]. Clearly, the efficacy of test results will be affected if only a number of relatives agree to cooperate[51].

All of these factors make recourse to genetic testing a hazardous business[52]. Moreover, the multiplicity of interests at stake makes the potential for conflict over the use of genetic information real[53].

4.1. - THE INTERESTED PARTIES

This section will consider four parties who might have an interest in the genetic information of an individual : 1) the individual him or herself (the *proband*); 2) relatives of the individual in question; 3) those employing or insuring the individual or seeking to do so; 4) the State. The nature of such interests will also be

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[49] *ibid*, at 396.

[50] It is the view of the Danish Council of Ethics that, '...no unsolicited approach may be made by...health authorities in the case of examinations which may evince an hereditary disease in the family. This can create undue anxiety on the part of the relatives concerned and, at worst, encroach radically on their lives, through no wish of their own...the regard for family member's integrity weighs heavier than the understandable need of the counsellee to be diagnosed and to have future options for action set out.', *op. cit.*, at 23.

[51] See Ball, D., Tyler, A. and Harper, P., *op. cit.*, at 66 - 69. As the authors state, '[l]inked marker studies are normally the only means of genetic prediction for a disorder until the causative gene is identified and specific mutations(s) isolated, whereupon direct mutational analysis becomes possible, allowing prediction to be made using a single sample from an applicant.', at 68. The genetic marker for Huntington's disease was discovered in 1983. It is located on the short arm of chromosome 4. The gene for Huntington's Disease was eventually located in March 1993. A genetic test became available in 1994. For comment see Miller, S.K.; 'To Catch a Killer Gene' *New Scientist*, April 3, 7, 1993, and Harding, A.E.; 'The Gene for Huntington's Disease', 307, *British Medical Journal*, 396, 1993.

[52] See, for example, Hayes, C.; 'Genetic Testing for Huntington's Disease - A Family Issue', 327(20), *New England Journal of Medicine*, 1449, 1992. Some researchers have even recorded an adverse effect in persons who are told that they are not at risk, see Hoffman, D.E. and Wulfsberg, E.A.; 'Testing Children for Genetic Predispositions : Is it in Their Best Interest?', 23, *Journal of Law, Medicine and Ethics*, 331, 1995, and Huggins *et al*; 'Predictive Testing for Huntington Disease in Canada: Adverse Effects and Unexpected Results in Those Receiving a Decreased Risk', 42, *American Journal of Medical Genetics*, 508, 1992.

[53] As an example, and for an account of the problems of prenatal testing from a French perspective see Lenoir, N.; 'Aspects Juridiques et Ethiques du Diagnostic Prenatal : Le Droit et Les Pratiques en Vigeur en France et dans Divers Autres Pays', in 'Human Genetic Analysis and the Protection of Personality and Privacy', International Colloquium, Zurich, Schulthess Polygraphischer Verlag, 1994.

considered. It is submitted that it is by an examination of the respective interests which parties have in genetic information that one can understand the nature of the problems which can arise. This also serves to bring the issues within the rubric of a common language, which in turn allows one to compare and contrast various, and at times competing, interests.

In this context of genetic information, an *interest* is defined as a claim that a benefit can come to the party in question by recognising that the party has a relationship with the genetic information. The basis of that relationship might be -

- *personal*: that is, the information is about the person;
- *economic*: that is, the information can affect one's employment or insurance business; or
- *paternalistic*: that is, the party is in a position to use the information to protect the individual or others from harm.

Of course, the question of whether or not a party has an interest in genetic information is an evaluative matter. Inherent in the notion of *interest* is the idea that it is *in* the party's *interest* to recognise the relationship with the genetic information. And, to do so will normally lead one to conclude that it is therefore *in* the party's *interest* to know, and to have access to the information in question. However, depending on the perspective one adopts, this might not always be the case. This is explained further below.

4.2. - An Individual's Interest in his/her Genomic Information

It is axiomatic that a person who has been tested for one or more genetic conditions has a significant interest in knowing and determining what happens to the resulting information. Arguably, genetic information is 'the most personal information of all'[54]. As we have seen, such information can help an individual to make informed decisions about his or her health and lifestyle and furthermore this can lead to the prevention of future disease. In addition, knowledge of one's genetic status permits informed decisions about future reproductive choices to be made. Whereas it has already been established that personal health information is inherently connected to and part of the private sphere of an individual's life, genetic information has a unique relationship with the individual in many other ways. For example, as Suter has noted,

> [w]hile contracting chicken pox has virtually no effect on identity, the knowledge that one carries a disease gene may influence one's self-perception and definition of "one's own concept of existence" in a way most infectious diseases do not.[55]

Furthermore, and again unlike 'conventional' health information, genetic information cannot be completely anonymised. It is a unique marker pointing the way to a single individual. As Gostin puts it,

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[54] See, Laurie, G.T.; 'The Most Personal Information of All : An Appraisal of Genetic Privacy in the Shadow of the Human Genome Project', 10, *International Journal of Law, Policy and the Family*, 74, 1996.

[55] See Suter, S.M., 'Whose Genes Are These Anyway? : Familial Conflicts over Access to Genetic Information', *loc. cit.*, at 1893.

> Genomic data are qualitatively different from other health data because they are inherently linked to one person. While non-genetic descriptions of any given patient's disease and treatment could apply to many other individuals, genomic data are unique. But, although the ability to identify a named individual in a large population simply from genetic material is unlikely, the capacity of computers to search multiple data bases provides a potential for linking genomic information to that person. It follows that nonlinked genomic data do not assure anonymity and that privacy and security safeguards must attach to any form of genetic material.[56]

Finally, genetic information does not simply provide us with information about an individual's medical past, which is the case with most medical records. In addition, genetic information furnishes us with knowledge about the individual's medical *future*. This knowledge can be vague, in that we know only that the person has a certain percentage risk of developing disease, or it can be certain; we know that given time, disease *will* develop. Either way, such knowledge permits those who hold it to make judgements about the future life of the individual. Thus the proband him or herself can make future life decisions based on this information. By the same token, insurers or employers might change their attitude towards the individual based on the predictive data. Such attitudinal shifts might not always be to the individual's advantage[57].

For these reasons and those which have already been advanced in chapter one, an individual has a very strong claim to a right to control what happens to such information. In essence, such persons have an interest in this information because it relates to them and can affect their lives. Furthermore, because of their status as moral agents and because of the close relationship which they have with such

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[56] Gostin, 'Genetic Privacy', *loc. cit.*, at 322.
[57] See *infra*.

information, respect is due not simply to them as individuals but also to their interests in such inherently personal material.

4.3. - The Interest of Relatives in a Proband's Genetic Information

In an entirely unique way, exactly the same reasons as above can be advanced by the blood relatives of a proband to claim an interest in genetic test results since a test result will also reveal information about them[58]. One significant difference between a proband and a blood relative, however, is that the proband has made a conscious decision to acquire the information. The same might not be true of blood relatives. Yet, once such information exists questions of security, access and control arise. Further, if the individuals to whom the information relates do not agree on such issues, problems of balancing the competing interests must be addressed[59]. A further complicating factor is the potential claims of non-blood related relatives such as spouses. An example of how conflict can arise can be seen from a recent French example.

4.3.1. - *The French Glaucoma Studies*

In the late eighties and early nineties the French *Institut National D'Etudes Démographiques* (National Institute for Population Studies) carried out studies in

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[58] The existence of this interest has been recognised by a variety of bodies, including Nuffield Council on Bioethics, Genetic Screening: Ethical Issues, December 1993, chapter five; The Royal College of Physicians of London, Ethical Issues in Clinical Genetics: A Report of the Working Group of the Royal College of Physicians' Committees on Ethical Issues in Medicine and Clinical Genetics, 1991, para. 4.19, and the Danish Council of Ethics, *op. cit.*, at 62.

[59] Because of technological advances in the last fifty years in the field of computers the means now exist to store and access all forms of information for indefinite periods of time. In this way, genetic information could also prove relevant for future generations of the same genetic line. See Barber, B.; 'Securing Privacy in Medical Genetics', Second Symposium of the Council of Europe on Bioethics, Strasbourg, 30 November - 2 December 1993, CDBI-SY-SP (93) 2 at 6, and Berg, K.; 'Confidentiality Issues in Medical Genetics : The Need for Laws, Rules and Good Practices to Secure Optimal Disease Control', Second Symposium of the Council of Europe on Bioethics, *op. cit.*, at 3.

the region of *Nord Pas De Calais* (near Boulogne-sur-Mer) into instances of hereditary glaucoma. Reported cases of this condition were unusually high compared to the rest of the country. The Institute was able to trace the ancestors of three families known to be sufferers from glaucoma back fifteen generations to a blind couple who lived in a small village in the region in the 16th century. Having done so, it was then relatively easy to retrace the descendants of the couple back to the present day in order to identify those individuals who were at increased risk of developing glaucoma. The nature of the condition is such that, if caught in its early stages, even before the individual patient has perceived that there is anything wrong, its advancement can be halted simply with a prescription of eye-drops. However, if glaucoma is not diagnosed at this early stage it can eventually lead to blindness, and the only treatment available at later stages is surgery. The French **INED** decided to consult the National Data Protection Agency to determine the correct procedure to be followed in order to inform the individuals at high risk. The Agency responded that the Institute should not, under any circumstances, take steps to inform these people of the information they had discovered. To do so, it was said, would be a breach of their privacy. This caused an outcry in France[60]. Of particular interest to this work is the nature of the questions which this sort of scenario raises.

4.3.2. - *Familial Issues and Interests in Genetic Information*

Many issues arise from the above scenario. It provokes us to ask appropriate questions which help us to understand the nature of the interests which individuals and relatives have in genetic information.

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[60] See, 'L'Express', N.2123, 20 March 1992.

For example, should relatives be informed of test results, especially if the results reveal a predisposition to a serious condition? Should the wishes of the tested person be taken into account? Should the wishes of relatives be taken into account? Could a relative demand disclosure of such information? Does the absence or presence of a cure make a difference? Could a relative refuse to receive such information? That is, could such a person have a claim *not* to know of a genetic predisposition? Might an interested third party such as the state have a claim in *requiring* that they know such information? Does the health care professional who has performed the test owe a duty to disclose to relatives of a tested person, even if they are not patients of the professional? If so, what is a professional to do if those to whom the duty is owed disagree about how the information should be treated? All of these questions have implications for the privacy of the persons concerned.

The need to address privacy issues in this context has already been appreciated by a number of international bodies. For example, the Bilbao Declaration, which was drafted at the International Workshop on Legal Aspects of the Human Genome Project which took place in Bilbao, Spain in May 1993, highlights the main problematic areas likely to arise from the work of the Human Genome Project and the areas considered to be worthy of immediate attention by the legal systems of the world. Included in this is,

> [p]rotection of the personal privacy or confidentiality of genetic information, and determination of cases in which it could feasibly be altered or overstepped.[61]

Moreover, in March 1995 the United Nations Educational, Scientific and Cultural Organisation (UNESCO) issued a revised outline of a Declaration on the Protection of the Human Genome. In paragraph B.9 it is stated,

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[61] *The Bilbao Declaration on the Human Genome*, May 1993.

> The confidentiality of genetic data associated with a named person and stored or processed for the purposes of research or any other purpose, must be protected from third parties except where the law provides otherwise and where justified by the general interest.[62]

The interests which surround personal and familial genetic information can be distilled to the following:

- *The Individual - an interest in the genetic information resulting from a test*

For the reasons already outlined above, the individual who has consented to a genetic test has an interest in the results of the test. This is so even if the test reveals information which was not expected, for example - a test for an inherited disease A also reveals a predisposition to disease B. The basis for this latter assertion is the individual's right to be respected as a moral agent. However, it is entirely contingent on the individual agreeing to receive the information[63].

- *The Individual - an interest in keeping the information in a state of non-access*

Because of potentially harmful outcomes which can befall an individual if personal information is not kept secure, the individual has an interest in keeping the information secret or private; that is, limiting access to those whom s/he authorises.

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[62] See, the revised outline of the Declaration on the Protection of the Human Genome by the United Nations Educational, Scientific and Cultural Organisation, 7 March 1995, BIO/CIB-COMJUR/95.

[63] See below.

Wolf has warned that our society runs a serious risk of applying a reductionist approach to genetic information[64]. This, she posits, will adversely affect individuals and will lead to what she terms 'geneticism'. Using the context of health insurance, she points out that too often individuals are seen 'as their genes'[65]. This, in turn,

> ...subdivid[es] communities by their genetic characterisitics, and promot[es] the idea that genetic differences are real, biological, and neutral grounds for different treatment.'[66]

Wolf's point is a valid one in that it highlights one serious danger inherent in the availability of genetic information. Genetic knowledge, *in se*, may be neutral, but it cannot be asserted that the uses to which it can be put are necessarily also so. Our recent past teaches us that genetic information can be seen as bringing 'scientific', and therefore 'credible', foundations to long-held prejudices and deep-ingrained bigotry. As more becomes known about the human genome it cannot be stated with certainty that such information will always be used for entirely 'neutral' ends. Consider, for example, recent discussion about the desirability and utility of a search for a 'gay' gene[67]. On the one hand, scientific proof that homosexuality has a genetic basis brings credence to the argument that homosexuals *are* 'made that way' and that homosexuality is not simply a life choice. By the same token, scientific proof of the 'gay' gene proves that all along homosexuals were correctly treated as 'deviants', for such a gene could easily be seen as a "mutation" from the "normal". Such divergent viewpoints not only call into question the appropriateness of 'gay' gene research but also indicate that individuals have a strong interest in maintaining

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[64] Wolf, S.M.; 'Beyond "Genetic Discrimination" : Towards the Broader Harm of Geneticism', 23, *Journal of Law, Medicine and Ethics*, 345, 1995.

[65] *ibid*, at 346.

[66] *id.*

[67] As an example of the discussion which surrounds this subject see, Vines, G.; 'Gene Tests: The Parents' Dilemma', November, *New Scientist*, 40, 1994, LeVay, S. and Hamer, D.H.; 'Evidence for a Biological Influence in Male Homosexuality', May, *Scientific American*, 20, 1994, and Byne, W.; 'The Biological Evidence Challenged', May, *Scientific American*, 26, 1994.

control and security over their own genetic information should it ever be discovered that they possess such a gene.

The above is an argument that individuals have an interest in the security of genetic information because harm can come to them if security is not maintained. However, this is not the only reason for claiming an interest in security of such information. In chapter one it was contended that as moral agents in a western liberal democracy individuals deserve respect and that this extends both to their person and their personal information. Deferrence to the wishes of individuals is one of the utmost forms of respect. Thus it should be enough that the individual express a wish or desire that information be kept secure to invoke the respectful response of maintaining non-access. No further justification should be required[68]. The interest which the individual has is the interest in having his or her wishes respected, and it is therefore related only tangentially to the information itself. Nonetheless, this is an important interest which affects the sum and nature of the overall claims to the genetic information.

- *Family Members - knowledge and security of genetic information*

For the same reasons argued above, blood-related family members have an interest both in knowing the test results from a proband *and* in ensuring that the information is not noised abroad without authority. The question of whether or not their interest is as strong as that of the proband is more difficult to answer. Certainly, the risk of more distant relatives being affected by a particular condition is reduced because of the different genetic influences which they have been subjected to compared with the proband[69]. Similarly, a spouse or partner can gain

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[68] Of course, this is not to say that respect should always be forthcoming, but it does imply that good reasons should exist before wishes or desires are not respected.

[69] See, Wilson, *et. al.*, *op. cit.*, at 30 : '...as the degree of relation becomes more distant, the likelihood of a relative inheriting the same combination of genes becomes less. Moreover, the chances of any

no knowledge at all about his or her own genetic constitution by knowing their partner's test result, but such a person could nevertheless claim several interests in knowing the information. For example, such knowledge gives an indication about possible future risks for any future progeny. Also, such information could weigh heavily in any decision of the partner to remain with the proband.

Those relatives with the strongest interest of all are the first degree relatives of the person who has been tested. This is so because they have the highest likelihood of genetic similarity with the proband. The interests of such relatives include those of the children of a proband who might want to know whether they have any risk of disease which might affect themselves or their progeny. Siblings, too, have a strong interest in a brother or sister's test results given their common parentage[70].

That said, it is important to stress once again that one's concern with genetic information should not be viewed simply as a desire to avoid harm in the guise of genetic disease. Even if test results show no risk of disease, it should not be presumed that individuals will automatically be happy to surrender control of such information. Relatives will still have an interest in each other's genetic information even if it reveals nothing sinister. Such information is nevertheless intimately connected with their private sphere and possibly their sense of self and therefore to disrespect the information is to disrespect the people involved. This point has been made above concerning the individual proband.

From the above it is clear that conflict will arise when the proband wishes to keep test results secure and family members wish to know them. That is, when the

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relative inheriting the right combination of genes decrease as the number of genes required for the expression of a given trait increases.'

[70] This is particularly true for (identical) twins. It should be noted, however, that the knowledge of a sibling's test result will *not* change *one's own* risk of ill health. The chances of being affected are the same for each sibling, eg- 50% chance of being affected by a dominant disorder or 25% chance of being affected by a recessive disorder (50% chance of being a carrier).

individual wishes to keep the data *private* and the family wish to invade that private sphere, or perhaps, become *part of* that private sphere.

- *The Individual and the Family - an interest in not knowing?*

Until now the discussion has proceeded on the basis that both the individual tested and the family members *desire* to know the information available. However, the question arises of whether individuals - either the proband or relatives - have an interest in *not* knowing test results. For example, the proband might agree to be tested but then change his or her mind. Equally, relatives might be approached by a proband willing to reveal test results but might refuse to accept the information. Let us consider the possible interests which individuals could have in *not* knowing such information.

It has been argued that knowledge of genetic information can bring many benefits to individuals. If a cure is available it can be sought and possible ill health may be averted. Even if a cure is not available, knowledge can nevertheless serve several ends. For example, because multifactorial conditions are by definition affected by many influences including the non-genetic, knowledge of a predisposition to such a condition can provide individuals with the opportunity to change aspects of their lifestyle. This can in turn influence the onset of disease[71]. Similarly, the discovery of disease or predisposition to disease means that any decision which will be taken thereafter regarding reproduction will be an informed one. Moreover, it has been argued that with knowledge comes preparedness for the risk of developing a disease at a later stage in life[72]. Unfortunately, such arguments all suffer from one

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[71] See, Ryan, M.P. *et al*, 'An Ethical Debate : Genetic Testing for Familial Hypertrophic Cardiomyopathy in Newborn Infants', *loc. cit.* and Reilly, P.; 'Rights, Privacy, and Genetic Screening', *loc. cit.*

[72] See Ball, D., Tyler, A. and Harper, P.; 'Predictive Testing of Adults and Children' in Clarke, A. (ed.), Genetic Counselling : Practice and Principles, *op. cit.* and, Pelias, M.Z.; 'Duty to Disclose in Medical Genetics : A Legal Perspective', *loc. cit.*

fundamental weakness: they presume that only benefit can result from knowledge. This is not necessarily so.

The availability of a cure carries with it the certainty that disclosure can avert harm uncontrovertibly[73]. For a third party to whom disclosure is made this can only be seen as a 'good thing'[74]. Unfortunately few cures are currently available for genetic conditions. And, if disclosure is made to avoid an ancillary harm such as psychological upset there is less of a guarantee that the harm in question will, *de facto*, be avoided. Evidence exists from empirical studies which both supports[75] and refutes[76] the benefits of disclosure to facilitate preparedness. Thus, it is entirely possible that individuals might be loath to learn of a relative's genetic status because of the implications which this knowledge can have for their own well-being. Indeed, the Danish Council of Ethics has warned of the risk of *morbidification*: the notion of 'falling victim' to some inescapable 'fate' through knowledge about risk of disease[77].

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[73] That said, in circumstances where a cure *is* available but an individual would not choose to take it - perhaps for religious reasons - it is hard to see how disclosure could ever be justified because the perceived harm could not be avoided. Of course, one could argue that faced with the reality of the situation the individual might nevertheless accept treatment, but this is to adopt a strong paternalistic perspective, the ethical propriety of which is doubtful.

[74] It is recognised that this might be a different matter for the individual who has had their genetic information revealed to others. Yet, both legally and ethically disclosure is justified because it can, in absolute terms, further the public interest in avoiding harm. We will return to this later.

[75] See Ball, D., *et al.*; 'Predictive testing of Adults and Children', *op. cit.*, quoting several others including, Hayden, M.R.; 'Predictive Testing for Huntington's Disease : Are We Ready for Widespead Community Implementation?', 40, *American Journal of Medical Genetics*, 515, and Brandt, J., *et al.*; 'Presymptomatic Diagnosis of Delayed-Onset with Linked DNA Markers : the Experience of Huntington's Disease', 261, *Journal of the American Medical Association*, 3108, 1989.

[76] See, Kevles, D.; 'In the Name of Eugenics: Genetics and the Uses of Human Heredity', London, Penguin Books, 1985 at 298,Andrews, L.; 'Legal Aspects of Genetic Information', 64, *The Yale Journal of Biology and Medicine*, 29, 1990, at 38, and also, Craufurd, D., Dodge, A., Kerzin-Storrar, L. *et al*; 'Uptake of Presymptomatic Predictive Testing for Huntington's Disease', 2, *The Lancet*, 603, 1989.

[77] *op. cit.*, at 60. Whereas this is arguably true of all disease, the problem can be particularly acute with genetic disease because individuals can have *future* ill health predicted. Thus a person can be affected even when they are perfectly healthy. With non-genetic disease usually one is actually affected by the disease before suffering psychological sequelae. An obvious example where this is not true is in the case of HIV and AIDS.

The possible adverse effects of knowledge of genetic predisposition have been well documented by Hoffman and Wulfsberg[78]. They cite three examples of child screening programmes in Sweden, the United States and Wales involving respectively, Alpha$_1$ -antitrypsin deficiency[79], Cystic Fibrosis[80] and Duchenne's muscular dystrophy[81].

In Sweden in 1972 the government initiated a nationwide screening programme of newborns. As part of the program parents were, a) told whether or not the child had alpha$_1$ -antitrypsin deficiency, b) counselled to protect the child from environmental factors such as smoking or high dense-particle atmospheres which could exacerbate the child's problems, c) followed to determine the psychological impact of the information. Follow-up studies showed that more than half of the families with affected children suffered adverse psychological consequences, some of which continued for five to seven years. This led directly to the abandonment of the programme by the Swedish government in 1974[82].

In like manner, Hoffman and Wulfsberg note that in the US Cystic Fibrosis screening programmes, which commenced as early as 1968, have been abandoned because 'many people think (even in cases where there is a familial risk for the disease) that early detection has no value and may, in fact, cause the family significant psychological distress prior to the time when the individual might

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[78] Hoffman, D.E. and Wulfsberg, E.A.; 'Testing Children for Genetic Predispositions : Is it in Their Best Interest?', *loc. cit.*

[79] This is a genetic enzyme deficiency which is common in persons of Scandanavian descent. Those with the gene have a high risk of developing adult-onset emphysema.

[80] Cystic Fibrosis is the most common recessively inherited disorder in the UK. It results in thick secretions in the lungs and pancreas which lead to chronic pulmonary and digestive disease.

[81] This condition is typfied by chronic muscle wasting. The disease usually manifests itself in children of between two and four years old. Death normally results by the nmiddle teenage years.

[82] Hoffman and Wulfsberg cite the following articles as authority, Thelin, T., *et al.*; 'Psychological Consequences of Neo-natal Screening for Alpha$_1$ -Antitrypsin Deficiency (ATD)', 74, *Acta Paediatrica Scandinavica*, 787, 1985, and McNeil, T.F., *et al.*; 'Psychological Effects of Screening for Somatic Risk : The Swedish Alpha$_1$ -Antitrypsin Experience', 43, *Thorax*, 505, 1988.

become symptomatic.'[83] For these reasons the authors assert that the United States has not instituted a programme of screening newborns for Duchenne's muscular dystrophy, unlike Wales where such a programme has run since 1990[84].

Similar evidence is available for adults. Citing several studies Kevles has noted that, '[t]he revelation of genetic hazard has been observed to result not only in repression but in anxiety, depression, and a sense of stigmatization'[85]. Also, Andrews has written that, '...deaths due to suicide are four times as prevalent among Huntington's disease patients than among the corresponding U.S. Caucasian population'[86].

Finally, it has even been observed that confirmation of one's status as an *non-affected* person can have adverse psychological effects. Huggins *et al*[87] and Wexler[88] have carried out studies in families affected by genetic disease. The results show that:

> [m]any may suffer "survivor guilt", particularly characteristic of wartime soldiers who live while their buddies are killed.[89]

The possibility that any or all of these forms of harm can result means that individuals can cite a strong interest in not knowing genetic information about themselves.

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[83] Hoffman and Wulfsberg, *loc. cit.*, at 333.
[84] *id.*
[85] Kevles, D.; 'In the Name of Eugenics: Genetics and the Uses of Human Heredity', *op. cit.*,at 298.
[86] See Andrews, L.; 'Legal Aspects of Genetic Information', *loc. cit.*, at 38.
[87] Huggins, M. *et al*; 'Predictive Testing for Huntington Disease in Canada : Adverse Effects and Unexpected Results in Those Receiving a Decreased Risk', *loc. cit.*
[88] Wexler, N.; 'Genetic Jeopardy and the New Clairvoyance', 6, *Progress in Medical Genetics*, 277, 1985.
[89] *ibid.*

However, and as with the arguments put above regarding an interest in knowing information, one should not imagine that potential harm is the only reason for claiming an interest in *not* knowing genetic information. The question of respect also arises. It is submitted that to disclose genetic information to someone who has not expressed a desire to know it is disrespectful in two ways.

First, if the individual has actually stated that they do not wish to know the information, to furnish the information nevertheless disrespects their wishes and is an affront to them as moral 'chooser'. This is the same argument made above about respecting an individual's desire for security of information.

Second, even if the individual has not expressed a wish not to know the information it is contended that it can be offensive to provide the information to them. That an individual might not express views about their desire to know genetic information is likely given that so many different conditions can manifest themselves with such irregular patterns through families[90]. That no wish has been expressed should not, however, lead one to believe that the individual has no interest in not knowing the information. Even if no tangible harm results from the disclosure, the fact that the individual's private sphere is invaded with such information - information which can alter considerably their peception of their self, their children and their role in society - is *per se* offensive. It requires them to take on board information which then cannot be unknown. The knowledge becomes a factor which will necessarily become part of many future life decisions of the individual. The individual is coerced into self-reflection and forced to evaluate and re-evaluate her/his *self*. Moreover, the information is given for reasons which are not those of the individual. It might be argued that it is in the individual's *best*

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[90] *supra*.

interests to know the information, but this is to make a evaluative judgement which does not consider the actual wishes of the individual[91].

For these reasons it is submitted that both the proband and the relatives of that person could have an interest in not knowing genetic information. This is not a fanciful argument. The interest has recently been recognised by the Council of Europe in its *Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine*, chapter III of which states (Article 10):

> 1. Everyone has the right to respect for private life in relation to information about his or her health.
>
> 2. Everyone is entitled to know any information collected about his or her health. *However, the wishes of individuals not to be so informed shall be observed.*
>
> 3. In exceptional cases, restrictions may be placed by law on the exercise of the rights contained in paragraph 2 in the interests of the patient.
>
> [emphasis added][92]

The recognition of this interest obviously complicates matters considerably. The most obvious conflict arises when one party wants to impart genetic information and another does not wish to receive it. Given that this can have implications for family members further down the genetic line, the respective claims require very close scrutiny.

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[91] Of course, one would take into account what one would believe the wishes of the indiviudal to be, but this is not the same thing as taking into account the individual's *actual* wishes.

[92] Council of Europe, *Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine*, Strasbourg, November 1996. The Convention was adopted by the Committee of Ministers on 19 November 1996. Reference DIR/JUR (96) 14.

4.3.3. - *Familial Issues and Interests in Genetic Information : A Conclusion*

The previous section outlines the various kinds of interests which a proband and his or her family members could have in their own genetic information. No attempt has been made to evaluate the respective merits of the interests, nor to determine the weight which they should receive relative to each other in conflict situations. Before this can be done it is necessary to consider the full range of interests which can exist in the information including the interests of employers, insurers and the State. Moreover, it is only after considering all such interests that it will be possible to identify principles, values and factors which are of relevance in resolving conflict scenarios. However, it should be noted that the interests which have been identified in this section include privacy interests of the nature defined in chapter one. First, it is submitted that an interest in keeping information secure and in a state of non-access is an example of an interest in *informational privacy*. Second, an interest in not knowing genetic information is an example of an interest in *spatial privacy*. This second example cannot also be an example of informational privacy because the interest in informational privacy is an interest premised on knowledge of the existence of the information. As we have seen, an interest in not knowing does not require such knowledge. Rather, the interest in question is protection of the private sphere around one's *self*[93]. As the eminent philosopher and jurist James Fitzjames Stephen wrote in 1873,

> [p]rivacy may be violated not only by the intrusion of a stranger, but by compelling or persuading a person to direct too much attention to his own feelings and to attach too much importance to their analysis.[94]

Invasions of privacy occur, in the case of informational privacy, when disclosures of the information take place *to unauthorised parties*. In the case of spatial privacy

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[93] That is, one's *self* in the sense of one's personality, body, mind etc., rather than oneself.

[94] Stephen, J.F.; Liberty, Equality and Fraternity (Henry Hold & Co 1873) at 160.

interests, these are invaded by unsolicited disclosure of genetic information *to the proband or relative.*

Finally, as an indication of a possible solution to the conflict, consider the US President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research which recommended that disclosure to relatives should be made *only if*[95] :

(a) reasonable attempts to persuade the proband to disclose have proved to be unsuccessful;

(b) there is a high probability of serious (that is, irreversible or fatal) harm to an identified third party;

(c) there is reason to believe that disclosure will prevent harm;

(d) the disclosure is limited to the information necessary for diagnosis and treatment.

This tries as far as possible to cater for the interests of the proband but fails to consider the possible spatial privacy interests of relatives which exist, *even if* a cure is available.

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[95] *President's Commission for the Study of Ethical Problems in Medicine and Biomedicine and Behavioural Research: Screening and Counselling for Genetic Conditions*, Washington DC, United States Government Printing Office, 1983.

4.4. - EMPLOYERS AND INSURERS

The range of parties with an interest in genetic information is not restricted to those directly affected. Genetic information has been perceived (rightly or wrongly) as a useful predictive tool and much interest in the results of genetic tests has been expressed by bodies such as employers and insurers[96]. That such bodies could have an interest in gaining access to genetic information is not surprising : the possible risk of future ill health is not to their financial advantage. This section will examine the nature of this financial interest together with other possible interests which employers and insurers can claim in personal genetic information.

4.5. - Insurance

Genetic testing and insurance have one important feature in common: both are concerned with the evaluation of risk. We have already considered the nature of genetic testing. The nature of the insurance industry has been concisely summed up by Roscam-Abbing,

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[96] See, Andrews, L. and Jaeger, A.S.; 'Confidentiality of Genetic Information in the Workplace', 17, *American Journal of Law and Medicine,* 75, 1991, Gostin, L.O.; 'Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers', 17, *American Journal of Law and Medicine*, 109, 1991, Greely, H.T.; 'Health Insurance, Employment Discrimination and the Genetic Revolution', in Kevles, D.J. and Hood, L., (eds.); 'The Code of Codes', Cambridge, Cambridge University Press, 1992, chapter 12, Harper, P.S.; 'Insurance and Genetic Testing', 23 January 1993, 341, *The Lancet*, 224, Rothstein, M.A.; 'Genetic Discrimination in Employment : Ethics, Policy and Comparative Law', and Roscam Abbing, H.D.C.; 'Predictive Genetic Knowledge, Insurances and the Legal Position of the Individual', in 'Human Genetic Analysis and the Protection of Personality and Privacy', *op. cit.* Also, Nys, H., Nederveen - van de Kragt, C.J.M., Roscam Abbing, H.D.C., and Gevers, J.K.M.; Predictive Genetic Information and Life Insurance : Legal Aspects - Towards European Community Policy?', Maastricht, Rijkuniversiteit Limburg, 1993. For comment on the latter, see, Gannon P. and Laurie, G.T.; 'Review - Predictive Genetic Information and Life Insurance: Legal Aspects - Towards European Community Policy?', 2, *European Journal of Health Law*, 282, 1995.

> Insurance firms work with homogeneous risk groups. These are groups whose members have risks that are approximately similar (risk-classification). Private insurers generally base their decisions on actuarial calculations of the likelihood of loss or damage. Premiums ought to be consistent with the risk being insured. Underwriting is fundamental to insurance. It involves the careful assessment of the risk so that the rate of premium commensurate with that risk can be charged. Therefore, insurance companies need information of proposals, including medical information, in order to assess the risk and to take decisions on the issuing of policies, the charges and the conditions accordingly. In case a person represents a high risk, the insurance company will either demand a higher premium, or lay down special conditions (exclusions) or even will turn down the application.[97]

There are many different kinds of insurance, but those of most relevance to genetic testing are life insurance (assurance) and health insurance. In the US where there is a very limited scheme of public health provision, private health insurance is essential. In the UK, private health insurance is currently less important because of the existence of the National Health System[98], but life insurance is required for certain types of loans, including mortgages for the purchase of property. Moreover, life insurance provides individuals with the best means to protect their loved ones in the event of their own death and so fulfil their responsibilities. In this way, insurance touches the lives of most of us. Denial of insurance can, therefore, have far-reaching consequences for both individuals and families.

Genetic information is clearly important to insurers in the assessment of risk and the establishment of premiums. It is entirely fair to say and to recognise that they have an economic or financial *interest* in the information. In particular, there are

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[97] Roscam Abbing; 'Predictive Genetic Knowledge, Insurances and the Legal Position of the Individual', *ibid*, at 146.

[98] Although the incidence of private health insurance is said to be steadily increasing.

two ways in which genetic information becomes of relevance. First, when the prospective insured already has knowledge about his or her own genetic make-up. This might be because of a family history of genetic disease or because of a genetic test taken by the individual him or herself. Because the nature of the insurance contract requires *uberrima fides* (utmost good faith), the prospective insured must disclose such knowledge as relevant and material information[99]. If she or he fails to do so the insurer can at any time render the contract void[100]. Second, if no such information is available the insurer might nevertheless require the insurance candidate to undergo genetic testing. Although at the present time insurance companies do not as a matter of course require prospective insured to undergo such testing[101], there is a fear that the increased availability of tests for a whole range of genetic conditions will lead to the 'development and proliferation of predictive

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[99] For a concise account of insurance law in Scotland see, Gloag and Henderson, 'The Law of Scotland', Tenth Edition, Edinburgh, W GREEN/Sweet & Maxwell, 1995, 24. For England and Wales, see Birds, J.; 'Modern Insurance Law', Third Edition, London, Sweet & Maxwell, 1993.

[100] The standard for materiality is discussed in Gloag and Henderson, *ibid*, at 24.6 : 'At present, under English law, the materiality of an undisclosed fact in both life and indemnity insurance is defined by reference to the reaction of a reasonable insurer to the non-disclosure (*Lambert v Cooperative Insurance Society* [1975] 2 Lloyd's Rep. 485; *Mutual Life Insurance Co. of New York v Ontario Metal Products Co. Ltd.* [1925] A.C. 344; *Highlands Insurance Co.* v *Continental Insurance Co.* [1990] 2 All E.R. 947 (H.L.)) In Scotland it has been held that in life insurance, the test is that of the reasonable insured (*Life Association of Scotland v Foster* (1873) 11 M. 351: referred to with approval by the Second Division in *Samuel Hooper v Royal London General Insurance Co. Ltd.* 1993 SLT 679). In indemnity contracts, it has recently been decided by a court of authority that the appropriate test is that of the reasonable insurer (*Samuel Hooper v Royal London General Insurance Co. Ltd.*, supra).

[101] The Association of British Insurers (ABI) has in the past repeatedly stated that it does not intend in the foreseeable future to require that insurance candidates undergo genetic testing, see Harper, 'Insurance and Genetic Testing', *loc. cit.*, at 225, the Nuffield Council on Bioteethics, *op. cit.*, paragraph 7.24, and the House of Common Science and Technology Committee Report on Human Genetics, *op. cit.*, paragraph 238. That said, the ABI announced in February 1997 that they do intend in the future to use genetic test results and genetic testing to determine insurance risk. The Association has issued a ruling in which it states that there will be a two-year moratorium during which test results will not be used against applicants for life policies linked to mortgages up to £100,000, and that testing will not be introduced before 1999., see Curphey, M. and Laurance, J.; 'Life Insurers Demand Gene Test Results', The Times, 19 February 1997, p.1, and Kmietowicz, Z.; 'Health Put at Risk by Insurers' Demands for Gene Test Results', 314, *British Medical Journal*, 625, 1997. The ABI has recently established a Genetics Advisory Committee to consider issues of genetics in the context of insurance. In the USA a study carried out by the Office of Technology Assessment has suggested that most insurers would not force individuals to undergo testing: Office of Technology Assessment of the US Congress, 'Genetic Tests and Health Insurance: the Results of a Survey', Washington DC, US Government Printing Office, 1992.

genetic testing'[102]. This will, allegedly, 'be employed as a loss avoiding device by insurers'[103]. Thus, we have a paradigm example of a potential 'conflict of interests'. But what is the exact nature of the interests in conflict?

4.5.1. - *The Interests of the Insurance Industry*

The concept of insurance is based on two principles: equity and solidarity. The principle of equity provides that the contribution of individuals should approximately reflect their level of risk. The more I am likely to claim insurance the higher my premium should be. The principle of solidarity, however, requires that the burden of bearing risks is spread throughout the general body of the insured.

From this we can identify two general interests of insurance companies in genetic information: the interest in making money and the interest in spreading the cost of insurance as widely as possible. That is, genetic information can assist the industry in calculating individual premiums but at the same time should not, where possible, discourage individuals from being tested. To do so would not be in the long-term interest of the industry. That said, an interesting paradox faces the insurance industry with genetic information. For just as the increased certainty which genetic information can bring permits the industry to identify high risk individuals, too much certainty could signal the downfall of the industry itself. As one expert on the economics of insurance has said, '[t]he insurance industry cannot cope with certainty.'[104] This is explained by Alper and Natowicz,

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[102] Chadwick, R. and Ngwena, C.; 'The Human Genome Project, Predictive Testing and Insurance Contracts : Ethical and Legal Responses', 1, *Res Publica*, 115, 1995, at 115.

[103] *ibid*, at 116.

[104] See the evidence of Dr Nicholas Barr of the London School of Economics to the House of Commons Science and Technology Committee, *op. cit.*, at paragraph 237.

> Traditionally, an insurance policy affords protection against very large costs resulting from the occurrence of an undesirable event whose probability is small. If the probability of loss is the same for each person then each will pay the same premium. But if the insurance company has information about the relative risk to each person it might charge premiums proportionate to the risk. In the extreme case there is sufficient knowledge to predict definitively to whom events will occur, the traditional concept of insurance breaks down...[105]

Thus genetic information is, for the industry, a double-edged sword.

A related interest of insurance companies concerns their public image. In particular, two perceptions among the public could have adverse consequences for the industry. First, if individuals feel that they will not receive fair treatment from insurance companies this might act as a disincentive to being tested. And, if individuals do not choose to be tested then no information will be available on which to calculate better the risk against which the individual seeks to insure. It might be argued that family history, which after all has *always* been part of the material information to be disclosed, will still be a guide. Perhaps so, but the unpredictability of many genetic conditions means that family history can often give no indication of an individual's particular risk. For example, in one study concerning Tay Sachs disease '82% of the incidents of the disease were initial occurrences within the kindred'[106].

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[105] Alper, J.S. and Natowicz, M.R.; 'Genetic Testing and Insurance', 307, *British Medical Journal*, 1506, 1993.

[106] Andrews, 'Legal Aspects of Genetic Information', *loc. cit.*, at 35 quoting Kaback, M.M. and Zeigler, J.L.; 'The John F. Kennedy Institute Tay-Sachs Program: Practical and Ethical Issues in an Adult Genetic Screening Program' in Hilton, B., Callahan, D., Harvis, M., Condliffe, P., and Berkley, B.; 'Ethical Issues in Human Genetics : Genetic Counseling and the Use of Genetic Knowledge', New York, Plenum Press, 1973.

The risk of individuals being deterred from seeking testing has been considered to be significant. The House of Commons Science and Technology Committee commented that,

> We accept that the insurance industry has collectively tried to deal with genetics in a responsible way; nonetheless we are concerned there is a real danger that people could decide to decline testing, even when such testing would be advantageous to them, because of the possible insurance implications.[107]

Second, if individuals are apprehensive about the security of the information given to insurance companies, - for example, if it will be passed on to employers or other third parties without authority - this once again might deter them from being tested for genetic conditions. Clearly, this has implication not just for the insurance industry but also for the individuals and the families of individuals involved.

One proposed solution is a moratorium on the use of genetic information. For example, Robert Cook-Degan has stated that insurance companies, 'may choose not to use such underwriting information because using it would cause too much of a public outcry, or would call the entire industry into question.'[108] Certainly, many countries have seen insurance companies self-impose a moratorium on requesting genetic testing[109]. Nys *et al* report that of all the countries which have legislated on

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[107] *op. cit.*, paragraph 242. The Committee continued, 'Not only will this act to the detriment of those directly concerned, but such reluctance could also hinder research which will be needed if genetic knowledge is fully to benefit society.', this will be discussed *infra*.

[108] Cook-Degan, R.M.; 'Public Policy Implications of the Human Genome Project' in Bankowski, Z. and Capron, A., (eds.); 'Genetics, Ethics and Human Values : Human Genome Mapping, Genetic Screening and Therapy', Geneva, Proceedings of the 24th CIOMS Conference, Tokyo, 22-7 July 1990, at 64.

[109] Nys, H. *et al.*, Predictive Genetic Information and Life Insurance: Legal Aspects - Towards European Community Policy?, *op. cit.* It should be noted that Dutch insureres imposed a moratorium on not requesting the results of genetic tests for a period of five years in 1990. This applied to life and private disability insruance cover up to D.FL. 200,000 (£81,300). The moratorium was recently renewed for a further five years period. Moreover, the Dutch Governement has asked insurers to revise their policy of not covering those with Huntington's disease or muscular dystrophy: see, Science and technology Committee Report, *op. cit.*, at 236.

the matter none considers that genetic testing solely for the purposes of insurance is acceptable[110]. Furthermore both the European Parliament[111] and the Council of Europe[112] have taken a firm stand in decreeing as unacceptable either the use of genetic information *or* genetic testing. However, 'the insurance industry's objections to a moratorium on the use of genetic information are based on the fear of adverse selection.'[113]

Adverse selection refers to the phenomenon of individuals taking out insurance for excessively high sums on learning of a genetic disorder or a predisposition to such. Of course, at the present time and given the strict 'full disclosure' nature of insurance contracts, adverse selection is unproblematic : a failure on the part of the individual to reveal his or her knowledge of increased risk automatically entitles the insurance company to avoid the contract. If, however, a full moratorium were imposed on both requests for genetic tests *and* access to medical history, the insurance industry has a genuine fear that adverse selection will result. Unfortunately, no clear evidence exists that self-selection of this kind is likely to occur. As Harper has pointed out, the concerns of the insurance industry do not mirror the concerns of individuals and families. For the former, the fear is of high sum claims being made by high risk individuals. For the latter, the concern is with obtaining insurance at ordinary levels for basic life and health cover[114]. This would tend to suggest that the fears of the industry are overstated.

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[110] *ibid* , at 6 - 15. Note, however, in 1992 California introduced a Bill which would allow insurers to test persons seeking an individual life insurance policy. Also, Canada would consider genetic testing in relation to excessively high policies.

[111] European Parliament, *Resolution on the Ethical and Legal Problems Concerning Genetic Engineering*, 16 March 1989, Official Journal of the European Communities, 17.4.1989, Nr C 96, p.168.

[112] Council of Europe, *Recommendation on Genetic Testing and Screening for Health Care Purposes*, no.R (92)3, 1992.

[113] House of Commons Science and Technology Committee Report, *op. cit.*, at 244.

[114] Harper, 'Insurance and Genetic Testing', *loc. cit.*, at 226. See also, Chadwick and Ngwena,'The Human Genome Project, Predictive Testing and Insurance Contracts : Ethical and Legal Responses', *loc. cit.*, at 119 - 121.

4.5.2. - *Individual and Family Interests*

There are considerable individual and family interests in genetic information required for insurance purposes.

- *Coercion*

The nature of western social structure dictates that individuals must rely heavily on insurance in order to receive many basic services. As a result, the prospective insured find themselves in a considerably weaker bargaining position compared with the prospective insurer. Standard term contracts are the norm in the insurance industry and there is precious little scope for negotiation. This has several implications for the personal interests of individuals seeking insurance and the relatives of such.

First, the principle of *uberrima fides* requires full disclosure of all material facts known to the prospective insured and likely to influence the grant of insurance. This obviously includes medical history and therefore requires that highly personal and private details be disclosed. To assert that this occurs 'voluntarily' is to stretch considerably the meaning of the word. That said, this is not to say that such information should not necessarily be disclosed (for one might prefer the freedom of contract of the insurer to the curtailment of the freedom of the individual), rather it is simply to state that the interests of the individual in the information are strong. They extend to seeking and receiving guarantees about the security of such information from those who now hold it. When this information includes genetic information the interests of relatives of the prospective insured are similarly involved. Thus, the interests of both individual and relatives in *informational privacy* are relevant here.

Second, for insurance companies to require individuals to undergo genetic testing places the individuals in a position of receiving information which they might not otherwise wish to know. This potentially offends against the interest which such individual have in *not* knowing information about their own genetic constitution. That is, the interest in *spatial privacy*. Moreover, because this information also reveals genetic data about relatives of the proband, the spatial privacy interest of such relatives in *not* knowing is also invoked.

- *Discrimination*

Discrimination is defined here as treating different groups of people differently for irrelevant reasons. An American study which addressed the issues surrounding genetic discrimination concluded that genetic conditions are,

> ...regarded by many social institutions as extremely serious, disabling or even lethal conditions without regard to the fact that many individuals with "abnormal" genotypes will either be perfectly healthy, have medical conditions which can be controlled by treatment, or experience mild forms of the disease. As a result of this misconception, decisions by such institutions as insurance companies and employers are made solely on the basis of an associated diagnostic label rather than on the actual health status of the individual or family.[115]

This would suggest that the fear of discrimination by insurers in possession of genetic information has some grounding. Individuals therefore have an interest in seeking to minimise instances of discrimination wherever possible, principally by retaining control of their own genetic information.

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[115] Billings, P.R. *et al.*; 'Discrimination as a Consequence of Genetic Testing', 50, *American Journal of Human Genetics*, 476, 1992, at 481.

- *Deterrence*

Relatedly, individuals and their relatives have an interest in not being deterred from seeking genetic information should they wish to do so. The issue of deterrence does not directly involve privacy concerns, but it is important nonetheless that it be highlighted. As has been shown, deterrence can unfortunately be an unlooked-for consequence of certain insurance practices. If individuals are deterred from seeking genetic information this can affect them in many ways : if a cure or treatment is available, non-diagnosis deprives the individual (and his/her family) of the benefit which these can bring. Also, the absence of knowledge can adversely affect future progeny if uninformed decisions to reproduce are taken. Finally, deterrence deprives the individual of the chance of discovering a low risk, or non-risk of genetic disease. This could not only substantially affect his or her insurance premium but could also offer certainty about his or her future and a degree of psychological stability[116].

4.5.3. - *Interests of Health Care Professionals*

This context of insurance takes the debate about genetic information outside the health care setting. This has implications not only for individuals and insurance companies, but also for health care professionals from whom information about patient genetic health will be requested and for whom the information can also represent a certain value. Two particular interests in the genetic information are discussed here.

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[116] This is premised on the fact that the individual *wants* to be tested but is deterred by fear of insurance consequences. The same arguments would not necessarily apply if the individual had no desire to know his or her own genetic constitution.

- *Research*

If insurance practices deter individuals from seeking genetic testing this can have considerable adverse consequences for genetic research. Statistical data are of fundamental importance in the fight against any disease and this is equally true of genetic disorders[117]. It is therefore imperative that clinicians continue to receive source data from individuals and families affected by genetic disease. If individuals do not seek to be tested for fear of possible discrimination or a lack of security of the information revealed, then the sources of clinical data will be diminished with a consequent effect on research and by extension society as a whole.

- *Professional Obligations*

Health care professionals have certain obligations to their patients which can be compromised by insurance practices. For example, requests for medical history might be viewed by clinicians as requests to breach patient confidentiality[118].

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[117] See Nanula who makes such an argument in the context of HIV/AIDS : Nanula, P.J.; 'Protecting Confidentiality in the Effort to Control AIDS', 24, *Harvard Journal on Legislation*, 315, 1986.

[118] There is some empirical evidence to substantiate this. In the 1980s Wertz and Fletcher carried out a survey of 295 geneticists in the United States. They found that the vast majority (88%) would not disclose genetic information to insurers without patient permission, see Wertz, D.C. and Fletcher, J.C., (eds.); 'Ethics and Human Genetics', New York, Springer Verlag, 1989. More recently, Geller *et al.* have carried out a comprehensive survey to determine the frequency with which various groups of health care professionals (HCPs) would disclose confidential genetic information to family members and unrelated third parties. 65% of a random sample of 1759 obstetricians, pediatricians, internists, family practitioners and psychaitrists, and 79% of medical geneticists and genetic counsellors in ten geopgraphically representative US states responded to the survey. The results make interesting reading. Inter alia, the HCPs were asked if they would disclose a patient's known risk of Huntington's disease to a health insurance company without the patient's permission. 0% of the genetic counsellors and the medical geneticists would disclose the information. Only 2.9% of the physician group would do so. More interstingly, when asked if they would disclose the fact that both members of a couple had tested positive for Cystic Fibrosis *when they had the couple's permission to disclose*, only 32.8% of physicians said that they would automatically disclose the couple's carrier status. The remaining 67.2% responded that they would discuss completion of the insurance form with the couple first. It is important to note that no legal obligation is imposed on professionals to do anything other than disclose information if patient consent has been given. The response to the survey would tend to suggest that the majority of

Similarly, if patients do not seek genetic tests for fear of insurance consequences, doctors might feel that they are denied the opportunity to care for their patients as best they can. Also, if individuals are required to undergo testing in locales chosen by insurance companies, doctors might feel concern about the adequacy of counselling which their patients will receive. Genetic counselling is an extremely important part of the testing procedure. Failure to offer it or carry it our properly can have severe ramifications for tested individuals on receipt of test results. All of these concerns relate to a health care professional's *interest* in the sanctity of the so-called 'doctor/patient relationship'. Requests by insurance companies for individual genetic information can place the parties against one another (breach of confidence) or can disempower the professional and thereby weaken the relationship s/he has with her/his patient. Given the benefits which can flow from a strong doctor/patient relationship, it is submitted that for both parties to such a relationship, there is arguably a strong interest in avoiding any unwarranted intrusions into the relationship or any externally imposed restraints.

4.5.4. - *Insurance Interests in Genetic Information: A Conclusion*

Insurance companies have a financial interest in genetic information because this can minimise the damage of a bad risk. Too much accurate information, however, is not in the industry's interests because this removes all element of risk from the enterprise. Fortunately for the industry, genetic testing cannot furnish such accurate information. As has been shown, the nature of genetic disease is such that only a few disorders are caused solely by a single gene dysfunction. The majority of

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physicians felt a moral or professional obligation not to disclose the information without first ensuring that all care had been taken to minimise any possible harm which could arise from disclosure: see, Geller, G., Tambor, E.S., Bernhardt, B.A., Chase, G.A., Hofman, K.J., Faden, R.R., and Holtzman, N.A.; 'Physicians' Attitudes Toward Disclosure of Genetic Information to Third Parties', 21, *Journal of Law, Medicine and Ethics*, 238, 1993.

disorders are polygenic and multifactorial. This means that alone, test results for most genetic disorders reveal little about future risk. In particular, they reveal nothing about the likelihood of onset, or the date of onset, or the severity of affliction. Even for disorders such as Huntington's disease or Duchenne's muscular dystrophy which are single gene dominant disorders and therefore carry a 50% risk of affliction for first degree relatives in each case, a positive test result cannot give any indiciation about onset or degree of affliction. Thus genetic tests do not and cannot provide a means of infallible predictability for the insurance industry. And, given that most conditions *are* multifactorial, the fact that several of one's relatives have died of heart disease, is likely to say more about the lifestyle of those individuals, than it does about a pattern of *genetic* disease. This limited value of testing and analysis of family history must be set against the privacy interests of individuals in keeping secure and/or not knowing their genetic constitution[119].

The two forms of privacy interest in genetic information - informational privacy and spatial privacy - correspond to the two ways in which genetic information is of relevance to the insurance industry; namely, through family history and through genetic testing. To ask about one's family history or to ask for the results of prior genetic tests is to ask about personal information known to the individual. Questions arise about the desire of the individual to surrender such information and the subsequent security which it will enjoy. These are clearly issues of informational privacy. To ask an individual to undergo genetic testing to determine genetic risk raises questions of spatial privacy : the individual is placed in a situation where s/he will receive information which s/he might not wish to know. In both

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[119] One thing should be made clear. The better understanding which genetic testing can give us of individual genetic risk does *nothing* to affect the incidence of genetic disease in the community as a whole. Genetic testing can simply give a more accurate indication of risk, and even that is restricted. As Roscam Abbing has argued : 'Not using genetic information in principle (except in case of adverse selection) is not a threat to the solvency of the insurance company: genetic risks have thus far (implicitly) been included in the coverage', in 'Predictive Genetic Knowledge, Insurances and the Legal Position of the Individual', *loc. cit.*, at 153.

of these circumstances an element of coercion is present in that information is revealed or discovered solely for the purposes of obtaining insurance. The powerful position of the insurer means that often individuals have no choice about complying with the insurer's requests. This makes for a potential conflict of interests and a need to determine which interests should prevail.

In contrast and in one respect, the interests of all parties concerned come together: no one wishes individuals to be deterred from seeking genetic testing. This has individual, familial and social consequences and deprives the industry of its perceived benefit of additional information. In order to avoid this the risk of discrimination and the concern about security of information must be addressed. A propos social discrimination and access to information this can be achieved by ensuring that individual and family informational privacy is adequately protected[120]. More problematic, however, is the industry itself[121]. As the Nuffield Council has commented,

> The Association of British Insurers emphasises that over 95% of life insurance policies are obtained at standard premium rate, while less than 1% of proposals are declined due to the mortality risk being too high. [However] the concern is that widespread use of genetic testing might sharply alter this balance[122].

The proposal of Nuffield is that those individuals with a known family history who decide to take a test and test positive should not be treated any differently by the insurance company compared to other family members. That is, they will still

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[120] For an account of the US position see, Rothenberg, K.H.; 'Genetic Information and Health Insurance: State Legislative Approaches', 23, *Journal of Law, Medicine and Ethics*, 312, 1995.
[121] See Billings, *op. cit.*
[122] Nuffield Council on Bioethics, 'Genetic Screening: Ethical Issues', *op. cit.*, paragraph 7.18.

be assessed at the same risk as those family members who have not been tested[123]. The rationale behind this is that since testing is most likely to occur in families with a known risk, and because the industry tends to interpret family history cautiously[124], 'there is unlikely to be a major difference in insurability between an individual with a family history of a genetic disorder and an individual who has had a positive genetic test result.'[125] By corollary, for those individuals who test negative the Council envisages that such persons should benefit from this result and be treated as someone with no family history[126]. In this way the Council hopes that individuals will not be deterred from having genetic tests and also that insurers will not be adversely affected since they can continue their present practice based on family history[127]. On one view this solution serves many interests; not only those of individuals who seek testing and the insurance industry, but also those of health care professionals and researchers who can gain access to test results if correct procedures are followed. However, it is interesting to note that the recommendations of the Council are somewhat different concerning population screening programmes. In such cases the majority of those taking part would not be aware of any family history of disease. The Council considers that,

> If insurers were to demand access to the results of population screening for polygenic or multifactorial disease (for example, for genetic predisposition to breast cancer), and premiums were increased for those who tested positive, many people would clearly be discouraged from participating in such programmes. This could have adverse consequences both for the health of individuals and for the public health[128].

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[123] *ibid*, at 7.28.

[124] For example, the Council notes that, 'Tables used by the insurance industry show that insurers treat 5% risk of developing Huntington's disease in the same way as a 50% risk: such indiviudals may be declined insurance or offered insurance at an increased premium, depending on their age at the time of application. Insurance prospects for individuals with a family history of Huntington's disease only improve when the risk is below 5%.', *ibid*, at 7.23.

[125] *ibid*, at 7.27.

[126] *ibid*, at 7.29.

[127] *id.*

[128] *ibid*, at 7.31.

The conclusion of the Council is that it is not acceptable for insurers to have access to genetic test results which arise from a population screening programme[129]. Furthermore, because of the principle of free and informed consent[130], genetic testing should not be made a prerequisite for obtaining insurance[131].

Thus, it can be seen that on one point the Council is emphatic. Genetic testing solely for the purposes of assessing insurance risk is not acceptable. This is true both for those who have a family history and for those who have no knowledge of their genetic constitution. Indirectly, this shows due deference to the interest which individuals have in not knowing information. The language used by the Council is that of free and informed consent which relates to the principle of autonomy (discussed in chapter three), but the interest in not knowing, and thereby the interest in spatial privacy, is protected nevertheless.

In contrast, the Council's recommendations about revealing existing knowledge diverge depending on how one comes into the knowledge : (a) knowledge of a so-called family history, or (b) knowledge through population screening. If there is no family knowledge but screening reveals a genetic condition or predisposition there is no need to disclose this information. If, however, a family history is known but no effort has been made to confirm one's genetic status, the Council considers that nevertheless the history should be revealed. Thus in one case genetic information about a specific individual can be withheld from the insurer, in another non-specific information must be disclosed. The justification for this disparity seems to be the fear of dissuading individuals from seeking testing. For those with a family history

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[129] *ibid*, at 7.32. That said, it was recommended that an upper limit be put on the moratorium. No sum was offered but approval was expressed of the Dutch system which imposes a ceiling of 200,000 guilders, at 7.33.
[130] Discussed *infra*, chapter 3.
[131] *ibid*, at 7.35.

of disease this is thought to be avoided by the scheme outlined above : those who are not tested are judged on the basis of the family history, those who are tested and test positive are also judged on the basis of family history but those who test negative should be treated as though there is no family history. For those with no family history, the solution to avoid deterrence from testing is to allow the individual to retain control of genetic information, *even if* this reveals disease or predisposition to disease. It is submitted that this is to place too much emphasis on family history. Furthermore, it does so at the expense of the privacy interests of the individuals within such a family. What this solution does not do is give due weight to an individual's interest not to know their own genetic constitution. By offering the incentive of possible lower premiums for those who seek testing and test negative, the Council makes a clear division between those who do and those who do not want to know. Those who do not want to know are judged on the basis of family history which is done in the favour of the industry. They cannot do anything to improve their chances of receiving insurance or lower premiums. Of course, one might argue that such a balance is fair since the insurance industry does not have any more accurate information on which to proceed and therefore it is entitled to judge based on the existing knowledge of family history. However, given the risk of overreaction to genetic information and the possibility of individuals receiving an unfair deal at the hands of insurance companies which fail to interpret properly family history[132], it might be argued that it is not acceptable to leave individuals to the whim of the industry. If one accepts that individuals have a strong interest in not knowing their own genetic constitution, we should surely not consider as acceptable a system which prejudices them as a result. Moreover, it should not be forgotten that a family history belongs to a collective of

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[132] This has been discussed above. Note, in addition, that evidence to the House of Common Science and Technology Committee suggests that: 'witnesses were concerned that...insurers were not able to interpret the relatively simple genetic information available to them. While there were no comprehensive studies of the extent to which genetic information was misinterpreted to a person's disadvantage, several cases in which this clearly had occurred were drawn to our attention.', *op. cit.*, at 239, referring to Memorandum (Volume III) at 1, 5, and 6 - 7.

individuals, each one of which has an informational privacy interest in the security of the information and a spatial privacy interest in not knowing information. It should not be thought however that a common history means that knowledge of that history is necessarily held in common. Many members of a family might not know of the existence of a pattern of disease. For such knowledge to be placed in the hands of insurers means, however, that they might be faced with the knowledge at some future date. Databases allow insurance firms to link up individuals with common histories and this might interfere in the future with family members' interest in not knowing genetic information. Given this, perhaps a solution different to that proposed by the Nuffield Council is called for.

One suggestion which was put to the House of Commons Science and Technology Committee was that:

> (1) *Insurance companies should not ask for any information on genetic tests at the time the contract was made*;
>
> (2) *If the insured dies of a genetic disease on a list maintained by an appropriate authority as predictable by a genetic test, then the sum paid by the insurance company need not exceed a ceiling specified at the time of the contract*;
>
> (3) *Insurance companies would re-insure in an industry pool against the risks of deaths from genetically identifiable causes on the list.*[133]

As was stated, 'the effect of this would be to spread the cost of payments from the genetically determined diseases on the list over the whole population of the insured'[134].

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[133] Science and Technology Committee, *op. cit.*, at 246.
[134] *id.*

The advantages of such a scheme are that individuals can maintain informational privacy of genetic test results however obtained, and individuals would not be dissuaded from taking otherwise desirable tests for fear of the cost of later insurance. What is not clear is whether this would extend to individuals who have a family history of disease but who have not taken a test. If it did not, then the same objections raised above would apply. Given that the scheme specifically mentions *information on genetic tests* it is unlikely that it would extend to such persons.

A final possible approach is to ban altogether the use of genetic information, whether it be specifically related to an individual (that is, a genetic test result), or whether it be of a more vague familial nature (family history). Support for such an approach has been advocated by various commentators[135]. For example, Roscam Abbing has argued that restrictive measures on insurance companies should include,

> - a ban on genetic predictive testing for serious diseases without the prospects of treatment;
>
> - a restriction on the possibility of obtaining existing genetic predictive information on serious diseases without prospect of treatment, provided the insurance will not exceed an equitable ceiling (in order to prevent adverse selection);
>
> - a restriction on asking for family history in the framework of medical underwriting if the insurance would not exceed a certain ceiling.[136]

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[135] See Roscam Abbing, *sub.*, and Churchill, L.R.; 'Self-Interest and Universal Health Care : Why Well-Insured Americans Should Support Coverage for Everyone', Cambridge, Harvard University Press, 1994 who argues that a system of universal coverage is a viable way forward to address the problems of US health insurance cover.

[136] Roscam Abbing, 'Predictive Genetic Knowledge, Insurances and the Legal Position of the Individual', *loc. cit.*, at 164.

These recommendations are linked to two relevant factors: the availability of a cure and the setting of a ceiling limit. The latter ensures that insurance companies do not suffer excessively should adverse selection prove to be a problem. The former recognises that the interests of individuals in knowing information change depending on whether anything can be done for their condition. The view taken is that to test people when there is no prospect of a cure for the condition solely to assess insurance risk is too great a burden for the individual to bear. However, if a cure is available testing can not only assist with insurance assessment but can also alert the individual to the possibility of disease. This approach is appealing because it considers the privacy interests of individuals in *both* specific genetic information *and* family history. Such information need only be revealed in rare circumstances which reflect the concerns of the insurance industry. The relevance of a cure or treatment to the recommendations is interesting and the sense of the arguments is self-evident. This writer would add, however, that one should not overlook the possibility that individuals might *not* wish to know information about their genetic make-up *even if* a cure or treatment were available. The basis of an objection to receiving genetic information in such circumstances would be that it offends against one's spatial privacy interests. Thus, it might not be enough simply to require that a cure be available or that a ceiling limit be set because such restrictions on the use of genetic information do not protect against invasions of spatial privacy.

Closing Comments

This conclusion highlights the relative interests of prospective insured, the insurer and health care professionals in the context of insurance. It also outlines several proposals for reform. The relative merits and demerits of the arguments will be discussed in full, *infra*.

4.6 - EMPLOYMENT

In ways similar to those concerning the insurance industry, current and future employers can have a use for genetic information that has either been derived from a person's family history or obtained directly by subjecting the person to testing. The interests of individuals in their own genetic information have already been outlined in detail above. In the employment context these interests must be balanced against the following interests of employers.

4.6.1. - *Financial Interest*

The ill health or potential ill health of employees can have numerous adverse financial consequences for employers. For example, ill health can lead to early retirement or redundancy requiring large payments to employees. This in turn means frequent turn over of personnel which affects efficiency. During employment, ill health means many days lost through sickness with consequent disruption to the work environment. Furthermore, in the United States much health insurance cover is provided by employers which means that ill employees can represent a considerable financial burden. Given that employers clearly have an interest in reducing as far as is practicable undue personnel costs, the supposedly predictive nature of genetic information is a very attractive tool in workforce management. As one body has put it,

> Healthy workers cost less: they are less often absent through illness, there are lower costs for hiring temporary replacements, and there are fewer precautions which would need to be taken to deal with health and safety risks[137].

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[137] The Nuffield Council on Bioethics, *op. cit.*, at 6.4.

In order to advance such a financial interest employers can seek and use genetic information at one or both of two different times: either when they are taking the decision whether or not to employ an individual, or at some later point once the individual is in employment. And, as we saw in the section on insurance, the source of such information can either be existing knowledge possessed by the individual (employee/future employee) or testing/screening to reveal previously unknown genetic conditions.

Let us first consider pre-employment requests for information. That is, genetic information is sought even before the employer/employee relationship has begun. In purely economic terms, this is the most effective means of reducing costs for the employer for several reasons. First, there is little expenditure incurred in obtaining the information - either the prospective employee is asked simply to reveal existing knowledge or s/he is asked to take a relatively inexpensive test. Second, there has been no previously incurred expenditure such as training or fringe benefits given to the individual, expenditure which would be lost if the genetic information which was discovered proved to be 'bad news'. Third, no future expenditure need be incurred in the guise of providing for the job applicant because there is no obligation which requires the employer to do so absent an actual employment contract.

With the exception of the first of these factors, an employer who seeks genetic information from a current employee is in a very different position. This is because s/he may well have spent time and money training someone who now cannot do the job, and also because an employment contract cannot simply be terminated without good reason; either the individual must be found another position or financial provision must be provided, for example, by early retirement.

All of this means that if an employer intends to use genetic information as a basis for managing his/her workforce, it is very much in the employer's financial interests to seek genetic information from *potential future* employees, rather than from actual employees. Of course, whether or not it is legitimate for employers to seek genetic information either before or during employment is another matter. This will be discussed presently.

4.6.2. - *Protecting Third Party Interests*

Certain onerous burdens are placed on the shoulders of employers in western society. They must provide acceptable standards of care and conditions for their workers, they must ensure health and safety at work, they must bear the cost of work-related accidents and they must take responsibility for the careless conduct of employees who cause harm or injury in the course of their employment. Moreover, it is frequently the case that employers are liable to third parties for any harm or damage occurring on the former's premises or as a result of their operations. Principally, these are obligations to avoid or minimise harm. And, because so much of this harm can occur at the hands of employees, once again genetic information is perceived as a useful tool in determining any potential future mishap or liability[138]. For example, if a worker who operates heavy machinery is found to be suffering from a genetic condition which makes him/her prone to a sudden heart attack beyond the age of forty five, then employers can take steps to ensure that the worker is given another less dangerous task to perform. Similarly, if an employee is found to have a predisposition to a particular condition which is exacerbated by environmental factors, the employee can be placed in working conditions which are absent such factors. For example, an environment which is dense with heavy

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[138] This interest is acknowledged both by the Nuffield Council on Bioethics, *op. cit.*, at 6.8 - 6.10, and the House of Commons Science and Technology Committee in its third report, *op. cit.*, at para. 232.

particles is very bad for individuals suffering from or prone to alpha$_1$-antitrypsin. In this way employers can act more responsibly and minimise risk both to individuals who are likely to have their own health affected by working conditions and to third parties such as co-workers who might be harmed if ill health strikes an individual at an inopportune time. And, perhaps better still from the perspective of the employer, one might argue that *future* employees can (and should) be excluded from employment if information about their genetic constitution becomes available and this reveals either the presence of a genetic disease or a predisposition to developing such a condition which means that they are likely to pose a risk to others if employed.

4.6.3. - *Protecting the Employee and the Prospective Employee*

Finally, it can be argued that employer access to genetic information will further not only the interests of employers themselves but also the interests of individuals, either *qua* employee or *qua* job applicant. As an example consider screening programmes for employees and potential employees. Not only would test results give the employer a better idea of who might be a suitable worker in a particular environment, but also such knowledge would allow the individual him or herself to make informed decisions about the desirability of such employment. As the Nuffield Council on Bioethics has stated,

> Employees would, in principle, be empowered to avoid occupations which would increase the risk of ill health and which in the long run might be life threatening. In this way they could protect the economic security of themselves and their families.[139]

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[139] *op. cit.*, at 6.6.

Of course, one would like to think that genetic information which could predict ill health could do so accurately enough to ensure the best interests of all concerned. However, as we know, the accuracy of genetic predictive information is far from assured, and the very factors which concern employers such as date of onset and degree of affliction are not currently known to us. Also, the sensitivity of such information and the apparent public misunderstanding which surrounds genetic information mean that there is a very legitimate fear that the information could be used to exclude individuals from employment or to terminate employment even when the employees in question are not affected by disease and are unlikely to be so for some time. The question therefore arises as to whether access to genetic information is an acceptable way to ensure the interests of employers and those of employees or job applicants.

4.6.4. - *Balancing Interests and Pondering on Privacy*

It should be evident from what has been said previously that each of the three interests postulated above raises serious problems of privacy for employees or prospective employees. Both the informational and spatial privacy interests of individuals are affected. Informational privacy interests are affected because personal information may be requested, disclosed and utilised in circumstances where the individual in question is not in a position to object by virtue of his/her weaker bargaining position, nor is s/he is a position to control the uses to which the information might be put at some future date. Spatial privacy interests are interfered with because individuals might be given previously unknown information, again in circumstances where they might otherwise not have chosen to know, but their freedom of choice is compromised by their desire to begin or remain in employment.

The privacy implications of employer requests for genetic information have been recognised both by the Nuffield Council on Bioethics[140] and the House of Commons Science and Technology Committee[141]. Relying heavily on the recommendations of the Nuffield Council, the Science and Technology Committee has recommended that legislation be introduced to protect the privacy of genetic information. It is suggested that the legislation be drafted so as to forbid employers from testing for genetic conditions other than those which might put the public at direct and substantial risk. Furthermore, any genetic testing for employment purposes should be strictly limited to specific conditions relevant to the particular employment and samples provided for testing should not be examined for evidence of other conditions[142].

In coming to such recommendations, the Committee agreed with the Clinical Molecular Genetics Society that "decisions on employment should be based on current ability to do the job"[143]. The clear message here is that access to genetic information must be justified on the grounds that the knowledge can have a direct bearing on the job of work to be done. If not, there can be no claim to have access to an individual's genetic information. In other words, for an employer to seek access to information, either pre-existing or previously unknown information, simply to further financial interests is not acceptable. This is all the more true when that access is sought to identify some *future* risk because such a future possibility does not affect the individual's current ability to perform his or her job of work.

It is also interesting to note that there is evidence that employment-based screening can actually be counter-productive, in that it can increase rather than reduce financial costs. For example, studies have shown that screening for hypertension

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[140] *op. cit.*, at paragraphs 6.20 - 6.23.
[141] *op. cit.*, at paragraphs 231 - 233.
[142] *ibid.*, at 232.
[143] *idem.*, quoting Memorandum (volume II) p.52.

has led to an increased sickness absence, increased anxiety and reduced self-perceived health status among persons found to be hypertensive. This is so *even when* their condition proved to be so slight as not to warrant treatment[144]. This further weakens any economic arguments that employers could put in support of claims for access to genetic information.

What, however, of the argument that genetic information should be revealed to protect the interests of employees and job applicants themselves? Once again, the Committee in this regard agreed broadly with the recommendations of the Nuffield Council[145] and concluded that,

> *Genetic Screening for employment purposes should be contemplated only where:*
>
> *(i) there is strong evidence of a clear connection between the working environment and the development of the condition for which the screening is conducted;*
>
> *(ii) the condition in question is one which seriously endangers the health of the employee;*
>
> *(iii) the condition is one for which the dangers cannot be eliminated or significantly reduced by reasonable measures taken by the employer to modify or respond to the environmental risks*[146].

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[144] See Stewart-Brown, S. and Farmer, A.; 'Screening Could Seriously Damage Your Health', 314, *British Medical Journal*, 533, 1997, quoting Johnstone, M.F., Gibson, S., Wayne, T.C., Haynes, R.B., Taylor, G.A., Sicurella, J. *et al.*; 'Effects of Labelling on Income Work and Social Function Among Hypertensive Employees', 37, *J Chron Dis*, 417, 1984, and Haynes, R.B., Sackett, D.L., Taylor, D.W., Gibson, E.S., Johnson, A.L.; 'Increased Absenteeism from Work After Detection and Labelling of Hypertensive Patients',299, *New England Journal of Medicine*, 741, 1978.

[145] Nuffield Council recommendations, *op. cit.*, at para.10.13.

[146] *ibid.*, at 233. The Committee added, however, that there should be defences for employers against action taken by employees who had excercised their right to refuse genetic screening and developed a work related illness to which they were particularly susceptible. It should also be noted that the Council's recommendation is premised on the requirement that employers consult with employee representatives and possibly also seek the approval of the Health and Safety Commission.

Importantly, the Committee stresses that 'employees should have the right to decide whether or not to participate in such screening'[147]. What neither the Committee nor the Council recommend, however, is that anti-discrimination provisions be introduced to protect those persons who choose not to know. We shall return to this below. It is also unclear whether the recommendations are intended to extend both to current employees and job applicants. No convincing argument could be put that this should not be the case, but it is significant that the Committee only mentions 'employees'. Yet, the interest of employees *and* job applicants in not knowing has been articulated by the Nuffield Council,

> [Genetic screening]...could operate to restrict job opportunities to those who, with few employment prospects, or for personal reasons, were prepared to assume the risk of ill health. It could provide a convenient excuse for employers to refuse either to take the reasonable steps necessary to accommodate those at higher risk or to employ certain categories of people able to work normally for an indefinite period[148].

What the recommendations do not do is to distinguish between testing for conditions in individuals who are likely to be affected when there is clear evidence to this effect (for example, family history), and the comprehensive screening of groups such as current employees or job applicants. This is a very important distinction for several reasons. To screen widely and randomly is tantamount to a fishing expedition. In such circumstances it is hard not to accept the fact that screening is done primarily out of financial motive. For, given the interest in not knowing, it is harder in such cases to argue that screening is done in the individual's 'best interests'. Whether or not such screening is done in the interests of third parties is a question of fact, but as Rothstein has correctly pointed out,

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[147] *idem.* The Nuffield Council is less clear about this matter. It simply states that any programme should be 'accompanied by safeguards for the employee', *op. cit.*, at 10.13.

[148] Nuffield Council on Bioethics, *op. cit.*, at 6.7.

> '[t]o justify genetic testing or subsequent exclusion, the danger should pose a *direct and immediate threat* of harm to the individual or third parties. Otherwise, genetic testing and exclusions will be justified by future risks - possible years away[149].

Rothstein criticises the recommendations of the Nuffield Council (which were adopted by the Science and Technology Committee and are outlined above) for being 'not nearly strong enough'[150]. These recommendations require simply that the genetic condition 'seriously endangers' the health of the worker or third parties. This is clearly not the same as a 'direct and immediate threat of harm'. The number of conditions likely to pose such a '*direct and immediate threat*' are few. If one accepts Rothstein's stricter language, the circumstances in which testing in employment is likely to be acceptable are severely limited[151]. The present writer prefers the latter approach primarily because of the privacy implications which surround employer requests for genetic information[152]. The precise nature of these implications is discussed in the following chapters.

Finally, Rothstein argues that there are in essence only two main issues which surround genetic testing and employment: the first is discrimination, the second, issues of privacy and confidentiality[153]. The latter of these has been dealt with cursorily for now, and will be considered more fully as this work progresses. The former merits some consideration from the United Kingdom perspective.

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[149] Rothstein, 'Genetic Discrimination in Employment: Ethics, Policy and Comparative Law', *loc. cit.*, at 138 - 139.

[150] *ibid.*, at 138.

[151] For a similar argument, see Andrews, L. and Jaeger, A.S.; 'The Human Genome Initiative and the Impact of Genetic Testing and Screening Technologies : Confidentiality of Genetic Information in the Workplace',17, *American Journal of Law and Medicine*, 75, 1991.

[152] Geller *et al., loc. cit.*, note that when health care professionals were asked if they would disclose genetic information about patients to employers without permission 0.5% of physicians, 0.7% of medical geneticists and 0% of genetic counsellors said that they would do so.

[153] *loc. cit.*, at 129.

4.6.5. - *Discrimination*

There is no specific legal regulation currently in existence in the United Kingdom which concerns genetic testing or screening. Matters of discrmination must, therefore, be dealt with under the current employment laws. In contrast, in the United States some states have introduced anti-discrimination legislation directly tailored to the problems arising from genetic information. This is the preferred approach to deal with the issues[154]. In the UK anti-discrimination law is governed by three pieces of legislation: the *Sex Discrimination Act* 1975, the *Race Relations Act* 1976, and the *Disability Discrimination Act* 1995. Under the 1975 and 1976 Acts, the protection afforded against discrimination is restricted to the precise remits of the Acts; that is, sexual or racial discrimination[155]. In light of the fact that many genetic conditions are sex-linked or affect particular ethnic and racial groups instances of different treatment of afflicted individuals could amount to discrimination within the terms of these Acts, probably as examples of indirect discrimination. It is not clear, however, how successful such arguments would be, there being no cases on point. More chances lie with the most recent legislation to be passed in this country which deals with discrimination.

The *Disability Discrimination Act* 1995 is the first piece of U.K. legislation to deal directly with discrimination against disabled people. The Act outlaws discrimination in a wide range of fields such as employment, the provision of goods, facilities and services, the sale and let of property, education, and public transport.

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[154] For comment see Rothstein, *loc. cit.*, at 139 - 140.

[155] Other recourse might, of ccourse, be available to the individual, for example, unfair or constructive dismissal procedures.

The Act defines "disability" and "disabled persons" in Part I[156] as follows,

> 1(1) Subject to the provisions of Schedule 1, a person has a disability for the purposes of this Act if he has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities.
>
> 1(2) In this Act "disabled person" means a person who has a disability.

In the context of employment, the provisions of the Act ensure that it is unlawful for an employer to treat an individual less favourably than he would treat others for a reason which relates to the individual's disability and when he cannot show that the treatment in question is justified[157]. Discrimination can occur, *inter alia*, in respect of:

- the arrangements which an employer makes for the purpose of determining to whom he should offer employment[158];
- in the terms in which he offers employment[159];
- by refusing to offer, or deliberately not offering, employment[160];
- by refusing to afford an employee opportunities for promotion, a transfer, training or receiving any other benefit, or by treating the employee differently in such opportunities[161];
- by dismissing an employee, or subjecting him to any other detriment[162].

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[156] ss. 1 - 3.
[157] s.5(1)(a) and (b).
[158] s.4(1)(a).
[159] s.4(1)(b).
[160] s.4(1)(c).
[161] s.4(2)(b) and (c).
[162] s.4(2)(d).

From what has been said above, these provisions could clearly go a long way to preventing discrimination against individuals based on information about their genetic constitution[163]. Note particularly, how pre-employment discrimination is also outlawed[164]. However, the question arises of whether the provisions of the Act actually extend to persons whose genome contains defective genes which do, or can have, a bearing on their ability to do their job. The crucial term here is '*can have*'. Clearly, persons who are already affected by a genetic condition come within the definition of "disabled person". But what of a person who merely has a predisposition to ill health? A literal interpretation of s.1(1) clearly excludes such a person for it speaks of one who '*has* a physical or mental impairment which *has* a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities'[165]. This section must however be read in conjunction with schedules one and two which allow for regulations to be made which will clarify the definitions in section 1. In particular, paragraph 8 of schedule one concerns 'progressive conditions'. The examples given of such conditions are cancer, multiple sclerosis, muscular dystrophy or infection with the human immunodeficiency virus. The paragraph provides, that (a) the Secretary of State can issue further regulations which can include or exclude other conditions as 'progressive', and that (b) someone who suffers from such a progressive condition will be treated as "disabled" provided that their condition results in an impairment which at least has (or had) an effect on their ability to carry out normal day-to-day activities, even if that effect is not a substantial adverse effect[166]. Note, however, that the individual must still in some way be symptomatic, thus still excluding those who will always be asymptomatic or who have at the relevant time 'merely' a

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[163] One limiting factor is the exemption for small business under s.7. The provisions of the Act do not apply to an employer who has fewer than 20 employees.

[164] The remedies provided by the Act in the context of employment are contained in s.8. The Act provides that cases can be heard before an industrial tribunal which has the power to order compensation to be paid, and/or to order the respondent to take action to obviate or reduce the adverse effect on the complainer.

[165] *supra.*

[166] Schedule 1, paragraph 8(1)(a)(b) and (c).

predisposition to disease. This means that discrimination against persons in the latter two categories is permitted by inference under the Act. In the Parliamentary debates this disparity and the question of genetic testing were raised, but the Minster in charge stated,

> ...except in a few well-publicised cases, genetic tests are not as yet a useful indicator of future actual disability. Their inclusion would open up the [Act] to large numbers of people who are clearly not, and may never become disabled...we cannot wander into a situation whereby, for some reason or another, potentially the entire population could claim protection under the [Act][167].

This is clearly a nonsense. It is certainly true that genetic tests are by no means accurate at the present time, but that does not mean that such tests cannot be misused by employers and others nor that they will not be used to exclude people from jobs and other services for irrelevant and irrational reasons. Surely, a 'disability discrimination' Act should be used to outlaw *all* forms of discrimination which are based on grounds of 'disability', whether or not that disability is actual *or* perceived, current *or* future. The provisions of this Act as they currently stand are inadequate and clearly prejudicial to persons likely to develop genetic conditions later in life. It is to be hoped that the Secretary of State will use the powers given under the Act to expand the definition of disability to include such persons as soon as possible. The ludicrousness and dangerousness of the current provisions was accurately summed up by Baroness Jay in the House of Lords,

> The paradox which is possible in the present situation is that where genetic counselling, genetic testing and identifying genetic markers is potentially one of the most exciting and liberating developments in medical science at the end of the 20th century, if it becomes the case that people feel that identifying those markers

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[167] *Hansard*, H.C., Volume 257, col. 887.

> in their own personal situation will lead to discrimination, they will be less likely to take advantage of those extraordinary scientific advances which may help their own condition and in which medical science may be able to help future generations of children[168].

4.6.6. - *Employment Interests in Genetic Information: A Conclusion*

The general consensus of commentators and official bodies is that access to genetic information by employers is acceptable only in very rare circumstances : 'decisions on employment should be based on current ability to do the job.'[169] Where the ability of individuals becomes affected by genetic or genetic-related disease it is very likely that they will have knowledge of the fact. This militates against arguments supporting employer-based genetic testing. Arguments about the predictive value of such testing and its possible benefits for both employers, employees and job applicants must be seen in the context of potential conflict with individual privacy interests. Testing puts at stake the spatial privacy interests of employees and potential employees. Access to existing genetic information by employers puts at stake the informational privacy interests of such persons.

Access to genetic information should only be permissible when no other means of assessing risk are available. Yet, even if access is granted the privacy interests of employees or potential employees should continue to be respected by the employers now in possession of the information. The question of discrimination requires to be addressed more forcefully than it is at present in the United Kingdom in the context of genetic information.

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[168] *Hansard*, H.L., Volume 564, col.1713.

[169] House of Commons Science and Technology Committee, *op. cit.*, at 232 quoting favourably the evidence of the Clinical Molecular Genetics Society.

5.1. - THE STATE

The above sections have identified many varied interests which both individuals and institutions have in genetic information. Two particular concerns arise from these interests : an inclination to reduce costs wherever possible and a desire to minimise or eliminate harm. These concerns are also central to the potential interests which governments might claim in the genetic information of their citizens. In addition and relatedly, the state has a role in protecting and advancing what is referred to as 'the public good'; that is the collective interests of society as a whole. This section outlines the nature of all of these interests which the State might have in genetic information.

5.2. - SOCIAL INTERESTS

5.2.1. - *Research and Anonymity*

It has already been argued that research into genetic disease can only progress efficiently by allowing clinicians access to personal genetic information from individuals and families. For the state as protector of the public good, there is a very strong interest in encouraging and facilitating such research. This can lead not only to therapies and cures for genetic conditions, but also to a better understanding of how genetic disease spreads through the population and how it affects particular familial and/or ethnic groups. This can in turn lead to better counselling services and more informed targeting of at-risk populations who can be offered screening and treatments where these are available. However, as has also been pointed out, one unique aspect of genetic information is that it is a genetic marker unique to each and every individual. This makes considerably more difficult the complete anonymisation of genetic data. Anonymisation has to date been the ethically acceptable means of securing the public interest in research while at the same time avoiding problems of conflict with individual interests in medical data. For example, in ante-natal clinics in the UK anonymous testing of pregnant women for HIV[170] is carried out routinely to determine vital statistics about the nature and rate of spread in the community. Figures released one year after the anonymous testing began showed some surprising results including an infection rate of 1 in 200 pregnant women in some areas of London[171]. The system assures anonymity to those women who agree to take part and it is thought that in this way various desirable ends are reached with minimal problems. Essential statistics about the virus are obtained while women (infected or otherwise) who have chosen not to know the results, are not forced to know the results[172]. This respects the spatial privacy interests of the women.

Genetic information by definition cannot be completely anonymised. That is not to say, however, that the information cannot be used in anonymised programmes of research. It is simply to state that the potential risk of the non-person specific information becoming person-specific is increased. The problem then becomes, initially at least, one of ensuring adequate protection of the informational privacy interests of those who provide sensitive genetic information. This is true of all anonymised information, but as Gostin has said,

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[170] HIV refers to the Human Immunodeficiency Viurs which is thought to be the progenitor of AIDS (Acquired Immune Deficiency Syndrome).

[171] Unlinked Anonymous HIV Surveys Steering Group; *Unlinked Anonymous HIV Seroprevalence Monitoring Programme in England and Wales - Data to the End of 1994*, London, Department of Health, 1995.

[172] There are, nevertheless, objections to the scheme which have been voiced. In particular, it is argued that a health professional fails in her/his duty to their patient if they are in possession of information about their health which is life-threatening yet they do not act thereupon.

> ...although the ability to identify a named individual in a large population simply from genetic material is unlikely, the capacity of computers to search multiple data bases provides a potential for linking genomic information to that person. It follows that non linked genomic data do not assure anonymity and that privacy and security safeguards must attach to any form of genetic material[173].

5.2.2. - *Clinical Benefits*

If genetic research is allowed to continue and to flourish it will lead (hopefully) to clinical benefit in the way of cures and therapies for genetic conditions and diseases. Gene therapy is still in its infancy but considerable benefits are promised by those working in this field[174]. Even if complete cures remain elusive - which is likely with many multifactorial diseases - increased understanding of the role of the genetic component in disease and its interaction with other factors can allow individuals to maximise their opportunity for a healthy future. Again, it is axiomatic that the state has a considerable interest in seeking to further this end.

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[173] Gostin, 'Genetic Privacy', *loc. cit.*, at 322. For comment on US legal attempts and proposals to protect patient interest while allowing access to genetic information see, Clayton, E.W.; 'Panel Comment : Why the use of Anonymous Samples for Research Matters', 23, *Journal of Law, Medicine and Ethics*, 375, 1995.

[174] Gene therapy consists of two separate techniques : somatic cell therapy and germ-line therapy. The former concerns manipulation of the cells in the body of a particular individual. The latter concerns manipulation of the germ cells and therefore has implications both for the individual concerned and the progeny of that individual and all future generations thereafter. In the UK the Clothier Committee considered the ethics of gene therpay in 1991: *Report of the Committee on the Ethics of Gene Therapy*, Cm 1788, 1991. It concliuded that somatic cell therapy 'does not represent a major departure from established medical practice; nor does it...pose new ethical challenges', *ibid*, at 21. The Committee did however recommend that a supervisory body be establish to authorise all instances of gene therapy in the UK. The Gene Therapy Advisory Committee was duly established in November 1993. In contrast, the Committee recommended that 'gene modification of the germ-line should not yet be attempted', *ibid*, at 18. This view has been supported by the House of Commons Science and Technology Committee, *op. cit.*, at 124 which is of the opinion that '[t]he current prohibition on manipulating the genetic structure of a human embryo should remain [under the Human Fertilisation and Embryology Act 1990, section 3(3)(d)] and there should be no manipulation of a human germ-line at any stage (including manipulation of gametes) without the approval of the GTAC.'

5.2.3. - *Protection of Public Health*

One of the most obvious state interests in the health care setting is the interest in securing public health. In chapter one it was shown how forceful arguments legitimise legislation designed to contain contagious disease; legislation which curtails to a degree the rights and interests of infected individuals. In like manner, it has been argued that free(er) access to genetic information irrespective of a proband's wishes could be justified on the grounds of halting the spread of genetic disease. Additionally, it has been argued that where such information is not readily available mandatory testing might achieve the same end[175]. Even if little or nothing can be done for those already afflicted by genetic disorders, disclosure might prevent the transmission of defective genes to future persons. Against this, however, is the potential infringement on privacy interests which such practices can represent. See *infra.*

5.2.4. - *Enhanced patient choice*

Related to the above, it can be argued that the state has an interest in facilitating individual choice. The state can adopt a more pastoral role towards individuals by providing them with information which can assist in the making of important life decisions such as the question of whether or not to have a child if both partners are cystic fibrosis carriers. Not only does this make individuals arguably more independent as moral choosers but also it might have the desired social end of preventing further spread of genetic disease. For example, Ball *et al.* have noted that this view is held by the Royal College of Physicians,

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[175] See Suter, *loc. cit.*, at 1897 citing Green, H.P. and Capron, A.M.; 'Issues of Law and Public Policy in Genetic Screening', in Bergsma, D., (ed.); 'Ethical, Social and legal Dimensions of Screening for Human Genetic Disease, 1974. See also Shaw , M.; 'Conditional Prosepective Rights of the Fetus', 5, *Journal of Legal Medicine*, 63, 1984 in which it is argued that prospective parents should faced mandatory screening for certain conditions.

> [the] Royal College of Physicians report suggests that as long as individuals have the right to decide for themselves whether to bear children it could be argued that such individuals should have access to the fullest possible information, including genetic, pertinent to that decision and therefore this should not be withheld.[176]

This would imply that the state should seek to further its interest in facilitating choice by providing comprehensive screening programmes, and a plethora of available genetic tests accompanied by suitable counselling services and other support mechanisms such as easy access to abortion. Cost implications aside, this would certainly further both individual and state interests by making free choice a market commodity. If such programmes were free of coercive measures the risk of conflict of interests is almost entirely eliminated[177].

The situation is more complicated, however, if the state seeks to further interests with existing information. In circumstances where prospective parents wish to know of a relative's genetic constitution in order to make a fully informed reproductive choice, there is real potential for conflict. If the parents' wish can only be granted by breaching the relative's informational privacy interests this poses the question of whether the interest in the information for reproductive purposes is enough to merit an invasion of the relative's privacy. Again, this will be analysed *infra.*

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[176] See Ball *et al*, *op. cit.*, at 77 referring to the Royal College of Physcians of London, *Ethical Issues in Clinical Genetics : A Report of the Working Group of the Royal College of Physicians' Committees on Ethical Issues in Medicine and Clinical Genetics*, 1991.

[177] But not quite. As the Nuffield Council has pointed out : '[i]t has been argued that the availability of prenatal screening and diagnosis, together with the termination of seriously affected pregnancies, both reflect and reinforce the negative attitudes of our society towards those with disabilities. Indeed medical genetics may add a new dimension if genetic disorder came to be seen as a matter of choice rather than fate.', *op. cit.*, at 8.11.

5.2.5. - *Uses of Genetic Information in the Criminal Justice System*

DNA Fingerprinting

DNA Fingerprinting has revolutionised the process of crime detection. The technique was invented and developed by Professor Alec Jeffreys, a biologist at the University of Leicester in 1984. DNA fingerprinting allows the identification of one individual among millions by simple analysis of a spot of blood, a few strands of hair, a sample of sperm or a drop of saliva. The method used relates to an analysis, in the chromosomes, of fragments of DNA which repeat certain sequences in abstract and complex patterns and which serve as a unique 'marker' for the individual in question[178]. In decrypting the order of these sequences biologists can thus produce what looks like bar codes on radiographic film. Each individual will produce a separate and unique pattern of lines: a genetic identity card of the individual[179]. This information clearly has implications for crime detection. Minute samples of evidence from the human body left at the scene of a crime can help to identify a particular individual within very small margins of error. Scientific establishments which carry out such tests normally work also with and for the police and justice departments. In order to be accepted in court genetic evidence must be accompanied by statistical data relating to the probability of another individual having the same genetic fingerprint as the accused. In order for the establishments in question to calculate such probability they must have at their disposal considerable amounts of genetic data on computer. Hence the reason that

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[178] Save identical twins.

[179] Professor Jeffreys, the founder of the technique, has recently made even more refinements to the test. Not only can the DNA now be analysed in a fraction of the original time (three days as opposed to three weeks), but also the presentation of the information has undergone something of a change. Instead of presenting the data in the form of "bar codes" on film, an individual's genetic profile can now be presented in the form of digital read out, capable of direct transfer onto computer. Thus it is now possible to have data banks of the genetic profiles of an entire country. For an up-to-date account of DNA Fingerprinting see, Robertson, B. and Vignaux, G.A.; 'Interpreting Evidence : Evaluating Forensic Science in the Courtroom', Chichester, John Wiley & Sons, 1995, chapter 9.

most laboratories keep detailed data banks of genetic information which they update regularly with new genetic profiles. These are used for comparison with criminal profiles, yet all profiles are kept together often without distinction between the private clients and those obliged by law to take the test[180]. Concerns have therefore arisen about the security of genetic information kept in such files together with the possible uses to which it is put.

One such data base is that of the London Metropolitan Police[181]. It is estimated that the Metropolitan computers contain biological profiles on several thousand criminals, covering incidents ranging from minor offences to unsolved crimes. In principle the genetic data of anyone excluded from enquiries is erased from the police files. However this has not prevented the Metropolitan Police being taken to the European Court of Human Rights by one such individual for failure to do so in direct breach of Article 8 of the European Convention guaranteeing the right to privacy[182]. The Court is unlikely to deliver its judgment for a few years but civil liberties groups supporting this action hope to convince the U.K. government before then to introduce some kind of legislation covering protection of genetic data. For the moment however this seems unlikely : the Home Office has expressed interest in establishing a national data bank of genetic fingerprinting[183].

The 1990 Schengen Convention proposed the abolition of border controls and the development of closer relations between European Community police forces with a

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[180] See, Note; 'The Advent of DNA Databanks : Implications for Information Privacy', 16, *American Journal of Law and Medicine*, 381, 1990.

[181] The German police however have recently recruited more than one hundred geneticists for a "confidential project", see; 'L'Express', *loc. cit.*, at 50.

[182] *ibid*, at 51.

[183] The genetic documentation of the prison population is equally gathering pace across the Atlantic with 13 states having already passed laws authorising the genetic fingerprinting of every criminal involved in a criminal incident. In the case of the state of Iowa this even extends to minor infractions of the law.

correlative sharing of criminal information[184]. The Schengen Information System which was born out of the Convention has been described as 'the most spectacular novelty' of the Convention[185]. This is a new computerised system which links national authorities and allows access to information and reports for the purposes of border checks and police enquiries. Based in Strasbourg, police forces and Immigration services Europe-wide ultimately will have access to information on the 320 million individuals who live within the Community borders[186]. Baldwin-Edwards and Hebenton have noted that this has clear implications for personal privacy,

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[184] Named after the agreement signed at Schengen, Luxembourg in 1985 relating to the free movement of persons within the European Community.

[185] See Schutte, J.E.; 'Schengen : Its Meaning for the Free Movement of Persons in Europe', 28, *Common Market Law Review*, 549, 1991, at 559.

[186] The system will contain, *inter alia*, data about persons wanted for arrest for extradition purposes, data relating to aliens, data relating to persons whose whereabouts are to be reported (eg-missing persons), data concerning witnesses or suspects summoned to appear before a criminal court, personal information in police reports including name, sex, date and place of birth, nationality, identifying physical features, and propensity for violence.

> The real danger lies not so much in the arcane details of data protection provisions but in what Schengen presents as the key practice of policing in the future: essentially this focuses on 'unwanted and undesirable' individuals and groups as the end-point in European police-work. In our view, effective policing requires public confidence: this can only be achieved with appropriate standards of transparency, accountability and judicial review. The standards of Schengen will amount in practice to little more than a complex, almost impenetrable, legitimation of state and inter-state invasion of personal privacy. The underlying trend is without doubt towards 'Big Brother'[187].

Legal Obligations of Disclosure to Prevent or Detect Crime

The public interest in crime detection and prevention is obviously considerable and disclosure of private information is usually required and justified by law in certain circumstances. For example, in the United Kingdom personal information must be disclosed, *inter alia*, in the following circumstances:

- The Road Traffic Act 1991, section 21 requires that 'any person' in possession of information which might lead to the identification of a driver thought to be involved in an offence under the Act must disclose this to the relevant authorities[188];

- The Prevention of Terrorism (Temporary Provisions) Act 1989, section 18 requires the disclosure of information which relates to acts, or potential acts, of terrorism;

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[187] See Baldwin-Edwards, M. and Hebenton, B.; 'Will SIS Be Europe's Big Brother?', in Anderson, M., and Den Boer, M., (eds.); 'Policing Across National Boundaries', London, Pinter Publishers, 1994, chapter 8. See also in the same volume, Raab, C.D.; 'Police Cooperation : The Prospects for Privacy', chapter 7.

[188] This extends to health care professionals, see *Hunter v Mann* [1974] QB 767; [1974] 2 All ER 414 (which concerned a similar provision under the Road Traffic Act 1972).

- The Data Protection Act 1984 permits disclosures of information held on computer for the purposes of the prevention or detection of crime or the apprehension or prosecution of offenders. This applies, however, only if the person making the disclosure has reasonable grounds for believing that a failure to disclose would be likely to prejudice one of these purposes.

- The lawful order of a competent court can compel disclosure of personal information.

Whereas none of these examples is specific to genetic information, all extend to cover such information if its disclosure could further the ends of the particular legal provision or order.

Genetic Determinism and Crime

The question of genetic components playing a part in disease has already been discussed above. A related question, however, concerns the extent to which any one individual's propensity towards criminality is genetically determined. In a recent Ciba Foundation Symposium this question was examined[189]. One major conclusion of the symposium was that far more work must be done to establish the role of genetics in crime and criminal behaviour but nonetheless a nexus could not be ruled out. Such evidence of a genetic element in criminal behaviour presents the western state with a series of interesting dilemmas. For example, if an individual commits crime because s/he has a predisposition to doing so - in much the same way as one might have a predisposition to developing ischaemic heart disease given the right (or wrong) conditions - then to what extent can one and should one hold that

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[189] Ciba Foundation Symposium 194; 'Genetics of Criminal and Antisocial Behaviour', Chicester, John Wiley & Sons, 1996.

individual *to blame* for his or her crimes?[190] If a system of criminal justice professes to be just because it only punishes those who intentionally commit crimes and excuses those whose freewill is somehow overcome or affected by uncontrollable factors, can it ever be argued that those who are 'genetically driven' to commit crime should be punished nevertheless? If not, how can the state ensure that those who are more likely to lose control because of their genetic constitution will not simply be those most likely to be absolved of crime and therefore those most likely to be released back into the community potentially to do more harm? There are no easy answers to these questions, but it is certainly arguable that *if* a genetic component proves to play a significant role in criminal behaviour then the state has a strong claim to an interest in knowing which individuals are likely to be affected.

5.3. - FINANCIAL INTERESTS

Any state or government has an interest in keeping costs to a minimum. In several ways genetic information can assist in this goal.

5.3.1. - *Testing to establish paternity*

DNA fingerprinting is not reserved for use only by the police or for medical statistics. One obvious advantage that genetic fingerprinting has over old methods of blood testing is that one can identify a precise individual, whereas with

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[190] Consider the case of Stephen Mobley discussed by Denno in the Ciba Foundation Symposium 194. This man shot and killed a pizza store manager after robbing the till in February 1991. He confessed to the crime one month later. At his trial, Mobley's lawyers sought to lead evidence that his behaviour was heavily influenced by his genetic make-up. This, they argued, did not affect his guilt but should be taken into account to mitigate his possible sentence from the death penalty to life imprisonment. Evidence was led that Mobley's family history displayed four generations of pattern violence. Mobley was characterised as a man who 'had an inability to control his impulses or to internalize any kind of value system'. However, the Court's view of such evidence was that '[t]he theory of genetic connection...is not at a level of scientific acceptance that would justify its admission.' On February 20 1994 the jury found Mobley guilty and he was sentenced to death. An appeal was, however, immediately lodged, see Denno, D.W.; '<u>Legal Implications of Genetics and Crime Research</u>' in Ciba Foundation Symposium 194, *op. cit.*, at 248ff.

traditional tests one could only establish who was not present or who was not involved. This has obvious implications for paternity suits because it is now possible to determine precisely who is the father of a child rather than determining simply who is not. In this country immigration officers have been using the technique since 1985 to reunite families, establishing with certainty the genetic link between immigration candidates and their supposed relative already resident in the U.K. The test is even carried out in the country of origin: the British Embassies in Pakistan and Bangladesh have recently been furnished with the necessary tools to carry out the test on suspect visa applicants even before they leave their respective countries. This relieves the U.K. of the problem of detaining and processing and possibly sending back such individuals[191].

In 1991 the Swedish social services department set up a programme to combat one of the biggest drains on its resources in recent years: the holiday romance syndrome. In the last decade statistics show that some 14,000 Swedish women have returned pregnant from holiday, principally from Mediterranean countries such as Spain, Italy and southern France. The Swedish government thus decided to initiate a programme to identify these "Latin lovers" in an attempt to recover some of the monies it had paid out in child maintenance and support. The unmarried mothers were asked to denounce the fathers of their children. 942 Spaniards, 550 Italians and some 60 Frenchmen were identified in this way. They were then offered the choice of either signing a document acknowledging paternity (and thereby accepting to pay maintenance) or of giving a sample of blood for genetic analysis. Almost two thirds of the Spanish accepted to pay, with the remaining 383 being summoned to the Swedish Embassy in Madrid to undergo the test, where they were joined by 172 of the Italians. The French, it would seem, accepted their fate without question[192]. This is indicative of an ever increasing demand to use such fingerprinting

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[191] "L'Express", *loc. cit.*, at 48.

[192] *ibid*, at 49.

techniques in paternity cases outside the judicial system. Such technology gives unprecedented scope to impinge on the lives of others in this respect. In Germany, in cases of uncertain paternity heavy reliance is placed on evidence to determine the identity of the biological father. Around 22,000 cases arise each year requiring either traditional blood tests or genetic fingerprinting[193]. This however is relatively minor compared to the situation in the United States where 160,000 tests are carried out annually. In England the Child Support Act provides for the possibility of legally obliging a single mother to reveal the identity of the father of her child; failure to do so may mean her sacrificing certain social security allowances and benefits. Clearly, these states have a significant financial interest in requiring individuals to take responsibility for their acts[194].

5.3.2. - *Health Care Resources*

Genetic information clearly has implications for questions of resource allocation within any system of health provision[195]. For countries such as the United Kingdom and France which operate national health systems, considerable public expenditure is lost on genetic diseases and genetic-related conditions. All moves to eradicate or eliminate such diseases and conditions are therefore, in addition to being of social interest, of financial interest to the state.

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[193] For an account of the German position and that in many other countries see, European Commission; 'Studies on the Socio-Economic Impact of Biotechnology - Genetic Fingerprints: Scientific Truth and Filiation Law', Luxembourg, Office for Official Publications of the European Communities, 1996. For the Scottish position on the use of genetic fingerprinting to establish paternity in Scotland, see Thomson, J.M.; 'Family Law in Scotland', Third Edition, Edinburgh, Butterworths, 1996, at 152 - 159.

[194] See Knoppers, B.M., Grimaud, M.A., Choquette, C. and Le Bris, S.; 'Les Tests Genetiques a des Fins D'Identification', in 'Human Genetic Analysis and the Protection of Personality and Privacy', International Colloquium, Schulthess Polygraphischer Verlag Zurich 1994, for a discussion of the validity of genetic test results in the context of both penal policy and paternity suits.

[195] For recent comment on resource allocation from an ethical perspective see, Maxwell, R.J.; 'Health Care Management: Are Ethics Relevant?' in Gillon, R. and Lloyd, A. (eds.), 'Principles of Health Care Ethics', Chichester, John Wiley and Son, 1994, at 819 - 828. Also, Williams, A.; 'Economics, Society and Health Care Ethics', *ibid*, at 829 - 842. For a comprehensive account of resource allocation problems facing the NHS, see Newdick, C.; 'Who Should We Treat? : Law, Patients and Resources in the N.H.S.', Oxford, Oxford Univesity Press, 1995.

5.3.3. - *Testing to prevent fraud in social benefits*

Another financial interest lies in the reduction of fraud at the hands of unscrupulous citizens. Genetic testing or access to genetic information could verify the existence of actual or potential disease and thereby legitimise individual claims for state assistance. By corollary, such testing and access could defeat fraudulent claims and thereby save the state considerable sums of money.

5.3.4. - *The State as Employer*

It has already been shown that in the United Kingdom the only employer currently making regular use of genetic testing is HM Forces. This ensures that at risk individuals are not placed in dangerous situations and saves the government money in not training those who are unlikely to perform their duties with the requisite degree of efficiency. In the United States, the Administration has instituted a programme of compulsory genetic testing of military personnel, which information is held on data bases. Never again will there be an 'unknown soldier'[196]. Such a database facilitates quick, efficient and low-cost access to personnel materials with potential multifactorial uses.

5.4. - *State Interests: A Conclusion*

One can see from the above account of potential interests held by the state in the genetic information of its citizens that a broad range of roles is adopted by the state in its relationship with its citizens. We see the state as protector from harm,

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[196] The database was established by the Pentagon and it contains the profiles of the two million military personnel in current service: Deputy Secretary of Defence Memorandum, No. 47803, 16 December 1991.

facilitator of choice, social regulator and employer. To many, these roles will seem entirely beneficent, but as was pointed out in chapter one, such roles also typify the western state as the interventionist state. This has clear implications for the division in our society between public and private life, and by corollary has implications for the privacy of individuals. The legitimacy of these 'beneficent' roles of the state must, it is submitted, be subject to close scrutiny to determine not only whether or not they do in fact impinge on individual interests, but also to establish where the boundary can and should be drawn between public and private, and therefore between legitimate and illegitimate involvement of the state in the lives of individuals.

6.1. - FUTURE PERSONS

Lastly, one further interest might deserve recognition. Given the obvious implications for reproductive choices linked to genetic information, and given the possible consequences of a decision to reproduce even when tests results reveal 'bad news' (namely, the birth of a child with genetic defects), is it possible to argue that an interest might exist *viz.* the progeny of affected individuals? Such an interest might arise in one of two ways. First, an argument might be made that the interests of future progeny should be considered, even if we do not consider that such interests can, or should, trump those of existing persons[197]. Second, the state might claim a valid interest in the outcome of individual's reproductive choices if this will result, with a relatively high degree of certainty, in the birth of a child which will be a drain on valuable resources. Once again, these issues will be examined presently.

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[197] Ngwena and Chadwick, have argued that it might be possible to take account of the interests of the unborn in such circumstances, see 'Genetic Diagnostic Information and the Duty of Confidentiality: Ethics and Law', *loc. cit.*, at 85.

7.1. - INTERESTS IN GENETIC INFORMATION: A CONCLUSION

Clearly there are a considerable number of potential interests which exist in relation to genetic information. The interested parties include:

- the proband
- the relatives of such a person (and their relatives)
- the insurance industry
- employers and potential employers
- the state
- those representing 'future persons'

As we have seen there is much potential for conflict, but also much scope for compromise. The next step is to consider how best to weight these respective interests, reach acceptable compromises where possible and to choose between interests where this is not possible.

It is submitted that in order to do this it is necessary to consider the relevant principles and values which bind together much of our social fabric in western society. These must be examined together with relevant factors about genetic information and disease which can sometimes tip the balance a particular way. In order to do this it is proposed that certain scenarios be considered which allow us to scrutinise examples of the interplay of interests and the potential nature of conflict. This also allows us to determine how the principles and values identified lead us towards possible solutions. Most importantly, because this thesis seeks to resolve problems and reconcile issues using legal means, the principles and values referred to will be examined from their legal perspective. Thus, this chapter will conclude by identifying the relevant principles, values and factors mentioned above and by outlining case scenarios which will be used to address the complex problems surrounding genetic information. These will be explored more fully from the perspective of the existing law in chapters three and four. In chapter five an argument will be made that a legal construct of privacy assists greatly in addressing the problems under scrutiny.

8.1. - WESTERN PRINCIPLES AND VALUES: A BRIEF ANTHOLOGY

8.1.2. Principles of Ethics

Much of western thinking and action, particularly in the medical and medical law spheres, is guided by the four 'principles of ethics' of moral philosophy. These four principles are:

- Autonomy;
- Beneficence;
- Non-maleficence;
- Justice[198]

Autonomy refers to a state of moral independence and an autonomous individual is one who is a 'moral chooser'[199]. The principle of respect for patient autonomy is fundamental to good medical practice and is the cornerstone of many ethical and

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[198] These four principles are derived from the model of bioethics developed by Beauchamp and Childress, *op. cit.* This is not the only model of medical ethics in existence, but is the one preferred by the present writer. Furthermore, it should be borne in mind that 'ethics' as a concept is not homogenous across different professions and different fields. Medical ethics is not the same as business ethics which in turn differs from professional ethics : see, Downie, R.S.; 'Professional Ethics and Business Ethics', in McLean, S.A.M., (ed.); 'Contemporary Issues in Law, Medicine and Ethics', Aldershot, Gower, 1996, chapter 1. The model used in this work is clearly that of medical ethics as articulated by Beauchamp and Childress. In circumstances where the discussion moves outside the purely medical sphere - for example, into insurance and employment - the medical model is still used because the focus of this work is *patient* privacy. This is not too problematic because even although notions of ethics change across fields, common themes are nevertheless to be found - for example, although one might not use the terminology of 'autonomy' or 'non-maleficence', 'respect' and 'public interest' convey in essence the same meaning and prescribe very similar conduct.

[199] This term is borrowed from Stanley Benn, *inter alia*, from his work, 'A Theory of Freedom', *op. cit.*

legal requirements concerning the way in which health care professionals treat their patients. *Inter alia*, the principle requires that patients be consulted about health care provision, that their wishes be sought to proceed with treatment and that their wishes concerning treatment be respected, even if such wishes run counter to the advice or wishes of the health care professional. This extends to respect for the patients' wishes about their personal health information.

Beneficence and *non-maleficence* prescribe, respectively, that one should strive where possible to bring benefit to individuals and that one should endeavour at all times to minimise harm to them and others.

Justice requires that individual cases be treat like with like and that no unjustifiable decisions are made which prejudice one individual or group over another.

8.1.3. - Confidentiality

It has been said of *confidentiality* that it 'has been elevated to the status of a principle of Medical Ethics'[200]. Confidentiality is characterised by a relationship involving two or more individuals one or more of whom has/have undertaken, explicitly or implicitly, not to reveal information concerning the other individual in the relationship. It is accepted universally that health care professionals owe a duty of confidence to their patients and that only exceptionally should disclosure without consent be made. Although exceptions to the duty exist, in practice no breach is made lightly or without good cause. Confidentiality is the *duty* of the health care professional and the *right* of the patient.

8.1.4. - Privacy

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[200] Ngwena and Chadwick, 'Genetic Diagnostic Information and the Duty of Confidentiality: Ethics and Law', *loc. cit.*, at 74.

The definition of privacy offered in this work and the justification for its value have already been argued. A defence of the concept will be mounted in chapter five, but it is here submitted that the notion of privacy is generally accepted as a value in western culture.

8.1.5. - Public Interest

The concept of public interest has already been mentioned on frequent occasions. It is an amorphous term which has a role to play both in ethics and law. It acts as a safeguard for both individual and collective interests but suffers from a lack of precise definition and has therefore a tendency to be open to abuse. Nevertheless, the concept reflects many important values and must be considered in this debate.

8.1.6. - Additional Factors

In addition to the above, there are several factors which must be considered when trying to resolve complex issues surrounding genetic information. These are not only highly relevant but context specific and can be invoked - alone or in combination - in particular situations to assist in making the strongest argument for the most appropriate outcome. These factors are:

- *The availability of a cure.* If death or disease can be avoided incontrovertibly it is trite that very strong arguments must be advanced to prevent disclosure of genetic information to those likely to be affected, especially in the absence of some other means of preventing harm. Contrarily, if nothing can be done to prevent the onset of genetic disease or alleviate suffering the argument for disclosure is weakened.

- *The severity of the condition and likelihood of onset.* A fatal condition intuitively calls for action if death can be prevented. In contrast, a mild condition for which nothing can be done makes arguing for disclosure more difficult. In like manner, a 50% risk of developing a genetic condition which lies with a first degree relative is more compelling than a 1% or 2% risk to non-specific third cousins.

- *The nature of genetic disease.* The affliction of one individual with genetic disease does not pose any direct threat to any other living human being. In this respect genetic disease is very different from many conventional diseases. Also, with recessive disorders which render people asymptomatic carriers, there is additionally no threat to the health of the carrier. Only future progeny might be affected. Facts such as this can have a bearing on how one views particular complex scenarios.

- *The nature of genetic testing.* The point has already been made forcefully several times that predictive genetic testing (and family history) are inaccurate in assessing future risk. Apart from the problems of determining likelihood of onset, date of onset, and severity of condition, genetic mutations make genetic tests fallible and reduce significantly their accuracy[201].

- *The nature of the request.* If individuals are asked to disclose or receive genetic information, the specific nature of the request might have a particular influence on the outcome one would recommend. For example, if an individual is asked simply to take part in linkage tests to determine a relative's particular risk (for procreative purposes) and the tested individual receives guarantees that s/he will

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[201] For example, current tests for cystic fibrosis can only detect up to 75% of at risk individuals in society. As Gostin states: '[a]pproximately one in every two couples from the general population identified by CF screening as "at-risk" will be falsely labeled.', in 'Genetic Privacy', *loc. cit.*, at 323.

not be given the test results, then such an altruistic gesture is unlikely to conflict in any way with that indiviual's interests. Compare this with an unexpected advance from a health care professional or relative requesting a moment of one's time to disclose a 50% chance of developing Huntington's disease within the next five years.

9.1. - THE LEGAL PERSPECTIVE

Many of the principles and values discussed above are enshrined in law, and in particular medical law, in the United Kingdom. For example, the principle of respect for patient autonomy receives legal recognition in several ways: patient consent must be obtained if a health care professional is to avoid a civil suit either for assault and/or negligence, and patient refusal of treatment must be respected save in rare circumstances[202]. Similarly, the duty of health care professionals to respect patient confidences receives legal sanction through the common law of confidence[203], and the concept of public interest serves to limit the scope of both autonomy and confidentiality when harm might result to third parties[204]. Noticeable by its absence, however, is a legally protected right of privacy. As has been stated in chapter one, this thesis argues that such a legal privacy right has a place in the legal systems of the United Kingdom. To facilitate the argument the following scenarios will be examined, first from the perspective of the law's protection of patient autonomy in chapter two, and then from the perspective of the law of confidence in chapter three. It will be shown that each area fails to protect adequately the interests at stake. A discussion of the 'public interest' will naturally feature in both of these chapters. Chapter five will consider in more detail the nature of the privacy concept advanced in this work and will test the concept

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[202] Chapter three, *infra*.
[203] Chapter four, *infra*.
[204] See *infra*, chapters three and four.

by an examination of its solutions to the problem scenarios already mentioned. The final chapter of this work will explore possible legal mechanisms for the introduction of such a privacy right in the United Kingdom.

10.1. - SCENARIOS

The range of interests in genetic information which has been outlined above has been used in this section to create four case studies, each one of which deals with different interests and different problems surrounding genetics. Inevitably, however, there will be overlap between the interests under scrutiny, and often it may be possible to put the same or similar arguments in different contexts. Certainly, the common theme which ties the scenarios together is that of privacy: how are the privacy interests of individuals affected by competing claims to have access to their genetic information? However, each scenario offers a different perspective on this question. Scenario one considers the interests of employers and insurers in introducing testing and requesting information as against the privacy interests of those from whom the information is taken. Scenario two considers the interests of the state in introducing various programmes of screening or testing, and again sets this against the privacy interests of citizens. Scenarios three and four focus on the family unit. Scenario three considers the merits and demerits of a family's 'right to know' a relative's genetic information and tests such familial claims against the privacy interests of the relative in question. Finally, scenario four considers the question of a family's 'right not to know' genetic information. In other words, the issue at stake here is the privacy interests of *family members* in not receiving information about themselves. Simply the facts each of these four scenarios will be offered here. No argument will be put at this stage. In chapters three, four and five, however, the merits of each case will be considered from, respectively, the perspectives of autonomy, confidentiality and privacy. That is, the utility of an appeal to each of these concepts to protect the privacy interests under scrutiny will be examined.

10.2. - SCENARIO ONE: *Employers and Insurers*

Alpha$_1$ - antitryphsin is a genetic enzyme deficiency. Those with the gene have a high risk of developing adult-onset emphysema. The condition can be exacerbated by adverse environmental factors such as dust or smoke-filled environments. Consider the acceptability of either employers or insurers:

a) having access to individual medical records to determine whether someone has this condition or whether they have been tested for the condition.

and/or

b) carrying out tests on individuals to determine current or future risk of developing the condition.

10.3. - SCENARIO TWO: *State interests*

A - Premarital Screening for Cystic Fibrosis

It has been the custom for many years in many American states, to require individuals to undergo premarital testing for various conditions such as syphilis or Rhesus compatibility[205]. Although this is no bar to marriage as such[206], it has been justified as best, most responsible practice. Consider the acceptability of such a

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[205] See Brandt, A.M.; 'AIDS in Historical Perspective: Four Lessons from the History of Sexually Transmitted Diseases', in McKenzie, N.F., (ed.); 'The AIDS Reader: Social, Political and Ethical Issues', London, Penguin Books, 1991.

[206] *ibid.*

programme of premarital screening of prospective couples for Cystic Fibrosis in the United Kingdom. This is the most common fatal recessive condition among Caucasians. Around 1 in 2000 people are affected. The risks are those common for recessive disorders; namely, when both parents are carriers there is a 50% chance that each child born of their union will also be a carrier. There is a further 25% chance that each child may be afflicted by the disease, and only 25% chance that a child will not be affected in any way. However, because all affected males and most affected females are infertile, it is unlikely that people will know of their carrier status before marriage[207]. The condition is present from birth and is characterised by salty sweat and the accumulation of mucous in the lungs. This leads to chronic and ultimately fatal lung disease. There have been some attempts to cure Cystic Fibrosis by somatic gene therapy with limited success.

B - Prenatal and Neonatal Screening

Consider the acceptability of a National Health Service programme of ante and post natal screening.

Prenatal screening is already offered for a range of condition including trisomy 21 (Down's Syndrome) and around 150 other 'single gene' disorders[208]. Neonatal screening occurs for hyperthyroidism[209] and phenylketonuria[210],[211]. Should, however, these programmes include testing for the following :

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[207] That is, if few of those affected have children, there will be even fewer children of affected persons who will know that they are carriers. Unless relatives have had children who affected by CF, in most cases people will be unaware of their carrier status.

[208] See Lippman, A.; 'Prenatal Genetic Testing and Screening' in Clarke, 'Genetic Counselling: Practice and Principles', *op. cit.*, chapter 7, note 22 and related text.

[209] Hyperthyroidism is a condition affecting the functioning of the thyroid gland which regulates metabolism.

[210] *Phenylketonuria* affects around 1 in 10,000 births. It is caused by the build up of toxic by-products of phenylalanine which itself is a natural bi-product of diet and digestion. If untreated this can lead to severe brain damage. However, if detected early enough the condition can be treated with almost 100% success by strict dietary control throughout childhood and sometimes into adulthood.

- *Sickle Cell Anaemia.* This is a recessive condition which affects primarily persons of Caribbean decent. The condition causes the red blood cells to adopt a sickle shape making them less efficient at carrying oxygen and more likely to block capillaries. Affected individuals are chronically anaemic and will die if the condition goes untreated. Although no cure is available, sickle cell anaemia can be treated with regular blood transfusions.

- *Huntington's disease.* This is a late onset dominant condition which therefore carries a 50% chance of affecting each child of an affected individual. The condition initially develops in adults of between 30 and 50 years of age and progresses in roughly four stages. Affected individuals typically exhibit abnormal 'jerk' movements and increasing dementia. Each stage lasts roughly 4-5 years. There is at present no cure for Huntington's disease.

- *Duchenne Muscular Dystrophy.* This is an X-linked disorder and therefore predominately affects male children. Around 1 in 4000 male births are affected. This is also an incurable degenerative disease, causing progressive muscular degeneration and weakness. Eventually affected individuals die from heart failure. This usually occurs in the mid to late twenties. DMD is the largest known gene and consequently has a high number of possible mutations. Not only does this affect the reliability of test results but also the severity with which individuals are affected : different mutations produce different levels of disability.

- *Ischaemic heart disease.* It is now widely recognised that many forms of heart disease have a genetic component to their pathogenesis. In combination with

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[211] For an indication of the range of screening programmes operating in the UK as of September 1993 see the Nuffield Council on Bioethics. *op. cit.,* at 27.

environmental factors a genetic predisposition to heart disease can reduce considerably one's life expectancy.

10.4. - SCENARIO THREE: *A Family's Right to Know?*

Dr Ian Smith discovers from a colleague that Kenneth, the nephew of Dr Smith's patient Ewan, has recently been diagnosed with haemochromatosis[212]. This is the most common recessive disorder in the UK. Around 1 in every 500 people have the gene (HFE). The condition causes excess accumulation of iron in the body. Where the iron collects fibrosis occurs. Liver cirrhosis, diabetes and heart failure are common related conditions. The symptoms and severity of the condition vary considerably between individuals but if caught early, the condition can be treated by periodic phlebotomy (blood letting). The condition is late onset and might not affect women until after menopause (menstrual loss of iron delays onset). As far as Dr Smith is aware there is no history of the disease in Ewan's family. However, because the condition is recessive both of Kenneth's parents must be carriers. This means that there is a chance that Ewan might also be a carrier since he is the brother of Kenneth's father (50%). Also, Ewan is married to Kenneth's mother's sister, Elizabeth who consequently runs the same risk of being a carrier (50%)[213]. This clearly has implications for Ewan and Elizabeth's children, Michael and

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[212] As will become apparent in chapter four, such a scenario involves a potentially serious breach of confidentiality on the part of Kenneth's doctor. The ethical problems which this in itself gives rise to are important, but are not the immediate concern of this work.

[213] In order for Kenneth's father and mother to be carriers at least one of their respective parents must also have been a carrier. If this was so then 50% of their offspring could also be carriers. That is, both Kenneth's father and Ewan and Kenneth's mother and Elizabeth each had a 50% chance of being a carrier and a 50% chance of being unaffected. Note, however, it is also entirely possible that both of the parents in the respective families were carriers. If so, then again 50% of children would be carriers, but 25% would have the condition and only 25% would be unaffected. It is entirely possible that no child of any of the parents had the disease, but the fact that both parents were carriers reduces Ewan and Elizabeth's chances of being unaffected from 50% to 25%.

Marlene, both of whom are patients of Dr Smith. If Ewan is the only carrier in the family, the risk of the children being carriers is 50%[214]. If Elizabeth is also a carrier the children run the same risk of being carriers, but in addition run a 25% risk of being affected and only have a 25% of being unaffected. However, if Ewan or his wife Elizabeth is actually affected by the condition the children will not only have a 50% risk of being carriers but a 50% risk of disease. Marlene is in her early teenage years and shows no symptoms. Michael is similarly asymptomatic and recently got married. He is trying for a baby with his wife. Ewan's wife Elizabeth is pre-menopausal. She too shows no signs of disease. Dr Smith faces several dilemmas:

- What is his obligation, if any, to Kenneth? Should Kenneth be approached and if so, to what extent should Kenneth's response dictate the subsequent acts of the doctor?
- Should he seek to inform Ewan, Elizabeth, Marlene and/or Michael? If so, how should he go about this?
- What about Michael's wife, Michele, who is hoping to become pregnant? Should the doctor, or indeed anyone else who knows, inform her of the family risk?

10.5. - SCENARIO FOUR: *A Right Not to Know?*

BRCA1 is the gene responsible for between five and ten percent of female breast cancers. It was discovered in 1994 and is known to be ten times longer than most human genes[215]. This fact means that the likelihood of mutations is increased and this in turn has implications for the efficacy of test kits designed to identify the

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[214] That is, what is said in the above footnote equally applies to Michael and Marlene.

[215] It is thought that the gene contains around 100,000 base pairs of nucleotides. It was discovered on 15 Spetember 1994 by a team of researchers at the University of Utah, USA.

gene[216]. There is a high risk of secondary cancers associated with this disease, but early detection and radical intervention in the form of mastectomy can reduce this risk. Preventative measures, also in the form of mastectomies, can also reduce the instances of disease. The condition is also thought to be multifactorial, further complicating matters.

Nicola is aware of a history of breast cancer in her family. Her mother, her great-grandmother and one of her aunts died from the disease. Nicola has a sister, Nadia, and three female cousins, Norma, Romana and Elvira. She does not know the extent to which the rest of the family are aware of the pattern of disease in the family. Recently, Nicola discovered a lump in her breast which was diagnosed as malignant. She is concerned that the family has the BRCA1 gene and that her sister and cousins are at risk. Nicola's GP has advised a mastectomy and has strongly urged Nicola to contact her relatives to arrange testing. Nicola considers the following question :

- Should she approach her sister and cousins with the news of her own disease and urge them to seek medical advice? She is aware, for example, that Nadia is phobic about operations and that Elvira is prone to bouts of depression.

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[216] As Pence has noted, even once a test is developed, 'a negative result would be indeterminable and could be expressed only as a probability', see Pence, 'Classic Cases in Medical Ethics', *op. cit.*, at 411 - 412.

CHAPTER THREE

AUTONOMY
AND
GENETIC INFORMATION

1.1. - INTRODUCTION

In the first chapter of this work parameters were set for this thesis. Those parameters are the role of privacy in regulating the relationship between individual and society in the western liberal democracy. In particular, the work focuses on the role of privacy in the health care setting in relation to genetic information. It is, however, also necessary to consider the consequences of this choice. What does it mean to be an individual in a western liberal democracy? How do the values and mores of such a culture affect individuals in the different spheres of their lives and, in particular, how are such values and mores reflected in the health care setting? This chapter will seek to examine these issues. The discussion will focus on the concept of autonomy as a medico-legal phenomenon and its role in addressing the genetic privacy issues identified in chapter two.

2.1. - AUTONOMY IN THE WESTERN LIBERAL DEMOCRACY

It has been shown that fundamental social changes in the last three centuries have culminated in the emergence of the western liberal tradition and a concomitant rise in concern for individual rights and personal privacy. Yet, such changes were not brought about without considerable assistance from writers of the times. Philosophical, political, legal and social writers have all had a crucial part to play in the development of western society. Principal among these was John Stuart Mill (1806 - 1873). His seminal work *On Liberty* is one of the foundational treatises of modern liberal theory and thought[1].

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[1] Mill, J.S.; 'On Liberty', London, Penguin Books, 1974. In the introduction to this edition Himmelfarb notes that, '...Mill's...immediate predecessors and contemporaries: Adam Smith, the Founding Fathers, Paine and Godwin, Emerson and Thoreau, Proudhon and Stirner...[e]ach celebrated liberty in one fashion or another, to one degree or another. But it remained for Mill to convert the idea of liberty into a philosophically respectable doctrine, to put it in its most comprehensive, extensive, and systematic form, the form in which it is generally known and accepted today.', *ibid*, at 9. Of course,

2.2. - *John Stuart Mill*

On Liberty represents a search for the limits of public interference with individual action. For Mill, the only purpose for which power may be exercised over an individual, against his or her will, is to prevent harm to others[2] : '[o]ver himself, over his own body and mind, the individual is sovereign'[3]. The motivation behind his exposition was what he called the 'tyranny of the majority'[4]. This has been explained thus,

> ...the reason a new doctrine of liberty had become so urgent, was the new form of tyranny confronting mankind. The old, familiar tyranny of despotic government in which rulers imposed their will upon the ruled, had ceased to be a threat in civilised society boasting representative or popular government, where the interest and will of rulers was becoming more and more identified with the interest and will of the ruled. But it was precisely the rise of popular government that [Mill] saw as the pre-condition of a new and more formidable despotism. For the 'tyranny of the majority' was now exerting itself not so much in politics as in the entire area of social life. "Society is itself the tyrant", and more oppressive than any tyrant of old because "it leaves fewer means of escape, penetrating much more deeply into the details of life, and enslaving the soul itself".[5]

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this is not to say that Mill's work was not the subject of criticism, see pp.35 - 44. In particular, see 'Liberty, Equality Fraternity' by James Fitzjames Stephen in 1872. This can be found under the same title edited by R.J. White, Cambridge, 1967.

[2] *ibid*, at 68. He continues, '[h]is own good, either physical or moral, is not sufficient warrant.', ibid. Indeed, Mill accepts only one further restriction: preventing a person selling him or herself into slavery. However, others have argued that the principle should be wider than this. In particular, it has been argued that the principle should, in certain circumstances, include prevention of harm to oneself, see, for example, Raz, J.; 'The Morality of Freedom', Oxford, Clarendon Press, 1986, at 412. In this work Raz also argues for the justification of certain paternalistic measures which promote safety and further that such measures, affecting matters which are merely of instrumental value, do not interfere with autonomy.

[3] Mill, *op. cit.*, at 69.

[4] *ibid*, at 62 - 63. As is stated in the edition, this phrase was used most prominently by Alexis de Tocqueville in his work 'Democracy in America', see, for example, volume I, chapter XV.

[5] *ibid*, at 34. Quotes from Mill are found at 63, *ibid*.

Thus as Mill himself put it,

> 'There is a limit to the legitimate interference of collective opinion with individual independence; and to find that limit, and maintain it against encroachment, is as indispensable to a good condition of human affairs as protection against political despotism.[6]

His work therefore represents an attempt to identify a means by which the limit between public and private life can be established and maintained.

Mill's concern was with the distinction between what he called *self-regarding* and *other-regarding* behaviour. The latter encompassed conduct which interfered, to a material extent, with the rights and interests of others. Such conduct was, according to Mill, the legitimate subject of social control. The former category, that of self-regarding behaviour, pertained to the sphere of life,

> ...in which society, as distinguished from the individual, has, if any, only an indirect interest: comprehending all that portion of a person's life and conduct which affects only himself or, if it affects others, only with their free, voluntary and undeceived consent.[7]

For Mill, all interference with self-regarding behaviour was unwarranted interference. This was so even if the interference was benevolent in nature,

> His own good, either physical or moral, is not sufficient warrant. He cannot rightfully be compelled to do or forbear because it will be better for him to do so, because it will make him happier, because, in the opinion of others, to do so would be wise, or even right.[8]

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[6] *ibid*, at 63.

[7] *ibid*, at 71.

[8] *ibid*, at 68.

Mill thought it not only possible[9], but also highly desirable[10], to draw a division between public and private life[11]. Over the years this view has not gone unchallenged. Feinberg argues, for example, that 'self-regarding' behaviour can be as dangerous and harmful to others, and indeed society in general, as 'other-regarding' behaviour[12]. Although the latter has a more direct effect, Feinberg argues that this is no more profound than the ultimate deleterious effect of 'self-regarding' behaviour. He states,

> A non-productive life devoted entirely to lotus-eating, opium smoking or heroin shooting, in which all of one's waking moments are spent cultivating or enjoying dreamy euphoric states, may be "no one else's business" when one, or a hundred or ten thousand self-supporting persons do it of their own free choice. But when 10% of the whole population choose to live that way, they become parasitical, and the situation approaches the threshold of serious public harm. When 50% choose to live that way it may become impossible for the remainder to maintain a community at all.[13]

According to Feinberg the notion of community can be deprived of meaning by the selfish acts of individuals. As a result other individuals will in turn be harmed. He argues that individualism, taken to extremes, undermines the whole notion of community and society and thwarts its end as an homogeneous collection of souls all directing their efforts towards the greater good of the whole. Whereas his approach tends to view individuals as adjuncts of society rather than important constituent parts, the concerns expressed are common among the critics of Millian-type theories[14].

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[9] *ibid*, at 147 - 152.

[10] *ibid*, at 69.

[11] Mill permitted only two exceptions to his theory: harm to others, or conduct preventing an individual from fulfilling a duty or obligation. In such cases society could intervene to prevent the harm or to remedy the breach of duty, *ibid*, at 148 - 9.

[12] Feinberg, J.; 'Harm to Self', Oxford, Oxford University Press, 1986, at 22 - 23.

[13] *ibid*.

[14] As John Donne wrote, 'No man is an island, entire of itself; every man is a piece of the continent, a part of the main.' Others have refined the basic ideas as represented by Mill's work. For example, Raz considers that '[a]utonomous life is valuable only if it is spent in the pursuit of acceptable and valuable projects and relationships', see Raz, J.; 'Autonomy, Toleration, and the Harm Principle', in Gavison, R. (ed.); 'Issues in Contemporary Legal Philosophy', Oxford, Clarendon Press, 1987, 313 - 333, at 330.

2.3. - *Immanuel Kant*

In contrast to Mill, Immanuel Kant (1734 - 1804) - another 'founding father' of the western philosophical ethos - put forward a theory of moral conduct based on the conception of persons as free and equal moral agents[15]. For him Reason governs the conduct of individuals. Each self-sufficient rational individual is guided by his reason to behave in a certain manner in social situations. Since every such individual is possessed of the same reason which guides him or her to act, interaction between individuals results in common behaviour which, according to Kant, includes a mutual respect for other members of the community. Similarly, the moral code of society derives its content from reason and serves therefore to reinforce the principle of mutual respect. For Kant, to respect others is to treat them as ends in themselves, and not as a means to an end. And, because individuals have reason and are therefore capable of determining their own destiny, to interfere with their chosen life path is to disrespect them. Thus, albeit by different means, we arrive at the same point: like Mill, Kant was concerned with the separation of public and private spheres of life.

This view is also found in Raz, J.; 'The Morality of Freedom', *op. cit.* Rapaczynski comments that, 'The standard critique of liberalism, whether it comes from the political right, nostalgic for the ancient or medieval model of a closely integrated social order, or from the political left, hopeful of a future society based on universal brotherhood, is that liberal individualism is predicated on a philosophical theory that makes moral and political obligations into functions of man's (mostly material) interest and that its lofty ideas are but a thin cover for a brutal system of competition and exploitation. The basic argumentative strategy of this critique was discovered by Rousseau, later developed by Hegel, the utopian socialists, Marx, the ideologues of nationalism, and many contemporary social critics. The positivistic or utilitarian approach to moral and political issues that these critics have seen as characteristic of capitalist society and its liberal doctrine leads, according to them, to ultimately nihilistic consequences.', see Rapaczynski, 'Nature and Politics : Liberalism in the Philosophies of Hobbes, Locke and Rousseau', London, Cornell Univeristy Press at 213. For a well-argued defence of individual rights and liberalism see, Dworkin, R.; 'Taking Rights Seriously', Cambridge, Harvard Univesity Press, 1977, especially chapters 10 and 11. For a range of liberalist viewpoints see, Pennock, J.R. and Chapman, J.W.; 'Liberal Democracy', New York, New York University Press, 1983, and Salvadori, M. (ed.); 'European Liberalism', New York, John Wiley and Sons, 1972.

[15] Of all of Kant's works, perhaps the most relevant for this thesis is 'Metaphysics of Morals' first published in 1785. The translation used in this work is that by T.K. Abbot, New York, Prometheus Books, 1988.

It is however for the exposition of his 'categorical imperative' that Kant is most famous. Kant posited a single 'categorical imperative' for testing the moral acceptability of all conduct. That is, he proposed one rule from which one could derive the rightness or wrongfulness of human actions. An act is only 'right' if it possesses moral worth and an act only possesses moral worth if it is performed by a moral agent possessed of 'good will'. To achieve good will is to act for reasons of moral duty and in accordance with the principle of mutual respect. Thereby one can see, once again, that central to Kant's thesis is the notion of respect for persons.

Yet, irrespective of the precise nature of the theory which provides an accurate account of the philosophical underpinnings of western society (if such a unitary theory even exists), it is irrefutable that in such a society individuals are perceived to be unique entities possessed of dignity and worthy of respect *in se*. The value system of a liberal democracy places much emphasis on concepts such as liberty which are considered to further the aims of the society and protect the rights and interests of individuals.

The 'freedom from interference' conception of liberty expoused by Mill has been a central theme in the works of many later writers on liberty[16]. Further, his treatise put forward a view of the individual as a self-governing, self-choosing social animal: the 'autonomous' individual[17]. This view has assumed increasing importance with the

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[16] According to Dworkin, 'Historically there have been two influential traditions that have explicated the idea of liberty in contrasting terms. On one view, associated with the names of Hobbes and John Stuart Mill, liberty is the absence of interference with a person's actions. Coercion and force are the main enemies of liberty. Another tradition, that of Jean Jacques Rousseau and T.H. Green, understands liberty as being more than simply the absence of intereference. as including the presence of a range of alternatives and opportunities. But whether the emphasis is on restrictions or opportunities the core notion of liberty is the ability of a person to effectuate his decisions in action.', see Dworkin, G.; '<u>The Theory and Practice of Autonomy</u>', Cambridge, Cambridge University Press, 1988, at 105.

[17] For example, at 123 he describes the kind of individual who, for him, is important, '[h]e who lets his world, or his portion of it, choose his plan of life for him has no need of any other faculty than the ape-like one of imitation. He who chooses his plan for himself employs all of his faculties. He must use

advance of the twentieth century. Yet, the boundaries between the two concepts of liberty and autonomy are not easy to establish[18]. At a general level of abstraction these concepts embody an ethos that holds that one is free to choose how to live one's life and to exercise that choice, save in exceptional circumstances, without challenge. Every individual is entitled to be respected, to have their choices respected and to be free from unwarranted interference[19]. This is not to suggest that autonomy and liberty are facets of the same notion, nor indeed that they are necessarily overlapping concepts[20]. But, it is accurate to say that in western liberal society, which values the role of liberty, the autonomous individual is generally accepted as the norm. That is, in terms of the relationship between society and individual, in the western liberal democracy the individual is a free and autonomous agent[21].

This view is also found in the philosophy of Kant. As has been said, his thesis requires that persons be treated as 'ends in themselves' and not as 'means to an end'. Kant posited that respect for the autonomy of individuals is a necessary adjunct to the

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observation to see, reasoning and judgement to foresee, and when he has decided, firmness and self-control to hold his deliberate decision.'

[18] Many have tried, see chapter 5, *infra*.

[19] To clarify, not every individual who exists is treated as autonomous. Mere 'presence' in the community is not sufficient. There are certain criteria which have to be met before one will be considered to be 'autonomous' and thereby enjoy the benefits of such a state. For example, children, the mentally incapax and animals are not deemed to be, or treated as, autonomous agents. In each case the principal reason for this is the same: they are not possessed of freewill and are thereby deprived of the capacity to exercise the choices which is the kernel of autonomy. Benn, 'A Theory of Freedom', New York, Cambridge University Press, 1988, at 240, is of the opinion that it is the existence of a 'natural personality' in a human being and not merely the fact that he is human which distinguishes men from animals and entitles the former to a degree of respect as persons.

[20] For an interesting discussion see, Young, R.; 'Personal Autonomy: Beyond Negative and Positive Liberty', London, Croom Helm, 1986.

[21] In recent years these concepts have even been the subject of criticism which challenges their value. For example, Benn points out that the entire liberal individualistic tradition has come under fire from critics who denounce it as 'dehumanising' and who consider the society which it forms as 'alienating'. As he states "[critics argue that the tradition] rests...on a model of man that is descriptively inadequate and morally defective, and the quasi-contractual theories of human association which derive from it are invalidated by their faulty foundation.", Benn, S.I.; 'A Theory of Freedom', *op. cit.*, chapter 12, esp. at p. 213. He cites Sheldon Wolin ('Politics and Vision') as a proponent of this rejection of liberalism and all of its so-called ideals.

recognition that all persons have unconditional worth: as a moral agent each person has the capacity to determine his or her own destiny[22]. To fail to respect a person's autonomy is therefore to treat him or her as a 'means' and not an 'end': the 'means' being one's own ends and not that of the other person.

Of course, this is not to contend that the general theories of Mill or Kant are the same or even that they are in any way similar. But, as Beauchamp and Childress have pointed out,

> Mill's position requires both noninterference with and an active strengthening of autonomous expression, whereas Kant's entails a moral imperative of respectful treatment of persons as ends rather than merely as means. In the final analysis, however, these two profoundly different philosophies both provide support for the principle of respect for autonomy.[23]

That is to say, the underlying reason why we consider that persons are worthy of respect, or that their choices ought to be respected, is secondary to the recognition that our actions towards each other, and the actions of the institutions of social order towards us, are driven by the acceptance of the view that each of us *is* an autonomous person[24].

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[22] See Kant 'Groundwork of the Metaphysics of Morals and 'The Doctrine of Virtue', Part II of Metaphysics of Morals.

[23] Beauchamp, T. L. and Childress, J.F.; 'Principles of Biomedical Ethics', Fourth Edition, New York, Oxford University Press, 1994, at 125.

[24] Yet, as Dworkin has indicated, '...unlike the concepts of liberty and equality, [autonomy] has not received careful and comprehensive philosophical examination.', see Dworkin, 'The Theory and Practice of Autonomy', *op. cit.*, at 4.

3.1. - AUTONOMY IN THE HEALTH CARE SETTING

One important feature of the principle of autonomy of particular importance for this thesis has been highlighted by Dworkin,

> ...the idea of autonomy has emerged as a central notion in the area of applied moral philosophy, particularly in the biomedical context.[25]

Indeed, Dworkin argues that autonomy is of particular importance in health care. He cites two reasons for this,

> First, one's body is irreplaceable and inescapable. If my architect doesn't listen to me and this results in a house I do not like, I can always move. I cannot move from my body. In addition because my body *is* me, failure to respect my wishes concerning my body is a particular insulting denial of autonomy.[26]

To this can be added two further reasons. In recent years the emphasis in health care in many western states has moved from paternalistic practices towards the greater involvement of patients in the health care process. This is evidenced in particular by the rise of the doctrine of informed consent to medical treatment[27]. The informed consent doctrine dictates that the patient be given knowledge which they understand about the nature and risks of the treatment proposed by the health care professional and that they give free and voluntary consent to the said treatment. To require that such informed consent[28] be forthcoming, is to recognise the patient as an autonomous

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[25] *ibid*, at 4 - 5.

[26] *ibid*, at 113.

[27] See McLean, S.A.M.; 'A Patient's Right to Know: Information Disclosure, the Doctor and the Law', Aldershot, Gower, 1989, Faden, R.R. and Beauchamp, T.L.; 'A History and Theory of Informed Consent', New York, Oxford University Press, 1986, and Schultz, M.M.; 'From Informed Consent to Patient Choice: A New Protected Interest', 95, *Yale Law Journal*, 219, 1985.

[28] Or, indeed, consent *simpliciter*, for the doctrine of informed consent is not universally accepted in the western world. For comment see, Kennedy I. and Grubb, A.; 'Medical Law: Text with Materials', Second Edition, London, Butterworths, 1994, at 151 - 233.

agent and to accept the need to respect his/her autonomy. The doctrine emphasises that the patient is an integral part of the therapeutic alliance between him/herself and the health care professional.

Second, the intimate connection between body and self which leads Dworkin to conclude that disrespect for wishes concerning the body is disrespectful of autonomy, is equally applicable to personal information. It has already been argued in chapters one and two that the nature of personal information is such that it represents an extension of the abstract notion of the self. It assumes the same character and importance as the body. Thus, just as disrespect for the body is an affront to individual autonomy, disrespect for personal information is equally so.

These examples demonstrate the increasing acceptance of the importance of the concept of patient autonomy in the western health care setting[29].

3.2. - THE PRINCIPLE OF AUTONOMY

What then, is autonomy? What does it mean to be autonomous? *Autonomy* is derived from the Greek words *autos* ('self') and *nomos* ('law' or 'rule'). As several writers have noted, the term was first used to refer to self-rule in Greek city states which had *autonomia* when their citizens legislated for themselves and were not subject to some conquering power[30]. Yet, applied to an individual, autonomy can mean a number of things. For example, to call a person autonomous can refer to the fact that they are in

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[29] For very different perspectives, see, Abdel Haleem, M.A.S.; 'Medical Ethics in Islam', in Grubb, A. (ed.); 'Choices and Decisions in Health Care', Chicester, John Wiley and Sons, 1993, at 1, and Morgan, P. and Lawton, C.; 'Ethical Issues in Six Religious Traditions', Edinburgh, Edinburgh University Press, 1996.

[30] See Dworkin, 'The Theory and Practice of Autonomy', *op. cit.* at 12 - 13, Beauchamp and Childress, *op. cit.* at 120 - 121, and Feinberg, 'Harm to Self', *op. cit.*, at 28, note 1.

an autonomous state: a *state* in which they are independent and in which they make their own choices. Similarly, one can refer to an autonomous person and mean that the person has *capacity* to make choices. Clearly, this precludes *all* persons from being autonomous. A person in a coma has no capacity to choose. In the same way, infants, children and persons suffering from serious mental dysfunction might not have the capacity to make choices. On this conception of autonomy, a person must be possessed of certain characteristics or traits before they can be called autonomous. Usually, these include reason and ability or competence[31]. Sometimes, however, it is argued that a person is only autonomous if certain strict criteria are met such as consistency in decision-making, resistance to external influence, and self-sufficient independence in the establishment of personal values and beliefs[32]. Other conceptions of autonomy perceive it as an ideal[33] or as the sovereign authority to govern oneself, akin to political independence enjoyed by States[34].

Unfortunately, these different conceptions do not provide us with a unifying definition of the principle of autonomy[35]. Nevertheless, it is submitted that certain core elements can be identified which offer us a workable model of autonomy for use in the health care setting.

First, as has already been stated, it would seem that central to the principle of autonomy is the idea of *choice*[36]. To be respected as an autonomous person is to have

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[31] See, for example, Downie, R.S. and Telfer, E.; 'Autonomy', 15, *Philosophy*, 301, 1971.
[32] See, for example, Benn. S.I.; 'Freedom, Autonomy and the Concept of a Person', 76, *Proceedings of the Aristotelian Society*, 123, 1976. See also, Raz, The Morality of Freedom, *op. cit.*, at 379 - 382.
[33] For example, see Downie, R.S. *et al*, 'Health Promotion: Models and Values', *op. cit.*, at 139.
[34] See, Feinberg, 'Harm to Self', *op. cit.*, at 27ff.
[35] This point is cogently made by Dworkin, 'Theory and Practice', *op. cit.*, at 5 - 6.
[36] See, for example, Feinberg, 'Harm to Self', *op. cit.*, at 54: '[t]he kernel of the idea of autonomy is the right to make choices and decisons...[p]ut compendiously, the most basic autonomy right is the right to decide how to live one's life'. In a discussion of 'positive' liberty, Berlin puts forward the view that this sense of liberty derives from the wish on the part of the individual to be his own master. As he says, 'I wish my life and decisions to depend on myself, not on external forces of any kind.', see, Berlin, I.;

one's choices respected. Second, crucial to this respect is *non-interference*. In order to make *one's own choices* - that is, for those choices to be autonomous - one must be unrestrained by unwarranted interference by others[37]. Finally, bound up with all of this is possession of the *capacity* to make one's own choices[38].

In addition to this, it is suggested that for a 'working' model of autonomy it is not necessary to conceive of the principle as an ideal or a condition achievable only on the attainment of certain elusive characteristics or qualities[39]. Although autonomy is

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'Four Essays on Liberty', Oxford, Oxford University Press, 1969, at 131. Similarly, Dworkin, 'The Theory and Practice of Autonomy', *op. cit.*, at 20, defines autonomy as, '...a second-order capacity of persons to reflect critically upon their first-order preferences, desires, wishes and so forth and the capacity to accept or attempt to change these in light of higher-order preferences and values.' For Raz, to be autonomous is to be 'the author of one's own life'. The autonomous life is opposed to coerced choices and further, to be autonomous a person must not only be given a choice but he must be given an adequate range of choices, see Raz, J.; 'The Morality of Freedom', *op. cit.*, at 370 - 373. This argument is repeated, in part, in 'Autonomy, Toleration, and the Harm Principle', in Gavison, R. (ed.); 'Issues in Contemporary Legal Philosophy', *op. cit.*,, at 313 - 333. Downie and Calman opine that '[t]o be an autonomous person is to have the ability to be able to choose for oneself or more extensively to be able to formulate and carry out one's own plans or policies', see Downie, R.S. and Calman, K.C.; 'Healthy Respect : Ethics in Health Care', Second Edition, Oxford, Oxford University Press, 1994, at 52. Finally, consider Beauchamp and Childress, *op. cit.*, at 121, '...we start with what we take to be essential to personal autonomy, as distinguished from political self-rule: personal rule of the self that is free from both controlling interferences by others and from personal limitations that prevent meaningful choice, such as inadequate understanding.' In support they cite Berlin, *op. cit.*, at 118 - 172, Feinberg, *op. cit.*, chapters 18 and 19, and Hill, T.E., Jr.; 'Autonomy and Self-Respect', Cambridge, Cambridge University Press, 1991, chapters 1 - 4.

[37] See, Beauchamp and Childress, *op. cit.* at 121 - 122, Berlin, *op.cit.*, at 131, and Dworkin, 'The Theory and Practice of Autonomy', *op. cit.* at 18 - 19. Raz, ''The Morality of Freedom', *op. cit.* at 408 - 411, argues that although autonomy is a valuable thing, and a constituent element of the 'good life', he does not include in his conception of autonomy as valuable the right to make 'bad' choices. He argues that restriction *can* be placed on autonomy and the making of autonomous choices if to fail to do so would result in harm to others, or even harm to the individual in question in the future. In this latter position Raz departs from Mill.

[38] Dworkin, 'The Theory and Practice of Autonomy', *op. cit.* at 20, considers 'capacity' a constituent element of his definition of autonomy. For Raz, 'The Morality of Freedom', *op. cit.*, at 408, the autonomous person has the 'capacity' to control and create his 'good life'. In 'Autonomy, Toleration, and the Harm Principle', *op. cit.*, at 314, he argues that, '...a person is [not] autonomous if he is paralysed and therefore cannot taken advantage of the options offered to him.' Downie and Calman, *op. cit.* at 52, consider that autonomy include not only choice but the 'ability' to choose. Beauchamp and Childress, *op. cit.*, at 132 - 141, discuss the role of 'competence' to take decisions and note that, '[c]ompetence judgments serve a gatekeeping role in health care by distinguishing persons whose decisions should be solicited or accepted from persons whose decisions need not or should not be solicited or accepted.', at 132. They point out, however, that '...a person should rarely be judged incompetent with respect to every sphere of life.', *ibid,* at 134.

[39] See, for example, Beauchamp and Childress, *op. cit.*, at 122 - 123.

concerned with choice and the exercise of that choice in relation to life decisions, realistically it must be accepted that no person can control, at all times, all aspects of his or her life[40]. Yet, that this is so does not mean that no person can be autonomous. In like manner, simply because *some* influence is exerted on an individual in making a choice[41], or that the individual has diminished capacity in *some* aspects of his/her life but not others[42], does not mean that such a person is not autonomous or that s/he cannot take autonomous decisions. For a working model of autonomy it is only necessary that a certain degree of autonomy is reached and that capacity to make a choice is present *in relation to* the choice which must be taken. One could argue *ad infinitem* about the characteristics which make a person 'autonomous', or the necessary degree of independence which equates with 'autonomy', but it is submitted that in practical terms the standard which is required is always a question to be answered with reference to the facts and circumstances of each case[43]. Rather, what is important is that autonomy is respected and, ancillary to this but in no way less important, that autonomous choices be respected. The question which then requires an answer is, how does one ensure that such respect is forthcoming?

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[40] See Raz, 'Autonomy, Toleration, and the Harm Principle', *op. cit.*, at 314.

[41] Indeed, arguably noone has an entirely influence-free life since we live in communities and families, are subject to cultural, religious and moral influence and are conditioned by our education and surroundings.

[42] I may not have the capacity to run because I am disabled, I may not have the capacity to vote because I am too young, I may not have the ability to understand quantum physics because my IQ is too low, but none of these limitations means that I cannot exercise my autonomy in other aspects of my life, see Skegg, P.D.G.; 'Law, Ethics and Medicine', Oxford, Clarendon Press, 1984, at 56 - 57. (This is also available in a 1988 edition).

[43] This point is made by Beauchamp and Childress, *op. cit.*, at 123.

3.3. - RESPECTING AUTONOMY: ETHICS

In the context of medical ethics, Downie and others have argued that the concept of autonomy is a basic and guiding principle which is presupposed by other principles[44]. That is, autonomy is a fundamental ethical principle from which other ethical principles derive their authority[45]. For Downie and Calman, for example, to respect the autonomy of an individual is to employ the four *core* principles of ethics in one's dealing with others: namely, the principle of beneficence, the principle of non-maleficence, the principle of justice and the principle of utility[46].

Downie and Calman argue that in the first instance the best way in which to accord respect to others is to leave them alone and do them no harm: the principle of non-maleficence. However, as they note, 'sometimes plans and projects go wrong and then benevolence [beneficence] might become appropriate'[47]. By this they mean compassionate attitude and behaviour towards a person which involves emotional empathy or sympathy, positive help and imaginative understanding[48]. Regarding the principle of justice, they comment that it can have at least two meanings in this context. First, it can require that all autonomous individuals are treated equally, in that they are accorded the same level of respect. Even if we ultimately treated them differently, we respect them because they have been considered on an equal basis and a defensible justification is offered for any different treatment which might occur. Second, on a purely individual level, justice can mean treating individuals appropriately in light of their own wants, needs and merits[49]. As the authors say,

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[44] See, for example, Downie and Calman, *op. cit.*, chapter four and Downie *et al*, 'Health Promotion: Models and Values', *op. cit.*, chapters 9 and 10.

[45] Downie and Calman, *ibid.*

[46] *ibid*, at 54ff. See also, chapter two, *supra*.

[47] *id.*

[48] *ibid*, at 56.

[49] *idem.*

'[j]ustice or fairness in this sense is sometimes expressed by the concept of 'deserts'. For example, we might say "He deserves better care than he got."'[50] Thus, to treat the individual 'fairly' is to respect him/her. Finally, the principle of utility is, for Downie and Calman, slightly less amenable to respecting individuals,

> The principle of utility tells us that we ought to seek the best possible consequences, or the greatest happiness, for the greatest number of people. In other words, utility is not concerned with individuals but with majorities, with aggregates.[51]

Yet, despite this recognition of utility as a means of developing policies and acceptable rules of behaviour, the authors still consider that the principle draws its authority from the principle of autonomy. For,

> ...there can be no sense in promoting the interests or happiness of aggregates of people unless one is already presupposing the supreme value of the persons who make up these aggregates.[52]

In this way they consider utility to be 'an administrative expression of respect'[53].

Not all ethicists agree with this analysis of ethical principles or the role of autonomy in this context. For example, Beauchamp and Childress consider that,

> ...making respect for autonomy a trump moral principle, rather than one moral principle in a system of principles, gives it an excessive value.[54]

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[50] *id.*

[51] *ibid*, at 57 - 58.

[52] *idem.*

[53] *id.*

[54] Beauchamp and Childress, *op. cit.*, at 181. See also, Gillon, R.; 'Medical Ethics: Four Principles plus Attention to Scope', 309, *British Medical Journal*, 184, 1994.

Yet, what is agreed is the *central* role of autonomy in the theoretical and practical framework of modern ethics. The principles of non-maleficence, beneficence, justice, utility and autonomy underpin the entire ethos of current ethical thinking[55]. Bioethics - which is the branch of ethical study devoted to the application of these principles in the medical sphere - is a relatively 'new' discipline which has developed out of a combination of factors which typify late-twentieth century life[56]. These include, an increase in concern for human rights, rapid advances in technology which have expanded the limits of medical science, and a rejection of the attitude that health care providers have authority to act as the sole arbiters in questions of health care. All of these changes have impacted considerably on the lives of individuals throughout western society. As a result bioethics and the concept of autonomy are more relevant and more pertinent to our lives than ever before. In the health care setting then, respect for autonomy is required by the common ethical principles which constitute medical ethics and which dictate the appropriateness of the conduct of health care professionals towards their patients.

3.3.1. - Conflicts in Ethics

It should not be thought that the principle of respect for autonomy and the other ethical principles discussed above always function harmoniously and without conflict. Indeed, it is easy to imagine situations where an individual might wish to exercise his or her autonomy in a manner which might interfere with the autonomy of others and/or cause them harm and/or treat them unfairly. As Beauchamp and Childress point out,

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[55] See, for example, Beauchamp and Childress, *op. cit.*, chapters 4 - 6, Gillon, R.; 'Philosophical Medical Ethics', New York, John Wiley and Sons, 1985, and generally for discussions of ethics in different settings, see Gillon, R., (ed.); 'Principles of Health Care Ethics', New York, Wiley and Sons, 1994.
[56] It is generally thought that bioethics began as a 'discipline' in the early 1960s.

> Respect for autonomy...has only prima facie standing and can be overridden by competing moral considerations. Typical examples are the following: If our choices endanger the public health, potentially harm innocent others, or require a scarce resource for which no funds are available, others can justifiably restrict our exercises of autonomy. The justification must, however, rest on some competing and overridding moral principles.[57]

Thus, just as the principles of non-maleficence, beneficence, justice and utility can serve to accord respect to individuals and their autonomy, the same principles can be used to impose restrictions on individual action and autonomy if this conflicts with wider, third party interests. This reflects the concerns of Mill with *other-regarding behaviour*: when one's conduct begins to affect the lives of others it becomes legitimate to curtail it to a degree. This, however, poses serious questions. How is one to decide when a conflict arises which is of sufficient seriousness to merit intervention and also, what form should such intervention take? The answer from ethics is a resounding silence. The principles of ethics do not and cannot provide us with guidance about when or how the limits should be set on autonomous individuals. Rather, they provide us with a framework of moral reference within which to analyse human behaviour and human interaction. Only in a very crude way do they provide us with the means of resolving conflict. Here is not the place to consider the intricacies of ethical debate concerning the resolution of conflicts between ethical principles. It is sufficient to note that given that this thesis considers its subject matter from the legal perspective, ethics can be helpful only in pointing the way forward or in giving broad guidance about the acceptability of proposed courses of conduct.

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[57] *op. cit.*, at 126.

3.3.2. - Ethics: A Conclusion

The importance of ethics to modern medical practice cannot be underestimated. Crucial to this body of knowledge is the principle of respect for patient autonomy. Unfortunately, ethicists disagree about the importance of this principle relative to other ethical principles, but do agree that it is a fundamental individualistic right. A non-trivial limitation of ethics is its inability to provide clear solutions to real problems. The discipline is such that it makes it possible to support competing arguments using the same core principles. This, however, is in no way meant as a criticism of the discipline of ethics. Rather, it is to state that the aim of ethics does not accord entirely with the aim of this work. The aim of ethics is to inform debate and provide a framework within which valuable discussion can take place using a common language and by reference to accepted principles. It is not the aim of ethics to provide concrete solutions. In contrast, it *is* the aim of this work to provide solutions to the problems posed by genetic information. And further, it is the aim of this work to provide such solutions by legal means. That is not to say, however, that in providing solutions law should not be informed by ethics. Indeed, this writer would argue that it is crucial that there be a relationship between the two. Thus, the discipline of medical ethics will remain central to this work and will provide both a framework within which, and a standard against which, the arguments and conclusions made herein can be tested.

3.4. - RESPECTING AUTONOMY: LAW

The centrality of autonomy to the western conception of the individual, and in particular its importance in health care, is reflected in legal decisions of the courts of most western states. The classic formulation of patient self-determination by a court was offered by Justice Benjamin Cardozo in *Schloendorff v Society of New York Hospitals*[58]. In this case an operation was carried out despite express patient wishes to the contrary and as a result the patient was physically injured. Although the action was unsuccessful[59], in his judgment Justice Cardozo affirmed categorically the importance of autonomy in medical treatment,

> Every human being of adult years and sound mind has the right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages.[60]

This reflects current thinking is society generally, for the idea of the human body as an inviolate entity is now common in the laws of western states. In cases where the body has been violated, the law provides that a civil action in assault or battery can be brought by the 'victim', and, usually, that criminal prosecution is also possible at the discretion of the state. In this way, 'respect' for autonomy is a legally prescribed phenomenon.

The importance of the role of the law in 'protecting' patient autonomy has often been reiterated ever since Cardozo's statement in 1914[61]. In the UK, arguably the turning

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[58] 211 N.Y. 125 (1914). For an excellent discussion of this case in the context of informed consent see Faden, R.R. and Beauchamp, T.L.; 'A History and Theory of Informed Consent', *op. cit.*, chapter 4.

[59] For a discussion see, Faden and Beauchamp, *ibid*, at 123.

[60] *Schloendorff, ibid*, at 128.

[61] See, *Chatterton v Gerson* [1981] QB 432, [1981] 1 All ER 257; *Hills v Potter* [1983] 3 All ER 716, [1984] 1 WLR 641; *Sidaway v Board of Governors of the Bethlem Royal Hospital* [1985] AC 871, [1985] 1 All ER 643, HL; *Reibl v Hughes* (1980) 114 DLR (3d) 1 and *Canterbury v Spence* 464 F 2d 772 (DC, 1972). More recently, see *Airedale v NHS Trust v Bland* [1993] 1 All ER 821 and *Re F (mental patient: sterilisation)* [1990] 2 AC 1. In Canada, *Malette v Shulman* (1990) 67 DLR (4th) 321 and in Australia *Department of Health v JWB and SMB* (1992) 66 ALJR 300. For comment on these cases see Kennedy and Grubb, 'Medical Law : Text With Materials', *op. cit.*, chapter 3.

point of the movement towards recognising the right of patients to be autonomous and self-determining was the case of *Re T*[62].

3.4.1. - *Re T (Adult : Refusal of Medical Treatment)*

Miss T, a pregnant Jehovah's Witness, suffered serious injuries as a result of a car accident. On arrival at the hospital and after discussion with her mother, Miss T signed a form refusing any future blood transfusion. Unfortunately, after a caesarean delivery of a stillborn baby, Miss T's condition deteriorated and a court order was obtained to authorise the transfusion of blood. The Court of Appeal heard arguments on the legality of this action. As part of the judgment the Master of the Rolls, Lord Donaldson, stated in very clear terms the position of the law in regard to patient autonomy. He said,

> [A patient's] right of choice is not limited to decisions which others might regard as sensible. It exists notwithstanding that the reasons for making the choice are rational, irrational, unknown or non-existent.[63]

A similar view was put by Butler-Sloss LJ,

> A man or woman of full age and sound understanding may choose to reject medical advice and medical or surgical treatment either partially or in its entirety. A decision to refuse medical treatment by a patient capable of making the decision does not have to be sensible or well-considered...[64]

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[62] [1992] 4 All ER 649; [1992] 3 WLR 782. See also, *Re F (mental patient: sterilisation)*, *supra cit.* The House of Lords has also endorsed the view that autonomous persons have an 'absolute' right to conduct their lives as they wish. This includes the right to refuse medical treatment, even if this will result in death see, *Airdale NHS Trust v Bland* [1993] 1 All ER 821.

[63] *ibid*, at 653, quoting *Sidaway, supra*, at 904 - 905.

[64] *ibid*, at 664, quoting *Sidaway, supra*, at 904 - 905.

Despite these strong words, on the facts before it, the Court of Appeal upheld the legality of the blood transfusion administered to Miss T. This was so because, in the opinion of the Court, Miss T was not 'capable' of making the decision which it had been argued required respect. The Court was of the view that the patient's condition had deteriorated to such an extent that she had not the capacity to make a decision between life and death. Faced with ambiguity, the court preferred life. Moreover, the court was not convinced of the strength of Miss T's belief and was doubtful that her 'decision' was entirely unfettered: she had consulted with her mother before signing the refusal form. In other words, because Miss T did not have the ability to make an autonomous choice, the Court of Appeal was not disposed to accord to her legal protection of her autonomy[65]. That this case was so decided on its facts, however, does not detract from the point at hand. For, it was made clear that *had* Miss T met the requisite degree of competence the Court was in no doubt that her autonomy *would* be respected by the law[66].

The words of Lord Donaldson and Butler-Sloss LJ are strong words indeed. They affirm a legal conception of patient autonomy which holds out as a supreme value the unfettered choice of the individual irrespective of the consequences for the individual chooser. Arguably this is a modern day expression of the Millian conception of *individuality*: all interference is unwarranted interference when it concerns self-regarding behaviour[67].

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[65] For comment, see Mason, J.K. and McCall-Smith, R.A.A.; 'Law and Medical Ethics', Fourth Edition, Edinburgh, Butterworths, 1994, at 229 - 231.

[66] *supra*, at 653, 664.

[67] It should also be noted that the authority of *Re T* has been upheld in *Airedale NHS Trust v Bland* [1993] 1 AC 789; [1993] 2 WLR 316, discussed in chapter one, and also in the recent case of *Secretary of State for the Home Department v Robb* [1995] 1 All ER 677 in which the right of a 27-year-old prisoner to go on hunger strike was upheld by the Family Division of the High Court of Justice on the basis of *Re T*. As Kennedy points out, however, this is strange given that the individual concerned was not a patient but a prisoner and the feeding in such case could hardly be termed treatment in the absence of any medical complication, see 'Commentary', 3, *Medical Law Review*, 189, 1995.

3.4.2. - *Re C (Refusal of Medical Treatment)*

The authority of *Re T* was applied shortly afterwards in very interesting circumstances of the case of *Re C*[68]. This was a decision by Thorpe J. in the Family Division of the High Court of Justice. Although simply a decision at first instance, the case is nevertheless an extremely important one. Not only does it reaffirm the authority of *Re T*, but it is the first case in which the right to refuse treatment has been respected by the UK courts.

The case concerned a 68-year-old patient suffering from paranoid schizophrenia who had developed gangrene in a foot while serving a seven year term of imprisonment in Broadmoor. On removal of the patient to a general hospital, a consultant diagnosed that the patient would die if the gangrenous limb was not amputated below the knee. It was estimated that the patient only had a 15% chance of survival without amputation[69]. The patient, however, refused the operation: he said that he preferred to die with two feet than live with one. The hospital nevertheless sought to proceed with the operation. An application was lodged on C's behalf to the court for an injunction restraining the hospital from carrying out the operation without his express written consent. The hospital questioned C's capacity to exercise his autonomy in this way.

Thorpe J. held that C was entitled to refuse the treatment even if this meant that death would result[70]. Quoting with approval to the dicta of Lord Donaldson in *Re T*, he stated that *prima facie* every adult has the right and capacity to accept or refuse medical treatment. He acknowledged that this might be rebutted by evidence of incapacity but

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[68] [1994] 1 All ER 819;[1994] 1 FLR 31.

[69] This was however averted by other surgical intervention short of amputation, at 821 (All ER).

[70] *ibid*, at 823 - 824.

this onus must be discharged by those seeking to override the patient's choice[71]. If capacity is challenged, as in this case, the sufficiency of capacity is to be determined according to the following criteria: has the capacity of the patient been so reduced (by his chronic mental illness) that he did not sufficiently understand the nature, purpose and effects of the proffered medical treatment? This depends on whether the patient has comprehended and retained information, has believed it and has weighed it in the balance with other considerations when making his or her choice[72]. As Thorpe said,

> Applying that test to my findings on the evidence, I am completely satisfied that the presumption that C has the right to self-determination has not been displaced. Although his general capacity is impaired by schizophrenia, it has not been established that he does not sufficiently understand the nature, purpose and effects of the treatment he refuses. Indeed, I am satisfied that he has understood and retained the relevant treatment information, that in his own way he believes it, and that in the same fashion he has arrived at a clear choice[73].

Several points of interest arise from this judgment. First, it reaffirms the commitment of the law to the principle of respect for patient autonomy. The value of autonomy is set up as a primary value which cannot be dispensed with lightly. There is a *prima facie* presumption of its existence and value which can only be overridden in established circumstances. Furthermore, the particular facts of the case show that incapacity in one or several areas of one's life does not preclude autonomous behaviour in other areas nor does it remove the presumption of competence to refuse. Indeed, the injunction obtained by the plaintiff extended not only to the particular operation contemplated by the hospital but to *all* future attempts to interfere with his bodily integrity without

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[71] *ibid*, at 824.

[72] *ibid*, at 824.

[73] *id.*

his express written consent[74]. If however incapacity can ever be established, then the patient must be dealt with in a manner which furthers his or her own best interests.

A problem with the judgment, however, concerns its vagueness. A patient's competence can be successfully challenged if it can be shown that s/he does not comprehend or absorb information to the extent that s/he understands it or if s/he is thought not to believe the information or if s/he cannot balance this information against other considerations when making his or her choice. These criteria place hurdles in the path of those seeking to exercise their autonomy when their capacity to do so is in question. What is not clear is how high they must jump in order to clear these hurdles. For example, the requirement that the patient must actually comprehend the information is not easy to assess. Importantly, it can depend as much on the amount of information which is given to the patient and the manner in which it is given as on the capacity of the patient to understand. Yet, the test is not *can* the patient understand, but rather *does* the patient understand. This places an onerous burden on medical staff to ensure that actual understanding is reached. This is, however, slightly paradoxical given that treatment staff might not want the patient to understand if they disagree with the nature of the decision which the patient seeks to make, as in the present case. Relatedly, it is not clear exactly what the patient must understand. The decision talks of the 'nature, purpose and effects' of the treatment. This is potentially very broad and can encompass elements ranging from the general aim of the procedure, to the technique to be employed during the procedure, to the risks of the procedure, to the consequences of refusal and beyond. Arguably, and as Andrew Grubb has pointed out, if excessive amounts of information require to be disclosed and understood, the

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[74] The importance of this should not be underestimated. In effect, this is tantamount to judicial recognition of the validity of advance refusals of treatment.

category of 'autonomous person' is reduced to all but the most 'comprehending' of individuals[75].

Finally, *Re C* confirms the role of the best interests test in the medico-legal field. If self-determination is successfully challenged then the only option left is to treat the patient in his or her best interests. However, as has been argued in chapter one, this concept is also vague and leaves considerable control and power with health care professionals. Neither the precise nor the general nature of best interests is defined by the UK courts. Cases such as *Re T* and *Re C* demonstrate that the principle of respect for patient autonomy and therefore patient choice is *prima facie* prescribed, but the tests which have been laid down do not give us more than a general idea of where the limits of the principle lie[76]. Moreover, these cases have to be read in conjunction with other decisions in which patient autonomy was overridden and the right of patients to choose for themselves denied.

3.4.3. - The Legal Limits of Autonomy

The decision of the Court of Appeal in *Re T* was not without its caveats. Just as Mill condoned (and even encouraged) intervention to prevent harmful *other-regarding* behaviour, so too the court in *Re T* imposed limits on its account of patient autonomy. At pp.652 - 653 Lord Donaldson said the following,

> An adult patient who...suffers from no mental incapacity has an absolute right to choose whether to consent to medical treatment, to refuse it or to choose one rather than another of the treatments being offered. *The only*

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[75] See Grubb, A.; 'Commentary', 2, *Medical Law Review*, 92, 1994, at 95.

[76] For comment on the problems arising from the issue of patient competence or incompetence, see, Jones, M.A. and Keywood, K.; 'Assessing The Patient's Competence to Consent to Medical Treatment', 2, *Medical Law International*, 107, 1996.

> *possible qualification is a case in which the choice may lead to the death of a viable foetus.* [emphasis added]

This 'possible qualification' was quickly tested in the soon-to-follow decision of *Re S*[77].

3.4.4. - *Re S (adult: refusal of medical treatment)*

In *Re S* a health authority applied for a declaration to authorise the surgeons and staff of an authority hospital to carry out an emergency Caesarean section operation on a 30-year-old woman who had been admitted to hospital with ruptured membranes and in spontaneous labour with her third child. On religious grounds the woman refused to submit to a section. The surgeon in charge was adamant that without intervention of this kind both patient and baby would die. After six days of Mrs S's labour, the health authority sought a judgment. The case was heard by Sir Stephen Brown.

The decision of Sir Stephen is approximately one page in length, one half of which is concerned with relating the facts. In agreeing to make the declaration there is nothing in Sir Brown's judgment which resembles legal argument or analysis. As he said,

> I [make the declaration] in the knowledge that the fundamental question appears to have been left open by Lord Donaldson MR in *Re T*..., and in the knowledge that there is no English authority which is directly in point.[78]

Despite the absence of authority[79], the decision in *Re S* nevertheless demonstrated a serious qualification to the 'absolute' right of choice expounded by Lord Donaldson[80].

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[77] [1992] 4 All ER 671. This case was decided only two and a half months after *Re T*.

[78] *ibid*, at 672.

[79] Sir Stephen did make a passing comment concerning American authority in the case of *Re AC* (1990) 573 A 2d 1235 at 1240, 1246-1248, 1252, in which a pregnant woman who had been fighting cancer for 15 years, and who was dying, had her apparent refusal of consent overruled by the court in favour of a caesarean to attempt to save the 26 and a half week fetus. Neither mother nor foetus survived. What the High Court in *Re S* failed to consider was the subsequent overturning of *Re AC* by the District of Columbia Court of Appeals three years after the woman's death. By a majority of seven to one the

It has been observed by commentators that the vagueness of the dictum of Sir Stephen Brown left open the possibility of further limitations being imposed on the autonomy of pregnant woman[81]. This has already happened in the U.S. where pregnant women with substance abuse problems have been detained until their pregnancy reaches term in order to avoid 'harm' to the fetus[82]. In the UK, although such draconian measures have not yet been employed, the conduct of women during pregnancy *has* been influential on courts in later decisions regarding such individuals. For example, in *D v Berkshire County Council* the House of Lords considered a mother's ante-natal conduct when deciding if 'a child's proper development had been avoidably prevented or its health had been avoidably impaired'[83] for the purposes of granting a care order[84]. The child had been born prematurely with drug dependency. The order was granted and the child removed. Although the establishment of this precedent involved no direct interference with the mother's autonomy, in an indirect manner her autonomy *was* affected. She was denied the chance of proving her capacity for motherhood and she was effectively put 'on warning' about her future conduct: if that was not curtailed the same result might signal the end of any subsequent pregnancy[85].

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court held that pregnant women retain an almost unfettered right to determine their own health choices, even if their decisions conflict with the apparent 'best interests' of the foetus. Maternal rights could only be trumped by the "most extraordinary and almost unthinkable circumstances". The facts of *Re AC* were held not to fall into such a category.

[80] For brief, yet astute comment on *Re S*, see Morgan, D.; 'Whatever Happened to Consent?', October 23, *New Law Journal*, 1448, 1992.

[81] See, Mair, J.; 'Maternal/Foetal Conflict: Defined or Diffused?' in McLean, S.A.M. (ed.); 'Contemporary Issues in Law, Medicine and Ethics', Aldershot, Dartmouth Publishing, 1996, chapter 5, Morgan, *loc. cit.*, Stern, K.; 'Court-Ordered Caesarean Sections: In Whose Interests?', 56, *Modern Law Review*, 238, 1993, and Alldridge, P.; 'Let me Die - My Mother Insists', *New Law Journal*, 1691, 1992.

[82] For comment on such practices, see De Gama, K.; 'A Brave New World? Rights Disclosure and the Politics of Reproductive Autonomy', 20(1), *Journal of Law and Society*, 114, 1993 and Storall, M.T.; 'In Re Valerie D and State Intervention in Prenatal Drug Abuse', 25, *Connecticut Law Review*, 1265, 1993.

[83] This is the wording of s.1(2)(a) of the Children and Young Persons Act 1969 under which the care order was sought.

[84] [1987] 1 All ER 20.

[85] Note, in *Re F (in utero)* [1988] 2 All ER 193 the Court of Appeal refused to extend the cloak of wardship over an unborn fetus. Only on its birth did the fetus become a legal person to whom the

That the exception in *Re S* was allowed in the case of the viable fetus demonstrates a more serious limitation on the autonomy principle for women. Because of the unique relationship which a pregnant woman has with her fetus, namely, that the conduct of the former has direct implications for the well-being and life of the latter, the court felt justified in refusing to respect the choice of the woman not to receive treatment. This was so even although the fetus was not, in the eyes of the law, a 'legal person' and therefore had no legal rights[86]. The consequence of this was that the woman was subjected to direct interference with her bodily integrity against her express wishes. In the particular circumstances of *Re S* this was, unfortunately, in vain for the child nevertheless died. The problems with this decision are manifold.

First, the case was seen simply as one of conflict between the interests of the woman and those of the fetus[87]. Yet, in 'resolving' the conflict the court made no attempt to weigh the relative merits or demerits of the respective interests. There was no discussion of the competency of the woman to make such a choice, nor was there any attempt to quantify the validity of her choice. Moreover, there was no attempt to establish criteria for determining in future cases when, if at all, such forced caesarean sections would be permitted. For example, must the fetus have a 'reasonable' or 'good' prospect of living? Or, would it be enough that it has a 'marginal' chance of survival?

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jurisdiction of wardship extended. Also, the court was reluctant to interefer with the woman's rights while pregnant.

[86] The legal position of the fetus is that it has no legal rights unless and until it is born alive, see in Scotland, *Hamilton v Fife Health Board* 1993 SLT 624, (1993) 13 BMLR 156; in England and Wales, *Paton v British Pregnancy Advisory Service Trustees* [1978] 2 All ER 987, *Burton v Islington Health Authority; de Martell v Merton and Sutton Health Authority* [1992] 3 All ER 833 and the Congenital Disabilties (Civil Liability) Act 1976. Most recently in England in the criminal law context see, *Attorney General's Reference (No.3 of 1994)* [1996] Crim LR 268. Finally, the Inner House of the Court of Session has held in *Kelly v Kelly* that 'the fetus is part of its mother's body, in the eyes of the law, in the same way as the placenta or umbilical cord.', The Times, 5 June 1997.

[87] This is not, however, the only approach which one can take to such cases, see, for example, Mair, *op.cit.*

Does the decision represent an exception to the 'absolute' right of choice laid down in *Re T* or does it reverse the burden of establishing validity of interference: that is, unlike *Re* C in which it was held that the right to self-determination *prima facie* exists, must a pregnant woman prove or establish her right to determine for herself what should happen to her body? It is also important to note that what this decision does not do is go so far as to impose a duty on doctors to intervene in such cases, it simply offers them a discretion to do so. Thus, the legality of intervention was established by the court but the power to interfere with the autonomy of pregnant woman was given to the health care professional[88].

3.4.5. - *Re M.B. (Caesarean Section)*

Most recently, however, the Court of Appeal has considered again the relationship between a pregnant woman and her fetus, and has ruled in a much more articulate manner on the position of the law in resolving conflict between the interests of the two. In *Re M.B.*[89] it was held that where a competent woman refused medical treatment in the form of a caesarean section the courts had no jurisdiction to declare such treatment lawful. On the facts of the case, however, the pregnant woman was declared incompetent because of a fear of needles which had led her to refuse the caesarean. At the end of the day she consented to the operation and a healthy child was delivered. This, of course, in no way detracts from the authority of the decision.

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[88] It is interesting to note that two recent decisions have been made by the High Court in England ordering women to have sections against their wishes, with no reference to legal authority to justify doing so: see, *Norfolk and Norwich Healthcare (NHS) Trust v W* [1996] 2 FLR 613 and *Tameside and Glossop Acute Services Trust v CH (a patient)* [1996] 1 FLR 762; 31 BMLR 93. In the latter it was held that the performance of a caesarean section on a schizophrenic woman could be 'treatment' of her mental disorder within the terms of the Mental Health Act 1983. For comment on this decision see Grubb, A.; 'Commentary', 1996, *Medical Law Review*, 193 - 198.

[89] *Re M.B.(Caesarean section* : 26 March 1997), The Times, 18 April 1997.

This decision is to be welcomed for it clarifies significantly the question of the respect due to the autonomy of the pregnant woman. The Court of Appeal was adamant in its ruling that a woman carrying a fetus is entitled to the same degree of respect for her wishes as anyone else. Furthermore, the court reiterated the general principle laid down in *Re T*[90] that a person of full age and sound mind cannot be treated against his or her will without civil and criminal law consequences. It also endorsed heavily the view that a refusal of medical treatment can be for any reason, rational or irrational, or for no reason at all[91]. In particular, it was stressed that the only circumstances in which non-voluntary treatment is permissible arise when the patient cannot give consent and the treatment is in the *patient's* best interests. But, in circumstances where a *competent* pregnant woman decides to refuse medical intervention, *even although* this might have as a consequence the death or serious handicap of the fetus she bore, the court has no jurisdiction to declare medical intervention lawful. In such circumstances, the question of the woman's own best interests do *not* arise.

This decision clearly prefers the autonomy interests of the woman to any interests which the fetus might have, including an interest in being born alive[92]. Yet, it is important to bear in mind that all of this is subject to the woman being competent when she makes her refusal. If she is not, she must be treated in her best interests. In the particular circumstances of *Re M.B.* the assessment that the operation was in her best interests is open to little question: both the woman and her husband wanted the child to be born, subject to her needle phobia. It is interesting to speculate, however,

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[90] *supra cit.*

[91] See, *Re T, supra cit.*, at 653.

[92] Indeed, the court specifically stated the under English law as it stands, the submission that the court should consider and weigh in the balance the rights of the 'unborn child' was untenable, see Times Report, *supra cit.* The court referred to the decisions of *Paton v British Pregnancy Advisory Service Trustees* [1979] QB 276, *C v S* [1988] QB 135 and *in re F (in utero), supra cit.*, in holding that the dictum of Lord Donaldson in Re T, *supra. cit.*, (regarding the possible different situation of a choice which might lead to the death of a viable fetus) could not be upheld. The same approach has been endorsed by the Inner House of the Court of Session in *Kelly v Kelly, supra cit.*

how the patient's best interests would be assessed if there was no clear indication of how the mother felt about the birth, or even if a previous statement of her wishes requesting that she and the fetus die together - made when she was competent - were available. In the final analysis, and despite the significant moves forward which *Re M.B.* represents, the decision does nothing to remove from the medical profession the discretion and power to decide on patient capacity to act autonomously, and ultimately, in cases of incapacity, to decide on patient best interests. These matters are explored further in the next section.

3.4.6. - *Further Limits on Autonomy: The Minor and the Adult Incapax*

Further limits on the scope of the principle of autonomy as laid down in *Re T* are found in the words of Butler-Sloss LJ in that decision,

> A man or woman of full age and sound understanding may choose to reject medical advice and medical or surgical treatment either partially or in its entirety[93].

This clearly shows that one must be of 'full age' and 'sound understanding' to qualify as an autonomous chooser. This suggests that in two categories the scope of autonomy is likely to be limited: the minor and the mental incapax. This has been borne out by the case law.

3.4.6.1. - *Minors*

Re S (A Minor) (Consent to Medical Treatment) was a decision of the Family Division of the High Court of Justice and concerned a fifteen and a half year old girl who was

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[93] *In re T*, *supra*, *per* Butler-Sloss LJ at 664.

suffering from a genetic condition, beta minor thalassaemia major[94]. The condition renders the body unable to produce red blood cells. Affected persons must receive monthly blood transfusions and daily abdominal injections in order to survive. *S* had been receiving such treatment since birth. In 1989 *S* and her mother began to attend meetings of Jehovah's Witnesses and in May 1994 *S* refuse a blood transfusion. An order was sought by the local authority requesting the court to authorise treatment under its inherent jurisdiction. In authorising the treatment the court held that although it had the power so to do, it must start from the premise that the patient's wishes should be respected unless the circumstances strongly indicated intervention. To be weighed in balance with the wishes of the patient (refusal) are the 'best interests' of the child. In determining such best interests the court held that one must examine the extent to which the decision to refuse treatment had been reached independently, and was based on a proper understanding of the illness and the consequences of refusal. In the particular circumstances of *S*, the court held that because the child entertained a hope of a miracle cure she did not fully understand the nature or implications of her choice. She was not, therefore, competent to make the decision and the treatment could go ahead contrary to her wishes[95].

At first sight this case seems to uphold the principle of autonomy: prima facie the patient's wishes must be respected. However, an analysis of the judgment reveals that in practice it will be very difficult for minors to choose for themselves when that decision goes against the views of attending health care professionals[96].

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[94] [1994] 2 FLR 1065.

[95] Consent and refusal cases concerning minors in England and Wales are governed by the House of Lords decision in *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112; [1985] 3 All ER 402, HL.

[96] For a vociferous attack on the approach of the English and Welsh courts see, Elliston, S.; 'If You Know What's Good for You: Refusal of Consent to Medical Treatment by Children', in McLean, S.A.M., (ed.); 'Contemporary Issues in Law, Medicine and Ethics', *op. cit.*, chapter 3.

The court overturned the refusal of the minor on the authority of previous case law which clearly established a 'best interests' analysis for the treatment of minors[97]. What is of interest, however, is the nature of the test which the court laid down to establish 'best interests'. It is hard to reject the view that what is in someone's best interests should ideally be determined by that person him or herself. However, if one cannot determine one's own best interests then this must be done on one's behalf. The question of competency to decide therefore arises here. In the present case the court held that because the child entertained a belief in a miracle cure and because she failed to appreciate 'the manner of the death and pain and the distress' which her decision would entail, she was not competent to refuse. This is to set a very high standard: some would argue, an impossibly high standard[98]. Johnson J. held that it was not enough simply that the child had 'an understanding that she will die'. What is required is not only a fairly detailed understanding of the processes of one's demise, but also evidence of having come to terms with one's own end. This standard is unlikely ever to be met by any child. Indeed, as one commentator has pointed out, it is also unlikely to be met by most adults[99]. Thus, in treatment decisions where refusal is likely to result in death, this case would tend to indicate that minors will never have the capacity to refuse and will, therefore, be treated in their best interests as determined by the treatment staff. As with cases previously discussed, in practice the same staff will be responsible for determining competency.

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[97] The position in England is currently that provided a court can find *a* consent to authorise medical treatment, then treatment of a minor will be lawful. Such consent can come either from the child, or if s/he refuses, the parents who retain a residual right to consent even if faced with a refusal by the child. Indeed, by virtue of its wrrdship jurisdiction, the court itself can consent for the child. Of course, all consent must be given in the child's 'best interests', see - *Re R (a minor)(wardship : medical treatment)* [1991] 4 All ER 177, CA; (1992) 7 BMLR 147, CA and *Re W (a minor)(medical treatment)* [1992] 4 All ER 627, CA. For comment see, Brazier, M. and Bridge, C.; 'Coercion or Caring: Analysing Adolescent Autonomy',16, *Legal Studies*, 84, 1996.

[98] See Gunn, M.; 'The Meaning of Incapacity', 2, *Medical Law Review*, 8, 1994.

[99] Grubb, A.; 'Commentary', 4, *Medical Law Review*, 84, 1996, at 86.

3.4.6.2. - *Minors in Scotland*

In Scotland, the position of children is governed by the *Age of Legal Capacity (Scotland) Act* 1991 and the *Children (Scotland) Act* 1995. The law is clearly established that persons over 16 have legal capacity to govern their own affairs, including medical decision-making[100]. On the position of those under 16, Elliston has suggested that,

> [a]lthough the question of a child refusing consent to treatment has yet to be litigated in the Scottish courts, there are powerful arguments that suggest a child who is competent...would have their decision respected. Such arguments hinge first on an interpretation of the existing legislation and second on the grounds of public policy.[101]

Elliston and others[102] point to the fact that the 1991 Act contains specific provision regarding medical treatment of minors which allows a minor to consent on his/her own behalf 'to any surgical, medical or dental procedure or treatment where, in the opinion of a qualified medical practitioner attending him, he is capable of understanding the nature and possible consequences of the procedure or treatment.'[103] These commentators argue that although no express mention is made of a child's right to refuse, logic dictates that this correlative right must accompany a right to consent[104].

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[100] Age of Legal Capacity (Scotland) Act 1991, s.1(1)(b).

[101] *loc. cit.*, at 49.

[102] Elliston, *op. cit.*, Wilkinson, A. B. and Norrie, K.McK.; 'Parent and Child', Edinburgh, W.GREEN/Sweet & Maxwell, 1993, at 183, and Edwards, L.; 'The Right to Consent and the Right to Refuse: More Problems with Minors and Medical Consent', 1993 *Juridical Review*, 52.

[103] *supra cit.*, s.2(4).

[104] For a very different view , see Mason and McCall-Smith, *op. cit.*, at 229: '...while consent involves acceptance of an experienced view, refusal rejects that experience - and does so from a position of limited understanding. Furthermore, a refusal of medical treatment may close down options - and this may be regretted later in that the chance to consent has now passed. The implications of refusal may, therefore, be more serious and, on these grounds, refusal of treatment may require greater understanding than does acceptance. A level of comprehension sufficient to justify refusal of treatment certainly includes one to

They submit that, unlike England[105], Scotland is not burdened by unhelpful court decisions which have twisted the law relating to minors and rendered it unjustifiable[106]. The relevant provisions of the 1991 Act are preserved in the *Children (Scotland) Act* 1995, section 90 of which ensures that a minor's consent is sought even in circumstances where the Act requires that the child submit to examination or treatment (for example under a warrant or supervision requirement)[107].

Of course, even if these views of the law in Scotland are correct, one should not forget that the respect for a minor's refusal is entirely contingent on a medical practitioner's view that the minor has sufficient capacity to take a decision for him/herself. In this respect, the laws of both Scotland and England are entirely in accordance.

3.4.7. - *The Incapax Adult*

It has already been established in chapter one that incapax patients are to be treated in their best interests. This was demonstrated by considering the PVS cases and that line of authority need not be re-examined here. It is important to note, however, that in addition to PVS cases (in which the individual is incapax to the extent that s/he cannot express his or her wishes), there also exist cases in which a person *can* express wishes but where s/he is nevertheless deemed to be incapax because s/he is thought to be incompetent through ill health or mental disorder. The Mental Health Act 1983 and

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accept treatment but the reverse does not hold; the two conditions cannot be regarded as being on a par.'

[105] See, *Re R (A Minor) (Wardship : Medical Treatment)* [1991] 4 All ER 177, CA and *Re W (A Minor) (Medical Treatment)* [1992] 4 All ER 627, CA.

[106] See Elliston, *loc. cit.* at 50 - 51, Wilkinson and Norrie, *op. cit.*, at 182 - 189, and generally Edwards, *loc. cit.* Norrie points out in his commentary in Scottish Current Law Statutes on s.90 of the *Children (Scotland) Act* 1995 that, 'Lord James Douglas Hamilton accepted in the Special Standing Committee of the House of Commons that capacity to consent implied the capacity to refuse (March 7 1995, col.532) as did Lord Fraser of Carmyllie in the Committee of the Whole House in the House of Lords (June 13 1995, cols. 132 - 134).'

[107] For comment see Norrie in Scottish Current Law Statutes.

the Mental Health (Scotland) Act 1984 both allow for involuntary treatment of individuals suffering from mental disorder[108]. This is, however, restricted to treatment for the mental condition from which the individual suffers. This begs the question of what amounts to a mental condition suitable for involuntary treatment under the Acts[109]. Conditions such a schizophrenia, manic depression, psychoses and neuroses are clearly within the scope of the provisions. However, some recent force feeding cases demonstrate that the definition is open to much wider interpretation.

In *B v Croydon Health Authority*[110] the Court of Appeal was asked to rule on the legality of force-feeding a woman compulsorily detained under the Mental Health Act 1983. The woman only had 2 -3 months life expectancy as a result of her refusal to eat. In holding that tube feeding against the patient's wishes was lawful, the court adhered to an interpretation of the 1983 Act which had earlier been advanced by the High Court in *Riverside Mental Health Trust v Fox*[111] and *South West Hertfordshire Health Authority v Brady*[112]. That view is that anorexia nervosa is a 'mental condition' within the terms of the 1983 Act and that feeding to avert death of the patient is 'treatment' of that condition under section 63. Because s.63 of the Act permits involuntary treatment, there is no need to determine the competency of the patient or to seek their consent.

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[108] See sections 58, 62 and 63 of the 1983 Act and ss. 97, 98 and 103 of the 1984 Act. For comment and analysis of the provisions see Mason and McCall Smith, 'Law and Medical Ethics', *op. cit.*, at 397 - 398.
[109] The term 'mental disorder' is very broadly defined in the Acts. For example, in the 1983 Act 'mental disorder' is defined as 'mental illness, arrested or incomplete development of the mind, psychopathic disorder and any other disorder or disability of mind', s.1(2). Similar provisions determine the scope of the Scottish legislation.
[110] [1995] 1 All ER 686.
[111] In *Riverside Mental Health Trust v Fox* [1994] 1 FLR 614 the English Court of Appeal heard an application from an NHS Trust requesting a declaration of lawfulness of force feeding a patient suffering from anorexia nervosa. The patient had been admitted to the respondent hospital under the Mental Health Act 1983. Her consultant feared that her condition had reached a stage where complications were likely to arise which could lead to death. An interim declarator allowing force feeding was granted at first instance but overturned on appeal on the procedural ground that such an interim declaration was ultra vires the court.
[112] sub. nom. *Re K.B. (Adult) (Mental Patient : Medical Treatment)* (1994) 19 BMLR 144. This case also dealt with the force feeding of a patient suffering from anorexia nervosa.

Implicit in the section is the authority to use force to administer the treatment. Most recently in *Re V.S. (Adult : Mental Disorder)*[113] the High Court applied the authority of *B* to declare lawful the feeding of a woman held for treatment under the 1983 Act and who faced imminent renal failure as a result of her persistent refusal to eat[114].

These cases demonstrate several things. First, 'treatment' of a mental condition extends to things done both to alleviate the condition directly as well as to remove symptoms of the condition, such as not eating. This is interesting because treatment of the symptoms does not necessarily do anything to alleviate the underlying mental disorder. The reason these women were made to eat was not to address their anorexia or depression but to prevent them from dying. Clearly, death is not a mental disorder. Is this interpreting the provisions too widely? Neill LJ considered in *B* that such an interpretation was necessary because to hold otherwise would lead to impractical distinctions and would make the provisions difficult to apply. It should also be noted that the court in that case was careful to delimit the scope of s.63 in holding that the condition to be treated must be 'connected to' the mental disorder. That is, the section does not authorise involuntary treatment of patients for *any* disorder or condition which arises while they have a mental disorder. Otherwise *all* medical treatment decisions concerning mental patients detained under the relevant provisions of the Act could be taken without any need to consult the patient. If, therefore, the patient suffers a condition unrelated to his or her mental condition then the common law rules must apply as laid down in *Re C*[115].

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[113] This case is discussed in 1995 *Medical Law Review* 292.
[114] Note too that *Re W (A Minor) (Medical Treatment : Court's Jurisdiction)* [1992] 3 WLR 758 (CA) is a case in which the Court of Appeal authorised the force feeding of an anorexic 16-year-old competent girl.
[115] *supra*.

Second, even if one accepts that it is accurate to categorise a condition such as anorexia nervosa as a 'mental disorder', it is not clear that to feed someone classifies as 'medical treatment'. Simply because the feeding is done by medical staff in a health care setting does not necessarily make it medical treatment. The medicalisation of the circumstances of these women makes it easier to apply the provisions of the Mental Health Acts but it is nevertheless difficult to accept that the administration of sustenance is 'treatment'[116].

Third, these cases throw the net wide and authorise serious interference with patient autonomy. As has been said, implicit in the terms of the Acts is the power to use force to 'treat' the patient. And, despite dicta by Douglas Brown J. in *Re VS*[117], it is now settled that the scope of the Acts includes force feeding: it will not, therefore, be necessary to apply to the courts in the future to force feed patients suffering from anorexia nervosa or other conditions which lead them to refuse to eat. Thus, once again considerable power to usurp patient autonomy rests with the medical profession. The difference with the statutory cases compared to the common law cases, however, is that, in the former, there is no legal requirement to consider the capacity of the patient to consent or refuse nor is there any obligation to consider as a relevant factor the autonomy of the patients.

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[116] This is essentially the same objection as has been made about the *Bland* case, discussed in chapter one. In response to that case, many commentators argued that it was not justifiable to classify artificial feeding and hydration as 'medical treatment' because such sustenance is essential for the very continuation of life itself and not for the alleviation of any pain or illness. Yet, for the argument of the House of Lords to succeed it was crucial that feeding and hydration could be so classified. For criticism of the case on this point see, Finnis, J.; '*Bland*: Crossing the Rubicon', 109, *Law Quarterly Review*, 329, 1993.

[117] *Supra* . For a persuasive argument dismissing Douglas Brown J.'s dictum see Grubb, A.; 'Commentary', 3, *Medical Law Review*, 292, 1995.

Finally, and most recently, consider the judgment in *Tameside and Glossop Acute Services Trust v C.H. (a patient)*[118]. In this case the English High Court ordered a woman detained under s.3 of the Mental Health Act 1983 for paranoid schizophrenia to be subjected to a caesarean section, with reasonable restraint if necessary, on the grounds that this was 'treatment' of her mental disorder under s.63 of the Act. Wall J. in that case said, '[i]t is not...I think stretching language unduly to say that achievement of a successful outcome to her pregnancy is a necessary part of the overall treatment of her mental disorder'. This, however, is clearly to take the step which the courts have avoided taking in the past; namely, to establish that treatment of *any* physical condition which can have an effect on one's mental condition can be 'treatment' for the purposes of the Act. This is surely to stray too far from acceptable qualifications to the principle of respect for patient autonomy[119]. What such a decision clearly displays is an unwillingness to let the fetus, and possibly the woman, die. This is an entirely understandable sentiment, but to attempt to achieve such an end in such a manner makes for astoundingly 'bad' law. We saw in the previous section which discussed forced caesarean sections that the Court of Appeal has recently upheld the right of a *competent* woman to refuse medical intervention even if this will result in harm or death to her fetus[120]. In cases where a woman has been declared *incompetent*, however, she must be treated in her own best interests[121]. Of course, the obvious questions are, when is a woman incompetent?, and what are her best interests? Arguably, a decision such as *Tameside and Glossop* endorses the power of the medical profession to declare pregnant women incompetent in very dubious circumstances and further, it sanctions

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[118] [1996] 1 FLR 762.

[119] For commentary on *Tameside and Glossop* see, Dolan, B. and Parker, C.; 'Tameside and Glossop Acute Services Unit v CH (a patient)', 314, *British Medical Journal*, 1183, 1997, Bewley, S.; 'Commentary: Bad Medicine and Bad Law', 314, *British Medical Journal*, 1184, 1997, Whitfield, A.; 'Commentary: A Decision that Stretches the Law Too Far', 314, *British Medical Journal*, 1185, 1997, and Bastian, H. and Conroy, C.; 'Commentary: Is Caesarean Section a Treatment for Medical Paranoia?', 314, *British Medical Journal*, 1187, 1997.

[120] *Re M.B., supra cit.*

[121] *ibid.*

the view that to give birth to the child is necessarily in the patient's best interests. This fundamentally undermines the autonomy interests of pregnant women[122].

3.5. - PATERNALISM

One cannot talk of the principle of autonomy, either in ethics or law, without reference to the concept of paternalism. An absolutist conception of autonomy considers respect for autonomy to be even more important than individual well-being, so that it is irrelevant if in the exercise of the former the latter is jeopardised. The case for such a view is based on pragmatism and the logical extension of the beliefs which underpin the concept of autonomy. If autonomy relates to an individual's 'right' to take decisions affecting his or her life - uninhibited by interference (because, after all, it is *his or her* life) - then it should make no difference what the nature of the decisions taken is. What is important is the fact that such persons can take the decision in at least three senses of the word: they have the ability and capacity to take the decision and also the unfettered opportunity to exercise that capacity[123]. Generally, however, such a view is not followed in western democracies. Rather, and as we have seen, a compromise solution is reached which allows unchallenged exercises of autonomy only in certain circumstances. This has already been noted above in relation to the possibility of harm to others. However, it is also the case that if there is the possibility of harm to oneself, or if some dubiety about the autonomy of the individual can be inferred, such exercises of autonomy will not be allowed unless they coincide with

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[122] A judicial review case has most recently been commenced by a woman who was forced to have a caesarean section under the provisions of the Mental Health Act 1983: see Dyer, C.; 'Court Case May Clarify Law on Caesarean Sections', 314, *British Medical Journal*, 624, 1997.

[123] This view is discussed by Feinberg, 'Harm to Self', *op. cit.*, at 59. See also, Feinberg, J.; 'Autonomy, Sovereignty, and Privacy: Moral Ideals in the Constitution', 58, *The Notre Dame Law Review*, 445, 1983, at 457 - 461.

what is objectively considered to be in the 'best interests' of the subject[124]. Intervention is therefore justified to curtail the individual's exercise of his/her 'rights' when such an exercise of rights departs from the individual's perceived 'best interests'[125]. And, it sometimes also happens that an assessment of best interests is used to decide for others *even when* those persons have the capacity to decide for themselves. The act of deciding and acting in another's 'best interests' is commonly known as *paternalism*[126]. Of particular relevance to this thesis is the willingness and frequency with which the State takes a seat at the bedside of most persons receiving health care and acts paternalistically[127].

In essence, paternalism is the very antithesis of autonomy and self-determination because implicit in its operation is a disregard for the wishes of the subject towards whom the paternalism is directed. Paternalism can take a variety of forms and in most, but not all, cases the patient is deemed to be *incapax* and therefore unable to exercise his or her autonomy. This is not to say, however, that the patient's wishes are not known or cannot be ascertained[128].

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[124] For a discussion of this latter point see, Grubb, A.; 'Treatment Decisions: Keeping it in the Family', in Grubb, A., (ed.); 'Choices and Decisions in Health Care', Chichester, Wiley, 1993, at 37 - 96.

[125] This approach is very similar to a model discussed by Feinberg in 'Autonomy, Sovereignty, and Privacy; Moral Ideals in the Constitution?', *loc. cit.*, at 460 - 461. This model is not, however, supported by him, *ibid.*

[126] For comment on paternalism, see, Dworkin, 'The Theory and Practice of Autonomy', *op. cit.*, chapter 8, Kleinig, J.; 'Paternalism', Manchester, Manchester University Press, 1983, Shapiro, D.L.; 'Courts, Legislatures and Paternalism', 74, *Virginia Law Review*, 519, 1988, Feinberg, 'Autonomy, Sovereignty, and Privacy; Moral Ideals in the Constitution', *loc. cit.*, esp. 457ff., and Buchanan, A.; 'Medical Paternalism', 7(4), *Philosophy and Public Affairs*, 370, 1978.

[127] Jinnett-Sack, S.; 'Autonomy in the Company of Others', in Grubb, 'Choices and Decisions in Health Care', *op. cit.*, at 111.

[128] It is interesting to note that neither Mill nor Kant imagined the adoption of a paternalistic role by the state regarding the 'best interests' of its citizens. As Beauchamp and Childress note, *op. cit.*, at 273, 'Philosophical analyses of paternalism are at least as old as Immanuel Kant, who denounced paternalistic government ("imperium paternale," he called it) for benevolently restricting the freedom of its subjects. Kant was concerned about a government that "cancels freedom". He never considered the possibility that a parental model of benevolent intervention - one that likens the state to a protective parent caring for an incompetent minor - might be considered paternalistic. Nor did John Stuart Mill contemplate the possibility that paternalism might encompass interventions with those who have limited or no autonomy.'

First, let us consider the situation where a patient is unconscious and treatment is required to avoid a threat to his or her life. To carry out such treatment without first attempting to ascertain the wishes of the patient is paternalistic, not only because it is done in what are considered to be the 'best interests' of the patient, but because it is done *irrespective* of his/her wishes. In such cases the law presumes that the urgency of the situation provides the health care professional with a defence of necessity and no action can be brought subsequently by the patient[129]. An example of this is the case of *Marshall v Curry* in which a Canadian court denied a claim in battery brought because a doctor removed a patient's diseased testicle discovered during the course of a hernia operation[130]. The court was of the opinion that it would have been unreasonable to delay the operation in order to seek the patient's specific consent[131].

Second, paternalistic approaches to patient treatment have been legally sanctioned even in circumstances where the patient has expressed wishes against treatment prior to lapsing into an incapacitated state. In the U.S. case of *Werth v Taylor* a civil action in battery failed against a health care professional who had authorised a blood transfusion to one of the plaintiffs despite her having signed a 'Refusal to Permit Blood Transfusion' form[132]. The fact that the patient had been unconscious at the time when a transfusion became necessary was decisive for the court. The conclusion reached by the justices was that the refusal of the patient was not 'informed' because it was not made at a time contemporaneous with the threat to her life. This permitted her refusal to be overridden. The difference between this and the first scenario is the evidence of a view/wish of the patient. However, the similarity between the two scenarios lies in the

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[129] See, Mason and McCall-Smith, *op. cit.*, at 220 - 221.
[130] [1933] 3 D.L.R. 260.
[131] *Cf* - *Murray v McMurchy* [1949] 2 D.L.R. 442.
[132] (1991) 475 NW 2d 426 (Mich. CA).

paternalistic practice of disregarding the patient's view: either it is not sought (a form of disrespect in itself) or it is ignored. In other words, absent from each scenario is the patient's consent: arguably, the ultimate expression of autonomy and self-determination in the health care setting.

A third example relates to the disclosure of information to a patient. If a health care professional considers that for a patient to hear that he or she has a terminal disease will advance his or her condition and seriously affect the patient's mental state, then to omit to convey this information is paternalistic. The disrespect for the patient's autonomy is once again present[133]. In the U.K. this practice is condoned by the courts which consider that no legal action can lie for non-disclosure of a medical condition provided that the judgment of the health care professional in withholding information was in accordance with a 'responsible body of medical opinion'[134]. That is, the standard against which the paternalistic conduct is tested is one set by the medical profession itself. No 'objective' or 'subjective' patient test is accepted in the UK[135].

Fourth, the courts might deem that a patient is not sufficiently autonomous to merit respect of their wishes (presuming that such can be expressed) and in such cases medical care will be approved, once again, in the best interests of the patient. This point has already been made above concerning children[136] and mentally ill adults[137]. Also, as

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[133] On this matter see, Bok, S.; 'Lying: Moral Choice in Public and Private Life', New York, Pantheon Books, 1978, at 220 - 241.

[134] See, *Bolam v Friern Hospital Management Committee, supra cit.*,*Chatterton v Gerson, supra cit.*,and *Sidaway, supra, cit.* It is thought that the position in Scotland is the same, see *Hunter v Hanley* 1955 SLT 213, *Moyes v Lothian Health Board* [1990] 1 Med. L.R. 463, *Goorkani v Tayside Health Board* [1991] Med. L.R. 33, and *Gordon v Wilson* 1992 SLT 849. For comment see, Norrie, K. McK.; 'Common Practice and the Standard of Care in Medical Negligence', 1985, *Juridical Review*, 145. For a recent change of opinion on information disclosure in Australia, see *Rogers v Whitaker* [1993] 4 Med. L.R. 79.

[135] The same is not true in other jurisdictions, for comment see Geisen, D.; 'International Medical Malpractice Law', London, Nijhoff, 1988.

[136] See *Re W (a minor)(medical treatment)* [1992] 4 All ER 627, (1992) 9 B.M.L.R. 22.

[137] For comment, see Kennedy and Grubb, *op. cit.*, chapter 4, 'Consent by Others'.

happened in *Re T*[138], those who are subjected to undue influence, or who are ignorant of the consequences of their acts, can also be deemed '*incapax*' for the purposes of the medical intervention in question[139].

Finally, in some (albeit rare) situations the law will sanction forced treatment of competent adults. Thus, it is common for Mental Health legislation to provide for compulsory detention and treatment of individuals suffering from prescribed disorders[140]. In this latter example it should be borne in mind that it is not simply because an individual suffers from a mental condition that they are thereby automatically *incapax* regarding all aspects of their life and incapable of making autonomous choices concerning those aspects. However, as we have seen above, recent decisions tend to blur this distinction (or ignore it all together[141]) and this, it is submitted, is wholly unacceptable.

It can be seen from the examples in this section that in many ways the 'absolute' right of autonomy is limited and fettered, either on grounds of public policy or paternalism. In other words, the State is concerned not only with behaviour likely to harm others (other-regarding behaviour) *but also* with matters of personal concern (self-regarding behaviour).

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[138] *supra.*

[139] There is also the possibility of decisions on the basis of 'substituted judgment', that is, decisions taken by others on behalf of the patient. The courts in the U.S. seem unsure about the status of this test, and both it and the 'best interests' test have been applied in various states. There has been no express use of the substituted judgment test in the UK, and there is dubiety about its usefulness and possible role, see, *Re T*, *supra*, and *Airedale NHS Trust v Bland*, *supra cit.*, discussed by Kennedy and Grubb, *op. cit.*, at 288 - 289.

[140] *Supra.*

[141] See, in particular, *Tameside and Glossop Acute Service Trust v CH (a patient)*, *supra cit.*

3.6. - AUTONOMY AND LAW: A CONCLUSION

The brief survey of cases carried out above gives us a clear picture of the state of protection accorded to patient autonomy by the law in the United Kingdom. In cases where one is an adult of sound mind there is an obligation on others to respect one's wishes and to consider as of paramount importance respect for one's autonomy. Three important limits are, however, placed on patient autonomy.

- *Conflict*

First, where the autonomy of the individual conflicts with other interests, the former may be compromised and/or sacrificed. Unfortunately, we have no clear indication of the extent to which the courts will consider other interests nor how they propose to approach the problem of resolving conflict. The only cases which deal with 'conflict' as such, have been those concerning pregnant women and forced caesarean sections[142]. We have seen that in the case of *Re S (adult: refusal of medical treatment)*[143] the court resolved the matter in the singularly unhelpful fashion of stating a preference for the interests of the fetus over the express wishes of the woman without offering any reasoned argument or analysis[144]. This decision has been overruled, however, in *Re M.B.*[145] in which the Court of Appeal upheld the right of pregnant women to refuse treatment provided they are competent. As has been stated, this later decision is undoubtedly correct since, in law at least, there is no real conflict in such cases because

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[142] *supra.*

[143] *supra cit.*

[144] Although it of course possible to see *Re S* as a case in which the interests of *both* the woman and the fetus were protected, since the medical consensus was that both would die if a caesarean was not performed.

[145] *supra cit.*

the fetus has no legal personality and therefore no autonomy to speak of. How the courts will respond to other 'conflict' cases, however, remains a mystery.

- *Minority*

Second, non-age restricts one's capacity to act as an autonomous chooser and this is especially so in circumstances where the choice in question is refusal of treatment and when that refusal entails a risk of death. Indeed, it is arguable that in such circumstances there is no choice available to a child in light of the high standards set by the case of *Re S (A Minor) (Consent to Medical Treatment)*[146]. In Scotland powerful arguments have been put that a minor can refuse treatment if s/he has capacity to do so, but the determination of this issue rests squarely with the medical professionals responsible for the care of the child. This gives rise to problems which are detailed in the following section.

- *Incapacity*

Whether one is an adult or a child, if one is unable to exercise choice one cannot act as an autonomous chooser. Choices must be made on our behalf. In the health care context incapacity can arise in myriad ways, but in each case the question of capacity will be judged by the medical profession. In refusal cases this leads to a potentially paradoxical situation because a Health Care Professional (HCP) is faced with the difficult task of assessing the competence of someone to do something which the HCP does not want them to do. This militates against the chances of the HCP respecting the patient's autonomy. In cases involving adults who have been admitted to health care under the provisions of the Mental Health Acts, treatment of their mental disorder can

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[146] *supra.*

proceed without the need to determine the patient's wishes or capacity to act. In all other cases of incapacity the onus is on those seeking to override the patient's wishes to challenge patient autonomy: *Re C (Refusal of Medical Treatment)*[147]. Unfortunately, the courts have not been clear about what must be shown in order to determine (in)capacity.

4.1. - AUTONOMY AND GENETIC INFORMATION

In this section the principle of autonomy will be examined as a possible means of protecting the privacy interests which individuals have surrounding their own genetic information. That is, we shall apply an autonomy analysis to the four scenarios detailed at the end of chapter two, to determine the success with which the principle of autonomy can protect individual interests in genetic material against claims from others such as employers, insurers, the state and relatives.

The relevance to genetic information of what has been said about autonomy in previous sections should be obvious. It has already been argued that aspects of the self such as the body and personal information require respect under the principle of autonomy. The principle also dictates that individuals deserve respect concerning the choices which they make about what happens to their bodies and/or personal information. Thus the principle prescribes that choices concerning genetic information are equally deserving of respect. Several problems, however, become immediately apparent. First, given that genetic information concerns many individuals in a family, how can the principle of autonomy help us to resolve conflicts which arise about the control and use of the information? For example, if Patient A is tested and found to be a carrier of cystic fibrosis, does his sister who is pregnant have a right to the

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[147] *supra cit.*

information so that she can make an appropriate and autonomous choice about her pregnancy? In other words, what is to be done when two autonomies conflict?

Second, it was noted earlier in this chapter that there exist in both ethics and law certain fundamental criteria which are necessary to be an autonomous individual. Central to the principle of autonomy is *choice*. In particular, choices must be taken free from *interference* and by someone who has the *capacity* to make those choices. Fundamental to such choices is knowledge. One cannot choose in a meaningful sense if one is not informed of the parameters within which one must choose. This is why informed consent is crucial to ethically and legally acceptable health care. However, in the context of genetics this causes a problem. In order to choose one must have knowledge, but in many circumstances the problems surrounding genetic information are precisely concerned with the absence of knowledge: this is the basis of the claim to respect the interest in not knowing genetic information. In such cases, the choice is one about 'knowing' itself: the choice is whether to receive or not to receive information about oneself. This is problematic for the concept of autonomy because it is difficult to see how one can exercise meaningfully a choice not to know unless one has a certain degree of knowledge about the subject matter of one's choice. Of course, an obvious practical solution would be to approach the individual and ask, 'do you want to know this information', but as Wertz and Fletcher have pointed out,

> [t]here is no way...to exercise the choice of not knowing, because in the very process of asking, 'Do you want to know whether you are at risk...?' the geneticist has already made the essence of the information known.[148]

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[148] See Wertz, D.C. and Fletcher, J.C.; 'Privacy and Disclosure in Medical Genetics Examined in an Ethics of Care', 5(3), *Bioethics*, 212, 1991, at 221.

This is not to say that one cannot simply state 'I wish to know no information about my genetic make-up whatsoever', nor is it to suggest that such a wish should not be respected. However, the requirement that autonomous choices be informed choices tends to imply that the credibility of an uninformed choice is more easily questioned. It leaves the way open for it to be argued that actual knowledge about circumstances might nevertheless affect the chooser who might choose differently if furnished with relevant information. The situation might be seen as analogous to the problem of the *incapax*. The individual who is incapax cannot choose for him/herself and so must have choices made for him/her. In the same way, the individual who is ignorant of genetic information might be seen as a pseudo-*incapax* and therefore it might be assumed that is legitimate to make choices about the genetic information on his or her behalf. At present and as we have seen, choices for the *incapax* are made in the best interests of the *incapax*. It is far from clear, however, how one would determine an individual's best interests concerning genetic information.

Let us consider the scenarios laid out in chapter two from the perspective of autonomy. This will clarify the nature of these problems and lay out the solutions offered by this concept.

5.1. - SCENARIOS

5.2. - SCENARIO ONE: EMPLOYERS AND INSURERS

In the context of alpha$_1$ - antitryphsin which is a genetic condition which can be exacerbated by adverse environmental factors such as dust or smoke, the question has been asked whether employers and insurers can:

a) have access to individual medical records to determine whether someone has this condition or whether they have been tested for the condition.

and/or

b) carry out tests on individuals to determine current or future risk of developing the condition.

5.2.1. - *An Autonomy Perspective*

The principle of autonomy dictates that an individual has the right to control what happens to personal information, including personal genetic information. From the perspective of insurers and employers a common interest which they have in genetic information is the financial interest which might be served by having a better idea of a particular individual's likelihood of developing disease. Also, both insurers and employers have a claim to genetic information in order to avoid harm, but in rather different fashions. From the insurers' standpoint, *financial* harm to the general body of the insured can arguably be averted or minimised if the risks of particular individuals can be better determined. From the employers' perspective, potential *physical* harm to other workers can be avoided if 'at risk' workers are identified and dealt with appropriately.

From the perspective of the individual, the prospect of employers and insurers seeking genetic information about them gives rise to concern about both kinds of privacy interests identified in this work. An individual's informational privacy interests are interfered with by requesting access to existing information. An individual's spatial privacy interests are interfered with by requiring him/her to undergo testing in circumstances when s/he is not entirely free to refuse.

5.2.1.1. - *Access to Existing Records*

An autonomy model sets up a paradigm of respect for the right of choice of the individual. It also calls on us to question the freedom of the choice of the individual when faced with requests for access to information by insurers or employers because the individual finds him or herself in a substantially weaker position compared to the other party. This has been explained in chapter two. Moreover, earlier in this chapter it has been explained that autonomy may properly be compromised if a threat of harm to others exists. However, this does not extend to financial harm. This point has already been established in the context of limiting autonomy for the financial interests of the State in the provision of health care. Thus, arguably an autonomy model renders unacceptable infringement of autonomy simply to further financial interests. By way of contrast, if physical harm is likely to occur to other persons, the autonomy of individuals may be curtailed. This, however, requires that there is a real likelihood of actual harm occurring. If not, then *prima facie* respect should be forthcoming to individual autonomy. Relatedly, for harm to be averted autonomy should be interfered with in the least intrusive manner. Thus, for example, it is not acceptable to dismiss an employee because a genetic condition is likely to affect his or her ability to work, if another position for the individual can be found. We can see then how the principle of respect for autonomy allows us to make a strong argument to protect an individual's informational privacy interests. Access to existing records should not be allowed except in the most justified of circumstances. The autonomy principle adds considerable weight to the arguments made in chapter two for reform of the current position regarding insurer and employer access to individual information.

5.2.1.2. - *Requiring Genetic Testing*

To require an individual to undergo genetic testing when his/her consent is not forthcoming or is given after subtle forms of coercion (for example, the threat of losing or not gaining employment or not receiving insurance), also offends against the principle of autonomy. Whereas this does not mean that genetic testing can never be legitimate, it does require strong justification to merit such an interference with autonomy. An example might be significant threat of serious harm to others. The onus is clearly on those seeking the information. Once again, arguably financial interests are not of sufficient seriousness or weight to justify coercive testing. As regards the threat of harm to third parties, this must be immediate and serious and must arise directly from the genetic ill health of the individual to justify coercive testing measures. An example might be a genetic condition which predisposes an individual to a sudden and fatal stroke. Clearly for those responsible for the safety of others, such as airline pilots or bus drivers, testing might be acceptable, again if no other means exist of ensuring that the potentiality for harm is kept to a minimum.

Another possibility is testing to further the interests of the individual. However, similar arguments have not gone down well in the United States. In 1991 the Supreme Court examined the issue of the legitimacy of employers claiming an interest in potential damage to the fetuses of female workers due to work-related environmental factors. The Court held that the employer could not claim a legitimate interest in denying fertile women employment supposedly *in the employee's best interests*: the decision about exposure to risk was for the women themselves[149]. Similar reasoning might be used to defeat claims by employers to have access to genetic information.

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[149] See, *International Union United Auto Workers v Johnson Controls, Inc.* 499 US 187, 1991.

In the UK the Nuffield Council on Bioethics has taken the view that,

> ...where the concern is limited to the health of the employee, it should be a matter for the individual employee to decide whether or not to participate in a screening programme[150].

Thus whereas the current legal position in the UK does not preclude employers from requesting employees to take genetic testing[151], it is the view of the Council that individuals should not be coerced into doing so. This reflects the attitude of respect due to the individual's autonomy to decide for him or herself whether or not to undergo testing. There is no valid reason why this should be any different in the context of an insurer's request for testing. In this way, the principle of respect for autonomy helps to protect the spatial privacy interests of individuals because it dictates that they should be given the choice whether or not to participate in any testing or screening programmes.

5.2.2. - *Employers' and Insurers' Interests: A Conclusion*

We can see that the principle of autonomy can help to protect an individual's informational and spatial privacy interests when faced with a request for genetic information from employers and insurers. The first line of defence is the concept of consent. Autonomy requires that consent be given both for release of personal

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[150] Nuffield Council on Bioethics, 'Genetic Testing: Ethical Issues', December 1993, at para.6.20.

[151] The only UK employer known to the Council to conduct testing is the Armed Forces who screen applicants likely to be involved in atypical atmospheric conditions for sickle cell disease. As the Nuffield Council says, 'Candidates who are carriers of the sickle cell gene are considered to be unfit for duty in such occupational categories. They may, however, be accepted for other duties. This is primarily because of the risk of sickling on exposure to reduced atmosphereic pressure or hypoxia. (Sickling is a change in the shape of the red blood cells which can lead to blockage of blood vessels).', *op. cit.*, at 6.18.

information (which has informational privacy implications) and for the collection of information by testing (which has spatial privacy implications). Unfortunately, in the context of employment and insurance the individual is in a substantially weaker position compared to the employer or insurer. This means that consent might be forthcoming, but not be entirely voluntary. Nonetheless, the principle of autonomy requires that before autonomy can be interfered with strong justifications are required. Thus, any claim to require access or testing must be well founded and must interfere with individual autonomy as minimally as possible. This too helps to protect the informational and spatial privacy interests of individuals.

5.3. - SCENARIO TWO: STATE INTERESTS

The interests of the State in screening programmes have been divided into two categories: pre-marital screening and ante-natal & post-natal screening. Let us consider the acceptability of such programmes from within an autonomy model, remembering that we are concerned with the efficacy of an appeal to autonomy to protect the privacy interests of citizens. In particular, it is the spatial privacy interests of individuals which are of concern here because the giving of knowledge in unwarranted circumstances impinges on the interests of citizens in maintaining a sphere of separateness around their 'self'.

5.3.1. - *Pre-marital Screening for Cystic Fibrosis*

The aims of any State in instituting screening programmes are varied[152]. Yet whatever the aims, the interference with individual autonomy which such programmes

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[152] These include a desire to reduce the incidence of disease, a need to further epidemiological studies and the motive of ensuring that individuals take informed reproductive choices.

necessarily entail must be justified both in the interests of individuals as well as the general public interest. Axiomatically, if such programmes do not achieve this, their justification is lost and their continuation is offensive by virtue of the affront they represent to the principle of autonomy. In the present context the question under scutiny is whether a screening programme for Cystic Fibrosis, which has as its aim the reduction of the instance of the disease, can be a justifiable interference with autonomy? Several arguments can be advanced which would suggest that this is not the case[153].

First, genetic testing can never detect all cases of genetic disease or carrier status. In the particular case of Cystic Fibrosis only 75% of CF chromosomes can be detected in the population because of the problem of mutations[154]. As Gostin has stated,

> Approximately one of every two couples from the general population identified by CF screening as "at risk" will be falsely labeled.[155]

Also, it has been asserted by the House of Commons Science and Technology Committee that,

> reduction of the birth incidence of CF through screening and genetic screening will have minimal effect on the gene pool.[156]

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[153] See also, Brandt, A.M.; 'AIDS in Historical Perspective : Four Lessons from the History of Sexually Transmitted Diseases', 78, *American Journal of Public Health*, 367, 1988, in which the author gives an historical account of the US syphilis screening programmes and argues against similar measures for HIV. He makes the interesting point that even with a disease such as syphilis which can be treated, screening programmes did not radically alter the incidence of disease in the community.

[154] See, Gostin. L.; 'Genetic Privacy', 23, *Journal of Law, Medicine and Ethics*, 320, 1995, at 323.

[155] *ibid.*

[156] House of Commons Science and Technology Committee, 'Report on Human Genetics', Third Report, HMSO, 1995, at xxxiv.

For the particular condition of Cystic Fibrosis this clearly fundamentally undermines any proposed screening programme[157].

Second, and more generally, it is crucial to bear in mind that unlike conventional disease (with the notable exception of sexually transmitted diseases), genetic conditions can only be transmitted and, in the absence of cure can only be controlled, through reproductive decisions and choices[158]. Undeniably, the public interest in preventing the spread of disease is an extremely important one but in the context of genetic disease its furtherance through screening is hindered by one factor: there is no certainty that even if disclosure is made people will no longer reproduce. Western society takes the view that reproductive autonomy forms part of the fundamental civil liberties of persons; liberties which can only be interfered with in very rare circumstances[159]. Given that society does not (or at least does not often[160]) actively prevent persons from

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[157] A further complicating factor in the United Kingdom concerns the cost-cutting practices adopted by CF screening services. In evidence to the Science and Technology Committee it was revealed that not all carriers of CF were informed of their status : 'A system of avoiding the costs involved in genetic counselling and informing the population on a large scale has been developed; this is based on offering the test to pregnant women and their partners. All they have to do is to provide a mouthwash sample in a bottle, both of them, these are both tested and the only people who are informed of their results are the couples where both are carriers; so that means that for several thousand tests you may only have to provide counselling to, say, eight or ten couples.', *ibid*, at 94. Clearly this is not only ill-advised because partnerships do not necessarily last for ever, but also it is offensive not to give individuals information about themselves when they have requested it, for reasons of financial saving.

[158] See Suter, S.M., 'Whose Genes Are These Anyway? : Familial Conflicts over Access to Genetic Information', 91, *Michigan Law Review*, 1854, 1993, at 1860.

[159] For a discussion see, McLean, S.A.M.; 'The Right to Reproduce' in Campbell, T., Goldberg, D., McLean, S. and Mullen, T., (eds.), 'Human Rights: From Rhetoric to Reality', Oxford, Basil Blackwell, 1986, at 99 - 122. Writing in the US, Andrews notes that, '[i]n April 1990, a federal judge explicitly held that the right to privacy specifically covers decisions concerning pre-natal genetic screening. Consequently, if a law infringes upon couples' reproductive decison-making rights with respect to the use of genetic services, the law will be upheld as constitutional only if it is necessary to further a compelling state interest in the least restrictive manner possible.', see Andrews, 'Legal Aspects of Genetic Information', *loc. cit.*, at 37. The case in question is *Lifchez v Hartigan*, No.82 C 4324 N.D. Ill. (April 26, 1990).

[160] For comment on the limits to such a 'right' see, Heginbotham, C., 'Sterilizing People with Mental Handicaps' in McLean, S.A.M., (ed.), 'Legal Issues in Human Reproduction', Aldershot, Gower, 1989, at 141 - 163. Recent cases of court-ordered sterilizations include that of a mentally incompetent adult (*Re F* [1990] 2 A.C 1) and that of a ward of court suffering from a chromosomal disorder (*Re HG* [1993] 1 F.L.R 587). For commentary on recent developments in the US concerning the use of long-term contraceptives and in particular their use as a punitive or coercive measure, see Hastings Center Report,

reproducing, it is unclear that the argument in favour of screening adults to prevent the spread of genetic disease succeeds. Also, there exist potentially more effective means by which this public interest can be furthered which do not involve interfering with the autonomy of individuals. Ante-natal counselling services, the direct availability of testing for fetuses[161] and the option of termination of pregnancy[162] are other means which are available to further this interest and which do not involve interfering with individual autonomy. Thus we see that to the extent that a screening programme interferes with the spatial privacy of individuals, autonomy can help in building an argument that such interference is unwarranted.

The situation is slightly different if a cure is available for the condition which might be passed on and if this condition can affect the health of the individual who has become the subject of State attention. Arguably in such cases the public (State) interest in public health is matched by an interest in the health of the individual. However, if testing is done to achieve such a dual 'benefit', it is submitted that the decision to force the individual to undergo testing must be followed through and accompanied by a compulsion to undergo treatment. Otherwise the interests of the state and individual are not served. Again, this is something which is extremely hard to justify in our society[163]. This is particularly poignant given the eugenics movements of the recent Western past which, if they teach us anything at all, teach us that social engineering

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'Long-Acting Contraception: Moral Choices, Policy Dilemmas', 25(1), Special Supplement January-February, 1995, especially Dresser, R.; 'Long-Term Contraceptives in the Criminal Justice System' at S15 - S18, and Steinbock, B.; 'Coercion and Long-Term Contraceptives' at S19 - S22.

[161] Such testing can, however, give rise to a new set of problems. An amniocentesis test carries a 1 in 200 chance of losing a normal pregnancy. In addition, such a test might reveal genetic defects which were not anticipated and not counselled for thereby giving rise to the problem of what to do with such information.

[162] It is, of course, appreciated that for many women termination is not an option.

[163] For example, from the American perspective Suter has argued that mandatory genetic testing/screening is unconstitutional, *loc. cit*, Part III.

through forced genetic manipulation is not only flawed, but comes at a price which few today would be willing to pay.

In light of these arguments it is submitted that mandatory screening programmes of adults, either for CF or other conditions, are highly questionable. By all means testing should be made available to permit individuals to choose to know their own status, but screening programmes are very hard to justify where the element of choice is removed and the principle of autonomy thereby compromised with the concomitant effect on the spatial privacy interests of the indviduals involved[164].

5.3.2. - *Pre-natal and Neo-natal Screening*

This section considers the acceptability of ante-natal and post-natal screening programmes for four genetic conditions. Before proceeding, however, several issues merit comment.

First, it should be noted that the motivation and reasons for offering such programmes are different depending on whether they are offered before or after birth. At present, pre-natal screening is offered principally to provide parents with the choice to continue with a pregnancy involving an affected or potentially affected child. In contrast, post-natal screening in the United Kingdom has so far only been carried out when a cure or treatment is available. Thus with pre-natal screening the practice facilitates parental choice and with post-natal screening it prevents harm to the child.

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[164] For comment on CF screening programmes, see, Elias, S., Annas, G.J. and Simpson, J.L.; 'Carrier Screening for Cystic Fibrosis : A Case Study in Setting Standards of Medical Practice', in Annas, G.J. and Elias, S.; 'Gene Mapping : Using Law and Ethics as Guides', New York, Oxford University Press, 1992, chapter 11.

Second, the question of whether such screening should be voluntary or compulsory is likely to be answered differently for ante and post-natal programmes. For example, it has been argued that compulsory ante-natal screening programmes represent a means for health authorities to avoid the costs of disabled children[165]. Such programmes would have serious implications for the rights and interests of parents who might come under considerable pressure to abort or who might be labelled as irresponsible for deciding to proceed with an affected pregnancy. For example, the House of Commons Science and Technology Committee noted that,

> We heard that in Edinburgh that if after counselling a prospective parent with Huntington's Disease insists on pre-natal testing for the condition this will only be offered on the understanding that the pregnancy will be terminated if the test proves positive; to do otherwise would burden the child with knowledge of its early death.[166]

This clearly offends against the principle of autonomy to an unacceptable degree.

In contrast, for compulsory post-natal screening the State has to date been able to advance strong justifications for potentially impinging on parental choice (autonomy) - if, for example, the parents refuse testing - when screening can lead incontrovertibly to the avoidance of harm to another individual (the child). Examples include screening for PKU and Hyperthyroidism. These are, however, easy cases. Matters are not so straight-forward when the benefit to the child is less obvious - for example where no cure or treatment is available.

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[165] See Science and Technology Committee, *op. cit.*, at 86, and the evidence cited therein.
[166] *ibid*, at 90.

Third, the ethical and legal rubrics discussed above must be borne in mind. As regards ante-natal testing, the law in the UK provides a woman with the 'right' to abort a fetus at any time if it suffers from serious mental or physical handicap. Thus, a screening programme entails no illegal practices and on one view supports the principle of respect for autonomy because it allows the woman to exercise her right to choose abortion[167]. The ethics of abortion is, however, a different matter. This thesis is not an appropriate forum in which to discuss this issue. From the ethical perspective it will be assumed that the right of the woman to choose is of considerable importance. This at least accords with the current legal position. For post-natal testing, the law requires that those with responsibility for a child act in its best interests[168]. Ethically the same view is prescribed. At the very least this means that some benefit must come from testing for the child which should not entail, or should at least outweigh, any harm to the minor in question.

Finally, we must determine whose privacy interests are at stake here. Primarily, it is the privacy interests of (a) the 'future person', that is, the fetus in the womb, and (b) the neonate. Both spatial and informational privacy interests are under threat. Concerning spatial privacy the threat comes from others deciding on one's behalf that information should be known. As regards informational privacy, the threat exists once

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[167] Strictly speaking it is not accurate to speak of a woman's 'right' to choose abortion in the United Kingdom because her so-called 'right' is entirely dependent on her receiving the approval of two registered medical practitioners (or in some circumstances only one such practitioner), see s.1 of the Abortion Act 1967, as amended.

[168] In England, see for example, the Children Act 1989 and the Family Law Refrom Act 1969, *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112, *Re R (A Minor) (wardship : medical treatment)* [1992] Fam 11, and *Re R (A Minor)(Blood Transfusion)* [1993] 2 FCR 544. In Scotland, see the Age of Legal Capacity (Scotland) Act 1991. Note recently, the English Court of Appeal has upheld a decision of parents to refuse a liver transplant for their child on the basis that this was an accurate assessment of the child's best interests and that the parents were best placed to decide those interests. This was so even in the face of overwhelming medical support for the procedure to be carried out. An influencing factor might have been, however, the fact that both parents were themselves, 'health care professionals', see *Re T (A Minor)(wardship : medical treatment)* The Times 28 October 1996, 146 NLJ 1577.

information *is* known because then questions arise about the security and control of such information.

From the autonomy perspective, let us consider the acceptability of a National Health Service programme of post and ante natal screening which targets the following conditions:

5.3.3. - *Sickle Cell Anaemia*

This is a recessive condition which affects particular ethnic groups[169] and which is not curable but is treatable with blood transfusions. Pre-natal screening might be useful for couples who have no idea that they are carriers or that they are affected by the condition. This would allow couples to consider aborting an affected fetus. The offer of screening ensures that the choice of parents not to continue with pregnancy is facilitated. However, concerning post-natal screening, it should be noted that screening programmes of populations for this condition have already been have carried out in the United States with worrying consequences. The schemes had to be abandoned because of the serious adverse consequences which resulted for the racial groups who were the target of the programmes. They experienced racial and general discriminatory treatment, were denied insurance and employment and suffered a high degree of stigmatisation. Furthermore, through public ignorance, even those who proved not to be affected by the condition were treated in this way[170].

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[169] The condition primarily affects Afro-Caribbeans.

[170] This experience is recounted by the Nuffield Council on Bioethics in its report on 'Genetic Screening: Ethical Issues', *op. cit.* chapter two, at 8.13 - 8.14. Skene also notes that similar discrimination and stigmatisation has arisen in Greece as a result of sickle cell anaemia screening programmes, see Skene, L.; 'Mapping the Human Genome: Some Thoughts for Those Who Say "There Should Be a Law On It"', 5, *Bioethics*, 233, 1991, at 238.

From the perspective of autonomy the argument that individuals must be allowed to 'choose' whether or not they would wish to know information about themselves carries all the more weight in such a context given the potential for serious adverse consequences which can arise from the fact of having been tested. Additionally, it is important to bear in mind that such group-centred programmes can lead to discrimination against persons *even if* they have not been tested because the mere existence of the programme gives 'cause' for such persons to be treated differently simply because of their membership of a 'high risk group'. This too has implications for autonomy, albeit in an indirect way. Such screening programmes can adversely affect the autonomy of the persons who constitute such a group because they can lead to a 'shutting down' of options and a 'closing off' of avenues, all of which restrict choice and the ability of group members to act as autonomously as they would like.

Such experiences teach us valuable lessons about offering screening for conditions such as sickle cell anaemia. If programmes are to avoid the kinds of outcome outlined above, they should not be implemented without corresponding public education programmes and other measures such as anti-discrimination laws to ensure that the US experience is never repeated.

Note, however, the paradox which appears here when we try to use the principle of autonomy to protect the privacy interests of future persons and neonates. For, in the case of pre-natal screening the autonomy which is at issue is not that of the future person, but rather that of the couple - their right to choose whether or not to continue with a pregnancy. And, in circumstances where the couple choose to know but do not choose to abort, the child will be born in circumstances where information about its genetic constitution is known: potentially this can interfere both with the child's spatial and informational privacy interests, and the principle of autonomy has not helped to avert this. Similarly, where a newborn child is tested for a condition such as sickle cell anaemia which is incurable and which carries with it a high risk of discrimination and stigmatisation, the beneficent approach of the state in requiring testing cannot easily be challenged by an appeal to the child's autonomy since the child as a minor traditionally receives less respect for such autonomy. This latter point will be dealt with more fully in the next section.

5.3.4. - *Huntington's disease*

This is a late onset dominant condition which carries a 50% chance of affecting each child of an affected individual[171]. There is no cure for Huntington's disease. The severity of the disease is such that it is not unusual for pre-natal testing to be offered solely on the condition that a positive test result will be followed by abortion[172]. However, to do so places considerable moral/social pressure on parents and can represent a subtle form of coercion to abort[173].

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[171] If an unfortunate soul finds him or herself with both parents affected by Huntington's disease, his or her chances of developing the condition are increased to 75% in each case.

[172] See, for example, the 'Edinburgh experience', note 166, *supra* and text.

[173] For comment see, Clarke, A.; 'Is Non-Directive Genetic Counselling Possible?', 338,*Lancet*, 998, 1991, Chadwick, R.F; 'What Counts for Success in Genetic Counselling?', 19, *Journal of Medical Ethics*, 43, 1993, and Clarke, A.; 'Response to: What Counts as Success in Genetic Counselling?', 19, *Journal of Medical Ethics*, 47, 1993.

The acceptability of post-natal testing for Huntington's disease is very questionable. As has been stated, parents can only legitimately request that their children be tested if it is in the childrens' best interests to do so. Arguably, the same should be true for the state. But, it is far from clear that to determine in an asymptomatic child a predisposition to develop an extremely debilitating and ultimately fatal disease later in life when nothing can be done to avert this outcome is in their best interests. For one thing such knowledge can be extremely upsetting for the child. But, even if the child is not informed of the result, it can be upsetting for the parents and can lead to the child being treated differently as a result. As Wertz *et al* have poignantly noted,

> "Planning for the future," perhaps the most frequently given reasons for testing may become "restricting the future" (and also the present) by shifting family resources away from a child with a positive diagnosis...In families with a chronically ill child, there is less socialization to future roles for the children, including those who are "healthy". Parents are less likely to say "When you grow up..." or "When you have children of your own..." to any of their children, because they cannot say these words to the ill child..."Alleviation of anxiety," another reason commonly given by parents for predictive genetic testing, does not necessarily benefit the children. A positive diagnosis may create serious risks of stigmatization, loss of self-esteem, and discrimination [by] family or by institutional third parties such as employers or insurers. Testing may disrupt parent-child or sibling bonds, may lead to scapegoating a child with a positive result or to continued anxiety over a child despite a negative result...[174]

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[174] See Wertz, D.C. *et al*; 'Genetic Testing for Children and Adolescents : Who Decides?', 272, *Journal of the American Medical Association*, 875, 1994, at 878, cited in Hoffman, D.E. and Wulfsberg, E.A.; 'Testing Children for Genetic Predispositions : Is it in Their Best Interest?', 23, *Journal of Law, Medicine and Ethics*, 331, 1995, at 333.

In other words, such practices can have serious implications for the child's privacy interests; both spatial and informational. However, the principle of autonomy cannot help children in such circumstances. As minors, the respect due to them and their wishes is given through their guardians who must act in their best interests. However, it is submitted that the best interests of a child are not served by a parent who requests a test for a condition such as Huntington's disease. There is no reason not to delay testing until the child can understand the implications of testing and can decide for him or herself whether or not to proceed. This view is supported by bodies such as the House of Common Science and Technology Committee[175], the International Huntington's Disease Association and the World Federation of Neurology[176]. Unfortunately, the treatment which minors receive under the principle of autonomy, as we have seen, does not augur well for ensuring that their privacy interests are in fact protected.

5.3.5. - *Duchenne Muscular Dystrophy*

DMD is an X-linked disorder which predominately affects male children. DMD is the largest known gene with a high number of mutations. Testing can, therefore, only detect a proportion of affected persons. Moreover, one third of boys born with DMD have no previous family history. This is because the gene defect has arisen spontaneously in the germ cells of one parent[177]. As with Huntington's disease, no cure is available for DMD. Yet, the British Medical Association has recently considered the merits of the introduction of screening for the condition. In evidence to the House of Commons Science and Technology Committee the justification was put thus,

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[175] *op. cit.*, at 80.

[176] See Ball, D, Tyler, A., and Harper, P.; 'Predictive Testing of Adults and Children' in Clarke, A., (ed.); 'Genetic Counselling : Practice and Principles', London, Routledge, 1994, chapter 3, at 69 - 74.

[177] See, Science and Technology Committee, *op. cit.*, at 92.

> One of the advantages of early screening is that it warns parents of the risk of recurrence in subsequent children...potential carriers in the family can be informed of the risk. The knowledge would also avoid a delay in diagnosis...and would enable parents to prepare themselves for the future, such as modifying their home to accommodate a wheelchair.[178]

However, as we have seen each of these justifications is open to question. First, a positive or negative diagnosis in one child tells us little about the future risk in future children: if present, the condition might be the result of spontaneous pathology; if a negative result is returned, this might simply be because the test is unable to detect a particular mutation. Second, early diagnosis and preparedness are not always beneficial as we have seen with the example of Huntington's disease. Third, the test is done not in the best interests of the child, and certainly not to protect the privacy interests of the child, but rather to favour the reproductive autonomy of the parents. The acceptability of this has already been questioned. And, as has already been argued, because the principle of autonomy is less strongly invoked for minors, the claim on behalf of the minor to prevent such an 'interference' with his/her privacy (and autonomy) is less well grounded if it is grounded in the principle of autonomy.

The above challenges would, it is submitted, render a screening programme for DMD unacceptable and probably unethical. For both Huntington's disease and DMD the nature of the disease as late onset and the absence of a cure are determinant factors[179].

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[178] *ibid*, Memorandum, Volume II, at 116. The Association did also note disadvantages : '[p]arents are told that their son will develop a fatal condition for which there is no cure, years before the first symptoms appear.', *id*.

[179] The Science and Technology Committee recommended that '[t]here should be no mass screening for public health reasons in childhood unless a treatment for the disorder exists.', *ibid*, at 92.

5.3.6. - *Ischaemic heart disease*

The question of the acceptability of ante and post-natal screening programmes for ischaemic heart disease raises in a particularly acute form questions about the limits of value of genetic testing. More than any of the other diseases so far discussed, a condition such as ischaemic heart disease is affected by a plethora of factors only one of which is genetic defect. A test can, therefore, at best only give an indication of a possible predisposition to disease at some far future date. This calls into question the legitimacy of a pre-natal test for the disease. Moreover, if such a test proves positive - that is, if it shows that there is some remote likelihood in the future and given the wrong conditions that the child might develop disease - does this entitle the woman to abort the fetus? In other words, would this be sufficient reason to allow the woman to exercise legitimately her autonomy and 'choose' an abortion? It is informative to examine this question in order to have a better understanding of the limits of women's autonomy in this field and the corresponding effect on the interests of fetuses.

5.3.7. - *The Abortion Act 1967, as amended*

The law in the United Kingdom provides that prior to 24 weeks of pregnancy a woman can lawfully request a termination of a pregnancy provided that, in the opinion of two registered medical practitioners who have formed an opinion in good faith, the continuation of the pregnancy would involve a risk, greater than if the pregnancy were terminated, of injury to the physical or mental health of the pregnant woman or any existing children of her family[180]. In practical terms, abortion is relatively easy to obtain since the definition of physical or mental health is drawn very

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[180] Section 1(1)(a) of the Abortion Act 1967, as amended by the Human Fertilisation and Embryology Act 1990, s.37.

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widely. In such circumstances, the question of whether or not the fetus is affected by disease or is likely to be affected by disease is irrelevant.

After 24 weeks an abortion is only lawful if one of a set list of circumstances is present. These are : a) there is a risk of grave permanent injury to the physical or mental health of the woman[181]; b) that the continuation of the pregnancy would involve risk to the life of the woman[182]; or, c) that there is a substantial risk that, if the child were born, it would suffer from such physical or mental abnormalities as to be severely handicapped[183]. Clearly it is the last of these that is relevant to the present discussion. The question arises: is a possible predisposition to heart disease in future life a '*substantial risk...of physical or mental abnormalities...as to be severely handicapped.*'? At first sight, one would reply no to this question. As has been stated, a test for ischaemic heart disease could not disclose a *substantial* risk and furthermore the disease, if it ever were to manifest itself, would only do so much later in life, probably when the child is no longer a child but an adult responsible for his or her own well-being. Thus, as a child, there would be no evidence whatsoever of serious *handicap*. Indeed, even as an adult it is unclear whether heart disease can easily be classified as a handicap. However, it has been argued by several commentators that the provision of section 1(1)(d) is *not* to protect the child from a seriously diminished life, but rather to protect the mother from having to rear a 'defective' infant[184]. This has several consequences for the possible interpretation of this provision. Williams justifies his assertion that the provision in question is designed to protect the mother/parents by stating,

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[181] *ibid*, section 1(1)(b). Note the requirement of *grave permanent* injury, cf - s.1(1)(a).

[182] *ibid*, section 1(1)(c).

[183] *ibid*, section 1(1)(d).

[184] See, for example, Mason, and McCall-Smith, 'Law and Medical Ethics', *op. cit.*, chapter 5, Mason, J.K.; 'Medico-Legal Aspects of Reproduction and Parenthood', Aldershot, Dartmouth, 1997, chapter 5, Kennedy, I. and Grubb,A.; 'Medical Law : Text with Materials', *op. cit.*, at 875 - 878, quoting, *inter alia*, Williams, G.; 'Textbook of Criminal Law', Second Edition, London, Stevens & Sons Ltd,1983.

> [t]hat this is the philosophy of the Act is borne out by the fact that it allows termination only where the child if born would be seriously handicapped, not where it is merely carrying undesirable genes.[185]

His view on what constitutes a '*substantial risk*' and '*serious handicap*' is that it is a matter to be determined by the clinician asked to perform the termination.

In addition, Kennedy and Grubb point out that crucial to the interpretation of this provision is the meaning of '*if born*'. As they state,

> Does this mean that the abnormalities must constitute or amount to a handicap *at birth* or will it suffice that a latent condition exists at birth which will, *or may*, manifest itself later in life? And, if the latter, must it manifest itself during *childhood* since section 1(1)(d) refers to the 'child' suffering serious handicap?[186]

Their answer is that the provision is open to an interpretation which *does* permit abortion *even if* the indication is only one of a likelihood of future, adult illness[187]. Their point is that there is nothing in the provision which requires that the child must suffer handicap at the time that it is born. This they conclude means that the provision can be interpreted to cover a situation where disease manifests itself later, for example - Tays Sachs disease. They continue that if one accepts that, then '[a]lthough it is more difficult to interpret the section as covering th[e] situation [of adult onset], once it is accepted that the handicap need not manifest itself at birth, it would seem to undermine the purpose of the provision narrowly to restrict it to childhood.'[188] Moreover, they note that what constitutes a '*substantial risk*' of disease is very

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[185] *ibid*, at 297.

[186] *ibid*, at 877.

[187] *id*.

[188] *id*.

subjective and therefore open to wide interpretation. Indeed, we have already witnessed the attitude in some quarters of the medical profession towards ante-natal testing for Huntington's disease: the 'Edinburgh experience' demonstrates that section 1(1)(d) is in practice interpreted to justify abortion in the case of late onset diseases.

A positive ante-natal test for ischaemic heart disease differs from a positive result for Huntington's disease only in one respect: the likelihood of onset is more uncertain. Yet, given the heavy reliance on the subjective interpretation by the medical profession, it is not beyond the bounds of possibility that this too could be the basis of a 'lawful' abortion. This is especially true if one sees the rationale of section 1(1)(d) as lying with protecting the woman - as opposed to the fetus - from harm: the likelihood of giving birth to progeny that might develop disease is certainly potentially harmful.

What the above proves is simply that the provisions of the Abortion Act 1967 (as amended) could be extended to cover a situation where a test for a multifactorial condition shows a predisposition for onset later in life. The question of whether this is ethically acceptable is another matter.

For example, Post has argued in the context of Huntington's disease that to test for this condition pre-natally is ethically abhorrent[189]. It is argued, *inter alia*, that to deny a person years of asymptomatic life by preferring death to life is an abuse of the limits of the abortion decision. Along similar lines, Lippman has argued that to offer a range of genetic ante-natal tests and to label a fetus as 'malformed' is to fail to appreciate that it might be society which is 'malformed' in being unable to 'accommodate the disabled in

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[189] Post, S.G.; 'Huntington's Disease : Prenatal Screening for Late Onset Disease', 18, *Journal of Medical Ethics*, 75, 1992.

its midst'[190]. This latter point is a very important one. Although it might be possible to 'legalise' the abortion of countless fetuses by wide interpretation of the provisions of abortion legislation and by offering a wide range of ante-natal genetic tests, it should not go unquestioned what the motivation for such testing actually is nor should one imagine that a woman's 'choice' of abortion is necessarily an unfettered one. This point has already been made above. It is equally valid here. To offer ante-natal testing for multifactorial and/or late onset disorders such as ischaemic heart disease by its very nature encourages abortion. As the Science and Technology Committee noted,

> ...providing a pre-natal screening test for a genetic defect, in the absence of any treatment for that defect, gives a signal that many people, at least, may consider the condition so serious it justifies termination of a pregnancy. If that is not the case, offering pre-natal screening is a waste of resources.[191]

The conclusion of the Committee was that,

> The objection to termination for late onset disorders may be so great that it outweighs the desire of parents to spare their child eventual suffering. There should be some mechanism whereby such matters can be discussed.[192]

Finally, regarding the acceptability of post-natal testing for ischaemic heart disease, most of the arguments made above concerning Huntington's Disease and Duchenne's Muscular Dystrophy apply equally here. Even if the condition is multifactorial and there therefore exists a possibility of avoiding the onset of disease by changing other

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[190] Lippman, A.; 'Prenatal Genetic Testing and Screening : Constructing Needs and Reinforcing Inequalities', in Clarke, A., (ed.); 'Genetic Counselling : Practice and Principles', *op. cit.*, chapter seven, at 160. See also, Schubert-Lehnhardt, V.; 'Selective Abortion after Prenatal Diagnosis', 15, *Medicine and Law*, 75, 1996.

[191] *op. cit.* at 90.

[192] *ibid.*

influential factors such as diet, there is a strong likelihood that knowledge about potential future onset of disease can lead to what has been called 'vulnerable child syndrome'[193]. That is, the parents become over-protective of the child and over-restrictive of the child's activities for fear of 'causing' the onset of disease. Clearly, this can have adverse consequences for both child and parents and interferes significantly with the privacy interests of the former. Yet, post-natal screening for such a condition becomes more acceptable the more one can do to affect the onset of disease. If, for example, it is known that a very low fat diet can reduce the chances of onset by 50% then screening becomes more justifiable. However, if the limit of knowledge is that certain factors such as diet and exercise might have a role to play in disease onset, it becomes more difficult to justify burdening parents and ultimately the child him or herself with such knowledge. Once again, for the child, an appeal to the principle of autonomy affords little in the way of protection: the question of whether or not such knowledge will be sought will be one for the parents who might fail to appreciate the significance of the knowledge and its effects on the lives of all concerned. Thus once again, the principle of autonomy does not do much to help the child protect his spatial privacy interests in such a scenario.

5.3.8. - *State Interests: A Conclusion*

For reasons similar to those advanced in scenario one, a state must offer strong justification to make acceptable a compulsory programme of adult screening. Such a programme necessarily interferes with the autonomy and the spatial privacy interests of adults and if its utility is to be at all doubted, it cannot be justified. In the context of ante and post natal screening, the principle of autonomy is of less use when one is concerned with the spatial and privacy interests of the future persons and newly born

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[193] See, Hoffmann and Wulfsberg, *loc. cit.*, at 334.

children who are the subjects of such programmes. This is so for two reasons. First, in the case of ante-natal screening the 'autonomy' with which we are concerned is likely to be that of the parents of the future person, rather than the future person itself. Second, even when we consider the autonomy of the child[194], the respect which is due is dictated by others in the child's best interests, and it is not certain that the assessment of those interests will adequately take account of the spatial and informational privacy interests which the child has in his/her own genetic information.

5.4. - SCENARIO THREE: A FAMILY'S RIGHT TO KNOW?

In this scenario we are concerned with the role which autonomy might play in resolving conflict between (a) family members who want to know about a relative's genetic information[195], and (b) the individual to whom the information relates who does not want to reveal it. On the one hand we have the autonomy rights of family members to 'choose to know', and on the other we have the question of whether or not the autonomy principle can help to protect the individual's informational privacy interests in not revealing personal information.

5.4.1. - *Scenario Three: The Facts*

It will be remembered that Dr Ian Smith discovers from a colleague that Kenneth, the nephew of Dr Smith's patient Ewan, has recently been diagnosed with haemochromatosis. Because the condition is recessive this means that there is a chance that Ewan and his family might be affected. This is particularly worrying because there

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[194] It is not possible to consider the autonomy of the future person.

[195] Note, we are not concerned in this scenario with the problem of family members who do *not* wish to know genetic information. That is dealt with in scenario four.

is also a history of the condition in the family of Ewan's wife, Elizabeth. The dilemmas which Dr Smith faces are the following:

- What is his obligation, if any, to Kenneth? Should Kenneth be approached and if so, to what extent should Kenneth's response dictate the subsequent acts of the doctor?
- Should he seek to inform Ewan, Elizabeth, Marlene and/or Michael? If so, how should he go about this?
- What about Michael's wife, Michele, who is hoping to become pregnant? Should the doctor, or indeed anyone else who knows, inform her of the family risk?

5.4.2. - *An Autonomy Perspective*

As an autonomous individual Kenneth has the right to control the uses of his genetic information. He also has the right to choose what to do with that information. That is, autonomy can *prima facie* help to protect Kenneth's interests in informational privacy. Thus, his first objection is likely to be to the fact that his doctor has disclosed personal information to Dr Smith without his permission. As will become clear in chapter four, this is technically a breach of confidence, and Kenneth could bring an action against his doctor for damages and an interdict/injunction to prevent further disclosure. Our primary concern here, however, is not with such a scenario, but rather with the dilemma of Dr. Smith who now possesses information which can affect his own patients. Undoubtedly, he will feel a professional ethical obligation to protect his patients, and ethically speaking Dr. Smith has an obligation to avert harm to his patients if this is possible. Certainly, informing the patients of the risks involved might have several health benefits. First, if there is a chance of anyone being affected, then blood transfusions can be commenced as soon as possible to avoid any tissue damage. Second, for those who are carriers, the information might allow them to make informed future choices about reproduction. This is particularly relevant for Michael and Michele who are trying to have a baby. There is, therefore, a strong argument that Kenneth should be approached to disclose the information. Best practice probably dictates that this should be done via Kenneth's own doctor. Ideally, if Kenneth agrees then Dr. Smith can discharge his obligations and maximise the number of informed choices which the family as a unit and as individuals can make. Clearly this has no adverse consequences for Kenneth's privacy or autonomy given that he consents to disclosure. If Kenneth disagrees, however, Dr. Smith must decide whether or not he should nevertheless use the information. From the perspective of autonomy, this dilemma can be viewed as follows. On the one hand, Dr. Smith faces disrespecting Kenneth's wishes and therefore disrespecting him as a person. In turn this involves a direct interference with Kenneth's informational privacy interests. On the other, Dr. Smith faces the problem of possessing information about patients which could avert harm if disclosed. Although the absence of information on the part of the relatives does not, *in se*, affect their capacity to make autonomous choices or to act autonomously (for all life decisions are based on a shortfall of information), Dr. Smith can nevertheless consider that he is in a position whereby he can enhance the autonomy of the relatives by furnishing them with information which will allow them to make informed choices about their lives[196]. Can the principle of respect for autonomy help Dr. Smith resolve this dilemma?[197]

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[196] For an account (and ultimately a rejection) of the sorts of arguments one might offer concerning the 'enhancement of the autonomy of third parties' in just such a context, see Husted, J.; 'Autonomy and a Right Not to Know' in Chadwick, R., Levitt, M. and Shickle, D., (eds.); "The Right to Know and the Right Not to Know', Aldershot, Avebury, 1997, chapter 6.

[197] Chadwick has argued that 'the tension between the autonomous desires of two parties, especially if they are family members, is best resolved by the individuals thenselves. Whilst a geneticist should respect the wishes of their patient to be tested or not, they should encourage their client to consider the implications and implications for others who will be affected.', see Chadwick, R.; 'Introduction' in, Chadwick, Levitt and Shickle, *op. cit.*, chapter one, at 7.

5.4.3. - *Ethics*

In ethical terms, the answer to the question, 'what happens when two autonomies conflict', is that such exercises of autonomy can be restricted if they cause 'harm' to others. In Millian terms, the shift has taken place between self-regarding and other-regarding behaviour[198]. Thus, when a person infected with a highly contagious disease poses a direct and serious threat to others in a community by his or her mere presence, the state feels justified in acting in a manner likely to minimise the threat of infection, even if this means imposing restraints on individual autonomy[199]. The 'good' which is thought to flow from such impositions is also thought to justify the intrusion[200]. Yet, a generally accepted definition of what is a 'good' outcome remains elusive.

For example, Downie *et al* argue that in a liberal democracy health is a value worthy of pursuit *in se*[201]. They posit that an application of the autonomy principle in a health care setting means that patients can only freely make decisions about their own health care if to do so does not harm others in their health. But, as they note, many forms of ill health by their very nature pose risk to others. This, they argue, justifies health legislation which curtails patient autonomy in the interests of others[202]. This has already been noted in chapters one and two, *supra*. However, they argue further that, because the interconnected nature of modern society means that the consequence of

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[198] *supra*.

[199] An obvious example is quarantine.

[200] Jinnet-Sack, *op. cit.*, observes that in the U.S. the State's interest in medical matters has been defined by the courts to encompass four matters: preservation of life, prevention of suicide, protection of third parties, and protection of the integrity of the medical profession. A fifth concern was enunciated by the Nevada Supreme Court in the case of *McKay v Bergstedt* (1990) 801 P2d 617 (Sup. Ct. Nev.): '[the concern] in encouraging the charitable and humane care of those whose lives may be artificially extended under conditions which have the prospect of at least a modicum of quality living.', at 621. *Cf* - *Cruzan v Director, Missouri Department of Health* 760 S.W. 2d. 408 (Sup. Ct. Mo. 1988), aff'd (1990) US, 110, S. Ct. 2841, 111 I. Ed 2d 224.

[201] Downie *et al*, 'Health Promotion: Models and Values', *op. cit.*, at 149 - 152, esp. 152.

[202] *ibid*, at 151.

one individual being unable to perform his or her social duties is either that others will be inconvenienced and/or harmed, or that someone else will have to perform the duties on his or her behalf, the ill-health of one individual can have a deleterious effect on the autonomy of others. This then, they submit, is the basis for arguing that we all have a *moral duty* to others to maintain our own health[203].

By extension, such a view would dictate that in our scenario Kenneth has a moral duty to share the information with his family members. The unique circumstances of shared genetic make-up within the family group arguably removes from Kenneth his right to claim unfettered control over his genetic information. Dr. Smith would then have an ethical basis for justifying disclosure of the information to Ewan and his immediate family. If, however, Kenneth refuses, can anything be done in law?

5.4.4. - *Law*

From the legal perspective little help is at hand for Dr. Smith. As we have seen, the question of conflict has only been dealt with by the courts in the context of forced caesarean section cases, and the Court of Appeal has recently confirmed that the preference is to be given to the wishes of the competent pregnant woman[204]. Of course, one would be correct to argue that such cases do not, in any event, represent an example of a conflict between two autonomies because the fetus is not an autonomous individual until born alive. The question therefore arises whether the courts would act differently faced with the present scenario which does involve a potential of harm to others and a conflict of autonomies? The uniqueness of the familial relationship demonstrates how the conduct of one person can adversely affect the lives of others.

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[203] *ibid*, at 151 - 152.

[204] *In re M.B.*, *supra cit.*

Given this, would a court be justified in intervening to prevent harm through unacceptable exercises of choice? This need be no more than a declaration stating that a particular course of conduct was lawful, such as informing family members of genetic information. Certainly, an argument along these lines could be made, but it is unfortunate that the courts give us no guidance on how such an argument might proceed or what, if anything, would be the relevant factors for a court.

Harm certainly, or rather the avoidance of harm, is a crucial factor. Yet, as always with genetic information one must bear in mind the caveat that test results carry limited certainty and should be regarded with caution as to their predictive value. With a condition such as haemochromatosis, or any other recessive disorder, the chances of family members being carriers or affected are quite clear and also high. The same is also true of dominant disorders. However, the picture is very different with multifactorial conditions, and one must always be alert to the risk of false positive and false negative results.

The nature of one's interference with an individual's autonomy and the likelihood of a 'successful' outcome from that interference must also be relevant factors. For Dr. Smith, there are three possible 'successful' outcomes. First, the avoidance of harm to Ewan's family. To achieve this the proposed course of conduct is disclosure of the family risk despite Kenneth's wish not to have the information divulged. What guarantee does Dr Smith have, however, that this will best achieve his ends? No cure is available for the condition and therefore harm cannot be avoided incontrovertibly, although treatment is available for those affected. This could be commenced early and minimise the risk of fibrosis, but it requires the individuals in question to take responsibility for themselves once furnished with the information in question. That is, in order to avoid harm the relatives must 'choose' to do something positive with the knowledge. Dr. Smith has no guarantee of this.

Second, the aim in disclosing the information to those who are carriers can further their autonomy by facilitating future choices. However, as Ngwena and Chadwick have said,

> [i]t is not clear...why choice in this area should be given higher priority than choice over the use of personal information...[and] it is not clear that harm to <u>choice</u> itself is sufficiently serious to warrant disclosure.[205]

Third, it should not be overlooked that Dr. Smith might decide to disclose the knowledge of Kenneth's status simply to respect the other family members as autonomous choosers, as opposed to disclosure to avoid harm. Such individuals have a strong claim to the information simply by virtue of the fact that in part it relates to them. Although Dr. Smith might not know the particular views of the relatives as to whether they would wish to know or not know such information, he might decide that it is in their best interests at least to be offered the information. Is it acceptable that he do so? From a legal perspective, once again, there is little guidance apart from the now defunct *Re S* which would suggest that there is a need to identify some harm to be avoided[206]. This is not the motivation of the health care professional in these circumstances. It is simply to offer the relatives information about themselves. Ethically, the principle of beneficence might support disclosure but it is difficult to reconcile this with the consequent disrespect for Kenneth's autonomy and privacy.

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[205] Ngwena and Chadwick, '<u>Genetic Diagnostic Information and the Duty of Confidentiality : Ethics and Law</u>', 1, *Medical Law International*, 73, 1993, at 86.

[206] *supra cit.*

In this scenario the dilemma faced by Dr. Smith is that he can facilitate many choices by revealing the genetic information of Kenneth. For, not only can he facilitate the choice of Michael and Michele in reproducing, but he can facilitate the 'choice' of other relatives to know whether or not they are at risk and thereby he can facilitate the 'choice' whether or not to seek further information by being tested themselves and/or seeking treatment. If he were able to establish that the relatives did want to know the information, their 'choice' to know would import a strong imperative to respect that choice, irrespective of the outcome which may ensue for those self-same individuals[207]. Unfortunately, Dr. Smith cannot simply ask the relatives if they would wish to know without interfering both with Kenneth's autonomy and his privacy.

Can an autonomy model resolve the conflict? Arguably, in such a scenario one could assert that it is the autonomy of Kenneth which deserves most respect. This could be so for several reasons. For example, Kenneth is the proband and as such is the autonomous chooser who has sought the information. His connection with the information is greater by virtue of this fact and the fact that the information is specifically about *his* genetic make-up. The claim of relatives is based on their connection with that information through common heritage but knowledge of a relative's genetic constitution is no replacement for knowledge of one's own. The autonomy of the proband can easily be respected by maintaining security of the information. Respect for the autonomy of relatives and avoidance of harm to them cannot be guaranteed by such a course of action. In such circumstances, the balance should perhaps be tipped in favour of the original chooser. If this approach is prefered then the inference is that Kenneth's informational privacy interests will also be protected.

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[207] This would be entirely in keeping with the decisions in *Re T*, and *Re M.B.*, *supra cit.*

However, consider this passage from Ngwena and Chadwick from a discussion of the role of confidentiality and genetic information,

> ...what has to be taken into account is the fact that respecting the autonomy of one person may have implications for the autonomy of others. As the Royal College of Physicians argue, "Blood relatives have an interest in knowing the truth which has nothing to do with influencing their behaviour towards affected individuals in their families, but as a necessary means to finding out the truth about themselves"...How is the choice between the autonomy of different people made?...What is clear is that the decision cannot be taken *on autonomy grounds*.[208]

This suggests that the inherent conflict which can arise in such a situation is irresolvable if one appeals simply to the principle of autonomy. Stalemate is reached and the concept ceases to have a meaningful or useful role. Thus, although we might argue that we should prefer Kenneth's autonomy (and privacy) over his relatives interests in furthering their own autonomy, it is not really possible to argue this conclusively simply by an appeal to autonomy alone. Other factors such as confidentiality and privacy *in se* and their potential role in helping to break stalemate will be discussed *infra*.

5.4.5. - *A Family's Right to Know: A Conclusion*

It is submitted that Dr. Smith owes a general obligation of respect to Kenneth as an autonomous individual in society. An argument can be made that Kenneth should be

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[208] See, Ngwena and Chadwick; 'Genetic Diagnostic Information and the Duty of Confidentiality: Ethics and Law', *loc. cit.*, at 77. This point is also made by Chadwick in 'The Philosophy of the Right to Know and the Right Not to Know' in Chadwick, Levitt, and Shickle, *op. cit.*, chapter one, at 15.

approached, perhaps through the medium of his own doctor, and an attempt should be made to persuade him to reveal his knowledge to family members. Should he refuse to do so, Dr. Smith could invoke the ethical principle of non-maleficence to justify contacting Ewan, Elizabeth, Marlene and Michael directly because of the availability of treatment for the condition. However, it is less clear that he would be justified in contacting Michael and Michele to further their reproductive autonomy. Even less obvious is the acceptability of offering information to relatives simply to further their autonomy where the motivation is not or cannot be the avoidance of harm, for example, if no cure or treatment is available for the condition in question. Importantly, it would seem that conflict between autonomies cannot be resolved simply by reference to the principle of autonomy itself.

This offers us a hierarchy of issues to balance against the autonomy of Kenneth, which if respected protects his informational privacy interests. First, if harm can be avoided by treatment then disclosure can be justified. Second, if that harm is simply harm to choice disclosure is less justified. Third, if disclosure is contemplated simply to further the autonomy of others generally, we face difficulties in resolving this solely through an autonomy model.

In practical terms Dr. Smith could best follow this guidance in the following manner: if those who can be treated deserve to know, his first task is to identify such individuals. In Ewan's family the starting point should be Ewan and Elizabeth. If one or both of them is not affected and/or is not a carrier then there is no need to proceed to inform Michael and Marlene since they themselves cannot be affected by disease. The only reason to inform them might be if they could be carriers but this, as has been argued, is less justified given that the perceived harm is simply one to 'choice'. In like manner, Michele cannot herself be affected by disease and the potential harm to her reproductive choice by not informing her of the family history is arguably not a justification for disrespecting Kenneth and invading his informational privacy interests.

5.5. - SCENARIO FOUR: A RIGHT NOT TO KNOW?

Scenario three considers the informational privacy interests of an individual in keeping secure from family members personal genetic information. The entire discussion proceeds on the assumption that the family members in question desire to know the information of their relative. Of course, this might not necessarily be the case and we must consider the possibility that members in a family unit might prefer *not* to know familial genetic information. Scenario four considers this question in the context of a problem concerning the breast cancer gene BRCA1. Everything that is said here, however, is equally applicable to a claim in other family contexts (such as that of scenario three) where family members might not want to know. Another contrast with scenario three concerns the nature of the privacy interest under discussion. Here it is the spatial privacy interest of individuals in not being given unsolicited information. Finally, as with all of the scenarios in this chapter, we shall examine the problem from the perspective of autonomy, and in particular we shall consider the extent to which the principle can afford adequate protection to spatial privacy interests.

5.5.1. - *The Facts of Scenario Four*

To recap briefly: Nicola is aware of a history of breast cancer in her family. After her own diagnosis of breast cancer linked to the BRCA1 gene she faces the following dilemma:

- Should she approach her sister Nadia and her cousins Norma, Romana and Elvira with the news of her own disease and urge them to seek medical advice? She is aware that Nadia is phobic about operations and that Elvira is prone to bouts of depression. She is also aware that for those who run an increased risk a mastectomy is the preferred clinical treatment.

5.5.2. - *An Autonomy Perspective*

The question to be considered here is that of the validity of a claim *not* to know genetic information. The arguments concerning a claim *to* know the information would be the same as those advanced in scenario three, and in the context of this particular scenario these would be affected principally by two factors: one, the gene for BRCA1 has been discovered and direct testing is now available, making a claim to have access to a relative's test results less valid; two, BRCA1 is only one factor in the development of breast cancer, making the predictive nature of a relative's test results less certain and thereby giving less weight to an argument for access by relatives.

It has already been argued that autonomy makes an uneasy basis for a claim not to know information, and therefore is dubious as a basis for adequate protection of spatial privacy interests. The principle of autonomy requires informed choice based on knowledge. Axiomatically, the foundation for a claim *not* to know sits awkwardly within the framework of autonomy. The only way in which one can be sure of whether or not an individual might want to know information is to determine his or her views, but this in itself can cause harm by alerting the individual to the fact that something might be wrong. Even if an individual has offered a 'blanket refusal' of genetic information, it might be argued that this is not a valid exercise of autonomy since the choice not to know was made in ignorance of relevant factors, such as the 'benefits' of low risk results or 'treatment'.

In the absence of any views about her relatives wishes, Nicola must determine whether to approach her relatives. What guidance is offered by ethics and law?

5.5.3. - *Ethics*

Ethically, because no views have been expressed by the relatives the principle of autonomy is of no help. Unfortunately, the principle of non-maleficence and beneficence are also unhelpful because of the nature of the condition and the circumstances of the family. These principles require that harm should be avoided and benefit conferred wherever possible. It is not clear, however, whether this could be achieved by Nicola disclosing information about her condition and the risk to relatives. As has been argued *supra*, harm can result from the mere fact of disclosure and the personal circumstances of both Nadia and Elvira would tend to indicate that psychological trauma is probable. Also, it is important to consider the nature of the treatment which is offered. Mastectomy is a very traumatic and potentially devastating operation for a woman to undergo. The sequelae can include altered perception of self-image and feelings of loss of identity. The preference for some women might be not to have the operation. This is likely to be particularly true of Nadia who is phobic about surgery. These factors mean that Nicola should consider very seriously whether or not to disclose the information. On an ethical basis the women might found their claim not to know genetic information on the principle of non-maleficence.

5.5.4. - *Law*

Once again the law in the United Kingdom provides little guidance for such a dilemma. If no individual views are available, an option for Nicola is to treat her relatives as *incapax*. The basis of her decision then becomes *her* interpretation of *their* best interests. The relevant factors to consider are the same as those outlined above. Should disclosure be forthcoming, however, and harm result, there is no existing legal remedy which would entitle any person so harmed to claim a breach of an interest not to know[209].

5.5.5. - *Autonomy and the Right not to Know*

Jorgen Husted has argued that one *can* base a right not to know in the principle of autonomy, provided that one adopts a 'thick conception' of autonomy[210]. By this he means a view of the autonomous individual as one who takes direct responsibility for his/her life, and for the decisions which form and shape that life[211]. Central to this conception is the idea of "self-definition": 'what makes a life *ours* is that it is fashioned by our choices, is selected from alternatives by a human being taking his or her life seriously and wanting to be, and be recognised as by others as [sic], the kind of person who makes decisions and accepts the responsibility for them.'[212]

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[209] If one accepts that this is a privacy issue, then an argument might be put that the common law of Scotland could protect such a 'privacy' issue invoking the *actio injuriarum*. However, this action is by no means established in Scots law. This is discussed in chapter six, *infra*.

[210] See Husted, 'Autonomy and a Right Not to Know', in Chadwick *et al.*, *op. cit.*

[211] He contrasts this with the 'thin conception' of autonomy which 'aims to explain the autonomous person and the autonomous life by way of explaining the kind of choice characteristically made by the former and defining the latter, *viz.* the autonomous individual choice.', *ibid.*, at 59.

[212] *ibid.*, at 61 - 62.

Husted argues that the imposition of unwarranted information is an autonomy issue because choices and decisions must now be taken in the knowledge of information never previously requested, and thereby the individual loses the ability to direct his/her life as s/he might otherwise have wished[213]. To the present writer this argument is not entirely convincing because it requires us to adopt a view of autonomy which is unrealistic - a view which requires us to say that informed choice is not autonomous choice. Consider this passage,

> ...in many cases [of unsolicited information] what were initially very valuable options for the person to choose (for one set of reasons) or not to choose (for a different set of reasons) were being closed down by disclosure. Of course, the option still remained open for the person, but the reason why he or she did not choose it was not that another one was considered more valuable. The reason was that she or he could not take the responsibility for choosing it, i.e. choosing it being aware of the genetic warning, because it would be a morally wrong thing to do, e.g. start building a family knowing in advance what kind of suffering this project of one's is bound to create for other people. Where the person concerned was formerly pondering the various options for trying to make something worthwhile out of life, accepting the normal hazards of life, she or he may now be struggling for survival. And as a result of this the history of that person's life may very well not be the history of an autonomous life, a life whose contents, for a significant part, are freely chosen among different and morally valuable alternatives. The history of that person's life might rather come to resemble the life of a person who had to become an electrician in order not to have to murder someone else[214] - a life of morally forced choices[215].

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[213] *ibid.*, at 66.

[214] This example to the person who must choose between becoming and electrician or a murderer is a reference to a discussion which occurs earlier in the chapter concerning Joseph Raz's view of autonomy. Raz opines that autonomous choices must be choices between moral 'goods' and that a choice between good and evil is not an autonomous choice, *ibid*, at 62.

[215] *ibid*, at 66 - 67.

This is a strange view of autonomy for several reasons. First, it is not the case that decisions taken in the light of knowledge (solicited or otherwise) are not autonomous decisions. *All* decisions we take are taken in light of the information and options available to us, and whereas it is correct to say that we may choose differently once exposed to certain knowledge, it is not accurate to imply that choices in light of unasked-for knowledge are somehow not *our* decisions.

Second, it is difficult to see how one can resolve the problem posed by Husted from within an autonomy model. He advocates a view of autonomy which is predicated on 'free' choices, but this seems to suggest that it is entirely possible to make 'free' choices about the direction of one's life. This is simply not accurate, or at least one must accept that 'freedom' in this context is a relative term. No choices are completely unfettered, and few choices are taken in a moral vacuum. And, whereas one's choices can certainly be adversely influenced by pressure from others, it is not clear that there is a significant enough degree of pressure from merely offering people information to warrant the conclusion that this somehow interferes with their autonomy. It does not, in the sense that these persons can still make choices for themselves according to their own values and moral code. The situation would be different if the information was accompanied by a prescribed course of conduct, for example - the offering of an ante-natal test for Huntington's disease on the condition that the pregnancy be terminate if the result is positive[216].

Finally, Husted does not draw any distinction between choices not to know and no choices at all. For, it is accepted that to offer unsolicited information to a person who

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[216] This is the so-called 'Edinburgh experience', *supra* note 166 and text.

has expressed a wish not to know it, is to disrespect the autonomy of that person[217]. In the circumstances spoken of by Husted, however, when there is no previously expressed wish (ie - an exercise of autonomy) in respect of the information, then it is unconvincing to argue that to offer the information is an unwarranted interference with autonomy.

Of course, the general sentiment expressed by Husted is shared by the present writer; namely, that it is unacceptable in many circumstances to give individuals unsolicited genetic information. However, it is argued here that the interference is with the spatial privacy interests of the individuals in question, rather than with their autonomy *per se*. This displays an interesting area of overlap between the two concepts of privacy and autonomy. So far in this chapter we have considered the extent to which autonomy can help to protect privacy interests. Here, it is argued that to attempt to subsume 'privacy interests' under a modified view of autonomy is unacceptable because not only does it distort autonomy, but also it denies a further possibility; namely, that protection for privacy *in se* is preferable. This, of course, is the thesis of this work, and it shall be pursued further in the following chapters.

5.5.6. - *A Right Not to Know: A Conclusion*

It is submitted that the principle of autonomy is particularly unhelpful in addressing the question of a right not to know. If a 'blanket refusal' is made it is submitted that it should be respected, but obviously for such a refusal to be possible some degree of information must be available to the individual who is refusing - for example, a family history or knowledge that test results exist. If there is no such knowledge it is difficult to see how such a refusal can be meaningful. Moreover, choices in such circumstances

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[217] This point has already been made, *supra*.

make a best interests or substituted judgment approach easier and ostensibly at least, more justified. However, in the absence of clearer guidelines from either ethics or law, it is hard to distinguish such an approach from the approach of following the subjective decision of the person with the genetic information. In the case of Nicola and her family, Nicola must weigh the 'benefit' of early discovery of cancer against the concerns of individual relatives such as Nadia and Elvira who might suffer as a result of information disclosure. A very relevant factor is the multifactorial nature of the condition. This means that the reliability of test results from relatives is limited. This affects the utility of disclosure in at least two ways. First, the chances of developing disease are not only more difficult to predict but are also reduced compared to monogenic disorders. The likelihood of multifactorial disease can be as low as a few percent[218]. Second, one can predict with much less certainty the range of relatives likely to be affected by multifactorial genetic disease[219]. To be truly effective disclosure would require to be made to a wide circle of persons with possible diminishing utility[220].

Ethically, an acceptable outcome might be to approach family members with the news of Nicola's own condition and the possibility of diagnosis and treatment for others. Given that the condition in question is potentially fatal and that some form of treatment is available, such an approach not only satisfies the principle of non-maleficence but also seeks to further individual autonomy. This way, individuals can choose whether to proceed with further tests to determine their own status and/or to

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[218] See, Wilson, J.D., Braunwald, E., Isselbacher, K.J., Petersdorf, R.G., Martin, J.B., Fauci, A.S., and Root, R.K.; Principles of Internal Medicine, Twelfth Edition, (McGraw-Hill Inc. 1991), at 30.

[219] *ibid*, '...as the degree of relation becomes more distant, the likelihood of a relative inheriting the same combination of genes becomes less. Moreover, the chances of any relative inheriting the right combination of genes decrease as the number of genes required for the expression of a given trait increases.'

[220] It should be noted, however, that if a high number of close relatives are affected by a severe disorder there is more of a chance that relatives will be affected. That said, the percentage rate remains below or around fifteen percent, *ibid*.

undergo a mastectomy and thereby hopefully avoid fatal consequences. If Nicola *does* decide to disclose the information to her relatives, then unlike scenario number three, there will be no problem about respecting her autonomy since she herself has chosen to disclose personal information. However, it cannot be overlooked that such disclosure might come as a burden to some relatives who might suffer a form of harm as a result and/or for whom the treatment option is not available. If so, even if the initial approach is thought to be ethically justifiable, in law no remedy currently exists to redress such a form of hurt. Importantly, this would tend to indicate that the basis for a claim not to know information cannot be the principle of autonomy.

6.1. - GENETIC INFORMATION AND THE PRINCIPLE OF AUTONOMY: A CONCLUSION

An important consequence of recognising the value of the concept of autonomy is that we recognise a duty to strive wherever possible to accord respect to the wishes of individuals. This in turn has several other consequences. First, in many cases there is a *prima facie* presumption of the existence and value of autonomy and therefore an onus on those who would seek to challenge such a presumption. Second, it means that if there is some way by which to avoid harm to the principle while furthering other ends then that solution should be preferred. That is, compromise is preferable to outright defeat of the principle, which is seen to have inherent value.

However, we can also see that in the legal context several restrictions are placed on individual autonomy in the health care setting. That limits must be imposed is not problematic, but the arbitrariness with which the courts have imposed restrictions has far reaching consequences for patient autonomy. The scope of the restrictions is unclear, the possibility of future restrictions is very real and the implications for individual autonomy are not always fully considered by the courts[221]. Similarly, from the ethical perspective there is little agreement about the relative weight which one should accord to the principle of autonomy relative to other principles. Furthermore, ethics is most unhelpful in assisting to determine particular outcomes in particular cases. Yet, from both the ethical and legal perspective it might be said that the potential for harm to others, in the main, 'trumps' the autonomy of patients in the health care setting, reducing considerably the value of the latter in real terms. Furthermore, it is important to note that it is not only when faced with the threat of harm to others that one can restrict autonomy. If an individual fails to 'qualify' as autonomous, then other measures are employed to deal with that person. Most notably, paternalistic approaches can be adopted and reference is made to the concept of 'best interests'. Yet once again the precise nature of how such interests are to be determined is not clear from either the discipline of ethics or the pronouncements of the UK courts. Rather, authority in this sphere is placed at the feet of the medical profession which exercises considerable discretion in dealing with patients.

More particularly, it is not at all clear that an appeal to the principle of autonomy will help to protect the interests of individuals who have been tested for genetic conditions nor that it will assist in resolving satisfactorily conflicts which might arise over familial genetic information. This is so for several reasons.

First, it is arguable that the principle of autonomy has received short shrift because it lacks a precise and clear definition. This is certainly true of ethics and, from the legal perspective no law has been passed in the United Kingdom which defines the essence of autonomy or its limits. This task is left to the courts. Yet, faced with emotive appeals which often involve matters of life and death, the courts have been quick to

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[221] An extreme example of this is *Tameside and Glossop Acute Services Trust v CH (a patient), supra cit.*

favour the opinions of the medical profession and/or to take decisions which avoid any prospect of harm, rather than to prefer the principle of autonomy. In this way the principle of respect for autonomy is whittled away by default. The result is that the concept of autonomy is ill-equipped to protect the individual interests which stem from 'new' problems such as those which arise from genetic information.

A second problem concerns the inherent nature of the concept of autonomy. It has already been established that autonomy is concerned with choice and the ability to choose. In order to choose meaningfully one must be sufficiently informed about the subject matter of one's choice. That is self evident. However, as has been discussed *supra*, one of the issues which arises from genetic information is the question of a right *not* to know one's genetic constitution. That is, can one ever claim the right not to be forced to know about a predisposition to a genetic condition? It is submitted that to argue for such a 'right' one cannot make an appeal to the concept of autonomy because autonomy requires choice which requires information. Yet in these circumstances, to inform the person of their predisposition in order to ascertain whether they want to know of any risk, is to defeat the purpose of the right not to know. Although one could argue that it is an exercise of one's autonomy to state simply that one does not wish to know of any predisposition, this is problematic from the competence aspect of autonomy: how can one be sure that one does not wish to know about something of which one knows nothing? Arguably, some other basis for such a right is required. Chapter four will consider the role of confidentiality in addressing the issues so far raised concerning genetic information.

CHAPTER FOUR

CONFIDENTIALITY
AND
GENETIC INFORMATION

1.1. - INTRODUCTION

This chapter will consider the legal, ethical and professional basis for the duty of confidentiality which is owed by health care professionals to patients in the United Kingdom. The relevance of confidentiality to the present discussion arises because in the health care context concerns about the use or abuse of personal health information have traditionally been addressed through the concept of confidentiality. Following the format of previous chapters, the chapter will conclude with a consideration of the role of confidentiality in resolving the problems and conflicts surrounding genetic information which were identified in chapter two.

2.1. - THE NATURE OF THE DUTY OF CONFIDENTIALITY

Confidentiality is concerned with security of information. To be precise, it is concerned with the security of *confidential* information. To be confidential, information must be in a state of limited access from individuals and institutions generally. Confidentiality is therefore characterised by a relationship involving two or more individuals one or more of whom has/have undertaken, explicitly or implicitly, not to reveal information concerning the other individual in the relationship[1]. Most particularly, it is accepted universally (and almost unquestionably) that health care professionals owe a duty of confidence to their patients and that only exceptionally should disclosure without consent be made[2]. Although exceptions to the duty exist, in practice no breach is made lightly or

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[1] Information which is in the public domain cannot be confidential and therefore cannot be protected by confidentiality. Similarly, once information moves from the private sphere where it is confidential to the public sphere, it loses the necessary quality of confidence.

[2] Ngwena, C. and Chadwick, R.; 'Genetic Diagnostic Information and the Duty of Confidentiality: Ethics and Law', 1, *Medical Law International*, 73, 1993, at 74, state that '[c]onfidentiality has been elevated to the status of a principle of Medical Ethics'.

without good cause[3]. Legal, ethical and professional justifications are advanced for this.

2.2. - THE BASIS OF THE DUTY OF CONFIDENTIALITY

2.2.1. - *The Professional Duty of Confidentiality*

The General Medical Council (GMC) is the governing body of the medical profession in the United Kingdom[4]. *Inter alia,* it has the responsibility of keeping the register of those professionals who are fit to practise[5], of disciplining those who are not[6], and generally of maintaining professional medical standards[7]. In October 1995 the GMC issued *Duties of a Doctor* - guidance to clinicians on the views of the GMC as to acceptable medical standards and the levels of care which patients are entitled to expect from British doctors[8]. The guidance comprises four booklets concerning the following matters: 'Good Medical Practice', 'Advertising', 'HIV and AIDS: The Ethical Considerations' and 'Confidentiality'. The importance of the information contained therein is two-fold : first, it provides patients with an account of their rights when dealing with health care professionals. Second, it establishes a minimum standard of care expected from those professionals which, in turn, implies that behaviour which falls below such a standard leads to questions of professional competence and possible disciplinary action. Of direct relevance to this work are the contents of the booklet on 'Confidentiality'.

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[3] See, *W v Egdell* [1990] 1 All E.R 835 per Bingham LJ at 851, '[o]nly the most compelling circumstances could justify a doctor in acting in a way which would injure the immediate interests of his patient, as the patient perceives them, without his consent.'

[4] See, the Medical Act 1983 as amended by the Medical (Professional Performance) Act 1995.

[5] *ibid*, s.2 and ss.30 - 34, as amended, see schedule to 1995 Act.

[6] *ibid*, ss 36 - 40, as amended.

[7] *ibid*, s.35, as amended.

[8] This replaces the so-called 'Blue Book', officially known as 'Professional Conduct and Discipline : Fitness to Practise', last produced in December 1993. Although this guidance does not have statutory authority, as has been stated : 'the General Medical Council in exercising its disciplinary jurisdiction does so in pursuance of the provisions of the Medical Act 1983', in *W v Egdell, supra cit.*, at 843f. Note, too, that guidance is also offered by the Department of Health, see, for example, 'Confidentiality, Use and Disclosure of Personal Health Information', Department of Health, 1994.

The GMC outlines several 'principles' which form the basis of its guidance on confidentiality[9]. As it states,

> Patients have a right to expect that you will not disclose any personal information which you learn during the course of your professional duties, unless they give permission. Without assurances about confidentiality patients may be reluctant to give doctors the information they need in order to provide good care.[10]

This displays two reasons for protecting patient confidences. In the first place, the intimate connection between the patient and his or her personal information gives the patient the right to control what happens to that information: this can be seen as a form of autonomy argument such as that advanced in chapter three. In the second place, there is the important social or public interest in ensuring that patients trust medical professionals which is thought to be best advanced by guaranteeing security of confidential information.

The guidance goes on to specify the nature of the duties which are encompassed by confidentiality. These extend to the following: the duty to ensure that confidential information is effectively protected against improper disclosure; the duty to ensure that when patient consent is given for disclosure patients are fully informed of the nature and consequences of their choice; if information is to be disclosed to other health care professionals then patients should be informed of this and given the opportunity to withhold permission; requests that information not be disclosed to third parties must be respected save in exceptional circumstances (see *infra*); information should be released only to the extent necessary for the particular purpose; all professionals are under a duty to ensure that other health workers to

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[9] GMC, 'Duties of a Doctor', London, GMC, October 1995, 'Confidentiality', paragraph 1.
[10] *ibid.*

whom information is disclosed understand that the duty of confidence exists and that it must be respected; and, importantly, professionals must understand that if they decide to disclose confidential information, they must be prepared to explain and justify their decision[11].

This final provision makes it clear that the *prima facie* obligation is to respect patient confidences as something of value. Failure to do so places a professional burden of the health worker to justify his or her conduct. Thus, in this way, confidentiality is seen as a professional obligation, the sanction for breach of which can be disciplinary action[12].

It should not be thought, however, that in the eyes of the GMC the duty of confidentiality which health care professionals owe to patients is an absolute one. The guidance goes on to outline the exceptions to the duty. For example, where disclosure of relevant information between health care professionals is essential to the treatment of a patient, and the patient has agreed to that treatment, then it is not necessary in each and every instance to seek patient consent[13]. Similarly, if because of an emergency the patient's consent cannot be obtained and information must be transferred to health workers, this can be done provided that it is in the patient's interests[14]. It is also stated that disclosure of patient information can be

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[11] *id.*

[12] In the past discipline of doctors has been carried out by the Professional Conduct Committee which ultimately has five methods of disposal of any disciplinary case : it can dismiss the case it can postpone determination of the outcome, it can impose conditions on registration (for example, that the doctor seeks help for alcohol abuse problems), it can suspend the clinician for up to a year, or it can remove his or her name from the register. The Medical (Professional Performance) Act 1995 modifies the procedures somewhat in that it creates two additional GMC committees : the Assessment Referral Committee and the Committee on Professional Performance. Both of these committees allow the GMC to do what it has not been able to do in the past; namely, to deal effectively with incompetent or unfit professionals who represent a danger to the public. The remit of the PCC has only ever been concerned with criminal offences, serious professional misconduct or impairment of health so as to render the professional unfit to perform his/her duties. This left much behaviour unregulated and did not give the GMC the power to assess and control the competency of its professionals. The two new committees now allow it to do so.

[13] 'Confidentiality', *op. cit.*, paragraph 5.

[14] *ibid*, paragraph 6. An example of where disclosure would not necessarily be acceptable concerns HIV infection. Imagine that an unconscious patient is brought into hospital bleeding and the staff

justified if it is in the patient's medical interests to do so[15]. For example, if the patient is incapable of giving consent because of immaturity or incapacity then the GMC advises that disclosure of necessary information to an appropriate person or authority is justified[16]. Interestingly, this includes circumstances where the health care professional believes that to seek consent from a patient would be damaging to the patient, but that disclosure to another could be in the patient's medical interests. The example given is where the professional determines that it would be in a patient's interests that a close relative should know about the patient's terminal condition, but that the patient would be seriously harmed by the information. In such cases it is the view of the GMC that information may be disclosed without consent[17].

Disclosure for medical teaching, medical research and medical audit are all thought to be acceptable by the GMC provided that patient consent is sought, or if this is not possible then the information must be anonymised. In research cases, where consent cannot be obtained, the proposed action should be brought to the attention of a research ethics committee for approval[18].

Disclosure required by law is an obvious exception to the duty of confidentiality and this is sanctioned by the GMC[19]. A clear example is notifiable diseases[20]. However, it is interesting to note that 'in the absence of a court order, a request for

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wishes to know his or her HIV status in order to determine whether they should take precautions. In such a case arguably the disclosure of the information is not in the interests of the patient but in the interests of others and is therefore not authorised by this provision. Of course, it might be argued that the information is necessary in order to avoid harm to third parties, but if the only thing that can ultimately be done is to take precautions then it is not clear why such precautions cannot be taken in the first place thereby obviating the need to breach patient confidentiality.

[15] *ibid*, paragraph 10.

[16] *ibid*, paragraphs 10 - 12.

[17] *ibid*, paragraph 12.

[18] *ibid*, paragraphs 15 - 17.

[19] *ibid*, paragraphs 20 - 23.

[20] Discussed in chapters one and two, *supra*.

disclosure by a third party, for example, a solicitor, police officer, or officer of the court, is not sufficient justification for disclosure without a patient's consent'[21].

Finally, the most complicated exception to the duty of confidentiality concerns disclosure in the interests of others. The GMC explains thus,

> Disclosures may be necessary in the public interest where a failure to disclose information may expose the patient, or others, to risk of death or serious harm. In such circumstances you should disclose promptly to an appropriate person or authority.[22]

Only three examples of this exception are given by the Council. 1) a patient who continues to drive when unfit to do so. The advice is to inform the Driver and Vehicle Licensing Agency. 2) a colleague and patient who places others at risk by continuing to practise medicine while ill. The advice is offered in the booklet 'HIV and AIDS: The Ethical Considerations' which recommends that those professionals who are ill should seek specialist advice on the extent to which they should limit their practice. For professionals who have an ill patient who is a doctor, the advice is to inform the appropriate regulatory body[23]. 3) Disclosure is necessary for the prevention or detection of serious crime.

2.2.2. - *The Professional Duty of Confidentiality: Conclusion*

The basis for the professional duty to respect patient confidences is the guidance of the medical profession's governing body, the General Medical Council. The Council in turn seems to base its advice on two values : a) patient autonomy (the right to choose what happens to personal information) and, b) what might be

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[21] *ibid*, paragraph 21.

[22] *ibid*, paragraph 18.

[23] GMC, 'Duties of a Doctor', London, GMC, October 1995, 'HIV and AIDS : The Ethical Considerations', paragraphs 8 - 9.

termed the public interest in maintaining trust in the doctor/patient relationship. This is public in the sense that if ill people are dissuaded from seeking treatment this has serious implications not just for the individuals concerned but for others as well. Moreover, it signals the demise of the social institution of medicine as we currently know it. However, there are extensive exceptions to the duty which cover a wide range of situations. This substantially weakens the right of the patient. Arguably, this is further compounded by the vague nature of some of the exceptions and the superficial advice of the GMC. This is particularly true of the 'public interest' exception which concerns the avoidance of harm to others. The terminology employed is vague: there must be a risk of 'death' or 'serious harm' (what is 'serious'?) and this must be linked to failure to disclose information, implying that there must be a likelihood that harm will be averted by disclosure. The opportunity to avert harm might not, however, be within the powers of the medical professional. This is especially true of the extremely vague example of 'disclosure for the prevention or detection of serious crime' (again, what is 'serious'?). In practical terms, this guidance places considerable onus on the health care professional to determine for him or herself the limits of the duty which s/he owes to patients.

2.2.3. - *Ethics and Confidentiality*

Although confidentiality does not form one of the core principles of ethics which were discussed in chapters two and three, for many the concept has nevertheless '...been elevated to the status of a principle of Medical Ethics'[24].

Ethical justifications for the duty of confidentiality are found in principles considered to be fundamental to our social value system. These appeal both to

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[24] See, Ngwena, C. and Chadwick, R.; 'Genetic Diagnostic Information and the Duty of Confidentiality : Ethics and Law', *op. cit.*, at 74.

public and private interests in security of personal information. For example, Ngwena and Chadwick argue cogently that justifications for protecting confidences are found both in the principle of utility and the principle of autonomy[25]. They contend that considerable utility can flow from respecting confidentiality since this can protect individuals from harm. Discrimination and stigmatisation can result from disclosure of sensitive personal information of any kind, and this is certainly true of genetic information. This point has been argued in chapter one. In addition, to keep confidences fosters trust in the health care relationship generally which can only be seen as a 'good thing'[26]. By the same token, and as has already been argued in previous chapters, adherence to an autonomy model of health care requires respect not only of individual patients *per se* but also of their interests, including interests in personal information. To protect confidentiality is, therefore, to respect the individual.

Raanan Gillon endorses this view. As he has stated,

> [The principle of autonomy] requires us to consult people and obtain their agreement before we do things to them. As an individual we do not have any general obligation to keep other people's secrets, but health care workers explicitly or implicitly, promise their patients and clients that they will keep confidential, the information confided to them. In other words, medical confidentiality is another implication of respecting people's autonomy. Without such promises of confidentiality, patients are far less likely to divulge the often highly private and sensitive information that is needed for their optimal care; thus maintaining confidentiality not only respects patients' autonomy but also increases the likelihood of our being able to help them.[27]

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[25] *ibid*, at 74 - 79.

[26] *ibid*, at 75.

[27] Gillon, R.; 'Medical Ethics : Four Principles Plus Attention to Scope', 309, *British Medical Journal*, 184, 1994, at 185.

2.2.4. - *Ethics and Confidentiality: A Conclusion*

It can be seen that these justifications are in essence the same as those used by the General Medical Council as the basis of its guidance. This is surely no coincidence. An appeal to principles such as autonomy and utility is important because it provides strong justification for protecting personal health information through the concept of confidentiality. It imbues confidentiality with a value of its own for the interests which it serves and protects. This sets up the concept as being of *prima facie* value and worthy of respect, in much the same way as the principle of autonomy. Yet, as has been shown in chapter three, ethics is concerned with the balancing of several, at times competing, values. Thus, it is also accurate to state that an ethical perspective on confidentiality, as with the professional perspective, does not permit a view which holds confidentiality out as a supreme value. If to maintain confidentiality risks harm to others the principle of non-maleficence might be invoked to justify not respecting confidentiality. Similarly, if to disclose personal details without the consent of the patient is thought to be in the patients' medical interests reference can be made to the principle of beneficence[28]. In each case the outcome depends on the facts and circumstances and the arguments which are put. Unfortunately, and again this has been noted in chapter three, this makes the value of an appeal to ethics limited and leaves much scope for uncertainty. For the health care professional ethics adds little if anything to the guidance s/he receives from the General Medical Council.

2.2.5. - *Confidentiality and the Law*

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[28] The terminology used here is that of medical ethics, but as was noted in chapter two, the concept of 'ethics' is not homogenous across different disciplines. For example, in many scenarios one would not use the principle of non-maleficence to justify not respecting confidences, but rather 'the public interest', see *infra*.

In law, confidential information is protected by the tortious/delictual action of breach of confidence[29]. This action is by no means restricted to the medical sphere or the protection of personal health information[30]. Indeed, it would appear that almost any form of information can come within an obligation of confidence provided that it has 'the necessary quality of confidence'[31]. Thus trade secrets[32], business practices[33], government data[34] as well as personal information can be confidential. The law in respect of all of these forms of information is the same. Thus medical confidentiality is merely a subset of the wider set of cases which make up the law of confidence generally.

The law of confidence is found in the common law and in the past much dissatisfaction has been expressed about its state. In 1981 and 1984, the English & Welsh and Scottish Law Commissions looked respectively at the law in their jurisdictions[35]. Both Commissions recommended reform of the law, and the English Commission went as far as to recommend a form of statutory protection. There has, however, been no parliamentary intervention subsequent to the release of these reports[36]. That this is so may be because many of the reforms recommended by the Commissions are no longer necessary because of common law developments in this field. In particular, the decision of the House of Lords in

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[29] For an account of the Scottish position see, Stair Memorial Encyclopaedia, 'Breach of Confidence', Volume 18, Part II: Title 10, Butterworths/Law Society of Scotland, 1993. For more 'anglicised' views see, Toulson, R.G. and Phipps, C.M.; 'Confidentiality', London, Sweet & Maxwell, 1996, and Gurry, F.; 'Breach of Confidence', Oxford, Clarendon Press, 1984.

[30] For an historical account of the action of breach of confidence, see Toulson and Phipps, *op. cit.*, chapter I.

[31] See, Megarry J in *Coco v A N Clark (Engineers)* [1969] RPC 41. This does not, however, cover 'trivial tittle tattle', *ibid*, at 48.

[32] See, *Printers and Finishers Ltd. v Holloway* [1965] 1 WLR 1.

[33] See, *Faccenda Chicken v Fowler* [1986] 1 All ER 617; [1987] 1 Ch. 117.

[34] See, *Attorney General v Guardian Newspapers No.2* [1990] 1 AC 109 and *Lord Advocate v Scotsman Publications Ltd.* 1989 SLT 705, HL.

[35] See, Law Commission; 'Breach of Confidence', Law Com. no.110; Cmnd 8388, 1981, and Scottish Law Commission; 'Breach of Confidence', Scot. Law Com. no.90; Cmnd 9385, 1984.

[36] The Scottish Law Commission made the following criticisms of the law : (1) the uncertainty of its extent, especially in relation to third parties; (2) the inadequacy of the structure of remedies; (3) the uncertain balance between private and public interests; (4) the lack of response to improper methods of obtaining information, and (5) the difficulty of protecting information disclosed in litigation: *ibid*, paragraphs 3.1. - 3.5.

Attorney General v Guardian Newspapers No.2 in 1990 clarified considerably the uncertain nature of the law of confidence[37].

2.2.5.1. - *Attorney General v Guardian Newspapers No.2*

Peter Wright was a former MI5 employee who sought to publish his memoirs under the title '*Spycatcher*'. This contained an account of alleged irregularities in MI5, and alleged unlawful activities of its members. Wright could not publish his book in the United Kingdom because of the provisions of the Official Secrets Act 1911, but he did seek to publish the volume in both Australia and the United States. On 22 and 23 June 1986 the 'Observer' and 'The Guardian' newspapers each published in the United Kingdom an article on the UK Government's attempts to prevent Wright publishing in Australia. Included in this was an account of Wright's allegations against MI5. The British Government successfully obtained an injunction preventing the newspapers from disclosing or publishing any information which they knew or had reasonable grounds to believe came from Wright and which concerned information obtained in his capacity as a member of the British Security Services. On 12 July 1987 'The Sunday Times' began to serialise *Spycatcher*. An injunction was sought by the Attorney General but this was rejected at first instance : it was held that although a duty of confidence *was* owed by the newspapers, the Government no longer had an interest in the information in question because it had ceased to be confidential, having been published in at least two other jurisdictions. The Court of Appeal similarly dismissed the appeal of the Attorney General and the cross-appeal by 'The Sunday Times'[38]. Both parties appealed once more to the House of Lords.

The House of Lords held as follows:

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[37] *supra.*

[38] The cross appeal of the newspaper concerned a challenge to the ruling that a duty of confidence was owed at all.

- A confidant who acquires or receives information in circumstances importing a duty of confidence, is bound to maintain the confidentiality of the information in question.
- A third party who acquires or receives information in circumstances in which s/he knows, or ought reasonably to know, that the information is confidential is equally bound by a duty of confidentiality[39].
- In the particular circumstances of this case, the onus was on the Crown to establish that disclosure would damage or had damaged the public interest before relief would be granted[40]. Because publication had already taken place in other jurisdictions, the secrecy of the information had been lost, and therefore no relief could lie.
- Neither the 'Observer' nor 'The Guardian' had been in breach of their duty of confidentiality by publishing the article on 22 and 23 June 1986, but 'The Sunday Times' was in breach of its duty by commencing serialisation and as a result was bound to account for its profits[41].
- Finally, because the information over which the dispute had arisen was now in the public domain, it was no longer and could no longer be confidential. Thus, no further harm could be done to the public interest. This meant that no further injunction could be placed on newspapers preventing them from publishing the contents of the book.

This seminal decision has done much for the law of confidence. It establishes that a general duty of confidentiality can arise whenever one has knowledge of the confidential nature of information or when one ought to have such knowledge given all the circumstances of one's position. That is, there is an objective assessment of the circumstances which can lead to the imposition of an obligation

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[39] For example, at 268E - G.
[40] at 258A - 259H.
[41] at 260A - 264A.

of confidence. Furthermore, the decision goes a long way to settling the question of whether detriment requires to be shown[42]. In the case of the UK Government this was most necessary and its failure to establish this proved to be the downfall of its case. On a more personal level, however, the question arises of what an individual would have to show to show detriment. This is addressed, *inter alia*, by Lord Keith,

> Information about a person's private and personal affairs may be of a nature which shows him up in a favourable light and would by no means expose him to criticism. The anonymous donor of a very large sum to a very worthy cause has his own reasons for wishing to remain anonymous, which are unlikely to be discreditable. He should surely be in a position to restrain disclosure in breach of confidence of his identity in connection with the donation. So I would think that it is sufficient detriment to the confider that information given in confidence is to be disclosed to persons whom he would prefer not to know of it, even though the disclosure would not be harmful to him in any positive way.[43]

This is an extremely important passage. It demonstrates that the law places considerable weight on the protection of individual interests through the medium of this cause of action.

Finally, it should be noted that this decision by the House of Lords paved the way for a harmonisation of the legal position in both England & Wales and Scotland as regards the action of breach of confidence. Shortly after the Spycatcher decision[44], a Scottish version of the case with very similar facts reached the House of Lords.

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[42] Lord Griffiths certainly believes this to be so, at 270D - H, although Lord Goff wished 'to keep open the question whether detriment to the plaintiff is an essential ingredient of an action for breach of confidence.', *ibid*, at 281H, see also comments on 282A - B.

[43] *ibid*, at 256A - C. Note too, in *X v Y*, *infra*, Rose J held that 'the initial disclosure and its immediate consequences, not subsequent publication...found the plaintiff's claim in...breach of confidence' at 658a - b.

[44] Spycatcher was decided on June 14, 15, 16, 20, 22, 23; October 13 1988. *LA v The Scotsman Publications Ltd.* was handed down on 6 July 1989.

2.2.5.2. - *Lord Advocate v The Scotsman Publications Ltd.*[45]

This case concerned Anthony Cavendish, a former employee of MI6 from 1948 to 1953. In 1987 Cavendish sought authorisation to publish a book about his life including information about his time as a member of the British Security Services. This book was entitled *Inside Intelligence.* Authorisation to publish was refused. Nevertheless, Cavendish had published 500 copies of the book, 279 of which he distributed to various private individuals as 'cards' for Christmas 1987. Copies of the book came into the hands of 'The Sunday Times' and 'The Scotsman' newspapers both of which published articles about the book and its contents. In England, the Attorney General was granted an injunction by the High Court of Justice against the Times Newspapers Ltd. restraining it or any other person with notice of the order from publishing any information obtained from Mr Cavendish and concerning the British security or intelligence services. In Scotland, the Lord Advocate brought a petition against the publishers and editor of 'The Scotsman' to prevent 'any person having notice...from disclosing or publishing or causing or permitting to be disclosed or published to any person all or any material or information obtained by Anthony Cavendish in the course of his employment with the British security and intelligence services...'[46] The case proceeded through the courts to the House of Lords[47].

In the course of its judgement the House of Lords confirmed that 'Scots law in this field [is] the same as that of England'[48]. Thus, applying the law as outlined in *Spycatcher*, the court came to the conclusion that the newspaper would indeed be under a duty of confidentiality if it had received confidential information.

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[45] *Lord Advocate v The Scotsman Publications Ltd* 1989 SLT 705 (HL).

[46] *ibid*, at 706.

[47] For comment on the case, see Walker, N.; 'Spycatcher's Scottish Sequel', 1990, *Public Law*, 354.

[48] at 708 - 709, *per* Lord Keith of Kinkel quoting with approval the judges of the Second Division of the Court of Session.

However, this could not be so in the present case because the appellants had conceded that the book did not contain any information damaging to national security. In this way, it was held, the appellant deprived themselves of a basis for their interdict because they had 'not pleaded a good arguable *prima facie* case that further publication by the respondents would do any damage to the public interest'[49].

This is a different conclusion from that reached in *Spycatcher*. In that case (Spycatcher) the appellants had clearly established a duty of confidentiality on the respondents but failed to show detriment because the information was part of the public domain. In the present case, because the contents of the book were innocuous, the respondents came under no duty of confidentiality at all. That is, the information failed to have the necessary quality of confidence. As Lord Keith said,

> It was argued for the appellant that dismissal of this appeal would have the effect that any newspaper which received an unsolicited book of memoirs by a present or former member of the security or intelligence service would be free to publish it. That is not so. If there had been no previous publication at all and no concession that the contents of the book were innocuous the newspaper would undoubtedly itself come under an obligation of confidence and be subject to restraint.[50]

This raises a fundamental question about the basis of the law of confidence in this country. What, exactly, is being protected by the law? If it were simply the wishes of the confider then it should not matter that the information was innocuous. What would be of concern would be the need to respect the confider's wish that the

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[49] *ibid*, at 709 - 710.

[50] *ibid*, at 710.

information not be noised abroad. This is a serious consideration in this area of law for it is not clear what is the true basis of the action of breach of confidence.

3.1. - THE FOUNDATIONAL BASIS OF THE DUTY OF CONFIDENTIALITY

Libling has argued that if one expends time, money and effort in obtaining or creating information, this is a 'valuable entity' in which one has a property right[51]. By extension one could argue that the basis of the action of breach of confidence is a desire to protect the property interest in the information. Yet, a property analysis of information suffer from serious problems. For example, what if the information arises from a relationship between two or more persons or bodies? Who owns the information? Is it an example of common or joint ownership? If so, how does one decide who should control the information? Moreover, how can one resolve disputes between parties given that the parties to the relationship can, simultaneously and yet independently, possess and control the 'valuable entity' in its entirety? For these reasons and others, Jones has argued that property cannot be the basis of the action of breach of confidence[52]. Rather, he posits that the basis of the action is the 'broad equitable principle of good faith', namely, that he "who has received the information in confidence shall not take unfair advantage of it"'[53] This relates, in part, to the general notion that one should not be allowed to take unfair advantage of another. This avoids the problems of trying to fit a concept such as

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[51] Libling, D.F.; 'The Concept of Property: Property in Intangibles', 94, *Law Quarterly Review,* 103, 1978.

[52] Jones, G.; 'Restitution of Benefits Obtained in Breach of Another's Confidence', 86, *Law Quarterly Review,* 463, 1970, at 464 - 465. He notes that: 'A cursory study of the cases, where the plaintiff's confidence has been breached, reveals great conceptual confusion. Property, contract, bailment, trust, fiduciary relationship, good faith, unjust enrichment, have all been claimed, at one time or another, as the basis of the judicial intervention. Indeed some judges have indiscriminately intermingled all these concepts. The result is that the answer to many fundamental questions remains speculative.'

[53] *ibid,* at 466 quoting *Seager v Copydex Ltd* [1967] 2 All ER 415, at 417 and *Fraser v Evans* [1969] 1 All ER 8, at 11.

information into an existing and rigid set of rules such as the law of property[54]. Because good faith is based on principle this allows the notion of the legal protection of confidential information to develop along its own lines into something of a *sui generis* form of protection[55]. This is certainly the view taken by the Law Commission in its 1981 report,

> ...the courts do not confine themselves to purely equitable principles in solving the problems which arise in breach of confidence cases and it would seem more realistic to regard the modern action as simply being *sui generis*.[56]

However, the *Spycatcher* case gives considerable weight to the argument that the basis of the action lies in the law of Equity[57]. Most recently, Toulson and Phipps have argued that the foundation of the action of breach of confidence in England and Wales is indeed an equitable obligation, binding in conscience, and arising from the circumstances in which one receives the information[58]. They agree with Jones that the law of confidence is *sui generis* in that has developed for itself a unique niche in law, but they argue that the foundational basis of the action is clear: Equity[59].

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[54] Another view is that the law seeks to protect the 'relationship' rather than the 'information' *per se*, see Wright, S.; 'Confidentiality and the Public/Private Dichotomy', 7, *European Intellectual Property Review*, 237, 1993. However, this argument is seriously undermined by the reality outlined by the House of Lords in the cases discussed above. In neither cases was there any form of relationship between the confider (the Government) and the third party coming under an obligation of confidence (the newspapers).

[55] See also, Wei, G.; 'Surreptitious Takings of Confidential Information', 12, *Legal Studies*, 302, 1992 who states that, '...the majority view is that the action is founded on equitable notions of good faith.'

[56] *op. cit.*, at 11.

[57] See, for example, Lord Keith at 255E, Lord Griffiths at 268A and Lord Goff at 281D - E. For comment, see Capper, D.; 'Damages for Breach of the Equitable Duty of Confidence', 14, *Legal Studies*, 313, 1994.

[58] Toulson and Phipps, *op. cit.*, chapter II generally, specifically at paragraphs 2.12 - 2.24.

[59] *ibid.*

Either way, whether the foundation of confidentiality be good faith or Equity, for the Scottish courts this poses a problem. First, to found the action in a general obligation not to treat others unfairly, lacks substance in both Scots and English law. There is, for example, no law of unfair competition as this is understood in other jurisdictions. Second, to imply that the basis of the action is founded in the English law of Equity tells us nothing about the Scottish source, for Scots law has no conception of the Law of Equity and such a law is of no standing in the Scottish system. Nevertheless, as Lord Keith stated in *Lord Advocate v Scotsman Publications Ltd*, '[w]hile the juridical basis may differ to some extent in the two jurisdictions, the substance of the law in both of them is the same'[60].

Despite the above, it is submitted that one common source for the duty of confidentiality can be identified from the cases. That source is the public interest. Furthermore, this source explains why the Government was denied protection in *Lord Advocate v Scotsman Publications Ltd* and also allows us to draw non-parallels between the Government cases and cases which involve individuals.

In both the *Spycatcher* case and *Lord Advocate v Scotsman Publications Ltd* the House of Lords makes it clear that the protection of confidences finds considerable justification in the public interest. For example, Lord Keith in *Spycatcher* states that '...as a general rule, it is in the public interest that confidences should be respected...'[61] and similarly in the same case Lord Goff states that,

> I start with the broad general principle...that a duty of confidence arises when confidential information comes to the knowledge of a person (the confidant) in circumstances where he has notice, or is held to have agreed, that the information is confidential,...[t]he existence of this broad general principle reflects the fact that there is such a public interest in the

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[60] *supra*, at 708.

[61] *supra*, at 256A.

> maintenance of confidences, that the law will provide remedies for their protection.[62]

From this it should be clear why a remedy was denied in the Scottish Spycatcher case. The Government failed to establish that a public interest would be served by the grant of the interdict. To repeat the words of Lord Keith,

> ...the appellant has not pleaded a good arguable *prima facie* case that further publication by the respondents would do any material damage to the public interest.[63]

This is not to imply, however, that in all cases the onus is on the confidant to establish that a public interest must be served before his or her confidences should be respected[64]. In particular, it is important to note that the Spycatcher cases were influenced by a competing public interest; that of freedom of speech[65]. In contrast, when the confidentiality of individuals is at stake it is generally always presumed that a public interest is served by respecting such confidences. This is especially true in the health care setting.

3.1.1. - *Confidentiality and Health Care*

Legal decisions on medical confidentiality stress the important public interest(s) served by respecting patient confidences. For example, it has already been noted that the court in *X v Y* preferred the public interest in maintaining confidences to the alleged 'public interest' in knowing the HIV status of two doctors[66]. And,

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[62] *supra*, at 281B - C.

[63] *Lord Advocate v Scotsman Publications Ltd, supra cit.*, at 709 - 710.

[64] Note, however, that the Law Commission suggested this as a possible approach in its 1981 report; that is, it suggested that confidentiality should be protected only where it was in the public interest to do so, *op. cit.*, paragraphs 6.77. - 6.84. For comment see, Stair Memorial Encyclopaedia, *op. cit.*, paragraph 1484.

[65] See *Lord Advocate v Scotsman, supra cit.*,at 710.

[66] *X v Y*, [1988] 2 All E.R 648, per Rose J at 653. See also, *Attorney General v Guardian Newspapers (No.2)* [1988] 2 All E.R 545 at 659; [1988] 3 W.L.R 776 at 807, *per* Lord Goff, '...the basis of the law's protection of confidence is that there is a public interest that confidences should be preserved

although it is recognised that individuals have a private interest in personal information, it is generally accepted that the true justification for protection is an appeal to 'the public interest'. Thus, in *W v Egdell*[67], Sir Stephen Brown commented,

> ...in so far as the [first instance] judge referred to the 'private interest' of W, I do not consider that the passage in his judgment[68] accurately stated the position...Of course W has a private interest, but the duty of confidence owed to him is based on the broader ground of public interest described by Rose J in *X v Y*.[69]

The question of justification aside, the next issue to address is that of the mechanism of legal protection of confidences : what circumstances must exist or be proved to establish a duty of confidentiality?

4.1. - THE LEGAL REQUIREMENTS OF CONFIDENTIALITY

For a legally enforceable right of confidentiality to arise several factors must be satisfied: first, the information must have the necessary quality of confidence about it[70]. Information which is part of the public domain cannot be considered to be confidential[71]. Second, the information must be imparted in circumstances which

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and protected by the law...'. Note however he continued, '...nevertheless the public interest may be outweighed by some other countervailing public interest which favours disclosure.', *ibid.*

[67] *W v Egdell* [1990] 1 All E.R 835, discussed *infra.*

[68] [1989] 1 All E.R 1089 at 1105.

[69] *X v Y* [1988] *supra*, at 660-661, *W v Egdell, supra cit.*, at 846g-h; also *per* Bingham LJ at 849d-e. See also, *Lion Laboratories v Evans* [1985] Q.B 526 at 536.

[70] *Coco v A N Clark (Engineers), supra.* Toulson and Phipps make the point that, '...information must be objectively confidential, and not merely treated as such, in order to attract protection.', *op. cit.*, at 3.04 - 3.05. A contrary view has recently been advanced by Jacob J in *Carflow Products (UK) Ltd v Linwood Securities (Birmingham) Ltd and Others* [1996] FSR 424 in which the judge preferred a subjective approach to the question of whether details of a design for a wheel lock had been imported in confidence and had the necessary quality of confidence. For comment on this see, Clark, S.; 'Circumstances Importing an Obligation of Confidence : A Subjective or Objective Test? : Carflow Products (UK) Ltd v Linwood Securities (Birmingham) Ltd and Others', 11, *European Intellectual Property Review*, 632, 1996.

[71] *Attorney General v Guardian Newspapers No.2, supra cit.*.

import a duty of confidence. This is done if a person receiving the information realises or should realises that the information is confidential and that the confidence is to be respected[72]. Finally, to be actionable the information must be disclosed or used by the confidant without authority from the confider or without lawful excuse[73]. It is also probably the case that a form of detriment must be shown, although in personal information cases it is sufficient that the individual would rather that the information not be disclosed[74].

As with the professional and ethical conceptions of confidentiality, the law in the United Kingdom does not see the duty of confidentiality as absolute[75]. The defences to an action for breach of confidence are: i) the disclosure or use of the information was in the public interest[76], ii) the information is already in the public domain[77], iii) disclosure is made with lawful excuse or justification, e.g. - statutory authority or discharge of a public function[78], and, iv) the defender already knew the information before it was disclosed to him in confidence[79].

Clearly, in the health care setting information of a confidential nature is common currency. *All* health care professionals come under a legal duty to respect patient

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[72] *supra.*

[73] For a discussion of the elements see, Toulson and Phipps, *op. cit.*, chapter III.

[74] *supra.*

[75] For argument in defence of an absolute duty see, Kottow, M.H.; 'Medical Confidentiality : An Intransigent and Absolute Obligation', 12, *Journal of Medical Ethics*, 117, 1986. For an account of the French position where an absolute duty is imposed and protected by the law . See, Lenoir, N.; 'Aspects Juridiques et Ethiques du Diagnostic Prenatal : Le Droit et Les Pratiques en Vigeur en France et dans Divers Autres Pays', in 'Human Genetic Analysis and the Protection of Personality and Privacy', International Colloquium, Schulthess Polygraphischer Verlag Zurich 1994, at 49ff.

[76] *W v Egdell, supra cit.; Lion Laboratories v Evans, supra cit.; cf - X v Y, supra cit.*

[77] *Attorney General v Guardian Newspapers No.2, supra cit.*

[78] See *Hunter v Mann* [1974] 2 All ER 414, *Malone v Metropolitan Police Commissioner* [1979] 2 All ER 620, and *R v Licensing Authority established under Medicines Act 1968, ex parte Smith Kline and French Laboratories Ltd (Generics (UK) Ltd intervening)* [1990] 1 AC 64, [1989] 1 All ER 175, CA (affd sub nom *Smith Kline and French Laboratories Ltd v Licensing Authority (Generics (UK) Ltd intervening)* [1990] 1 AC 64, [1989] 1 All ER 578, HL. In this last case it was held that a public authority exercising powers under a UK statute as well as Community law could make use of confidential information to exercise properly its official function. The Court of Appeal stressed the public health function of the body concerned.

[79] *Johnston v Heat and Air Systems Ltd* (1941) 58 RPC 229.

confidences. Problems arise, however, in determining the limits of such a duty. Primary among these is the question of when disclosure is in the public interest[80]. Several medical law cases have addressed this issue in recent years.

5.1. - THE LIMITS OF THE LEGAL DUTY OF MEDICAL CONFIDENTIALITY

The cases of *X v Y* and *W v Egdell* have already been mentioned. They have been instrumental in clarifying to a degree the legal limits of the medical duty of confidentiality. For this reason alone they deserve closer attention.

5.1.1. - *X v Y*

The case of *X v Y* concerned the disclosure of personal health information relating to two general practitioners with AIDS by an employee of a health authority to a newspaper reporter of a national newspaper. The health authority sought and obtained an order restraining the publication or use of the confidential information. Nevertheless, an article was published and a further item was intended. The plaintiffs therefore sought, *inter alia*, an injunction restraining the defendants from identifying the two doctors and an order from the court to the newspaper requiring disclosure of its sources. In reply, the defendants argued that publication was justified in the public interest and that the public had a right to know that doctors were continuing to treat patients while infected by AIDS.

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[80] See Lord Goff in *Attorney General v Guardian Newspapers No2*, *supra*, at 282D - E : '...although the basis of the law's protection of confidence is that there is a public interest that confidences should be preserved and protected by the law, nevertheless that public interest may be outweighed by some other countervailing public interest which favours disclosure. This limitation may apply...to all types of confidential information. It is this limiting principle which may require a court to carry out a balancing operation, weighing the public interest in maintaining confidences against the countervailing public interest favouring disclosure'.

Rose J refused to authorise disclosure in the public interest. He held that the plaintiffs were entitled to a permanent injunction against the defendants to prevent them from publishing the confidential information in any form. Whereas he did not deny that there was a public interest in public health, he did not accept the argument that this interest would be furthered by disclosure of the sensitive, personal and confidential information. Indeed, his view was that the public interest which formed the basis of the protection of confidence in the first place, would be compromised to an unacceptable degree if the confidences were not respected. He noted that public health was not under threat from doctors who continued to practise general medicine, although the situation might be different if they were engaged in invasive procedures. Also, he noted that there was a public interest in freedom of the press but that this was not sufficiently strong in the circumstances of the present case to merit breach of confidence[81]. Moreover, he approved of a very important distinction when dealing with the public interest : [t]here is a wide difference between what is interesting to the public and what it is in the public interest to make known'[82].

From this decision several conclusions can be drawn. First, there is a strong public interest in protecting patient confidences. Second, there is no absolute duty to do so, but when conflict arises the balance must be between competing public interests. Third, the breach of confidence, to be acceptable, must at least, assist in furthering the competing public interest. This was clearly not possible in *X v Y*. Finally, in determining legitimate public interests, some tangible benefit to the public must be demonstrated and not mere titillation or entertainment.

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[81] *ibid*, at 658d - 661g.

[82] This is the frequently cited quote from Lord Wilberforce in *British Steel Corporation v Granada Television Ltd* [1981] AC 1096 at 1168.

The value of this case lies in its defence of the individual's confidentiality. Its weakness lies in its failure to express more clearly the precise nature of the concept of public interest.

5.1.2. - *W v Egdell*

The question of public interest arose again in the case of *W v Egdell*[83]. This case involved a patient, W, detained in a secure hospital who had been convicted of criminal offences after having shot and killed five people and wounded two others. Ten years after his initial detention he applied to a mental health review tribunal to be discharged or transferred to a regional secure unit as a first move to his eventual release. As part of proceedings Dr Egdell was asked to prepare a report on W's mental health and suitability for transfer. The report which Dr Egdell produced was extremely unfavourable to W's chances and as a result W withdrew his application. However, Dr Egdell was concerned that neither the tribunal nor the hospital had sight of his report and so he took it upon himself to send copies of the report to the hospital which sent a copy to the Secretary of State who in turn passed it to the tribunal. On discovering this W issued a writ against Dr Egdell which sought (a) to restrain any use or disclosure of the report by its recipients, (b) delivery up of all copies of the report, and (c) damages for breach of confidence. This was contested on the basis that the action of the doctor was justified in the public interest.

The Court of Appeal took the same line as Rose J in *X v Y* and sought to consider the competing *public* interests at stake in this case: namely, the public interest in protecting confidences as against the public interest in ensuring that dangerous

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[83] *supra cit.*

individuals were not released prematurely back into society[84]. This time the court preferred the public interest which supported disclosure. Bingham LJ put it like this,

> Where a man has committed multiple killings under the disability of serious mental illness, decisions which may lead directly or indirectly to his release from hospital should not be made unless a responsible authority is properly able to make an informed judgment that the risk of repetition is so small as to be acceptable. A consultant psychiatrist who becomes aware, even in the course of a confidential relationship, of information which leads him, in the exercise of what the court considers a sound professional judgment, to fear that such decisions may be made on the basis of inadequate information and with a real risk of consequent danger to the public, is entitled to take such steps as are reasonable in all the circumstances to communicate his concern to the appropriate authorities.[85]

There are several things to note about this judgment. First, the defence of public interest operates only in limited circumstances. For example, Dr Egdell's disclosure was only acceptable because it was to '*the appropriate authorities*'. Had it been to other persons or bodies it would amount to a breach of confidence[86]. This re-inforces the point made in *X v Y* that disclosure of confidential information is acceptable only if it has a likelihood of furthering the public interest which justified breaching the confidence. It would seem fair to assert that the degree of that likelihood is one of *reasonable likelihood*. Second, the threat to the public interest must be 'real'. Insignificant or trivial interference with public interests is not

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[84] It is interesting to note that at first instance in this case Scott J sought to balance the public interest defence against what he perceived to be the private interest of the prisoner, [1989] 1 All ER 1089 at 1105. This was rejected by the Court of Appeal, *ibid*, at 846f - g and at 849d - e.

[85] *ibid*, at 852h - 853a.

[86] *ibid*, *per* Sir Stephen Brown P : '[i]f...Dr Egdell had sold the contents of his report to a newspaper, I do not think any court of equity would hesitate for a moment before concluding that his conduct had been a breach of his duty of confidence', at 842f -g. Note, however, that it has been accepted that in some circumstances disclosure to the press is acceptable, see *Lion Laboratories, v Evans, supra cit.*

sufficient. Finally, the case, unfortunately, gives no clearer indication of the precise nature of what counts as 'public interest'. Indeed, Bingham's dictum reads like a very case-specific judgment, although it is not intended to be. In this case the avoidance of harm to the public was clearly in the public interest. In *X v Y* the public interests were freedom of the press and the public's right to know. But beyond this, neither of these cases gives any indication of what, in the future, this defence will encompass. This has two important consequences; one for the law and the other for the medical profession. The law remains in a state of uncertainty, condemned to piecemeal development. For the medical profession it represents an onerous burden, for it is clinicians themselves who must decide whether disclosure is to be justified in the public interest. And, should they do so wrongly, they may face a legal action for breach of confidence.

Other subsequent cases have extended the application of the public interest defence, notably; *R v Crozier*[87], *Re C (a minor)(evidence : confidential information)*[88] and the non-medical case of *Hellewell v Chief Constable of Derbyshire*[89].

5.1.3. - *R v Crozier*

The case of *R v Crozier* simply represents an application of the law as interpreted in *W v Egdell*. In criminal proceedings before the Crown Court at Reading on 3 November 1988 the accused, Peter Michael Anthony Crozier, pleaded guilty to the attempted murder of his sister. Despite having gone through psychiatric evaluation, when sentence was pronounced one week later no report was available to the defence. The judge therefore proceeded in the absence of medical evidence and sentenced Crozier to nine years' imprisonment. As this was happening the doctor who had most recently assessed the accused entered the court and was alarmed to

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[87] [1990] 8 BMLR 128.
[88] [1991] 7 BMLR 138.
[89] [1995] 1 WLR 804.

hear that a custodial sentence was to be imposed. He approached counsel for the Crown and disclosed the contents of his report which concluded that the accused was suffering from a mental illness of a psychopathic nature and that he should be detained under the provisions of the Mental Health Act 1983. As a result the Crown sought a variation of the sentence under S47(2) of the Supreme Court Act 1981 to replace the custodial sentence with a hospital order. At the third hearing counsel for the appellant argued that the judge should disregard the evidence contained in the psychiatric report because it should never have been placed in the hands of the Crown as a confidential document between the appellant and the examining physician. It should have been a matter for the appellant and his counsel to decided whether or not to disclose the report. Had correct procedure been followed neither the Crown nor the judge would be aware of the report's contents. The judge ruled, however, that justice demanded that he consider any medical evidence put before him. An appeal was lodged to the Court of Appeal challenging the trial judge's disposal and arguing that it was invalid because it took into account a report which was released in breach of patient confidentiality.

The Court of Appeal asked two fundamental questions: did the psychiatrist (Dr. McDonald) breach confidentiality, and, if he did, was he justified in doing so?[90] Quoting heavily from the dicta of Bingham LJ in *W v Egdell*[91], the Court regarded Dr. McDonald as very much in the same position as Dr. Egdell. That is, the clinician was in possession of information which he felt was of vital importance concerning the treatment of one who had previously committed violent crime. It was held that, as in *W v Egdell*, there was a strong public interest which favoured disclosure. Dr. McDonald was, therefore, acquitted of any 'impropriety'[92] and the disposal confirmed.

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[90] *ibid*, at 134.

[91] In particular (1989) 4 BMLR 96 at 111-112, [1990] Ch 359 at 419-420, and, (1989) 4 BMLR 96 at 117, [1990] Ch 359 at 424.

[92] *R v Crozier, supra*, at 136.

Typically for a medical confidentiality case, *R v Crozier* does not contain any deep analysis of the content of the 'public interest'. The Court of Appeal relied exclusively on the decision in *W v Egdell* but the facts of the two cases are not on all fours. In *Egdell* the decision which was to be taken concerned the first move in the process of release of the patient. In *Crozier* there was no question of release of the accused; rather it was a matter of appropriateness of disposal. That is, there could not have been any immediate or even foreseeable danger to the public arising from the instant decision of the trial court. Certainly, a difference in the two proposed disposals is the question of time limits: the initial imprisonment was for a period of nine years, whereas the hospital order could be imposed without limit of time. But it is surely better (and more credible) to argue that a hospital order was in the *patient's* (better) interests rather than in the *public* interest. Unfortunately, the law of confidence does not seem to provide for this. Another distinction between the cases concerns the relative 'threat' which the respective patients pose to the 'public interest'. Unlike patient *W* who had attacked and killed several individuals randomly, Crozier's crime was person specific and arose from particular circumstances in his family[93]. From this it is arguably less clear that *Crozier* posed as great, if any, threat to the general public. What the Court says about the public interest defence is in effect very little, except perhaps that it can be used to justify breaches of confidence when there is no immediate threat to the public interest and where it is far from clear how 'dangerous' the individual in question actually is.

5.1.4. - *Re C (a minor) (evidence: confidentiality information)*

Re C (a minor) concerned adoption proceedings and the fitness of the natural mother to care for her child. C was born on 26 September 1988 and four days later

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[93] He attacked his sister with an axe when, as co-trustee for a trust set up for Crozier's daughter, she disputed Crozier's management of the monies.

was placed with foster parents with a view to adoption. Maternal consent had been obtained. Subsequently, however, the mother withdrew her consent prior to the completion of adoption proceedings. In response the prospective adoptive couple served an affidavit on the mother detailing evidence from the mother's general practitioner which cast her in an unfavourable light and called into question her ability to care for her child. The mother's representatives argued that the doctor's evidence should be inadmissible on the grounds that by volunteering such evidence the doctor was in breach of his duty of confidentiality owed to the mother. The judge ruled that the evidence was admissible but granted leave to appeal. The case was then heard by the Court of Appeal.

The argument put by counsel for the appellant was that the case involved a need to decide between two competing public interests : the public interest in maintaining confidentiality between doctor and patient and the public interest that justice in the particular case should be done[94]. Sir Stephen Brown P, Stuart-Smith and Mann LJJ each delivered separate judgements; all agreed that disclosure was justified, but each differed on his reasons for so holding.

Sir Stephen Brown held that the doctor's affidavit was highly relevant to the matter of adoption of the child and that it should therefore be placed before the judge in that cause if it were at all possible[95]. Although undecided on the question of whether in fact there had ever been a breach of confidence[96], he held that the doctor was justified in making available her evidence. This he argued was because the court should have before it all relevant and significant information which will assist it to make 'the right decision', and that if a judge had to carry out a balancing exercise between full disclosure and respecting confidentiality, he would be fully justified in admitting the doctor's evidence. Beyond this we are not offered a more

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[94] (1991) 7 BMLR 138, at 140.
[95] *ibid*, at 143.
[96] *ibid*.

detailed account of why breach of confidence is acceptable or why full disclosure is to be preferred. He stressed, however, that an important feature of the disclosure was its limited nature. The doctor did not make her report available to the public at large but only to those who were directly involved in the question of the adoption of the child, that is, the judge and those who were bound by the confidentiality of the hearing in judicial chambers[97]. This is in line with similar views expressed in *W v Egdell*[98].

Stuart-Smith LJ agreed that the appeal should be dismissed. Like Sir Stephen Brown he was undecided about the question of whether the doctor had ever breached her duty (although he indicated that he thought not)[99]. Nonetheless, he held that the judge was entitled to admit the evidence of the doctor as a matter of judicial discretion. In other words, he turned the case into one of judicial review, thereby tying the hands of counsel and the Court of Appeal by restricting them to considering whether or not the judge had exercised his discretion appropriately. To challenge successfully such an exercise of discretion one must establish one of only three things: either, that the judge took into account irrelevant matters, or that he failed to take into account relevant matters, or that his decision was plainly wrong[100]. Stuart-Smith LJ concluded that,

> The adoption of a child is a matter of very great public importance. It affects the welfare of the child for the rest of its life, and the issue before the court in this case, namely whether the mother had unreasonably withheld her consent, is therefore one of very great importance. On the assumption, therefore, that there was a breach of confidence here, in my judgment, the judge was entirely correct to exercise his discretion as he did and to admit the evidence. There was not basis for saying that he was wrong.

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[97] *ibid*, at 143.
[98] *supra cit.*
[99] *ibid*, at 144.
[100] *id.*

Like his fellow Lord Justices, Mann LJ also called into question the assertion that the doctor had breached her duty of confidentiality. This was so even although it had been conceded in the original hearing that a breach of confidence had occurred. The basis for his view seems to be that the evidence was relevant to the future of the child and that the dissemination of the evidence was restricted on a 'need to know' basis[101]. At the end of the day, however, he too seems to turn the case into one of judicial discretion and concluded that the judge was 'plainly right' in the exercise of his discretion in allowing the evidence[102].

This judgment calls us to question several aspects of the duty of confidentiality. For instance, what is the difference between a breach of confidence for which one has a defence - for example, the defence of public interest - and the disclosure of confidential information in circumstances which do not amount to a breach of confidentiality even when the confider objects to disclosure? Does the latter imply that no duty exists in those circumstances? In this case it would seem that the Court of Appeal was suggesting that it is possible for information to be disclosed without a confider's consent and yet that this would not amount to a breach of confidence. Unfortunately it is not clear whether this means simply that a defence is available or whether the court intended that there was no breach of duty because in those circumstances there was no duty at all to breach. As we have seen, if the former is the case, it is not clear which defence was relied upon by the court to justify its decision. The most likely candidate, once again, is the public interest, but no argument is made for this defence except for a few comments in the course of the judgement which do not bear close scrutiny. Stuart-Smith states, for example, : 'It is in the public interest, it seems to me, that the doctor should have had in mind the welfare and well-being of this child.'[103] Mann LJ simply states : 'I think it could

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[101] *ibid*, at 146.

[102] *id.*

[103] *ibid*, at 144.

be argued that there is a strong public interest in the future of the child.'[104] However, nowhere is an argued case made which sustains these views. This is not a matter of mere sophistry. It matters very much whether or not a *prima facie* duty is owed but breach is justified or whether no duty is owed at all. For one thing, it means that patients are not entitled to expect that as a matter of course their confidences will be respected. Furthermore, it has consequences for evidential burdens. If no *prima facie* duty is owed then the task of proving breach of confidence becomes increasingly difficult for the pursuer/plaintiff. Clearer explication of the parameters of the duty and indeed of when such a duty comes into being, or ceases to be, is required. Perhaps the closest indication we have of the true views of the court comes from Stuart-Smith LJ,

> It seems to me that the doctor was plainly under a duty to treat the information given by the patient in confidence *in general terms*. For example, she would plainly be in breach of that duty to disclose any matters to the press or people who were not concerned. The court is concerned with the breach of the duty. I am by no means satisfied that, in the circumstances of this case, there was any breach of that duty in disclosing these matters to those who were concerned with the welfare of the child, namely the court and the solicitors for the adopters.[105] [emphasis added]

It is reasonable to interpret this passage as meaning that the duty owed by doctors to patients is one of a general nature, which does not necessarily extend to specific circumstances, an example of which arose in the instant case. If this is true, arguably it removes the *prima facie* assumption that health care professionals owe their patients a duty of confidentiality over all information received as soon as the therapeutic alliance is formed. This then has the consequences outlined above[106].

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[104] *ibid*, at 146.

[105] *ibid*, at 144.

[106] Although it is not argued in the case, support for such a view can be found (albeit tentatively) in the dicta of Lord Goff in *Attorney General v Guardian Newspapers Ltd (No.2), supra cit.*, where at 281 ([1990] 1 AC 109) he says : 'I start from the broad general principle (which I do not in any way

Even if this is not the case, and the justification of the court in its decision is the public interest defence, the judgment extends the defence quite considerably. It is not immediately clear to the present writer how the case of *one* prospectively adopted child fits into the rubric of *public* interest. Certainly there is a *private* interest at stake, in that the child should be dealt with according to *its* best interests. To say, however, as does Stuart-Smith LJ, that, '[i]t is in the public interest...that the doctor should have in mind the welfare and well-being of this child'[107], does not necessarily transform the child's case into a matter of public interest. While it is undeniable that a child's interests are of considerable importance, it would seem logical that if these are to be preferred to the public interest in protecting confidentiality, an account of the relevant factors to be weighed should at least be given. That the court fails to do so in *Re C* further weakens the duty of confidence owed to patients and renders potentially unruly the public interest defence.

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intend to be definitive) that a duty of confidence arises when confidential information comes to the knowledge of a person (the confidant) in circumstances where he has notice, or is held to have agreed, that the information is confidential, *with the effect that it would be just in all the circumstances that he should be precluded from disclosing the information to others.*' [emphasis added]. Arguably, by extension this would mean that in certain circumstances justice would dictate that a duty need not arise. On the facts of this case, it will be remembered that the interests at stake (as articulated by counsel for the appellant) were those in maintaining confidentiality and those of justice. Rather than balancing the two (as counsel argued) one might choose, on the authority of Lord Goff, to submit that justice requires that no duty be seen to arise in the first place. This is borne out if one accepts the arguments that, in England and Wales at least, the duty of confidence is based in Equity. What this means is that a court can recognise a right but refuse to protect it in particular circumstances because the rights are discretionary. See, for example, Wacks, R.; 'Privacy and Press Freedom', London, Blackstone Press Ltd, 1995, at 96. This would certainly provide an explanation for the decision of the Court of Appeal in *Re C* even if the judges in that case do not choose to articulate their judgements in such terms. Of course, this explains nothing from the Scottish perspective. Finally, it is interesting to note that Toulson and Phipps are of the opinion that '...no obligation of confidence exists in contract or equity, in so far as the subject matter concerns a serious risk of public harm (including but not limited to cases of "iniquity") and the alleged obligation would prevent disclosure appropriate to prevent such harm', *op. cit.*, at 6.11. At 6.19 - 6.20 they discuss *W v Egdell* and conclude that, '[t]he danger to the public was such that, although there was a confidential relationship between the parties, the duty of confidence impliedly undertaken by the defendant *did not extend* to withholding information about the plaintiff's state of health from the responsible medical authorities.' [emphasis added]

[107] *ibid*, at 144.

5.1.5. - *Hellewell v Chief Constable of Derbyshire*

The final case to be examined does not concern medical matters but does clarify certain issues surrounding the action of breach of confidence. This case involved one Paul Hellewell who was detained by police on 11 May 1989 and charged with offences of theft of petrol and attempted theft of petrol. At the time of his arrest he was fingerprinted and photographed. He was later convicted of the said offences and by February 1993 he had a total of 32 convictions, 19 of which were for theft. On 16 November 1992 the police of Long Eaton in Derbyshire, where the plaintiff lived, issued photographs of known criminals to the Long Eaton Shop Watch Scheme: a crime prevention group established with the support of the police force. This was done in an attempt to assist staff to know who was likely to be a troublemaker and to identify those who were banned from shops. The photographs were distributed on the understanding that only staff of shops, and not the general public, should have access to the photographs. In June 1993 the plaintiff learned that his photograph had been distributed and he commenced proceedings for declaratory relief, injunction and damages against the Chief Constable of Derbyshire for use of the photograph taken in May 1989. In response, the Chief Constable applied to have the claim struck out on the grounds that there was no cause to answer and the claim was scandalous and an abuse of process.

The case was heard by Laws J. in the Queen's Bench Division and he delivered his opinion on 21 December 1994[108]. In that judgment he proceeds on the basis that there could only be one potential cause of action, namely; breach of confidence[109]. Moreover, he starts from the premiss that the unauthorised disclosure of a photograph can be actionable as breach of confidence[110]. The first question with which he had to deal, however, was whether or not the police could be the subject

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[108] The case is reported at [1995] 1 W.L.R 804.
[109] *ibid*, at 807.
[110] Quoting *Pollard v Photographic Co* (1888) 40 Ch.D. 345.

of a duty of confidence in the circumstances of the present case[111]. To determine this Laws J. considered the criteria for establishing a right of confidentiality as summarised by Sir Robert Megarry V.C. in *Malone v Metropolitan Police Commissioner*[112], the dicta of Lord Goff in *Attorney General v Guardian Newspapers Ltd (No.2)* (which suggest that a duty of confidence can arise when an objective perspective would so dictate[113]), and the case of *Marcel v Commissioner of Police of the Metropolis*[114] (which concerned documents seized by police officers and in which it was held that a private law duty to the owner of such documents existed and that the nature of that duty was one of confidentiality[115]). In light of this he held that a duty of confidence *was* owed to the plaintiff[116]. However, the confidential information which was the subject of the duty was not just the photograph of the plaintiff, but the photograph taken in police custody which would 'convey to anyone looking at it the knowledge that its subject is or has been known to the police.'[117] Clearly, someone's facial features are a matter of public knowledge and cannot count as confidential information. In contrast, the fact that someone is known to the police is not 'a public fact'[118]. The consequence of establishing this duty was that the police could not use the photograph in any way they liked,

> In my judgment, the use which the police may make of a photograph such as this is limited by their obligations to the photograph's subject as follows. They may make reasonable use of it for the purpose of the prevention of and detection of crime, the investigation of alleged offences and the apprehension

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[111] *Pollard* concerned portrait photographs of a woman taken by a professional photographer, one of which was used by him as a Christmas card and displayed in his shop.

[112] [1979] Ch.344 at 375. These have already been discussed *supra*. They are : 'first, the information must have the necessary quality of confidence about it. Secondly, that information must have been imparted in circumstances importing an obligation of confidence. Thirdly, there must be an unauthorised use of that information to the detriment of the party communicating it...'.

[113] [1990] 1 AC 109 at 281.

[114] [1992] Ch. 225.

[115] *ibid*, per Nolan LJ at 261.

[116] *Hellewell, supra* at 810.

[117] *ibid.* The photograph was of the nature of a 'mugshot' - instantly recognisable to anyone as a police photograph.

[118] *id.*

> of suspects or persons unlawfully at large. They may do so whether or not the photograph is of any person they seek to arrest or of a suspected accomplice or of anyone else. The key is that they must have these purposes in mind and must, as I have said, make no more than reasonable use of the picture in seeking to accomplish them.[119]

This clearly sees the duty of confidentiality as of *prima facie* value. The question then for the court was whether or not the activities of the police fell within such 'reasonable use'. Laws J concluded that they did[120]. In framing his dictum into the rubric of the public interest defence, he held that the police use of the photograph was done in good faith for the prevention or detection of crime (accepted unquestioningly as a public interest). Moreover, the dissemination of the photograph by the police was limited to shopkeepers in the shop watch scheme, that is, only to persons who had a reasonable need to make use of it[121]. Thus, the Justice held that although a duty of confidentiality was owed, if the case went to trial the Chief Constable was bound to succeed in establishing a public interest defence.

This case does nothing to further our understanding of the public interest. As noted above, it was accepted unquestioningly that the prevention and detection of crime is in that interest which few would, or could, dispute. However, the case is interesting for several other reasons. First, it confirms Lord Goff's view from *Attorney General v Guardian Newspapers No2* that a duty of confidence can arise irrespective of a specific contract between parties, or a 'traditional relationship' (such as doctor/patient), or express notice from confider to confidant. Second, it has been argued that this case provides the basis for the protection of many privacy

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[119] *id.*
[120] *ibid*, at 811.
[121] *id.*

interests which, to date, have not been protected in the United Kingdom[122]. This possibility will be discussed in more detail in chapter six where we shall also examine the desirability of accepting such an argument[123].

As a final point, it should be noted that the question of the scope of the public interest defence has been addressed in other non-medical cases dealing with breach of confidence. Traditionally, it was thought that the general rule that 'there is no confidence as to the disclosure of an iniquity...'[124] embodied the entire scope of the defence. That is, matters of serious misconduct or criminality could not be protected by the law of confidence and their disclosure would clearly be in the public interest[125]. However, a series of cases beginning in the late 1960s took a view of the public interest defence which was much broader[126]. The zenith of this movement came with the decision of the English Court of Appeal in *Lion Laboratories Ltd v Evans*[127]. Here, two ex-employees of Lion Labs disclosed to a newspaper internal memoranda concerning a breath test device developed by Lion Labs for the detection of drink drivers. This device was already in use but the memoranda revealed concerns about its accuracy. In holding that such a disclosure fell clearly within the public interest, the Court of Appeal said that the public interest defence was not restricted to cases of iniquity. Such cases were merely instances of the public interest defence : there was not always the need to show criminality or misconduct on the part of the confider. Cripps has stated in relation

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[122] See, for example, Wee Loon, N-L.; 'Emergence of a Right to Privacy from Within the Law of Confidence?', 5, *European Intellectual Property Review*, 307, 1996. For a more general argument that the law of confidence can protect privacy interests see, Fenwick, H. and Phillipson, G.; 'Confidence and Privacy: A Re-Examination', 55, *Cambridge Law Journal*, 447, 1996.

[123] The passage which has excited interest is the following : 'If someone with a telephoto lens were to take from a distance and with no authority a picture of another engaged in some private act, his subsequent disclosure of the photograph would, in my judgment, as surely amount to a breach of confidence as if he had found or stolen a letter or diary in which the act was recounted and proceeded to publish it. In such a case, the law would protect what might reasonably be called a right to privacy, although the name accorded to the cause of action would be breach of confidence.', see *Hellewell, supra cit.,* at 807. This passage is also discussed *infra.*

[124] *Gartside v Outram* (1856) 26 LJ Ch 113 at 114.

[125] For a discussion of this see Wacks, R.; 'Privacy and Press Freedom', *op. cit.*, chapter 4.

[126] *ibid.*

[127] [1985] 1 QB 526.

to this decision that it is: '...a deeper inroad into actions of breach of confidence...than any previous case on the public interest defence.'[128] But, as Wacks points out,

> ...an important feature of this case is that the alleged inaccuracy of the Intoximeter could have had an effect on "the life, and even the liberty, of an unascertainable number of Her Majesty's subjects".[129]

That is, the likelihood of averting considerable, possibly immeasurable, harm was a strong influential factor[130].

5.2. - CONFIDENTIALITY AND THE LAW: A CONCLUSION

The above survey of legal cases concerning the protection of confidential information reveals the essential features which give rise to a legal duty of confidence and also the circumstances in which such a duty can be breached with just cause. It is now well settled that a duty arises where confidential information (that is, information to which there is limited access) is exchanged between parties in circumstances where the parties know, or *ought to know*, that the information should remain confidential. This is so even if there is no contractual agreement between the parties or even an express undertaking to maintain confidentiality. Clearly then, in the health care setting a duty of confidence is owed by all health care professionals to their patients by virtue of the nature of their relationship and the sensitive nature of information which is exchanged in the course of the relationship. This view is supported by both ethical principles and professional guidelines. The question of when confidential information can be disclosed to

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[128] See Cripps, Y.; 'Alcohol Measuring Devices and Breaches of Copyright and Confidence', 44, *Cambridge Law Journal*, 35, 1985, at 36.
[129] Wacks, 'Privacy and Press Freedom', *op. cit.*, at 104, quoting Stephenson LJ in *Lion Labs* at 546.
[130] This view was endorsed by Lord Goff in *Attorney General v Guardian Newspapers No.2*, *supra cit.*, at 282.

persons outside the relationship is dealt with, in the first instance, by reference to patient consent. Since confidentiality is the right of the patient and gives rise to a duty on the doctor, the patient should *prima facie* be consulted about any disclosure of information to others. If consent is forthcoming there can be no question of breach of confidence. If, however, consent is not forthcoming and the health care professional nevertheless discloses the information in question, this constitutes a breach of duty. The only justification possible is that the disclosure was necessary and within the terms of one of the defences to an action for breach of confidence. These have been articulated above. As we have seen, the most frequently used defence, and yet the most difficult to define, is that of public interest. In such cases, when faced with a question of justified breach of confidence, the courts must balance two public interests : that of maintaining confidentiality and that put forward as a defence for the breach.

The category of public interests which can qualify for the defence is clearly not closed. From the above cases this includes: the prevention and detection of crime, the protection of the public from dangerous individuals, and the welfare of children (or a child). However, as has been argued, the courts have been reluctant to define in clear terms the scope of this defence. In certain cases one might consider that the defence has been stretched to justify a particular outcome, as for example, the decision in *Re C*. In each case, however, the concern of the courts has been to avoid harm to third parties, be they a non-specific group such as 'the general public' or even a single child.

Thus, the determining factor in recognising third party interests - and indeed in balancing such interests with those of the confider - has been whether significant harm can be avoided by disclosure of confidential information. All of the above cases demonstrate that just as the duty of confidentiality is founded on public interest, so too can health care professionals invoke the public interest to justify breaching individual patient confidentiality if this will avoid harm to others[131]. In practical terms this places a heavy burden on the shoulders of the health care professional for neither law nor ethics nor their own professional body offers clear guidance - except in the most general of terms - as to the circumstances in which breach of duty of confidence will be justified. The matter is left entirely to the discretion of the individual health care professional.

By way of contrast consider the situation in the United States. There the courts have taken a further step in holding that in certain circumstances there is a *duty* to disclose information to third parties if this can avoid harm. If the duty is not discharged, the health care professional can face an action in negligence. Authority for this was established in *Tarasoff v Regents of the University of California*[132].

5.2.1. - *Tarasoff v Regents of the University of California*

The facts of this case involved a young man, Prosenjit Poddar, who became infatuated with a young woman, Tatiana Tarasoff. She rejected his advances and he consulted a therapist at the University of California, to whom he disclosed fantasies about killing Ms. Tarasoff. The therapist alerted the police who failed to detain Poddar successfully. On his release he disappeared and did not return to the therapist. A short time later Poddar shot and killed Tatiana Tarasoff. An action was brought by the deceased woman's parents against the University alleging that the therapist owed a duty of care in negligence to their daughter because of the knowledge he had gained from Poddar. The Supreme Court of California agreed

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[131] The public interest in maintaining confidentiality was noted in *X v Y, supra.* A recent example of the balance being struck in favour of confidentiality is found in *Morrow and Others v Director of Public Prosecutions and others* (1993) 14 B.M.L.R. 54.

[132] *Tarasoff v Regents of the University of California* 529 P 2d 55 (Cal,1974); 551 P 2d 334 (Cal, 1976).

and found the University vicariously liable. This judgment has now been applied in many of the United States[133].

The scope of the obligation to inform third parties was laid out by the Supreme Court of California as follows,

> [w]hen a [professional] determines, or pursuant to the standards of his profession should determine, that his patient presents a serious danger of violence to another, he incurs an obligation to protect the intended victim against such danger. The discharge of this duty may require the [professional] to take one or more various steps, depending on the nature of the case. Thus it may call for him to warn the intended victim or others likely to apprise the victim of the danger, to notify the police, or to take whatever other steps are reasonably necessary under the circumstances.[134]

The justification for this is found, once again, in the need to balance competing public interests. Quoting the American Medical Association the court took the view that the revelation of a communication in a *Tarasoff*-scenario is not a breach of trust or a violation of professional ethics,

> '[a] physician may not reveal the confidence entrusted to him in the course of medical attendance...unless he is required to do so by law or unless it becomes necessary in order to protect the welfare of the individual or of the community.'...[i]f the exercise of reasonable care to protect the threatened victim requires the therapist to warn the endangered party or those who can reasonably be expected to notify him,

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[133] For comment see, MacKay, R.D.; 'Dangerous Patients : Third Party Safety and Psychiatrists' Duties - Walking the Tarasoff Tightrope', 30(1), *Medicine, Science and the Law*, 52, 1990. Much criticism has, however, been levelled at the decision. First, because it requires an assessment of 'dangerousness to others' which is, arguably, impossible, it places an intolerable burden on health care professionals. Second, because the decision gives no definition of public interest this not only makes the burden on professionals doubly onerous, but also leaves the status of patient rights in a state of considerable uncertainty.

[134] *ibid*, (1976), at 340. The original text refers to the duty of the 'therapist' but in various states this has been extended to include a range of health care professionals, see MacKay, *loc. cit.*

> we see no sufficient societal interest that would protect and justify concealment. The containment of such risks lies in the public interest.[135]

This was an exceptionally unpopular decision with the professional bodies of psychiatrists and other therapists - so much so that the Supreme Court heard the case twice. Nonetheless, the decision stands to this day and has been adopted by a considerable number of states. This is an example of clear conflict of legal duties between which health care professionals are caught. The question of whether such reasoning could be extended to the UK and further, whether it could apply to the subject matter of this thesis; namely, genetic information, will be discussed in the next section.

6.1. - CONFIDENTIALITY AND GENETIC INFORMATION

As with the principle of respect for autonomy discussed in chapter three, the relevance of what has been said to genetic information and the topic of this thesis should be self-evident. Clearly, although a health care professional owes a duty to respect as confidential a patient's genetic information, conflicts can arise about access to that information and its control, and the problem becomes whether or not legally, ethically or professionally the health care professional would ever be justified in disclosing such confidential genetic information. In the particular context of this chapter, two questions present themselves. First, how do the rules relating to confidentiality apply to genetic information, especially when one considers that third parties such as relatives or the state can claim a significant

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[135] *ibid*, (1976) at 347. Most recently the Supreme Court of Tennessee has affirmed the *Tarasoff* principle in *Bradshaw v Daniel* (1993) 854 S.W.2d 865. This decision takes the rule further because it concerned a duty to warn third parties of a risk of infection from disease. Clearly, unlike *Tarasoff*, there was no threat of violence between individuals, and indeed the decision is all the more interesting because the disease which was transmitted was not contagious. For comment see, 1994 *Medical Law Review* 237 - 239.

interest in such data? Second, can there ever be a duty to disclose genetic information based on the reasoning in *Tarasoff*?

6.1.1. - A Duty to Disclose? : Confidentiality and Negligence

It is pertinent to answer the second of these questions first. What significance does *Tarasoff* have to genetics? It is interesting to note the considerable differences which exist between the facts in *Tarasoff* and any possible scenario involving a health care professional disclosing genetic information to relatives of a proband or some other interested third party. The case of *Tarasoff* was brought by the parents of Tatiana Tarasoff who had been killed by Prosenjit Poddar, a former patient of a therapist employed by the University of California. The action in negligence against the therapist's employers was successful : the court held that a duty of care was owed by the therapist to the identified third party and that this could only have been discharged by breaching the confidentiality of the original patient. The justification for imposing this duty was the avoidance of harm.

What do the facts about genetics tell us about the possibility and propriety of a *Tarasoff* duty to warn being imposed on health care professionals who deal with genetic information?[136]

First and foremost, we must remember that genetic information only allows an uncertain prediction of risk concerning the relatives of a proband. With diseases such as Huntington's Disease there can be a one in two chance that first degree relatives will be affected, but with multifactorial conditions this probability drops

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[136] This matter is also discussed by Ruth Macklin in her chapter 'Privacy and Control of Genetic Information' in Annas, G.J. and Elias, S.; 'Mapping the Human Genome: Using Ethics and Law as Guides', New York, Oxford University Press, 1992, chapter 9, at 162 - 163. See also, Husted, 'Autonomy and A Right Not to Know', in Chadwick, R., Levitt, M. and Shickle, D., (eds.); 'The Right to Know and the Right Not to Know'', Aldershot, Avebury, 1997, at 64 - 65.

considerably[137]. It might therefore be very difficult to predict the likelihood of harm to relatives[138]. Second, we must ask what kind of harm merits the imposition of a duty of care. In *Tarasoff* the harm in question was the death of a third party. Although with some genetic conditions death is an inevitable consequence of disease, with many more the most likely way in which relatives will be affected, if at all, is that they will be carriers of the condition. That is, they will suffer no adverse effects on their own health and the only physical harm which might occur will be to their future progeny[139]. Is this threat of harm enough to impose a duty of care on the health care professional? Could it ever be argued that a duty is owed to such 'future' persons? Third, we must consider the purpose of disclosure. In *Tarasoff* the court held that had confidentiality been breached, the harm would probably have been averted. With genetics, given the very limited number of conditions for which there is a cure, should a duty be imposed if nothing can be done to prevent the onset of disease? Arguably not, because the public interest advanced to justify disclosure cannot be realised by that disclosure. A final point to note concerns the cause of harm. In *Tarasoff* the duty of care to the third party was imposed because of the therapist's relationship with the patient and his knowledge that the patient might cause harm to the third party: if the therapist determines that 'his patient presents a serious danger...to another...he incurs an obligation to protect the intended victim'[140]. Genetic conditions are not 'caused' by relatives in this sense. No person poses a 'serious threat' to any living relative. This must surely be seen as another relevant factor. Yet, the extent to which these factors might influence the imposition of a *Tarasoff*-duty in the context of genetics is unclear. It is submitted, however, that courts should be very cautious about making such a move

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[137] See chapter two, *supra*.

[138] A similar argument was put in *Tarasoff* that the impossibility of predicting dangerousness should mean that no duty be imposed, *supra*, (1976) at 344 - 345. Although this was rejected, it is submitted that it should remain a valid consideration for any future extension of the duty to genetics.

[139] As is always the case with genetics, exceptions to the rule exist. For example, carriers of fragile-X syndrome *do* suffer adverse health. In the main, however, carriers are asymptomatic. Those persons with a balanced chromosomal translocation are also known as carriers.

[140] *Tarasoff* (1976), *supra cit.*, at 340.

for it is not certain that a duty could be justifiably imposed except in a few rare cases[141].

Although a *Tarasoff* duty to warn has found favour in many US states[142], the likelihood of such a duty ever being imposed in the United Kingdom is slight. As Norrie has correctly stated,

> [t]here is no 'Good Samaritan' principle in our law. The law only requires *positive* preventative action when there is a special relationship between the parties, or when the danger is caused by one of them.[143] [emphasis added]

Thus, only if a third party were a patient of the *same* health care professional (and therefore there existed between the two the necessary 'special relationship' spoken of by Norrie) would a duty of care be imposed. However, if *both* proband and relative *are* owed duties of confidentiality *and* duties of care there is real possibility of conflict for the clinician. Consider the following example. If a health care professional is aware of a genetic disorder in a family through tests on patient A, yet does not wish to offer a pre-natal test to patient B (a relative of A) for fear of alerting them to A's afflicted status, if no test is done and a baby is born with a debilitating condition, might an action lie in negligence?[144]

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[141] An additional factor warrants consideration. If a duty to warn were imposed, which did not take account of the particular facts of each condition, and primarily whether or not a cure existed, then 'a duty to warn...would not only conflict with the right of confidentiality of the patient but also with the right not to know of the relatives.' see, Nys, H.; 'Genetics and the Rights of the Patient: Informed Consent and Confidentiality Revisited in Light of Reproductive Freedom', in Westerhall, L. and Phillips, C., (eds.), 'Patient's Rights - Informed Consent, Access and Equality' (Nerenius and Santerus Publishers 1994) at 137 - 154 especially 153. The essence of such a potential 'right' is discussed *infra*. If, however, it is accepted that such a right might exist, this is another reason not to impose a duty to disclose.

[142] See MacKay, *loc. cit.*, for comment.

[143] See Norrie, K. McK.; 'Medical Confidence: Conflicts of Duties', 24, *Medicine, Science and the Law*, 26, 1984 at 29. Also, Ngwena and Chadwick, *loc. cit.*, at 87 - 89. More recently, see advice of Kennedy and Grubb in the case comment on *Bradshaw v Daniel*, *supra cit.*, 1994 *Medical Law Review* 237.

[144] Clearly, the appropriate action would be one of negligence or 'wrongful birth'. A wrongful life action brought by the child would be unsuccessful in the UK. For a discussion of these actions see, J.K. Mason and R.A. McCall-Smith, Law and Medical Ethics, Fourth Edition, London, Butterworths, 1994 at 134 - 145. See also, Beaumont, P.M.A.; 'Wrongful Life and Wrongful Birth',

This writer knows of no case decided in the UK which addressed this issue directly. Nonetheless, there might be a strong case in negligence for the general failure to inform of a risk of genetic disease[145]. Indeed, there is no difference between disclosure of a known risk of genetic disease and the disclosure of any other kind of known risk. Thus, in *Gregory v Pembrokeshire Health Authority*[146] the failure of a doctor to inform of a failed amniocentesis test[147] was held to be negligent[148].

However, such a case is different from a three-party scenario because the latter involves a conflict faced by the doctor in trying to reconcile two duties: the duty of confidentiality to the original proband and the duty of care to prospective parents. In one respect this is akin to the circumstances in *Tarasoff* in that the clinician faces a dilemma in the guise of two duties, only one of which can be discharged effectively. However, in contrast to *Tarasoff*, a 'special relationship' *does* exist between the third party (as patient) and clinician and further, the knowledge of the risk imposes a considerable burden on the clinician to disclose information in order to meet the standard of care required.

It is submitted that in such circumstances disclosure is more advisable than maintaining confidentiality[149]. This is so for two reasons. First, the harm which is

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in McLean, S.A.M.; 'Contemporary Issues in Law, Ethics and Medicine', Aldershot, Dartmouth, 1996, chapter 6.

[145] The determination of this question would almost entirely concern the domain of 'current practice'. That is, the question to be asked would be, what would other clinicians have disclosed? See, *Hunter v Hanley* 1955 S.L.T 213; *Bolam v Friern Hospital Management Committee* [1957] 2 All E.R 118; *Sidaway v Board of Governors of Bethlem Royal and Maudsley Hospital* [1985] 2 W.L.R 480. In a few recent cases, however, the English courts have been more willing to challenge medical opinion on what should or should not be disclosed to patients, see *Defreitas v O'Brien and Another* [1995] 6 Med LR 108, *McAllister v Lewisham and North Southwark Health Authority* [1994] 5 Med LR 343, *Smith v Turnbridge Wells Health Authority* [1994] 5 Med LR 334, and *Bolitho v City and Hackney Health Authority* [1993] 4 Med LR 381.

[146] [1989] 1 Med. L.R. 81

[147] Such a test can disclose fetal predisposition to a range of genetic disorders.

[148] The case failed, however, on the point of causation: the plaintiff failed to show that if she had known of the result of the first test she would have had an abortion.

[149] This is subject to the application of a calculus of risk test. That is, an assessment of likelihood of disease, severity of injury likely to be sustained, the availability of precautions etc.

likely to occur if disclosure is not forthcoming and which can be avoided by disclosure, will be enough to justify breaching the duty of confidence within the rules specified *supra* and further discussed *infra*. Second, on a pragmatic point, it is more likely that an action will be brought in negligence rather than breach of confidence simply because of the respective states of development of the two areas of law. The law of confidence is less well developed than the law of negligence and few are willing to act as test cases to further the development of an uncertain area of law. The myriad negligence actions mean that there is more certainty of the parties' rights in this field and even if this does not lead to a court action, the chances of an out-of-court settlement are high[150].

Such cases aside, if no 'special relationship' exists between the third party and practitioner, it is submitted that the only way sensitivity can be shown to all interests concerned is if no *duty* to disclose is imposed. At best, health care professional should be given a *discretion* to disclose confidential information[151]. The limits within which such discretion could operate are dictated by the public interest exception.

6.2. - THE PARAMETERS OF PUBLIC INTEREST

It has been shown that an appeal is made to the public interest to justify both the existence of, and the limitations on, the duty of confidentiality. *Prima facie* it is assumed that the duty is owed by a health care professional to a patient but that this can, in justifiable circumstances, be overridden. Although the legal cases studied above offer little guidance, and ethics is also of limited assistance, it is

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[150] Mason and McCall-Smith, *op. cit.*, are of the opinion that 'most cases [of wrongful birth] are settled out of court', at 135.

[151] This view is supported by the Nuffield Council on Bioethics; 'Genetics Screening: Ethical Issues', December 1993, at 5.29.

nevertheless possible to identify certain factors according to which the public interest defence must operate.

Axiomatically, in order to determine which circumstances provide justification for breaching a confidence at the discretion of the health care professional it is necessary to identify a relevant public interest. Furthermore, it is necessary to demonstrate that the breach of the confidence will *de facto* further the competing public interest, or at least that there is a reasonable likelihood of this. Thus, for example, the public interests of preventing harm to others and halting the spread of disease are relevant factors when treating patients infected with HIV. Arguably, these interests can be furthered by informing the sex partner of an intransigent seropositive patient of the infected state of the latter[152]. In this way, the sex partner can make future informed decisions, *inter alia*, about unprotected sexual relations with the infected person. If they choose to act responsibly infection will not take place and the public interests which served as justification for breaching the patient's confidentiality will be furthered[153].

If, however, a public interest cannot be realised, the justification for breaching patient confidentiality is, arguably, lost. It might be argued, for example, that it is in the public interest to make HIV and AIDS notifiable diseases[154], but in the absence of therapeutic treatment this would not, of itself, prevent further spread of either condition. What possible justification for disclosure could then be made? One might argue that other public interests could be served such as the collection of valuable data about the spread of HIV and AIDS. Whereas this is true, it poses the question of whether other means could be used to realise such an aim while at

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[152] For commentary on this see, Boyd, K.M.; 'HIV Infection and AIDS: The Ethics of Medical Confidentiality', 18, *Journal of Medical Ethics*, 173, 1992 and Guttmacher, S.; 'HIV Infection: Individual Rights v. Disease Control', 17(1), *Journal of Law and Society*, 66, 1990.

[153] Of course, this must always be balanced against the perceived risk of harm to the therapeutic relationship more generally, see *X v Y*, *supra cit.*

[154] In the UK neither AIDS nor HIV is notifiable.

the same time maintaining patient confidentiality: in this case, anonymised screening programmes.

From the above, several conclusions can be drawn about the role of 'the public interest' in determining the scope of the duty of confidentiality in the therapeutic alliance between health care professional and patient. First, it is important to identify the public interests which might compete with the weighty public interest in maintaining confidences. Second, it must be asked whether such interests are strong enough to compete. Third, there must be a reasonable likelihood that the competing interest will be realised if a breach of confidence is made. Finally, alternative means of realising the competing public interest should be explored and if such exist, they should be preferred to a breach of confidence.

In addition, what has been said about the nature of genetic disease and the relative paucity of cures must be borne in mind. These factors have a direct bearing on any decision concerning the use to which genetic information is put. Indeed, together with what has been said about the role of the public interest, these facts provide a model to determine the legitimate boundaries of the duty of confidentiality with regard to genetic information.

A consideration of the genetic information conflict scenarios outlined in previous chapters will facilitate a full and proper discussion of the adequacy of the law of confidence in addressing the issues detailed above and the problems surrounding genetic information and the protection of individual privacy interests. That is, as with the format adopted in chapter three, we shall apply the concept of confidentiality to each of the four scenarios in order to determine the extent to which it provides adequate protection of the informational and spatial privacy interests of the individuals who are the subject of these scenarios.

7.1. - SCENARIOS

It will be remembered that the privacy interests which arise in the four scenarios are as follow:

First, scenario one concerns (a) the informational privacy interests of individuals in preventing employers and insurers gaining access to existing genetic information, and (b) the spatial privacy interests of individuals in resisting testing at the behoof of employers and insurers.

In the second scenario we are concerned primarily with the spatial privacy interests of adults, children and 'future persons' who are subjected to screening programmes by the State. Relatedly, in the case of ante and post-natal screening the informational privacy interests of neonates and 'future persons' are also at stake.

In scenario three the privacy interest under scrutiny is the informational privacy interest of a proband who resists disclosure of his test results to relatives.

Finally, scenario four concerns the spatial privacy interests of family members in not being given unsolicited information by a relative about a familial genetic disorder.

It should be immediately apparent that the law of confidence can only assist in addressing two of the scenarios outlined. These are :

- *Scenario one* which relates to an employer or insurer's right to have access to patient files, and

- *Scenario three* concerning the family's right to know the genetic information of a relative who is a sufferer of haemochromatosis.

Scenario two - which involves questions of the acceptability of state programmes for premarital, ante-natal and post natal screening, and *scenario four* - which deals with a family's right not to be told genetic information - cannot be considered successfully from the perspective of confidentiality for the reasons offered below.

7.2. - Scenario Four: The Limits of the Law of Confidence

It is appropriate to begin by examining scenario four because it most clearly involves a relationship between the parties in conflict (important for the law of confidence), and furthermore it most clearly demonstrates the reasons why confidentiality is not helpful in protecting the spatial privacy interests of individuals.

In scenario four the question at issue is whether a sister should tell family members that she is affected by breast cancer and that they too might be affected. We are concerned here simply with the question of a right not to know information, and that right - if it exists - is that of the family members[155].

Prima facie, the sister will be owed a duty of confidence by her health care professional. This entitles her to decide whether and how the information which is the source of the duty should be disclosed to others. If, then, she decides to disclose it to the other members of her family then there could be no question of a breach of the doctor/patient duty of confidence. Clearly she cannot herself breach a duty which is owed to her by another. Her's is not the duty but the right. Thus, for her

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[155] Similarly, we are not concerned with the question of whether the sister is *required* to disclose genetic information.

disclosure to amount to a breach of confidence it must be seen to be an invasion of *someone else's right* and a breach of *her duty* to maintain confidentiality. Can the family scenario envisaged by scenario four fit into this rubric?

The first matter to determine is whether a duty of confidence arises as between the relatives. In order to determine this it is necessary to ask the following questions: does the information have the necessary quality of confidence, and was the information imparted in circumstances which impose an obligation of confidence[156]. The answer to the first of these questions is easily given as yes. It is now well settled that personal information which is not of the nature of tittle tattle and which is not part of the public domain can be protected as confidential information[157]. The second question is unfortunately less easy to answer. The confidential information must be *imparted* in circumstances which give rise to an obligation of confidence. This would tend to imply that the confider must furnish the confidant with the confidential information. Yet, in our scenario the person to whom a duty might be owed, namely the relative, does not even know that the information exists, and therefore certainly could not *impart* it to any other person. That said, in the context of the doctor/patient relationship one can easily imagine a scenario where information might be known to the doctor about the patient and yet the patient might not be aware of its existence. In such a case one would never say that a duty of confidence is not owed. An example of this is blood test results. A doctor may be in receipt of blood test results and feel that it would not be in a patient's interests to reveal them, but, if the doctor revealed the results to a third party without just cause, there can be no doubt that he would be in breach of patient confidentiality. Of course, this might be because of the professional ethical obligation - embodied in materials such as the Hippocratic oath - which binds a clinician in the terms such as the following : '*all* that may come to my knowledge

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[156] *supra*, section 4.1.

[157] First confirmed in *Stephens v Avery* [1988] Ch 449 at 454 - 455.

in the exercise of my profession or outside of my profession or in daily commerce with men, which ought not to be spread abroad, I will keep secret and will never reveal.'[158] If so, this example does not help us in our present problem.

In the *Spycatcher* decision[159], it was held that persons can come under a duty of confidence even when confidential information is not given to them by the confider directly or by someone who is clearly under such a duty: for example, where an obviously confidential document is wafted by a fan out of a window into a crowded street, or a private diary is dropped in a public place[160]. One could then, perhaps draw the analogy between reading someone's private diary without their permission and having knowledge of the person's genetic information without the other's knowledge (through one's own test results). Again, however, this analogy is not helpful because in the example of the diary the person to whom the duty is owed is aware of the existence of the confidential information. The same is not true concerning the genetic information. In essence the question being asked here is the following: do we require an original confider or can information assume the necessary quality of confidence even if the person to whom the right is owed does not know of its existence. A possible answer might come from the recent decision in *Hellewell v Chief Constable of Derbyshire*, discussed above. In that case, albeit in *obiter dicta*, it was stated that,

> If someone with a telephoto lens were to take from a distance and with no authority a picture of another engaged in some private act. His subsequent disclosure of the photograph would...as surely amount to a breach of confidence as if he had stolen a letter or diary in which the act was recounted and proceeded to publish it[161].

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[158] There are various texts of this Oath, all of which, however, embody the same sentiment. The passage cited was taken from Mason and McCall-Smith, 'Law and Medical Ethics', *op. cit.*, Appendix A.

[159] *supra cit.*

[160] *ibid*, at 281, *per* Lord Goff.

[161] *ibid* at 807.

This is interesting and helpful for several reasons. Note, first, that there is no need that the person 'taking' the information be engaged in illegal acts in doing so. In previous cases it had been held that those who acquire confidential information illegally are bound by a duty of confidence, even if there is no relationship between the parties[162]. Second, there is no need for a pre-existing confidential relationship between any parties from which the duty of confidence can be passed to others. In older decisions it was always thought to be the case (except with illegally obtained information) that such a relationship must exist. Wacks has argued that authority exists to support the view that a relationship is no longer necessary[163], and if this is so, one might be able to argue in the circumstances of our problem that a duty of confidence can be owed between the sister who has been tested for breast cancer and her female relatives also likely to be affected by the disease.

A related issue concerns the question of the proper person to whom the duty is owed. In the *Hellewell* example the implication is that a duty of confidence is owed to the person who is the focus of the telephoto lens because the information which is received is about that person. In the context of genetic information, as has been discussed in previous chapters, the information relates only in part to relatives. It is not, therefore, entirely about them. This might alter the view one takes of the appropriateness of saying that a duty of confidence is owed to relatives concerning such information[164]. That said, if one accepts the points put in the foregoing paragraphs, it would be sufficient to take a marginally liberal view of the 'shared' nature of the genetic information to hold that a duty could be owed between relatives.

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[162] See, for example, *Franklin v Giddins* [1978] 1 QdR 72.

[163] Wacks, Privacy and Press Freedom, *op. cit.* at 59 - 71.

[164] This is not a merely pedantic point. It matters very much whether or not a duty can be owed to someone simply because the confidential information is about that person. If, on the other hand, the duty is owed to the confider (who him or herself might be under a duty of confidence) then the person with whom the information is concerned will not be able to avail him or herself of a remedy using the law of confidence.

Yet, even if one is persuaded that a duty of confidence exists, the far more crucial question is whether or not that duty can be breached by one relative *telling the person to whom the duty is owed* the information in question. This must surely be a nonsense. A duty of confidence is breached when the confidential information is used or disclosed to those outside the confidential relationship. This is well established[165]. Inherent in the concept of confidentiality is the idea that a breach of duty is constituted by the making of the information in some way 'public'[166]. Precisely how 'public' use or disclosure must be is a matter of debate, but it cannot be the case that disclosure of information from one party to a confidential relationship to the other party in anyway makes the information 'public'. This then means that even if a duty of confidence is owed by one sister in our scenario to her female relatives, she could not breach that duty by disclosing the information to the women themselves[167].

To conclude these arguments concerning scenario four: it is submitted that the law of confidence cannot help to establish a valid legal basis for a right not to know information because it is not clear that, even if a duty of confidence is owed between relatives concerning their common genetic information, such a duty could ever be breached simply by telling the relatives themselves about their own personal information.

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[165] See, for example, Stair Memorial Encyclopaedia, volume 18, *op. cit.* at para. 1476, Halsbury's Laws of England, Fourth Edition, volume 8(1), paras. 480 - 482, Gurry, Breach of Confidence, *op. cit.*, chapter twelve.

[166] If the information is already in the public domain no duty of confidence can arise. Relatedly, if a duty does exist but the 'confidential' information is put into the public domain then the duty in question immediately ceases to exist. If the confidant is the person who has put the information into the public domain, s/he can, at least in commercial circles, be barred from exploiting the information thereafter for his/her own ends by virtue of the 'springboard doctrine', see: *Terrapin Ltd. v Builders' Supply Company (Hayes) Ltd.* [1967] RPC 375.

[167] Of course one might argue that for A to disclose information to C would be a breach of the duty that A owed to B, but given that the same information is the source of the same duty to the respective relatives, it is not clear that this argument would succeed because this would be to argue that A was in fact breaching her duty to B by disclosing information to C which was nevertheless also about C and concerning which A also owed a duty to C.

7.3. - Scenario Two: The Limits of the Law of Confidence

It should also be noted that scenario two as described above - which concerns the acceptability of screening programmes - cannot be addressed adequately through the law of confidence[168]. This is because the requirement by the State that certain persons undergo genetic testing may well give rise to a duty of confidence (which would exist between those who receive test results on behalf of the State and those who are the subjects of such tests), but the law of confidence cannot help in addressing all of the interests which arise from such testing practices. Principally, and as discussed in previous chapters, such interests include an interest in not being forced to know information which might be to one's detriment. The arguments for this are essentially those made above in relation to scenario four. Thus the interference with spatial privacy interests which is inherent in the practices outlined in scenario two, cannot be prevented by an appeal to the law of confidentiality. The only help that the law could offer in such cases concerns the screening of new-born children who have informational privacy interests in the test results. Arguably, as has been stated, those who possess such results should maintain confidentiality.

It thus becomes apparent that the law of confidence cannot address the question of protecting a possible right not to know information that might arise in either of the two scenarios described above. As with the law of autonomy, this is a serious limitation on the role of the law of confidentiality in the field of genetic information given the not inconsiderable interests which individuals might have in

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[168] The same is true of part of scenario one which deals with the right of employers and insurers to require individuals to undergo genetic testing.

such a right. Put otherwise, the law of confidentiality is entirely ill-equipped to protect individual spatial privacy interests.

Accepting this limitation, what now follows is an account of how the law of confidence deals with the issues arising in scenarios one and three.

7.4. - Scenario One: The Interests of Employers and Insurers and the Law of Confidence

Does confidentiality protect individual informational privacy interests of those suffering from $alpha_1$ - antitrypsin when employers or insurers seek access to medical records to determine whether someone has this condition or whether they have been tested for the condition?[169]

In these circumstances it matters very much whether the health care professional is in the employ of the insurance company or the employer in question. If so, then he or she owes a duty of fidelity to his or her employer and this will require that they pass relevant information on. This is why insurers will frequently require that prospective insured attend the insurers' own clinicians. Similarly, a workplace doctor who is employed to carry out regular 'check ups' on staff is bound by the terms of his or her contract to deliver information to the employer which might have a bearing on the employer's business. In such circumstances the legal positions of the doctor and the 'patient' are laid out primarily in the *Access to Medical Reports Act* 1988. This Act establishes a right of patients to have access to reports prepared by a health care professional for employment or insurance purposes[170]. Section 3 of the Act provides that an employer or insurer shall not

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[169] The other question posed by scenario four cannot be adequately dealt with by the law of confidentiality. The question is whether employers or insurers can carry out tests on individuals to determine their genetic status. For the same reasons argued in respect of state practices which amount to the same, the law of confidence cannot adequately address the issues and interest which arise.

[170] Access to Medical Reports Act 1988, c.28, s.1.

apply to a medical practitioner for a medical report relating to any individual unless (a) the individual is notified in advance, and (b) written consent is provided by the individual. In this way the possibility of breach of confidence is avoided because consent is provided by the subject in question[171].

The rights provided to the individual under the Act include[172]: the right to be informed that disclosure is sought[173], the right to request sight of the report before it is supplied[174], the right to refuse disclosure[175], the right to request amendment of the report[176], the right to attach one's own comments to a report which the health care professional (HCP) has refused to amend[177], and the right to have access to any report supplied in the previous six months[178].

It should be noted that the right of access is limited in certain important respects. First, access to the report in whole or in part[179] can be denied if the HCP considers that disclosure would be likely to cause serious harm to the physical or mental health of the individual or others or would indicate the intentions of the practitioner in respect of the individual[180]. Second, disclosure need not be made if the report - in whole or in part[181] - is likely to reveal information about another person, or to reveal the identity of another person who has supplied information to the HCP about the individual, unless the third party consents or the third party is an HCP[182].

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[171] Of course, one could easily mount an argument that consent in such cases will rarely be 'freely' given in that the individual is in a substantially weaker position compared to the employer or insurer for fear that a refusal would affect employment or insurance chances.

[172] The Act only relates to reports prepared after 1 January 1989, the date of coming into force of the Act.

[173] *ibid*, s. 3.

[174] *ibid*, s.4(1).

[175] *ibid*, s.5(1).

[176] *ibid*, s.5(2).

[177] *ibid*, s.5(2)(b).

[178] *ibid*, s.6(2).

[179] *ibid*, s.7(3).

[180] *ibid*, s.7(1).

[181] *ibid*, s. 7(3).

[182] *ibid*, s.7(2).

The most important limitation on this Act is, however, that it only extends to reports prepared by an HCP who 'is or has been responsible for the clinical care of the individual'[183]. Thus an insurer or employer can avoid these provisions simply by requiring the individual to see a new doctor (possibly their own). In such cases before information is revealed to the employer or insurer it will be taken that the patient has tacitly consented to disclosure by virtue of the fact that s/he has presented him or herself for examination. However, the question of whether such 'consent' can be seen to be valid or informed consent arises. Certainly, if the examination is carried out as a form of 'fishing expedition' it is hard to see how previously unknown information about one's health can be disclosed with one's consent, if one does not know that it exists and if one is not informed of this before disclosure. Moreover, the element of coercion which is inherent in a request to see an unfamiliar health care professional further calls into question the validity of tacit consent. An individual may of course refuse to attend for examination but the consequence may well be refusal of insurance or employment or adverse consequences for current employment[184]. Fear, rather than a willingness to allow disclosure, might be the motivating factor in such cases. Nevertheless, this analysis of tacit consent is the most convincing to explain the limits of an HCP's duty in confidence to those examined on behalf of employers or insurers.

Thus, although it has already been explained that genetic testing in such cases does not presently occur in the UK, and further it has been argued that it should not, the present legal view of such medical examinations from the perspective of confidentiality is that disclosure to those seeking the information, namely the employer or insurer, would not be a breach of confidence because of the 'consent' implied from the individual's apparent willingness to undergo examination.

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[183] *ibid*, s.2(1) and *Data Protection (Subject Access Modification) (Health) Order 1987*, S.I. 1987/1903.
[184] Subject, of course, to protection measures in employment law.

7.4.1. - Scenario One: A Conclusion

The law of confidence is stretched to its limits in the context of requests for access to information by employers and insurers. It is questionable whether it adequately protects the informational privacy interests of individuals from whom the information is sought. In the main, the concept of individual consent 'authorises' disclosure in such cases. If the request for a medical report is made to an HCP who has treated the individual in the past the provisions of the *Access to Medical Reports Act* 1988 require that written consent be obtained and that access be granted within limited circumstances. Arguably on one view this goes a long way to ensuring that the interests of the individual are taken into account. However, if the request concerns an HCP who has never before treated the individual then the provisions of the Act do not apply. In such cases an argument can be made that tacit consent to disclosure can be inferred from the fact that the individual attends the HCP, but the nature and quality of such consent is open to serious question. That said, it is the opinion of the present writer that in circumstances where such an HCP disclosed medical data to an employer or insurer on request and to no other person, an action for breach of confidence would not be successful. This is so even if the medical information was not previously known to the individual in question.

7.5. - Scenario Three: The Family's Right to Know and the Law of Confidence

Scenario three concerns the dilemma of a health care professional (HCP) who has knowledge that a relative of his patients has haemochromotosis. From what has been said about the law of confidence it should be clear that the unauthorised receipt of such information by the health care professional from the doctor of the affected relative is in itself a breach of confidence for which a common law remedy could be sought. From the perspective of the HCP who receives this information, the dilemma which he faces is whether he should reveal the information to his own patients when this directly interferes with the original patient's informational privacy interests. It has already been argued in chapter three that in the first instance the most ethically acceptable course of conduct would be to approach the affected individual (either directly or through his own health care professional) to encourage him to inform relatives or to seek permission allowing others to do so. If, however, permission is refused but the health care professional considers that he should nevertheless inform his own patients of their relatives' condition, the obvious question which arises is whether he can do so without breaching the law of confidence.

However, the logically prior question is whether the health care professional (Dr. Smith) owes a duty of confidence to the affected individual (Kenneth) given that the latter is not a patient of the former. For all of the reasons outlined above, and because of the nature of the practice of medicine itself, the answer to this must surely be affirmative. This means that *prima facie* Dr. Smith is bound to respect the confidentiality of Kenneth, and so the wishes of Kenneth to keep his genetic information private. Thereby, it would seem that the law of confidence *can* protect Kenneth's informational privacy interests. However, as we know, the duty of confidentiality is not absolute. And, given that Dr. Smith faces a dilemma about whether he should nevertheless inform his own patients of Kenneth's status, we must ask on what grounds could he justify disclosure against Kenneth's wishes? The most likely answer lies in the public interest.

7.5.1. - *Competing Public Interests?*

One way to consider the public interest defence is to turn it on its head and ask: which public interests might be *jeopardised* by non-disclosure of genetic information?[185] As we have seen, the interest in preventing harm to others is of paramount importance and considered to be of sufficiently significant weight to challenge confidentiality. However, can harm be prevented by disclosure in the context of genetics? Arguably, if a cure for a particular debilitating condition existed it would be foolhardy not to inform relatives of their predisposition to such a condition. This is especially true if pre-emptive treatment could prevent the onset of disease[186]. With haemochromatosis it has already been explained that although no cure is available early diagnosis can lead to effective treatment by phlebotomy and this can reduce considerably the risk of fibrosis. Because haemochromatosis is a recessive disorder the average chances of relatives in a family being affected range from 25% - 50% in each case[187]. However, there is also a 25% - 50% chance in each case that relatives might be asymptomatic carriers and it becomes less clear in the case of these individuals that disclosure of information about risk which is in breach of another's confidence is justifiable *in the public interest*. In such cases the risk of harm is harm to choice (the choice whether or not to procreate) and this, it is submitted, weakens considerably the force of the public interest argument[188].

One answer might lie in the minimisation of harm generally. This involves the recognition that various forms of harm can arise from disease; the unrelenting progress of disease itself is but one form of such harm. Psychological harm can

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[185] This is indeed how the public interest is currently viewed by the courts, see Stair Memorial Encyclopaedia, volume 18, paragraph 1484. See the Law Commission which recommended in 1981 that confidentiality should only be enforced when it was in the public interest to do so, thus making it the case that a public interest defence would succeed if the public could benefit from disclosure. (*ibid* 1484).

[186] Yet, in circumstances where a cure *is* available but an individual would not choose to take it - perhaps for religious reasons - it is hard to see how disclosure could ever be justified because the perceived harm could never be avoided. This point has been made in chapter three where it was argued that to proceed to disclose the information in such circumstances would be unduly paternalistic.

[187] *Supra*, chapter two.

[188] As Ngwena and Chadwick have pointed out (and as has been argued in chapter three) '[i]t is not clear...why choice in this area should be given higher priority than choice over the use of personal information...[and] it is not clear that harm to *choice* itself is sufficiently serious to warrant disclosure.', Chadwick and Ngwena, 'Genetic Diagnostic Information and the Duty of Confidentiality: Ethics and Law', *loc. cit.*, at 86.

occur, for example, from the unpreparedness of sufferers faced suddenly with a clinical condition or the knowledge that they could pass such a condition to their progeny[189]. Such harm can, arguably, be minimised by the knowledge that disease will, one day, manifest itself. This allows the individual time to come to terms with their fate and to commence, where possible, early supportive counselling. The view that this provides justification for disclosure of an individual's test results to relatives has found support from several commentators[190]. Yet, as has been argued above, if disclosure is made to avoid an ancillary harm such as psychological upset there is less of a guarantee that the harm in question will, *de facto*, be avoided[191]. That is, it is not clear that the public interest which one seeks to further by disclosure, will be achieved by disclosure.

Relatedly, the health care professional faced with this dilemma is restricted in at least one further way. Although one can establish statistically the abstract chances of members of a family being affected by a recessive disease (as has been done above), in practice there is no way of knowing which individuals might or might not be affected or have carrier status. To be truly effective disclosure would require to be made to a wide circle of persons with possible diminishing utility[192]. Thus the confidentiality of the proband would be breached on many occasions with unpredictable, and possibly minimal, results. Whereas this is certainly true with multifactorial conditions, it is less true with monogenic conditions such as

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[189] See Ball, D., Tyler, A. and Harper, P.; 'Predictive Testing of Adults and Children' in Clarke, A. (ed.), 'Genetic Counselling : Practice and Principles', London, Routledge, 1994, at 70 - 72 quoting several others including, Hayden, M.R.; 'Predictive Testing for Huntington's Disease: Are We Ready for Widespread Community Implementation?', 40, *American Journal of Medical Genetics*, 515 and Brandt, J. *et al*, 'Presymptomatic Diagnosis of Delayed-Onset Disease with Linked DNA Markers: the Experience in Huntington's Disease', 261, *Journal of the American Medical Association*, 3108, 1989.

[190] *ibid.*

[191] Kevles, D.; 'In the Name of Eugenics: Genetics and the Uses of Human Heredity', London, Penguin Books, 1985, at 298, Andrews, L.; 'Legal Aspects of Genetic Information', 64, *Yale Journal of Biology and Medicine*, 29, 1990, at 38, and Craufurd, D., Dodge, A., Kerxin-Storrar, L. *et al.*; 'Uptake of Presymptomatic Predictive Testing for Huntington's Disease', 2, *The Lancet*, 603, 1989.

[192] It should be noted, however, that if a high number of close relatives are affected by a severe disorder there is more of a chance that relatives will be affected. That said, the percentage rate remains below or around fifteen percent.

haemochromatosis. As has been argued, in the case of this family scenario, if Dr. Smith can establish that the parents are not affected and are not carriers then there can be no further risk to other family members. Thus if he decides to use the public interest defence to justify a breach of Kenneth's confidentiality, his approach should, in the first instance, be simply to those two individuals.

7.5.2. - *Public Interest in Public Health*

In addition to the above, the question arises of whether different public interests might be invoked to justify disclosure. For example, it might be argued that disclosure of genetic information to relatives could be justified on the grounds of halting the spread of genetic disease. Although little or nothing can be done for those already afflicted by genetic disorders, disclosure might prevent the transmission of defective genes to future persons.

The public interest in preventing the spread of disease is an extremely important one but the point has already been made in chapter three that in the context of genetic disease the furtherance of this public interest is hindered by one factor: there is no certainty that even if disclosure is made people will no longer reproduce. This, coupled with the fact that the interest can only be furthered through a breach of confidence, casts considerable doubt on this justification. Furthermore, potentially more effective means by which this public interest can be furthered exist (such as counselling services, prenatal testing and abortion) which do not involve breaching confidentiality.

7.5.3. - *Who is the 'Public' in the Public Interest?*

A final question mark hangs over the acceptability of an appeal to the public interest in our scenario. Who is the 'public' in the public interest? Clearly, it cannot be the general public, in the sense of the community at large, for the only public interest which serves them is that concerning the reduction of the general incidence of disease (primarily a cost argument), but this has been questioned above. More cogent is the argument that the public interest at stake is that concerning reduction of harm - even if such harm is restricted to members of the affected person's family who are patients of our doctor. In particular, our scenario identifies five individuals: Ewan, the uncle of Kenneth who is affected by haemochromatosis, his wife Elizabeth (whose family also has a disease history), their children Michael and Marlene, and Michael's wife Michele (who cannot be affected herself, but might give birth to a child who is a carrier). Do these people constitute a 'public'? The cases which have been decided on public interest to date do not address the question of 'who' is the public. Yet the case of *Re C (a minor) (evidence : confidential information)*[193] - in which it was held that a doctor was entitled to disclose a confidential report on the fitness of a mother to care for her child because it was in the 'public interest' to do so - might be seen as authority for arguing that the family could in our scenario constitute a 'public' which had an interest in receiving confidential information. Certainly the ruling in *Re C* offers a generous interpretation of public interest, given that the interests at stake were those of a single child[194].

7.5.4. - *Scenario Three: A Conclusion*

The above demonstrates that although Dr. Smith owes a duty of confidence to Kenneth, it might be possible for him to argue a public interest defence if he chose

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[193] *supra cit.*

[194] In *Schering Chemicals Ltd v Falkman Ltd* [1981] 2 WLR 848 at 869, Shaw L.J. said : 'If the subject matter [of the duty of confidence] is something inimical to the public interest *or threatens individual safety*, a person in possession of knowledge of that subject matter cannot be obliged to conceal it although he acquired that knowledge in confidence'. Cripps has commented on this that, '[t]he specific reference to the safety of an individual as opposed to the safety of "the public" or "the State" is new and welcome', see Cripps, Y.; 'The Legal Implications of Disclosure in the Public Interest', Second Edition, London, Sweet & Maxwell, 1994 at 198.

to disclose Kenneth's medical condition to members of Kenneth's family. This would mostly justifiably be done with a view to avoiding harm. However, that this could be justified is due largely to the vague terms of the public interest defence as defined by the courts and this argument must be accompanied by the general caveat that the defence must satisfy the three basic criteria outlined at the beginning of this section, namely; (1) a relevant public interest must be identified (here it is avoidance of harm), (2) breach of the confidence should further the competing public interest or at least that there is a reasonable likelihood of this (there is some doubt about this in our scenario), and (3) if alternative means of realising the competing public interest exist, they should be preferred to a breach of confidence.

7.5.4.1. - *The Limits of Confidentiality*

The above analysis of the role of the public interest allows us to determine more clearly the rights and duties of the parties to the confidential relationship as well as those of interested third parties concerning genetic information.

From what has been said it is clear that the following factors are important and should be given due consideration when a health care professional is contemplating a breach of confidentiality. These are: the existence of therapies or cures for the condition; the probability of manifestation and the severity of the condition; the question of whether the individual relative will be affected directly or whether s/he is a carrier, and the question of whether disclosure can actually further the public interest which concerns the confidant. If disclosure is made, the problem arises of balancing the public interest in maintaining confidentiality and the public interest in disclosure to determine the nature and scope of the rights and duties of parties to the initial confidential relationship. Emphasis is placed on the restricted nature of the public interest exception: disclosure should only be to those who can further the public interest in question[195]. In our scenario, these parties are the health care professional and Kenneth who is affected by the genetic condition, haemochromatosis. *Prima facie*, the law of confidence ensures that the security of Kenneth's information should be respected and this ensures respect for his informational privacy interests. An argument might, however, be made that breach may be justifiable in the interests of Kenneth's relatives. If this is accepted no action will lie against the health care professional. Arguably, for this to be accepted disclosure should only be made in the first instance to Ewan and Elizabeth to determine their status. This is in keeping with legal authority which holds that disclosure of confidential information in the public interest is acceptable only if it is done to those who can further the interest and if that circle of disclosure is restricted[196]. Yet, all of this presupposes that it is indeed in the interests of third parties to receive such information and further that the determination of this matter falls to the health care professional. However, and as has been argued, with genetic information this might not be the case. Furthermore, what the law of confidence cannot do is give any recourse to relatives if they feel that disclosure should not have been made or that they have been harmed as a result. Nor does it require that the health care professional take account of the willingness of third parties to receive such information. That is, whereas the law of confidence may protect in certain circumstances individual informational privacy interests, the same is not true for individual spatial privacy interests.

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[195] See, for example, *W v Egdell, supra cit.*

[196] See *Re C* and *W v Egdell, supra cit.*

8.1. - CONFIDENTIALITY & GENETIC INFORMATION: A CONCLUSION

Despite the uncertain nature of the precise basis upon which the duty of confidence lies, in the medical context it is indisputably held out as a valuable principle drawing authority from ethical, professional and legal quarters. However, it has also been shown that the duty is by no means seen as absolute by any of these fields in the United Kingdom. Confidentiality is seen as the right of the patient and the duty of the health care professional within certain rather ill-defined parameters. Focusing primarily on the legal perspective, this chapter has attempted to outline the limits of the legal duty of confidence. From the perspective of genetic information, it has become clear that the law of confidence is of limited value in resolving the problems which arise from our case scenarios. In particular, it is wholly inadequate in protecting spatial privacy interests.

9.1. THE PROTECTION OF PRIVACY INTERESTS BY AUTONOMY AND CONFIDENTIALITY

This section draws to a conclusion the first part of this thesis. We have examined the nature of privacy interests which individuals have in genetic information and identified those as being of two kinds: informational privacy interests which concern issues of security of existing information, and spatial privacy interests which relate to the protection of the self from unwarranted intrusion, including intrusion with information about one's own self. We have seen in the last two chapters how the existing concepts of autonomy and confidentiality fare in protecting both of these types of privacy interests. We can conclude easily that the major problem arises in the context of spatial privacy. The law of confidentiality is entirely useless in protecting this interest, and the law of autonomy does not achieve much better. Both confidentiality and autonomy can, to an extent, help to protect informational privacy but it is submitted that to leave protection to these concepts is a wholly unsatisfactory situation. What is needed is a useful, precise and effective means not only of talking about all of the interests involved, but also of protecting them in an appropriate fashion. The solution which is proposed in the next chapter is that of a legal concept of privacy. The notion of privacy which has so far been advanced in this work is expanded and fitted into the framework of the broader debate about privacy *in se*. The definition of privacy already argued for is defended further and applied to the genetic information scenarios to show how the *privacy* interests involved can best be protected by an appeal to *privacy* itself.

CHAPTER FIVE

PRIVACY AND GENETIC INFORMATION

1.1. - INTRODUCTION

Previous chapters have outlined the nature of the definition of privacy offered in this work and have given an account of the problems which arise from genetic testing and the availability of genetic information. It has been argued that the concepts of autonomy and confidentiality go some way to addressing these problems but that in doing so these concepts give rise to problems of their own. This chapter seeks to give an account of how privacy - as a general concept - has been explained and applied to date. Broadly, the chapter will examine how various accounts of the concept lie with the view of privacy offered in this work. In particular, this chapter will defend this latter definition of privacy and apply that definition to the problem scenarios which are set out in chapter two and which have already been examined in chapters three and four from the perspectives of autonomy and confidentiality. The chapter will conclude that the concept of privacy as here presented is a valuable adjunct to the existing concepts of autonomy, confidentiality and liberty all of which already play an important role in the provision of health care. It will be argued that proper protection of individual rights and interests and the attainment of balance between these and competing rights and interests in the context of genetic information cannot be achieved without due recognition of the complementary value of privacy.

2.1. - THE PUBLIC/PRIVATE DISTINCTION

It has already been stated that the existence of a distinction between public and private spheres of life is central to the western liberal tradition[1]. This phenomenon arises from the commitment of that tradition to *individualism*. Thus, the public/private distinction grew in importance with the rise of popularity of

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[1] See chapter one.

individualism in western culture in the course of the last few centuries[2]. The existence of such a distinction was 'concretised' in American legal and political thought in the nineteenth century. As Horowitz has noted,

> One of the central goals of nineteenth century legal thought was to create a clear separation between constitutional, criminal, and regulatory law - public law - and the law of private transactions - torts, contracts, property, and commercial law[3].

Similarly, writing in the middle of that century, Mill produced his classic treatise *On Liberty* which was concerned with the prevention of public intrusion into private action[4];

> There is a limit to the legitimate interference of collective opinion with individual independence; and to find that limit, and maintain it against encroachment, is as indispensable to a good condition of human affairs as protection against political despotism[5].

As this suggests, the public/private distinction is concerned with the identification of different spheres of life, and ensures that the legitimacy of interference with individual action is continually scrutinised. This implies that in at least one sphere - the private sphere - individuals and individual action are of considerable importance, and further, that it is a 'good' thing that the boundary between the two spheres is maintained. Two points should be noted concerning this. First, it is not to be inferred that the placing of conduct in the 'private' sphere automatically prohibits regulation. There might be strong and valid reasons for regulating such

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[2] For a collection of a range of views on the public/private distinction, see 'Symposium on the Public/Private Distinction', 130, *University of Pennsylvania Law Review*, 1289, 1992.

[3] See, Horowitz, M.J.; 'The History of the Public/Private Distinction', 130, *University of Pennsylvania Law Review*, 1423, 1982, *ibid*, at 1424. Horowitz also links the development of the distinction with the rise of the sovereign nation state in the sixteenth and seventeenth centuries and the emergence of 'natural rights' theories in the seventeenth century, *ibid.*, at 1423. This is also noted in Wacks, R.; 'Personal Information, Privacy and the Law', Oxford, Clarendon Press, 1989, at 8.

[4] Mill, 'On Liberty', London, Penguin Books, 1974.

[5] *ibid*, at 63.

conduct. For example, most people would classify the decision to abort a genetically defective fetus as a 'private' matter, yet all western governments require that abortions (if permissible) are carried out under medical supervision and are reported[6]. In this way the State seeks to prevent harm to pregnant women at the hands of unqualified individuals. Indeed, even in jurisdictions where abortion is accepted, women are frequently denied the procedure in the latter stages of pregnancy because the State considers that it has a 'good reason' to do so - that is, to allow the potential child to have an independent existence. Nevertheless, there is considerable normative appeal in classifying conduct as 'private'. Thus, although there is no absolute prohibition on regulation of conduct in the private sphere, it can be taken that there is a *prima facie* presumption that arbitrary interference is impermissible. Such a presumption is not irrebutable but requires strong justification to rebut it. The corollary of this is that conduct in the 'public' sphere is not subject to such a presumption. Regulation in the public sphere is, therefore, more commonplace and *a priori* permissible.

Second, it should not be thought that the importance attached to individuals and individual action in the private sphere signifies the location of all individual rights in that sphere. Many individual rights are located in, and protected in, the public sphere. Obvious examples include civil liberties and equal protection laws.

The public/private distinction assumes a role in a variety of forms in a wide gamut of social life. For example, in politics one talks of public and private sector ownership of utilities and services, thereby distinguishing between governmental and individual control. Similarly, we talk of individual existence in terms of public and private life. On this distinction we consider it to be more acceptable to examine

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[6] In the UK the relevant law on abortion is the Abortion Act 1967 as amended by s.37 of the Human Fertilisation and Embryology Act 1990. In Scotland, abortion details must be reported under the Abortion (Scotland) Regulations 1991, s.4, SI 1991/460, and in England & Wales the same provisions are contained in the Abortion Regulations 1991 (SI 1991/490).

the 'private' life of 'public' officials such as politicians simply by virtue of their status as 'public' figures. However, for those of us not considered to be 'public' figures, the unsolicited ingress by others into one's 'private' life is considered offensive and an unwarranted intrusion[7].

On a philosophical level, we debate the function of public morality and seek to distinguish it from private morality: the subject of the classic Hart/Devlin debate. As a response to the Wolfenden Report of 1957, Lord Devlin wrote *The Enforcement of Morals* in which he argued that,

> 'the suppression of vice is as much the law's business as the suppression of subversive activities; it is no more possible to define a sphere of private morality than it is to define one of private subversive activity'[8].

This was a challenge to the conclusion of Wolfenden regarding the decriminalisation of homosexuality that,

> '...there must be a realm of morality and immorality which is not the law's business.'[9]

In response to Devlin, H.L.A. Hart published *Law, Liberty and Morality*[10]. This series of Stanford Lectures challenged Devlin and argued for a clear division between public and private morality. The debate continues today[11].

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[7] This of course is not to suggest that 'public' figures do not and cannot have 'private' lives, but the mere fact that such categorisation is used *does* make it more difficult for such figures to maintain the boundaries between the public and private aspects of their lives, see Prosser, W.L.; 'Privacy [A Legal Analysis]', 48, *California Law Review*, 338, 1960.

[8] Devlin, P.; 'The Enforcement of Morals', Oxford, Oxford University Press, 1959, at 13. - 14.

[9] Sir John Wolfenden (Chairman); *Report of the Committee on Homosexual Offences and Prostitution*, Cmnd. 247, 1957, paragraph 61.

[10] Hart, H.L.A.; 'Law, Liberty and Morality', Oxford, Oxford University Press, 1963.

[11] See, for example, Dworkin, G.; 'Morality, Harm and the Law', Boulder, Westview Press 1994, also Benn, S.I.; 'Public and Private Morality : Clean Living and Dirty Hands', in Benn, S.I. and Gaus, G.F.; 'Public and Private in Social Life', London, Crook Helm, 1983.

Finally, in the realm of the law one of the foundational divisions between legal categories is between *public law* and *private law* : the former concerns the regulation of State and its relationship with individuals, and the latter governs the relations of individuals between themselves. So pervasive is the schism between these two areas that the structural organisation of most western legal systems, courts and social interaction is based on this model.

Thus from this very brief survey we can seen how the public/private distinction pervades very many areas of our lives. The next section considers the value, if any, which is derived from such a construct.

2.1.1. - *The Value of the Public/Private Distinction*

In a recent analysis of public and private roles Ruth Gavison provides valuable insight into the 'senses' of public and private used in the above examples[12]. Gavison notes that a central sense of the distinction is concern about being known or observed. The private represents a sphere where one can remain anonymous and unobserved; the public sphere offers no such guarantee. Similarly, the private is seen to represent an aspect of freedom: freedom from interference and regulation. Finally, the division 'polarises the unitary entity of the individual'[13] with the collective sense of the group. The 'private' concerns individual action, the 'public' regulates collectives such as the company, the village, the community or the society.

The above observations are premised on a view of the public/private distinction as an identifiable phenomenon. That is, it is presumed that such a distinction exists. However, this view is by no means universally held. Moreover, the above analysis might lead one to believe that the spheres of public and private (if, indeed, they do

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[12] Gavison, R.; 'Feminism and the Public/Private Distinction', 45, *Stanford Law Review*, 1, 1992 at 6 - 7.

[13] *ibid*, at 7.

exist) are clearly separate and independent states. To assert that this were the case however would be wholly misleading. The reality is that the spheres of public and private life exist in very indeterminate states. A constant shifting of classification of conduct occurs between the two and their interface is perpetually obfuscated. As a consequence, the limits of these spheres of life are not easily determinable and as a result require constant re-evaluation. This in turn has important consequences.

For example, if the private sphere is seen as the sphere of 'non-regulation' or 'non-interference' then the main tool with which regulation and interference are legitimated, namely law, requires to be manipulated in very many different ways to accommodate the constant changes. Thus, in a real sense the question of the boundaries between public and private is a question about the legitimacy of legal intervention and the limitations of law as a social expedient.

Proponents of the public/private distinction hold it out as a thing of value to both society and the individual alike. Benn and Gaus, for example, argue that the concepts of publicness and privateness help to structure society[14]. Not only do these notions perform a descriptive function, but also they provide normative rules according to which our lives are organised. Thus, for example, to read correspondence without the permission of the addressee is normatively an invasion of privacy in western culture. Benn and Gaus argue further that in a liberal conception of society and its relationship with the individual, the public/private distinction has a key role to play. As they state,

> [The] idea of the "public" as the overwhelming mass is central to liberal theory. Liberalism is committed to the protection of the individual's conscience and projects; and when his beliefs and plans are unpopular,

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[14] Benn, S.I. and Gaus, G.F.; 'The Public and the Private : Concepts and Action', in Benn, S.I. and Gaus, G.F.; (eds.); 'Public and Private in Social Life', *op. cit.*, chapter one, at 11ff.

> this commitment translates into a defence of the individual from the pressure of public opinion.[15]

Ryan has argued for the maintenance of the public/private distinction as a means of allowing individuals to 'escape' the pressures and strains of everyday public life[16]. He sees a division between the natural persons that we are and the social roles which we are called upon to play. Sometimes society (the 'public') requires that we assume roles not in keeping with our natural character and therefore the 'private' provides an opportunity to 'step out' of such roles and 'be ourselves'. Similarly, the division between these spheres of life allows individuals to assume different roles in different situations as an elaborate coping mechanism. Different personae can be adopted to cater for different scenarios. To remove this facility, it is argued, is to endanger the psychological security of the individual[17].

In contrast, Sennett argues that trends in western civil society over the last two centuries have had profound effects on public life as a social institution. As a result this has blurred beyond recognition the divisions between public and private in social and political life[18]. He contends that the twin influences of secularisation and capitalism have been instrumental in this phenomenon[19]. Their development has brought about a shift in individual expectations: bastions of the private sphere such as intimacy and the expression of personal feelings have broken free of their boundaries and assumed a role in the public sphere. For Sennett, this is to be regretted. For, not only does he recognise the existence of different spheres of life, but he calls for a separation in their function and a respect for their differences.

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[15] *ibid*, chapter two, 'The Liberal Conception of the Public and the Private', at 36.

[16] Ryan, 'Private Selves and Public Parts', in Benn and Gaus, 'Public and Private in Social Life', *op. cit.*

[17] This has already been discussed in chapter one. Additionally, and for an excellent discussion of this kind of theory from the perspective of anthropology/psychology see, Goffman, E.; 'The Presentation of Self in Everyday Life', London, Penguin Books, 1969. See also, Schoeman, F.D.; 'Privacy and Social Freedom', Cambridge, Cambridge University Press, 1992, chapter four: 'Social Freedom from the Perspective of Cognitive and Social Psychology'.

[18] Sennett, R.; 'The Fall of Public Man', London, Faber and Faber, 1986.

[19] *ibid*, especially chapter seven and eleven.

Running through Sennett's work is a mistrust of the private sphere and what it represents. He sees the concern of the western state with individualism as a near-narcissistic obsession with the self, a condition which leads to the imposing of individual 'values' on all spheres of life, public and private. This, he argues, results in the public sphere being regarded as an inferior state, one which cannot provide the individual with self-affirming affection and gratification through self-expression. His argument is that this destroys the worth of both the public *and* the private. The public is reduced to a state entered under feelings of obligation rather than volition. Political life and city life are thereby rendered hollow experiences. By the same token, the private sphere ceases to serve a useful function since intimacy is sought everywhere and yet can be found nowhere[20]. Moreover, for Sennett the public sphere has its own 'values' which can be sought and enjoyed only if the public/private distinction is not blurred. As he puts it,

> 'How is society injured by the blanket measurement of social reality in psychological terms? It is robbed of its civility. How is the self injured by estrangement from a meaningful impersonal life? It is robbed of the expression of certain creative powers which all human beings possess potentially - the powers of play - but which require a milieu at a distance from the self for their realization. Thus the intimate society makes of the individual an actor deprived of an art.' [21]

In essence Sennett argues for a clear division between public and private life; which spheres he regards as having separate and distinct functions. For him, the two must work in tandem to produce a 'good' society inhabited with rounded individuals. His aim is to make a case for the maintenance of the public/private distinction. He does not, however, provide us with a view on how such a distinction is to be maintained.

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[20] *ibid*, chapter eleven, especially at 262 - 264.

[21] *ibid*, at 264.

The above views of Benn & Gaus, Ryan and Sennett are similar, even if they argue for different ends, because they perceive the public/private distinction to be of value. Yet, a considerable body of opinion would refute such a claim. As an example of the rejection of the public/private distinction as a useful construct (that is, either as a construct at all, or as a useful one), it is appropriate to examine the feminist perspective.

2.1.2. - *Feminist Views of the Public/Private Distinction*

The supposed existence of a public/private distinction in liberal society has been the source of much concern for many feminists[22]. The main thrust of argument against the recognition or acceptance of the distinction focuses on the exclusion of women from legal rights and legal protection by the classification of many areas of women's lives as 'private' matters and therefore beyond law and legal intervention. It is argued that this is so because the (male) organisation of (male) legal and social systems uses the public/private distinction to establish limits on the authority of law. That which is in the public sphere is open to scrutiny and can be regulated and controlled by law. By corollary, that which is private is in a sphere beyond significant regulation and control. On one view this can be liberating[23], but on another view this provides much opportunity for abuse. Feminists who have

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[22] As an example consider the following works: Thornton, M. (ed.); 'Public and Private: Feminist Legal Debates', Melbourne, Oxford University Press, 1994; Dallmeyer, D.G. (ed.); 'Reconceiving Reality: Women and International Law', Studies in Transnational Legal Policy, No.25, Washington D.C., The American Society of International Law, 1993, Part Two; Thornton, M.; 'Feminism and the Contradictions of Law Reform', 19, *International Journal of the Sociology of Law*, 453, 1991; O'Donovan, K.; 'Sexual Divisions in Law', London, Weidenfeld and Nicolson, 1985, in particular Part One: 'Definition and History of Public and Private'; Burrows, N.; 'International Law and Human Rights: The Case of Women's Rights', in Campbell *et al* (eds.); 'Human Rights: From Rhetoric to Reality', Oxford, Basil Blackwell, 1986, chapter five; Olsen, F. E.; 'The Family and the Market: A Study of Ideology and Legal Reform', 96, *Harvard Law Review*, 1497, 1983, Pateman, C.; 'Feminist Critiques of the Public/Private Dichotomy', in Benn and Gaus, *op. cit.*, at 281ff., Klare, K.E.; 'The Public/Private Distinction in Labour Law', 130, *University of Pennsylvania Law Review*, 1358, 1982, and MacKinnon, C.A.; 'Feminism Unmodified : Discourses on Life and Law', Cambridge, Harvard University Press, 1987, 'Towards a Feminist Theory of the State', Cambridge, Harvard University Press, 1989.

[23] See notes 3 and 4, *supra* and text.

criticised the public/private distinction have argued that divisions in society such as the State/Civil Society dichotomy and the Market/Family dichotomy represent not only clear divisions between (respectively) public and private spheres, but also the division between (respectively) male and female worlds[24]. That is, men have constructed a social world in which men inhabit the public worlds of state and the market and in which women inhabit the private worlds of civil society and the home (family life). Women then tend to spend their lives in a sphere - the private sphere - which is beyond considered legal regulation and protection. This is not to say, of course, that women do not enter the public sphere nor that men cannot exist as individuals principally in the private sphere. Rather, it is suggested that as a group the lives of women are predominantly relegated to the private sphere. The public/private distinction is then seen to be a gendered construct which can be used as an instrument to control the lives of women. As one commentator has put it,

> ...the non-regulation of the private realm legitimates self-regulation which translates ultimately into male dominance.'[25]

Such arguments have been made most recently in the context of the protection afforded to women by international law. For example, Burrows has argued that there are several reasons why the field of public international law has not addressed the question of women's rights with particular vigour[26]. First, international law has traditionally been concerned with the relations between states themselves and not between individuals themselves or relations between states and individuals. Second, even when international law does intervene in state/individual relations it does so in a limited fashion, bound by the principle of sovereignty. This principle dictates that states have exclusive control over those persons on or in its territory[27] and

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[24] See, for example, Olsen, *loc. cit.*, Klare, *loc. cit.*, and O'Donovan, *op. cit.*, chapter one.
[25] See Charlesworth, H.; 'Alienating Oscar? Feminist Analysis of International Law', in Dallmeyer, *op. cit.*, at 10 - 11.
[26] Burrows, *op. cit.*
[27] *ibid*, at 89.

therefore only in the most serious of circumstances can there be interference with the relationship between state and individual. This is a view which is premised on a belief that international law should not interfere with the domestic relations of a state[28]. Looking at it another way, it is an example of the operation of the public/private distinction at international level: legal intervention between State and State is a public matter; but the legitimacy of legal intervention in matters between state and individual is essentially a private matter of the state concerned[29]. This, Burrows argues, is particularly problematic for women seeking international legal protection since they predominantly exist in the private sphere of their State. Charlesworth puts it succinctly thus : '[t]he sovereign state is simply irrelevant to most women's experience.'[30] Of course, the same can be true for men living within a state. The point, however, is that women are doubly disadvantaged. First, on an international level, except for the most gross of human rights violations, women are seen as an exclusively domestic (private) concern of the state. Second, compounding this is the national treatment which women receive - as we have seen, in the main they are relegated to the private sphere in family life and civil society where abuse can occur at the hands of private (male) individuals, yet where law rarely intervenes:

> If states sustain gendered hierarchies in national contexts, this is reinforced on the international plane.[31]

What is the response of feminists to this? Principally, responses fall into one of two categories. Either it is argued that the (male) view of the world as existing in two separate spheres stands in the way of protecting women and therefore a

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[28] Article 2(7) of the United Nations Charter (1945).

[29] Although as Burrows points out, '...since 1945, it has come to be accepted that states may not use the argument of domestic jurisdiction to mask gross violations of human rights.', *ibid*, at 89 - 90.

[30] *loc. cit.*, at 9.

[31] Charlesworth, *op. cit.*, at 8. She later opines, '[the public/private distinction]...sustains women's oppression on a global level.', at 10.

reconceptualisation of the public/private distinction is required[32]. Alternatively, it is argued that the public/private distinction is a false construct which is used as an illegitimate tool to exclude women from the protection of law. On such a view the public/private distinction 'is both irrational and inconsistently applied'[33]. It is irrational because the distinction '[is] drawn for political reasons... it is not one which is inherent in the nature of society, neither is it natural, nor necessary.'[34] It is inconsistently applied because law *does* intervene in the private sphere to prohibit offensive acts such as slavery, violence and child abuse. Advocates of this second view argue that the distinction should be 'collapsed' to allow the reach of law into the lives of women[35].

These views stand in stark contrast to those expressed by commentators such as Benn & Gaus and Sennett who favour a distinction between public and private spheres of life. Each of these feminist standpoints holds out that private is 'bad' for women. Such a view is not, however, universally held among feminists.

Consider, for example, the writings of Karen Engel[36]. She challenges the notion that 'private' is *necessarily* bad for women. She argues that the private sphere can afford protection to women, primarily in the areas of reproduction and termination of pregnancy :

> The language of privacy, and sketching out zones of privacy, many would argue, is our best shot at legally theorizing women's sexuality. In the United States legal jurisprudence, the First Amendment has been used to a similar end, as often seen in the debates about pornography.[37]

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[32] For an explanation see Engel, K.; 'After the Collapse of the Public/Private Distinction: Strategizing Women's Rights', in Dallmeyer, *op. cit.*, at 143 - 155.

[33] *ibid*, at 144.

[34] Burrows, *op. cit.*,at 82.

[35] See Engel, *op. cit.*, at 143 - 145.

[36] *ibid*.

[37] *ibid*, at 148. She also cites Schneider who has argued that privacy can have a role to play in protecting women from those who batter and abuse them : Schneider, E.M.; 'The Violence of Privacy', 23, *Connecticut Law Review*, 973, 1991, at 994 - 998.

Engel also warns that by collapsing the public/private distinction one runs the risk of not paying due respect to the principle of cultural relativism : not all women in a particular culture who are happy to stay at home or wear certain items of clothing are 'replete with false consciousness'[38].

A further point made by Engel concerns the assumptions upon which much of feminist argument against the public/private distinction is based. A frequent assumption is that the private sphere is devoid of regulation making it a 'bad' place for women to be[39]. However, Engel challenges this : '...the private - or protection of the private - does not have to mean lack of interference.'[40] Her point here is that interference can sometimes be welcome if it protects women from threats to their rights by others (men). In other words, the private sphere need not be seen as an unregulated void and in particular, privacy can be used as a concept to further rather than defeat women's rights[41].

A reluctance to accept the 'private' or 'privacy' as undesirable notions is seen very clearly in the works of Ruth Gavison. Of particular interest in this context is her article, *Feminism and the Public/Private Distinction*[42]. Here Gavison sets out to examine the nature of the arguments made by feminists who challenge the existence and/or worth of the public/private distinction. She identifies two forms of criticism which have been levelled at the distinction - internal and external,

> Internal challenges are criticisms of specific uses of terms like "public" and "private" or of specific

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[38] *ibid*, at 149.

[39] Yet, Engel's point that such 'freedom' can assist women's rights has already been made.

[40] *ibid*, at 150.

[41] As Engel says, 'Privacy...is an indeterminate concept; in itself it neither creates nor requires a space outside of the state's protection or regulation.', *ibid*. For a similar view and another defence of privacy against feminist arguments, see Allen, A.L.; 'Taking Liberties : Privacy, Private Choice, and Social Contract Theory, 56, *Cinncinnati Law Review*, 461, 1987.

[42] Gavison, R.; 'Feminism and the Public/Private Distinction', *loc. cit.*

> arrangements designated by these labels. External challenges invite us to abolish or delegitimate such distinctions altogether.[43]

These two forms of challenge correspond to those broad categories of argument outlined above: either it is argued that the public/private distinction serves the wrong purposes and should be reconceptualised (an *internal challenge* for Gavison) or it is argued that the distinction is useless and/or harmful and should be collapsed as a result (an *external challenge* for Gavison). In assessing the validity of such arguments Gavison makes some distinctions of her own which are of fundamental importance to our understanding of 'public', 'private' and the 'public/private distinction'.

Gavison examines what she calls 'senses of public/private' to determine what, if any, differences exist between these two concepts and further what, if any, purpose the making of a distinction between them actually serves or could serve. This is an invaluable exercise because it reveals that often, if not always, feminists and others who criticise the public/private distinction use different terminology and/or use terminology inconsistently as between themselves. Axiomatically, this has profound consequences for any debate about the use or value of the distinction. Gavison identifies the following senses of public/private.

- *Accessible/Inaccessible*: '[t]he private is that which is unknown and unobserved; the public is that which is known and observed, or at least is capable of being known and observed, because it occurs in a public place'[44].

- *Freedom/Interference*: '[h]ere, the "private" is "free", the sphere in which others do not interfere. The "public" will acquire a different meaning depending on the

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[43] *ibid*, at 2.
[44] *ibid*, at 6.

source of the interference'[45]. That is, State interference renders the "public" 'political'. Market influences and communitarian influences cast the "public" as 'social'.

- *Individuals/Society(Groups)*: 'the public/private distinction can highlight differences between individuals and various sorts of groups or collectives. The distinction here is a matter of degree, with small voluntary groups existing somewhere in-between - labelled "private" when compared to larger, more anonymous "publics", but "public" when compared to individuals[46].

- *Complex Meanings*: 'finally, all these senses may combine to create cluster-meanings'[47].

This sort of exercise greatly facilitates the clarification of issues. It shows how confusion is not easily avoided and it stresses the importance of conducting debate on the same, level playing field. Yet, such an exercise also demonstrates that although such different senses of public and private are used, they are not necessarily distinct from one another. That is, one might legitimately talk of something as 'private' in the normative sense of requiring not only non-interference *but also* inaccessibility: a 'private' room or a 'private' meeting. Similarly, to use the expression 'private life' invokes normative feelings of non-interference, inaccessibility and individual, as opposed to societal, value. This realisation serves to complicate the task of ensuring that debate is indeed conducted on the same field.

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[45] *id.*

[46] *id.*

[47] *ibid*, at 7. As an example Gavison offers the following: 'we find such [complex] meaning in the idea of "private life" signifying that part of life which is often unknown and inaccessible, at least to the public at large. People often view the "private life" as a realm entitled to non-interference and freedom from accountability due to its basic self-regarding nature, connection to the intimate, and importance to one's self-indentity and welfare., *id.*

A main point made by Gavison is that the arguments of feminists are valuable and insightful because they call us to question so-called social 'norms' concerning women and to assess the ways in which women are treated at the hands of men. Yet, she defends the use of the public/private distinction and warns against challenges which are misdirected,

> ...they become misleading and counterproductive and may actually facilitate the devaluation of important aspects of human life that are currently identified as "private" and "personal"[48].

Gavison clearly finds utility and protection for women (and others) in the private sphere. She argues for this on a variety of grounds. For example, the recognition by the Supreme Court of the United States of women's rights to abortion in *Roe v Wade*[49] (using the concept of privacy[50]) displays a commitment on the part of the US to protect individual (private) interests unique to women. Similarly, she puts forward the powerful argument that the development of individual interests such as intimacy, the establishment of relationships and personality can only be achieved through the protection of a private sphere of life. Moreover, she argues that such 'value' in privacy or the private *is* recognised by most feminists,

> ...it is rare to find feminists who argue consistently either that everything should be regulated by the state, or that the family and all other forms of intimate relationships should disappear in favour of public communities...[w]hen pushed feminists explicitly deny that this is their ideal. They advocate only local changes in the existing mix of private and public and in the existing institutionalization of both realms, with more equal access to the two main realms for both genders. They also want the freedom to explore these questions boldly and creatively[51].

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[48] *ibid*, at 2.

[49] *Roe v Wade* 410 U.S. 113 (1973). Gavison mounts a strong argument against MacKinnon in this respect, *ibid* at 30 - 35. The latter has argued that the *Roe* decision does not guarantee women anything beyond that which they could receive from men in private, see MacKinnon, C.; 'Privacy v Equality: Beyond Roe v Wade', in MacKinnon, 'Feminism Unmodified: Discourses on Life and Law', *op. cit.*

[50] Discussed *infra*.

[51] *ibid*, at 28 - 29.

In other words, feminists who mount internal challenges to the public/private distinction do not ultimately consider that nothing should ever be private. Their challenge should thus be seen, not as one against the 'private' or 'privacy' as such, but rather as one against the use to which the distinction is currently put. Their solution then is re-establishment of the boundaries of the private and the public on more equal, less gendered grounds.

Gavison's response to those who mount external challenges to the public/private distinction focuses on the call for the *terminology* of public and private to be 'abandoned or delegitimated'[52]. This view holds that the language of 'privacy' and 'public and private spheres' is somehow operational in the creation and maintenance of the marginalisation and ill-treatment of women. Gavison refutes this and warns against the sophistic attack on 'public' and 'private' as the progenitors of the evil that subjugates women. Her argument is three-fold : first, attacking the concepts *in se* does not necessarily address the true reasons why women are marginalised and ill-treated in our society. Second, although 'private' and 'privacy' invoke, *inter alia*, normative responses of non-interference, the confusion which surrounds these terms and their meaning should not lead us to conclude that the terms are meaningless nor that the confusion cannot be clarified. And, in clarifying what we mean, we might have a better idea of which 'private' acts legitimately invoke non-interference and which do not. Consider the case, as Gavison does, of domestic violence. It is not because domestic violence occurs primarily in the 'privacy' of the home that one should accept that such behaviour is, by that fact alone, outside the boundaries of legitimate legal regulation[53]. It may be that we think that this is so because of normative confusion about what we mean by 'private', but Gavison argues that if we were less confused about what is truly

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[52] *ibid*, at 29.

[53] *ibid*, at 35 - 38.

private - and therefore truly deserving of non-interference - then we would be more willing to intervene and more likely to address the true causes of domestic violence. In particular, Gavison notes that the abandonment of language alone cannot help us to achieve such an end,

> Public treatment of domestic violence is plagued by dubious uses of the notion of privacy. The police are often extremely reluctant to interfere in domestic disputes, even when violence is alleged. Often, the reasons offered for this reluctance is the private nature of the marital relationship. The potential for confusion generated by this variety of uses is not unique to the public/private distinction or to the feminist context. In fact, this kind of problem is pervasive in legal reasoning, especially when the conclusion must be justified in terms of interpretations of authoritative texts. Moreover, the confusion appears in many different fields of law. Although these mistakes should be avoided, a reform of the language and terminology is not necessarily the cure. Reforming the language by delegitimating the use of "private" and "privacy" will not clarify distinctions between descriptive and normative claims. The descriptive-normative ambiguity exists for all alternative candidates[54].

Third, 'privacy' for Gavison has valuable uses and the abandonment of terminology which accurately reflects how we feel about private matters is lamentable, unnecessary and potentially harmful in itself. She asserts that the private can be 'good' for women just as it can be 'bad' for women and therefore what is necessary is a differentiation between the 'good' and 'bad' arguments about privacy[55]. One way to do this is to determine the value of the conduct which occurs in the private sphere : if privacy facilitates the development of personality and relationships it is 'good', but if it promotes domestic violence or other forms of exploitation of women it is 'bad'. Gavison accepts this to a point but is quick to add a rider. The language of privacy should not be abandoned in favour of a 'value' analysis of the behaviour concerned because (a) 'privacy' provokes normative responses in us which can protect behaviour in which many may find no value but in which those

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[54] *ibid*, at 35.

[55] *ibid*, at 37.

involved might find much (for example homosexual conduct)[56] and (b) a respect for 'privacy' as a social construct performs a valuable function in promoting association between individuals and ensuring non-interference from the state - to examine the 'value' of such association rather than respecting its private nature would be detrimental in both social and personal terms[57].

In sum, Gavison values the feminist debate as revealing much about privateness and publicness and about the potential abuses of women which can occur through such concepts. Her basic argument, however, is this : the abandonment of 'public' and 'private' as linguistic tools to describe our social order will not further the cause of women because it will not necessarily address the reasons why these tools have been used in the past to abuse women. Moreover, she argues that the tools of 'public' and (particularly) 'private' do have value both for women and men and that their abandonment would be a tragic loss.

2.1.3. - *The Public/Private Distinction: A Conclusion*

The above section serves as an introduction to the discussion of privacy to follow in this work. It highlights many of the arguments which are made about privacy and which we shall encounter presently. Obviously, the role of 'privacy' in the public/private distinction is crucial, but just as the function and parameters of the public/private distinction are by no means universally accepted, the same is true of the function and parameters of the concept of privacy. The following section will give an overview of the range of opinions which have been advanced about privacy and will include a brief account of how the concept has been used to provide legal protection of various interests in several legal systems.

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[56] As Gavison says, '...while privacy and intimacy should not provide blanket immunity from public interference, it does not follow that we *always* look at the substance of the activity rather than its context...[w]e do *not* want to reduce the question to a debate about the morality of the conduct.', at 37.

[57] *ibid*, at 38.

3.1. - PRIVACY: ANTI-SOCIAL CONCEPT OR FUNDAMENTAL RIGHT?

Consider these two views of privacy:

> [Privacy] can be seen as the protector of reputations and sanities, a developer of intimate and personal relationships, and even a defender of hard-done by individuals maltreated at the hands of overly-bureaucratic government departments[58].

> [Privacy] is seen as creating the context in which both deceit and hypocrisy may flourish: It provides cover under which most human wrongdoing takes place and then it protects the guilty from taking responsibility for their transgressions once committed... Concern for one's privacy may be regarded as a sign of moral cowardice, an excuse not to state clearly one's position and accept whatever unpopularity may ensue. Privacy may be seen as a culturally conditioned sensitivity that makes people more vulnerable than they would otherwise be to selective disclosures and to the sense of comparative inferiority and abject shame - a sense engendered by ignorance about the inner lives of others[59].

To an extent these views of privacy mirror the arguments of Gavison and many feminists concerning the public/private distinction. These arguments have been advanced, however, not in the context of that debate, but in the context of privacy *simpliciter*. And, just as the views of feminists and those who disagree with them reveal much about the public/private distinction, so too do these two (competing) views reveal much about the nature of privacy. Furthermore, each view has much to support it and can be defended well depending on one's perspective and theoretical standpoint. A communtarian, for example, would have no problem defending the negative view of privacy, for privacy seems to stand for many notions antithetical to communitarianism such as solitude, individuality and the furtherance

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[58] Schoeman, F.D.; 'Privacy : Philosophical Dimensions of the Literature', in Schoeman, F.D. (ed.); 'Philosophical Dimensions of Privacy : An Anthology', Cambridge, Cambridge University Press, 1984, chapter one, at 1.

[59] *ibid.*

of personal interests generally. In contrast, one committed to a more individualistic approach to social relations would favour the first interpretation offered[60]. We have already seen that Ruth Gavison is one such individual and she has mounted a strong defence of the positive view of privacy[61]. Indeed, the sorts of argument put by Gavison in defending the value of privacy for individuals, groups and society generally perhaps explains in part why some legal systems have chosen to protect the concept in law. By the same token, the indeterminate nature of privacy has caused problems of definition for those systems which have chosen to do so[62]. Indeed, the problem of defining a 'valuable' concept fit for legal protection has been a recurring problem in this field. As one commentator has rightly observed: 'Privacy, like an elephant, is more readily recognised than described'[63]. Such problems have prompted many writers such as Walter Pratt to conclude: '[a] concept flexible enough to comprise opposite ideals is not a likely subject for legislation'[64]. This might, in part, explain the dearth of specific privacy legislation in the United Kingdom[65].

The above factors allow us to draw two important conclusions about the problems which face any writer or legislature examining privacy as a possible subject of legal protection. First, does 'privacy' have sufficient value to be deserving of protection? Second, even if the answer to this first question is given in the affirmative, is privacy sufficiently amenable to definition to make legal protection viable and effective? The rest of this chapter will be devoted to addressing the first of these questions and will argue that privacy *is* indeed a valuable concept, especially in the

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[60] For a good account of both individualistic and communitarian (or republicanism) arguments in respect of privacy, see Rubenfeld, J.; 'The Right of Privacy', 102, *Harvard Law Review*, 737, 1989, at 761 - 770.

[61] See, for example, Gavison, R.; 'Privacy and the Limits of Law', 89, *Yale Law Journal*, 421, 1980, 'Information Control : Availability and Exclusion', in Benn and Gaus, (eds.), 'Public and Private in Social Life', *op. cit.*, and 'Feminism and the Public/Private Distinction', *loc. cit.*

[62] see *infra*.

[63] Taken from Young, J.B. (ed.); 'Privacy', Chichester, John Wiley and Son, 1979, at 5.

[64] Pratt, W.F.; 'Privacy in Britain', London, Association University Press, 1979, at 63.

[65] This has been discussed in chapter one, *supra*.

context of genetic information. In the conclusion to this work we will accordingly examine the second question, namely; which legal means could best ensure a fully efficient and equitable protection of individual privacy in the United Kingdom in the context of genetic information.

3.2. - A REVIEW OF THE PRIVACY LITERATURE

One need only look at the bibliography of any work dealing with privacy to appreciate just how many diverse and interconnecting definitions of privacy have been proposed over the years. These are almost as numerous as the number of works written on the concept itself. Nonetheless, valuable work has been done by commentators such as Schoeman[66] and Parent[67], who have undertaken to categorise privacy writings into groups according to their approach to privacy. From works such as these and others, one can identify three categories of privacy commentators:

- Those who advance sceptical approaches to privacy and its value in society;
- Those who seek some fundamental core element which ties all privacy examples together and explains the concept as a whole, and
- Those who seek to define privacy in certain precise terms for use in specific areas.

Let us consider some examples of each of these approaches.

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[66] See Schoeman, F.D.; (ed.); 'Philosophical Dimensions of Privacy : An Anthology', *op. cit.*, especially chapter one.

[67] Parent, W.A.; 'Recent Work on the Concept of Privacy', 20, *American Philosophy Quarterly*, 341, 1983, Parent, W.A.; 'A New Definition of Privacy for the Law', 2, *Law and Philosophy*, 305, 1983, and Parent, W.A.; 'Privacy : A Brief Survey of the Conceptual Landscape', 11, *Computer and High Technology Law Journal*, 21, 1995.

3.2.1. - *The Sceptical Approach*

It has already been said that a problem for anyone interested in the study of privacy concerns the apparent indeterminate nature of the concept and its seemingly dubious functionality - sometimes promoting 'good', sometimes promoting 'bad' outcomes for individuals and society. Thus privacy writers divide, in the first instance, into those who see privacy as a 'good' thing and those who perceive it as 'bad'. As an example of the latter, we have already examined the feminist literature. But, even among writers who acknowledge that the private sphere (as opposed to privacy *per se*) does promote certain 'goods', many consider that 'privacy' as a concept is nothing more than an extension of existing concepts which can be protected by means other than an appeal to a difficult-to-define concept such as privacy.

One example of this is Judith Jarvis Thomson who has claimed that there is nothing morally significant about the concept of privacy as such[68]. Instead, she argues that any right we may choose to claim as a privacy right can be more easily dealt with by reference to existing rights in other fields, such as property rights or rights over one's person. Thus all problems can be resolved without having ever to refer to privacy at all. Thomson suggests that the reason a peeping-tom does wrong is *not* because he invades our privacy but because he breaches the personal right we all have not to be looked at. Similarly, if I read someone else's correspondence I am *not* violating their right to privacy but merely their property right in owning the papers, which in turn gives them the right to control access[69].

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[68] Thomson, J.J.; 'The Right to Privacy', 4, *Philosophy and Public Affairs*, 295, 1975. For a full critique of Thomson, see Scanlon, T.; 'Thomson on Privacy', 4, *Philosophy and Public Affairs*, 315, 1975.

[69] Of course this presupposes that I own the documents containing information about me. For personal correspondence that is likely to be true (although my correspondee will own other papers *from* me containing information *about* me), but in other contexts this model might be less helpful. In the health care setting, for example, it is now settled in law that a doctor or a health board/authority owns medical records and not patients - see the *R v Mid Glamorgan Family Health Services Authority and Another, ex parte Martin* [1995] 1 WLR 110. Thus, on Thomson's analysis the

Unfortunately, an obvious problem with Thomson's view is that it requires us to accept the existence of a plethora of ancillary rights which in themselves have little or no moral justification. For example, what is the basis of a right not to be looked at? Even in circumstances where one could make an appeal to another area of existing, legally-recognised rights - such as property rights - the important question arises of whether the interests in not being looked at or in not allowing others access to one's personal information are *adequately* protected by the existing area of law. Consider the central problem of this work : genetic information. In many respects the problems which have so far been discussed are unique as well as deserving legal recognition. Yet, chapters three and four of this work have shown that existing rights such as autonomy and confidentiality cannot adequately protect the interests surrounding genetic information. That is why this work argues for recognition of privacy and why this author would reject the work of Thomson as a meaningful way of examining the concept of privacy.

A similar sceptical treatment of privacy comes from William Prosser[70]. In his 1960 paper *Privacy : A Legal Analysis* Prosser examines the US common law tort of privacy and outlines four distinct kinds of invasion of privacy which are recognised by the courts and three different kinds of interests protected by the "law of privacy". His analysis is based on the 'privacy' cases decided before the US courts. His approach is similar to Thomson's in that he identifies abstract interests in need of protection, for example, protection of reputation, avoidance of emotional stress and property interests. He concludes that, on this view, all so-called *privacy interests* are adequately protected by the existing law. Yet, this view is subject to the same criticism made of Thomson above. Even if an argument can be made that many

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doctor or health authority would have the right to control access. However, this right might be exercised in ways which offend me and my interests. In such cases Thomson's analysis offers me no means of redress.

[70] Prosser, W.; 'Privacy : A Legal Analysis', 48, *California Law Review*, 338, 1960.

'privacy' interests are already protected indirectly by other interests, it does not necessarily follow that 'unique' privacy interests cannot be found. Moreover, Prosser's approach has been questioned as 'philosophically unsound'. As Wacks has observed,

> ..it is a singularly unrewarding and pointless exercise to comb through the case law in search of instances where courts have either employed the word 'privacy' or accorded protection to certain interests which are now (rightly or wrongly) conceived as privacy issues. Since this process requires distortions in the meaning of privacy and involves the application of past situations to present problems, it is both legally and philosophically unsound[71].

This is true up to a point. If one trawls the case law, as Prosser does, to prove that all interests so far decided upon as privacy interests are already protected by other laws, then it is not acceptable to draw the conclusion that all *future* privacy interests will necessarily find protection in existing areas of law. If, however, one examines the law to measure the breadth of understanding of 'privacy' by the courts in a particular jurisdiction in order to evaluate the sorts of interests *currently* protected, then that *is* a valuable exercise[72].

The approach of writers such as Thomson and Prosser has been called the *Reductionist Model of Privacy*, which denies that there is anything worthwhile or specific about privacy which is worth protecting. However, some sceptics go further and argue the 'negative side' of privacy.

Richard Wasserstrom has suggested that not revealing information about oneself may be equivalent in moral terms to deception and therefore normatively

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[71] Wacks, R.; 'The Protection of Privacy', London, Sweet & Maxwell, 1980, at 5.

[72] See, as an example, Hogg, M.; 'The Very Private Life of the Right to Privacy', in Hume Papers on Public Policy, 2(3), 'Privacy and Property', Edinburgh, Edinburgh University Press, 1994.

unacceptable[73]. He posits that in society we make ourselves unnecessarily vulnerable as individuals by accepting the notion that there are thoughts and actions about which we ought to feel ashamed or embarrassed. He suggests that we would be less embarrassed and therefore less vulnerable if we were to be honest about our lives and by doing so we would realise that many other individuals share similar 'embarrassing facts'. Unfortunately, such a view fails to take account of considerable anthropological evidence which indicates that the 'desire' to hide is culturally conditioned and therefore unlikely to change without fundamental changes in society[74]. In other words, Wasserstrom's view may well be correct in an ideal world, but it is not accurate in our world.

Goffman has argued convincingly that a measure of privacy *is* necessary precisely because of the pressures (and hypocrisy) that each individual is subjected to by society[75]. Likewise, Murphy has put the case for the value of social distancing mechanisms such as privacy. His view is that privacy is not only recognised and institutionalised in all societies (albeit in relation to different matters and to varying degrees), but that a measure of privacy is absolutely essential to the maintenance of both social relationships and one's own sense of self[76].

Westin considers this sort of evidence at length in his seminal work *Privacy and Freedom*[77] and concludes,

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[73] Wasserstrom, R.A.; 'Privacy: Some Arguments and Assumptions', in Schoeman, F.D., (ed.); 'Philosophical Dimensions of Privacy: An Anthology', *op. cit.*

[74] See, for example, Moore, B. Jr.; 'Privacy', New York, M.E. Sharpe Inc., 1984, Murphy, R.F.; 'Social Distance and the Veil', 6, *American Anthropologist*, 1257, 1964, Westin, A.; 'The Origins of Modern Claims to Privacy', in Schoeman, F. D.; 'Philospohical Dimensions of Privacy', *op. cit.*, at 56 - 74, and Arendt, H.; 'The Human Condition', Chicago, University of Chicago Press, 1958.

[75] Goffman, E.; 'Stigma', London, Penguin Books, 1963, also 'The Presentation of Self in Everyday Life', *op. cit.*

[76] Murphy, R.; 'Social Distance and the Veil', *loc. cit.*

[77] Westin, A.; 'Privacy and Freedom, London, The Bodley Head, 1970. For criticism of Westin see Lusky, L.; 'Invasion of Privacy : A Classification of Concepts', 72, *Columbia Law Review*, 693, 1972.

> ...privacy appears to be a cultural value in all known human communities, although the forms it takes vary enormously[78].

The tension between writers such as Westin, Murphy and Goffman and Wasserstrom might best be explained as a tension between individualistic notions of privacy and communitarian notions of privacy. Wasserstrom's negative view of privacy sees the concept as anti-social or anti-communitarian, and to a lesser extent anti-individual. This is because he sees the potential for harm rather than the potential for benefit seen by others. Yet the 'need' in humans for a sphere of 'the private' arguably forces us to go some way to accepting that recognising that need is a good thing[79]. Of course, this is not to say that privacy should assume a place of paramountcy in our value hierarchy, and it certainly does not mean that we need accept protection of privacy if this has harmful or 'bad' outcomes[80], but it does suggest that a 'core' of interests can be served by recognising the need for a degree of privacy. If one accepts this view arguably Wasserstrom and those who think like him are not too far removed from Westin and his followers : the question becomes not one of the goodness or badness of privacy, but rather one concerning the drawing of limits of the kinds of interests which should and will be protected and the degree of privacy which can be expected[81].

Richard Hixson has advanced an argument which would seem to follow this line, although ultimately it comes down in favour of a narrow construction of 'privacy'. In *Privacy in a Public Society* Hixson considers privacy to be a 'privilege' and thereby 'something well worth protecting', but '*not* on the grand scale that claims

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[78] *ibid*, at 87.

[79] Compare, Collins, H.; 'Decline of Privacy in Private Law', 14, *Journal of Law and Society*, 91, 1987.

[80] See Gavison's arguments above concerning feminist challenges to the public/private distinction.

[81] And in this respect this brings us to a position not too far removed from that of Gavison in respect of feminist writings, *supra*.

for privacy are pressed today.'[82] He asserts that: 'an open and democratic society cannot tolerate a high degree of privacy'[83].

The value which Hixson attributes to privacy is based on a view of the relationship between society and the individual which favours society as the ultimate value. This is a little surprising for a North American writer, given the considerable commitment of Americans to individualism. Nevertheless, Hixson considers that privacy threatens the American view of 'community' or rather 'collective individualism'[84]. His view of American society holds that a commitment to 'public service' is more important than 'singularity'[85]. Whether or not one agrees, his approach is interesting because it shows how our view of privacy can shift, even when we consider that it is important. It also shows that the question of protection is a question of degree, depending on how one views the relationship between society and the individual and what relative value one attaches to one or other party to that relationship. It has already been put in chapter one of this work that privacy in essence concerns the boundaries of the society/individual relationship and as Negley has pointed out,

> ...any consideration of whether privacy *is* a right of the individual will entirely depend on what definition of the individual we accept[86].

That definition is in turn dependent on the definition of society we accept. As has already been argued, the particular context for this work is the individual in the western liberal democracy. That view, which is committed to notions of liberty and autonomy, will find it hard to reject out of turn the idea that individuals have a

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[82] Hixson, R.F.; 'Privacy in a Public Society', New York, Oxford University Press, 1987, at 4.
[83] *ibid*, at 96.
[84] *ibid*, at 100 -102.
[85] *id*. Thus, rather than recognising and protecting a widely defined privacy right, Hixson proposes that the law should direct itself to the protection of specific instances of abuse concerning sensitive information.
[86] Negley, G.; 'Philosophical Views on the Value of Privacy', 31, *Law and Contemporary Problems*, 319, 1966.

set of core interests in the private sphere of their lives where they can be free from interference, develop their relationships and personalities and engage in consensual acts which at times might be frowned upon by others. That this is so is related to the commitment of the liberal society to notions of freedom, liberty and autonomy. So many of the so-called 'privacy' interests overlap with liberty and autonomy interests that it becomes difficult to separate them or to deny that a degree of recognition should be forthcoming for privacy. We will discuss presently the problem of overlap between these concepts. For the moment, if one accepts what has been said then the arguments of privacy sceptics distil into arguments about the degree of protection which should be afforded to privacy rather than denying that privacy has any value whatsoever. This leads logically to a consideration of the question of which, if any, 'core' interests are privacy interests.

3.2.2. - *The Fundamentalist Approach*

This section examines the works of those writers who search for a fundamental, internally consistent and distinctive core to privacy concerns. Their search is always motivated by the notion that there *is* something special about human or moral character - overlooked by reductionist accounts - which can be called 'private'. Consider the following views.

Edward Bloustein focuses on the idea of an 'inviolate personality' which he associates with the 'right to be alone'[87]. 'Inviolate personality' is taken to include such notions as individual dignity and integrity, personal uniqueness and personal autonomy. Bloustein's case is that respect for these values 'both grounds and unifies our concept of privacy'.

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[87] See Bloustein, E.J.; 'Privacy as an Aspect of Human Dignity [An Answer to Dean Prosser]', 39, *New York University Law Review*, 962, 1964. Also, Bloustein, E.J.; 'Privacy is Dear at Any Price : A Response to Professor Posner's Economic Theory', 12, *Georgia Law Review*, 429, 1978, Posner, R.A.; 'An Economic Theory of Privacy', in Schoeman, 'Philosophical Dimensions of Privacy', *op. cit.*

Stanley Benn follows a similar line in asserting that the core element of privacy is a respect for persons as individual moral choosers[88]. His argument is essentially one of consistency - a commitment to values such as freedom and autonomy require us to respect persons and to respect their choices, some of which are choices to be left alone or to be separate from others. For the sake at least of consistency, privacy interests should therefore be respected and protected.

Other writers such as Gerety[89] contend that privacy is concerned with control over the intimacies of personal identity, and Jouard has posited that there are sound psychological reasons why individuals need privacy as an aspect of the control they have over others' perceptions and beliefs vis-à-vis themselves[90]. Yet others argue that the creation and maintenance of personal and social relationships are the key elements; see for example, Fried[91], Reiman[92] and Inness[93].

Gavison argues that privacy consists of three elements: *secrecy*, *anonymity* and *solitude*[94]. The functions which the combination of these elements serve are considerable and include, development of individual autonomy and growth and deepening of personality, establishment of human relations, promotion of liberty of action, and general support for the 'desirable' ends of a free society[95].

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[88] This argument is made in many areas of Benn's work. For example, Benn, S.I.; 'A Theory of Freedom', New York, Cambridge University Press, 1988, and Benn, S.I.; 'Privacy, Freedom and Respect for Persons', Nomos XIII, 1971, chapter one. Also, Benn, S.I.; 'The Protection and Limitation of Privacy', in Schoeman, 'Anthology', *op. cit.*, at 223.

[89] Gerety, T.; 'Redefining Privacy', 12, *Harvard Civil Rights and Civil Liberties law Review*, 233, 1977.

[90] Jouard, S.M.; 'Some Psychological Aspects of Privacy', 31, *Law and Contemporary Problems*, 307, 1966.

[91] Fried, C.; 'Privacy', 77, *Yale Law Journal*, 475, 1968.

[92] Reiman, J.H.; 'Privacy, Intimacy and Personhood', 6, *Philosophy and Pulbic Affairs*, 26, 1976.

[93] Inness, J.C.; 'Privacy, Intimacy and Isolation', New York, Oxford University Press, 1992.

[94] Gavison, 'Privacy and the Limits of Law', *loc. cit.*

[95] *ibid.*

Finally, from the British perspective, Feldman has recently argued that privacy should best be seen as a civil liberty which consists of the following elements : *secrecy* (which he considers is concerned with control of personal information), *autonomy* (which he classifies as being concerned with choosing the direction of one's life and social interactions) and *dignity* (which involves the giving and receiving of respect towards the choices and standards of oneself and others)[96].

It is clear even from this brief account that the speculation on the fundamental nature of privacy concerns is wide-ranging. Agreement is unlikely to be achieved. Nevertheless, what is achieved by these writers is commitment to the protection of privacy. From the legal perspective this is a first but very crucial hurdle to overcome. The question of the details of any particular legal protection becomes jurisdiction-specific - details can always be defined in more specific terms depending on the particular aims of the particular legal system. It is the view of the present writer that each of these works presents a viable view of privacy and that each is to a high degree convincing. Of course, each view has its critics and no view is perfect. Clarity of terms and definition of scope are especially problematic for the concept of privacy. Privacy *is* very amorphous, and one cannot and should not deny that. This should *not*, however, lead us to conclude that privacy should not be protected by legal means. We use many ill-defined and indeterminate terms in law : the 'public interest', the 'reasonable man', 'freedom of speech', 'breach of the peace' etc. Difficulty of achieving one's aims should be no reason not to seek to achieve those aims. And, if one can agree on common aims, we make a sincere commitment to the protection of privacy. In the above account of the views of various writers on the fundamental nature of privacy we *can* identify common aims. Despite the broad range of views expressed about the specific nature of privacy, more generally there are clear common elements. For example, a commitment to the public/private

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[96] Feldman, D.; 'Secrecy, Dignity, or Autonomy? Views of Privacy as a Civil Liberty', 47, *Current Legal Problems*, 41, 1994.

distinction, protection of individual interests, the recognition of the need of individuals to possess a degree of privateness, and the need to strike a balance between individual rights and public interests. The legal issue then becomes a search for a particular definition.

3.2.3. - *The Search for a Definition of Privacy*

Our final category contains those works in which the authors have attempted to produce a definition of privacy, either in philosophical or legal terms. Stanley Benn and Ferdinand Schoeman have both very helpfully identified five different types of definition which have been advanced as possible means for explaining or protecting privacy[97]. It is useful to follow this model. The following are the five basic categories which have been used in the search for a definition of privacy:

- Privacy as a right;
- Privacy as a claim;
- Privacy as an interest;
- Privacy as an aspect of control;
- Privacy as a state or condition.

Benn notes that those who define privacy as a right automatically beg the question of whether anyone ought to have the power to deny access to any places or activities called 'private'. His view is that a 'right' only exists to provide someone with a normative capacity to choose whether or not to maintain or relax a state. A right is always something conveyed on a person by another (excepting natural rights) to provide protection and/or show acknowledgement of some capacity, state

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[97] Benn, S.I.; 'A Theory of Freedom', *op. cit.*, at 266ff. and Benn, S.I.; 'The Protection and Limitation of Privacy', 52, *Australian Law Journal*, 601, 686, 1978, (note, Benn also speaks of privacy as a *power* which is a form of control theory). See also, Schoeman, F.D.; 'first chapter', in Schoeman, F.D., (ed.), 'Philosophical Dimensions of Privacy: An Anthology', *op. cit.*

or entitlement. In this respect to classify the nature of privacy as a 'right' immediately confers a value on the concept as something worth protecting. Whereas this is not an undesirable end-point, many writers have warned against ' value bias' in the search for a definition of privacy. For example, Lusky has opined that it is very simple to start with an idea that privacy *is* a good thing and then to claim that it must be protected : such a beginning 'naturally demands affirmative justification throughout one's discussion and biases of this kind are the enemy of just balance'[98]. In other words, one must be careful about the use of value-laden language which presupposes value where that value might not exist. Thus we should not confuse the concept of a 'right to privacy' with privacy *simpliciter*. That said, as Gavison has stated,

> Insisting that we start with a neutral concept of privacy does not mean that wishes, exercises of choice, or claims are not important elements in the determination of the aspects of privacy that are deemed to be of value[99].

Returning to Benn, he notes that a 'claim' is often described as an argument that someone deserves something, and so a 'right' is a justified 'claim'. This too carries with it a value judgment on privacy[100]. Thus writers such as Westin[101] who describe privacy as a 'claim' are presuming, as are those who use the term 'right', that privacy is automatically of value and therefore worth protecting. Benn's objection to this is not that privacy is not or cannot be valuable, rather he objects to the lack of moral justification (in the absence of legal definition) which tends to accompany the writings of those who classify privacy as a 'right' or a 'claim'.

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[98] Lusky, 'Invasions of Privacy: A Classification of Concepts', *loc. cit.*, at 697.

[99] Gavison, 'Privacy and the Limits of Law', *loc. cit.*, at 426.

[100] Wacks, 'Personal Information, Privacy and the Law', *op cit.*, at 14 also criticises this approach, quoting McCormick, D.N.; 'Privacy: A Problem of Definition', 1, *British Journal of Law and Society*, 75, 1974.

[101] *op. cit.*

Those who argue that privacy is an 'interest' are thought to be mistaken on two grounds. First, they make the same mistake of evaluating privacy before offering a neutral definition of it. Second, as Benn says,

> We cannot take for granted that giving people what they want is necessarily in their interests. Adults and children alike can be worse and not better off, for getting what they want[102].

Whereas Benn's view is undoubtedly factually correct - that is, it is certain that in some cases giving people what they want might make them worse off - it is less easy to reject the strong normative imperative in western culture that would lead us to believe that the best determination of an individual's interests are the wishes of the individual him or herself.

A different and popular option in privacy literature has been the control-based definition. Amongst others, this has been advocated by Westin[103], Lusky[104], Fried[105], Wasserstrom[106] and Feldman[107]. The majority of such writers views privacy as a concern about personal information (and sometimes access to the person) and quite naturally conclude that control of such information (or access) is the key element in privacy recognition and protection. And, as Benn further points out, such theories appear more attractive because they avoid the moral question-begging provoked by definitions couched in terms of rights, claims or interests[108]. Despite these apparent benefits, however, control-based definitions have been

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[102] Benn, 'A Theory of Freedom', *op. cit.*, at 277.
[103] *op. cit.*
[104] *loc. cit.*
[105] *loc. cit.*
[106] *loc. cit.*
[107] Feldman, 'Secrecy, Dignity, or Autonnomy? Views of Privacy as a Civil Liberty', *loc. cit.*
[108] Benn, 'A Theory of Freedom', *op. cit.*, at 271 - 273.

heavily criticised[109]. In particular, Parent has argued that such theories fail because they are both conceptually and empirically too broad,

> To define privacy as the control over (all) information about oneself implies that everytime I walk or eat in public my privacy is compromised[110].

Even if one were to restrict such a definition to control over personal information, Parent would still challenge this as unacceptable: 'The comatose patient example should convince us that control over personal information is not a necessary condition of privacy.'[111] This latter point is of particular interest to this work and is in line with arguments made earlier in chapter one using the example of the unconscious patient. To classify privacy as being solely concerned either with personal information or its control, arguably excludes much of that which can legitimately be claimed under the privacy rubric[112]. However, Parent also discredits definitions which focus on control of access to the person. *Inter alia*, his argument relies once again on the example of the comatose patient[113]. If someone cannot exercise control, control-based theories offer us no option but to conclude that privacy has been compromised, yet this might not be the case. No third party may have personal information about the comatose patient and similarly no third party may have access to the *incapax*. As Gavison has commented,

> "control" suggests that the important aspect of privacy is the ability to choose it and see that the choice is respected. All possible choices are consistent with enjoyment of control, however, so that defining privacy in terms of control relates it to the *power* to make certain choices rather than the way in which we choose to exercise the power. To be non-pre-emptive (that is, non value-laden), privacy must *not* depend upon

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[109] See, in particular, Gavison, 'Privacy and the Limits of Law', *loc. cit.*, Parent, 'Recent Work on the Concept of Privacy', *loc. cit.*, Parent, 'A New Definition of Privacy for the Law', *loc. cit.*, and Wacks, 'Personal Information, Privacy and the Law', *op. cit.*, at 15.

[110] Parent, 'Recent Work on the Concept of Privacy', *loc. cit.*, at 344.

[111] *ibid.*

[112] Wacks roundly criticises control-based arguments on this and other grounds in 'The Protection of Privacy', *op. cit.* at 10 - 11.

[113] *ibid*, at 345.

> choice. Furthermore, the reasons why we value privacy may have nothing to do with whether the individual has, in fact, chosen it.[114]

Parent's overriding objection to control-based theories is that they all 'confuse the two distinct values of privacy and liberty or freedom'[115]. His definition of freedom/liberty is 'absence of coercion or restraint on choice'[116] which some, this writer included, might see as overlapping with autonomy[117]. Either way, his point is a valid one : control issues are already dealt with by other 'valuable' concepts such as liberty or freedom (or autonomy) and it is necessary to avoid conceptual confusion between these and privacy. Whether or not one should conclude that such concepts are and need always be mutually exclusive is, of course, a different matter which will be discussed *infra*.

Parent's solution is to conceive privacy as 'the condition of a person's not having undocumented personal information about himself known by others.'[118] With such a definition he does many things, primary amongst which are the following two : first, he follows the lead of many writers who argue that privacy is concerned with personal information; second, he opts for Benn's final category of candidates for best describing privacy, namely, - as a state or condition[119].

Parent defends his approach thus. By defining personal information as 'facts that most persons in a given society choose not to reveal about themselves (except to friends, family, advisors, etc.) or...facts about which a particular person is extremely sensitive and which he therefore does not choose to reveal about himself'[120] he casts his net very wide and includes both objective and subjective assessments of the

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[114] Gavison, 'Privacy and the Limits of Law', *loc. cit.*, at 427 - 428.
[115] *ibid.*
[116] *id.*
[117] See chapter three, *supra*.
[118] *ibid*, at 346.
[119] Gavison also supports this, see 'Privacy and the Limits of Law', *loc. cit.*
[120] Parent, *supra*, at 346 - 347.

'personal'[121]. His view that 'personal information' is crucial to privacy is motivated in large part by a desire not to confuse privacy with other social concepts such as liberty, autonomy, property, secrecy etc.[122] By choosing to see privacy in terms of personal information he allocates a relatively clearly defined niche to privacy which, on his view, allows this latter concept to lie relatively easily within the community or family of concepts. That he insists on conceptual clarity is not likely to be a point of contention. However, that he focuses privacy concerns solely on personal information is more open to question. For example, it has already been argued in this work that privacy interests relate both to informational and spatial interests. Whereas it is not denied that these interests overlap to an extent with interests protected by other concepts such as confidentiality and autonomy it has, hopefully, been shown that this is indeed a matter of 'overlap' and not necessarily 'encroachment'. Furthermore, it has been argued that in the context of genetic information these existing concepts cannot protect all informational or spatial interests which exist. That a case might be made for privacy to 'fill this gap' and that in doing so one must produce a concept of privacy which overlaps in places with the reach of existing concepts is not, to the mind of this writer, fatal to the development of a clear concept of privacy. Indeed, it might lead us to understand better the relationships and inter-relationships of the family of concepts which are thought to be so important in our society.

Parent's choice to categorise privacy as a condition is welcomed. Such an approach, which is advocated by Benn[123], Gavison[124] and Wagner DeCew[125], avoids all of the moral question-begging which arises from the use of value-laden language and allows us to see privacy for what it is, distinct from what we think it ought to be.

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[121] Parent refines his arguments about a subjective evaluation of 'personal information' in 'A New Definition of Privacy for the Law', *loc. cit.* at 306.
[122] *ibid* at 347 - 348.
[123] *loc. cit.*
[124] *loc. cit.*, especially 'Privacy and the Limits of Law'.
[125] Wagner DeCew, J.; 'The Scope of Privacy in Law and Ethics', 5, *Law and Philosophy*, 145, 1986.

That is, we attempt in the first instance to *describe* privacy and not to *evaluate* it. This is not to say that one might not in the future attribute value to privacy through one's conduct or through laws, but to do so is a step *beyond* describing privacy for what in essence it is and in terms of the function which it serves. This approach is favoured by the present writer and we shall return to this point presently.

3.3. - A Core Concern for Privacy: Personal Information or Beyond?

It is important at this juncture to address one of the most common features found in the privacy literature which is concerned with defending privacy. This is the view that privacy is primarily concerned with personal information, and that this should be the proper subject of legal protection. We have already seen that Parent advocates such a position. He is by no means alone. Indeed, doyen among those who advance this position is Raymond Wacks.

The works of Wacks[126] have made a considerable contribution to the debate about the propriety and practicalities of privacy protection by legal means. In particular his work *Personal Information, Privacy and the Law*[127] sets out 'to obviate the confusion that afflicts the question of "privacy" and obstructs the satisfactory legal protection of the interests with which it is concerned'[128]. Thus, while acknowledging that individuals might have a wide range of interests in privacy which can legitimately include the use of contraceptives, the abortion decision, or homosexual conduct, he argues that in order to secure viable legal protection of 'privacy' one must start with a workable and relatively narrow concept of 'privacy'. This, he submits, we cannot do if we seek to include such wide-ranging

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[126] See bibliography.
[127] *op. cit.*, 1989, reprinted with amendments in paperback in 1993.
[128] *ibid*, at 1.

interests. Rather, Wacks identifies as crucial to privacy interests concerns with 'personal information'. This he defines as follows,

> 'Personal information' consists of those facts, communications, or opinions which relate to the individual and which it would be reasonable to expect him to regard as intimate or sensitive and therefore to want to withhold or at least to restrict their collection, use or circulation.[129]

Clearly this is an *objective* test: it determines the 'personal' nature of 'information' by reference to the 'reasonableness' of the individual's expectations of privacy. Wacks argues that such an assessment is the only viable option since a subjective assessment of 'personal information' would not only require the protection of 'spurious' privacy interests but would also require the protection of 'illegitimate' privacy claims, for example, the claim that the fact that I beat my children is personal information. In other words, Wacks' definition sees the nature of the entity to be protected - namely, personal information - as something which *earns* protection by a combination of its *quality* and the *reasonableness of the expectation* of the individual claiming protection[130]. The reliance on 'reasonableness' is crucial here. In many ways this approach casts a wide net of protection. For example, as Wacks points out, a reasonableness-based assessment of what qualifies for protection allows an individual to claim that even if s/he has chosen to disclose personal information in one circumstance, it does not mean that s/he has forfeited protection for all circumstances. I might be happy to tell my doctor that I am impotent but would be very much aggrieved if my employer found out[131]. Similarly, Wacks notes that his definition allows an individual to claim protection even if s/he has no idea that information about him or herself exists or has been used without authority. This is so because one can determine if the individual might reasonably be expected to view the information as sensitive or intimate '*if*

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[129] *ibid*, at 26.
[130] *ibid*, at 24.
[131] *ibid*, at 27.

s/he were aware' of the unauthorised activities in question[132]. The obvious question which this approach begs, however, is how does one determine the matter of reasonableness? In turn, this question can be broken down into a number of related questions. For example, who is to answer the question of reasonableness? Are there any basic preliminaries which allow one to claim the status of 'personal information' for certain issues as a matter of course? And, is the determination of reasonableness open to influence from other interests of other individuals or from society at large?

Wacks' approach to the practical problem of how to protect personal information is to apply to that general class of 'personal information' a model for assessing the normative degree of protection which can reasonably be expected by the subject depending on the *sensitivity* of the information in question. This he calls 'Information Sensitivity Grading'[133]. The models works as follows. Different types of personal information are categorised into one of three indexes: (1) High Sensitivity, (2) Moderate Sensitivity, and (3) Low Sensitivity. The purpose is to aid in determining the role of the law in regulating the collection and/or the use of such information. Information concerning how one voted at the last general election, how frequently one has sexual intercourse with one's partner, one's divergent sexual habits, one's mental health, suicide attempts, misuse of drugs or alcohol and genetic predispositions to illness or congenital handicaps are classified as 'Highly Sensitive'. In comparison, information relating to one's previous address, the fact that one is adopted, one's NHS number, one's absences from work or one's credit rating are examples of information of 'medium sensitivity'. Finally, information of 'low sensitivity' includes one's sporting activities, one's membership of clubs, one's employer details, one's home address and the fact that one wears

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[132] *id.*
[133] *ibid*, at 226ff.

glasses. To assist in the categorisation of personal information into one of these three categories Wacks identifies six factors. These are:

- *The reasonable expectations of the data subject*
- *The recipient of the data*
- *The scale of the disclosure*
- *The age of the data*
- *The context of the collection, use or disclosure*
- *The purpose of collection, use or disclosure.*

In this way he answers to an extent the question of how one determines the reasonableness of a claim to protection for personal information, in that he provides us with a means of assessing the claim through a range of objectively assessed criteria. That said, primary among these is still the very general question of how 'reasonable' are the expectations of the data subject.

Wacks also accepts that his model is principally a normative one, in that it is not value-free because it classifies information by reference to existing norms and attitudes towards certain kinds of information. Thus, as Wacks himself notes : 'medical information accounts for the preponderance of "highly sensitive" data'[134]. He also accepts that any such model can never be exhaustive and will never attract universal approval. This, however, he sees as an advantage rather than a disadvantage: information can shift between categories as social and political norms themselves change[135].

In essence, however, Wacks' classification system is based on a concern with harm. The over-arching question to be asked of information is this: to what extent will

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[134] *ibid*, at 242.

[135] *ibid*, at 226 - 227.

unauthorised use or disclosure of the information result in a greater or less degree of harm to the subject? Thus, the classification of personal information in Wacks' model becomes an attempt at risk management and damage limitation. Whereas one can have no first degree objection to such an approach, it does suggest that information which - objectively assessed - is thought to cause little or no harm if misused, cannot be classed as highly personal and therefore is less likely to receive strong protection. But, in certain cases particular information which falls outside Wacks' model or which has been classed as 'low sensitivity' might, for a particular individual, be *de facto* harmful if used or disclosed. That is, on a subjective analysis harm can still result but Wacks' model is unlikely to protect against that. Now, this is not to say that Wacks' adoption of an objective test is in itself wrong. It is simply to assert that a model which is concerned primarily with the avoidance of harm is weakened if it does not provide, at least in some small measure, for cases where harm is likely to result even if those cases do not fit neatly into the model which has been devised[136]. If Wacks' response to this point is that his list of six factors which determine into which category should fall any particular form of information will operate in function of the particular views of the individual - for example, depending on how s/he views the purposes of disclosure, or how s/he sees the context of disclosure - then this is a move towards introducing a subjective element to his assessment of personal information, and should be recognised as such.

The consequence of Wacks' threefold classification system is that the form of protection offered to personal information depends upon the category into which any particular piece of information falls. For information of a highly sensitive nature he suggests that there is a strong case to be made that such information

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[136] Wacks himself admits that his model is concerned with the avoidance and/or reduction of harm: '[t]he threefold classification used in the above index of 'personal information' is based on the extent to which the collection or use of the data holds a potential for *serious harm* to the subject.', *ibid*, at 238.

should, perhaps, not be gathered at all. The implication is that if such information is not gathered, control cannot be lost and therefore harm cannot result from misuse or unauthorised disclosure. For moderately sensitive information Wacks submits that it is difficult to argue that it should not be collected at all, but rather that once collected, it should receive a high degree of protection because 'the potential for harm is of a very high order'[137]. Finally, low sensitivity information concerns in the main biographical information about an individual; that is, information which is generally available (for example, address, telephone number, employment details etc). Of itself, this information is unlikely to cause harm, but it can become harmful when used to piece together other sources of information which are of a greater degree of sensitivity. In this respect low order information deserves a degree of protection.

Wacks' aim in this exercise is admirable: he offers a model for dealing with personal information which is viable and which provides a relatively sound base upon which to further legal protection. He is, however, fully cognisant of the objections which might be raised, and does not pretend to offer a definitive account of how personal information should be classified. But, as he himself says,

> ...the purpose is to demonstrate that personal information is susceptible of this sort of analysis, and that it might offer a more effective means of regulating the collection and use of such data[138].

This he does well and it is not the intention in this work to criticise that attempt *in se*. However, from the perspective of the present work there are two objections which can be raised in respect of Wacks' analysis. First, the question of third party interests, and second, the restriction of his protection of privacy to personal information.

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[137] *ibid*, at 229.

[138] *ibid*, at 230.

The question has been asked above, to what extent is the determination of reasonableness open to influence from interests of other individuals or from society at large? In the first instance, Wacks avoids saying that information in which others have an interest is no longer 'personal' or 'highly sensitive'. His model is designed to be applied to all kinds of personal information irrespective of 'external' factors such as third party interests[139]. However, when he comes to address the question of whether or not information which is highly sensitive should be gathered or used at all, Wacks then introduces the question of third party interests. In fact, this factor leads him to conclude - using the example of patients afflicted by AIDS - that legitimate third parties interests *should* be furthered if possible. He then argues that it is not an answer to the question of appropriate legal protection for (highly) sensitive personal information to say that it should not be collected at all. His solution in the context of AIDS is anonymisation. That way, he submits, the risk of harm to the individual is minimised but the public's interest in statistical data concerning the spread of HIV and AIDS can also be furthered. Unfortunately, such a solution is not open to us in the context of genetic information when we are concerned with the interests of family members as well as individuals. Anonymity is not an option. Furthermore, we face the very difficult question with genetic information of determining to whom the information relates. Wacks' analysis proceeds on the assumption that 'personal information' concerns one 'person' and therefore that s/he should control that information by virtue of that fact. As we have seen, the position is considerably more complex with genetic information when the 'personal' nature of the information becomes 'familial'. Wacks' model does not provide us with a means of assessing such circumstances. This can be seen, *inter alia*, from his views on the question of the use of medical data. He posits that one approach to the problem of the legitimacy of using highly sensitive medical

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[139] *ibid*, at 226 - 227.

information is to argue that the use occurs in the patient's *best interests*[140]. This, however, he rejects as paternalistic and prefers instead the option of seeking the patient's consent. This is viable in the context of the single doctor/patient relationship, but individual patient consent provides us with a problem in the context of familial genetic information. Even if patient A refuses to allow access to genetic information, how does one assess the interests of patient B or patient C who are relatives of A and who might want or need to know the information? Arguably, Wacks' model is insufficiently sophisticated to allow us to address such problems.

The second objection to be raised to Wacks' thesis is his decision to restrict privacy protection to the protection of personal information. We have already considered his reasons for doing so - in the main such a construct encompasses *most* concerns we express in 'privacy terms' and it is suggested that such a concept is more amenable to effective legal protection. Against this, however, it is submitted that it is crucial to consider the thesis of the current work. It is conceded that the present thesis is narrow and relates to only a very small area of privacy concern. Furthermore, it is accepted that Wacks' aims are much wider and seek to strike 'the best deal' for a plurality of privacy interests. And, it is acknowledged that in the main Wacks puts forward a convincing and important argument - one which has a sound basis and which provides much of practical utility for those considering the problems of legal protection of privacy. However, as has already been argued in chapter one, it is a primary aim of this thesis to show that privacy concerns are *not* restricted simply to concerns about information and further it is argued through the example of genetic information that to fail to recognise this leaves many important non-informational interests unprotected. As an illustration of this consider two examples which cause problems for Wacks' model : the PVS patient and the individual who does not want to know about his/her own genetic

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[140] *ibid*, at 242 - 243.

constitution. Both of these examples have been used in this work before to illustrate the limits of an information-based analysis of privacy.

In the case of the PVS patient, how is such a person 'harmed' by the taking of information about them? They are not conscious, they will never regain consciousness and the information which is gained is completely beyond their control. Arguably, Wacks' model would lead us to classify all information about such a person as of low or no sensitivity because the person cannot be 'harmed' by the misuse of such information. Yet intuitively one would still say that the patient's privacy had been invaded if newspaper reporters burst into his/her hospital room and took photographs and recorded details of his/her condition. Surely, what is invaded here is not privacy in information, but rather privacy in the self - a sphere of physical privateness which others should not invade without authority and good reason. Moreover, arguably such a sphere exists *irrespective* of whether one can control it or is conscious of its existence. This is so because that sphere is linked not just to information and fear of harm, but rather individuality, dignity and respect for the person. Respect can be measured against the conduct of the aggressor and can therefore be forthcoming even if the aggressee is unaware of the other's presence. A harm-based analysis such as that of Wacks requires a degree of likelihood of harm before one's interests are protected. If that is not possible - protection is not possible.

The individual who does not want to know information about his/her own genetic make-up is similarly unlikely to be protected by Wacks' analysis. Wacks' entire assessment of sensitivity is concerned with harm arising from unauthorised use or misuse of information by others which occurs by the communication of that information to third parties[141]. However, the concern of an individual who does

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[141] Wacks' defines 'personal information' as follows: '"Personal information" consists of those facts, communications, or opinions which relate to the individual and which it would be reasonable to

not want to know about familial genetic information is a concern that information *about* his/herself is communicated *to* him/herself. Furthermore, and as has been argued *supra* and will be argued further *infra*, it is not clear that the interest which an individual has in not knowing information is properly an informational interest. Rather, the view presented here is that such an interest is a spatial privacy interest: something which Wacks would reject as part of his model.

The above comments should be taken not so much as criticisms of Wacks, but rather as defences of the approach adopted in this thesis. This thesis argues for a view of privacy which encompasses *both* informational privacy interests *and* spatial privacy interests. The utility of this can be summed up as follows. At best it is hoped that the thesis of this work will facilitate a wider recognition of the range of interests which are legitimately subsumed under the privacy rubric. Less ambitiously, it is hoped that this thesis will draw attention to the fact that strong arguments can be made against 'narrower' constructs of privacy, even if in the short term one must concede that protection along the lines suggested by Wacks are necessary and important first steps. But, even if that is the case, this thesis argues that one should not stop at that point. One should not give up simply because we find a way to protect *some* privacy interests. This work is designed to show that the limits of the law can and should be pushed ever further forward in the pursuit of adequate protection for legitimate privacy interests. Thus, even if one must accept that Wacks provides a strong and viable first step towards privacy protection, we must see it for what it is : a first step. This work hopefully paves the way for future and further steps along the privacy path. For these reasons, this work rejects Wacks' 'narrow' construction of privacy. Finally, the aim of this work and that of Wacks can be summed up in the following paradoxical fashion: Wacks seeks to 'narrow' the meaning of privacy in order to 'broaden' the range of protection

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expect him to regard as intimate or sensitive and therefore to want to withhhold or at least to restrict their collection, use or circulation.'

which can be afforded to privacy by law. In contrast, this work seeks to examine a 'narrow' area of privacy concern in order to 'broaden' the privacy debate itself. The following section will defend the current thesis.

4.1. - SPATIAL AND INFORMATIONAL PRIVACY - A MEDICO-LEGAL DEFINITION OF PRIVACY

In chapter one 'privacy' was defined broadly as a state of separateness from others. Such a *state* encompasses two forms of separateness. Physical separateness from others (*spatial privacy*) and separateness of certain intimate adjuncts to one's personality; namely personal information (*informational privacy*). The argument for viewing privacy in such terms has already been made and need only be repeated here cursorily.

First, consider informational privacy. Undoubtedly patients have considerable interests in their own medical information because it can be used against them by others and this can lead to harmful outcomes such as upset, discrimination, prejudice etc. Informational privacy therefore concerns the interest of the patient in maintaining such information in a state of non-access and preventing unauthorised use or disclosure of that information by third parties to other third parties. The question of what kinds of information qualify as 'personal information' need not lead us to an analysis such as that undertaken by Wacks. For the purposes of this thesis, the information in question is genetic information which relates to the individual. Thus a concern about informational privacy is a concern about maintaining a state of non-access to personal genetic information.

Second, let us examine spatial privacy. As a caveat to the above, it has been argued earlier in this work that a concept of privacy which is defined solely in informational terms does not adequately reflect the interests which patients have in privacy matters and so cannot purport to protect comprehensively such interests. In particular, the notion of spatial privacy has been advocated and this is complementary to the notion of informational privacy. The concern of spatial privacy is not simply information. Rather, spatial privacy relates to the sphere of the self - a 'bubble' of privateness around the individual which cannot and should not be invaded without due cause. Such a sphere can be invaded either by unwarranted physical contact (such as unauthorised treatment or continued futile treatment, e.g.- the PVS patient) or by unwarranted observation which can occur even when there is no trespass to the actual person. In the latter example it could of course be argued that what is offensive is the gathering of information rather than the observation, but such a view requires us to conclude that there is no invasion of privacy if no information is gathered. This surely cannot be true. The better view is that the invasion of privacy arises from the unwarranted observation and this is so even if no information is gathered. Yet, this view can be defended only if one accepts that the interest which is compromised in such cases is not an informational privacy interest but rather a spatial privacy interest[142]. Moreover, in the context of genetic information, it has been argued that spatial privacy can be invaded by the revelation of genetic data about an individual to that self-same individual (if there is no indication that s/he would want to know such information). Again, this cannot appropriately be seen as an informational privacy issue because this latter privacy interest concerns the interest in maintaining non-access vis-à-vis third parties. In the example under discussion, the concern is revelation of information about oneself to oneself.

The justifications for this two-fold conception of privacy are numerous. First, as has been argued in chapter one, the conception of what is 'private' in lay terms - which has been established by the Younger Committee[143] and Raymond Wacks[144] -

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[142] The basis for this interest is human dignity and respect, see *supra*.

[143] Younger, *The Report of the Committee on Privacy*, Cmnd. 5012, July 1972, discussed *supra*, chapter one.

accords to a high degree with the view of privacy here advocated. This is important because it goes a long way to helping us formulate a view of the law which can address actual 'social needs'.

Second, as the Calcutt Committees have made clear, concerns with spatial interests are particularly important to members of the public and, perhaps more importantly, are thought to be the appropriate focus of legislative action[145]. Also, the point is made indirectly by Calcutt that these cannot be subsumed under the rubric of an informational analysis[146].

Third, for the reasons outlined earlier in this chapter, to define privacy as a *state* rather than a right or a claim helps us to describe the concept while at the same time avoids imputing value to the concept. As has been stated, privacy is defined as a state of separateness from others, be that society in general, the family or one or two other individuals. This is not to say that 'others' cannot enter that sphere or that individuals can simply act howsoever they would wish when in such a sphere, or that such a state necessarily protects undesirable activities. Rather, it is to say that *prima facie* a state of privacy places the individual apart from others. This notion can of course extend to the privacy of groups which are apart from other groups or society in general, but the common denominator is the individual and his or her separateness. Yet, merely to say that I am apart from others will not always lead us to conclude that I am in a state of privacy. For example, if I am marooned on an island I am certainly apart from others, but few of us would say that I have *privacy*. Certainly this is in part because *privacy* implies something more than mere isolation which can be seen as undesirable. As one commentator has said, 'the problem for such a person [on an island] is that he has too much privacy'[147].

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[144] Wacks, 'Personal Information, Privacy and the Law', *op. cit.*, chapter four.
[145] See chapter one.
[146] See chapter one.
[147] Unattributed.

However, in such a case the present writer would not say that such a person had privacy at all, simply that s/he was in a state of isolation. For, in order to be in a state of privacy there must be others from whom one can be separate. On a desert island this is not possible for I am alone. Isolation implies a state of enforced non-access to others. Privacy on the other hand is a state which can easily be relaxed or maintained since it occurs in a social context. *Isolation* concerns the removal of individuals from a social context and therefore cannot accurately be described as *privacy*[148].

Similarly, simply because I am in the presence of others does not necessarily mean that I cannot claim privacy interests. For example, an aspect of spatial privacy is the interest in maintaining bodily integrity. It is not because I am in a crowd that unwarranted interferences with my bodily integrity are not offensive and cannot be classed as invasions of privacy. Of course, mere jostling or accidental contact is subject to the *de minimis* principle, but intentional contact with my person by another can easily be seen as an invasion of privacy. By corollary, we would not say that one's privacy interest in not being observed is invaded by being in a crowd. Arguably, in such a case one has consented to a degree of observation - that which flows directly and naturally from one's presence in the public sphere[149]. However, if one's movements were to be recorded clandestinely, a strong argument could be made that this does indeed infringe privacy interests. There is a big difference between the anonymity of the crowd and the specific identification of an individual within a crowd. In the former case any observation which occurs is merely incidental and can be readily anticipated by the individual in question. If, however, one is being clandestinely observed, not only can one not reasonably anticipate

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[148] Consider the position of the prisoner condemned to solitary confinement. S/he has been removed from a social context (not simply society in general but also the community of the prison population) and has been placed in *isolation*. Such a person does not have privacy. But, a prisoner who retires to her/his cell to read does have privacy in that they are separate from the rest of the prison community.

[149] Indeed, one could say precisely the same about bodily contact and spatial privacy interests in a public crowd.

being the focus of someone else's attention, but also one becomes a means to someone else's end: a factor which in itself is *de facto* offensive and disrespectful of the individual[150].

Fourth, to describe privacy as a *state* and therefore to seek to offer a neutral description of the concept of privacy does not preclude us from attributing value *to* such a state. Nor does it prevent us from seeking to accord (legal) protection to such a state for the good ends which it can further and for the interests which it can protect. It has already been argued in previous chapters that a state of separateness *can* protect 'good' ends - both private and public. In essence, such a state can be seen as one in which the interests of the individual are *a fortiori* paramount. If one chooses to accord respect and protection to such a state this is evidence of a degree of commitment to valuing individuals. But, the obvious question which arises from this is why should we seek to protect such a state of privacy when we already have mechanisms for respecting individuals and protecting their interests? The response which this thesis suggests is that such existing mechanisms cannot always provide *adequate* protection and furthermore, the concept of privacy advanced here allows us to recognise a broad range of interests which we might not otherwise have recognised. To view privacy either as solely concerned with personal information, or to argue that autonomy, confidentiality or liberty can adequately protect privacy interests is to fail to protect many important interests and to miss many interesting nuances. That said, one criticism which might be levelled at the view of privacy presented here is that it confuses privacy with concepts such as autonomy, liberty or even confidentiality. For example, a state of separateness implies a state of non-interference which is arguably simply one definition of liberty or freedom. Similarly, it might be argued that the state in question is one which depends largely

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[150] Of course, this is not to say that strong counter arguments cannot be made to justify such observation - for example, close circuit television in shopping malls for security purposes. However, if such tapes are sold to television shows for entertainment purposes arguably this becomes an offensive use of the images obtained.

on the notion of autonomy - the individual as self-ruler. This would be an important criticism and even if it were not raised in respect of the definition of privacy advanced here, the relationship between privacy and these other, related concepts must nevertheless be examined.

4.2. - Privacy and Related Concepts

Many writers associate the beginning of western legal interest in privacy with the seminal article by Warren and Brandeis *The Right to Privacy*, published in the 1890-91 volume of the Harvard Law Review[151]. This article was written at the instigation of Mr Warren, a once-notable Boston lawyer, after he took umbrage at what he saw to be excessive press intrusion into the events of his daughter's marriage. From such humble beginnings was born the US tort of invasion of privacy[152]. Warren and Brandeis looked at cases drawn from areas as diverse as defamation[153], breach of confidence[154] and copyright[155] and concluded that the common law recognised a general right to privacy[156]. This they classified as a 'right to be alone'[157]. This work has been much praised[158] and much criticised[159], but undeniably its influence has been unimaginably far-reaching. For present purposes, it is neither intended to praise nor particularly criticise this work, but rather to use it as an illustration of a

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[151] Warren, S.D. and Brandeis, L.D. 'The Right to Privacy', 4, *Harvard Law Review*, 193, 1890-91.

[152] For analysis see Prosser, *supra cit.*

[153] Warren and Brandeis, *loc. cit.*, at 205.

[154] See, for example, *Abernathy v Hutchinson* 3 L. J. Ch. 209 (1825) and *Prince Albert v Strange* 1 McN. & G. 25 (1849).

[155] For example, *Tuck v Priester* 19 QBD 639 (1887).

[156] It is often pointed out that ironically the authors relied heavily on English common law cases to support their argument and yet to this day no common law right to privacy has been recognised in England.

[157] The 'right to be alone' was first expounded by Cooley, T.M.; 'Cooley : A Treatise on the Law of Torts', Second Edition, 1888, at 29.

[158] For example, see Gavison, R.; 'Too Early For A Requiem : Warren and Brandeis Were Right on Privacy vs. Free Speech', 43, *South Carolina Law Review*, 437, 1992.

[159] For example, Zimmerman, D.L.; 'Requiem for a Heavyweight : A Farewell to Warren and Brandeis' Privacy Tort', 68, *Cornell Law Review*, 291, 1984, Pratt, W.F.; 'The Warren and Brandeis Argument for a Right to Privacy', *Public Law*, 161, 1975, Bloustein, E.J.; 'Privacy, Tort Law and the Constitution : Is Warren and Brandeis' Tort Petty and Unconstitutional as Well?', 46, *Texas Law Review*, 611, 1968, Kalven, H.; 'Privacy in Tort Law : Were Warren and Brandeis Wrong?', 31, *Law and Contemporary Problems*, 326, 1966.

common problem which arises in the field of privacy study - conflation of concepts and confusion of terminology. The association of privacy with the 'right to be alone' has been made by many writers since Warren and Brandeis[160], and all have been subject to the same criticism : by conceiving privacy to be a 'right'[161] to be free from intrusion or interference they have equated privacy with liberty[162]. This is not only confusing generally, but for those who seek to argue positively about privacy it can have adverse consequences. For example, Fried has recognised that,

> ...to present privacy only as an aspect of or an aid to general liberty is to miss some of its most significant differentiating features[163].

Similarly, Posner has observed,

> ...we already have perfectly good words - Liberty, Autonomy, Freedom - to describe the interest in being allowed to do what one wants (or chooses) without interference. We should not define privacy to mean the same thing and thereby obscure its other meanings[164].

4.2.1. - *The United States' Constitutional Right of Privacy*

The conflation of privacy with liberty is a common problem in the United States. Indeed, this is the primary criticism levelled at the US Constitutional right of privacy which was interpreted out of the US Constitution by the Supreme Court in *Griswold v Connecticut*[165]. This case concerned Estelle Griswold who was the Executive Director of the Planned Parenthood League in that state. In defiance of a statute criminalising contraception and acts aiding and abetting the use of

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[160] See, for example, Blom-Cooper, L.; 'The Right to Be Let Alone', 10, *Journal of Media Law and Practice*, 53, 1989.

[161] The classification of privacy as a 'right' *in se* might also be problematic for some, see *supra*.

[162] Parent warns against this very specifically, *supra*.

[163] Fried, 'Privacy', *loc. cit.*, at 490.

[164] Posner, 'An Economic Theory of Privacy' in Schoemnan, 'Privacy: An Anthology', *op. cit.*, at 274 - 275.

[165] 381 US 479 (1965). For an account of the historical lead-up to *Griswold* see, Rubenfeld, *loc. cit.*, at 740 - 744.

contraception[166], Griswold provided information, instruction and medical advice to married couples as to the various means of preventing conception. She was successfully prosecuted under the law and fined $100. The constitutionality of the statute was immediately challenged and the case was ultimately heard by the Supreme Court of the United States. In a seminal decision, the Supreme Court 'interpreted out' of the US Constitution a right to privacy which is not expressly included therein. It did so by reference to what it called 'penumbras': '...emanations from those guarantees [in the Bill of Rights] that help give them life and substance.' Various guarantees create 'zones of privacy'. In other words, various rights expressly guaranteed in the Bill of Rights, such as the right of association[167] or the right against self-incrimination[168] or the right not to have soldiers quartered in one's home during peacetime[169], as applied to states through the Fourteenth Amendment's due process clause[170], create spheres of life which are protected and '*private*'. And, in order for that protection to be complete, the true extent of the zones of privacy which exist must be recognised, *even if* there is no express mention of their existence in the text of the Constitution. As the Court said in *Griswold*,

> The present case...concerns a relationship lying within the zone of privacy created by several fundamental constitutional guarantees. And it concerns a law which, in forbidding the *use* of contraceptives rather than regulating their manufacture or sale, seeks to achieve its goals by means having a maximum destructive impact upon that relationship. Such a law cannot stand in light of the familiar principle [that] a "governmental purpose to control or prevent activities constitutionally subject to state regulation may not be achieved by means which sweep unnecessarily broadly and thereby invade the area of protected freedoms"...Would we allow the police to search the sacred precincts of marital bedrooms for telltale signs of the use of contraceptives? The

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[166] The provisions in question were paragraphs 53-32 and 54-196 of the General Statutes of Connecticut (1958 rev.).

[167] Part of the First Amendment.

[168] Part of the Fifth Amendment.

[169] The Third Amendment.

[170] see 482-85. In all the Court held that the penumbras emanated from the first, third, fourth, fifth and ninth amendments.

> very idea is repulsive to the notions of privacy surrounding the marriage relationship.[171]

In this way the Court ruled the Connecticut statute unconstitutional and in doing so gave birth to the Constitutional Right to Privacy[172]. It is important to note that at this stage that the right was concerned with family life and its protection[173]. It was, however, soon extended to 'individual rights' and beyond in cases such as *Eisenstadt v Baird*[174] (in which prohibitions on contraceptive use by single persons was held to be unconstitutional[175]), *Roe v Wade*[176] (in which the right of privacy was held to be broad enough to encompass a woman's decision to terminate a pregnancy[177]), *Planned Parenthood v Danforth*[178] (in which the Supreme Court held unconstitutional a statute requiring a woman to obtain her spouse's consent to abortion) and *Planned Parenthood of Southeastern Pennsylvania v Casey*[179] (in which the Court re-affirmed the authority of *Roe* and *Danforth*[180])[181]. These decisions

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[171] *per* Justice Douglas, at 485.

[172] Heavy reliance was also placed on the Ninth Amendment (*per* Justice Goldberg, at 493) and the Fourteenth Amendment (*per* Justices White and Harlan, at 500 - 502, 502 - 508).

[173] In particular, Justice White made it clear that the policy behind the statute - namely, an attempt to ban 'illicit sexual relationships' (and by this was meant all forms of "promiscuity" and sexual relations between non-married couples) - was perfectly permissible as a legislative goal.

[174] 405 U.S. 438 (1972).

[175] *per* Justice Brennan, '[i]f under *Griswold* the distribution of contraceptives to married persons cannnot be prohibited, a ban on distribution to unmarried persons would be equally impermissible. It is true that in *Griswold* the right of privacy in question inhered in the martial relationship. Yet the marital couple is not an independent entity with a mind and heart of its own, but an association of two individuals each with a separate intellectual and emotional make-up. If the right of privacy means anything, it is the right of the *individual*, married or single, to be free from unwarranted governmental intrusion into matters so fundamentally affecting a person as the decision whether to bear or beget a child.', *ibid*, at 453.

[176] 410 U.S. 113 (1973).

[177] *Roe v Wade* is easily *the* most analysed US Constitutional right of privacy case. As an example of the range of arguments which have been made surrounding it consider, Ely, J.H.; 'The Wages of Crying Wolf: A Comment on *Roe v Wade*', *Yale Law Journal*, 920, 1973.

[178] 428 U.S. 52 (1976).

[179] 112 S.Ct. 2791 (1992); 505 U.S. _.

[180] Note, however, the court also held certain restrictions on a woman's abortion decision to be constitutional in this case. The case concerned several provisions of the *Pennsylvania Abortion Control Act* which provided that (except in an emergency) a physician could not perform an abortion within 24 hours of a request, that such physicians had to furnish women seeking an abortion with information pertaining to the nature of abortion, the risks involved and available alternatives to abortion, the risks of continued pregnancy, and the age of the fetus. There were also provisions concerning parental consent, spousal notification and public recording of abortions performed. Although a majority of the Supreme Court held that 'the essential holding of *Roe v Wade* should be retained and once again reaffirmed' (at 2804), it struck down only the provision of

extend considerably the rights of persons (particularly women) in the area of reproduction. More generally, we see how the 'right of privacy' started as a 'family right' and has become an 'individual right' which guarantees many personal and sexual freedoms[182]. It does, however, have its limits. This point was made quite categorically by the Supreme Court in *Bowers v Hardwick*[183].

4.2.1.1. - *Bowers v Hardwick*

In this case the constitutionality of a Georgia statute which criminalised sodomy was challenged by Michael Hardwick who had been prosecuted under the law. He argued that his homosexual activity was 'a private and intimate association' beyond the legitimate reach of state intervention and protected by his Constitutional Right to Privacy. Justice White, who wrote for the 5-4 majority upholding the statute, framed Hardwick's case rather differently. He asserted that the essence of the case was whether '...the Federal Constitution confers a fundamental right upon homosexuals to engage in sodomy'[184]. Thus put, it is hardly surprising that Hardwick's case was unsuccessful.

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the Pennsylvania Act which concerned spousal notification. The remaining provisions were not 'unduly burdensome' on the woman and therefore acceptable in constitutional terms. This language is revealing. It represents a significant shift away from the language of *Roe v Wade* which required the state to show a 'compelling interest' to justify interference with the abortion decision. This shift in terminology is not mere sophistry. The need simply to avoid an 'unduly burdensome' provision means that states can legitimately give information to women about abortion and its risks and consequences in an attempt to persuade (but not coerce) them into opting out of abortion. Such an outcome, arguably, was not possible with the language of Justice Blackmun in *Roe v Wade*.

[181] For critical comment on these and other right of privacy cases in the area of reproduction, see Keynes, E.; 'Liberty, Property and Privacy: Towards a Jurisprudence of Substantive Due Process', Pennsylvania, Pennsylvania State University Press, 1996, chapter 8.

[182] As Rubenfeld has noted, '[t]he great peculiarity of the privacy cases is their predominant, though not exclusive, focus on sexuality - not "sex" as such, of course, but sexuality in the broad sense of that term; the network of decisions and conduct relating to the conditions under which sex is permissible, the social institutions surrounding sexual relationships, and the procreative consequences of sex. Nothing in the privacy cases says that the doctrine must gravitate around sexuality. Nevertheless, it has.', *loc. cit.*, at 744.

[183] 478 U.S. 186 (1986).

[184] *ibid*, at 190.

Of the varied and disparate bases of the decision in *Bowers v Hardwick*, that which is of most relevance to the present discussion is the following. Justice White noted that to date the Constitutional privacy cases 'protected' three categories of activity: marriage, procreation and family relationships[185]. Since the activities of homosexuals fall into none of these, he argued, their activities cannot be protected by the privacy right. This is bizarre reasoning by anyone's standards. First, all that Justice White did in *Bowers* was to *describe* the nature of the Court's prior decisions on privacy. What he did not do, and yet which is surely fundamental to his argument, was to provide an explanation of the underlying doctrinal philosophy which ties these three areas together. In the absence of such, these three categories can only be examples of the sphere of life protected by privacy, they cannot be determinative in any way. Second, Justice White also failed to explain why he thought (as he and the majority obviously did) that the Constitutional right of privacy should be *restricted* to areas of life which do not include homosexual conduct. This latter point should not be misinterpreted. It does not say that no justification for upholding the Georgia statute was advanced. Rather, it asks the question, why is privacy - which is clearly concerned with sexual conduct and sexuality - not concerned with the sexuality of all, including homosexuals? It is no longer possible to argue, for example[186], that the right of privacy is concerned with families and marital activity, for the court's decision in *Eisenstadt v Baird* permitted single people to have access to contraceptives and this can *only* be seen to be about sex. *Bowers* then is surely inconsistent and unprincipled. It refuses to extend the authority which we *do* have from previous cases (which indicate that sexual freedom should be protected), yet offers no justifiable rationale for its departure from such cases which clarifies for us the true basis of the US Constitutional Right of Privacy.

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[185] *ibid*, at 190 - 191.

[186] As one might have done after *Griswold v Connecticut, supra cit.*

Not surprisingly the *Bowers* decision has been heavily criticised[187]. Those who analyse the aftermath primarily ask the question, 'what does privacy mean now?' Many see privacy as being concerned with choices and decisions, but this simply begs the question, *which* choices and decisions are protected by privacy? And, as Rubenfeld has pointed out, '[o]n this point the Court has offered little guidance.'[188]

> We are told that privacy encompasses only those "personal rights that can be deemed 'fundamental' or 'implicit in the concept of ordered liberty'" [*Roe v Wade* at 152], that it insulates decisions "important" to a person's destiny [*Whalen v Roe* 429 US 589, 1977, at 600], and that it applies to "matters...fundamentally affecting a person" [*Eisenstadt v Baird* at 438, 453]. Perhaps the best interpretation of these formulations is that privacy is like obscenity : the Justices might not be able to say what privacy is, but they know it when they see it.[189]

Rubenfeld himself argues, however, that this is an unsatisfactory state of affairs, leaving privacy open to allegations of conceptual confusion (see *infra*) and ill-considered development. For him the underlying principle which binds together privacy cases and which provides a consistent and justifiable rationale for them is that of 'the fundamental freedom not to have one's life too totally determined by a progressively more normalizing state'[190]. This is an aspect of liberty, but not the

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[187] See, for example, Rubenfeld, *loc. cit.*, Kohler, M.H.; 'History, Homosexuality, and Homophobia: The Judicial Intolerance of *Bowers v Hardwick*', 19, *Connecticut Law Review*, 129, 1986, and Thomas, K.; 'Beyond the Privacy Principle', 92, *Columbia Law Review*, 14331, 1992. Thomas argues not only that *Bowers* is inconsistent with prior case-law, but also that the decision legitimises homophobic violence in that it sanctions the existence of anti-sodomy (and therefore anti-homosexual) laws. Furthermore, he argues that the language of 'privacy' is ill-equipped either to protect the interests of homosexuals or to challenge adequately the Court's reasoning in *Bowers*.

[188] Rubenfeld, *loc. cit.*, at 751.

[189] *ibid.*

[190] *ibid*, at 784ff. Rubenfeld rejects 'personhood' as the unifying principle which represents the interests which should be protected by privacy. He does so in the context of the *Bowers v Hardwick* case and primarily on the grounds that to argue that privacy protects a 'homosexual identity' essential to one's self-conception and being is to buy into the heterosexual classification of homosexuality as a deviance. As he says, '[t]o protect the rights of the "homosexual" would of course be a victory; doing so, however, because homosexuality is essential to a peson's identity is no liberation, but simply the flip side of the same rigidification of sexual identities by which our society simultaneously inculcates sexual roles, normalizes sexual conduct, and vilifies "faggots"...Thus personhood, at the instant that it proclaims a freedom of self-definition, reproduces the very constraints on identity that it purports to resist.', *loc. cit.*, at 780 - 781. Such an argument is not dissimilar to arguments made by feminists concerning the public/private distinction, *supra*.

aspect commonly understood which prohibits laws which restrict specific conduct. Rather, Rubenfeld's thesis is that privacy concerns laws which 'take over' the lives of individuals because they are concerned with aspects of life which are profoundly and extensively affected by such laws. One's liberty or freedom is not merely restricted in certain aspects; one's entire life is directed down a state-proscribed path. He puts it thus,

> ...laws against abortion, interracial marriage, non-nuclear family residences, and private education all involve a peculiar form of obedience that reaches far beyond mere abstention from the particular proscribed act. It is a form of obedience in which the life of the person forced to obey is thereafter substantially filled up and informed by the living, institutional consequences of obedience. The person finds himself in a new and sharply-defined, but also broadly encompassing institutional role because of their affirmative direction of individuals' lives, these roles - whether as mother, spouse, student or family member - have profoundly formative effects on identity and character.[191]

Moreover, this analysis explains and justifies the protection of rights in the *Bowers v Hardwick* scenario. The obedience of anti-sodomy laws has the product of forcing homosexuals into relations with the opposite sex and requires that they adopt 'normalised' social roles as between themselves and the opposite sex. Undeniably, this has profound implications for the everyday lives of such persons[192].

The appeal in Rubenfeld's analysis is strong. He not only provides us with a unifying concept of privacy which at the same time provides consistent explanation of past cases and allows clear prediction for future cases, but he also provides a valid theoretical basis on which to defend Hardwick's claim and to criticise the Supreme Court's rejection of that claim. The content of his right of privacy is a right 'not to have the course of one's life dictated by the state'[193]. As an aspect of a liberty argument, however, Rubenfeld's thesis is open to the criticism which is made so

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[191] *ibid*, at 792-793.

[192] *ibid*, at 799 - 802.

[193] *ibid*, at 807.

often of the Constitutional right of privacy and those who write about it; namely, that privacy is confused with and conflated with liberty. Before we examine this charge, there is a more obvious question which must be addressed. If, indeed, Rubenfeld and others are right and it is liberty which is the issue and not privacy, why then should the Supreme Court persist with privacy analyses?

Gavison notes that the use of the language of privacy rather than liberty was deliberate on the part of the US Supreme Court[194]. This is primarily because a problem for the Court in *Griswold* was the need to distinguish 'the substantive due process rationale' established in *Lochner v New York*[195]. This 1905 decision represents the extreme 'liberal' approach once adopted by the Court towards the legitimacy of state intervention in the lives of individuals. In that case the Court held as unconstitutional a New York law which sought to restrict the hours that a bakery worker could work in any one day[196] or any one week[197]. The rationale behind the statute was that the state sought to develop consistent labour law policies and to protect the health and safety of workers. The Supreme Court, however, rejected these arguments and held by a majority that the principle of liberty of contract was unduly compromised by such an act. Taking as its authority the due process clause of the Fourteenth Amendment[198], the Court held that to uphold the constitutionality of such an Act would be effectively to deprive individuals of their liberty interests in contracting upon terms agreed privately between themselves and their employers[199]. The Court saw the case as an attempt to impose external constraints on economic relations rather than one truly concerned

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[194] See Gavison, 'Feminism and the Public/Private Distinction', *loc. cit.*, at 31 - 32, and 34 - 35.
[195] 198 US 45 (1905).
[196] 10 hours per day.
[197] 60 hours per week.
[198] The Fourteenth Amendment guarantees the protection of life, liberty and property, none of which can be taken away without 'due process of law'. The clause is not, however, merely concerned with procedural requirements but has been interpreted to mean *substantive* due process; that is, it acts to restrict the substantive power of the state to regulate the lives of individuals without good reason.
[199] *ibid*, at 53.

with worker welfare - an end not acceptable as a legislative goal in its eyes. The immediate consequence of this decision was that economic regulation was treated as an issue requiring strict scrutiny if contained in any statute, the implication being that freedom in economic matters was a fundamental freedom under the Constitution. Post-*Lochner*, the Supreme Court was, however, very heavily criticised. As an interpretation of 'liberty' in the Fourteenth Amendment, the decision is not only very broad, but also it arguably ignores the very real problem of inequality of bargaining power between employer and employee. The protection of individuals was seen to be abandoned to the vagaries of the marketplace.

Although the specific ruling in *Lochner* was overturned only twelve years later[200], the effects of the decision continued to be felt long afterwards[201]. In particular, the protection of 'liberty' under the Constitution as a matter of substantive due process came to be seen in a bad light as a result of the *Lochner* economic rights analysis[202]. Thus, when the Court came to decide *Griswold* in 1965, it was keen (a) to extend the protected rights of individuals to include the use of contraceptives between married couples, but (b) to avoid using the rationale of *Lochner* (and therefore 'liberty' as it had been used previously) for fear of undermining the protection to be afforded[203]. As Gavison has observed: 'Privacy reasoning offered a way out of the *Lochner* dead end'[204]. Of course, it should not be forgotten or

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[200] *Bunting v Oregon* 243 U.S. 426 (1917).

[201] The decision in *Nebbia v New York* 291 U.S. 502 (1934) signaled the beginning of the end-point of Lochner-type thinking towards the regulation of economic matters. Here the Court held that strict scrutiny was no longer necessary and that the law need only not be 'unreasonable, arbitrary or capricious' and the means selected to achieve the particular legislative end should have a real and substantial relation to that end. Eventually, in *West Coast Hotel Co. v Parrish* 300 U.S. 379 (1937) the Court upheld a statute requiring a minimum wage for women even although it interfered with freedom of contract *because* the Court recognised in real terms that there was a very great inequality of bargaining power between the parties concerned.

[202] For account of the 'demise of substantive due process', see Keynes, *op. cit.*, chapter six.

[203] To see how this is done see *Griswold, supra cit.*, at 482.

[204] Gavison, 'Feminism and the Public/Private Distinction', *loc. cit.*, at 34. She also notes, '[t]he privacy argument identified reasons for which non-interference was justified : the personal nature of the choice; the intimate area of life invovled; and the centrality of the decision to one's self-identity. All of these reasons help to justify the choice of privacy over liberty arguments.', *id.* For a discussion of the events of this time and the key decisions of the Court, see Keynes, *op. cit.*, chapter seven.

allowed to be obscured that the primary constitutional provision used remains the same - the substantive due process clause of the Fourteenth Amendment. This brings us to the crucial question: are 'liberty' and 'privacy' under *Lochner* and *Griswold et al.* the same things under different guises?

Various arguments have been advanced on both sides[205]. Some have argued that the *Lochner* cases were concerned solely with economic interests and that the flaw with those cases is that the Court cannot and should not act as a dictator of state economic policy. Given that the privacy cases do not involve the Court in acting as a 'super legislature', the cases can be distinguished. However, as Rubenfeld points out: '[i]n its own eyes, the *Lochner* Court was not regulating economics; it was protecting liberty - the liberty of contract.'[206] Furthermore, he points out quite rightly that that which is 'private' can easily extend to economic matters, even if the Supreme Court has thus far chosen to restrict privacy cases principally to matters of sexuality[207]. Rather, his defence of the two sets of cases focuses on the 'pre-political' nature of the *Lochner* decisions. The concerns of those cases - that is, liberty of contract cases - were property rights which pre-existed the Constitution and so did not require the explicit protection of the Constitution. Privacy rights, however, have evolved because of 'creeping totalitarianism' and are thus political rights created in response to societal influences. Unfortunately, the utility of this analysis is limited for the purposes of the present discussion. Rubenfeld provides *a* means of distinguishing the privacy and liberty cases, but he does not address the criticism that his 'privacy' analysis is simply a 'liberty' analysis by another name. Similarly, Gavison provides us with an explanation of the Court's use of 'privacy' and not 'liberty', but this still begs the question whether, at the end of the day, 'privacy' is not simply confused with 'liberty' as a general metaphysical concept.

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[205] See, in particular Rubenfeld, *loc. cit.*, at 802 - 805.
[206] *ibid*, at 803.
[207] *id.*

4.3. - Conflation of Concepts

Commentators criticise the US Constitution's privacy right on many different levels[208]. As discussed, one major criticism which is frequently voiced is the alleged confusion of 'privacy' with 'liberty'. Parent, for example, shows deep concern about the confusion that surrounds such notions[209]. He argues,

> The defining idea of liberty is the absence of external restraints or coercion. A person who is behind bars or locked in a room or physically pinned to the ground is unfree to do many things. Similarly, a person who is prohibited by law from making certain choices should be described as having been denied the liberty or freedom to make them. The loss of liberty in these cases takes the form of a deprivation of autonomy. Hence we can meaningfully say that the right to liberty embraces in part the right of persons to make fundamentally important choices about their lives and therewith to exercise significant control of different aspects of their behaviour. *It is clearly distinguishable from privacy, which condemns the unwarranted acquisition of undocumented personal knowledge.* [Emphasis added - Parent's definition of the concept of privacy].[210]

He feels that all of the U.S. constitutional privacy cases however, '..conflate the right to privacy with the right to liberty.'[211] Whereas one may not agree with his particular definition of privacy, his point on confusion of concepts is, nevertheless, a valid one[212]. Wagner DeCew offers the following explanation,

> Given early association of a legal right to privacy as a right to be let alone and the well-known explanation of a concept of negative liberty in

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[208] Henkin, L. 'Privacy and Autonomy', 74, *Columbia Law Review*, 1410, 1974 has argued that *Griswold* and its progeny have given rise to 'an additional zone of *autonomy* of presumptive immunity to governmental regulation'. This Constitutional right of privacy he considers, '...may not add much protection to "traditional value privacy."', at 1424 - 1425. A similar criticism has been advanced by Gross, H.; 'Privacy and Autonomy', in Feinberg, J. and Gross, H. (eds.); 'Philosophy of Law', Second Edition, USA, Wadsworth Inc., 1980, at 246 - 251.

[209] Parent, 'Privacy, Morality and the Law', *loc. cit.*

[210] *ibid*, at 274 - 275.

[211] *ibid*, at 284.

[212] Although by no means altogether novel; see, for example, Gross, H.; 'Privacy and Autonomy', Nomos XIII, 180 - 181, and Henkin, 'Privacy and Autonomy', *loc. cit.*

> terms of freedom from interference, it is hardly surprising that privacy and liberty should often be equated.[213]

There is, however, an additional problem which stems from the fact that although one may accept wholeheartedly that privacy and liberty, as defined by Parent, are completely separate, it does not necessarily follow that the two concepts, *in se*, raise issues wholly unconnected with each other. Furthermore, as Wagner DeCew points out in relation to the U.S. cases,

> '...it is not at all clear that Parent has shown that the constitutional privacy cases involve no "genuine" privacy interests.'[214]

Clearly, however, the two concepts are by no means synonymous. As Wagner DeCew herself states, it is simple to show how one's notion of privacy can be shown to be distinct from that of liberty. The example she gives is where one's privacy is being constantly invaded by surreptitious surveillance, of which one is unaware, thereby having no effect on one's liberty. To this one could add the example of genetic testing where information is gathered about oneself from family members when one is wholly ignorant of the fact. Both of these examples involve invasion of one's private sphere yet involve no impingement on one's liberty. Indeed Wagner DeCew states,

> While the word "privacy" could be used to mean freedom to live one's life without governmental interference, the [U.S.] Supreme Court cannot so use it since such a right is at stake in every case. Our lives are continuously limited, often seriously, by governmental regulation.[215]

In fact the Supreme Court has expressly rejected this idea[216]. However, we can once again accept that perhaps this particular conflation of privacy with liberty is

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[213] Wagner DeCew, 'The Scope of Privacy in Law and Ethics', *loc. cit.*, at 162.
[214] *ibid*, at 161.
[215] *ibid* at 162.
[216] *Paris Adult Theatre I et al. v Slaton, District Attorney, et al.* 413 U.S. 49. De Cew makes this point at 163 - 164.

wrong, yet this does not necessitate that we reject completely the possibility of a relationship between the two concepts. Just as Wagner DeCew gives examples of privacy issues which do not involve liberty, and vice versa, she equally talks of autonomy examples which exclude all mention of privacy[217]. She qualifies this immediately, however, by acknowledging,

> '[that] a subset of autonomy cases, however, certain personal decisions regarding one's basic lifestyle, can plausibly be said to involve privacy interests as well. They should be viewed as liberty cases in virtue of their concern over decision-making *power*, whereas privacy is at stake due to the *nature* of the decision. More needs to be said about which decisions and activities are private ones, but it is no criticism or conflation of concepts to say that an act can be both a theft and a trespass. Similarly, acknowledging that in some cases there is both an invasion of privacy and a violation of liberty need not confuse those concepts.'[218]

She also comments that,

> '..loss of privacy can diminish freedom. Nevertheless defending privacy cannot always protect liberty.'[219]

What a defence of privacy can do, however, is protect some forms of liberty; principally those relating to the personal sphere of individuals' lives. The same is true for autonomy. And, in the case of personal information, this can be said of confidentiality too. This point cannot be stressed too strongly. Many commentators who concern themselves with the concepts of liberty or autonomy face problems of conceptual confusion, difficulty of definition and ambiguities of scope. Beauchamp and Childress, for example, point out that autonomy is terribly conceptually confused and 'not a univocal concept in either ordinary English or

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[217] *ibid*, at 164 - 165.

[218] *ibid*, at 165.

[219] *ibid*.

contemporary philosophy'[220]. Similarly, Dworkin considers a plethora of definitions of autonomy offered by writers in that field almost none of which is in conformity with one another[221]. Similarly, in the context of liberty, Berlin has noted that,

> Almost every moralist in human history has praised freedom. Like happiness and goodness, like nature and reality, the meaning of this term is so porous that there is little interpretation that it seems able to resist.[222]

In light of this it is important to recognise the fact that concepts such as liberty, autonomy and privacy are *interrelated.* Indeed, one could go as far as to say that they are interdependent, each one relying on another in order to fulfil its true function in the best possible way[223]. Consider the impossibility of making autonomous choices without a degree of freedom from interference[224]. Consider the residual value of liberty if one's life choices are never respected. And, consider whether it is feasible to be truly free or fully autonomous without some sphere of the private? It is submitted here that liberty and autonomy cannot properly fulfil their function or potential in protecting individuals and their interests without a concomitant commitment to a respect for privacy. Each of these concepts performs the same function, albeit in different ways: each represents an expression of the

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[220] Beauchamp, T. L. and Childress, J.F.; 'Principles of Biomedical Ethics', Fourth Edition, New York, Oxford University Press, 1994, at 120 - 121.
[221] Dworkin, 'The Theory and Practice of Autonomy', *op. cit.* .
[222] Berlin, I.; 'Four Essays on Liberty', Oxford, Oxford University Press, 1969, at 121.
[223] This is supported *inter alia* by Hallborg, R.B. Jr.; 'Principles of Liberty and the Right to Privacy', 5, *Law and Philosophy*, 175, 1986 who argues for a view of privacy which is deduced from fundamental principles of liberty. This he does 'in order to obtain a right to privacy which is not easily defeasible, and a right which ought to be a permanent part of our legal system.' That is, he sees the essence and value of privacy as being derivative.
[224] Greenawalt has argued, for example, that '[g]iven a society in which many life-styles and points of view evoke *negative* reactions if publicly known, a substantial degree of freedom from observation is essential if there is to be any genuine autonomy; and real choice also depends on the ability of persons to enjoy states of privacy without intrusion, see Shattuck, J.H.F.; 'Rights of Privacy', New York and Skokie, Ill., National Textbook Company in association with American Civil Liberties Union, 1977, at 199. The original version of this material is to be found at Greenawalt, K.; 'Privacy and its Legal Protections', 2, *Hastings Center Studies*, 45, 1974.

fundamental respect which a liberal society has for its citizens. Yet, each is also open to criticism as ill-defined, anti-communitarian and conceptually obfuscated. That said, it may be that we see liberty and autonomy as ends in themselves rather than as means to an end, while we may view privacy purely as a device to reach a certain end. Even so, it is submitted that it is not necessary to show privacy to be a fundamental and ultimate value of itself in order to argue validly for its protection. Furthermore, as Gavison points out,

> 'Privacy has as much coherence and attractiveness as other values to which we have made a clear commitment, such as liberty. Arguments for liberty, when examined carefully, are vulnerable to objections similar to the arguments..[against] privacy, yet this vulnerability has never been considered a reason not to acknowledge the importance of liberty, or not to express this importance by an explicit commitment so that any loss will be more likely to be noticed and taken into consideration.'[225]

She feels that the case for an explicit commitment to privacy is made by pointing out the distinctive functions of privacy in our lives. Are there then, specific functions for privacy to perform over and above a general support for other concepts such as liberty and autonomy?

It has been argued thus far in this work that this is indeed the case in the context of genetic information. Chapters three and four have shown how concepts such as autonomy and confidentiality do not and cannot address the concerns and interests which surround the availability of genetic information. The work of this chapter so far has been to examine current thinking on privacy and to outline common themes and criticisms relating to the views of privacy which have been advanced to date. In the course of this, the elements which support the view of privacy proposed in this work have been covered.

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[225] Gavison, 'Privacy and the Limits of the Law', *loc. cit.*, at 468.

Above, the definition proposed of privacy in this work has been defended in the abstract and can be summed up as follows. Privacy is a state of separateness from others which primarily protects two kinds of interest: informational privacy and spatial privacy. Privacy as so defined finds its roots in moral notions about individuality and presupposes social norms such as respect for individuals. In this it is allied to the related concepts of liberty and autonomy, and all three perform essentially the same function - they define how individuals are perceived and treated in western society and they operate to establish and maintain the boundaries between the individual and society. Moreover, they are all adjuncts to a view of human dignity and respect which is prevalent in our society. Privacy (and liberty and autonomy) is (are) not solely concerned with protection from harm but also with according respect to individuals, irrespective of the ability of such individuals to control, comprehend or command situations. To see privacy in such terms allows one to comprehend better why a state of separateness should be sought. It further allows us to put forward valid and legitimate reasons for arguing that such a state should be protected and that invasion should only be on legitimate grounds and for legitimate reasons. Below, in the final section of this chapter, a more specific defence of privacy is presented which applies the definition here advanced to the four genetic information scenarios outlined at the end of chapter two to show how privacy *in se* can best protect the interests involved.

5.1. - SCENARIOS

5.1.1. - *A Privacy Analysis*

Many arguments concerning the case scenarios have already been made in this thesis. It is pointless to recount them again here. Rather, it is proposed that the responses of the laws of autonomy and confidentiality - discussed in chapters three and four respectively - be briefly laid out in relation to each of the above scenarios and then an account given of how privacy as defined in this work could assist in addressing the problems in question.

5.2. - SCENARIO ONE: Employers and Insurers

In this, our first scenario two questions require to be addressed: that of access to existing genetic information and that of testing to reveal genetic information. As should now be perfectly clear, the first of these involves issues of informational privacy. The second concerns spatial privacy. What can a privacy analysis add to the way in which we might address these questions?

First, what is the role of informational privacy? We have seen how both confidentiality and autonomy set up strong reasons and important legal requirements to protect the interests an individual has in maintaining security of personal information. A means of ensuring specific and strong informational privacy protection would add to this and could require not only that consent to use the information be obtained, or that confidential information remains confidential, but also that respect for the information as relating to a specific individual and having special significance because of that be forthcoming during the entire time that the information is kept. Thus all uses and all disclosures would have to be done with express consent *or* for the strongest and most justifiable of reasons. For example, it could be argued that even where information is no longer confidential (and therefore no longer protected by the law of confidence) it should continue to receive respect and should not be used arbitrarily. This recognises the continuing privacy interest which an individual has in information about him/her - for even if information has been released into the public domain sufficiently to remove a duty of confidence, in real terms that information is not public knowledge (in the sense that the 'public' as a collective knows it). That is, disrespect for the information can still be displayed and harm to the individual can still result. Continued protection of privacy interests would ensure that this is minimised where possible. Similarly, the mere obtaining of widely drawn consent from an individual should not be seen as carte blanche to use or disclose the personal information without further concern. Autonomy ensures that consent must, in the main, be given, but thereafter autonomy does little to protect information. Arguably once again a continued informational privacy interest could ensure that respect is always forthcoming to personal information as long as it remains linked to an identifiable individual.

A final point about informational privacy is unique to the context of genetic information. We should not forget that information obtained about one person also relates to the genetic relatives of that person. Thus, the information that insurers and employers keep private and secure is so kept not just for the prospective insured, employee or job applicant with whom they deal, but also for the relatives of such a person. Such persons might never have consented to the information being passed on (that is, exercised an autonomous choice), nor even be aware of the existence of such information. They are, nevertheless, entitled to security of that information. It is submitted that only by recognising this through a specific informational privacy right can adequate protection be accorded to all involved.

Second, how does the concept of spatial privacy help to resolve matters when prospective insured, employees and job applicants are asked to take a genetic test? Arguably, to recognise a specific spatial privacy right is the best means to prevent the harm and affront which can arise from such testing practices. As we have seen, the law of confidentiality is of no use in such a context, and the law of autonomy which simply requires 'consent' can ill protect individuals who may feel that they are in no position to refuse consent in the face of an insurer or (prospective) employer. A legally protected spatial privacy right would suffer from none of these weaknesses. This is so because, (a) there would be a *prima facie* presumption that all individuals are in a state of separateness as regards unknown genetic information, and (b) strong reasons would therefore be required to invade that sphere in certain circumstances. In the employer/insurer context a financial interest would never be sufficiently strong to justify interfering with spatial privacy interests. If harm could be avoided by testing then interference may becomes more acceptable, but as has been argued in previous chapters, in this context this arises only very rarely. Furthermore, neither employers nor insurers are best placed to deal with information of this kind because of the potential inherent conflict they have between acting in their own interests and acting in the interests of individuals. Given this, a strong case can be put that *even if* harm can be avoided by the discovery of genetic information through testing, that testing should not be done by employers or insurers.

5.2.1. - *Scenario One: A Conclusion*

The recognition and protection of informational and spatial privacy interests would strengthen considerably the rights of individuals who face requests for genetic information from employers and insurers. We saw in chapter two how various reforms have been advocated to protect individuals in this context, and it is submitted that everything that is said here not only accords with such proposals, but add considerable weight to the arguments in their favour. Indeed, to embody the privacy interests enunciated here into a legal right would be a very good way of instituting such reforms.

5.3. - SCENARIO TWO: State Interests

In the context of state interests in screening programmes, once again arguments have already been made above that such programmes are open to question. The two kinds of privacy interests articulated in this work help to strengthen arguments against state programmes in two different ways.

First, let us consider informational privacy. This interest requires that any use or disclosure of genetic information which is linked to an identifiable individual is kept secure and not made subject to unwarranted or unauthorised activities. This is so irrespective of the existence of a relationship between the person holding the information and the subject of the information, it is non-dependent on the confidential nature (or otherwise) of the information and it does not require any express provision from the subject requiring that the information be kept secured. In other words, although the laws of confidentiality and autonomy can help to keep personal information secure, their particular provisions which might otherwise hinder protection do not do so here. Thus, from the perspective of the state which might wish to gather together genetic information - for example, to compile genetic databases - a strong presumption exists *against* such practices which, if it cannot prevent them, at least requires minimal usage, strong security measures, patient consent to use and disclosure and/or the use of anonymisation[226].

Second, what is the position regarding spatial privacy? This interest can be used to counter arguments that support the compulsory testing of individuals since these programmes require individuals to know information about themselves which they might not otherwise choose to know. As we have seen, this is potentially harmful and inherently disrespectful. That said, if a state can show a compelling interest[227] in requiring testing then such testing might prove to be acceptable. The point, however, is that to recognise spatial privacy interests in this context is to place an ever-more-onerous burden on the state to justify its programmes.

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[226] For a discussion of possible uses and means of protection concerning databanks see Macklin, R.; 'Privacy and Control of Genetic Information', in Annas, G.J. and Elias, S.; 'Mapping the Human Genome: Using Ethics and Law as Guides', New York, Oxford University Press, 1992, chapter 9, especially at 165 - 169.

[227] The use of US Constitutional language here is not meant to imply any connection with the debate about the legitimacy of US state intervention. It is simply convenient use of language.

5.3.1. - *Pre-marital Screening*

Arguably, for pre-marital testing no state interest is sufficiently strong to override individual privacy interests. This is so because the interests of the state in such cases are clearly centred around reproductive choice rather than concern with individual health (if this were not the case then testing would be carried out on individuals irrespective of their intentions to marry)[228]. And, as has been argued in previous chapters, such an interest is not strong because it is an interest in future persons (which is weak compared to the interests of existing persons) and also it is an interest which cannot be successfully furthered because the facilitation of choice does not and cannot ensure that the 'correct' choice (from the state perspective) will be made. The recognition of the individual spatial privacy interest fundamentally undermines the state's case in such circumstances.

5.3.2. - *Ante-natal and Neo-natal Screening*

In the context of ante-natal and neo-natal screening the point has already been made that the motivation behind testing is different depending on when the testing occurs. For ante-natal screening the primary motive is to facilitate parental choice in continuing with the pregnancy. The only variable is where there is an available cure for the tested-for condition in which case, clearly, concern for the fetus is also a factor[229]. In contrast, neonatal screening is carried out primarily to protect the

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[228] That said, if the concern of the state was individual health, and provided something could be done about the conditon, then mandatory testing becomes more acceptable. In such a case, however, the testing should be of the population at large and not just those who intend to marry. If the programmes is restricted to those who intend to marry its status once again becomes questionable not just on autonomy and privacy grounds but also those of justice - why are single persons excluded?

[229] Note, in the case where a test detected a fetal abnormality, it is very clear that the law in the United Kingdom would still permit an abortion *even if* a cure for the condition was available, see *supra* chapter three. Thus, arguably even in the case of cure, the paramount consideration with ante-natal screening remains parental (women's) choice.

interests of the child. These motivations are important for assessing the validity of such screening programmes from the privacy perspective.

5.3.2.1. - *Ante-natal Screening*

The question of whether or not parental choice can and should be facilitated has already been discussed. The acceptability of such an act depends on several factors such as (a) the right of the parents to have their choice facilitated , and (b) the interests of others which might be compromised in an attempt to facilitate parental choice. The first of these factors refers to the autonomy of the parents in question - are they, as individuals, given the right to 'choose' to receive further information about their reproductive practices? If so, then the aim of facilitating choice is an admirable one because it furthers individual autonomy. If, however, the parents do not themselves 'choose' to know but the information is thrust upon them in an effort to help them to choose, this is offensive to their spatial privacy interests in not knowing. It is submitted that it is better to protect the individuals in such a case by reference to a spatial privacy concept than by reference to autonomy because autonomy itself can be turned against the individuals in an attempt to justify the action: we do it to facilitate your choices - to 'enhance' your autonomy. A clearly recognised spatial privacy interest would provide an excellent means for defeating such an argument.

In such cases it is hard not to conclude that the primary motive of a state in forcing people to make informed choices is a desire to reduce costs of expensive future (defective) children. But, even if a state proclaims child welfare as a laudatory aim of its screening programme, one cannot avoid the fact that the means offered to achieve that aim is abortion. Thus, two birds are killed with the same stone - no child will suffer but also it is still the case that no extra costs will be incurred. And, the message which is attached to this stone reads that death is preferable to 'defective' life and that the state in which we live is short on compassion and tolerance. A dangerous path to follow.

5.3.2.2. - *Neo-natal Screening*

The objective of neonatal screening is to secure the health and welfare of the child. It has already been suggested in previous chapters, however, that to further this concern some further end must come from testing beyond the mere acquisition of knowledge. The recognition of a child's spatial privacy interests bolsters considerably this argument. Consider the cases of Huntington's disease and Duchenne Muscular Dystrophy. While no cure is available for these conditions, the case for carrying out neonatal testing for their presence in children is considerably weakened by the spatial privacy interests of those children. This case was made in chapter three where we saw a powerful argument by Wertz *et al* outlining the actual harm which can result from such early testing[230]. Preparedness of carers cannot be ensured and it is far from clear that the child's own best interests are served in such cases. We also saw, however, that the principle of autonomy could not help children in such cases. A recognition of spatial privacy interests can. Such interests dictate that it is for the child him or herself to decide, when sufficiently competent, whether or not to undergo such a test.

The question of testing for sickle cell anaemia (SCA) poses slightly different problems because, although not curable, the condition is treatable with regular blood transfusions. Testing will, however, also disclose those who are asymptomatic but carriers. The acceptability of such a screening programme must consider still the child's spatial privacy interests. And, in light of the US experience

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[230] Wertz, D.C. *et al.*; 'Genetic Testing for Children and Adolescents: Who Decides?', 272, *Journal of the American Medical Association*, 875, 1994, at 878, cited in Hoffman, D.E. and Wulfsberg, E.A.; 'Testing Children for Genetic Predispositions: Is it in Their Best Interests?', 23, *Journal of Law, Medicine and Ethics*, 331, 1995, at 333.

which led to racial discrimination and harassment, it might be better *not* to implement a screening programme for such a condition. Rather, individuals should be treated on an individual basis. If screening were not implemented racial groups at 'high risk' from SCA would not be set apart *in* the community and therefore would be less likely to be set apart *by* the community. Also, not to test large groups of persons simply because of their race means that the privacy interests of such persons will be protected because they will not be required to know information. Yet, for individual children who experience symptoms or in whose family there is already an incidence of SCA, testing could be carried out. Although this potentially impinges on the child's privacy interests, this is mitigated by the availability of treatment for the condition. Furthermore, if one waits until symptoms appear, this approach does not impinge on the interests of carriers because they will remain asymptomatic and therefore will never have to submit to testing. If these individuals choose at a later date to know their status that is entirely within their domain.

Finally, the condition known as ischaemic heart disease raises yet another set of problems. Although such a condition is multifactorial - and therefore suggests that an element of 'control' can be exercised over a child's environment to affect the onset or severity of the condition - it is imperative to stress that a test result in such cases can at best only give a very unclear indication of a possible predisposition to disease at some far distant date. Thus, a child who is subjected to screening is likely to suffer the same fate as those undergoing screening for Huntington's disease or Duchenne Muscular Dystrophy; namely; that they come to be seen as fragile victims waiting to be consumed by some terrible fate. It then becomes important to ascertain exactly what one can do to prevent or affect the onset of disease. If the answer is: 'we do not know' or 'not very much' then arguably the child's spatial privacy interest would support an argument against screening. If, however, we could be relatively certain that, given a predisposition, a strict dietary regime or a controlled home environment could affect to a significant degree the child's chances of developing disease, then the balance is more likely to be tipped in favour of screening.

5.3.3. - *Scenario Two: A Conclusion*

The conclusion which we can draw for this section is as follows. Spatial privacy interests help us not only to reflect on the interests at stake in screening programmes but also to argue against the acceptability of such programmes in the absence of clear and convincing evidence that strong interests *of benefit to the individuals concerned* can be furthered by the testing. If such evidence is not available, these privacy interests undermine such screening programmes and call their validity seriously into question. Direct protection of privacy in such cases is preferable to any other option considered because (a) in the case of the law of confidentiality, no protection is afforded at all, (b) the law of autonomy does not protect to a satisfactory extent the interests which children have in not knowing because they are classed as incapax and decisions about the control of their information is given to others who might not appreciate the spatial privacy interests at stake or ignore them, and (c) in the case of ante-natal screening, the law of autonomy can actually be used to further the interest of parents rather than the child or future person. This last point leads us to an interesting question. Must we conclude that future persons have spatial privacy interests, and/or that these should be preferred to the autonomous choices of their parents? The first of these questions can be answered in the affirmative, because we *can* and *do* recognise the interests of future persons in a variety of ways[231]. But, it is not necessary to go so far as to prefer these to the autonomy interests of living persons. Indeed, it is not

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[231] For example, in many jurisdictions the interest of the fetus in being born alive once it has reached a certain stage of development is recognised. Similarly, we recognise the interest of fetuses in not being harmed in the womb by requiring pregnant women to refrain from engaging in certain activities while pregnant, such as working with dangerous substances.

argued here that this should ever be the case. Nonetheless, awareness of such interests can help to inform living persons in the autonomous choices that they make, for example, whether or not to have an ante-natal test for Huntington's disease if one has no intention of aborting the fetus should the test prove to be positive.

5.4. - SCENARIO THREE: A Family's Right to Know

In this scenario the problem is one for a health care professional (Dr. Smith) to decide whether or not to disclose to his patients genetic information about a relative (Kenneth) who does not want the information to be disclosed. Kenneth is not a patient of Dr. Smith.

It will be recalled that the principle of respect for autonomy requires that individual choice be a determining factor in resolving our problem scenarios. To be autonomous an individual must be allowed to choose for him or herself the direction of his or her life, must be capable of making choices and must be free from interference by others in doing so. Autonomy therefore requires that we seek and respect where possible the choices of individuals. A problem with this model is that of conflicting autonomies. What does Dr. Smith do if Kenneth 'chooses' to keep his medical details private and yet in the opinion of Dr. Smith harm can be avoided and the autonomy of relatives can be enhanced by disclosure? As we saw in chapter three, Ngwena and Chadwick have made the powerful point that,

> ...what has to be taken into account is the fact that respecting the autonomy of one person may have implications for the autonomy of others. As the Royal College of Physicians argue, "Blood relatives have an interest in knowing the truth which has nothing to do with influencing their behaviour towards affected individuals in their families, but as a necessary means to finding out the truth about themselves"...How is the choice between the autonomy of different

> people made?...What is clear is that the decision cannot be taken on *autonomy grounds*[232].

We saw in chapter three how such a problem was irresolvable simply by an appeal to autonomy. Our other options then are confidentiality and, now, privacy.

The approach of confidentiality shows us that a duty of confidence is owed to Kenneth both by his own physician and our doctor. There is legal, ethical and professional authority for this. However, none of these sources imposes an absolute duty on a health care professional. We have seen in chapter four that confidentiality allows the doctor to breach confidences to inform the family if he can argue that to do so is in the public interest. In legal terms, and despite the restricted class of persons to be informed, it is probably the case that he *can* do so, invoking the public interest exception, given that a real risk of harm can be avoided by the availability of treatment for the recessive condition in question. Thus, we could say that for those individuals who are likely to be harmed by non-revelation of the genetic information of Kenneth, we disclose the information in question without breaching a duty of confidence to Kenneth[233].

From the perspective of privacy, this is an issue involving informational privacy - revelation of the information to others impinges on Kenneth's interest in the security of his personal information. The question which arises is, is this a legitimate and justifiable infringement? We can approach this question from different perspectives. First, we can consider the acceptability of an absolute right of privacy. Second, if we reject this, we should consider the factors which might build

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[232] Ngwena, C. and Chadwick; R.; 'Genetic Diagnostic Information and the Duty of Confidentiality: Ethics and Law', 1, *Medical Law International*, 73, 1993, at 77.

[233] When it is said that we do not breach the duty of confidence owed to Kenneth, it is meant that the existence of a valid 'public interest' has the consequence that a duty is probably not owed to Kenneth as regards the information in question, see Toulson and Phipps, 'Confidentiality', London, Sweet & Maxwell, 1996, at para. 6-11.

a strong case in favour of disclosure. In doing so we delimit the scope of the privacy interest.

Is the right to privacy advocated here an absolute one? This would not be in keeping with the general medico-legal ethos of most western states, and to argue for an absolute right would run counter to our views on the related concepts of autonomy, liberty and confidentiality, none of which receives absolute protection. This writer cannot see any sufficiently strong arguments which could be advanced to support such a claim. What, then, are the exceptions to privacy protection? It is difficult to reject the argument that 'public interest' is a valid exception to such a right, just as it is a determining factor in the law of confidentiality. However, what we need is a clearer idea of what we mean by 'public interest' - something which we certainly do not have in the law of confidentiality.

In the context of genetic information relevant factors have already been identified in chapter two which have a direct bearing on the strength of competing claims to information. These are:

- *The availability of a cure*
- *The severity of the condition and likelihood of onset*
- *The nature of the genetic disease*
- *The nature of the genetic testing*
- *The nature of the request*

To this we should add the very relevant factor that invasion of privacy must have a reasonable likelihood of furthering the competing interest. Also, we should be clearer, if possible, about who constitute a public for the public interest exception to be used in the context of privacy.

5.4.1. - *Promoting Public Interest*

In the context of our present scenario it is submitted that the health care professional must consider the nature of the condition in question, the nature of the interests at stake and their respective 'strengths'. On the one hand Kenneth has an interest in having his autonomy, confidentiality and informational privacy respected by not disclosing the information. Arguably, each of these is very 'strong' given the arguments which have already been put elsewhere. On the other hand, the doctor faces two different kinds of interests from relatives: (1) the autonomy interests of those who might want to know and who are likely to be physically harmed by non-disclosure, (2) the interests of the son and wife who are contemplating having a family.

It has already been argued in chapter three that the interest of the couple wishing to have a baby is simply an interest in a choice to reproduce and it has been stated, following Ngwena and Chadwick[234], that harm to such a choice by not revealing information is not sufficiently weighty to justify disrespecting Kenneth. That was on the grounds of autonomy. A privacy argument along the lines made out above adds more weight to this viewpoint. Thus, even if one were not convinced that Kenneth's autonomy should be enough to defeat the claims of the couple, the additional factor of his privacy interest serves to weaken considerably any competing claim.

The issue is somewhat different concerning relatives who themselves may suffer physical harm if not informed of Kenneth's condition. There is an additional imperative if they expressly wish to know. Arguably, if disclosure can both avoid physical harm and respect the wishes of relatives then there is a strong argument to be made that the information *should* be disclosed. If we assess the factors to be

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[234] *loc. cit.*

considered in relation to the specific disease in question we see that there is force in the argument that exceptions to the duty of confidentiality and the right to informational privacy should be invoked. However, and as was argued in chapter four, if the information *is* to be disclosed this should happen in a limited fashion. First, to the parents of the family in question to establish if they are both carriers. If they are not, no one else need know because no one else is at risk.

5.4.2. - *Who is the 'public' in the privacy 'public interest' exception?*

The question of whether the family constitutes a 'public' is a difficult one to answer. A 'public' is a collective defined, like 'society', by reference to the individual[235]. It is submitted that, relatively speaking, the other individuals in a family unit *can* constitute a 'public' by virtue of the fact that as a common collective with a common interest in familial information they have a claim to the information in question. What is not argued here, however, is either that (a) the 'familial public' has necessarily the *same* common interest in the information[236], or (b) that the 'familial public', by virtue of its strength of numbers alone, should have an automatic strong(er) claim to the information in question. In other words, it is not argued or even accepted that the family is a distinct group with rights or interests of its own. It is a collective of *individuals*, each of which can derive benefit from the claim of the collective to the information, but the collective itself does not, and cannot have a unitary claim.

Consider the nature of the claims which family members can have: either a claim to know the information or a claim not to know. These are diametrically opposed and

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[235] See *supra*, chapter one.

[236] Note, however, that Chadwick has pointed out that the concept of 'solidarity' can be invoked to found a claim that families *do* have a collective claim concerning the use and control of their genetic information, see Chadwick, R.; 'The Philosophy of the Right to Know and the Right Not to Know', in Chadwick, R., Levitt, M. and Shickle, D., (eds.); 'The Right to Know and the Right Not to Know', Aldershot, Avebury, 1997, chapter 1 at 20.

a single group or family cannot logically put the same two claims at the same time. Only individual members of the group or family can do so. But, how then can one claim a 'public interest' if, in the final analysis, the claim is an individual one? An answer might be to consider the essential nature of the 'public interest' exception: it is a claim that on policy grounds competing interests should be put in the balance with those interests seeking protection; in this case, privacy interests. It is a recognition of the legitimate nature of the interests in question. Although we can see these interests as individual in nature (relative X wants to know and relative Y does not etc.), we *can* meaningfully see them as public in nature too. An analogy can be drawn from the law of confidentiality. In *X v Y*[237] and *W v Egdell*[238] it was made clear that the interests which had to be weighed in the balance were the *public* interest in maintaining confidentiality and the *public* interest in disclosure, even although the courts recognised the essentially private nature of the claims. Similarly, one can argue that a family's interests are public interests and that these should be weighed in the balance with the public interest in respecting the privacy of individuals generally. We have already seen in this and previous chapters how such a public interest in privacy exists. To so contend is not so much to make 'public' the interests of individuals, but to engage in a debate about the legitimacy of the competing interests. That this is not simply done on an individual level (individual v. individual) is a reflection on the unfairness of such a balancing exercise: for, it would not be a balance at all at the end of the day - the greater number of 'individual family' interests would always outweigh the unitary privacy interest of the patient in question. A 'public interest' analysis allows for a fairer balance to be undertaken. And, the fairness of the exercise depends on the factors to be considered. These have been outlined above[239]. Thus, in our current problem, arguably the fact that something can be done to alleviate harm and suffering, and that the circle of individuals to be informed can be kept small until there is a real

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[237] *X v Y* [1988] 2 All ER 648, chapter four *supra*.

[238] *W v Egdell* [1990] 1 All ER 835, chapter four, *supra*.

[239] Section 5.4., *supra*

likelihood of harm, means that Kenneth's informational privacy could be compromised to allow our doctor to inform the parents of the family unit of the history of disease. Of course, the position might be very different if nothing could be done for the family. Arguably in such a case, disclosure simply to facilitate preparedness is not a sufficiently strong reason to invade someone else's privacy. This has been argued above, and *inter alia*, this conclusion has been reached because it is not at all clear that disclosure in such cases can *de facto* avoid harm or accord respect to the individuals in question. Indeed, it might cause harm in that individuals might be unable to cope with the information.

This last point merits close attention before we leave this matter. Everything which has been said so far about this scenario presupposes that the relatives either want to know Kenneth's genetic diagnosis, or that it is in their interests to know. Of course, as has often be repeated in this work, it is very difficult to assume either of these in the context of genetic information. This is so because unwarranted disclosures of information can interfere with spatial privacy interests, and in this context those would be the spatial privacy interests of Kenneth's relatives. This factor affects considerably the outcome of this scenario from a privacy perspective. It means, for example, that everything that has been said above about a legitimate disclosure of information and interference with Kenneth's information privacy is valid *only* in cases where we know that relatives of a proband actually *want* to know. If such a wish has been expressed then the argument stands that disclosure is permissible in the particular circumstances of this scenario to avoid physical harm on the basis of the privacy 'public interest' exception. And, whereas Kenneth's informational privacy interests will be compromised, the spatial privacy interests of his relatives will not be affected because they choose to know. If, however, we do not know what the wishes of the relatives are (or if they have expressed a wish not to know) then our privacy perspective must change. We cannot simply assume that disclosure *is* in a public interest (because harm may result rather than be averted), and it may well be the case that in such circumstances the concern for the spatial privacy interests of relatives actually helps us to respect the informational privacy interests of Kenneth because it prevents us from carrying out an unsolicited disclosure to unsuspecting relatives.

5.4.3. - *Scenario Three: A Conclusion*

Privacy arguments in this case assist greatly in resolving the dilemmas faced by our health care professional. For example, the claim of the couple trying to have a family is doubly defeated on both autonomy *and* privacy grounds. Indeed, whether the claims of the couple would be grounds to breach confidentiality is similarly questionable.

For those relatives who wish to know information, arguably privacy strengthens the proband's position but at the end of the day also yields the same result as the law of confidentiality: namely, that disclosure *in the particular circumstances of this scenario* is acceptable. This is so because it is not argued here that privacy should be an absolute concept, and because it is accepted that a form of public interest defence should exist, as in the law of confidentiality. However, the difference between the privacy analysis of this problem compared to a confidentiality analysis is the nature of the 'public interest' exception which permits disclosure. In the case of privacy it is articulated in more detail. Relevant factors are identified such as severity of injury from disease, likelihood of onset and availability of harm-reducing measures etc. This allows for a more informed - and arguably more justified - invocation of the public interest. This, it is submitted, is a crucial element in the success of any privacy law. Arguments in favour of privacy protection are often challenged and defeated on the grounds that 'privacy' is too amorphous a concept. The same is true of 'public interest'. In the context of this work it has been shown that it *is* possible to articulate specific privacy interests which can be protected in tandem with clearly definable public interests.

Finally, the recognition of both forms of privacy interest - informational and spatial - brings a whole new dimension to the problem of information disclosure. For, we see that just as one individual can have informational privacy interests in keeping information secure, relatives of that person can have spatial privacy interests in not being subjected to unwarranted disclosure of that information. The source of each of these interests is the same - the common heritage in the genetic information. And, in cases where we do not know whether those with spatial privacy interests would wish to know the information in question, a strong case can be put that they should not be subjected to this information. This argument is all the more strong for the fact that not to disclose also protects the informational privacy of another. Neither autonomy nor confidentiality allow such an argument to be made. We shall explore this matter further in our last scenario.

5.5. - SCENARIO FOUR: A Right Not to Know?

Finally, we come to consider the familial right not to know. In chapter four it was argued that the law of confidence cannot help in securing a right not to know information[240]. The discussion in this section will, therefore, proceed on the basis of the law of autonomy and the definition of privacy proposed in this work.

In chapter three it was argued that autonomy makes an uneasy basis for a claim not to know information[241]. Such a possible claim can arise in two circumstances, either (a) when the individual in question has absolutely no idea that information is available, or (b) when the individual has some information, e.g. - family history, but

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[240] *supra.*

[241] *supra.*

nothing more specific. An autonomy perspective of (a) would suggest that we should seek to establish the views of the individual about whether or not s/he would like to know the information in question, because autonomy requires choice and choice requires information. However, if we ask the individual to 'choose' not to know, we alert them to the fact that there might be something to know (indeed, this must be so or we would not approach them at all) and thereby deprive them of the opportunity to exercise meaningfully an interest in not knowing. That is, how can one respect the interest in not knowing if one seeks to help the individual choose by informing them that such a choice must be made? In the circumstances of (b), a limited degree of information might solicit a blanket refusal from the individual and arguably this should be respected, even although it is based on scant data. However, as was argued in chapter three, every autonomy analysis leaves open the possibility of challenge if the individual's choice can be questioned because of limited capacity or material interference by others. Thus, arguably, a blanket refusal to know might be open to challenge by those with more information if it is felt that the 'choice' in question was not legitimate because it was based on too little information. Thus, on an autonomy analysis the exercise of the choice not to know even in cases where there is some basis for that choice, might lay open the possibility of a paternalistic approach to the treatment of genetic data. In other words, in both cases an autonomy analysis alone does not offer a strong basis for an argument for a right not to know. How then, if at all, can privacy assist in this problem?

The argument has already been put above in favour of the interest in not knowing in certain cases. In the context of genetic information those '*certain cases*' can be determined, once again, by reference to the factors identified above and in chapter one as relevant for genetic privacy cases. These are:

- *The availability of a cure*
- *The severity of the condition and likelihood of onset*
- *The nature of the genetic disease*
- *The nature of the genetic testing*
- *The nature of the request*
- *The question of whether disclosure can further a valid public interest*
- *The question of how the individual might be affected if subjected to unwarranted information*

A spatial privacy analysis founds a right not to know information. Consider the following examples. First, if the individual has no knowledge at all that familial information exists, the spatial privacy interest stands as a *prima facie* bar to the person being approached and told the information. Before such an approach is made spatial privacy requires that we consider how the individual might be harmed by disclosure and what 'good', if any, might come from disclosure. It requires that we reflect on the act of disclosure and places the onus on us not to disclose unless faced with compelling reasons to do so. Finally, it goes some way to ensuring that the decision-maker does 'not rest content with assumptions that flow from preconceived value preferences'[242]. That is, a privacy analysis reveals the broader and more complex reality of scenarios involving genetic information. This does not happen if we analyse the issue from the perspective of autonomy or confidentiality. Autonomy arguments are open to the possibility that one can argue for 'autonomy enhancement' by disclosing information. Confidentiality is so replete with ill-defined exceptions that disclosure can easily be justified at the discretion of those in possession of the information. Indeed, in the context of disclosure to family members confidentiality is utterly useless in protecting a right not to know because

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[242] Macklin, 'Privacy and Control of Genetic Information', in Annas, and Elias, 'Gene Mapping: Using Law and Ethics as Guides', *op. cit.*, chapter 9, at 164.

one cannot breach a duty of confidence by giving someone information about themselves.

Second, all of the above is equally true in the case of a refusal based on limited knowledge. However, in addition we have an indication that an individual might not wish to know information. Autonomy requires that we respect such a wish and a spatial privacy analysis gives us a excellent reason to do so. It is accepted that a privacy analysis does not necessarily make it easier for us to respect a wish not to know if that wish seems irrational (e.g.- if there is a complete cure for the condition and yet refusal is still given) but, it does give us all the more cause to reflect that the 'refusal' should be respected nonetheless. And, it is submitted that a privacy analysis leads us to do so, *even if* we would like to act more paternalistically towards the individual. In contrast, an autonomy model allows us to act paternalistically, because of the susceptibility of autonomy to 'enhancement' and 'facilitation' arguments. Arguably a privacy model in conjunction with an autonomy model persuades us not to do so.

Thus, in the circumstances of scenario four Nicola must consider the privacy interests of her female relatives in not knowing of the history of breast cancer in the family. In chapter three it was argued from the perspective of autonomy that Nicola could approach her relatives with the news of her own condition and let them decide for themselves whether they should do something about discovering their own genetic composition. From the perspective of privacy, Nicola must seriously consider the spatial privacy interests of her relatives. This might lead her to conclude that the information should *not* be imparted, for example, in the case of the sister who is unlikely to be able to take advantage of the 'cure' available because she is phobic about operations, or the cousin who is likely to react badly to the information given that she is prone to bouts of depression.

5.5.1. - *Scenario Four: A Conclusion*

In light of the above, our spatial privacy analysis provides Nicola with a more sophisticated model than is currently available from either of the concepts of autonomy or confidentiality with which to determine how she should proceed with the news about her condition. In particular, given the circumstances of her sister and cousin who might react very badly to the news and who might refuse to undergo the available treatment (mastectomy) even with the knowledge of their greater risk, Nicola might decide that the privacy of these persons should not be invaded with the news that there is a history of breast cancer in the family or that she herself has the disease. That said, because there is a risk that these relatives might die if not informed, Nicola would arguably require strong and clear evidence that they would not wish to be informed[243]. This situation is different from that in scenario three, because there is no competition between the privacy interests of the proband and his/her relatives. If Nicola chooses to tell her relatives this clearly has no implications for her informational privacy. The same was not true in scenario three where a third party in possession of familial genetic information sought to disclose it in direct conflict with the proband's informational privacy interests. In the circumstances of individual cases this might be enough to tip the balance a different way.

It is not forgotten when discussing these scenarios that in a real-life context matters would not be so straight-forward. It is acknowledged that in a family context it is very difficult to keep matters 'secret' or 'private'. Also, faced with the prospect of death, many would consider that everyone would wish to know of a predisposition to disease, no matter how upsetting the knowledge. This work cannot address such issues. But, the point to be made is that the privacy analysis advanced here can be

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[243] Arguably, however, Nicola's decision not to disclose would be stronger in a case where no treatment were available at all.

seen as a reflection of a wider trend in medicine and the care of others. The principle of sanctity of life is no longer seen to be the absolute value in health care. Quality of life has taken over that position. And acceptance of this requires many paradigm shifts. If one thought that the 'supreme value' were to save life at all cost, then subtle privacy issues such as those advanced here would not arise. If, however, one values quality of life and accepts that we might prefer quality to mere continuation of life itself, then this requires us to accept that individuals might have an interest in preserving their current quality of life, even if that comes at the cost of life itself. The privacy model suggested here provides us with one way of seeking to respect such an interest.

6.1. - ASSESSING PRIVACY PROTECTION MEASURES

It can be seen from the study of the four case scenarios that the arguments for protecting privacy are strongest in the case of employers, insurers, the state and when a health care professional is in possession of genetic information. In such cases it would be entirely possible to institute legal protection for both informational and spatial privacy interests. In the case of informational privacy the burden on third parties would be to ensure that any genetic data held on individuals were kept as secure as possible and used/disclosed only in the most justified of circumstances. The basis for saying that the information should be kept secure stems from the fact that it relates to individuals who have a strong privacy interest in it. It should not matter how the information was gained (e.g. - because of a confidential relationship) nor how often it has been disclosed by others in different contexts (i.e. - if it becomes part of the public domain). However, we have seen that, to an extent, measures exist to protect the security of information generally, and these measures are likely to become even tighter after 1998 once the United Kingdom has introduced into domestic law the provisions of the Data Protection Directive[244].

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[244] See chapter one, *supra*.

Nevertheless, specific privacy legislation designed to protect informational privacy interests in genetic information would be by no means superfluous, because it could take account of the unique fact that the security is maintained not just for the proband but also for his/her family.

Legal protection of spatial privacy interests does not currently exist in the United Kingdom. There is no 'right not to know'. It has been argued that a specific commitment to protecting such interests is legitimate and worthwhile. But would it be viable? This question deserve close attention and is the subject of the next section.

7.1. - A RIGHT NOT TO KNOW: A LEGAL FRAMEWORK?

7.1.1. - *A duty not to inform*

One way to enshrine a right not to know in law would be to make an unauthorised disclosure a cause of action leading to the payment of damages either for harm caused or simply because the privacy of the information is not respected. In the former case, the harm is upset rather than physical injury. Some may argue that this is insufficient injury, but we can see in many areas that a precedent has already been set for recognising such injury. For example, the Sex Discrimination Act 1975 and the Race Relations Act 1976 contain identical provisions that 'damages in respect of an unlawful act of discrimination may include compensation for injury to feelings whether or not they include compensation under any other head.'[245] Similarly, in the law of confidence damages are payable even in the absence of detriment[246]. Whereas it is by no means settled that the law of confidence does or does not require detriment to be shown[247], powerful arguments exist that detriment is *not*

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[245] 1975 Act, s.66(4); 1976 Act s.57(4).
[246] *supra*, chapter four.
[247] *id.*

necessary because the offence is to the confidential nature of the information and/or the relationship created by the confidential information either or both of which are injured *a priori* by the use or disclosure of the information. In like manner, one could argue that it is the disrespect for the individual's privacy interests manifest in an unauthorised disclosure of genetic information which is offensive and not necessarily the resultant 'harm' in the guise of upset.

The legal recognition of such a right of action would give much weight to the privacy claim under scrutiny, which is that of spatial privacy. It would help to ensure that proper reflection is given to cases involving spatial privacy interests and would have a deterrence effect on those who would seek to act in an overly paternalistic way towards others. An obvious problem with this approach, however, is that the existence of a 'right' not to know implies that a 'duty' should exist in certain cases not to disclose information. Yet, an important factor in determining whether such a 'duty' exists is the question of how the individual might react. This is a very subjective matter which can be especially difficult for any third party to assess. It leads to the possibility that individual A might determine that individual B should not be informed of information, when in fact individual B would actually want to know, had s/he been given the opportunity. As we have seen, the privacy argument about not disclosing is based primarily on a desire not to harm and a desire to respect the individual, but in such a case the very fact of non-disclosure might *cause* harm and might be an act of disrespect in itself. The problem is that the determining factor for deciding whether a duty not to disclose exists is a subjective assessment of how the individual will react. Not only is this difficult to assess but arguably it is simply another form of paternalism. Is then, an objective analysis preferable? In such a case, the person in possession of the information would assess factors such as likelihood of onset, availability of cure etc. together with an objective consideration of what a person in the subject's position would or would not want to know. Such a 'reasonable subject' could assume the particular characteristics of the actual subject. At the end of the day, provided that the assessment was a reasonable one, no legal action could lie against someone who had decided not to disclose information. Of course, the assessment of such factors is much easier when done by a health care professional, or a party with access to expertise such as the state, employers or insurers. It is far less clear whether family members are in a position to make meaningful assessments of such factors, let alone whether they should be the subject of a legal action if they disclose information in unjustified circumstances. It is more permissible to impose a duty on third parties who seek genetic information or who seek to disclose it, not to do so or to do so only in the most justified of circumstances.

Yet, even if such an objectively assessed privacy right were accepted, it might be objected that it is open to the same criticism as has been levelled at Wacks[248], in that it does not take account of cases where actual harm occurs to an actual individual. That said, the criticism of Wacks was primarily one concerned with consistency. Wacks' model is about avoiding harm, and it does not do that across the board. The privacy model advanced here is concerned not solely with avoiding harm but also with according respect - it tries to offer a way of recognising the subtle and wide-ranging privacy interests which can exist in genetic information. It does not pretend to offer an ideal solution for all cases. Perhaps, then, an objective approach *is* the best way forward. For it provides a means of reflecting on the question of respect and the nature of harm and seeks to incorporate such reflections into the decision-making process concerning the use to which information should be put. That in doing so it adopts an objective stance allows us at least to move away from an entirely subjective approach and allows us to reach decisions based on the actual facts about the circumstances in question including the nature of the disease, its spread, its chances of harm, prior views of the patient etc. Furthermore, an objective approach can be given direction by the law - we can prescribe, for

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[248] *supra*, section 3.3.

example, that prior indications of a wish not to know should be respected, or that circumstances involving a disease for which there is no cure should primarily be treated as non-disclosure cases. The same is not true of a subjective approach.

Finally, even if all of the above is accepted, one question still remains: does this approach avoid a paternalistic assessment of spatial privacy interests? To an extent it does not, but perhaps this can never be avoided in any cases where one cannot approach the individual him or herself to determine how one should proceed. Rather, it might have to be conceded that the worth of this approach is more limited, but not necessarily any less valuable. For although one must come to an objective assessment of how one should proceed (based on an objective assessment of how the individual subject might react), one can nonetheless come to a decision in an ethically acceptable and respectful way. An example of an unacceptable approach would be to determine the individual's best interests by reference to, for example, the standards of the medical profession[249]. A preferable approach would be to attempt to put the decision-maker in the position of the subject and to give the decision-maker the responsibility of determining what the individual would want by reference to all available evidence, for example, written advance directives, evidence of relatives, prior oral evidence from the subject him/herself. In addition, a well-defined spatial privacy right could bring to this a clear account of the kind of factors which would make disclosure in different circumstances acceptable or unacceptable.

7.1.2. - *No duty to inform*

An alternative means of enshrining in legal terms an interest in not knowing would be to avoid imposing a duty to disclose information, save in exceptional

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[249] This is the (unfortunate) position now applicable in the United Kingdom. See *Airedale NHS Trust v Bland* [1993] 1 AC 789 and *Law Hospital NHS Trust v Lord Advocate* 1996 SLT 848; 1996 SLT 869.

circumstances. This becomes a policy matter which could affect the future direction of the existing law. For example, one could refuse to recognise an action in negligence for failure to disclose genetic information, except perhaps in circumstances where there is an incontrovertible means available for avoiding harm. This is particularly relevant for wrongful birth actions. Should, for example, a woman who is misled about the results of a prenatal genetic test and gives birth to a 'genetically defective' child as a result, be able to claim a wrongful birth action because she was denied the chance to avoid the 'harm' (namely the birth of the child) by having an abortion? In such a case it is argued that the harm is to her (primarily financially). Undeniably, the right to choose abortion is hers. But, should the spatial privacy interest of the future child - in not knowing that it might suffer from a genetic condition - be used to deny the woman an action of wrongful birth? This is surely very difficult to accept. For in such a case there is, arguably, no privacy interest sufficiently strong to challenge the woman's right. This, however, is because the privacy interests of the future child are minimal given its (legal) status as a non-person.

Perhaps a better example comes from the law of confidence. We saw in chapter four that the law of confidence is sufficiently vague to allow for variable interpretations of its scope, especially through the public interest exception. And a popular interpretation of the public interest exception is that it recognises that a health care professional owes a duty not just to his patient but also to the public[250]. In the context of genetic information, it has been argued on this basis that a doctor has a *duty* to disclose information, either as part of the law of confidence, or as part of a duty of care in negligence as in *Tarasoff*[251]. Arguably to <u>refuse</u> to recognise such duties is a more viable way than the wrongful birth case of recognising and giving legal weight to privacy interests in not knowing. Thus, in cases where there is no

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[250] See *W v Egdell, supra cit.*

[251] Discussed *supra*, chapter four.

treatment or cure available and/or the condition is late-onset, or the degree to which others will be affected is minimal, the courts could not allow actions in negligence or could refuse to uphold breach of confidence actions as a way of sending a message that in determining whether or not a duty to disclose exists a very important feature is the interest of others in not knowing. The problem with such an approach is that it leaves the matter of the recognition of spatial privacy interests to the judiciary who can only recognise such interests as and when relevant disputes come to court. Also, and more importantly from the individual's perspective, such an approach does not accord any right of compensation to those who have had their privacy interests invaded, it merely acts to pay abstract lip-service to such interests - perhaps an unsatisfactory and insufficient legal response.

7.1.3. - *Protecting Spatial Privacy & Ante-Natal Screening*

In the particular case of ante-natal screening a final, more subtle way of recognising an interest in not knowing is to ensure that genetic counselling is comprehensive and detailed *prior to testing* and that it is never presented as routine. At the moment counselling, screening and testing is unregulated in the United Kingdom. Indeed, as the House of Commons Science and Technology Committee has observed,

> Some witnesses were...concerned that in many places patients were not provided with the information they needed if they were to give informed consent to pre-natal screening. For example, Professor Marteau found that "on about 50 per cent of occasions [screening] tests were presented as routine"; since such tests were presented as being for reassurance, rather than as a means of giving the choice of whether to continue with an affected pregnancy, women took them without consideration...[t]here is ample evidence that some, at least, of the screening currently offered in the

> course of antenatal care falls far short of best practice.[252]

In such cases and with proper counselling the consequences of testing can be evaluated in most cases by individuals in the abstract and an indication of their willingness to receive test results (either positive or negative) can be given in an informed manner. If at this stage the potential spatial privacy implications for the future person were also articulated this might help to protect such interests or at least ensure that decision about the future were taken in full knowledge of them. Legally, those with the responsibility for counselling might be given an express obligation to ensure that individuals are made aware of such interests.

8.1. - GENETIC INFORMATION AND PRIVACY: A CONCLUSION

This chapter has defended the definition of privacy presented in this work by setting out the existing thinking on privacy and offering the definition against the works of other writers, indicating areas of agreement and disparity. The US Constitutional position was also examined as a means to address the debate about conflation of terms in the privacy debate. Thereafter the definition of privacy proposed was used to show how it can assist in resolving the complex problems which arise from the four scenarios outlined earlier in this work concerning familial genetic information. It has been argued that a commitment to privacy *in se* is the best way forward for only this can adequately ensure that the interests which individuals have in their own genetic information - both spatial and informational - are protected. It has been accepted that the most problematic reform would be to enshrine in law a right not to know, and it has been conceded that this is most probably viable as against health care professionals, the state, employers and insurers. Nonetheless, such protection is exceptionally important and valuable. In

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[252] House of Commons Science and Technology Committee, 'Human Genetics: The Science and the Consequences', Third Report, HMSO, July 1995, para. 87.

the family context, even if one does not accept that a legal right not to know should be recognised and enforced, an appreciation of the privacy interests at stake can go a long way to ensuring that decisions involving the disclosure and use of genetic information are taken in the most sensitive manner possible.

In the conclusion to this work, an account will be given of how one could proceed to protect by legal means such privacy interests as are identified in this work.

CHAPTER SIX

CONCLUSION

1.1 - INTRODUCTION

It now becomes clear that the nature of the privacy concept advanced in this work is specific to two kinds of interests which patients in a health care setting might have in genetic information about themselves. As was stated in chapter one of this work, this relatively narrow view of privacy has been chosen to allow a more in-depth analysis of the concept, and no warrant can be given of the necessary value of this conception of privacy in other contexts. That said, one could easily extend the definition of privacy advanced here to other scenarios, both within the health care context and beyond. For example, similar issues arise concerning knowledge about one's HIV antibody positive status. Also, knowledge about one's parentage could equally be analysed using the privacy rubric of this thesis[1]. It is not, however, the function of this chapter to undertake such a task. Rather, this chapter will consider the ways in which legal effect could be given to informational and spatial privacy in the health care context concerning genetic information. The chapter is divided into three parts. Part one considers arguments for extending existing laws to address privacy issues. This is a common argument which is advanced in the wider privacy debate and also merits consideration here. Included here will be a discussion of the Roman law *actio injuriarum* which some have submitted could assist in the protection of personal privacy in Scotland. Second, the role of legislation will be examined, focusing particularly on recent American attempts to protect genetic privacy by statute. Finally, part three will reflect on the aims of recognising and protecting informational and spatial privacy and will set the discussion of legal protection of these interests in the wider context of optimal health care solutions, that is, we shall examine the question of whether legal solutions are the best solutions in this field.

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[1] *Cf* - O'Donovan, K.; 'A Right to Know One's Parentage?', 2, *Journal of Law and the Family*, 27, 1988.

2.1. - NEW PROBLEMS, OLD LAW?

In the debate which has raged for many years about the value of privacy and the proper method of its protection both in the United Kingdom and elsewhere, an option which has been frequently advanced is the extension of existing legal actions to protect 'privacy interests'[2]. In the health care context, the most likely candidate to protect privacy is the action of breach of confidence. Recent judicial developments have made this option all the more favourable, as they have removed some of the more obvious stumbling blocks to using this action to protect privacy. Thus, for example, the House of Lords in *Spycatcher* finally settled the point that a relationship need not exist between parties in order for a duty of confidence to arise[3]. Similarly, in *Hellewell*, the decision of the court that a duty of confidence could arise merely from the circumstances of taking a photograph, has led some to argue that the duty can be imposed unilaterally[4]. As Fenwick and Phillipson say,

> It seems that there is only one ingredient which is essential : it must be shown that a reasonable person who acquired the information would have realised that it was confidential[5].

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[2] See, for example, Seipp, D.J.; 'English Judicial Recognition of a Right to Privacy', 3, *Oxford Journal of Legal Studies*, 325, 1983, Prescott, P.; '*Kaye v Robertson* - a reply', 54, *Modern Law Review*, 451, 1991, *cf* - Wilson, W.; 'Privacy, Confidence and Press Freedom : A Study in Judicial Activism', 53(1), *Modern Law Review*, 43, 1990. Hogg considers a range of cases which can and have protected privacy interests, although ultimately he concludes that these are not adequate to protect the full range of interests subsumed under the privacy rubric, see Hogg, M.; 'The Very Private Life of the Right to Privacy', 2(3), 'Privacy and Property', Edinburgh, Edinburgh University Press, 1994. See too,Thomson, J.J.; 'The Right to Privacy', 4, *Philosophy and Public Affairs*, 295, 1975, discussed in chapter five. The Calcutt Committee considered this option and examined, *inter alia*, the laws of trespass, breach of confidence and defamation, but concluded that '...most of the serious infringments of privacy...involve no relationship or duty of confidence', para.8.7., Calcutt; '*Report of the Committee on Privacy and Related Matters*', Cm1102, HMSO, June 1990 (Calucutt I).

[3] *Attorney General v Guardian Newspapers No.2* [1990] 1 AC 109, discussed in chapter four, *supra*. Arguably, however, this point was already settled in *Stephens v Avery* [1988] Ch. 449, at 482.

[4] See, for example, Fenwick, H. and Phillipson, G.; 'Confidence and Privacy: A Re-examination', 55, *Cambridge Law Journal*, 447, 1996, at 451 - 452.

[5] *ibid*, at 452.

This they use as part of an argument that the law of confidence can now go a long way, in the context of personal privacy and invasions by the press, to protecting the interests with which one is concerned in such cases. In fact, they argue that the case of *Kaye v Robertson*[6] could have been effectively dealt with as a breach of confidence case. Similar arguments have been made by Wee Loon who has submitted that 'judicial activism is...the answer to the inability of the present law in England to give better protection to an individual's privacy.'[7] Whereas this might be true, the present writer would respond that it is not true if that activism takes place in the context of the breach of confidence action. This is so for two reasons. First, as MacQueen has rightly pointed out, '[w]hatever the merits of the debate, it is clear that confidentiality is not a complete substitute for privacy, and that there may be various problems which the law of confidence cannot reach'[8]. Despite the developments outlined above, it is submitted that this is still true. As Wacks has said,

> ...in general terms, the action for breach of confidence is inadequate to deal with the archetypal 'privacy' complaint because the action is largely concerned with: (a) disclosure or use rather than publicity, (b) the source rather than the nature of the information, and (c) the preservation of confidence rather than possible harm to the plaintiff caused by its breach[9].

Also, as Hogg has noted, there must be use or disclosure of information before an action in confidence can lie, yet with privacy arguably the invasion occurs when the information is obtained. Similarly, it is the case that only the person to whom the duty is owed can sue for breach of confidence, and not necessarily the persons to

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[6] [1991] FSR 62, discussed in chapter one, *supra*.

[7] Wee Loon, N-L.; 'Emergence of a Right to Privacy from within the Law of Confidence?', 5, *European Intellectual Property Review*, 307, 1996, at 312.

[8] *Stair Memorial Encyclopaedia*, volume 18, paragraph 1456.

[9] Wacks, R.; 'Privacy and Press Freedom', London, Blackstone Press Ltd., 1995, at 56.

whom the information relates[10]. One additional point should also be noted. An action of breach of confidence is possible only so long as the confidential information remains confidential. Once it becomes part of the public domain it is no longer protected. In contrast, privacy is concerned with interests in personal information; those interests do not necessarily change, nor does the information become any less 'personal' simply because more people have access to it.

Secondly, and of more direct relevance to this thesis is the failing of the law of confidence to take account of the so-called 'spatial privacy' interests discussed in previous chapters. The argument for this has been made above, but is repeated here to refute the notion that the law of confidence in the health care setting can dispel effectively our privacy concerns: if privacy is conceived not simply as a desire to control personal information, but rather as a general sphere of separateness from others, and so also encompasses notions of spatial separateness, then it is no answer to say that an action which is concerned solely with information is an acceptable solution to privacy invasions. It may be that such an action can address many of the privacy concerns that arise in the health care context, but to settle for such protection is, arguably, to adopt an unsophisticated view of the true nature of the problems at hand. For this reason, the piecemeal development of confidence must be rejected[11].

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[10] Hogg, *loc. cit.*, at 14 - 15. Note, however, that Hogg comments that the move towards a 'reasonable person' approach to the establishment of a duty might ease the way for recognition of the fact that the duty should be owed to the person about whom the information relates, and not the person from whom the information has come.

[11] An attempt has been made to introduce statutory provisions governing personal information in the health care setting. However, this has not been successful so far and does not encompass issues of spatial privacy. It is, therefore, not considered in any depth in this work: see, 'A Bill Governing the Use and Disclosure of Personal Health Information', A Draft Bill by the Multi-Disciplinary Professional Working Group, July 1994.

Other less likely candidates for protecting privacy have also been examined elsewhere such as trespass[12], defamation[13] and intentional infliction of emotional distress[14]. It is not necessary to investigate these in any depth here, however, because to do so would do nothing to further the thesis of this work. For, it is submitted that to adopt a piecemeal approach to privacy protection is to miss the importance of privacy as a value *in se*; a value which has been argued for throughout this work. Each of these areas has been found lacking in the context of the general privacy debate, and this would be all the more true in the setting of this work.

In similar vein, it is submitted that recourse to the European Court of Human Rights would be an ineffective means of protecting the kind of privacy interests which surround genetic information. Under Article 8(1) of the European Convention on Human Rights citizens are guaranteed 'respect for [their] private and family life, [their] home and [their] correspondence.' Under Article 8(2) exceptions are permissible only if they are 'necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder and crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.' Whereas, as we have seen, it might well be possible to argue that genetic information can and should be disclosed in circumstances which fall within some of these exceptions, it is not clear that the privacy right enjoyed by citizens would necessarily cover the protection of genetic information in the first place. The Court has tended to give a wide margin of appreciation to Signatory States. The attitude tends to be that unless there is a commonality of approach between the States to a certain issue, the Court

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[12] See Calcutt I, *op. cit.*
[13] *ibid.*
[14] Wacks, 'Privacy and Press Freedom', *op. cit.* at 80 - 89.

is reluctant to extend Convention protection to that area[15]. With a subject as new and uncertain as genetics, privacy protection is, therefore, unlikely to be extended to encompass genetic privacy. Furthermore, the standing of the Convention generally within the United Kingdom is not high, it not being a part of domestic law as such[16]. Yet, even once the Convention is incorporated into UK law[17], it will still be the case that interpretation of 8(1) will fall to courts, and thus the protection of genetic privacy will turn on the whim of the judges. In the opinion of this writer this would be an unsatisfatory state of affairs.

Finally, it is interesting to consider the proposition that in Scotland at least, the common law action of *actio injuriarum* might provide a remedy for invasions of privacy. Several commentators have advanced this notion but none has examined the issue is any real depth[18]. In the civilian tradition, the origin of the *actio injuriarum* lies in the XII Tables[19] and its scope concerned instances of affront to a person (*injuria*) which were not dependent on a particular form to result in liability. That is, interference with one's actual bodily integrity was not necessary,

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[15] See, most recently, *X, Y and Z v UK* (75/1995/581/667), 22 April 1997.

[16] *See, R v Khan (Sultan)* [1996] 3 All ER 289 (HL).

[17] Which is likely to occur in Parliamentary session 97-98.

[18] Among those who have suggested this route are Blom-Cooper, L.; 'The Right to be Let Alone'', 10, *Journal of Media Law and Practice*, 53, 1989, Carey Miller, D.L.; 'Privacy: Interception of Communications - Could Scots Law Have a Remedy?', 1980, *Scots Law Times (News)* 209, Carey Miller, D.L. and Lardy, H.; 'Calcutt II: Comments from a Scottish Perspective', 1993 *Scots Law Times* 199, Lord Kilbrandon, ''The Law of Privacy in Scotland', 2, *Cambrian Law Review*, 35, 1971, and Shapiro, E.E.; 'A Peek at Privacy', 36, *Journal of the Law Society of Scotland*, 103, 1991. The possibility was considered both by the Younger Committee (*op. cit.*, Appendix I, para.72) and the Scottish Law Commission in its consultative memorandum on the protection of confidential information (SLC; 'Confidential Information', memorandum No.40, 14 April 1977, paragraphs 48 - 58.) However, the Commission did not include recommendations on this area in its 1984 report on reforms of the law of confidence (SLC; 'Breach of Confidence', SLC No 90, 1984, para 1.7.). Others still have argued that the existing general common law of Scotland could provide protection for general privacy interests, see Hogg, M.; 'Privacy : A Valuable and Protected Interest in Scots Law', 1992 *Scots Law Times* 349, Hogg, 'The Very Private Life of the Right to Privacy', *op. cit.*, and McLean, J.A.; 'Privacy, Scots Law, Human Rights and Europe', 38, *Journal of the law Society of Scotland*, 21, 1993.

[19] For the best account of the action by far, see Zimmerman, R.; 'The Law of Obligations: Roman Foundations of the Civilian Tradition', Oxford, Clarendon Press, 1996, chapter 31. XII Tables, tab.8,4 read in conjunction with tab.8,2 and tab. 8,3, *ibid.*, at 1050.

and affront could take many forms such as raising a rabble against a specific person, approaching an unmarried woman with libidinous intentions, generally bringing a person into disrepute, beating or torturing another man's slave, or preventing a person using his own property[20]. Common to all of these was an 'attack' on the personality of another[21]. As Zimmerman points out,

> ...the actio injuriarum afforded a strong and efficient protection against injury to immaterial interests, and in particular against insulting behaviour of any kind[22].

More particularly, the action was thought to protect three kinds of interest : person (*corpus*), reputation (*fama*) and dignity (*dignitas*). The action was constituted by an intentional 'attack' on such aspects of the person (*animus injuriandi*)[23] and damages were payable for sentimental damages. Modern reception of the action has been seen in many countries including Germany, Holland and South Africa. The relevance of all of this to privacy comes from the argument - which had been made principally in South Africa[24] - that *dignitas* encompasses much more than just honour or dignity and in fact encompasses all residual rights of personality not covered by *fama* or *corpus*[25]. Given the nature of general privacy interests discussed in this work it is not difficult to see how such interests might be subsumed under the rubric of 'rights of the personality'[26]. The South African courts have accepted such an argument[27] and, as has been stated, the common heritage of Scots law with

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[20] *ibid*, at 1053 - 1059.

[21] *ibid*, at 1059.

[22] *ibid*, at 1062.

[23] *ibid*, at 1067.

[24] See, for example, McQuoid-Mason, D.; 'The Law of Privacy in South Africa', Johannesburg, Juta and Co., 1978.

[25] Zimmerman, *op. cit.*, at 1084.

[26] Zweigert and Kotz discuss this notion of 'rights of the personality' in a comparative context: see Zweigert, K. and Kotz, H.; 'An Introduction to Comparative Law', Second Edition, Oxford, Clarendon Press, 1987, paperback 1992, chapter 50.

[27] See, for example, *O'Keefe v Argus Printing and Publishing Co. Ltd* 1954 (3) SA 244 (C), *S v A* 1971 (2) SA 293 (T) and *S v I* 1976 (1) SA 781 (RAD) - cited by Zimmerman, *op. cit.*, at 1084, note 263. Most recently see *National Media Ltd. v Jooste* 1996 (3) SA 262 (A) in which the South African

such a system, has led commentators to argue for common law recognition of such an action in Scotland to protect privacy[28]. Such an argument is initially appealing for those keen to laud the uniqueness and distinctiveness of Scots law, but in the context of the present work it is not an option which merits serious consideration for several reasons. First, it is by no means clear that the action has indeed been received into Scots law. Second, even if reception has occurred no one has a clear idea of the form in which reception has taken place. Of course, to this one can respond 'we should find out', but the third objection to this route must also be considered; namely - we are entirely dependent on judicial intervention to establish the parameters of such an action. In most cases this would take a considerable amount of time, but in the context of genetics the time to act is now. Finally, the recognition of such a right of action at common law in Scotland might well be a triumph for that jurisdiction, but in real terms the right is restricted to a small number of persons and/or offensive acts occurring within the jurisdiction. A disparity of protection as between Scotland and the other jurisdictions in the United Kingdom is not, it is submitted, a desirable or adequate response to the problems under review in this thesis. For these reasons it is necessary to turn away from the option of common law developments to consider an analysis of 'privacy-specific' laws which have as their primary (or even sole) concern the kinds of interests which are important in this thesis[29].

Appellate Division held that privacy was a *sui generis* interest of personality. It should also be noted that the South African courts have held that juristic persons have a right to privacy: *Financial Mail (Pty) Ltd. v Sage Holdings Ltd* 1993 (2) SA 451 (A); *Motor Industry Fund Administrators (Pty) Ltd. v Janit* 1994 (3) SA 56 (W).

[28] In particular, see Carey Miller, *loc. cit.*

[29] For a discussion arguing in favour of specific privacy legislation in the UK, see Lord Bingham of Cornhill, 'Opinion: Should There Be a Law to Protect Rights of Personal Privacy?', [1996] *European Human Rights Law Review*, 450, and Eady, D.; 'Opinion: A Statutory Right to Privacy', [1996] *European Human Rights Law Review*, 243.

3.1. - LEGISLATIVE PROTECTION OF GENETIC PRIVACY

It is proper to focus the discussion of this section on any available legislation which directly concerns issues of genetics and privacy. This leads us to the United States where the *Genetic Privacy Act* has recently been drafted concerning the collection, analysis, storage and use of DNA samples and the genetic information derived from them. This section will examine in some depth the provisions of this Act and the problems which have surrounded it[30].

3.2. - The Genetic Privacy Act

This piece of law was produced for the US Human Geonome Project's ELSI[31] division by George Annas, Leonard Glantz and Patricia Roche of the Boston University School of Public Health[32]. The draft is in the format of a federal statute and has already been introduced in several states[33].

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[30] This Act is not the only piece of legislation to be created in the US directed specifically at genetic information. For example, in November 1995 Congress introduced the *Genetic Privacy and Non-Discrimination Act 1995* which is concerned with disclosure and use limitations on genetic information. The provisions are, in the main, similar to many of those contained in the *GPA*, although this Act also addresses the question of access to information by employers and insurers. The Act prohibits employers from gaining access to genetic information for the purposes of discriminating betweeen or restricting the rights of current or prospective workers (s.5). Those providing health insurance cannot use genetic information to affect health insurance and also prevents the use of genetic information to induce individuals to buy insurance (s.6). Prior even to this, in September 1991, the California state legislature voted for a bill which concerned genetic privacy. The Act, if passed, would have prohibited discrimination on genetic grounds and would have imposed an eight-year moratorium on the use of genetic test results by insurers. The bill was, however, vetoed by the state's Governor on 14 October 1991. For comment see, Wilkie, T.; 'Perilous Knowledge: The Human Genome Project and its Implications', London, Faber and Faber, 1993, at 11. It should also be noted that the International Bar Association and the Human Genome Organisation have been working together for some five years on a treaty which will guarantee minimum standards of respect for individuals and their genetic information, see Dyer, C.; 'Agreement Near on Use of Human Genetic Information', 313, *British Medical Journal*, 1223, 1996.

[31] Ethical, Legal and Social Issues concerning the HGP.

[32] For information on this see, *Human Genome News*, 6(6), March - April 1995, at 4.

[33] The text of the Act can be found on the internet at the folloiwng site: http://www.ornl.gov/TechResources/Human_Genome/resource/privacy/privacy1.html It would seem that the most far-reaching legislation has been passed in New Jersey (for comment, see Charatan, F.B.; 'New Jersey Passes Genetic Privacy Bill', 313, *British Medical Journal*, 71, 13 July

As the introduction to the Act states :

> The Act is based on the premise that genetic information is different from other types of personal information in ways that require special protection. The DNA molecule holds an extensive amount of currently indecipherable information. The major goal of the Human Genome Project is to decipher this code so that information it contains is accessible. The privacy question is, accessible to whom?[34]

It continues,

> [T]he overarching premise of the Act is that no stranger should have or control identifiable DNA samples or genetic information about an individual unless that individual specifically authorizes the collection of DNA samples for the purpose of genetic analysis, authorizes the creation of that private information, and has access to and control over the dissemination of that information[35].

Thus we can see that the Act envisages a highly individualistic approach to the question of control of genetic samples and information. In particular, the person from whom a sample has been taken (the 'sample source') has the following rights:

- The right to determine who may collect and analyse DNA[36];
- The right to determine the purposes for which a DNA sample can be analysed[37];

1996), but in Maryland a bill based on the GPA was defeated in the Maryland Senate (for comment, see Holtzman, N.A.; 'Panel Comment : The Attempt to Pass the Genetic Privacy Act in Maryland', 23, *Journal of law, Medicine and Ethics*, 367, 1995). In May 1997 it was reported that as of April 1997 at least 15 states had enacted genetic privacy laws, and according to a survey conducted by the Biotechnology Industrial Organisation, more than 75 similar bills were pending in more than 30 states: see, *The Gene Letter*, volume 1, Issue 5, May 1997 on internet site - http://www.geneletter.org/0597/humangenome.htm

[34] *ibid.*

[35] *ibid.*

[36] *ibid*, s.101.

- The right to know what information can reasonably be expected to be derived from the genetic analysis[38];
- The right to order destruction of DNA samples[39];
- The right to delegate authority to another individual to order the destruction of DNA samples after the death of the sample source[40];
- The right to refuse to permit the use of the DNA sample for research or commercial activities[41]; and
- The right to inspect and obtain copies of records containing information derived from the genetic analysis of the DNA sample[42].

A person who collects a DNA sample from an individual has the following corresponding duties:

- To provide specific information verbally to the sample source prior to the collection of the DNA sample[43];
- To provide notice of the rights and assurances which the sample source has, prior to the collection of the DNA sample[44];
- To obtain written authorisation which contains required information[45];
- To restrict access to DNA samples to persons authorised by the sample source[46];
- To respect a sample source's instructions regarding the maintenance and destruction of DNA samples[47];

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[37] *ibid*, s.102(a).
[38] *ibid*, s.101(b)(3).
[39] *ibid*, s.104(b).
[40] *id.*
[41] *ibid*, s.102.
[42] *ibid*, s.113.
[43] *ibid*, s.101(b)(1).
[44] *ibid*.
[45] *ibid*, s.101(a).
[46] *ibid*, s.111(a) and (b).
[47] ibid, s.104(b) and (c).

- To keep genetic information derived from samples confidential, and to obtain written consent from the sample source prior to any disclosure of such information, except where disclosure is limited to access by specified researchers for compiling data[48].

It should be noted, however, that the Act defines the term "private genetic information" to mean,

> ...any information about an identifiable individual that is derived from the presence, absence, alteration, or mutation of a gene or genes, or the presence or absence of a specific DNA marker or markers, and which has been obtained; (1) from an analysis of the individual's DNA; or, (2) *from an analysis of the DNA of a person to whom the individual is related*[49]. [emphasis added]

This clearly seeks to take account of the not inconsiderable interests which relatives of a 'sample source' can also have in genetic information. And yet, very interestingly the Act gives a property right in the DNA sample to the sample source[50]. The very pressing question which then presents itself is, how does the Act seek to reconcile the interests of sample source and family members to whom the information also relates?

The individualistic approach of the Act is very prevalent in its provisions. For example, section 111 provides that anyone in possession of private genetic

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[48] *ibid*, ss.111 - 112.

[49] *ibid*, s.3.

[50] *ibid*, s.104(a). This move clearly has very far-reaching implications for a great number of areas within the disciplines of law, medicine and science generally. These are, however, outside the scope of the current work. For comment see, Lin, M.M.J.; 'Conferring a Federal Property Right in Genetic Material: Stepping into the Future with the Genetic Privacy Act', 22, *American Journal of Law and Medicine*, 109, 1996.

information in a business or professional capacity must obtain written authorisation before disclosure to others is permissible, but section 112 provides that it is for the sample source or his/her representative[51] to authorize such disclosure[52]. Similarly, in section 113 the right to inspect and request a copy of private genetic information records is only given to the sample source or his/her representative[53]. The right to request amendments to such records is also restricted to such persons[54].

Section 115 deals with disclosures pursuant to compulsory process and lays down that compulsory disclosure is permissible only in certain clear cut circumstances[55], and even then the sample source or his/her representatives have the right to be given notice of any such demands and to lodge objections[56].

Part C of the Act deals with exceptions to the general rules of genetic privacy. These extend to, access to information for the identification of dead bodies[57], the collection, storage and typing of DNA samples for federal, state or local law enforcement purposes[58], and collection and analysis of samples pursuant to court

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[51] The term 'sample source's representative' is defined in section 3 of the Act as : '...any person who has the legal authority to make health care decisions concerning a minor or an incompetent person, or the administor or executor of a deceased person's estate, if any, otherwise the next of kin of a deceased person.' Clearly, this definition does not necessarily mean that the represetattive will be a family member, but even where s/he is, this role will not extend beyond one or two familial intimates such as mother, father or siblings.

[52] *ibid*, s.112(a)(1).

[53] *ibid*, s.113(a).

[54] *ibid*, s.114(a).

[55] *ibid*, s.115(a): 'No person who maintains private genetic information may be compelled to disclose such information pursuant to a request for compulsory disclosure in any judicial, legislative, or administrative proceeding, unless - (1) The person maintaining the genetic information has received the authorization of the sample source or the sample source's representative to release the information in response to such a request for compulsory disclosure; (2) The sample source or the sample source's representative is a party to the proceeding and the private genetic information is at issue; or (3) The genetic information is for use in a law enforcement proceeding or investigation in which the person maintaining the information is the subject or party;'.

[56] *ibid*, s.115(b).

[57] *ibid*, s.121.

[58] *ibid*, s.122.

ordered analysis[59] (for example, paternity suits). Each of these is, however, restricted to actions 'necessary' for the furtherance of the specific goal. In addition, Part D provides for regulations and safeguards concerning research on genetic material and allows disclosure of private genetic material for research purposes, once again only with the specific consent of the sample source or his/her representative[60].

It is not clear how well the distinction is drawn in this Act between a DNA sample and private genetic information derived from a sample[61]. Axiomatically, the first is unique and personal to the person from whom the sample was taken. The same is not true of the information, yet as the above examples show the exclusive right over such information (as with samples) is nevertheless retained by the sample source. In fact, the issue of relatives' rights arises only rarely in the Act. One such place is in the provisions of section 131 which concerns research involving genetic analysis.

Subsection (e) of section 131 relates to pedigree analysis and family linkage studies. It provides that:

> When a research project includes analysis of DNA from family members for pedigree analysis or linkage analysis---
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> (1) the Institutional Review Board...shall...require---(A) that education and counseling regarding how pedigree

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[59] *ibid*, s.123.

[60] *ibid*, s.132. Note too that this section allows limited access to private genetic information without subject autority if that access is only for statistical or epidemiological reasons and no copies of the information are made and no further disclosure occurs. For comment on the general perceived effect of the Act on the practice of medicine, see Reilly, P.R.; 'Panel Comment: The Impact of the Genetic Privacy Act on Medicine', 23, *Journal of Law, Medicine and Ethics*, 378, 1995.

[61] Part A of the Act deals with collection and analysis of DNA samples, Part B concerns disclosure of private genetic information.

> analysis is conducted and the kind of information that results from such analysis is provided to research subjects; (B) that as far as practicable separate records are maintained on each subject.
>
> (2) prior to the participation, and in addition to the disclosures required by section 101 of this Act, subjects shall be-- (A) informed that one risk of their participation is that by the end of the project other family members may learn private genetic information about them; (B) informed of what will be done with records and data generated during the project; (C) informed that the project may determine that some members of their family are not genetic relatives.

This must be read in conjunction with subsection (f) which states that:

> When complying with the provisions of section 113 of this Act, no person shall provide an individual in the pedigree with private genetic information about another person without that other person's authorization.

This serves to re-inforce the individualistic approach to the idea of rights and interests over private genetic information. Arguably, subsection (e) is merely a guarantee that informed consent to proceed with the research is obtained - individuals are given the *choice* to continue or not based on clear information about what might come from the work. Subsection (f) in contrast, makes it clear that participation in the pedigree or linkage analysis gives one no claim to familial genetic knowlege, if that knowledge identifies another family member specifically. Thus the notion of a familial interest in the general information derived from individual members of a family is either non-existent, or substantially weakened as compared to individual rights in individual genetic information. That is, any information one might be able to access on one's family will be of a general, anonymised nature. This is not to judge the appropriateness or otherwise of such an approach, it is simply to outline the general thrust of the legislation under scrutiny.

As further evidence of the general attitude underlying this legislation, consider the provisions of s.101(b)(8). This section provides that prior to the collection of a DNA sample from an individual the person should be informed, *inter alia*,

> [T]hat the genetic analysis may result in information about the sample source's genetic relatives which may not be known to such relatives but could be important, and if so the sample source will have to decide whether or not to share that information with relatives[62].

It is fortunate that the text of this Act is accompanied by a commentary prepared by its authors in which they seek to clarify their general aims and to expand up the specific terms of the Act. Of the above provision they say the following,

> Creating either a contractual or statutory obligation for individuals to share [genetic] information with their family members would not only be unprecedented, but inadvisable. The creation of new substantive rights or duties of family members is not our intention and is beyond the scope of this Act. However, because the Act creates rules that govern the use and disclosure of information, it is imperative that individuals be informed of the fact that by seeking genetic information about themselves through genetic analysis, they may also become privy to information about other family members who would also want and/or need such information...[w]hile it will be an individual choice as to whether or not to share that information with others, this disclosure should

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[62] *ibid*, s.101(b)(8).

instigate discussion between the sample source and the collector of the sample[63].

3.2.1. - Informational Privacy and the Genetic Privacy Act

Two initial questions arise for informational privacy interests - as defined in this thesis - from what has been said above. First, is it correct that no obligation is imposed on a sample source to reveal information given that genetic information also concerns relatives? Second, does the Act adequately protect the informational privacy interests of relatives when genetic information is in the hands of third parties, such as employers/insurers or the state?

3.2.1.1. - *No Duty to Disclose*

It should be clear from the thrust of argument in preceding chapters that the present writer would agree that no general obligation should be imposed on any individual to share genetic information with his/her family members. Thus, to this extent it is agreed that the approach of the provisions of the Genetic Privacy Act is correct in that they accord a high degree of protection to the individual sample source's informational privacy interests[64]. Such interests allow the sample source to determine the use to which information is put and the disclosures which can occur.

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[63] See also, Annas, G.J., Glantz, L.H. and Roche, P.A.; 'Drafting the Genetic Privacy Act: Science, Policy, and Practical Considerations', 23, *Journal of Law, Medicine and Ethics*, 360, 1995.

[64] The authors of the Act also note that, 'One suggestion is that access to genetic testing in some circumstances be made conditional on a prior agreement to disclose information to other family members who become identified as at risk. This suggestion, however, has not been widely supported for several reasons, including the fact that it would deter individuals from seeking information about themselves'. As an example of a work which supports this view the authors cite The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research, *Screening and Counseling for Genetic Conditions*, Washington D.C., U.S. Government Printing Office, 1983, at 43. For an opposing view they refer to Chapman, M.; 'Invited Editorial: Predictive Testing for Adult Onset Genetic Disease : Ethical and Legal Implications of the Use of Linkage Analysis for Huntington Disease', 47, *American Journal of Human Genetics*, 1, 2, 1990.

The case for agreeing that a duty to disclose to relatives should not be imposed on a sample source can be made on two different levels.

First, if a general duty to disclose were imposed irrespective of whether any attempt were made to establish if relatives would wish to know, this would lead to intrusion on the spatial privacy interests of such relatives. More is said of this presently, but the general argument has in essence been made in chapter five; namely - unsolicited approaches are rarely justified. What, however, if relatives *do* wish to know? Should a duty to disclose be imposed in such cases?

It is submitted that even if relatives wish to know, no general duty to disclose should be imposed[65]. As has been been suggested previously[66], the primary right to information derived from an individual lies with that individual. Other 'familial rights' must be very stong and clear-cut before they can legitimately challenge those of the individual. Here we have the strong informational privacy interests of the sample source faced with a claim to know by relatives. What is the basis of this latter claim? Arguably, it should only be that there is a strong 'public interest' in knowing the information. For example, because a cure exists for the condition potentially affecting relatives, or because effective treatment is available. In other words, following the argument in chapter five, the claim of relatives to know is valid *only if* some objectively identified 'public' (familial) interest could be served by interfering with the informational privacy interests of the sample source. If such a public interest cannot be found, it is submitted that no information need be disclosed against the wishes of the sample source. If one accepts the arguments of

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[65] The authors of the Act expressly disapprove the imposition of a 'duty to warn' on the grounds that it would be 'impossible to set logical boundaries on such an exception' and also because 'the "no exception rule" maximises the privacy between individuals who receive services that result in private genetic information and their health care providers': see, Annas, Glantz and Roche; 'Drafting the Genetic Privacy Act: Science, Policy, and Practical Considerations', *loc. cit.*, at 364.
[66] In chapter three and chapter five, *supra*.

chapter five that a privacy 'public interest' could be developed which has a high degree of specificity about what is and is not in the interests of relatives to know, then a more accurate and fair balance could be struck between the interests of sample source and relatives concerning genetic information.

Importantly, it should be noted that the claim of relatives to know is not to be based on their *own* informational privacy interests. Any claim based on such interests can only be made regarding the use and security of genetic information vis-a-vis third parties outside the familial context. This is so because privacy is concerned with preventing unwarranted interference with *one's own* private sphere. It is, therefore, not appropriate to appeal to the concept to invade *someone else's* private sphere (in this case that would be the sphere relating to the informational privacy interests of the sample source).

3.2.1.2. - *The Informational Privacy Interests of Relatives*

The focus which the Genetic Privacy Act puts on the (sole) right of the sample source[67] to determine, *inter alia*, the purposes for which a sample may be collected[68], analysed[69] or used[70], demonstrates a failure of the Act to take due account of the important informational privacy interests which family members also have in shared genetic information. It is also a failure to respond to the realities of genetic information.

The informational privacy interests of relatives are potentially impinged upon when, for example, information is released by the sample source into a public or

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[67] Or his/her representative.
[68] *supra*, s.101.
[69] *supra*, s.102(a).
[70] *supra*, s.112(a)(1).

quasi-public domain when such a disclosure could have implications for his/her relatives (e.g. - insurance matters). Similarly, if the state or other organisations wish to compile databases of genetic information, they could easily build up relatively accurate pictures of family inheritance simply by gaining access to the genetic data of a few individual family members. Thus questions of security and control of *family* information arise, but these are left by the Act to be decided by the sample source alone. It is submitted that it is particularly narrow-minded approach. It allows the entire determination of family informational privacy to rest with one individual. This is not to suggest, however, that the 'family' should somehow decide collectively. Not only would this be practically impossible, but it is also highly probable that the 'family' would not be able to participate as a collective[71]. But, the recognition of family informational privacy interests and a commitment to their protection <u>could</u> be achieved by ensuring that third parties who come into possession of genetic information must treat it with the utmost security, and further that they should not be permitted to use it in respect of family members who are not themselves sample sources. This could be the case even if a particular sample source gave his/her consent for such uses. Thus, for example, the Act might be amended to provide that employers, insurers or the state should not be allowed to compile 'familial' databases from genetic information provided by one or a few members of a family. In this way the informational privacy interests of families could be protected without any need to involve the individual family members at all, and it would ensure that one individual could not 'consent' to practices which unduly impinge on family privacy.

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[71] This would be so either because not all family members would know the information, or because certain families members might be exercising a right not to know, or because the sample source might not want family members to know the information.

3.2.2. - Spatial Privacy and the Genetic Privacy Act

The Genetic Privacy Act allows sample sources to decide for themselves whether or not to disclose genetic information to relatives. Many would argue that this is not necessarily a 'bad thing' because often such a person will be better (or even best) placed to establish how the relative in question might feel about receiving such information. However, the Genetic Privacy Act does not give any guidance to a sample source on *how* to decide whether or not disclosure should happen. In particular, there is no recognition of the possible spatial privacy interests which relatives who are the potential recipients of such information might have in *not* knowing. The arguments for this have been rehearsed above and need not be repeated here. Yet, if it is accepted that individuals can have valid interests in such notions, then it is submitted that an Act which purports to deal with genetic privacy should include provisions aimed at recognising and protecting such interests.

The only part of the Genetic Privacy Act which comes close to recognising such interests is that concerned with minors. Section 141 of the Act provides that:

> (a) INDIVIDUALS UNDER 16 -- Except as provided in sections 131(c) and 151, the individually identifiable DNA sample of a sample source who is under 16 years of age shall not be collected or analyzed to determine the existence of a gene that does not in reasonable medical judgment produce signs or symptoms of disease before the age of 16, unless :
>
> (1) there is an effective intervention that will prevent or delay the onset or ameliorate the severity of the disease; and
>
> (2) the intervention must be initiated before the age of 16 to be effective; and

> (3) the sample source's representative has received the disclosures required by section 101 of this Act and has executed a written authorization which meets the requirements of section 103 of this Act and which also limits the uses of such analysis to those permitted by this section[72].

The authors justify these provisions as follows:

> 'There are two reasons for this prohibition on the exercise of parental discretion. First, if someone learns that the child is a carrier of a gene that disposes the child to some condition later in life, this finding may subject the child to discrimination and stigmatization by both the parents and others who may learn of this fact. Second, a child's genetic status is the child's private genetic information and should not be determined or disclosed unless there is some compelling reason to do so.

This corresponds precisely with arguments which have been made in previous chapters concerning the spatial privacy interests of individuals. Arguably, what the Genetic Privacy Act does here is to recognise the spatial privacy interests of children, and further, it recognises that these should not be invaded without due cause[73]. Where the Act is deficient, it is submitted, is in not recognising the spatial privacy interests of *all* persons about whom genetic information is known but who have not sought it out themselves. There is no valid reason why such interests should only protected for minors.

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[72] Note too that although under section 131(c) research on samples taken from identifiable minors is permitted provided that the parent or guardian agrees in light of all relevant facts, if that research reveals genetic disease which is incurable the parent or guardian will *not* be given access to that information. Access will only be granted if the information in question concerns a condition which in reasonable medical judgment can be effectively ameliorated, prevented, or treated while the child is under 18. The exception under s.151 provides that: 'Regardless of her age, a pregnant woman shall have all the rights and authority of an adult sample source in regard to her DNA sample and the DNA sample of her fetus unless she is otherwise incompetent under the provisions of section 143.'

[73] The Act does not, however, go so far as to recognise any spatial privacy interests for fetuses. Section 151 and 152 provide that a competent pregnant woman has the sole right to determine both when DNA samples shall be taken from her fetus and how genetic information about the fetus shall be used.

Of course, the situation of the minor is not exactly the same as that of the adult relative of a proband. One clear point of difference concerns the actual existence of information. In the case of the minor the legal prohibition concerns the initial collection or analysis of genetic material. In the case of an adult relative of a proband, this is not the point at issue since no one can prevent anyone else from seeking to have their own genetic material analysed. This, however, is a superficial and ultimately unhelpful distinction. For, the true issue in both cases is essentially the same in that it concerns the unwarranted intrusion of private genetic information into the private sphere of the individual in question. Thus the interest of the adult relative is not in seeking to control the proband's access to the information, but rather simply in having his own spatial privacy interests of non-access respected. For the minor precisely the same interest is at stake.

Relatedly, the minor in such cases is him/herself the proband, and therefore s/he has the primary right to decide what happens to genetic information. Given this, one might argue that the above provisions simply ensure that the choice of accessing genetic information be left until the child is capable of making choices for him/herself. In contrast, no such specific provision is necessary in the case of an adult because it is axiomatic that the adult may choose to know or not to know his/her own information. This is true, but as we have seen in the previous paragraph, the question here is not simply one of access, but also one of non-access. Although one might classify the child's interest as one of autonomy and choice, under the *Genetic Privacy Act* the child is only protected from attempts to gain specific access to the child's genetic information. It does not protect the child from unwarranted disclosure of genetic information coming from relatives. Adults are in an equally vulnerable position. In fact, one can draw a clear parallel between the child and the unknowing adult in that, in many senses, they are both incapax as regards the genetic information. Now, whereas the child is generally incapax, the adult can certainly make a choice to know (in that s/he has the capacity to choose). But, as has been pointed out previously, in spatial privacy cases, to offer the individual the opportunity to choose might be to offend against the very interests with which one is concerned. Thus, it is submitted that it is acceptable in the case of genetic information to adopt the position that both adult and child are incapax. The consequence of this is equally the same, namely, that both should only be approached in rare circumstances and with due cause. This in essence is what has been argued in chapter five about spatial privacy interests.

It is further submitted that in the case of genetic privacy legislation such as the *Genetic Privacy Act* it would not be too difficult to extend this form of protection to adult relatives of a proband. The example of the above provision concerning children could be adapted to include adults. The prohibition would not only be on direct testing of the adult or child, but would extend to unwarranted approaches to family members with genetic information. What constitutes a 'warrantable' approach would have to be settled by more debate on the legitimate nature of competing interests and a proper assessment of genetic risks and consequences within the family and wider community setting. The question of remedies could be dealt with in a straight-forward manner, as the *Genetic Privacy Act* already provides (*infra*).

3.2.2.1. - *Incapable Adults*

Finally, we must consider the position of incapable adults. The provisions of the Act give rise to concerns for both the informational and spatial privacy interests of such persons.

Section 143 provides that genetic material shall not be collected from an incompetent person nor analysed unless the following provisions are satisfied:

> (1) the analysis is necessary:
>
> (A) to diagnose the cause of incompetence; or
>
> (B) to diagnose a genetic condition which in reasonable medical judgment can only be effectively ameliorated, prevented or treated while the sample source is incompetent; or
>
> (C) to diagnose a genetic disease of a parent, sibling, child or grandchild of the sample source provided that the disease in reasonable medical judgment can be effectively ameliorated, prevented, or treated;
>
> (2) the analysis is limited to that which is necessary for such diagnosis; and
>
> (3) the sample source's representative has executed authorisation which meets the requirements of section 103 of this Act.

Section 144 continues:

> Private genetic information about an incompetent person shall not be disclosed unless :
>
> (a) the information -
>
> (1) is necessary for the diagnosis of a genetic condition which in reasonable medical judgment is effectively ameliorated, prevented or treated while the person is incompetent; or

> (2) is necessary for the purposes of genetic counselling for a relative of the person;
>
> (b) the information disclosed is limited to that which is necessary to conduct such treatment or counselling; and
>
> (c) the sample source's representative executes an authorization that meets the requirements of section 112 of this Act.

Note how the interests of family members are considered to be legitimate reasons for collecting and using genetic information from an incapax under these provisions. Strict limits are applied - rightly so - but the absence of an ability to consent seems to be the overriding factor here. This sends out an interesting message. The interests of relatives in a sample source's genetic information do not change in the slightest depending on whether the sample source does or does not possess capacity to consent, but under the Act it is only in the latter case that such interests are recognised. Some may argue that this is prefectly legitimate given the primary rights of the competent adult, but to others such an individualistic view perhaps places too much emphasis on the value of consent and pays undue deference to the fact of having capacity to exercise autonomous choice. It cannot be denied that the privacy of the incapax is interfered with in such circumstances. The provisions concerning the collection of genetic material clearly raise concerns for spatial privacy. In like manner, the provisions relating to disclosure of genetic information invoke informational privacy issues. Can this be justified?

A good starting point is the premiss that an incapax is no less possessed of rights than is a capax. To justify touching the incapax or disclosing his/her genetic data one might argue that it is therefore reasonable to assume that the incapax might have voluntarily consent to either act had s/he been able to do so. This is certainly an argument, but for the present writer it is not a convincing one unless one has clear indications that the incapax would indeed have consented. For example, the presence of an advance directive. Absent this, it is difficult to see how the incapax could exercise his/her 'right to choose' except through the medium of a third party who, in such circumstances, would have to choose on the basis of no evidence of what the incapax would wish. Of course, it could be asked why should we imagine that the incapax would refuse rather than consent? But, this leads us into a minefield of legal sophistry which it is fruitless to pursue here. Rather, the present writer would prefer to argue that because of the interference with the incapax's privacy interests which these provisions entail, they are can only be justified in two rare circumstances: (a) the 'best interests' of the incapax, (b) the privacy 'public interest' outlined in chapter five. That is, we must ask, is there a strong and valid reason for infringing privacy which either helps the incapax or advances a legitimate interest of family members?

A 'best interests' argument applies in all cases of incapacity[74]. We see it here and we see it in the provisions relating to minors. The question of what is in the best interests of an incapax must, axiomatically, involve an assessment of all relevant factors, the most important of which are clear medical benefit and competent patient wishes if any are available. Added to this should be the spatial privacy interests of individuals. This places a heavier onus on those seeking to 'treat' the patient for all of the reasons enunciated previously in this work.

As to whether a legitimate public interest defence is incorporated in the provisions of the Genetic Privacy Act relating to incapax adults, it is submitted here that there

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[74] At least, this is true in the United Kingdom.

is not. This is so because information can be sought and used for the diagnosis in others of *any* condition which 'in reasonable medical judgment' can be effectively ameliorated, prevented or treated. It is also permissible to use information for the genetic counselling of relatives. The former is objectionable because no distinction is made between the severity of affliction as between different diseases, nor is any distinction made between conditions for which relatively little can be done and those for which much can be done, or which can be cured. Also, the provisions make no attempt to require that all other means be exhausted before information is sought from the incapax. It is suggested that on the analysis offered in this work, all of these would have to be considered to establish a sound argument that would justify interfering with the privacy interests of the incapax.

The question of releasing genetic information about an incapax for counselling of relatives is objectionable because the information is used simply to facililate choices for others, and it has been argued strongly already that this is not a valid reason to interfere with genetic privacy. For these reasons, it is submitted that the provisions relating to incapax adults inadequately protect the privacy interests of such individuals.

3.3. - Informational and Spatial Privacy Interests and the Genetic Privacy Act

The Genetic Privacy Act is to be welcomed as a significant advance in the field of genetics and the law. It contains some very useful provisions and highlights well many of the problems which surround genetic privacy[75]. However, as has been

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[75] For a brief discussion of the Act and an argument that legislators would do better to concern themselves with particular examples of misuse of genetic information rather than genetic privacy *in se*, see McGleenan,T.; 'Rights to Know and Not to Know: Is There A Need For A Genetic Privacy Act?', in Chadwick, R., Levitt, M., and Shickle, D., (eds.); 'The Right to Know and the Right Not to Know', Aldershot, Avebury, 1997, chapter five.

established, the Act does not adhere completely to the view of privacy interests which is advanced in the present work. The Act has been criticised for this primarily because the view which it does take is insufficiently sensitive to the true nature of the interests at stake, as well as to the positions of both sample sources and family members in relation to genetic information. That said, it has hopefully been well demonstrated that an Act such as the Genetic Privacy Act could be easily adapted to take account of the recommendations which have been made. The same is true of what is said in the next section, which deals with the question of remedies.

4.1. - REMEDIES

Part H of the *Genetic Privacy Act* outlines the various remedies available to those given rights under the Act[76]. These are as follows:

- A private right of action in civil law for damages or equitable relief if one's rights are violated[77];
- A right to damages and costs for any negligent collection or use of a sample, or disclosure of private genetic information in violation of the Act[78].
- Wilful violations of the Act also provide the sample source or his/her representative with an action for damages (including punitive damages) and costs[79].
- The attorney general also has the powers to award injunctive relief for any potential violations of the Act and to issue civil penalties for violations (not exceeding $50,000[80].

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[76] *ibid*, s.171.
[77] *ibid*, s.171(a).
[78] *ibid*, s.171(d). This right is given solely to the sample source or his/her representative.
[79] *ibid*, s.171(e).

Precisely the same, or substantially similar remedies could be extended to recognise the privacy interests of family members in genetic information which are not currently protected by the Act. This is true both of informational and spatial privacy interests. As the Act currently stands informational privacy interests of relatives are left to the whim of the sample source and spatial privacy interests are recognised only for minors. It has been argued, however, that the Act should be extended to protect familial informational privacy by ensuring that third parties outside the family who are in possession of genetic information are not only under an obligation to keep the information secure, but also are prohibited from using the information to the potential detriment of the family. This should be so even if individual family members' consent to such uses.

For the better protection of spatial privacy interests, it is submitted that unauthorised disclosures of information or attempts to obtain information be made actionable. This would be most viable once again against third parties outside the family unit. It is proposed that any person or organisation who comes into possession of genetic information without the knowledge of the individual(s) to whom it relates should be provided with detailed guidance on the law and the nature of interests at stake, the relative merits and demerits of disclosure and security, the limits of genetic information and the current state of medical developments concerning gene therapy and other treatments and cures. A right of action could be brought against *anyone* who made an improper disclosure to an individual, but it is likely that in the vast majority of cases health care professionals will be put in a position of receiving such information in the first instance. It is they who will decide whether or not testing should be carried out and it is they

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[80] *ibid*, s.172.

who will decide how genetic information should be used and/or disclosed. Of course, in many circumstacnes the HCP will be working for employers, insurers or the state, upon whom a duty is clearly also imposed, but it will be through HCPs that respect for individual privacy will first be tested[81]. It is fitting, therefore, that health care professionals assume the primary duty not to disclose. Should there be a conflict between an HCP's duties to his/her patient and his/her employers, the patient should be fully informed of this and the reasons why genetic information is being sought must be made clear. The uses to which the information will be put must be disclosed, and if these are surpassed a *prima facie* breach of duty to respect privacy will have occurred.

Where the HCP receives information directly from a sample source s/he should be charged with the task of counselling the sample source and establishing as clearly as possible the limits of their relationship, taking into account the wider familial interests where appropriate. Arguably, part of the counselling should cover the limits of the proband's own powers to decide unilaterally what should be done with genetic information. It is not envisaged that this would be a system of strict liability, for no health care professional could reasonably be held responsible for the conduct of relatives who inform others, but it would serve to develop a more sophisticated approach to the management of familial genetic information and would help to ensure the responsible handling of such information by those who first discover it or who subsequently use it in a professional capacity. One might of course argue that any counselling which is given should be non-directive, but it is the view of the present writer that the reality is that this is an impossible state of affairs to maintain[82]. It is far better to accept the reality that counselling is driven by

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[81] It is trite law that the employer would be vicariously liable for the failings of the HCP.

[82] For examples of this argument, see Chadwick, R.; 'What Counts For Success in Genetic Counselling?', 19, *Journal of Medical Ethics*, 43, 1993 and Clarke, A.; 'Is Non-Directive Genetic Counselling Possible?', 338, *Lancet*, 998, 1991.

various policy considerations and adopt as a policy the view that as much respect as possible should be given to privacy interests.

5.1. - GENETIC INFORMATION - AN ETHIC OF CARE

This writer is not so naive as to imagine that a legal framework such as that proposed above would prove to be easily workable in practice. For one thing, it would prove to be very difficult in practice to control the free-flow of information within families. To some, the imposition of legal sanction for certain instances of information exchange within a family might prove to be too large a sledgehammer to crack too small a nut. And, it is hard to get away from the conclusion that in many circumstances families are best left alone to deal with familial issues in their own way. To attempt to police something as ethereal as 'information' within the family unit, might prove to be foolhardy. This is why it has been emphasised that it would be preferable to focus legislative action on third parties outside the family - such as employers, insurers, health care professionals and the state - in an attempt to protect genetic privacy. Certainly, in many cases the most serious of threats will come from such quarters.

This work has sought to highlight the unique problems posed by the free availability of human genetic information, and has sought to give a new and fresh perspective to the privacy debate. The interests which have been identified not only expose a highly complex structure of interconnecting issues which develops from the availability of genetic information, but they also indicate the need for due recognition of the true subtleties of this area. We have examined how we can better protect genetic privacy from the perspective of the law, and it has been forcefully argued that much can be done in legal terms to protect privacy interests. However, in complement to any legal provisions that might be instituted, other things could be done which would go a long way to developing the optimal framework within which problems of genetic information can be tackled. For example, the idea of giving a high degree of responsibility to health care professionals who deal with genetic information and who provide genetic counselling to families can be formalised to an extent by ensuring that proper guidelines are issued to such persons, that they be professionally trained, that they have a clear idea of the interests at stake, that they can properly communicate the intricacies of these interests to all concerned. Arguably such persons should, in certain cases, advise on appropriate courses of action. All of this can be informed by ethics, and crucially, it would revolve around the recognition and protection of the privacy interests argued for in this work. In turn, appropriate bodies could be established with statutory authority to issues guidelines, train professionals, provide advice and regulate counselling practices. At the present time in the United Kingdom we have no such scheme which operates at a national level. The House of Common Science and Technology Committee recommended the establishment of a *Human Genetics Commission*[83] which would have, *inter alia*, the reponsibility to:

- monitor the availability of genetic servies in different regions;
- advise local research ethics committees on genetic research protocols;
- approve screening programmes before they are introduced;
- disseminate best practice and keep it under constant review;
- prescribe the circumstances in which particular types of genetic diagnosis and screening should be provided or proscribed.

No action has, as yet, been taken to introduce such a body. In the United States, the Joint National Institutes of Health and Department of Energy Report on the

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[83] House of Commons Science and Technology Committee; 'Human Genetics: The Science and Its Consequences', Third Report, 1994-95:HC41-I, July 1995, paragraphs 140 - 147.

Ethical, Legal and Social Implications of the Human Genome Project[84] has recommended the establishment of a federally-chartered Advisory Committee on Genetics and Public Policy. *Inter alia*, powers would be given to the Secretary of the Department of Health and Human Services[85] and other government departments to regulate and monitor matters concerning genetic policies and practice, legislative and regulatory policy, professional education, public education, access to and security of personal health files containing genetic information and issues of genetic privacy and confidentiality. These models are ideal to further the aims outlined in the current work. Such bodies would be established by statute and would thereby have considerable authority in the field. They would bring a degree of homogeneity to professional dealings with genetic information and with appropriately drafted guidelines[86] would ensure a high degree of protection for the individuals who are the subjects of that information.

6.1. - CONCLUSION

To conclude this work, we should consider the path that we have followed and the end point which we have reached. Within a framework of disputed value, namely privacy, we have considered the delicate problems of access and non-access to genetic information. We have examined the unique problems which arise from the fact that genetic information relates not only to the individual from whom the

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[84] The Committee was established on 30 April 1996. To see its interim report see Internet site: http://www.ornl.gov/hgmis/archive/elsirept.html

[85] It is envisaged that the Advisory Committee be established within this Department.

[86] The NIH-DOE Working Group on Ethical, Legal and Social Implications of Human Genome Research has, for example, already produced '*Interim Principles of the Task Force on Genetic Testing*' which include reference to protection of indivdiual privacy. Principle III-15 states that test results should not be released without the prior written consent of the tested individual. Neither employers, insurers, government agencies nor relatives can receive genetic information without such consent. Principle III-16 provides that relatives will only be informed in very rare circusmtances such as when failure to inform will result in irreversible or fatal harm and the person tested refuses to communicate the information. The text of these principles can be found at: wysiwyg://77/http://infonet.welch.jhu.edu/policy/genetics/index.html

information is initally derived, but also to relatives of that individual. We have distilled the concepts of informational and spatial privacy from an examination of the nature of the interests which such parties have in the information in question, and it has been argued that current laws and practices do not provide us with appropriate means to recognise the existence of such interests, nor do they protect them adequately. As an alternative approach, we have considered the matter from the perspective of the legal and philosophical debates surrounding the value and utility of privacy, and a strong case has been made that a useful and valuable construct of genetic privacy can be established which is amenable to legal protection. The case for legal protection of genetic privacy has been put, supplemented by recommendations concerning the establishment of appropriate bodies with legal powers to ensure that genetic information is handled in the most sensitive manner possible. The law has a crucial role to play in ensuring professional responsibility towards the use and treatment of familial genetic information. What is urgently required is a uniform and formalistic framework to determine the optimal approach to dealings in genetic information - one which takes due account of the wide range of interests at stake and one which shows due deference to the special role within that framework for privacy.

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