Mental health service users', carers' and professionals' perceptions of the named person provisions of the Mental Health (Care and Treatment) (Scotland) Act 2003

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Abstract

Background: The Mental Health (Care and Treatment) (Scotland) Act 2003 reduced the role of the nearest relative, identified by a hierarchy of relationships, who previously could admit and discharge a patient as well as receive information about their care. This role is now reduced to one of receiving basic information only and the hierarchy for identification has been modernised. Service users may now nominate a named person with similar rights to service users to help protect their interests. This person cannot admit or discharge but is entitled to information and consultation about their care. If a patient has not appointed a named person, then the primary carer is appointed by default and, if there is no primary carer, the nearest relative assumes the position.

Aims: To explore service users', carers' and professionals' perceptions and experience of the named person provisions.

Method: Twenty service users, ten carers, seven MHOs and nine professionals with influence on government policy were interviewed about their experiences. Interviews were carried out face-to-face (service users and some carers) and by telephone (carers, MHOs and policy influencers). The resulting transcripts were analysed using thematic analysis.

Findings: The majority of all interviewees welcomed the introduction of the named person provisions because of the increased choice it gave service users. Service users often did not wish to nominate their nearest relative, many choosing to nominate a friend. Important factors in making a nomination were that the nominee knew the service user's wishes and could be trusted to carry them out. Some service users chose not to nominate relatives to spare them responsibility. However, the provisions were not without their problems; uptake was perceived to be low and there were particular problems in relation to the level of understanding of the implications of a nomination by service users and of the lack of accessible information and support to increase this understanding. The imbalance of power in relationships between service users, carers and professionals was thought to impact on the autonomous choices of service users and carers. Further problems were identified with named persons appointed by default in relation to service user choice and confidentiality.

Conclusion and recommendations: Although the choice is welcome to some service users, there appears to be a lack of full understanding of the role, and continued awareness-raising is required with service users, carers and professionals which should further be supported by accessible information for both service users and carers. There is currently a lack of support for carers in particular and it is recommended that this be addressed using carers' services. It seems that many named persons are being appointed by default (itself an anomaly in Scots law) which threatens human rights, because of the lack of choice of the service user about who is involved in their care and their inability to prevent the sharing of confidential information with the default named person. The current lack of a right of service users to reject having a named person at all restricts choice and autonomy, and may further place unwanted responsibilities on carers and relatives which are difficult to remove. To ensure that service users' rights are fully protected, the named person should become an optional nominated position and the default mechanisms removed.

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Acknowledgements

Author's Declaration

The research presented in this thesis was performed solely by the author, undertaken at the Public Health and Health Policy Section within the University of Glasgow between October 2004 and March 2009, under the supervision of Professor Jacqueline Atkinson.

List of Acts[1]

Act:	Jurisdiction:
*Access to Health Records 1990	UK
*Act to regulate madhouses in Scotland June 1815	Scotland
Act of Union 1707	UK
*Adults With Incapacity (Scotland) Act 2000	Scotland
*Adult Support and Protection (Scotland) Act 2007	Scotland
Carers (Recognition and Services) Act 1995	UK
Civil Partnership Act 2004	UK
*Community Care and Health (Scotland) Act 2002	Scotland
Crime and Disorder Act 1998	UK
Criminal Justice & Licensing (Scotland) Bill	Scotland
Criminal Procedure (Scotland) Act 1995	Scotland
Curators and Tutors Act 1696	Scotland
Curators Act 1585	Scotland
*Data Protection Act 1998	UK
*Human Rights Act 1998	UK
*Lunacy Act 1845	England and Wales
*Lunacy and Asylums Act, Scotland 1857	Scotland
*Mental Capacity Act 2005	England and Wales
*Mental Deficiency and Lunacy (Scotland) Act 1913	Scotland
*Mental Deficiency (Scotland) Act 1940	Scotland
*Mental Health Act 1983	England and Wales
*Mental Health Act 1986	Victoria, Australia
*Mental Health Act 2007	England and Wales
Mental Health (Amendment) (Scotland) Act 1983	Scotland
*Mental Health (Care and Treatment)(Scotland) Act 2003	Scotland
*Mental Health (Scotland) Act 1960	Scotland
*Mental Health (Scotland) Act 1984	Scotland
Mental Health (Patients in the Community) Act 1995	UK
Mental Health (Public Safety and Appeals)(Scotland) Act 1999	Scotland
*National Health Service (Scotland) Act 1947	Scotland
*National Health Service and Community Care Act 1990	UK
Public Health etc. (Scotland) Act, 2008	Scotland
Poor Law Act 1579	Scotland
Scotland Act 1998	UK
Tutors and Curators Act 1672	Scotland

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[1] *Indicates Act used as primary source.

List of Cases

C (Adult: Refusal of medical treatment), Re: [1994} 1 WRL 290; [1994] 1 All ER 819; [1994] 1 FLR 31; [1994] 2 FCR 151; [1994] Fam Law 131; 15 BMLR 77; (1993) NLJR 1642.

HL v United Kingdom, 2004 Application No. 45508/99

JT v United Kingdom, 1998 Application No. 26494/95

In re Guardianship of Kowalski, 478 N.W.2d 790 (Minn. Ct. App. 1991)

R (on the application of SSG) v Liverpool City Council (1) Secretary of State for Health (2) and LS (Interested Party) Administrative Court (22nd October 2002)

R (on the application of M) v Secretary of State for Health [2003] EWHC 1094 (16th April 2003)

RE T (Adult: refusal of medical treatment) [1992] 4 All ER 649

Tarasoff v Regents of the University of California, 17 Cal. 3d 425, 551 P.2d 334, 131 Cal. Rptr. 14 (Cal. 1976)

Z v Finland, 1997 Application No. 22009/93

Abbreviations

2003 Act: Mental Health (Care and Treatment) (Scotland) Act 2003

AMHP: Approved Mental Health Professional

AMP: Approved Medical Practitioner

ASW: Approved Social Worker

AWISA: Adults with Incapacity (Scotland) Act 2000

CMHT: Community Mental Health Team

CPN: Community Psychiatric Nurse

CTO: Compulsory Treatment Order

DMP: Designated Medical Practitioner

ECHR: European Convention on Human Rights

ECT: Electro Convulsive Therapy

GBMHAC: Great Britain Mental Health Act Commission

GMC: General Medical Council

GP: General Practitioner

LREC: Local Research Ethics Committee

MHO: Mental Health Officer

MWC: Mental Welfare Commission for Scotland

NHS: National Health Service

RMO: Registered Medical Officer

Dramatis personae

Medical

Health Boards are the agencies responsible for the strategic planning of health services and for managing hospitals. As hospital managers they have a duty to ensure that certain functions under the Mental Health (Care and Treatment) (Scotland) Act 2003 (2003 Act) are carried out correctly.

Under the Act, **Physicians** can be **Registered Medical Officers** (RMOs), **Approved Medical Practitioners** (AMPs), **Designated Medical Practitioners** (DMP) or **general medical practitioners**. An RMO is a consultant psychiatrist based at the service where the patient is being treated; each patient affected by measures under the 2003 Act must have a named RMO. The RMO must ensure that the consent to treatment rules are being applied correctly and must play a major role in decisions regarding compulsory measures. An AMP has to have experience in psychiatry and be trained in the Act. Second opinions can be requested from Designated Medical Practitioners who are all consultant psychiatrists (yet need not be AMPs).

Government

Local Authorities are the agencies of local government in Scotland. Part of their role under the 2003 Act is to provide community-based services (including independent advocacy services) and appoint **Mental Health Officers (MHOs).**

Mental Health Officers are qualified social workers with experience and training in the Act. Any person subject to compulsory measures must have an identified MHO. They play a key role in explaining patients' rights, preparing applications for compulsory measures and, with a physician, can consent to short term detentions.

The **Mental Welfare Commission for Scotland** (MWC) is an independent body which protects the rights of people with mental health problems or incapacity. It appoints **commissioners** from a range of backgrounds including medicine,

nursing, social work and service users. The MWC monitors the operation of the 2003 Act and encourages best practice by producing guidelines and carrying out inquiries. Guidelines are not legally binding but failure of agencies to comply could be subject to legal challenge (Patrick, 2006). The MWC receives reports about people subject to compulsory measures and carries out visits to patients. Any patient can request a private interview with a commissioner. The MWC maintains a register of DMPs for the purposes of obtaining second opinions.

Judicial

The **Sheriff Court** is the local civil court in Scotland, presided over by a **Sheriff**. Prior to 2003 the Sheriff Court dealt with mental health legislative proceedings with appeals usually heard by the **Court of Session**.

The **Mental Health Tribunal Scotland** (the tribunal) was created by the 2003 Act and has taken over the role previously held by the Sheriff Court in mental health proceedings dealing with applications, appeals and variations to orders. It is independent of the government and Health Boards and has the power of a court. Tribunals consist of three members, one legal, one medical and one general member (often from a social work background, or a service user or carer).

A **Welfare Guardian** is a person appointed by the courts under the Adults With Incapacity (Scotland) Act 2000 (AWISA 2000) to make ongoing decisions about finance and welfare on behalf of persons who are incapable of making these decisions themselves. A **welfare attorney** is legally appointed under AWISA 2000 and in the event of incapacity has control over decisions regarding care and treatment.

Curators ad litem are legal representatives appointed by the court when a person is thought to lack the capacity to make their own decisions. They act in the best interests of the person in court, but although they are usually a solicitor, they do not take instruction from the person.

Personal

The term mental health **service user** is used to refer to any person who uses mental health services. The term **patient** is used to refer to any person subject to, or liable to be subject to compulsory measures under mental health or incapacity legislation[2].

The term **carer** is used to refer to any informal and unpaid carer of a service user or a patient. The term **primary carer** is used to refer to any carer who provides the most care to a service user or patient with reference to the 2003 Act.

The **nearest relative** is a legal term under the 2003 Act referring to either the spouse or the nearest blood relation to a service user or patient, determined by using a fixed hierarchy. The **named person** is a person formally nominated by a service user or patient under the 2003 Act to represent their interests when they are subject to compulsory measures.

An **independent advocate** must be available to all mental health service users under the 2003 Act. They support the service user to express their views about their care and treatment, particularly during applications for compulsory measures, for example, during a tribunal.

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[2] The researcher acknowledges that the terms *'patient'* and *'service user'* are potentially problematic by defining people by the health services that they use. However, the terms have been chosen in this instance to distinguish between different legal status.

Introduction

In Scotland it is thought that approximately 15% of admissions to psychiatric hospital take place using mental health legislation (I.S.D. Scotland, 2008). Prior to 2003 the Mental Health (Scotland) Act 1984 awarded automatic rights to the nearest relative of the detained patient using a hierarchy of relatives based on marriage and biological closeness, with little exception, continuing a long trend of family involvement in the compulsory detention of patients. The nearest relative had powers to commit and discharge a patient, as well as receiving information about their care and treatment. There were obvious problems with this system: the nearest relative may not necessarily have been the most suitable person to take on such a role, but there was no mechanism for the patient to prevent their appointment. Furthermore, the hierarchy of relatives did not give equal status to same-sex relationships.

The Mental Health (Care and Treatment) (Scotland) Act 2003 brought about some of the most radical changes in mental health legislation in over a century. One of these changes aimed to solve the problems caused by the nearest relative system under the 1984 Act by introducing the named person, a non-professional role in the form of a person whom a service user could formally nominate to help protect their rights and influence the way that they were treated under the new Act. The role of the nearest relative was still retained albeit in a greatly reduced role with the powers of discharge and admission removed and not subsequently bestowed on the named person. Both the nearest relative and the named person have rights rather than powers, for example, both have the right to receive certain information about a patient. If a patient had not nominated a named person then the role would default to their primary carer or if there was no primary carer, their nearest relative identified by using an updated hierarchy.

Since the introduction of the 2003 Act there had been no previous research exploring the use of the new named person provisions, it was not known to what extent or how service users would use the provisions, or how carers perceived the role. No research had been carried out into how professionals implementing the Act, namely the MHO, had experienced changes in practice associated with the new measures and what the view from the broader policy perspective was.

The aims of this research were to explore service users', carers', MHOs' and policy influencers' perceptions of the introduction of the named person provisions.

Chapters One to Three provide a context for the research. Chapter One provides a general context of the broader issues that mental health legislation affects, including current grounds for the use of compulsory measures and how these impact on patients' autonomy, informed consent and right to confidentiality. Chapter Two provides a historical context to the introduction of the Mental Health (Care and Treatment) (Scotland) Act 2003 before describing the introduction of the named person provisions under the 2003 Act. Chapter Three describes the potential family involvement in the care and treatment of mental health service users, focusing on the issues affecting relatives and carers when compulsory measures are used. Previous research into the nearest relative role and similar legal provisions are described before an overview of research evidence around proxy decision-making that may inform how people are likely to use the named person provisions.

Chapter Four states the aims of the research and describes the methods employed with particular reference to interviewing people about sensitive subjects and to informed consent before the findings are presented across three chapters. Chapter Five provides a background, describing the interviewees and their overall perceptions of the named person provisions. Chapter Six presents findings within the context of autonomy as supported by understanding and information about the named person provisions. It describes whom service users wanted to nominate as a named person and their reasons why. Chapter Seven looks at the power imbalances between service users, carers and professionals and how they can affect autonomous choice. Chapter Eight looks at the introduction of the named person provisions from a human rights perspective, in particular the problems caused by the default named person with regard to choice and confidentiality.

The findings are discussed over the next three chapters, Chapter Nine starting with a reflection of the methods used to collect the data. The overall opinion and uptake of the provisions are discussed before Chapter Ten discusses how

service user autonomy can be promoted through increased awareness and understanding and other factors surrounding making a nomination. Chapter Eleven addresses the power imbalances between service users, carers and professionals before discussing the potential human rights difficulties of the named person and then proposes a solution.

The thesis concludes by drawing the findings together and concluding that the introduction of the service user nominated named person is a welcome provision, increasing choice and autonomy of service users. However, it is not without its problems, including the lack of full understanding surrounding the implications of making a nomination, the further potential erosion of autonomy through power imbalances and the specific problems surrounding the default named person regarding freedom of choice and confidentiality. In the light of these conclusions, a series of recommendations is made, applicable to agencies involved in the care and treatment of people with mental health problems.

Chapter One: The context of mental health legislation

Introduction

The literature review is in three parts. The first part provides a general context of the broader issues affected by mental health legislation including current grounds for compulsory measures and how they impact on patients' autonomy; and informed consent and rights to confidentiality. The second part provides a historical context to the introduction of the Mental Health (Care and Treatment) (Scotland) Act 2003 before describing the role of the nearest relative prior to 2003, and the introduction of the named person under the 2003 Act. The third part describes family involvement in the care and treatment of mental health service users with a particular focus on the issues affecting relatives and carers when compulsory measures are used.[3]

1.1 Literature review method

Several approaches were used to identify the literature discussed in this review. (See Figure 1 for keyword search strategy and summary of results[4]):

- Electronic database searches were carried out using four databases: Ovid Medline for medical literature (Ovid, 2009), BIDS International Bibliography of the Social Sciences for social science literature (BIDS, 2009); NexisLexis for legal literature (NexisLexis, 2009) and Google Scholar (2009) for general literature. All potential studies were subject to inclusion criteria that the research must have been published after 1960 and be written in English.

- Certain journals thought to be of high relevance were hand-searched (These were the *Journal of Mental Health Law*; *International Journal of Law and Psychiatry*; *Journal of Mental Health*; and the *British Journal of Psychiatry* and its associated journals)

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[3] References to the law are references to Scots law unless otherwise specified.
[4] Not all databases permitted recording of the number of *'hits'* per search term so it has not been possible to provide a total.

- A keyword search was carried out on the university library catalogue, the relevant shelf marks were further hand-searched for relevant texts.

- Grey literature (for example, government documents) was accessed using the internet (for example, the Scottish Government and the Mental Welfare Commission for Scotland web pages).

Figure 1: Summary of literature search
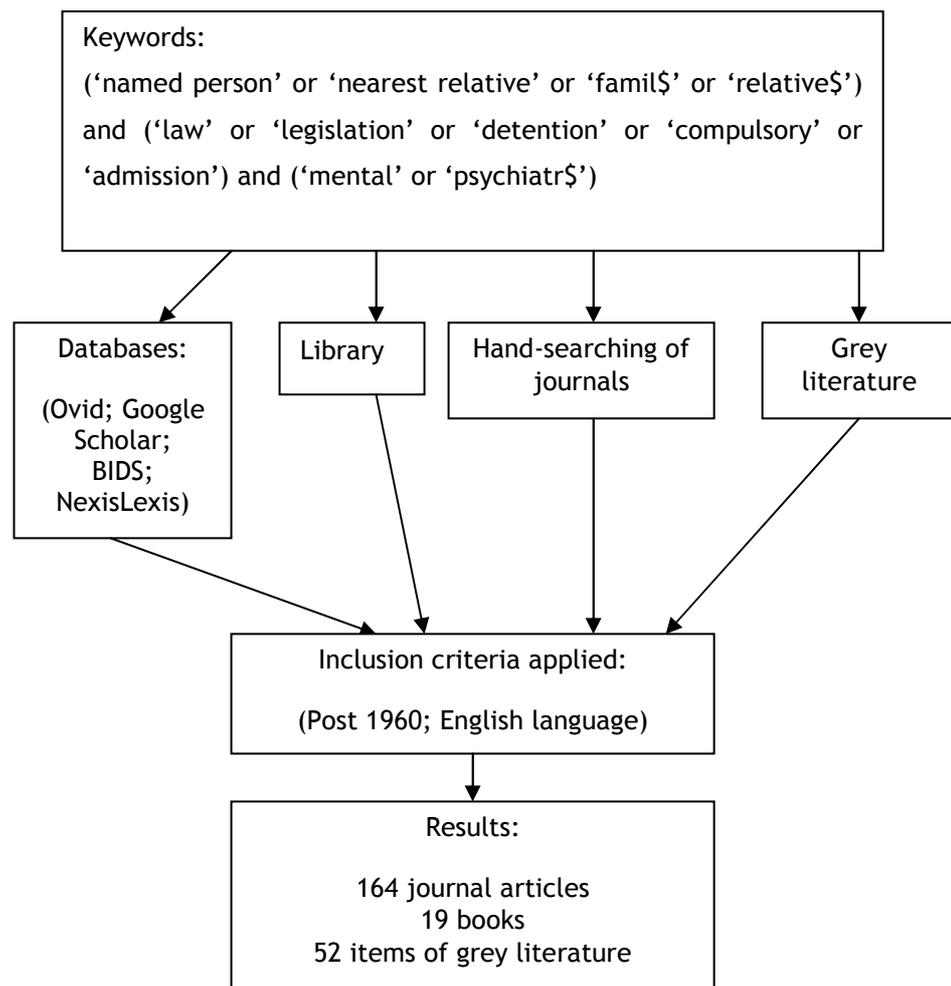
The review was an iterative process with further articles and sources being sourced through citations and bibliographies of papers. References were organised using EndNote XI (Thompson Scientific, 2007).

1.2 Decision-making for others

In every society there will always be people who are unable to make capacitous decisions for themselves. In some cases there can be reasonably simple rules put in place, such as the power parents are awarded over children, but there are other groups that present more complex situations including people with: dementia; learning difficulties; brain injury and mental disorder. Decisions that may need to be made cover all aspects of everyday life from where someone resides and how their finances are managed, to the more controversial, such as decisions governing medical treatment. Patients who are unconscious present the most straightforward cases for such proxy decision-making as they clearly have no capacity to object to decisions being made on their behalf at the time. This is not always the case for people with mental disorders who may vociferously object to the proposed intervention and in these cases their autonomy is directly challenged and overridden. It is thought that approximately 15% of admissions to hospital for treatment for mental disorder in Scotland take place using compulsory measures (I.S.D. Scotland, 2008).

The problems attached to making these decisions are many. They have historically been dealt with within a legal framework with the law playing an important part in deciding for the incompetent[5] person, either as they cannot communicate their wishes, or overriding the person's autonomy, as they have been deemed incapable of making their own decisions. These are not recent legal provisions; there has been Scottish legislation in place to manage the property and residence of people incapable of making decisions for themselves for over 600 years. As the law provides the framework for how decisions are made, its workings are of crucial importance to people with impaired decision-making although the law can only respond to cases brought before it or apply legislation developed to manage those anticipated situations. The law does not always offer satisfactory solutions, becoming out of date from both medical developments and changing views on the rights of patients. Patients' rights have increased over the past half century with the law placing increasing importance

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[5] It is generally accepted in the UK that *'capacity'* is the clinical term referring to a person's ability to make rational and considered decisions whereas *'competence'* is the legal term for the same ability. It is acknowledged there has been debate on the conflation of these terms in medical law, for example, Bielby (2005), although both terms are used throughout this thesis.

on the known wishes of the incapable person rather than solely making a decision in what is considered to be their best interests.

1.3 Compulsory measures in psychiatry

There are two components to compulsory measures in psychiatry: detention and treatment, but before compulsory measures can be undertaken there needs to be a definition of mental disorder, itself a controversial area, essentially due to its diagnosis necessarily requiring a somewhat subjective judgement concerning behaviour and rationality (Dunn, 1998). The World Health Organisation advises that the legal definition of mental disorder should be in accordance with international guidelines (such as the ICD-10 Classification of Mental and Behavioural Disorders 2005 (WHO, 1996)).

Scots law currently defines mental disorder as consisting of: *'mental illness; personality disorder or learning disability however caused or manifested'* (2003 Act [s328(1)]. A person cannot be considered to be mentally disordered by reason of sexual orientation; deviancy; transsexualism; transvestism; substance misuse; behaviour that may alarm or *'acting as no prudent person would act'* [s328(2)].

Mental disorder is only sufficient grounds for using compulsory measures if it also impairs a person's decision-making regarding treatment for that mental disorder [s36(4)(b)]. Although mental illness can affect the capacity for competent decision-making such as understanding, reasoning and applying values, there can also be mental disorder that affects none of these, for example, a specific delusion of persecution that is quite isolated and focused (Zalta, 2002; Atkinson, J., 2007a). It can be viewed as if it were not for the illness the person would consent to hospitalisation or treatment, or it is at least uncertain what they would do.

Compulsory detention under mental health legislation allows a person to be deprived of their freedom, despite never having committed an offence or having appeared in court. In general there is a focus on detention being necessary to prevent harm to the self and others, with a particular focus on preventing harm

to the self. There can still be an element of public protection in the decision to hospitalise a patient if the patient is considered to present a risk to others. In these cases the decision is being made not in a solely patient-centred manner but by also taking into account the interests of others[6].

The patient can be involuntarily hospitalised, yet still deemed competent to refuse treatment for their illness. This can put the detaining psychiatrist in a difficult situation as they are essentially incarcerating the patient without actually providing any treatment (Pilgrim, 2006). This has led to the detention of somebody in hospital being included in the definition of *'treatment'* under the 2003 Act [s329(1)].

The 2003 Act only allows a person to be detained: if they have a mental disorder for which medical treatment is available which could stop their condition getting worse; if they do not receive treatment there would be a significant risk to the service user or to others; their decision-making ability regarding medical treatment is significantly impaired. Finally, the use of compulsory measures must be considered necessary [s36(5)(a)]. The Act views decision-making capacity regarding medical treatment as context specific, for example, a person may have the capacity to make some decisions some of the time, but not others, rather than be deemed wholly incapable.

Psychiatry differs from other areas of medicine in one fundamental way: treatment for physical illness almost always depends on the consent of the patient, whereas treatment for mental illness need not. Compulsory treatment allows a person to be subject to treatment that otherwise would be classed as assault against the person. The treatments themselves are often controversial with medications that affect the mind having the potential to affect a person's essential sense of self (Mason, 2003). The *'treatability'* of mental disorder is a further area that attracts much debate. It was introduced in relation to anti-social personality disorders to distinguish between the roles of mental health and criminal justice services in the management of such people, essentially, to ensure that public protection did not become the primary function of mental

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[6] In some circumstances a person suffering form a *'notifiable'* disease (for example, TB or anthrax) can be detained in hospital to prevent infection but they cannot be forced to accept treatment (Public Health etc. (Scotland) Act, 2008 [s41]).

health legislation but that of the criminal justice system. Having a treatability requirement ensures the protection of people with personality disorder from detention without conviction and prevents professionals from becoming *'substitute agents of social control'* (Eastman, 2006).

There is now a broad definition of treatment under the 2003 Act that includes nursing care, psychological interventions, education and training for work, rehabilitation and independent living skills, as well as the more traditional definition of treatment as direct medical intervention [s329(1)].

1.4 Autonomy

Autonomy is commonly accepted to be the capacity to live one's life according to one's own values, principles and motives and not those of external forces (Zalta, 2002). It is a central concept in the area of both medical ethics and legal freedom. Autonomy can be seen as operating through the two distinct areas of self-determination and self-government (Atkinson, J., 1991). Self-determination is the individual controlling their own life by carrying out their own individual plans and wishes, and self-government is the individual governing their life by rules and values. These values can conflict with the wishes and desires of self-determination but during the process of decision-making the individual balances these factors against each other. It is beyond the scope of this review to provide a full exploration of autonomy, but a comprehensive review of the theory and practice of autonomy has been carried out by Dworkin (1988).

Overall, philosophical and ethical theory focuses on the treatment of the competent autonomous adult, rather than the incapacitated. Philosophical theory has questioned whether it is ever justified to intervene in the actions of a competent adult but has tended to avoid the issue of what we do with those deemed incompetent. John Stuart Mill, who wrote extensively on autonomy (Mill, 1859; 1989), was strongly opposed to interference in the actions of competent adults but merely stated that it was justified to interfere in the actions of those deemed incompetent in order to promote their own good or to prevent them from harming others.

1.4.1 Assumption of global competence

In legal, health and social care agencies there is a presumption of global competence in adults, unless there has been a legal finding of incompetence. This general presumption assumes that the person's decision-making regarding health care will be in accordance with their best interests and well-being. For minors there is an opposing presumption of incompetence regarding health care decisions (although there are exceptions, for example, 14 to 16 year olds have limited competence following the Fraser Guidelines in relation to sexual health (NHS Scotland, 2008)). The age of competency varies in different situations within the same jurisdiction and across different jurisdictions. For example, in Scotland a minor is a person aged under 16 although at the time of writing, a minor has criminal responsibility at the age of eight[7]; however, this is due to be raised to 12[8]. In England and Wales a minor is a person aged under 18 and has criminal responsibility at the age of ten[9].

There can also be a general assumption of incompetence in that an adult who is deemed incapable of making one specific decision may also be deemed incompetent to make other decisions. This is problematic as people often have different capacities in different settings, for example, a person detained under mental health legislation due to being considered mentally disordered to such an extent that they were thought to present a risk to themselves, could still retain the capacity to refuse treatment. Scots incapacity law (AWISA, 2000) now allows for the capacity to make decisions to be considered within the context of the individual situation.

Decisions made about a person can be classed as either being decisions of *'substituted judgement'* or decisions of *'best interest'*. Substituted judgement decisions seek to establish as far as is possible what the patient would have chosen were they capable and then act as follows (Degrazia, 1988). This can be difficult to ascertain, particularly in the absence of an advance directive of some description. Those people to whom the person is closest, usually relatives, will often be consulted as they are thought to be the best placed to have this

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[7] Criminal Procedure (Scotland) Act 1995 [s41]
[8] Criminal Justice & Licensing (Scotland) Bill [s38]
[9] Crime and Disorder Act 1998 [s34]

knowledge of the person. However, this approach holds the risk that relatives may not actually be contributing to a substituted judgement decision as their own opinions may influence the responses they give (Bailey, 2002). Where a person has fluctuating autonomy, perhaps due to mental disorder, to promote the right of the patient to have as much involvement in their treatment as possible, the patient's wishes can be sought during times of lucidity in order to maximise the accuracy of substituted judgement decision-making.

Best interest judgements seek to assess what action would be most beneficial to the patient in the circumstances, the person's known preferences will usually be taken into consideration but importantly they do not have to be (Wrigley, 2007). The grounds for overriding autonomy are that it is in the patient's best interests thus the overriding is an essentially paternalistic action. Paternalism is central to how people are treated when their own decision-making capacity is compromised and paternalistic approaches can be essential in preventing a person from harming themselves or others, but can be harmful as if left unchecked, they can erode both autonomy and personality (Atkinson, J., 1991).

There are two ways in which autonomy has particular relevance in psychiatry: consent to treatment and confidentiality.

1.4.2 Autonomy and consent to treatment

Informed consent

It is generally accepted that wherever possible, patients should make their own decisions about the treatment they receive. These decisions are ideally made with the patient having full understanding of the facts of their situation, having taken into account the recommendations of their physicians, weighing up the options available to them, how these fit with their values and what impact they might have on their life. Consent must be free and informed; if the patient has been coerced into receiving a particular treatment, or has not understood the information, then the process is flawed (Dworkin, 1988). This consent may either be explicitly given through the signing of a form, or implied, through the patient attending for treatment (Mason, 2003).

However, people are often required to make decisions about their health care and treatment at times when they are anxious and fearful, as well as experiencing health problems, all of which can serve to diminish their capacity to make decisions regarding both their current and future well-being. There are some circumstances where consent clearly cannot be provided, for example, if a patient were unconscious after an accident. In this event it is widely recognised that acting out of necessity *'legitimates an otherwise wrongful act'* (Mason, 2003) the unlawful act of intervening without the person's consent is justified by the resulting event of the person's life being preserved.

The level of capacity required for decision-making must balance respect for the patient's autonomy with protection of their well-being. Furthermore, the level of capacity required might vary between decisions. A judgement of capacity is essentially a legal decision made after consideration of medical evidence (Patrick, 2006). If someone has capacity to make a decision then their decisions must be respected, if somebody is found not to have capacity then they cannot give consent and the law must be used to make the decision on their behalf.

Refusing consent to treatment

A competent adult person has the legal right to refuse medical treatment, even if this refusal will result in their death[10] and a patient does not have to justify their decision and need give no reason at all. A physician who treats a patient against their will is committing an assault, and as described above, the presence of a mental disorder does not automatically invalidate a person's capacity to consent. In one case[11] a person diagnosed as having schizophrenia refused the amputation of a gangrenous limb. Despite this wish appearing irrational, the court found that this did not automatically mean that the person did not have the capacity to make that decision. However, a seemingly irrational decision may indicate the presence of a mental disorder that may prompt further investigation into the actual capacity of the patient, it has been suggested that

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[10] *RE T (Adult: refusal of medical treatment)* [1992] 4 All ER 649.
[11] *C (Adult: Refusal of medical treatment), Re*: [1994} 1 WRL 290; [1994] 1 All ER 819; [1994] 1 FLR 31; [1994] 2 FCR 151; [1994] Fam Law 131; 15 BMLR 77; (1993) NLJR 1642.

competence is rarely questioned when treatment is not refused (McCubbin &
Weisstub, 1998).

1.4.3 Autonomy and confidentiality

A further way in which autonomy is threatened within mental health services is
through the sharing of confidential information about the patient between
professionals, agencies and in some circumstances relatives, the right to privacy
being related, although not identical to, a person's autonomy (Dworkin, 1988).

Confidentiality is a mainstay of medical ethical practice originating in the
Hippocratic Oath (Holloway, 2004) and it is generally assumed that health
professionals do not share information about a patient without the patient's
consent (Ramsay, 2001). Furthermore, confidentiality is considered to be
particularly important for people with mental health problems as the potential
stigma associated with using mental health services can mean that patients have
to know that their confidences will be kept or else they may be reluctant to seek
treatment (Holloway, 2004).

Confidentiality has a legal basis in the European Convention on Human Rights
(ECHR) under Article Eight (incorporated into the Human Rights Act 1998)
reinforcing the right to privacy (Morris, 2003):

> *'(1) Everyone has the right to respect for his private and family life, his
> home and his correspondence. (2) There shall be no interference by a
> public authority with the exercise of this right except such as in
> accordance with the law and is 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 or crime, for the protection of
> health or morals, or for the protection of rights and freedoms of others.'*
> Article Eight, Human Rights Act 1998

It has subsequently been ruled that this privacy includes personal data including health records and that respect for the confidentiality of health records is a right[12]:

> *'It is crucial not only to respect the sense of privacy of a patient but also to preserve his or her confidence in the medical profession and in the health services in general. Without such protection, those in need of medical assistance may be deterred from revealing such information of a personal and intimate nature as may be necessary in order to receive appropriate treatment and, even, from seeking such assistance, thereby endangering their own health...'*

Confidentiality in the UK is further supported by common law, the Data Protection Act 1998, as well as professional codes of practice (Patrick, 2006). There remains a duty of confidentiality if the patient lacks capacity to enter into a confidential relationship with a physician, for example, in the case of a disabled child (Patrick, 2006) and access to medical records can even be prevented after a person's death (Access to Health Records Act 1990 [s4(3)].

When confidentiality can be breached

There are several generally accepted circumstances in which confidentiality may be breached without the consent of the patient. The key tenet is that the breach is justified if it will prevent harm to a person. In the United States, this principle was upheld in the Tarasoff case in 1974[13] after a patient told his psychologist of his intention to kill a woman with whom he had previously had a relationship; the psychologist did not warn the intended victim who was subsequently murdered by the patient. However, situations that justify a breach of confidentiality need not be as extreme as in the Tarasoff case. The most frequent circumstances in the UK have been summarised by (Holloway, 2004):

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[12] *Z v Finland,* 1997 Application No. 22009/93.
[13] *Tarasoff v Regents of the University of California,* 17 Cal. 3d 425, 551 P.2d 334, 131 Cal. Rptr. 14 (Cal. 1976).

- Where there is a duty defined by an Act of Parliament
- When a court orders disclosure
- Where serious harm may occur to a third party
- When the patient is a victim of abuse and lacks capacity to consent
- When the patient is at serious risk of self-harm
- During child protection procedures
- To allow the prevention, detection or prosecution of serious crime
- Where the fitness to practise of a health professional is in question
- To inform the DVLA that a person is unfit to drive

(Holloway, 2004).

Further identified are *'threats'* to confidentiality including multi-disciplinary working and multi-agency working (Szmukler *et al.,* 1996; Holloway, 2004), specifically the use of electronic records and duties to inform statutory services and carers (Holloway, 2004).

This chapter has outlined the context in which mental health legislation operates; the following chapter describes the development of Scottish legislation and the involvement of relatives and carers over several centuries to the present day.

Chapter Two: A brief history of Scottish mental health law

Introduction

There have been legal procedures in place to manage people with mental disorder for several hundred years. This part outlines how relatives have been involved in these procedures, along with varying degrees of influence from the medical and legal professions by providing a history of this legislation. It goes on to describe the provisions of the Mental Health (Care and Treatment) (Scotland) Act 2003, specifically those provisions affecting patient representation, relatives and carers.

The law in Scotland comes from two dominant sources, the common law (including custom, legal writings[14] and precedent) and from statute. Statutes may be passed by the Scottish and Westminster Parliaments as well as by the Parliament of the European Union.

2.1 The law up to 1984

2.1.1 Early Modern Scotland

Although the care and treatment of people with mental disorder has changed dramatically, there are more similarities than differences in how the law provided for people with mental disorder in early modern Scotland, with relatives playing an important role. In early modern Scotland, those requiring care from others were (depending on their income) either cared for by their families; looked after by paid keepers in their own home; boarded out to another family; placed with a private madhouse keeper; placed in a charitable asylum (established from 1782) or left to rely on *ad hoc* charity, often from the church (Michael & Hirst, 1999; Houston, 2001a). There was little tolerance of obvious mental disorder, a person living with their family would be given a certain amount of freedom if they were peaceable, but those who were agitated or disruptive may have been locked away and even chained (Jones, 1993).

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[14] For example, James, Viscount of Stair *The Institutions of the Law of Scotland* (1681).

If people with mental disorder were not supported by their families there was minimal relief available through the Poor Laws 1579. These provisions sought to provide a system of distributing relief to the poor, with certified *'lunatics'* being classed as *'poor'* if they were not being cared for by relatives. Poor laws gave a very limited responsibility to people to support their relatives financially, there was no obligation to house and provide direct care for a relative (Twigg, 1994). This system was suited to a rural society and smaller settlements but with the advent of the industrial age in the second half of the 18th Century and subsequent urban migration, it became less workable.

A statute dating from the 1580s gave the closest male relative on the father's side guardianship of the insane (Houston, 2003)[15]. In the 18th century patients' *'friends'* (meaning family) retained ultimate control, with the medical practitioners essentially employed as service providers.

Financial responsibility for care lay with the family, and relatives had to contribute, if they were able, to the costs of treatment in an institution (Houston, 2001a). Friends or family who wished to care for an incarcerated individual could remove him or her whenever they wished (Houston, 2001b). This whole system was open to abuse although Scots law took account of this, and Acts dating back to the late 17th Century[16] instituted safeguards by requiring full inventories and accounts of the person's affairs, overseen by two relatives from each side of the family. These safeguards proved too stringent to satisfy and had to be diluted by the Curators and Tutors Act 1696 (Houston, 2003).

In the 18th Century when it came to judging capacity (usually with regard to the administration of property), relatives of the person in question could request a formal legal hearing to assess capacity in a process known as *'cognescence'* (Houston, 2003). As these procedures had their origin in administering the property and assets of the individual and were limited to those classes of people with wealth, it is unlikely that the pauper lunatic would have been subject to them. Any person was able to purchase a *'brieve'* (to initiate the hearing) but it

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[15] Curators Act 1585.

[16] For example, the Tutors and Curators Act 1672.

was advised in Balfour Practicks[17] that the purchase should be made by the next of kin from either the mother or father's side of the family (Houston, 2003).

On the receipt of a brieve a judge would summon a jury of 15 men and question the individual concerned and people associated with them, for example, relatives. Juries were selected who had no financial interest in cognosing the person, although they may have known both the person and the witnesses; this was even seen as desirable, as it provided a context for the person's current state. The identification of mental incapacity was carried out by those without medical expertise, the professional involvement being legal rather than medical (Houston, 2003). If the person was judged incapable the court sent a *'retour of inquest'* to Chancery, containing the name of the person, their nearest *agnate*[18], the reason for and duration of the incapacity. The person purchasing the brieve would also usually seek to become the *curator bonis*[19] or *tutor dative*[20] of the person (Houston, 2003). These were the provisions made for decision-making for others dating back to the Middle Ages. This law was complex and relied on an all or nothing approach, not recognising that people could be capable of making some decisions yet not others (Patrick, 2006).

Safeguards against wrongful cognition were available in appeal procedures to the Sheriff Court or Court of Session. The person cognosed, or their relative, could request another inquest, have the verdict set aside if procedures had not been properly followed, or could accept the original verdict but prove recovery and have legal capacity reinstated. Furthermore, there was a Scottish equivalent of *habeas corpus* that could be used by individuals, their relatives or friends to secure release from incarceration.[21]

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[17] Early Scottish legal textbook
[18] Nearest male relative
[19] A curator bonis was a person appointed by a Court to administer the finances of an incompetent person.
[20] A tutor dative was a person appointed by a Court to manage all aspects of an incompetent person's life.
[21] An act for preventing wrongous imprisonment, and against undue delays in trials, January 31, 1701.

2.1.2 19th Century reform

Changes in both law and medicine contributed to making the 19th Century a dramatically different society. The specialism of psychiatry developed, in part due to the increase in the building of asylums providing a common practice environment. In 1815 a House of Commons Committee investigated the care of lunatics across the UK with scheming relatives and unscrupulous madhouse keepers of particular concern. The findings of this investigation led to an Act to Regulate Madhouses in Scotland June 1815[22] that required annual licensing of madhouses [sII-III] and twice yearly inspections by the Sheriff Depute and appointed medical practitioners [sV]. Despite the 1815 Act, conditions were still far from satisfactory, even taking into account the average living conditions of the era. Further reform in England and Wales (the 1853 Lunacy Bill) prompted a condemnation of Scotland from Lord Ashley who regretted the fact that the Bill could not be extended to Scotland as:

> *'I believe that not in any country in Europe, nor in any part of America, is there any place in which pauper lunatics are in such suffering and degraded state as those in Her Majesty's Kingdom of Scotland.'* Tuke, D (1882) quoted in Robinson (1989)

In 1854 the continuing sorry state of the mentally disordered in Scotland was reported by Dorothea Dix[23], an influential social reformer from New England. Her report prompted a Royal Commission to enquire into the asylums and lunacy laws of Scotland. This in turn led to the 1857 Lunacy and Asylums Act, Scotland. This was the first Act to create a statutory duty to provide for the mentally ill, seeking to replicate the spirit of the English Asylums and Lunatics Acts of 1845 with the creation of a public, tax-supported asylum system. This was a begrudging acceptance of state responsibility for areas that had hitherto been considered the responsibility of the family or individual. It established a central inspectorate [sIV] (the General Board of Commissioners in Lunacy for Scotland) for both institutions and community-based care; brought the range of different private, charitable, and pauper asylums under a single authority [sIX]; and

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[22] From the Act of Union 1707 to devolution in 1999 (Scotland Act, 1998), Scotland had its own separate legal system, but was governed by a single United Kingdom parliament.
[23] 1802 – 1887 Early activist for the rights of patients in psychiatric institutions, Robinson (1989).

initiated a comprehensive legal system of medical certification (an application supported by two medical certificates) with associated right of appeal to the Sheriff [sXXXIV]. Similarly, a person could be discharged from an institution on the certification of two physicians [sXLVII-III]. There were safeguards to ensure relatives could visit the detained patient and the nearest relative was awarded rights to information, for example, if the patient died or was discharged [sXCVII] (although there was no hierarchy determining who was the nearest relative).

2.1.3 20th Century reform

The Mental Deficiency and Lunacy (Scotland) Act 1913 increased state responsibility and changed the General Board of Commissioners in Lunacy for Scotland to the General Board of Control for Scotland [s19]. It allowed patients to admit themselves voluntarily, after a written application [s59]. Private patients could be discharged by whoever had made the application for them to be committed or discharged [s55(3)], or on the request of the person who last made a payment towards the patient's board, or those determined by a precursor to the nearest relative hierarchy:

> '...or the husband or wife or if there is no husband or wife or the husband or wife is incapable... the father, or if there is no father or the father is incapable..., the mother of the patient, or if there is no mother or she is incapable then any one or more of the nearest of kin.'[s55(4)]

Mental deficiency and mental disorder were later separated in law, the former removed from the Lunacy Act and given an act of its own with the passing of the Mental Deficiency (Scotland) Act 1940. The National Health Service (Scotland) Act 1947 led to mental health services being integrated into general medicine [s49] and responsibilities for care and after-care were widely increased [s51]. The arrangement of committing patients was transferred to the local authority [s51] and the financial element for the individual or their relatives removed with the onset of universal free healthcare provision.

By the second half of the 20th century the assorted legislation still in effect had become outdated and did not reflect the emerging view of mental illness as having medical rather than legal status (Atkinson, J., 2007a). The findings of an

English Royal Commission (Percy Commission, 1957) on mental health legislation were considered by the Scottish Dunlop Committee (Department of Health for Scotland, 1959) and resulted in the Mental Health (Scotland) Act, 1960. The 1960 Act repealed the Lunacy (Scotland) Acts 1857 to 1913, and the Mental Deficiency (Scotland) Acts, 1913 to 1940 to make fresh provision with respect to the care and treatment of persons suffering from mental disorder. This act further brought learning disability and mental disorder back together.

The 1960 Act carried out broad reforms, particularly in relation to detention, with a liberalising focus aiming to prevent automatic detention and protect the rights of patients. Despite the increased medical role, in Scotland the detention and appeal was considered by Sheriffs, whereas in England and Wales appeals became the work of the Mental Health Review Tribunals (a three person panel consisting on one legal, one general and one medical member) [s3]. In Scotland the Mental Welfare Commission for Scotland (MWC) replaced the General Board of Control as the independent scrutineer of proceedings under the 1960 Act [s2]. The 1960 Act assumed that the historical practice of relatives' involvement should continue, formally introducing the nearest relative by introducing a hierarchy based on blood ties [s45].

During the 1960s the rise of the anti-psychiatry movement and allegations of abuse in asylums fuelled the mental health debate, although there was no new Act for nearly 25 years. When it came, the 1984 Mental Health (Scotland) Act did not introduce substantial new measures but rather consolidated the 1960 Act and an amendment Act of 1983[24] to incorporate legal safeguards for patients concerning treatment (which had been unclear under the 1960 Act). The 1984 Act created the post of the Mental Health Officer (MHO) [s9(1)], a specially trained social worker, and the role of local authorities was developed giving them responsibility for providing aftercare services for those who had been detained [s8(1-2)]. Under the 1984 Act the rights of the nearest relative remained largely unchanged. The 1984 Act remained in force until the implementation of the 2003 Act but was amended by a series of further Acts before it was finally repealed[25].

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[24]Mental Health (Amendment) (Scotland) Act 1983.
[25] For example, the Mental Health (Patients in the Community Act) 1995 which introduced the community care order in Scotland, for patients who were detained in hospital but were to be

2.1.4 21st Century reform

At the beginning of the 21st Century the Adults with Incapacity (Scotland) Act 2000 introduced a new legal framework for adults who lacked capacity to make decisions for themselves, due to mental disorder or an inability to communicate. It related to financial, personal and medical decision-making and allowed other people to make decisions for adults with incapacity and replaced the guardianship provisions in the 1984 Mental Health (Scotland) Act. Prior to AWISA 2000 no other adult could consent on behalf of another, unless a curator bonis or a tutor dative had been appointed by the courts, which was still, as in the 18th Century, viewed as anachronistic, cumbersome and rarely used (Laurie (2004) commentary on Booth *et al.*, 2004). The AWISA 2000 sought to replace this with a modern system of proxy decision-making with the primary authority given to physicians. This can be somewhat usurped by the appointment of a proxy (the welfare attorney), but even then there is no right to refuse treatment, with disagreements judged first by a medical arbiter and then by the courts [s50(5)]. The Act rejected the use of a best-interest test (described as essentially paternalistic) and opted for substituted-judgement.

The AWISA 2000 created a power of attorney allowing an individual to arrange in advance that their welfare and property be safeguarded in the future if their capacity were to deteriorate [s15-16]. A person could now award power of attorney to whomever they chose; these instructions might involve looking after property, financial affairs and making decisions about medical treatment and other personal welfare issues. If somebody were to be granted power of attorney over another they must be registered with the Public Guardian in order to be able to use those powers [s22]. Interventions and guardianship orders could be applied for depending on the circumstances; if it were to be a one off requirement, for example, selling property then an intervention order would suffice [s53], if it was an ongoing and longer term need such as the continuous managing of funds, then a guardianship order might be required [s57]. The local authority or any person with an interest in the adult's affairs could make this

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discharged to the community. The Mental Health (Public Safety and Appeals) (Scotland) Act 1999 was the first Act passed by the Scottish Parliament and added public safety to the grounds for not discharging certain detained patients, whether or not they were receiving treatment and added personality disorder to the definition of mental disorder.

application (s53(1)(3)]. The AWISA (2000) contains rights for the views of the adults nearest relative to be taken into account [s1(4)(b)] and for them to receive information about certain proceedings, such as an authority to intromit with funds [s26(3)], and request information about the adult [s41(f)]. AWISA (2000) initially used the nearest relative hierarchy of the 1984 Mental Health Act later replaced by the one used by the 2003 Act [Schedule 4].

2.2 The nearest relative under the Mental Health (Scotland) Act 1984

The nearest relative formalised by the 1960 Act remained largely unchanged in the 1984 Act [s53]. The powers of the nearest relative were introduced as a safeguard to compensate for the lack of rights of the patient (Hewitt, 2007a) and were ideally thought to be able to provide a historical and personal background to the patient's case. Rapaport (2004) proposed that an early 20th Century emphasis on family obligation explains the introduction of the nearest relative in the 1960 Act (and England and Wales 1959 Act) and why the relative was the preferred applicant (over a social worker) for compulsory measures. The powers were focused on involvement in both admission [s19(1)] and discharge [s33(5)], as well as receipt of information [s110(4)].

2.2.1 Identification of the nearest relative

The 1984 Act gave certain powers to the nearest relative as defined by a prescribed hierarchy, of spouse; child; parent; sibling; grandparent; grandchild and uncle or aunt. The nearest relative must have been resident in Britain and aged 18 or over unless they were the spouse or parent of the patient. Where there was more than one relative in a category, the eldest became the nearest relative and whole blood relatives took preference over half-blood. A person was treated as a spouse if they had lived for six months as man and wife, or for five years in a same-sex relationship or as a close friend, and not if they were married to someone else, unless separated. The child of an unmarried couple could not be treated as a nearest relative of the father unless they had lived with him for five years and / or cared for him. Any relative living with the patient took primacy over the nearest relative [s53].

A relative or any person living with the patient could also apply to become the nearest relative by applying to the Sheriff Court [s66(2)]. Grounds that permitted the court to make an order were that there was no nearest relative or they were unable or unwilling to act [s56(2)]. An application for the nearest relative to be changed could be made to a Sheriff by the nearest relative, an MHO or a person living with the patient, although the patient themselves did not have a right to request a change [s56(2)]. The grounds on which this change could take place were if the patient had no nearest relative, the relative was unable to act due to illness or the nearest relative had made a petition as they did not wish to act in this position [s56(3)]. Additionally, the nearest relative could delegate the role to another person [s57]. The Sheriff Court could appoint an acting nearest relative if there was no relative, or it was not practical to ascertain who it was; the nearest relative was incapable of acting; the nearest relative unreasonably objected to an application for admission; or they were acting against the best interests of the patient [s57].

2.2.2 Powers of detention and discharge

The nearest relative was given powers in relation to detention and discharge:

- Consent to an emergency or short term detention (a MHO could also consent)[s24(2)]
- Apply to the Sheriff Court to have the patient detained (with a report from a psychiatrist and a MHO)[s19(1)]
- Request a MHO consider a detention and if not, be provided with written reasons why [s19(3)]
- Attend court and be heard, represented and call witnesses [s21(2)(b)]
- Request an independent psychiatrist examine the patient [s35(3)]
- Discharge a patient: if the patient was already detained the nearest relative could apply for a discharge from hospital (except for forensic patients)[s33(5)].

The nearest relative had a right to receive information if the person were to be detained although the patient could prevent the nearest relative from receiving information about them [s110(4)].

2.2.3 Problems with the nearest relative under the 1984 Act

There were two main problems with the nearest relative provisions. The first problem was the hierarchy determining who the nearest relative was. This did not give equity to same-sex partnerships and furthermore, treated more distant relatives or unrelated people as secondary to the nearest relative, even if they were the primary carer of the patient. Similar to same-sex partners, an unrelated person would have to have lived with and cared for the patient for five years before they could qualify for the role. This meant that a person who had been living with and caring for the patient could be supplanted by a biologically closer relative who provided no care.

The second problem was that the patient was given no choice of who their nearest relative could be and the process for removing a nearest relative was difficult (Rapaport, 2003). There were further problems about a lack of awareness of the role, particularly the rights to consent to detention and discharge which are discussed in more detail below.

A major reason why the 1984 Act required updating was due to the England and Wales 1983 Act having been subject to legal challenge and found to be in breach of human rights legislation. No actual cases were brought in Scotland but the English cases were applicable due to the similarity of the 1983 and 1984 Acts.

The first legal challenge to the England and Wales 1983 Act was the case of JT v UK[26] in 1998. The patient requested her mother be removed as her nearest relative due to an alleged history of abuse from the mother's partner. This change was permitted before the court made a formal judgement, but it set a precedent. A second English case in 2003[27] raised a further problem with the nearest relative. The nearest relative of the patient was her adoptive father whom she alleged had sexually abused her as a child, but was unable to raise an objection to his appointment. She sought a declaration that sections 26[28] and

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[26] *JT v United Kingdom*, 1998 Application No. 26494/95.
[27] *R (on the application of M) v Secretary of State for Health* [2003] EWHC 1094 (16th April 2003).
[28] S26 defines the hierarchy of nearest relatives.

29[29] were incompatible with the Human Rights Act (1998) Schedule I, Part I, Article Eight. The government accepted the sections were incompatible with the Human Rights Act (1998), as it had in J.T. v UK.

In a case brought in 2002 in England, the Administrative Court approved same-sex partners as being nearest relatives under section 26 of the 1983 Act. The parties were two women who had been cohabiting since 1999[30]. The patient's nearest relative was her mother, from whom she was estranged and thus wished her partner to take on the role. This was not permitted solely as they were a same-sex couple and would have had to have cohabited for five years before the partner would be treated as a nearest relative. The patient's mother was asked to appoint the partner instead but did not respond to the request. Judicial review was applied for and found that the case breached Article 14 on grounds of discrimination due to sexual orientation. The discrimination was evident as an unmarried heterosexual couple need only cohabit for six months whereas for a same-sex couple it must be five years. It was argued that the use of the term *'spouse'* (26(6)) could be interpreted as including a same-sex couple and an Order was pronounced in open court stating that a same-sex partner could thus be treated as a nearest relative within section 26 of the 1983 Act (Cho, 2002). The introduction of the Civil Partnership Act 2004 for same-sex partners further reinforced this right.

These verdicts required that for the new Scottish mental health legislation to be compliant with human rights legislation it must allow for the patient to both choose a nearest relative (or any similar role) and give parity to same-sex couples.[31]

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[29] S29 makes provision for the court to change a nearest relative.
[30] *R (on the application of SSG) v Liverpool City Council (1) Secretary of State for Health (2) and LS (Interested Party)* Administrative Court (22nd October 2002).
[31] Despite the 2007 Mental Health Act amending the 1983 Act in England, the GBMHAC still hold concerns that any patient that objects to their nearest relative will *'be put in the invidious position of having to explain to a court why that person is not suitable to act as such' (GBMHAC, 2008)*. This may yet be open to further challenge under human rights legislation.

2.3 Renewing Scotland's mental health law: The Millan Review

In 1999 the Mental Health (Scotland) Act 1984 was subject to a review by the Millan Committee and in 2001 they submitted their findings to Scottish ministers (Scottish Executive, 2001). The committee believed that there were two issues affecting the nearest relative provisions. Firstly, the powers given to the nearest relative were to allow the relative to protect the interests of the patient by advocating on their behalf, and, secondly, that carers have their own rights to help them provide care and represent the patient. It was recommended that service users should have the opportunity to identify the person they wanted to represent them (albeit with procedures in place to protect against decisions made as a result of impaired judgement). This person would be called the named person and they would have the right to request an assessment of the patient, to be notified and consulted when compulsory measures were being considered, to be heard by the tribunal and to have the right to appeal against a decision to impose compulsory measures. The named person would not be able to consent to admission and would not be able to discharge the patient. Millan considered that although they had recommended named persons should not be asked to consent to detentions, there should be a duty to ascertain and take into account the views of the named person and reasons given if that had not been possible.

It was thought that in many cases the named person nominated by the patient would either be the primary carer or nearest relative or both, thus, if the patient had not nominated a named person, the primary carer would assume the role by default; if there was no primary carer, it would be the nearest relative, although the nearest relative hierarchy should now include same-sex partners. At each of these stages the appointment could be challenged by the patient, or other interested parties and the nominated named person could turn down the role. The tribunal would also be able to remove the named person if the nomination had been made when the patient was incapable, subject to duress, or if there was evidence that the named person was unsuitable, or had been incorrectly identified as the primary carer or nearest relative. The tribunal could also appoint any other person as the named person.

The Millan Committee recommended that all informal carers should be kept involved and informed, unless there was reason not to do so. In particular the named person was thought to require information to be able to fulfil their role so they should also be informed of the patient's legal status under the new Act, any application for compulsory measures, tribunal hearing and any discharge of the patient from compulsory measures.

Apart from in an emergency situation, it was recommended that information be provided to the named person in good time to allow action, for example, to oppose an application for compulsory measures. The patient would not be allowed to refuse for this information to be given although they could nominate a new named person or apply to the tribunal to discharge the current named person. These recommendations were submitted to Scottish ministers and for the most part were translated into statute.

2.4 The Mental Health (Care and Treatment) (Scotland) Act 2003

The Mental Health (Care and Treatment) (Scotland) Act 2003 was passed by the Scottish parliament in March 2003 and subsequently implemented in 2005. The principles on the face of the 2003 Act must be applied to any action taken under it [s1(1)-(11)], these principles are based but not identical, on the principles agreed by the Millan Committee (See Box 1) which are more readable than those on the face of the 2003 Act and form the basis for Scottish Government policy on mental health law, although they have no legally binding effect in themselves. The tribunal, MHO and RMO are bound by the principles, the service user, carer, named person and any other non-professional roles are not [s1(1)].

Box 1: The Millan Principles

1. Non discrimination
People with mental disorder should whenever possible retain the same rights and entitlements as those with other health needs.
2. Equality
All powers under the Act should be exercised without any direct or indirect discrimination on the grounds of physical disability, age, gender, sexual orientation, race, colour, language, religion or national or ethnic or social origin.
3. Respect for diversity
Service users should receive care, treatment and support in a manner that accords respect for their individual qualities, abilities and diverse backgrounds and properly takes into account their age, gender, sexual orientation, ethnic group and social, cultural and religious background.
4. Reciprocity
Where society imposes an obligation on an individual to comply with a programme of treatment and care, it should impose a parallel obligation on the health and social care authorities to provide appropriate services, including ongoing care following discharge from compulsion.
5. Informal care
Wherever possible care, treatment and support should be provided to people with mental disorder without recourse to compulsion.
6. Participation
Service users should be fully involved, to the extent permitted by their individual capacity, in all aspects of their assessment, care, treatment and support. Account should be taken of their past and present wishes, so far as they can be ascertained. Service users should be provided with all the information necessary to enable them to participate fully. All such information should be provided in a way which renders it most likely to be understood.
7. Respect for carers
Those who provide care to service users on an informal basis should receive respect for their role and experience, receive appropriate information and advice, and have their views and needs taken into account.
8. Least restrictive alternative
Service users should be provided with any necessary care, treatment and support both in the least invasive manner and in the least restrictive manner and environment compatible with the delivery of safe and effective care, taking account where appropriate of the safety of others.
9. Benefit
Any intervention under the Act should be likely to produce for the service user a benefit which cannot reasonably be achieved other than by the intervention.
10. Child welfare
The welfare of a child with mental disorder should be paramount in any interventions imposed on the child under the Act.

The 2003 Act confirmed the role of the MWC [s4(1)] to monitor the use of the 2003 Act, visit patients and encourage best practice [s5(b)]. The MHO was awarded duties to identify the named person [s59] and it is considered good practice by the Code of Practice (COP) for them to ensure the patient knows the role will default and to whom [COP Vol. 1 pg.84; Para.8] (Scottish Executive, 2005). It introduced the mental health tribunal as a replacement for the Sheriff Court as the forum for hearing cases under the 2003 Act [s21(1)]. Each tribunal consists of three members, one medical, one legal and a general member (Schedule 2 1(1)(c)(i-ii)). Tribunals were assumed to be less intimidating than the Sheriff Court and to promote participation by the patient and others with an interest in their welfare such as carers and relatives. Patients and named

persons can both apply for legal aid for representation by lawyers which is not means tested, and named persons can also apply for travel expenses to attend a tribunal (MHTS, 2009a) although no loss of earnings can be claimed (MHTS, personal communication).

The 2003 Act changed compulsory measures introducing short term detention straight from the community [s44(5)(a)] and the Compulsory Treatment Order (CTO) [s63]. The CTO could be either hospital or community-based allowing compulsory treatment in the community [s63(2)(a)(ii)].

The patient and the named person receive a copy of the information prepared and submitted to the tribunal which consists of the application, care plan and supporting reports (MHTS, 2009b). The MHTS (Practice and Procedure) Rules allow information submitted to the tribunal as part of proceedings to be withheld from the patient or *'another person'* if it is judged that to do so may cause serious harm. If information is withheld from the patient and they have no representative then a *curator ad litem*[32] may be appointed to ensure the patient's rights are upheld (SSI 396[33]). The patient does not have the right to prevent information from being shared with either the named person or nearest relative. Under the 1984 Act the patient could prevent a RMO from giving information to the nearest relative [s110(4)] and similarly, in England and Wales a patient can still prevent information being given to a nearest relative [s133]. The nearest relative power to consent to short term detention and emergency detention was removed and not awarded to the named person, although appeals against a CTO and other compulsory measures can be made to the Sheriff Principal [s320(1)] by the patient, named person, guardian, welfare attorney [s320(5)(a-d)]. The nearest relative still exists albeit with a changed hierarchy (taking into account cohabitees including same-sex relationships) [s254(2)(a-j)] and a reduced role meaning that they, the named person and any person living with patient must be informed of any emergency detention [s38(4)(a)] or removal to a place of safety [s298(2)(ii)]. The 2003 Act widened patient representation making it the right of patients not only to appoint a named

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[32] A *curator ad litem* is a legal representative (usually a solicitor) appointed by a Court to represent the best interests of a person lacking capacity in court, they do not take instruction from the person.

person but also to access an independent advocate [s259(1)] (the patient can as previously, also choose to instruct a lawyer). Advance statements[34] [s275] were introduced allowing service users to detail how they would wish to be treated if they lost capacity in the future. These are not legally binding but consideration must be given to them by anyone treating the patient under the 2003 Act [s242(5)(a)(iv)].

2.4.1 Detail of the named person provisions

The aim of the named person was to *'help protect your interests if you have to be given care or treatment under the new Act'*(Scottish Executive, 2004). Any patient over the age of 16 has the right to nominate a named person as long as a witness (from an approved list of professionals[35]) can verify that they understand the implications of a nomination and they have not made the decision under duress or undue influence. There is no requirement to ensure the named person either knows they are being nominated or understands the role.

Anyone can be a named person as long as they are over 16, understand the role and the nomination has been signed and witnessed [s250(1-2)]. A nomination must be put in writing and witnessed by somebody who fulfils one of the following roles: registered clinical psychologist; medical practitioner; registered occupational therapist; person working in or managing (some) care services; registered nurse[36]. A nomination can also be revoked in writing [s250(4)]. It is recommended that the named person nomination is communicated to anyone with a responsibility for treatment of the service user, for example, this may include the RMO, GP, MHO, Community Psychiatric Nurse (CPN), solicitor and independent advocate, carers, and other relatives [COP Vol. 1 pg 88 Para 20] Scottish Executive (2005). The named person cannot appoint somebody else to act in their place (as the nearest relative could under the 1984 Act [s56]). It is generally accepted and stated in the Code of Practice that the named person should not be anyone who has responsibility for providing care although this is

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[34] The term *'advance statement'* will be used with specific reference to the 2003 Act. The term *'advance directive'* will be used for all other similar provisions in other jurisdictions.
[35] The Mental Health (Patient Representation) (Prescribed Persons) (Scotland) (No.2) Regulations 2004 (SSI No. 430).
[36] The Mental Health (Patient Representation) (Prescribed Persons) (Scotland) (No.2) Regulations 2004 (SSI No. 430).

not specifically prohibited by the 2003 Act, similarly the named person cannot also be an independent advocate [COP Vol. 1; Pg. 84; Para. 09] Scottish Executive (2005).

The named person only has rights when measures under the 2003 Act are being initiated. The rights given to the named person are parallel to those of the patient and they can both act independently of each other (See Box 2).

Box 2: The rights of the named person

- 'to be consulted when a detention or compulsory treatment order is being considered
- to be notified when changes to a patient's circumstances occur, for example, an order or detention occur
- to receive copies of information given to the patient
- to make applications or appeals to the tribunal
- to speak and give evidence at the tribunal
- to consent to two medical examinations taking place where an application has been made for detention or compulsory treatment order (and the patient is not capable of consenting)
- to ask for a needs assessment from the local authority or Health Board'

(Scottish Executive, 2004)

The named person is a party to the tribunal and as such must receive copies of the application and supporting information [s60(1)(b)].

2.4.2 The default named person

If a person does not nominate a named person, their (adult) primary carer will become their named person by default [s251(1)]; if there is more than one carer, they will decide between themselves who does it [s251(3)]; if there is no primary carer, the nearest relative will become the default named person [s251(5)]. A person to whom the role falls cannot be passed over because the MHO thinks they are inappropriate; a formal application to the tribunal must be made [s255(6)(b)]. If there is no primary carer or nearest relative, the tribunal can appoint somebody else, dependent of course on whether there is an

appropriate person available [s257(1)]. The default named person is unique, there is no comparable default role elsewhere in Scots law. It is no longer possible to change a nearest relative as the provisions allowing for this disappeared with the repeal of the 1984 Act.[37] If a patient has nominated a named person, then it prevents the nearest relative assuming the role by default, but it does not remove the right of the nearest relative to receive basic information, for example, that a patient has been taken to a place of safety [s298(2)(ii)].

The default named person is entitled to exactly the same level of information as a nominated named person and the patient is unable to prevent this information being shared. This means that the full details of an application for a CTO, for example, would be sent to a default named person even if the patient does not give permission. The issue of the unsuitability of the named person can only be raised at the tribunal by which point, it can easily be argued, the confidentiality of the patient has been breached by the disclosure of the application and supporting information. The patient can apply to the tribunal to have a default named person changed [s256(2)(a)]. The tribunal must take this information into account, but can act as it thinks fit [s257(2)(b)]. Even if the patient has the capacity to refuse treatment, the tribunal can still override a nomination for a named person which may be seen as undermining the right of the service user to make the nomination in the first place.

The patient can make a (witnessed) declaration to stop a certain person, for example, their nearest relative, becoming their named person either by default or being appointed by the tribunal [s253(1)]. The tribunal can appoint any other person they think suitable but the patient has the right to appeal the decision and for it to be changed [s256(2)(a)]. Any person with an interest in the patient's welfare can also apply to the tribunal to have the named person removed or changed [s256(2)(h)] and after an application, the tribunal itself can stop a person considered inappropriate continuing in the role [s257(2)]. If a service user changes an existing nomination by making a (witnessed) revocation,

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[37] Although the AWISA (2000) permits the changing of a nearest relative for the functions of that Act only, although not in advance of incapacity occurring [s4] (amended by the Adult Support and Protection (Scotland) Act 2007).

the default named person will be automatically appointed [s251]. The default named person can refuse the role by giving written notice to the local authority [s251(6)].

Only two situations can arise where a patient has no named person: where the patient has declared against any of the available people, or where there is no primary carer or nearest relative, or they have declined to take on the role and no other person has been appointed by the tribunal (MWC, 2006).

2.4.3 Other roles of relevance to carers and relatives

There are several other roles that are of relevance to carers and relatives under the 2003 Act. As well as the named person the nearest relative and the primary carer have rights to varying amounts of information and the named person and primary carer have specific rights to be consulted in addition to becoming the named person by default in the absence of a nomination by the patient (See Table 1 for a summary of roles relevant to carers and relatives). Although there are the three distinct roles of named person, nearest relative and primary carer, they are not mutually exclusive, a person can be a patient's nearest relative, named person and primary carer or one, two or all of the three. This potential to fulfil more than one role means that they may be entitled to different things at different times when compulsory measures are underway.

Table 1: Summary of rights

	Named person	Guardian	Welfare attorney	Primary carer	Any person[38]	Nearest relative	Any carer	Any relative	Person living with patient
Views consulted about any function discharged under the act [S1]	Y	Y	Y				Y		
Removal of the patient to a place of safety [s298]						Y	Y		Y
Be informed of details of emergency detention (where it is practicable) [s38]	Y[39]					Y			Y
Be consulted about application for short term detention, where practicable [s44]	Y								
Apply for revocation of short term detention [s42]	Y								
Informed when short term detention granted [s46], including revocation [s48] or extension [s49]	Y	Y	Y						
Given notice a CTO application is to be made[40] [s60] or application for extension or variation [s91]	Y								
CTO order, revocation [s74], extension [s87] review etc.	Y	Y	Y						
Apply for revocation or variation of CTO [s99-100]	Y								
Right to make representation to the tribunal [s50] [s64] [s65] [s102] [s103] [s104] [s166] [s167] [s171] [s193] [s215] [s264-70]	Y	Y	Y	Y	Y				
Right to appeal [s320-322]	Y	Y	Y						
Can request assessment of needs [s228]	Y			Y					
Be informed of transfer to another hospital [s124]	Y			Y					
Consent to medical examination of the patient [s58]	Y	Y	Y						
Informed when advance statement is not followed [s276]	Y	Y	Y						
Can make application to have someone else appointed as named person [s256]		Y	Y		Y			Y	

In addition to roles awarded under the 2003 Act, relatives and carers may also simultaneously hold roles under the AWISA, 2000[41] bringing the total of potential roles up to five.

This chapter has described the present legislation and its development. The following chapter outlines the experiences of carers and previous research into the nearest relative role and other relevant research.

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[38] Appearing to the tribunal to have an interest.
[39] If known.
[40] Discretionary, notice can be withheld.
[41] Welfare attorney and guardian.

Chapter Three: Families, carers and the law

Introduction

This chapter looks at what previous research has shown to be important factors for both patients and their relatives and carers when compulsory measures are used. It begins by providing a broad context of the relationships between carers and service users and the challenges of being a carer. It then goes on to describe the small body of research into patient and carer experiences of mental health legislation before looking at the findings of proxy decision-making research. The chapter concludes by reviewing evidence concerning public understanding and the use of provisions for service users and carers in mental health and capacity legislation.

3.1 Who are the carers?

Family relationships are known to be important to many people with mental health problems, particularly if they are isolated from the rest of society due to phenomena such as stigma. Link and colleagues *(*1987) showed that family are likely to be less stigmatising, together with other *'insiders'* such as other service users' families and mental health professionals. Thus, family relationships can be crucial to receiving highly valued and essential instrumental and emotional support. Whereas many service users have supportive relationships with their families who in turn have the best interests of the service user foremost, this is not always the case and there is the danger of positive assumptions being made. Mental health service users' family relationships may not only be not supportive but non-existent, occasional or even abusive. For example, a Scottish study found that one fifth (21%) of service users surveyed had experienced harassment from within their family (Berzins *et al.,* 2003). Similarly, a recent New Zealand study exploring family involvement in compulsory measures, found that a significant minority of over a fifth (22%) of assessments did not involve family as they were either unknown, unavailable or the patient did not wish them to be involved (Spencer & Skipworth, 2007). Merely the presence of a choice does not necessarily mean that the service user feels they can make a free choice, there

is still the potential for abusive relatives to influence the nomination, emphasising the importance of the witness (Rapaport & Manthorpe, 2008).

There has been found to be a high rate of marriage breakdown amongst people with psychoses and as a result they are less likely than the general population to be married or partnered, more likely to be divorced, less likely to have children and many more live alone (ONS, 2002). For example, one study reported nearly all (94%) of its sample of service users as single (Lefley, 1987) another 73% (Perlick *et al.*, 1999) and another more recent Scottish study found 75% were single (Berzins, 2006). The quality and quantity of interactions with others is related to levels of social support and research has shown that people using mental health problems with low social support are twice as likely to be admitted under Section 4 of the Mental Health Act 1983 in England and Wales (Webber & Huxley, 2004).

The cumulative effect of potential estrangement from the family of origin, the increased likelihood of not having a partner or family of reproduction indicates that there can be expected to be a significant minority of patients subjected to compulsory measures who have not been able to appoint a named person as they have no one suitable to select from.

This problem of isolated service users was raised during debate of the England and Wales Mental Health Act 1983 where it was suggested that in some cases it may be a problem for Approved Mental Health Professionals[42] (AMHP) to identify a *'nominated person'*[43]. It was suggested that local pools of potential nominees be created (Rapaport, 2003; 2004) which has some similarities with the Scottish independent advocacy system, in that a patient with no named person or nearest relative will still be able to have access to an independent advocate. However, the key element missing from these relationships is the historical and personal knowledge of the patient that it was assumed the nominated person would have.

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[42] Approved Mental Health Professional, would have replaced the Approved Social Worker under the originally proposed reforms in England and Wales.
[43] *'Nominated person'* was the term that was used for a proposed role similar to the named person proposed for England and Wales.

The majority of service users are likely to have relationships with carers or relatives and previous research into these relationships can provide context for the introduction of provisions such as the named person.

3.1.1 Personal relationships and mental health service users

The relationships between mental health service users and carers are as individual and complex as relationships between any individuals, involving obligation, concern and reciprocity as described by Herring:

> *'We are not self-sufficient but interdependent; not isolated individuals but people in relationships; not people with rights clashing with those who care for us and for whom we care, but people who live with entwined obligations and interests with those we love. We are not easily divided up into carers and cared for. We are in mutually supportive relationships'* (Herring, 2007).

Research has shown that the most frequently reported person fulfilling the role of carer is that of the parent. One study of carers (Rethink, 2003) found the majority (73%) of the carers surveyed were supporting an adult child. Szmukler *et al.,* (1996) found that in a study of 626 relatives, the relationship to the patient was a parent in 71% of cases (further breaking down to 60% mothers and 11% fathers) and only 16% were spouses. Similarly Bloch and colleagues (1995) found 62% of carers to be parents and 14% spouses. One exception to this was a study of people with bi-polar disorder that reported 60% of the carers as being partners (Hill *et al.,* 1998) although this study was carried out with members of the Manic Depression Fellowship which may indicate that this was not a representative sample. Friends do not appear to be reported as carers very frequently with only 5% of carers in a Rethink study of carers using their services and those of their partner agencies (Rethink, 2003) and 6% in Hill and colleagues' study (1998) describing themselves as friends.

3.1.2 Parents caring for adult children

Family relationships are thought to be unlike friendships as they do not always follow reciprocal exchanges and norms (Rook, 1984) but gain strength through the shared past and future that relatives have (Horwitz *et al.,* 1996). Adults with mental health problems who are cared for by their parents are thought to *'violate'* these age-related norms through their continuing dependency (Rook, 1984), although other studies have shown that these adults can and do make a number of positive contributions to both the relationship and to wider family life (Greenberg *et al.,* 1994) as well as gaining personal satisfaction from their contributions to the family (Nelson *et al.,* 1992).

Parents caring for adult children with mental health problems report some common feelings across a number of studies. The constant concern and anxiety about their child, regardless of whether they live with them or not, is described by Pejlert (2001) as *'endless parenting'* and by Eakes (1995) as *'chronic sorrow'*. Parents also experience the loss of potential they saw in their child, perceived as having been removed by the mental disorder (Hervey & Ramsay, 2004). Their increasing age is an additional ever-present concern in carers of adult children and these feelings can dominate the parent carers' middle-age (Howard, 1994) and even be projected beyond death as concerns for the future of their child, when they are no longer able to care for them (Tuck *et al.,* 1997).

Particular distress was reported by parent carers if the adult child explicitly did not want contact with the parent at certain times, or parents felt that their visiting of their child (for example, in hospital) was detrimental. Feelings of perceived blame from professionals were common as well as feeling excluded from their child's treatment (Pejlert, 2001). Caring for a child with problems could further impact on other siblings in the family and cause them to feel they were coming second to the ill child (Pejlert, 2001). It is mostly mothers' experience of caring that has been the subject of research although one study looked specifically at the experiences of fathers (Howard, 1998). The fathers' experiences were found to be similar to those of the mothers, although there was an acknowledgement that, generally, mothers carried the greater caring responsibility whereas fathers contributed more financially.

3.1.3 Partners as carers

One criticism of the study of carers is that the relationship in which the caring takes place has been somewhat neglected, in particular that of the partner of a person using mental health services (Henderson, 2001).

One study of spouses of patients with depression found that there were specific issues for spouses regarding decreased family income and a strain placed on marital relationships. However, despite this, the majority reported that they remained committed to staying with the patient (Fadden *et al.,* 1987b). Similarly, Mannion and colleagues (1994) compared experiences faced by partners who were carers with those of parents. One major difference was concern about the future; whereas parents worried about who would care for their child once they were unable to continue, partners were more concerned about whether they should continue in the relationship (Mannion *et al.,* 1994).

A study of people with bipolar disorder and their partners saw some interviewees reject the concept of their partner as their carer, thinking that it undermined the relationship for both parties. Similarly, some partners reported that they felt that they were under pressure to accept a policing or nursing role that they did not want. Service users in this study described the stresses their illness had caused their partner, for example, the unpleasant things they had said to their partner when they were unwell (Henderson, 2001). The training and support offered to carers ran the risk of professionalising their role that could have a negative effect on the original relationship. The study illustrates that not all people whose partners have mental health problems want to view themselves as carers or as part of a *'care team'* (Henderson, 2001).

The lack of acknowledgement of same-sex relationships was highlighted by the legal proceedings concerning the nearest relative (Cho, 2002). This has further been found to be a difficulty for people in same-sex relationships where the family may not want to acknowledge the role of the partner (Quam, 1997) and may step in and take over when care and decision-making is required (Donovan *et al.,* 1999). Manthorpe (2003) suggested that many people in same-sex

relationships are more likely to exert their rights in these areas and it has been suggested that this is due to increased politicisation and rights-based campaigning leading to a strong *'consumer identity'* (Hubbard & Rossington, 1995). Previous cases have highlighted the particular importance of same-sex couples determining their wishes prior to any loss of capacity, one key example being the Kowalski case[44] where a same-sex partner was excluded by the biological family of her partner who became incapacitated after an accident (Evans & Carter, 1995).

3.1.4 Friendship

Friendship has been described as an emotionally supportive relationship that encourages personal autonomy and individuality (Wellman, 1992). Friendship ties differ from kinship ties as they are voluntary, based on shared interests and tend to be more reciprocal (Dono, *et al.*, 1979) with people feeling less obligation to friends than to kin (Rossi & Rossi, 1990).

Some theorists have proposed that people are more likely to form supportive relationships with others similar to themselves on several dimensions (for example, Feld, 1982; Marsden, 1988). Suitor and colleagues (1994) concluded that experiential similarity can contribute towards this and people who have been through similar experiences can be more supportive and empathetic, and are thus less likely to reject a person. *'Rank theory'* (Gilbert *et al.*, 1995) is a different way of explaining the same behaviour but holds that people confine themselves to people of a similar *'rank'* for support and affiliation.

The disadvantage of these patterns of friendship is that they can place restrictions on the quality of relationships with others as, for example, if a depressed person can only draw support from other depressed people, there may be a limit to how much support is available for them to receive. Labelling theorists believe that the stigma of having a mental health problem has consequences for the future life of the person and can lead to social rejection and negative relationships, which in turn leads to a lower quality of life (Link *et al.*, 1991). Additionally, patients can self-isolate, limiting their opportunities to form friendships due to the fear of social rejection (Link *et al.*,1991). Similarly,

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[44] *In re Guardianship of Kowalski,* 478 N.W.2d 790 (Minn. Ct. App. 1991).

normalisation theory proposes that having social contact only with those who also have mental health problems creates a stigmatised group, which then has a further negative impact on quality of life (Rosenfield & Wenzel, 1997). Berzins (2006) found that 71% of service users of community mental health services had made friends through these services. When this group were asked who was the one person they could confide in, 20% said it would be a friend rather than a relative.

3.2 Carers' experiences

Regardless of the type of relationship between the service user and their carer there are some broad issues that are common to carers and it is useful to briefly consider some of the issues for carers and how their role has developed. Although people have always cared for one another, particularly in the family setting, the concept of the carer is a relatively new one, thought to have only emerged as a distinct self-identifying group over the past 40 years (Bytheway & Johnson, 1998) with the term *'carer'* as it is understood today being first used in 1978 (OED, 2009).

In the UK the increasing visibility of carers has been mirrored in legislation with the term *'carer'* first being used in legislation in the 1990 NHS and Community Care Act [s46(2)(d)] and simultaneously the use of the term *'relative'* diminishing (Twigg, 1994). Five years later the Carers (Recognition and Services) Act 1995 introduced formal recognition of carers although only permitted an assessment for support if the person they care for was also being assessed [s2(1-3)]. In Scotland, the Strategy for Carers in Scotland (Scottish Executive, 1999) was introduced with the aim of improving information and support, and emphasising the provision of services for carers in their own right. The Community Care and Health Scotland Act (2002) expanded on these rights, placing duties on statutory services to inform carers of their rights [s12AB(1)] and take into account their views when planning services [s8]. By the time the Partnership for Care (Scottish Executive, 2003) policy document was published, the carer had become a *'partner'* in the care team. In the same year the primary carer became a formal role under the 2003 Act, both with rights to

involvement [s64, s104)] and information [s124(8)(c)] as well as becoming the named person by default [s251(1)].

Despite these policy and legislative developments, research into the caring experience often describes a group who feel undervalued and undersupported (for example, Hirst, 2005). Two commonly reported problems are lack of involvement with the care team and, as described above, lack of information about the person being cared for. Many professionals do not focus on carers (Hervey & Ramsay, 2004) and as a result many carers report feeling marginalised by services (Rethink, 2003). For example, in one study, relatives reported that professionals thought they knew the patient better than the family (Pejlert, 2001).

Despite these problems, carers and relatives have often been consulted in decision-making should a person become incapable. This informal consultation may have led to decision-making taking place informally (Dickenson, 2001) and was challenged in the Bournewood case[45] (an English case although also applicable to Scotland) resulting in formal proxy decision-making processes being essential in any case where capacity is lost, regardless of whether there is objection to treatment by the patient or not. The changes in practice required by this ruling, whilst safeguarding patients' rights, may have lessened carers' perceptions of being involved unless they have been formally appointed proxies. Although, if carers are viewed as a distinct group with their own specific needs, the appropriateness of them acting as advocates or decision-makers must be questioned (for example, Buchanan & Brock, 1990; Inwald *et al.*, 1998).

3.2.1 The impact of caring

The role of the carer is complex and can include tasks such as formal and informal proxy decision-making, acting as a gatekeeper to services and advocating for the service user (Keywood, 2003) as well as the provision of day-to-day care and support. Twigg considers there to be four elements that

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[45] *HL v United Kingdom*, 2004 Application No. 45508/99. Known as the *'Bournewood ruling'* this concerned the legality of treating a person who lacks capacity to consent without using formal legal powers (Robinson & Scott-Moncreiff, 2005).

describe the understanding of the term *'carer'*; firstly, the physical task of care such as feeding and bathing; secondly, the kinship element as much caring takes place within a family; thirdly, the emotional motivation to care, typically characterised by love; and fourthly, responsibility. The process of caring has consequences for the carer (Twigg, 1994) as carers not only hold concerns about their own needs, but the needs of the patient, as well as the needs of other relatives. Furthermore, they may also hold concerns around the availability and provision of services as well as experiencing stigma themselves (Bloch *et al.*, 1995). Becoming a carer is not usually a planned activity and many people have negative experiences as a result. Relatives are often expected to take on the role of carer with no training or support (Dickenson, 2001) and there can be particular difficulties for those people who care for a person with mental health problems.

The earliest research on families of people with mental disorder focused on their potential aetiological role and subsequent influence on the service user's prognosis (Kuipers, 1993). Until recently it was theorised that the family environment could cause schizophrenia, leading both to service users blaming their families and families feeling guilt as a result of their pathogenic status (Rutz, 1995). Deinstitutionalisation and the increase in community care from the 1980s onward shifted the research perspective to explore the effect that people with mental health problems had on their families, for example, Fadden and colleagues (1987a) reviewed what was known of the impact on carers. This perspective continues with more severely ill patients often cared for in community settings in contrast to the long periods of hospitalisation typical of earlier decades (Cornwall & Scott, 1996; Peljert, 2001). The *'burden'* of care giving was first explicitly described in the 1950s (Clausen & Yarrow, 1955) and research focused on the negative aspects such as stress, mental health problems and economic and social costs (for example, Mandelbrote & Folkard, 1961). Similar findings were reported nearly fifty years later with 90% of carers of people with mental health problems saying that their health was adversely affected by the experience (Rethink, 2003). They described family relationships as being adversely affected in three out of five cases and half the carers said they did not have a choice about whether they continue to provide care (Rethink, 2003). Further studies have reported the need for carers to share their

experiences; their dissatisfaction with mental health services; concerns that they were not doing enough; and competing demands from other relatives (Bloch *et al.*, 1995). Carers also face challenges in their working lives, with many feeling employers were unsympathetic to their needs and only those carers in more senior positions having the flexibility to meet the needs of the person they care for (Hill *et al.,* 1998).

Unsurprisingly, in the light of the research evidence, feelings of helplessness in carers have been described (Bloch *et al.*, 1995) with the issue of control appearing to play a role in perceptions of burden. Perlick and colleagues (1999) reported that levels of distress were greater amongst carers (of people with bipolar disorder) reporting little perceived control over the person's behaviour. It is easy to overlook the other side of the caring relationship. Explorations of caregiver burden cannot give us the whole picture of the caring experience (Tuck *et al.*, 1997) and there has been some research reporting more positive aspects of caring such as feelings of satisfaction and strengthening of relationships (Bulger *et al.,* 1993) as well as reciprocation between the carer and the person being cared for (Horwitz *et al.,* 1996).

3.2.2 Confidentiality and carers

There have been particular difficulties between carers and professionals surrounding information-sharing and confidentiality (for example, Domenici & Griffin-Francell, 1993; Marshall & Solomon, 2000) and this has become a more complex area since deinstitutionalisation with more relatives becoming carers. To best fulfill the role of the carer a person may be seen to require information about the person they are caring for (Szmukler, 1999; Ramsay, 2001). However, in recent English research 44% of carers had been told matters of patient confidentiality prevented them from being given information. Research has shown that when carers were provided with sufficient information about their relative's illness, the relapse rate and number of readmissions to hospital decreased (Bogart & Solomon, 1999). These findings were supported by research were carers thought lack of information hampered the service user's recovery as they could have used it to improve the care they provided (Rapaport *et al.,* 2006). Although this is not reason enough to breach confidentiality there are

ways of providing information to carers. The most obvious is to obtain the consent of the person for information about them to be shared, although research has found that only 12% of service users reported being routinely asked by professionals to consent to the sharing of information with their carers (Rapaport *et al.*, 2006). Similar to implied consent, a person can permit another person access to confidential information about them by implication, for example, by inviting them to attend a consultation with them (Patrick, 2006).

The Royal College of Psychiatrists has produced guidance on confidentiality for professionals working with both service users and carers (Royal College of Psychiatrists, 2004). Information about providing care in general can be provided to the carer in such a way that does not breach confidentiality. For example, a carer supporting a person experiencing auditory hallucinations can be given information about the ways this phenomenon is generally experienced and possible strategies for managing it (Atkinson & Coia, 1995). The emergence of psychoeducation for families and carers in the late 1970s was in part a reaction to the previous beliefs that family dysfunction contributed towards mental illness and additionally recognised that families and carers could support the service user better if they were equipped with information and coping strategies (McFarlane *et al.*, 2003). For example, Leff and colleagues in the UK developed relatives groups with a combination of family education, family member discussion groups where the patient was not present and interventions involving the family and the patient (Leff *et al.*, 1985).

Confidentiality is a particularly difficult ethical issue when the service user objects to the family involvement yet family inclusion appears justified to professionals (Szmukler & Bloch, 1997; Szmukler, 1999). Szmukler (1999) suggested that involving family against the service user's wishes is facilitated if the relative's relationship to the patient is seen as not only familial but also as their *'carer'* thus awarding them rights, regardless as to whether they are relatives or not. This argument supports the awarding of formal rights to informal carers (Szmukler & Bloch, 1997) and Twigg suggests that when people adopt the term *'carer'* in relation to themselves it can indicate *'a shift towards a more assertive attitude to the negotiation of public recognition and support'* (Twigg & Atkin, 1994).

There are conflicting perspectives of the nearest relative under the ECHR in relation to Article Eight (respect for privacy and family life). The family may view it as their right to be involved in the decisions about the care of their mentally disordered relative (Yeates, 2005). The problem of these disclosures is that it is not only a one-way flow of information and may cause difficulties when carers hold concerns that information they provide to professionals may be repeated back to the patient (Rapaport, 2004). On the other hand, the patient may argue that it is within their right to privacy to declare that their family have no involvement. The views of a capable patient would take priority here, as there may be valid reasons why the nearest relative may not be the most appropriate person to become involved in these decisions. Each individual case will present a unique challenge that must be negotiated by professionals in such a way to protect the rights of the person's privacy but still promote the most effective support.

3.3 Previous research into the role of nearest relative

There was very little research into the role of nearest relative under the England and Wales 1983 Act (Rapaport, 2003) and only one specific report written in Scotland (Summers *et al.*, 1999). Rapaport described the nearest relative as *'better known for its vices than its virtues'* (Rapaport, 2003) although the research literature and commentary concerning the nearest relative is more balanced, with more research focusing on the (potential) benefits of the role rather than the potential problems. The development of the 2003 Act in Scotland was a relatively straightforward process in comparison with the difficulties the UK government has had in attempting to update the 1983 Act[46]. Perhaps as a result, there has been far less published discussion of the Scottish changes but, due to the legal similarities, recent commentary on developments in England and Wales is of relevance to the Scottish situation and is discussed below.

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[46] The attempt to introduce a new Mental Health Act for England and Wales has ultimately failed and resulted in amendments being made to the existing 1984 Act rather than the introduction of a new statute (Mental Health Act 2007).

3.3.1 Understanding and awareness of the role of the nearest relative

In Scotland, Summers and colleagues (1999) looked at the experiences of families consenting to compulsory measures under the 1984 Act and reported a lack of understanding of the procedures amongst relatives, recommending further investigation into both relatives' and patients' experience of the process. Similarly in England and Wales, Rapaport, (2004) reported that the role was little publicised and information about it was both difficult to retain and understand, and concluded that the scant knowledge of the rights to discharge and request an assessment rendered this protection almost useless. Another English study concluded that better information was required for patients and carers to strengthen the role, ensure correct procedures were followed and for relatives to exercise their rights (Marriott *et al.*, 2001). Figures published by the MWC show that in relation to short term detentions in 2007-8, 74% of patients had a named person identified yet only 46% recorded consultation with the named person (MWC, 2008a). It is not known how many of these named persons were nominated rather than having been appointed by default, but it seems that, even when identified, they are not taking part in the process, although, again, it is not known whether this is through their own reluctance or lack of engagement from professionals. The fact that a patient may nominate a different person than the primary carer was thought to have the potential for confusion and a potential source of friction in family relationships (Yeates, 2005) although this was already an existing possibility under the 1984 Act by which a nearest relative need not be a primary carer. As described earlier, a carer or relative can hold up to five roles; awarding them different rights and information about each of these may be necessary to ensure the person is clear about their rights.

Rapaport (2004) further found there was inertia amongst professionals about involving carers and keeping them involved. The Great Britain Mental Health Act Commission (2008) reported that in their experience there was no statutory form of information provided to nearest relatives, particularly those faced with an application for their displacement from the local authority (GBMHAC, 2008). It also suggested that judges were more likely to defer to professionals than carers (GBMHAC, 2008), and Yeates (2005) suggested that the judiciary should receive

training to allow them to recognise the potential expertise of carers with regard to the treatment of their relative.

3.3.2 Lack of choice for the mental health service user

Research on caring has shown a wide interpretation of family commitments and Finch (1989) suggested kinship relationships in western society no longer provide a normative base for care, but that these responsibilities are built up over time and between individuals where there is not necessarily a legal or familial basis. As a result the changing nature and structure of families was a particular problem with the 1984 Act hierarchy, not reflective of the way many individuals live.

English research exploring service users' and carers' perceptions of the nearest relative provisions found that, perhaps unsurprisingly, the ability of the nearest relative to act in the best interests of the patient depended entirely on the quality of the relationship between them (Rapaport, 2004). Yeates (2005) makes the similar point that the problem was not the extent of the powers awarded to the nearest relative, but that a person unwanted by the patient may be awarded such powers. Accounts of nearest relatives behaving manipulatively can be hard to accept for those carers who put time and energy into supporting a service user, and, unsurprisingly, these reports come most often from service users and professionals (Rapaport, 2003). In England and Wales, Approved Social Workers (ASW)[47] had reported being compromised when they had to contact a nearest relative against a patient's wishes and patients becoming angry. Although the ASW could take action to displace a nearest relative, the process was time consuming, costly and the procedures were not widely known (Rapaport, 2004).

In Scotland under the 1984 Act an application for the nearest relative to be changed could be made to a Sheriff by the nearest relative themselves, an MHO, or a person living with the patient [s56(2)(a-c)], although the patient themselves did not have the right to request a change. The grounds on which this change could take place were when the relative was unable to act due to illness or the nearest relative had made a petition stating that they did not wish to act

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[47] The Approved Social Worker is the England and Wales, equivalent to a MHO.

[s53(3)(a-c)]. Furthermore, displacement of the nearest relative by the local authority could cause alienation between the nearest relative and mental health professionals (Cooke *et al.*, 1994). The Millan Committee was of the opinion that there were further reasons that should permit this change, namely that the patient did not wish the person to be the nearest relative, they were unsuitable for a reason other than illness, or that they were not acting in the best interests of the patient. The committee concluded that the rights of relatives and carers should be predominantly based on the presence of a supportive and caring role rather than solely based on blood relationships. A service user consultation on the planned new Act was carried out by the Scottish Executive Equality Unit and Public Health Division in July 2001. It reported that:

> *'The proposals for a service user to be able to nominate a named person were considered to be a good idea'* (Scottish Executive Equality Unit and Public Health Division, 2001).

Similarly, the idea of patient choice, backed up with safeguards, was welcomed by interviewees in Rapaport's English study of the nearest relative (Rapaport, 2004).

In its plans for reform the UK Government resisted introducing a nominated person as concerns were raised that it could undermine the ability of a nominated person to act in the patients' best interest rather than according to their wishes (Hansard, 2001). The very term *'nominated person'* itself was criticised as being too vague and by moving too far from nearest relative not reflecting family closeness (Andoh & Gogo, 2004).

3.3.3 Nearest relative powers of detention and discharge

Under the 1984 Act the nearest relative was able to authorise applications for detention [s24(2)] as well as discharging a patient [s33(5)]. For long-term detention, the nearest relative had a right to apply as long as they had the appropriate medical recommendations [s20(1-2)]. The Millan Committee found this power was rarely used and again may have damaged relationships as well as bypassing the MHO (Scottish Executive, 2001), although Summers and colleagues

(1999) reported that only one of 15 nearest relatives interviewed said they would not consent again, seven reported improved family communication and only three others reported negative consequences of giving consent. The Committee concluded that there was no gain in preserving this right (despite the shortage of MHOs in Scotland (Grant, 2004) and access to the proposed tribunal would reduce the need for the powers of committal and discharge. In England and Wales the Richardson Committee[48] had already drawn a similar conclusion (Department of Health, 1999), although the Joint Parliamentary Scrutiny Committee later recommended that the nominated person retain roughly the same rights of the nearest relative, including the power to discharge (House of Lords, House of Commons, 2005), although this was later rejected, due to the proposed presence of independent advocates and the tribunal (Hansard, 2005b). A number of Scottish studies have reported the percentages of committals consented to by the nearest relative in both rural and urban localities, these show that on average, 41% of detentions were authorised by the nearest relative (Deering, 1994; Stevenson, 2003; Taylor & Idris, 2003; Begum *et al.*, 2004). There is one earlier study under the 1960 Act which reported 56% were consented to by nearest relatives in a 1979 study of the decade 1962-72 in Glasgow (Elliott *et al.,* 1979) indicating a possible drop in detentions with nearest relatives' consent after the 1984 Act. All these figures are higher than the figures reported by the MWC (2004) who receive notification of all compulsory measures, which suggests that the samples used were not representative.

The nearest relative provisions were criticised as potentially allowing unregulated actions within a family that could lead to an abuse of power using compulsory hospitalisation (Alldridge, 2000). These criticisms tend to disregard the fact that the nearest relative also had the power to discharge the patient and that the nearest relative could potentially have a more in-depth knowledge of the patient and use this knowledge appropriately to resist an application for compulsory detention. An English study (Shaw *et al.,* 2003) followed 51 patients discharged by their nearest relatives (against psychiatric advice) in London and found that they did not differ from other patients in clinical outcomes such as readmittance to hospital and length of stay. This may not be a reliable indicator

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[48] The Richardson Committee carried out a review of the Mental Health Act 1984.

of outcome as psychiatrists may have been more reluctant to readmit someone who has previously been discharged by the nearest relative, regardless of their own view of their health. The authors recommended that the then plans in England and Wales to replace the nearest relative with a nominated person should be supported by evidence showing that the nearest relative role was problematic. They did not comment on inappropriate nearest relatives being awarded these powers by default.

Views on default appointments have been mixed. The Richardson Committee decided against a default position as they considered it unnecessary (particularly in relation to requesting an assessment), as there would be a wider right of access to the tribunal to request one, similar to the current Scottish situation. The committee recommended using the Scottish default system (Hansard, 2005a), although it has been acknowledged that a default duty could be an unwanted burden on carers (Rapaport, 2003), and ASWs may not be adequately resourced to help them appoint someone else (Rapaport, 2004). The alternative proposal that a nominated person should be appointed by an AMHP was criticised as giving this professional *'immense discretion'* over appointment and not thought to be protective of patients' autonomy (Yeates, 2005).

There has been some commentary surrounding the default named person in Scotland in the MHO Newsletter where it was reported that most named persons have assumed the position through default (Stewart, 2006). It has further been described as a *'considerable imposition'* on a relative, with the role seen as difficult to understand and difficult to take in, particularly in the often acute circumstances when appointment takes place. The difficulty in renouncing the role (in writing to the local authority) has also been noted (Mental Health Officers Newsletter Advisory Group, 2006).

3.3.4 The role of nearest relative as protection of patients' rights

There is one basic protection that the nearest relative provisions offered, which remains the case under the 2003 Act in that it can be seen as a civil right that another person is informed of the detention of the patient (de Stefano & Ducci, 2008). Scottish researchers (Taylor & Idris, 2003) writing prior to the

implementation of 2003 Act, raised concerns about the removal of the nearest relative role, further proposing that the loss of the power to discharge was the loss of a protection for the patient. This area also attracted attention in England and Wales. Yeates (2005) expressed concern that the removal of the family from both detention and discharge processes removed a level of protection from the patient and would mean that the carer (here assuming the carer is the nearest relative) was keeping the *'responsibilities without commensurate rights'* and was at risk of becoming a *'passive source of information'*. The proposed nominated person would have *'rights'* but not *'powers'* (Rapaport, 2003) and Yeates (2005) further suggests that the England and Wales 2004 Draft Bill could be seen as an:

> *'Unsubtle attempt by the state to wrest back control from the private family arena by replacing the robust but flawed nearest relative concept with limited rights for nominated persons and carers'*.

However, Hewitt (2007b) said that if the primary carer was *not* the nearest relative they would be awarded additional rights if the nominated person role defaulted to them, or they were nominated by the patient.

3.4 Research into proxy decision-making

The named person provisions are too recent for there to be any published research around the role. However there is a relevant body of research exploring the issues surrounding appointing proxy decision-makers within a health care setting. When capacity is absent and the patient is treated without their consent, the decision to do so is a legal one. Relatives have no legal right to order either the commencement or withdrawal of treatment, medical staff may consult them as good practice, but their opinion remains merely opinion. In some circumstances proxy medical decision-makers can be formally appointed, for example, the AWISA 2000 allows a person appointed welfare attorney, or holding a guardianship or intervention order to make medical decisions, but only up to a certain point [s50]. Similarly, in the United States Health Care Proxy Laws often allow a patient to nominate a proxy decision-maker as part of an advance directive. Generally, these proxy decision-makers may have been

appointed by the patient before they lost capacity, or have been appointed by the court. However, in the UK even if the person appointed the proxy themselves when they had full capacity, the proxy cannot have the final say about treatment, this remains with physicians and the courts. Although the named person role is not that of a proxy decision-maker *per se*, there are enough similarities to make this literature of interest. There is a massive diversity of potential decisions that may be required of a proxy on behalf of the patient but there has been little research into how proxy decisions in mental health care have been made (McCubbin & Weisstub, 1998); most is known about general health care decisions.

3.4.1 Whom people appoint as proxy decision-makers

When people appoint a proxy the majority appoint relatives (*'relatives'* here including spouses) (Hanson *et al.,* 1997). For example, Gamble and colleagues (1991) report that 93% of a sample of older people wanted family to make decisions for them and, similarly, a study of 401 patient-appointed proxies (Ditto *et al.*, 2001) showed that 62% of patients appointed their spouse, 29% their child, and only 9% another person. Whereas many non mental health service users select their partners as proxy decision-makers (Ditto *et al.*, 2001), this is clearly not an option open to many service users who, as described above, are less likely to have a partner.

That a proxy decision-maker is usually an individual can cause difficulties as the full responsibility falls on one person in the family, and research focused on end of life decision-making has found a preference for a consensual group decision (Tilden *et al.,* 1995; Swigart *et al.,* 1996; Hanson *et al.,* 1997; Pierce, 1999). It is not difficult to imagine how proxy decision-making by committee could easily become very complex.

There is little research reporting people who do not wish to appoint a proxy although one study has reported nearly one third of service users preparing an advance directive choosing not to appoint a proxy at the same time. This was either as they were unable to find someone to act or that they did not want another person awarded such powers (Backlar *et al.*, 2001).

3.4.2 Why people appoint whom they do

There is additionally a lack of empirical research into how decisions are made to appoint a proxy. From the little research there is, it seems that two factors are important: that the proxy is trusted and that they know the patient well. A study by Manthorpe and colleagues explored service users' and carers' views of the England and Wales Capacity Act 2005 and found that both groups thought, somewhat unsurprisingly, that it was better to appoint an attorney with whom the service user had a trusting relationship and who knew them well (Manthorpe *et al.,* 2008). This same study identified the concerns that service users have around making an appointment. These included the potential of proxies to abuse the role (although this was not thought to be a risk that outweighed the benefits of the provision) and that relationships with the proxy could deteriorate post-appointment. It was also noted that not all proxies would have the capacity or commitment to carry out the role when it was required of them (Manthorpe *et al.,* 2008), particularly as it would inevitably be a stressful time (Jezewski *et al.,* 2003).

The burden of acting as a proxy has also been acknowledged by patients. Libbus and Russell (1995) found that patients with chronic illnesses' perceptions of burden on the family was the third most reported concern (after being able to care for themselves and pain), although none of the relatives and potential proxy decision-makers in the study expressed concerns about this burden. It has been suggested that this burden could potentially be reduced through support for the proxy (Manthorpe *et al.,* 2008).

3.4.3 Do proxies get it *'right'*?

It stands to reason that before a proxy can make a substituted judgement decision they must be aware of the wishes of the patient. End of life studies have shown that only a low percentage of carers have discussed end of life decisions with the patient (for example, 16% in Seckler *et al.,* (1991). A systematic review found that this discussion does not necessarily improve accuracy of decision-making (Shalowitz *et al.,* 2006) although only two studies

explicitly measured this, with Matheis-Kraft and Roberto (1997) detecting a worsening effect and Ditto and colleagues (2001) finding no significant differences. Despite these apparent low levels of explicit discussion both proxies and patients predict there will be high levels of accuracy of the actual decisions made. Seckler and colleagues (1991) found that nearly all patients thought that their physician would accurately predict their wishes (90%), and nearly as many their relatives (87%). Similarly, proxy decision-makers have been found to rate their own accuracy higher than it actually is, often as they perceived they could predict the wishes of their relative on the grounds that they had known them for a long time (Uhlmann *et al.,*1988; Tomlinson *et al.,* 1990; Hare *et al.,* 1992).

A systematic review of proxy decision-making found that decisions were accurate, (where accuracy is judged by how closely the proxy's decision corresponds with the patient's wishes) in 68% of cases across different populations including people with terminal illness, chronic illness and older people. They did not find that patient-appointed proxies (as opposed to state appointed) or prior discussion of treatment preferences affected the accuracy of decision-making (Shalowitz *et al.,* 2006). Despite this inconclusivity of proxies discussing future wishes with the patient, it is still recommended by several studies (Sulh *et al.,* 1994; Sulmasy *et al.,* 1994; Layde *et al.,* 1995). The rate of accuracy was found to increase in scenarios involving the patient's current health (79%) but to be least accurate in dementia scenarios (58%). There was little difference between the patient appointed proxies' (69%) accuracy and those that had been state-appointed (68% accuracy). Four studies included in the review did find that physicians were less good at predicting decisions than proxies.

There appears to be a common feature in the types of decisions proxies make in that a proxy is more likely to subject a patient to a treatment than to not consent to it. In end of life scenarios this may be guilt because they feel they are allowing the patient to die (Uhlmann *et al.,* 1988; Booth *et al.,* 2004). One example of this was out of a sample of patients who did not want to be resuscitated only 50% of their proxies would have predicted this (Layde *et al.,* 1995).

The research surrounding proxy decision-makers is inconclusive with some studies showing that prior discussion does make a difference and some that it does not. Physicians may be less good at predicting the wishes of patients than proxies but there does not seem to be much difference between the nature of appointment of the proxy, whether selected by the patient or state appointed on their behalf. However, state-appointed proxy decision-makers will usually be whoever is considered to be the most appropriate person which will often be a relative who may have been chosen anyway if the patient had capacity, rather than an agent of the state, for example, a local authority representative. Overall, there is concordance with the patients' actual wishes in around two thirds of cases, often lower than predicted by both patients and their proxies.

3.5 Public understanding and uptake of legal provisions

The introduction of new legal rights and a new mental health or incapacity Act is a time of great change for those professionals whose practice is affected by it. However, the experiences of the introduction of other Acts shows that awareness of changes may take a long time to filter down to the lay person. There has so far been no duty on local authorities to publicise the possible roles under mental health and incapacity legislation across the UK (Rapaport, 2003) and there is currently no requirement for any agency to provide education or information regarding the variety of roles that it is possible to be assigned under both AWISA 2000 and the 2003 Act. As such, many patients and carers may not be aware of their own rights, or in a carer's case, also those of the person they care for.

The area of provision for proxy consents is an area that has been found to cause confusion in the general population. Research exploring the introduction of the Mental Capacity Act 2005 in England and Wales found that 88% of relatives of people in intensive care thought they already had proxy decision-making powers awarded over a relative by virtue of their relationship. It was proposed that this misunderstanding was in part due to the tendency of medical professionals to discuss treatment with relatives as a substitute for direct discussion with the patient (Booth *et al.,* 2004).

This is illustrated by a Scottish study of patients in intensive care that found very low awareness of the AWISA 2000. Ninety per cent of relatives were not aware of the new law and those who were aware had a professional interest, for example, one relative was a social worker (Booth *et al.*, 2004). Patients themselves have been shown to have little understanding of their own legal status under mental health legislation. Two Canadian studies reported low levels of knowledge of legal status amongst patients. Toews and colleagues (1984) reported that approximately one week after admission half of detained patients were unaware that they had been legally detained and two thirds said they had not been given the opportunity to be voluntary patients which half of them said they would have chosen. Bradford and colleagues (1986) similarly reported that 39% of patients were unaware of their legal status and half said they had not been given the option of admitting themselves as voluntary patients, which nearly a third said they would have done (31%). One study looking at awareness of advance statements under the 2003 Act found that there was little prior knowledge of this provision prior to the education provided by the study (less than 10% of patients) and it was concluded that this may explain the limited take up (Foy *et al.*, 2007).

It stands to reason that a certain degree of understanding is necessary before people will exert their rights. Bradley and colleagues (1995) found that English detained patients were more likely to attend a tribunal if they had previous admissions under the 1983 Act (thus gaining understanding by experience), or had been educated to at least A-level standard. This suggested that legal rights were not being explained in such a way that people could easily understand, which is supported by research reporting that patients often did not understand their status as a voluntary or involuntary patient (Monahan *et al.*, 1995). The actual process of using provisions and exerting rights may also be important. Bradley and colleagues (1995) found that people were deterred by having to apply in writing. There are examples where verbal communication of wishes about future treatment are treated as legally binding (for example, in Arizona state legislation (Arizona Secretary of State, 2009) but this is more difficult to manage than a written document.

Regardless of awareness and understanding there may be a tendency for people to be reluctant to prepare for illness and death. Despite the inevitability of death many people die intestate indicating that just because people know they should prepare for something, they do not necessarily take the required action. Research carried out in 2005 by Amnesty International (to promote their will-making service) reported that over half (55%) of Scottish adults had not made a will (Amnesty International, 2005). Mostly as they *'hadn't got round to it'* although amongst the over 75s three-quarters (75%) had made a will, so the increased closeness of death seemed to increase motivation. Personal circumstances such as these do appear to have an impact, with one study of proxy decision-making reporting that nearly two thirds (63%) of patients with a terminal illness had discussed end of life issues with somebody, one third (33%) had an advance directive, and nearly as many (31%) a durable power of attorney (Sulmasy *et al.*, 1998). Similarly, those with recurring psychotic illnesses may be more receptive to forward planning. Two studies have reported that 36% of patients were willing to develop a crisis plan (Henderson *et al.*, 2004) and 40% of a sample of patients wanted to develop a joint crisis card in order to provide information in an emergency (Sutherby & Szmukler, 1998). It may be that these are the same 40% who felt their detention under that Act was justified (Priebe & Katsakou, 2009), perhaps making such future planning more acceptable. Two US studies have shown higher rates of service users interested in completing a formal Psychiatric Advance Directive with Swanson and colleagues (2003) reporting 67% of people being treated for schizophrenia having an interest and Srebnik and colleagues (2003) reporting interest in 53% of their sample of people with serious mental illness.

There is little research on the use of such provisions in Scotland although it appears there has been low take up of advance statements permitted under the 2003 Act (Foy *et al.,* 2007). The MWC has published figures concerning the use of named persons amongst people subject to long-term compulsory treatment and reported that two thirds of this group were aware of the named person provisions, and just over half had made a nomination with a third having a named person appointed by default (MWC, 2008a). Considering this is the group for which the named person provisions have most relevance, the level of awareness and uptake appears low.   It has been suggested in the MHO

Newsletter that there is not the time to nominate named persons and prepare advance statements when people are unwell and may not have capacity, and furthermore, when they are well they may not want to think of it (Stewart, 2006).

There have also been problems around identifying whether a person has made an advance directive or not, for example, where is it kept, by whom and how can it be accessed (Smith, 2006). In one study Papageorgiou and colleagues found that psychiatrists reported that they were unaware of the presence of an advance directive in the form of a *'Preferences for Care'* booklet, even though it had been placed at the front of the patient records (Papageorgiou *et al.*, 2004). One method of increasing accessibility of resources such as advance directives is the establishment of a web-based register to which institutions can have access. There are examples of this in the US such as the state-wide Washington State Living Will Registry (Washington State Department of Health, 2009) or the national US Living Will Registry (2009).

There is little research into how the uptake of these types of provisions can be increased amongst mental health service users although, in Srebnik and colleagues' (2003) study of psychiatric advance directives the attitudes of clinicians were associated with interest amongst service users. Research into advance directives and appointment of proxy decision-makers for general health care shows that professionals can have a positive influence. For example, Dexter and colleagues (1998) used computer generated prompts to remind physicians to discuss uptake of advance directives with elderly patients and found that nearly half (45%) of the patients with whom they were discussed went on to complete either an advance directive or appoint a proxy. Similarly, Meier and colleagues (1996) in a randomised controlled trial found that 48% of the intervention group appointed a proxy compared with only 6% of the control group. This research indicates that if prompted, around 40% of patients will use some form of advance directive or proxy decision-making facility. It has been found with one exception (Rubin *et al.*, 1994) that patient education has had little or no effect on uptake unlike training professionals. There have been further difficulties reported as it has been shown that both patients and physicians believe the responsibility of discussions around advance directives lie with the other (Dexter

et al., 1998). A further influence on whether people make provisions for themselves is by observing the experiences of others. This has been shown to prompt discussion of what the patient would like to happen to them if they were in a similar situation (Meeker, 2004).

Although patient education may have been found to have less effect in promoting uptake of forward planning provisions, it has been identified as a need amongst those people potentially affected by the England and Wales Mental Capacity Act 2005 (Manthorpe *et al.,* 2008). Interviewees stated that accessible information should be available in different formats and at key contact points and professionals should raise awareness generally by speaking to interest groups. Furthermore, individual verbal information also appeared to be valued (Manthorpe *et al.,* 2008). Booth and colleagues (2004) recommended wider public education about AWISA 2000 and encouraged people to discuss their wishes with relatives, seeing advance directives and the appointment of a welfare attorney as processes to facilitate this discussion. US research on psychiatric advance directives has also reported service users' perceptions that they did not get enough support with both the understanding and preparation of advance directives (Backlar *et al.,* 2001; Peto *et al.,* 2004).

There is a need for accessible information due to the complexity of the legislation itself. If a lay-person were to read the primary legislation they would probably find it difficult (for a majority to understand written information it is recommended to have a reading age of below 10 (National Literacy Trust, 2009), with its multiple cross-references obscuring meaning. Thus, it is recommended by that for most people to be able to understand it, a booklet should have a reading age of 10 or below. Thomson (2005) proposes the Australian State of Victoria's 1986 Act as an example of more user-friendly legislation. Two corresponding parts of the 2003 Act and the Victoria 1986 Act are shown in Box 3 to show the differences in readability of the respective Acts. The Scottish Act would be far simplified if cross-referencing alone was reduced.

Box 3: Comparison of Scottish and Victoria State mental health legislation on notification of involuntary detention

Victoria Mental Health Act 1986, s.12ae

Notification of guardian

If a person becomes an involuntary patient, the authorised psychiatrist must ensure that any guardian of the person is notified that the person has become an involuntary patient and the grounds for the person becoming an involuntary patient.

Mental Health (Care and Treatment) (Scotland) Act 2003 s.38

Duties on hospital managers: examination, notification etc.

(1) This section applies where a patient is detained in hospital under authority of an emergency detention certificate.

(2) As soon as practicable after the period of detention authorised by the certificate begins as mentioned in section 36(8)(b) of this Act, the managers of the hospital shall make arrangements for an approved medical practitioner to carry out a medical examination of the patient.

(3) The managers of the hospital shall—

(a) before the expiry of the period of 12 hours beginning with the giving of the certificate to them, inform the persons mentioned in subsection (4) below of the granting of the certificate; and

(b) before the expiry of the period of 7 days beginning with the day on which they receive notice under section 37 of this Act—

(i) give notice to the persons mentioned in subsection (4) below of the matters notified to them under that section; and

(ii) if the certificate was granted without consent to its granting having been obtained from a mental health officer, give notice of those matters to the persons mentioned in subsection (5) below.

(4) The persons referred to in subsection (3)(a) and (b)(i) above are—

(a) the patient's nearest relative;

(b) if that person does not reside with the patient, any person who resides with the patient;

(c) if—

(i) the managers know who the patient's named person is; and

(ii) that named person is not any of the persons mentioned in paragraphs (a) and (b) above,

the patient's named person; and

(d) the Commission.

(5) The persons referred to in subsection (3)(b)(ii) above are—

(a) if the managers know where the patient resides, the local authority for the area in which the patient resides; or

(b) if the managers do not know where the patient resides, the local authority for the area in which the hospital is situated.

3.6 Conclusion of literature review

This review began by describing the broader issues that are affected by the use of compulsory measures in psychiatry: autonomy, consent to treatment and confidentiality. There will always be people who experience incapacity on a temporary or permanent basis and this necessitates a legal framework in which decisions can be made for and about them. These structures involve mechanisms for imposing treatment on an individual against their will and the sharing of medical information between professionals without consent.

It is important that the rights of the patient to representation and self-determination are maximised wherever possible and the 2003 Act has advanced these rights by the introduction of the named person and the advance statement. It is additionally important that carers' rights are recognised and these have also been included in the Act.

The history of mental health legislation in Scotland shows that there has been formal family involvement for several centuries, initially tied to financial responsibility for the patient but determined through blood and marital relationships. The financial element disappeared with the advent of the NHS but the awarding of rights over a patient through blood and marital relationships alone persisted until the implementation of the 2003 Act in 2005. The 2003 Act did not completely remove the automatic entitlement of relatives as it retained a much reduced nearest relative role, with a revised hierarchy to reflect changing patterns of relationship, the nearest relative remaining entitled to some basic information if a detention takes place. However, the important role of the nearest relative is now that they become the named person by default when there is no primary carer.

The named person was a novel introduction to the legislation as for the first time the patient was allowed choice over who would be involved in decisions about their care and treatment under mental health legislation.

It was thought likely that the named person role would largely be fulfilled by carers and relatives. The literature relating to carers and relatives showed that

carers were likely to be the parents of an adult patient, although partners, other relatives and friends do feature. There are particular issues for parent carers in that they may have to plan for a time when they are not able to provide care due to their own age. Partners and friends seem to feature less in the literature as people with serious mental health problems are less likely to have a partner or have a wide circle of friends. They may also not have positive relations with their relatives and may have lost contact or even experienced abuse at the hands of relatives.

Caring can be a demanding activity, one that is not usually chosen by the carer but occurs through circumstance. Some of the particular difficulties of caring involve balancing the needs of the individual as a carer against meeting the needs of the service user. There can be particular problems with information-sharing with professionals where carers feel excluded as the service users' confidentiality must be protected.

Within this already difficult situation comes the potential for involvement in legal proceedings when compulsory measures are deemed necessary. There was little previous research into the role of the nearest relative but it has been found that there was little understanding of it amongst carers and relatives and it may have caused conflict when there were disagreements about events such as admission and discharge. However, it is a mixed picture as research evidence has also shown that patients discharged by relatives have no worse outcomes and, when powers were used appropriately, they may have protected patient rights. Nevertheless, carers may not always have wanted the role and found it hard to reject although this was possible. The one certainty was the problem with the lack of choice for the patient about who became involved in their care which was deemed unlawful under European human rights legislation.

As there was no research on who patients would choose to nominate as their named person, the health-care proxy decision-making literature provided some relevant conclusions. People did seem to nominate family more than friends and often a spouse. These people were nominated as they were trusted and thought to know the patient well. There has been found to be a tendency for patients to

overestimate how much the wishes of their proxy decision-maker will correspond with their own, accuracy generally being found in only about two thirds of cases.

Finally, the awareness of legal roles that relatives and carers can assume (by nomination or default), was found to be generally low amongst patients, relatives and carers with little supporting information available, and the statutes themselves difficult to read. There is further confusion about where the responsibilities lie for the use of such optional provisions as appointing proxy decision-makers and whether a nomination should be encouraged by professionals or left up to the patient. Even where there has been a nomination made, it is not always able to be located in an emergency or is sometimes disregarded by professionals.

There was no research evidence on the named person provisions and how they are perceived by patients, carers and professionals. This research aims to explore these perceptions so that the use of such provisions can be better understood.

Chapter Four: Research Method

4.1 Aim and research questions

There was no research evidence reporting how any stakeholders perceived the named person provisions of the Mental Health (Care and Treatment) (Scotland) Act 2003 and there was only limited literature and case law highlighting the disadvantages of the previous nearest relative mechanisms. In the light of these deficiencies this research set out to explore the perceptions of mental health service users, their (potential) nominees, MHOs and policy influencers' perceptions of the role of named person under the 2003 Act.

This research aimed to show how service users perceived and understood the named person provisions and the factors they considered when planning a nomination. The views of carers as potential nominees aimed to show their perceptions and understanding of the role. The research then sought to explore the provisions from the perspective of the MHO, the key professional involved in applications for compulsory measures under the 2003 Act and to collect their experiences of applying the law to service users facing compulsory measures. Finally, a broad perspective of the implementation was sought from a range of people who had all been involved in either shaping the development of the 2003 Act or its subsequent implementation.

The research sought to answer the following research questions:

- What are the views of stakeholders on the introduction of the named person provisions?

- What are the perceptions of the extent to which the named person provisions are being used by service users?

- What factors do service users consider when planning the nomination of a named person?

- What is the nature of the relationships between service users and their planned named person?

- What are stakeholders' opinions and experiences of the default named person provisions?

The research took a qualitative approach using interviews to collect data from the four different groups of interviewees. This chapter describes the rationale for the method, the ethical considerations and the processes of accessing, recruiting and interviewing participants.

4.2 Review of literature relating to methods

It was clear from the research questions that the research instruments would have to be flexible to capture the differing experiences of the different groups of stakeholders. There were several issues that required consideration during the development of the method. These were the choice of an interview; gaining access to closed groups; the potentially sensitive nature of the interviews; and the relationship between the interviewee and the interviewer.

4.2.1 Interviewing

The semi-structured research interview allows the main questions to be asked in the same way in each interview but allows the interviewer to alter their order and to ask supplementary questions and probes as judged necessary. This allows the interviewer to adapt each interview to the individual interviewee, with regard to their level of comprehension and allow the interviewee to talk as freely as possible, for example, often answering later questions before they have been asked (Fielding, 1993).

4.2.2 Gaining access to participants

A mental health service can be considered a *'closed access'* group where access is only regularly granted to the service users or service staff, although some people may fulfil both roles. Cassell's two-stage process of penetrating a closed access group can be applied to this scenario: the first stage *'getting in'* and the second *'getting on'* (Cassell, 1988). *'Getting in'*, is usually achieved through the validation of the researcher by a trusted member of the group, thus acting as a *'patron'* (Lee, 1993) and sanctioning access. Once admitted to the group the second stage of *'getting on'* must be achieved. According to Cassell the researcher must *'adopt a role or identity that meshes with the values and behaviour of the group'*, albeit with the caveat of *'not compromising the researcher's own values and behaviour'* (Cassell, 1988).

4.2.3 Interviewing about sensitive subjects

Lee (1993) proposes three areas where sensitivity can arise during research: areas considered private or stressful, for example, sexuality or death; those that may cause stigma or fear; and those that that may cause political threat. By the very act of inviting the interviewee to discuss potentially painful experiences the interviewer can become *'a catalyst for revisiting very private and/or unhappy' experiences'* (Birch & Miller, 2000), furthermore, asking an interviewee to discuss relationships can risk the interview process itself impacting on these relationships (McCosker *et al.,* 2001). Research has shown that interviewees can

view the interview as both a positive and a negative experience with the discussion of painful experiences being both traumatic and cathartic, sometimes simultaneously (Cowles, 1988).

4.2.4 The role of the interviewer

The role of the interviewer when distressing subjects are under discussion is of great importance and has been a matter of debate in the methodological literature. One approach is to acknowledge the distress of an interviewee and allow time for the interviewee to express how they are feeling and to feel they are being listened to sympathetically, not just as a means of gathering information. This approach has been argued to detract from the quality of the data (Field & Morse, 1985) but it is countered that acknowledging and accepting the distress of the interviewee enhances the presence of a supportive environment for the interviewee, leading to them feeling comfortable disclosing further information and feeling supported in doing so (Cowles, 1988).

There can be a *'blurred boundary'* between the interview on potentially sensitive subjects and the therapeutic interview. Both the interviewer and therapist seek to create a space where the interviewee can feel comfortable in revealing and reflecting on painful experiences. Dickson-Swift and colleagues (2006) use the term *'boundary management'* to describe the process of establishing and working within such professional boundaries. Much of professional intervention and therapeutic work with people with mental health problems is underpinned by the therapist maintaining a *'boundary'* with the service user. This strategy is thought to prevent the professional becoming over-involved with the service user and as such, protect their own mental health. However, similar skills are used in both situations, the building of rapport with the interviewee often involves a negotiation of boundaries involving strategies to build rapport, commonly these can include social acts with the interviewee such as having a cup of tea together and discussing benign *'off topic'* subjects such as the weather and travel to the interview. A level of self-disclosure on the part of the interviewer is a common part of this negotiation.

4.2.5 Telephone versus face-to-face interviewing

There is a small body of research exploring the differences between interviewing by telephone and face-to-face. Overall it has been found that the data does not vary in quality (Miller, 1995; Sturges & Hanrahan, 2004) but there are some factors to be considered.

The primary difference is the lack of non-verbal behaviour that occurs in a face-to-face scenario so it must be decided how important these might be. There are however advantages of not being seen, the interviewer can take notes to remind themselves to return to a topic (Sturges & Hanrahan, 2004) and can concentrate on their questions rather than their physical presentation.

It has been found that sometimes interviewees prefer to be interviewed about sensitive topics by telephone (Fenig *et al.*, 1993), perhaps as it can enhance a sense of anonymity (Greenfield *et al.,* 2000) although this depends on why the interview is sensitive; if this is due to illegal behaviour being the subject of the interview it may lead to more honest responses, but if it is an emotionally sensitive topic or participants are likely to be vulnerable, a supportive environment may be better provided in person. Telephone interviewing can make it easier to access hard to reach groups (Tausig & Freeman, 1988). It also reduces risk to the interviewer and furthermore, is cost-effective (Sturges & Hanrahan, 2004).

Consideration must therefore be given to how important a face-to-face encounter is in the data collection process.

4.3 Justification of methods

The decision to access the four groups of stakeholders influenced the choice of method. The individual nature of the experiences and perspectives of the named person provisions were thought unable to be captured by a survey or questionnaire. A less structured method was required fully to allow the range of experiences both between and within groups of stakeholders to be captured. Due to the personal nature of the subject under investigation the interviewees

from both the service user and carer groups were thought to have varied experiences to report. Likewise, the nature of social work practice may have meant that the MHOs had different experiences. The policy level interviewees were to be sought from distinctly different organisations and would have a variety of specialisms. This meant that there would be no standardised instrument that could collect the potential variety of this information without restricting the richness of the data. Therefore, the most appropriate method of data collection was qualitative, the choice being between the focus group and the individual interview.

The focus group is often used to gather qualitative information from a group of similar people and is cost-effective in terms of time, allowing access to a range of experiences in one encounter. The focus group would not have been suitable for the service users and carers for two reasons: Firstly, the personal nature of the subject matter with service users and carers. It was thought that people would not feel comfortable discussing these potentially sensitive subjects in front of other people regardless of whether they knew them or not and it was considered unethical to place people in such a situation. Secondly, it was thought that the data gathered through such a method would not be as in-depth as that which could be gained from a range of individual interviews that would allow interviewees time to describe their experiences. Interviews are more costly in terms of time, organisation and administration; however they were thought to have the potential to yield a richer body of data.

The focus group was considered as a method of interviewing MHO participants but was not used for two reasons. Again, a focus group only allows a certain amount of information from each interviewee. This is appropriate when there is a very clear issue under discussion but not when researching a subject about which less is known, such as the named person provisions. There is also the difficulty in arranging a focus group that a significant number of MHOs would have been able to attend. As they often get called away to attend to unplanned situations it would have been difficult to ensure adequate attendance so the individual interview allowed greater flexibility for the participant.

The focus group would not have been appropriate for the policy interviewees due to the lack of homogeneity anticipated in the group. To be able to explore their background and perspectives it was thought that the allocated time it was possible to request from each interviewee was best used individually. Furthermore, it would not have been possible to physically gather these people together due to the other demands on their time. Similar to the MHO interviewees they required flexibility to accommodate unforeseen circumstances.

Thus, the semi-structured interview was planned as the most suitable method of data collection with all participants.

It was anticipated that it would be very difficult to carry out all interviews face-to-face. This was due to the availability of some interviewees, particularly policy influencers and MHOs who may be called away at short notice. It was considered essential that service users were interviewed face-to-face as this ensured a supportive environment and allowed the researcher to manage any distress. Carers were not thought to have the same needs in this respect although it was decided to offer them the choice, where possible, although location might dictate otherwise.

4.4 Justification of choice of participants

To address the research questions it was thought necessary to access people from several different groups. Service users were the key group as they would be able to provide their perspective and experiences of the named person provisions; if and how they planned to use them; and the factors that would be important to them in making a nomination. It was thought that this information could not be gained from any other source than service users themselves.

Carers were thought to be able to contribute their perspective from either the role of a carer, a named person or both such as how they felt about involvement in decision-making, and their experiences of becoming a named person (if they had been nominated). It was of specific interest how they would feel as a carer if another person were chosen to be a named person. As in the case of mental

health service users, this was thought to be information that could only be obtained directly from carers.

The third group thought to have a specific perspective on the provisions was the MHOs. As the key professionals in identifying named persons when compulsory measures are initiated, their experiences were thought to be key to both the implementation and promotion of the procedures. It was considered that the most valuable data would come from MHOs implementing the 2003 Act on a daily basis and not, for example, from service managers.

A broader perspective was sought from the fourth group of those who had contributed to the development and implementation of the 2003 Act. These people were anticipated to be a range of senior practitioners from a range of disciplines. It was thought that accessing this group would give a broader overview of the development and implementation of the named person provisions.

4.4.1 Inclusion and exclusion criteria for interviewees

Twenty service user interviewees were sought as this was to allow for a range of experiences which would form the basis for the rest of the interviewees. The aim was to access carers or potential named persons through some of the service user interviewees to allow comparison of the perceptions of each member of a dyad resulting in interviews with ten carers. Ten interviewees from each of the three others groups were sought. The reason for this number was thought to allow for a range of experiences to complement to the primary focus of the service users themselves.

Mental health service users

Service users must have been in regular contact with at least one specialist mental health support service (from any sector). Interviewees must all have been aged 18 or over with no upper age limit and have been living in the community. Interviewees must have been considering or have already completed a nomination to appoint a named person. People suffering from dementia or

people subject to the AWISA 2000 were not included as it was thought they formed a distinct group of people with specific needs and experiences, and may lack capacity to consent. Although people with a dual diagnosis were not automatically excluded, those with a primary problem of substance misuse were excluded, again due to them forming a distinct needs group and being specifically excluded from provisions under mental health legislation. People who were experiencing a level of mental ill health, such that a professional involved in their care judged that participation in the research may present a risk to either the service user or the researcher, were further excluded. Furthermore, people who were experiencing a level of mental ill health such that the professional's judgement was that their ability to give informed consent might be diminished were also excluded. People who were currently detained or subject to a compulsory treatment order under the 2003 Act were excluded as it was thought that they could be experiencing a level of mental ill health that might compromise their ability to give informed consent and it may cause distress to discuss compulsory measures with a person currently subject to them.

Carers (as potential named persons)

Carers must have been likely to be (or already have been) nominated to act as a named person by a person with mental health problems. They must have been involved in the care and support of a relative or friend who was using mental health services and be aged 18 or over with no upper age limit. People who had themselves been involved in proceedings under mental health legislation were excluded as it was thought they would have been unable to talk solely of their perceptions of the named person role from the perspective of a carer. Carers who were themselves currently experiencing major mental health problems or people subject to the AWISA 2000 were excluded.

Mental Health Officers

MHOs must have been working within Scottish local authorities. There were no exclusion criteria.

Policy Influencers

Policy influencers were people who had contributed to the development and implementation of the 2003 Act. There were no exclusion criteria.

4.5 Development of the interview schedule

After the decision to use interviews was made it was clear that a separate interview schedules would be required for groups of interviewees. The overall approach to the design of the different interview schedules was iterative with the service user and carer interviews taking place simultaneously and the findings from these interviews informing the interviews with MHOs and policy makers.

4.5.1 Interview schedule for mental health service users

The research questions that arose out of the literature and legislation formed the basis for the interview with service users and carers. The interview was designed in three parts: The first part established service users' knowledge and awareness of the named person and provided information as required, using the Scottish Executive publication *'The New Mental Health Act: A Guide to Named Persons'* (Scottish Executive, 2004). The second part asked about their own use of the provisions, whom they might nominate and for what reasons. Finally, three vignettes were used to facilitate broader discussion which described situations where a family member was in potential conflict with a partner; a person with no named person but the potential for an MHO to identify a friend as a possible named person candidate; and a person selecting a relative as named person but then requesting a friend to intervene (See Appendix 2 for interview schedule and vignettes). Questions were asked in relation to each vignette about how the individual people should act and what factors might influence them. The vignettes were placed at the end of the interview to broaden the discussion and move it away from the personal and potentially sensitive, to the more abstract. As the structure of the interview had been described to the interviewee beforehand, the vignettes also served to signify that the interview was drawing to a close.

Each section was semi-structured, the schedule consisting of a list of topics to be covered but no set order was maintained as this allowed the interviewee to talk about their individual experiences and situation without being interrupted. Previous experience had led the researcher to consider the maximum length of an interview with service users and carers to be one hour. This meant that there was a limited number of subjects that could be discussed and it was not possible to cover all the potential issues.

4.5.2 Piloting the interview

Due to difficulties in accessing participants (see Section 4.8.1) no separate pilot of the interview schedule was carried out. However, as the interviews progressed they were piloted *in vivo*. There were two questions added after the topic had been introduced by an interviewee. The first few interviews did not ask about whether an interviewee would act as a named person him or herself. This became a topic of discussion in one interview when the interviewee was asked to consider the advantages and disadvantage of a fellow service user acting as a named person. The interviewee turned this question back to himself, considering whether he would be prepared to take on the role. This question was added as a prompt when discussing the issue with later interviewees. A further prompt was added when a different interviewee said that she would only consider acting in such a role as the named person for a member of her biological family. It was thought this was an interesting distinction and was thus incorporated in further interviews.

The vignettes were piloted using an opportunistic sample of non mental health service users and tested for clarity and comprehension. It was thought that if they could be understood by people with no experience of mental health services, then they would be likely to be understood by interviewees. Minor changes were made to the vignettes as a result of this piloting exercise.

4.5.3 Interview schedule for carers

Similar to the interview with service users, this interview commenced with an introductory section discussing the Scottish Executive information booklet (Scottish Executive, 2004) and ascertaining their level of knowledge of the role. If the carer had not read or understood the booklet, a full explanation was provided and any questions they may have had were answered (See Appendix 2 for interview schedule).

Feelings about undertaking such responsibilities as the named person were explored, with reference to making decisions on behalf of others and the conflict that may occur between what the carer thinks is best and what they know the other person would want. They were asked about how they would feel if they as a carer were not nominated as the named person. When the interview was with a carer of a service user who was also being interviewed, care was taken not to introduce discussion of the service user they supported as it was important that each member of the dyad did not think they were the focus of the interview with their partner. The same vignettes were used to focus the interview around decision-making in a less personal context and to allow comparison between the two groups.

4.5.4 Interview schedule for MHOs

The interviews with MHOs focused on the named person provisions in practice. They were asked about their overall perception of the introduction of the role before being asked about their experiences in practice. This included levels of uptake amongst service users and the understanding of provisions amongst both service users and carers. The default named person and the tribunal system were discussed and their related responsibilities as MHOs. Vignettes were not used as it was assumed that MHOs would gain no benefit from being distanced from the issues and would have a full understanding of the issues the vignettes sought to exemplify with service users and carers. A checklist of prompts was used to ensure similar subjects were included (See Appendix 2 for interview schedule).

4.5.5 Interview schedule for policy influencers

The interviews with policy makers were the most unstructured due to the variety of backgrounds and perspectives of the interviewees and a topic list was used to ensure that all areas of interest were discussed. Generally, interviewees were asked about their involvement with the development of the 2003 Act and its implementation. They were then asked for their perspective on the uptake and use of the named person provisions, the implications for service users and carers and they were specifically asked about the use of the default named person. As with the case of the MHOs, vignettes were not used but the same checklist of prompts as was used with the MHOs (See Appendix 2 for interview schedule).

4.6 Data analysis

Interview transcripts were coded using Atlas ti (Scientific Software Development, 2009), a qualitative data analysis package that allows organisation of data so that key themes can be examined and links made between them.

4.6.1 Thematic analysis

The nature of the data generated required a qualitative approach to analysis. Qualitative analysis methods can be divided into two types: those taking a particular theoretical position, and those that can be applied across a range of theoretical approaches. Thematic analysis is the latter and is a method for *'identifying, analysing and reporting pattern (themes) within data'* that provides both an organisation of the data and is then followed by an interpretation. It can be flexible and responsive to the data allowing a detailed and complex analysis. It has been described as a *'foundational method for qualitative analysis'* as it may also be used as a tool within other forms of qualitative analysis, for example, grounded theory analysis. It can however, be used as a method in its own right (Braun & Clarke, 2006) and this is how it has been employed in this research.

Thematic analysis is a widely used yet often poorly defined method not often referred to by name in the same manner as discourse analysis or grounded

theory are, yet being used and reported and either being mislabelled as other approaches or not being named at all. This makes findings difficult to explore for the reader as there is scant information given as to how the data were analysed, makes replication of method difficult and can result in charges of lack of rigour (Boyatzis, 1998; Attride-Stirling, 2001; Tuckett, 2005).

As qualitative reporting often lacks detail of how the analysis was carried out (Attride-Stirling, 2001) this research sought to adopt a clear method based on the six stage process of thematic analysis adapted from Braun & Clarke (2006), influenced by Fereday & Muir-Cochrane (2006) and incorporating the thematic networks approach (Attride-Stirling, 2001). It combined both a data driven inductive analysis (Boyatzis, 1998) with a deductive approach stemming from an *a priori* template of codes (Crabtree & Miller, 1999) to interpret the data (Fereday & Muir-Cochrane, 2006).

The analysis was dependent on the development of first codes and then themes. Before this process is described it is important to clarify what was meant by both these terms

Codes

Codes were *'first-level'* labels applied to parts of the transcripts. These sections could be as short as a few words or may be several paragraphs. Each section can be coded as many times with different codes as considered necessary. Some codes were created *in vivo* using the actual word or phrase the interviewee had used and some were created *a priori*, influenced by key issues that had arisen from the literature review and the researcher's recollections of the actual interview process.

Themes

Research exploring the use of the term *'theme'* in nursing research concluded that it was used inconsistently and should be clearly defined for research to maintain rigour. The concept of theme used in this research is taken from the following definition:

'A theme is an abstract entity that brings meaning and identity to a recurrent experience and its variant manifestations. As such, a theme captures and unifies the nature or basis of the experience into a meaningful whole.' (DeSantis & Ugarriza, 2000)

The aim was to unify the data into several themes that would enable the findings of the research to be described in a cohesive manner.

Stages of the analysis

The phases of thematic analysis used in this research are described in Table 2 below (taken from Braun & Clarke, 2006).

Table 2: Phases of thematic analysis (taken from Braun & Clarke, 2006)

Phase	Description of process
1. Familiarisation with the data	Transcribing data, reading and re-reading the data, noting down initial ideas.
2. Generating initial codes	Beginning with *a priori* codes from the initial transcribing and reading of the transcripts (Fereday & Muir-Cochrane, 2006). Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code. Testing the reliability of the code by reviewing content, frequency of use and where necessary, merging and splitting codes (Boyatzis, 1998).
3. Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes	Testing if the themes work in relation to the coded extracts and the entire data set, generating a thematic *'map'* of the analysis.
5. Defining and naming themes	Development of the thematic network. Ongoing analysis to refine the specifics of each theme, generating clear definitions and names for each theme and producing a visual representation of the thematic network.
6. Producing the report	The final opportunity for analysis. Selection of extract examples, final analysis of selected extracts, relating back to the analysis to the research question and literature before writing the report of the findings.

Once transcription was completed the transcript was read and re-read and initial notes made regarding possible codes. As the researcher had carried out and transcribed the interviews this minimised fragmentation of the narratives (Atkinson, P., 1992) and retained a close relationship with the data (Bowling, 1997). It has been argued that the act of transcription contributes towards the interpretive process (Lapadat & Lindsay, 1999) minimising the misinterpretation of quotations, especially shorter ones, being placed out of context (Coffey & Atkinson, 1996) and in this case the researcher became very familiar with each transcript, being able to remember specific discussions held with specific interviewees and to locate them quickly. This existing knowledge of their content led to some initial thoughts regarding codes and possible themes.

Initial coding then began using Atlas ti (Scientific Software Development, 2009). Each transcript in a data set was re-read and parts that could potentially be of interest to the analysis were assigned codes. Systematic coding using specialist software is thought to enhance credibility of data analysis (Sandelowski, 1995). This systematic process contributes to the analysis as the data began to be organised into groups. Codes could be retrieved within individual data units, sets or across the whole of the data. After each transcript had been coded, codes were reviewed; some had little associated text and could logically be incorporated into a similar code. Other codes that contained unwieldy amounts of text were split into two or more different codes.

Once the codes were established they were arranged according to salient themes. If a code did not fit into a theme, it was further examined to establish whether it had been too loosely coded and could be split and turned into a theme itself, or whether it was a valid code of relevance to the developing analysis and had yet to fit in with a theme.

The themes were then constructed into a thematic network (Attride-Stirling, 2001), using the network feature on Atlas ti which allows the individual codes and themes to be visually moved around and linked to each other (See Appendix 3 for tabular representation of thematic analysis framework).

The next stage was the description of the network, returning to the text through the lens of the theme rather than the original codes. At this stage illustrations were taken from the text to support the themes and to ensure that the interpretation remained directly connected to the words of the interviewees. The themes were then in turn, related back to the original research questions.

4.7 Ethical issues

Given the potentially sensitive nature of the interview with service users and carers, there were a number of ethical considerations. Informed consent, and the revelation of distressing information were the two foremost concerns, with data storage and lone working also addressed.

4.7.1 Informed consent

The *'Declaration of Helsinki'* (World Medical Association, 2004) outlines a set of principles for medical research which places informed consent at the centre stating that research participants should understand the anticipated risks and benefits of the research. The declaration further requires that the benefits, risks and justifications for any research are subject to external review and assessed by autonomous, informed participants, who have both the time to reflect upon the implications of taking part in the research and the opportunity to request clarification of any issues (Singleton & McLaren, 1995).

Informed consent has been defined as being an:

> *'Uncoerced decision made by a sufficiently competent or autonomous person, on the basis of adequate information and deliberation, to accept or to reject some proposed course of action.'* (Singleton & McLaren, 1995)

The two clear ways that would highlight the potential loss of capacity to consent were if the participant was subject to measures under either the AWISA 2000 or the 2003 Act, therefore, people in these groups were excluded from taking part

in the research. Otherwise, the General Medical Council (GMC) (2008[49]) recommendation for medical professionals was used; this advises that one should:

> '…work on the presumption that every adult has the capacity to decide whether to consent to, or refuse, proposed medical intervention, unless it is shown that they cannot understand information presented in a clear way.' GMC (2008).

Potential participants would have the research fully explained to them and receive a copy of the project information leaflet (See Appendix 1). This included a summary of the aims of the project, a description of what taking part in the research would involve as well as the potential risks and benefits. The risk of potentially becoming distressed as a result of discussing personal experiences was stated and that a current service provider might be informed of this distress, with the consent, or at least the knowledge of the interviewee. Assurances of confidentiality were given, that the data would be anonymised at the transcription stage and participants' names would only routinely be recorded on the consent form. The information sheet provided an explanation of how the data would be used and that quotations that risked identifying a person would not be used. The right to withdraw from the project at any stage, without giving a reason was stated and the contact details of both the researcher and her supervisor were provided directing any complaints about the conduct of the research directly to the supervisor.

Those who agreed to participate would be asked to sign a consent form after it had been fully explained by the researcher; furthermore, they would retain a copy of the form. The consent form confirmed receipt and understanding of the information sheet, confirmed the right to withdraw without any consequences, and all participants would be offered the opportunity to opt to receive a summary of the findings, considered by the researcher to be good research practice.

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[49] 2008 is the most recent published guidance. A similar policy was in place at the time of fieldwork was carried out.

4.7.2 Distress caused by revelation

A study of mental health service users and their families and carers must be particularly alert to ensure that any research activity does not exacerbate any existing difficulties. The interview with service users explicitly asked about both their personal relationships and the impact of their mental health problems. In asking questions around the nomination of a named person the interview was not only asking about relationships that were ongoing, but simultaneously raised issues around relationships that had either never existed, or had broken down. This was particularly the case for family relationships as it was anticipated that some interviewees would no longer have contact with their biological families. Furthermore, the fact that each service user used mental health services meant that they were likely to discuss the stigma they may have experienced as a result of their illness, particularly the experiences of being subject to compulsory measures in the past. Where their family breakdown was as a result of their mental health problems, or exacerbated by them, these two issues could have had a causal relationship in either direction.

It was imperative that the interviewer have a carefully thought out strategy for managing such situations. All mental health service users who were invited to take part would be in contact with at least one specialist support service and this ensured both that individuals were approached to participate in a supportive context and that, should any necessity for extra support emerge after the interview, resources were available. There was the potential, however small, for service user and carer interviewees to reveal information for the first time during an interview that the researcher was not sufficiently trained to manage, for example, an experience of sexual abuse. To manage this risk it was clearly stated in the protocol and the participant information sheet that in the event of an interviewee demonstrating a need for further support the researcher might refer the interviewee to a service provider, although it was anticipated it would be with the interviewee's consent, or if they did not consent and the researcher judged it necessary to inform a service provider, the researcher would inform the interviewee of the planned action.

4.7.3 Lone working

A further risk was due to the researcher being a lone researcher. Although it was anticipated that the majority of the interviews with service users and carers would be carried out at service premises, with the associated health and safety systems in place, it was thought that offering to visit service users in their own home might maximise inclusion in the research. As the researcher had several years experience of home-visiting whilst working in community mental health services she was very familiar with the health and safety aspects of this and required no additional training. Procedures were put in place where a colleague at the university agreed to be a contact for the researcher whilst she was interviewing in the community. The name, address and contact details of the interviewee would be left with the colleague, as well as the time of the interview. The researcher would ensure she always carried a mobile telephone and called after the interview to say that she had finished the interview without incident.

4.7.4 Data storage

All data would be anonymised as soon as the interview was completed and the resulting transcript assigned a unique identifier number. The participants' names and contact details would be retained until the interview was completed (for health and safety reasons if home visiting), or consent withdrawn, at which point they would be destroyed. Names and addresses would only be retained if the participant wished to be kept informed as to the findings of the research, in which case they gave consent (in the form of a signature on the consent form) for their details to be kept on a specific mailing list that would be destroyed after the findings had been disseminated and would not be used for any other purpose.

Data generated by the project would be stored by the researcher on a laptop computer and backed up to both a university network computer and a university maintained web-based document storage site. All three would be password protected and could only be accessed by the researcher. The original audiotapes

would be kept in a locked drawer on university premises and labelled only with the identifier numbers.

4.8 Accessing the settings, recruitment and procedure

The following section will describe how the different groups of interviewees were accessed and recruited.

4.8.1 Accessing, recruiting and interviewing mental health service users

It was originally planned to access mental health service users through NHS mental health services. Thus, an application to the Local Research Ethics Committee (LREC) was submitted.

Application to the Local Research Ethics Committee

The application (See Appendix 4 for correspondence and supporting paperwork) to the LREC described how letters inviting potential participants meeting the inclusion criteria (as described above) would be distributed by a professional at a mental health service. If a service user wished to participate they would consent to the professional passing the researcher their contact details, or they could contact the researcher directly to arrange an interview. Interviews would take place at the service they attended or occasionally at the service user's home (after an appropriate risk assessment).

The proposal was reviewed by the LREC and a favourable opinion was not given. This was for sixteen different reasons (See Appendix 4). The majority of these queries were easily addressed, such as those concerning the content of the interview; methodological queries; and the researcher's experience and qualifications. However, there was a key query raised about the capacity of patients to provide valid consent as a result of them being a mental health service user. The response from the researcher restated (as in the protocol) that no participant would be subject to either the AWISA 2000 Act or the 2003 Act, therefore legally their capacity to consent was not in doubt. Furthermore, they

would have only been passed the letter of invitation by a professional who had no concerns about them taking part in the research.

The researcher attended the re-review of the application by the LREC and took part in a discussion about the capacity of mental health services users to consent. The researcher held the position that capacity to consent to take part in a research interview should not be doubted merely because a person used a mental health service. The committee held the position that the fact that they used a mental health service showed that their capacity to consent was likely to be diminished. Neither of these positions changed during the discussion. The committee were in effect treating mental health service users as a vulnerable *'class'* rather than as individuals who may or may not be vulnerable (Atkinson, J., 2007b).

The committee approved the application only after the recruitment procedures had been changed to mean that service users had to opt into the research by returning a form to the researcher by post, attached to a three page invitation letter, increased from the original version by two additional pages. The researcher had to further agree to contact the participant's clinician immediately prior to the interview to ensure that there was no risk to the researcher by carrying out the interview and was advised that another person should be present during the interview, for the protection of the researcher. In hypothetical discussions this process has recently been challenged by service users researched by Ulivi and colleagues (2009) who thought approaches through services they used regularly were more appropriate and perceived no necessity for their psychiatrist to be involved in their choice to take part in non-therapeutic research. Regarding the issue of capacity to consent the letter from the committee stated:

> *"It is totally inappropriate to assume capacity to consent unless proven otherwise."*

This issue remained unresolved between the researcher and the committee although the researcher stressed on several occasions that the requirement

placed on her by the committee to contact a clinician prior to interviewing the participant would further ensure capacity to consent was present.

The three page, LREC approved letter of invitation was passed to a Consultant Psychiatrist who had agreed to pass it on to service users who he thought might be interested in being interviewed. His immediate comment was that the information was too detailed and lengthy and the procedure for opting into the research was too complex. As predicted, no service users opted to take part. These events are discussed in Chapter Nine.

As a result of these difficulties it was decided to recruit service user and all other participant group interviewees through non-NHS sources. An application for ethical review was submitted to the University of Glasgow Faculty Of Medicine Sub Committee for Non Clinical Research Involving Human Subjects (See Appendix 5). It was approved after the clarification of two points; one was already contained in the consent form (that participation would not affect any services being used) and the other, again regarding capacity to participate:

> *"One minor comment relates to the individuals with mental health problems. Could I just check that there will be some mechanism put in place to ensure that these individuals are deemed competent and fully understand the nature of the study?"*

The responses clarified that only individuals who were not currently subject to measures under either the 2003 Act or the AWISA 2000 would be interviewed. Furthermore, any person would not be interviewed if they were thought by a member of staff at the service they attended or indeed by the researcher to be experiencing a negative fluctuation in their mental health that may temporarily affect their capacity at the time of interview. The committee were satisfied with this clarification and approved the research.

Accessing service users through voluntary sector organisations

Service users were accessed through two voluntary organisations which both provided a range of services including employment support, volunteering

opportunities and a range of fora and information services. Contact was made with the first service through a prior research relationship. This organisation was particularly interested in raising awareness of the named person provisions and because of this the researcher was invited to attend a series of four service user meetings to speak about the named person provisions, with the aim of raising awareness and answering service users' questions. After providing the host organisation with the information about the research, it was agreed the researcher could inform service users about the research and invite them to take part. At the end of the presentation the researcher described the research and asked service users who were interested in taking part in an interview to take an information sheet and if they were willing to be interviewed to tell a named member of staff at the service who would pass their details on so that an interview could be arranged.

On average twelve people attended each of the four meetings and this resulted in eleven service users agreeing to be interviewed. The majority of the interviews took place at the service premises where a private room had been made available. One interview took place in the researcher's office at the university at the request of the interviewee and a further three took place in the service users' homes.

The arrangement with the second mental health service came about after the researcher was invited to run a fifth information session at a different service. Fifteen service users attended this session as well as two staff members. Invitations to take part in the research were left with the service and as nine service users agreed to be interviewed the researcher arranged to attend the service on two more days to conduct the interviews; a private room was reserved for this purpose.

All service user interviews took place face-to-face, which allowed the creation of a safe and supportive environment to discuss the areas under investigation. This was of particular importance due to the potential vulnerability of the interviewees and it allowed the researcher to judge the response of the interviewees to the interview experience and to ascertain whether they may require further support. A consent form was discussed and signed by each

interviewee prior to the interview taking place, one copy was given to the interviewee to keep and the researcher retained the other (See Appendix 1). Interviewees were informed that they could withdraw consent at any point without giving a reason and that any information they gave would remain confidential. Furthermore, it was ensured that all interviewees had an information sheet (containing the researcher's contact details) (See Appendix 1) and a copy of the Scottish Executive Guide to Named Persons[50] (Scottish Executive, 2004). Service users were given a £10 gift voucher as a token of thanks for taking part, this was introduced in the information sheet about the project that interviewees were given prior to deciding to take part.

4.8.2 Accessing, recruiting and interviewing carers

It was originally planned to recruit as many of the carer interviewees via the service user interviewees as possible but most service users did not want this contact to be made. Of the twenty service users interviewed, only three thought that their (potential) named person would agree to be interviewed. The researcher returned (to the interviewees' homes as both dyads lived together) on separate days to interview two of the carers but one dyad requested they be interviewed together.

Only those service users who had a definite named person whom they had either nominated, or planned to nominate, were asked if that person might be prepared to be interviewed, and only then if it seemed appropriate. One interviewee was reluctant to discuss his named person by name despite the confidential nature of the interview. This may have been because he revealed she had previously been a member of staff at a service, had ceased employment there but subsequently became his friend. The judgement was made that it would be intrusive to make the request. Most interviewees said that they thought the person would be too busy.

To increase the number of potential named person interviewees contact was made with a local carer organisation that was carrying out work promoting use of the named persons, however due to staffing changes and disruption at the

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[50] The Scottish Executive provided the researcher with a box of these booklets for distribution to service users and carers.

service, this did not result in any interviewees. An advert for potential interviewees was then posted on an internet forum for carers in the UK but this did not attract any responses. A further national voluntary sector carer support organisation was contacted which agreed to distribute an advert to their service users. This resulted in seven carers contacting the researcher for further information and agreeing to participate.

The seven carers were interviewed via telephone due to geographical distance. Similarly to the service users, interviewees interviewed face-to-face signed a consent form, whereas those interviewed over the telephone gave consent verbally after the form was read to them. This was because it was felt it would reduce the numbers participating if they had to wait to receive and then return a written consent form. It was ensured they had copies of the project information and the Scottish Executive named person guidance (Scottish Executive, 2004) and, as with service users, carer interviewees were given a £10 gift voucher as a token of thanks for participating. Ten carers were interviewed in total.

4.8.3 Accessing, recruiting and interviewing MHOs

Initially it was planned to access MHOs by approaching local authority teams so in order to obtain blanket approval, a letter outlining the request and providing information relating to the study was sent to the Association for Directors of Social Work in Scotland. No response was received and when the request was followed up by telephone and email, the researcher was informed that the person with responsibility for research was unlikely to respond due to workload issues. This meant that approval to interview social workers was instead sought from individual local authorities.

Before any planned recruitment had taken place, a team leader of a Community Mental Health Team (CMHT) saw a newsletter article the researcher had written on the named person provisions and invited her to give a presentation to the CMHT about the named person. It was agreed that after the presentation, MHOs within the team would be invited to take part in an interview about their experiences as practitioners. Details of the research were sent to the lead for

research within the Social Work Department who after approving the project, sought and received further approval from the Director of Social Work. A short presentation was given followed by a group discussion. Information sheets about the research were provided and the four MHOs present agreed to be interviewed. The CMHT leader had contact with several other MHOs in neighbouring local authorities and contacted them on the researcher's behalf to ask if they would be prepared to be interviewed. Three MHOs agreed and, after information was sent about the research to the relevant Directors of Social Work, three further interviews were carried out bringing the total to seven. Once seven interviews had been carried out it was decided not to pursue any further MHO participants as it was thought that data saturation had occurred after the first four interviews. All MHO interviews were carried out over the telephone, with consent provided verbally, as it was anticipated that interviews might need to be cancelled at the last minute due to unplanned events, which proved to be the case with several interviews.

4.8.4 Accessing, recruiting and interviewing policy influencers

Policy influencer interviewees were primarily accessed by publicly available minutes from the Scottish Executive co-ordinated Mental Health Law Reference Group (Patient Representation Sub Group), a group established to guide the development of the 2003 Act, several members had also been part of the original Millan Committee. There were 21 members of this subgroup so the overall list of attendees was reviewed and those people representing learning disabilities interest groups excluded. The remaining members were categorised as to the type of organisation they represented to ensure that no agency, for example, the Scottish Executive, with eight members, was over represented. Ten members were then invited to take part by email in which they were provided with a brief summary of the research, information sheet and research protocol (See Appendix 1). Six members responded saying they were willing to be interviewed and for the same reasons as with the MHOs interviews were carried out over the telephone and consent was given verbally. A further three interviewees were contacted after having been recommended by the original interviewees.

4.9 Timescale and recording of interviews

The fieldwork was carried out between October 2005 and March 2007. All interviews (except one at the request of a service user) were audio-taped and transcribed verbatim by the researcher. Interviews lasted between 30 and 90 minutes.

4.10 Presentation of findings

The data are presented in five parts over the following four chapters (Five to Eight) and begin with the background of the interviewees before describing their perceptions of the introduction of the named person provisions. Chapter Six reports the findings central to the autonomy of the service users with regard to nomination a named person. Chapter Seven presents the findings relating to the power imbalances between service users, carers and professionals and Chapter Eight reports how the provisions relate to the human rights concerns of choice and privacy.

The findings from the four groups of interviewees are reported together. Due to the pertinence of the theme being described some interviewee groups had more comments than others therefore some groups are quoted more than others. For example, MHOs had a lot to say about the administrative procedures under the 2003 Act, whereas service users did not.

Chapter Five: Background and findings: Perceptions and uptake of the named person provisions

Introduction

This chapter begins by describing the characteristics of the interviewees before going on to present their perceptions of the introduction of the named person provisions, the advantages for service users and carers and their explanations for the low number of proactive nominations.

5.1 Background

Forty six interviews were carried out with people from the following groups:

- Service users (n=20)
- Carers (n=10)
- MHOs (n=7)
- Policy influencers (n=9)

Table 3 shows a summary of the characteristics of the service user and carer sample. There were more females than males; three quarters of the sample described themselves as single and age ranged from the late twenties to the late sixties.

Table 3: Characteristics of service user and carer interviewees

Service users		Carers	
Characteristic	N=20	Characteristic	N=10
Gender		Gender	
Male	8	Male	4
Female	12	Female	6
Age		Age	
20-30	2	20-30	-
31-40	5	31-40	2
41-50	5	41-50	3
51-60	5	51-60	3
61-70	3	61-70	1
		>71	1
Named person status		Named person status	
Nominated	2	Nominated	3
Nominating	7	Considering	4
Considering	11	Not considering	3
Relationship status		Relationship to service user	
Single	15	Parent	4
Partnered	5	Child	1
		Partner	5

Only two people had formally lodged a named person nomination in their medical records. A further seven were clear about whom they would nominate and were at varying stages of the nomination process, some had completed the form but had not yet had it witnessed and were unsure where to send it next. The remaining eleven service users were interested in the provisions and were considering whether to use them. Four of these people were undecided about making a nomination, primarily due to a lack of an obvious candidate.

There were slightly more female carers than males; they were on average older than the service users and two, both parents carers of adult children, were over 70. Of the two carers in their thirties one cared for a parent and the other for a partner. Three carers had been nominated as named persons (two partners and a child). Another wished to become a named person but the relationship between

her and her son had become very strained. Three of the carers were accessed through the service user they cared for, forming three dyads: two being husband and wife and the other one mother and daughter.

The MHOs were all employed by local authorities. They all had several years of experience and had worked as MHOs under the previous Mental Health (Scotland) Act 1984. All were interviewed confidentially and were speaking personally, not as representatives of the local authority.

The policy influencers came from a range of backgrounds. They included people working in service user organisations; voluntary organisations; advocacy; legal services; Scottish Executive policy; and statutory services including the MWC and Mental Health Tribunal Scotland. Many of these interviewees described experiences in their daily practice, for example, voluntary sector service provision or as a member of a tribunal, as well as from their policy involvement perspective. As with the MHOs, all policy interviewees were speaking personally and not on behalf of their organisation.

5.2 Perceptions of the introduction of the named person provisions

The overall opinion from all interviewees was that the change from nearest relative to named person had been a positive move. The policy influencers were all positive, at least in theory, about the developments, seeing them as removing many of the previous legal problems with the nearest relative provisions and increasing choice for the service user, particularly those who did not receive support from their relatives:

> *"Yes, definitely, it was a good move and brought the legislation into the 21st century and recognised that not everybody has a good relationship with their family."* POLICY #3

However, all policy interviewees had become aware of the problems in implementing the provisions:

> *"I think that, certainly, in theory, they're a positive thing and, certainly, as an organisation and me personally, we supported them and thought they were a really good idea. We did lots of consultation with service users and our members and, certainly, everyone was very keen. Certainly, there have been problems in practice with the way they've been working."* POLICY #1

Similarly, the carers were all positive about the provisions, again due to the element of choice for the service users and the formal rights it gave them if they were nominated as a named person:

> *"In some cases it could be a very good idea. I mean we actually got married in 2003 but there was a very, very awkward time prior to that because there was a time when X____'s sister in particular, was trying to push her towards ECT and I was totally against it, but after we were married we were ok."* CARER #10

A carer who was already the nearest relative thought that, even though it would have defaulted to him, he was still positive about having been formally nominated:

> *"I think it's a good idea. Aye. Well, it didn't change much for me and her because I'm her husband and next of kin[51] anyway so I've always been involved, as long as this has been going on."* CARER #1

All but two of the MHOs thought it was a wholly positive development and the remainder thought that it had not made much difference. A positive reason frequently given was the choice it allowed the service user:

> *"Much better, much better, I think it allows choice that people didn't have before... I mean many people were happy to have the nearest relative involved but now it allows the person choice."* MHO #5

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[51] The term *'next of kin'* was often used by many interviewees to refer to the nearest relative although these are legally different positions. *'Next of kin'* is generally interpreted as being a person's nearest blood relation (Andoh & Gogoh, 2004).

Also recognised was the parity given to same-sex partners:

> *"I think it's a positive development in the sense that on some occasions people that were kept out of the loop like same-sex partners… can now be included."* MHO #6

The two MHOs who were more sceptical about the new arrangements had reservations based on the actual differences to their practice:

> *"I really, really don't know. It's not that much better than the old way where it defaulted and it only became problematic where there was a relationship issue or some kind of problem with the person it had defaulted to. I really don't know, I haven't really noticed a lot of difference."* MHO #3

This MHO did acknowledge the difficulties when the nearest relative was problematic but did not refer to how these problematic situations had been managed under the 1984 Act.

The majority of service user interviewees had a positive opinion toward the provisions, all but two thought the changes were a good idea. This was again primarily due to the introduction of choice and the recognition that not everybody's nearest relative would be an appropriate person to be involved:

> *"I thought it was a good idea as nearest blood relative wouldn't work for me and wouldn't work for a lot of people I know. And hasn't worked for people I know, so having someone I could choose would always be a good thing."* SERVICE USER #20

The two service users who were not as positive about the provisions had differing reasons. One thought that you could not be confident that the nominated named person would turn out to support your best interests and the other thought that family were usually the best people to be involved, although neither of these service users disputed the right to choose.

Overall, all interviewees supported choice for service users, with particular reference to problematic family relationships. Service users and carers were more positive in their views of the provisions, whereas MHOs and policy influencers all held concerns about the implementation and impact on practice. One comment encapsulated the overall opinion that choosing a named person was an important provision for those people whose circumstances would cause them to choose to use it:

> *"I think for a few key people that I've come into contact with, it's made a difference and they've felt better about it and could choose who would be there and who would be informed."* MHO #7

5.2.1 Advantages for service users and carers

There were a number of specific benefits identified by interviewees that the named person role brought. Over half of the service users thought that the main benefit of the role was that it could provide additional support from a person who knew the patient well during a time of crisis:

> *"I think she* [the person in the vignette] *is at a disadvantage just now because there's nobody… that knows her well speaking for her."* SERVICE USER #9

Many other interviewees thought that the key advantage of having a named person was that it gave a specific personal perspective concerning the patient, rather than a professional view:

> *"There may be relatives, carers, friends who say: 'We've been here before. I'm here to help out and as long as he gets the right support in the community, we can get through this together' and if they hadn't been involved and had that say…."* POLICY #9

Another interviewee expanded on the idea of the tribunal being one point in time, whereas an advantage of the named person was that they had a historical perspective of the patient:

"The named person is somebody who knows them and can understand them in the context of their life over time, whereas when you bring in an [independent] advocate or a lawyer at a point where things are in crisis then you don't get the same type of representation. So for those people who can't get named persons that can be a disadvantage." MHO #1

Two carers thought that a benefit of becoming a named person had led to them being more involved in care and support. The rights of the named person do not technically apply until the service user is under compulsory measures, but it appeared that the formalisation of the position had led to improved communication with professionals even when there were no compulsory measures in place:

"… At least if I'm the named person I can do stuff, I can be proactive behind her back. I can tell the GP or social worker, or whoever's involved at the time, what is going on and what she's not telling them and they have to include me. Because one of the things I found was that before I became the named person I was only getting information from mum and unless I went to seek the information out, the story I was getting from her was completely different from what I was getting from the social worker." CARER #4

The three carers who had been formally appointed named persons all appeared to be more confident about making decisions on behalf of their relative. They had all discussed the provisions with their relative and, as two of these service users were also interviewed, it allowed the dyads to be looked at as a whole. They were two very different couples. The first (CARER #2 and SERVICE USER #17) appeared more articulate and educated, being particularly involved in service user and carer organisations. However, the second couple's (CARER #1 and SERVICE USER #8) technical knowledge of the named person provisions was more accurate and they thought they had received good support from a hospital discharge team in putting the provisions into place. Both couples had obviously discussed the provisions at length and there was internal consistency within each dyad. For example, the service user had previously been treated with electro convulsive therapy (ECT) but she no longer wanted this to be the case:

"I was a bit concerned about the ECT. I've had ECT a way back, 24 years ago, I was concerned as I read in leaflets and it can give you long-term damage and I read that somewhere and I said I was frightened in case it gives me early Alzheimer's." SERVICE USER #8

Her husband and named person was quite clear about this:

"She's worried about the ECT now so she doesn't want that now unless it was a last resort, but we all know that because she's talked to the doctors about it and she comes home and tells me what they've said, or sometimes I go along with her." CARER #1

Each dyad felt that the discussion of the role of the named person had been a useful exercise in communicating their wishes.

5.2.2 Low uptake

Despite the perceived advantages of nominating a named person it was reported that there were few proactive nominations made by service users for named persons and the default option was the most common mechanism of appointment. This only occurs when compulsory measures are imminent, and when the service user will inevitably be in considerable ill health and their capacity to make a nomination may be diminished. As this is likely to be an acute situation with procedures moving quickly, nominating a named person in these circumstances was seen by some interviewees as not being a priority for the service user:

"I don't know numbers but it's unusual to see a nominated named person in that it's usually a default named person… It requires forethought to nominate a named person and people tend to react as things develop, rather than planning things in advance." POLICY #2

Other reasons given were concern over what the role entitled the named person access to:

"…For others there a wee bit of: 'I'm a wee bit worried of what this role actually is, does this person have more information than I would want them to have?'" MHO #5

Several interviewees commented that nominating a named person required an acknowledgement on the part of the service user that they may one day be subject to compulsory measures and that this was not easy for people to accept. It was compared with making a will, an example given being that many people do not have a will, despite the inevitability of death. As well as the acknowledgement of potential relapse, the issue of actively planning for it by appointing somebody to act on their behalf was thought to be off-putting for service users:

"I think the reason for that is that patients, when they're well, believe they're going to be well for evermore and the very notion of making an advance statement or appointing someone to act for them when they are ill, gives them the heebie jeebies, as it's almost an admission that at some point they're going to end up in hospital." POLICY #8

Several service users agreed they did not want to think about becoming ill when they were experiencing good health:

"When you're well the last thing you think about is hospitals and the illness. The last thing you want to think about is what you don't want to happen because you don't want to think about bad things." SERVICE USER #14

It was thought that there would be an organic increase in uptake due to those repeatedly subject to compulsory measures and thus being assigned a named person:

"Inevitably it will increase, as people become subject to the Act they're going to be exposed to the provisions and have a named person

appointed, so as more people become exposed to the Act the numbers will increase." POLICY #1

This gradual increase as a result of compulsory measures was not thought to be the solution to increasing uptake. One interviewee thought that measures such as this inevitably took a long time to take effect:

"People are just generally are very slow and I've done a lot of stuff on Adults With Incapacity[52] and low take up of making wills and executing powers of attorney." POLICY #6

Lack of motivation, difficulties with completing forms and satisfaction with the default named person were all thought to further contribute to the lack of uptake.

This chapter has provided the background to the findings and the perceptions of the named person provisions. The following chapter presents the findings related to service users' choice of named person.

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[52] The Adults with Incapacity (Scotland) Act 2000

Chapter Six: Autonomy and choice

Introduction

This chapter describes how a lack of full understanding of the named person provisions could undermine the autonomy of the service user in making a nomination. Although understanding could be increased by accessible information about the provisions, this did not seem to be available. It goes on to describe the people whom service users planned to nominate as their named persons and the reasons for their choices. Features of different relationships are described, in particular, a wish to use the nomination to spare responsibility falling to a carer.

6.1 Autonomy: Understanding and information

The named person provisions had the aim of promoting the involvement of the service user by allowing them choice about who is awarded rights to represent their interests and to be consulted during their care and support if they became subject to compulsory treatment. The nomination, made when the service user has full capacity, could be seen as an autonomous choice. However, there are factors that may undermine the autonomy of this choice, one of these being the understanding of the provisions which is further associated with the available information to promote this understanding.

6.1.1 Service users' and carers' understanding of the named person

One major concern of both MHOs and policy interviewees was the extent to which patients being treated under the 2003 Act understood the role of the named person, particularly, the capacity of the named person to act independently and the information the named person would receive (discussed further in Chapter Nine). Despite several service users referring to this right of independence, including those who had made nominations, they generally thought that unless a named person could be relied upon to support the wishes

of the patient, they should not have been nominated. One policy interviewee spoke of recognising this lack of understanding with service users:

"From the conversations I've had with a few people, I would think and this sounds really patronising, that they haven't really thought it through because a lot of people have said: 'I want a named person because I want somebody else on my side' and they haven't thought it through and something is missing in terms of the named person having the power to disagree and when you say: 'You know they could disagree with you?' there's a light that goes on in people's eyes and you think: 'Oh no'." POLICY #3

It was clear that, when considering a future or existing nomination, it was very important for service users that their named person carry out their wishes:

"She agreed to be his named person and I think she should abide by his wishes." SERVICE USER #17

This was reinforced by the majority of carers who also perceived the role as representing the patient:

"As long as that person is a voice for them." CARER #4

This lack of understanding was also thought to extend to the named person themselves in many cases, particularly where they had assumed the role by default, due to concern about the health of their relative:

"I do suspect in the midst of all the trauma, especially at the first time, you know your son's away at university and you appear at some sort of meeting and somebody says: 'Do you want to be your son's named person?' but you're not really listening as you're far too distressed. You realise it's something quite important and you care about your son so you say yes... I suspect that in the throes of all this information that can easily happen." POLICY #5

This emphasises that it may be particularly difficult for a default named person to understand their responsibilities if they have had no prior contact with mental health services or legislation. This was seen as unavoidable, particularly with default named persons for first episode patients as a result of the timing of the procedures and the circumstances surrounding them:

> *"I think the revisiting of it is important and we stress that... just because someone ends up with someone who's down as the default named person that should be reviewed and discussed with the person as soon as they're in a position to do that and not just set in stone."* POLICY #9

The ability to change the named person was viewed as a way of ensuring the service user was consulted about whether they were happy with the default named person at a later date. The default named person was also potentially problematic because a service user with some information and understanding could choose not to make a nomination as they thought themselves happy with the default situation until it came into effect, and only then might they realise the powers and rights awarded the named person.

6.1.2 Sources of information about the named person

Whereas all those professionally involved with mental health care were already aware of the named person provisions, service users and carers were not always. Eleven service users said they were already aware but the remaining further nine had only heard about the provisions due to the researcher attending their service to deliver an information session. Those who had already heard of the provisions had usually done so through using a voluntary organisation, although two people had been introduced to the idea through their CPN on discharge from hospital after a detention. Awareness was lower amongst the carers interviewed although all ten carers were the nearest relative to the person they cared for and as such would have been default named persons in the event of compulsory measures.

There has been one information booklet published by the Scottish Executive providing guidance about the named person provisions (Scottish Executive,

2004). It is aimed at service users rather than named persons although a named person could ascertain what their responsibilities and rights are from reading it. Awareness of this booklet was low amongst service users, only seven had ever seen it before.[53] Half of the carers had seen the booklet although none had read it all the way through, preferring to access support from a carers' service or mental health professional, which had always been their primary sources of information.

MHOs reported that the booklet was their only source of information to give to service users and their families. It was not seen in a particularly positive light by any of the MHOs; one commented on the inaccessibility of the booklet:

> *"A lot of the clients we have are not hugely academic and these things often read like they've been written for lawyers. It is difficult and even if you try without being patronising to break it down into layman's terms and I think they've tried to do that. But people are not going to understand the concept until it's put into practice and they really see what we're talking about."* MHO #3

Several of the policy interviewees had been involved with the working group that contributed to the writing of the Scottish Executive guide. They spoke of the group having only one afternoon to work on it and the different information needs of users and carers:

> *"Another problem was those leaflets are called information guides for users and carers but they were aimed at service users, carers have got different questions and they need to know different things."* POLICY #4

One interviewee thought it was inevitable that the guide was long due to the nature of the role:

> *"It turned into a very big volume but there's an awful lot to say. It's not a simple piece of legislation and the duties and the things that the named person can do, there's lots of them."* POLICY #7

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[53] All the interviewees were given a copy of the booklet if they did not already have one and any questions they had were answered.

Another policy interviewee thought that the potential implications of holding the responsibility warranted clearer guidance and support:

> *"Say you've been really opposing all the stuff and they don't make the order and the person takes their own life, where does that leave the named person? There are huge ramifications in this aren't there? So that's what I think, we should have had a guide for named persons really spelling out their duties and what they would be involved in."* POLICY #5

Concern about the accessibility of the information was not just about how it was written in English. One MHO had tried to access the information in a South Asian language and had been unable to:

> *"I tried to get a family information from the Scottish Exec website as they're supposed to have info in other languages and I couldn't get access to it. I just had to give the information verbally, because I speak the actual dialect I had to do that."* MHO #2

However, it was thought to be useful for potential named persons to discuss the provision with somebody who could explain it to them:

> *"WHAT INFORMATION DID YOU HAVE TO GIVE THE GRANNY?*
> *The purple book[54] but verbal communication, which I think she probably appreciated more, the verbal communication. I went to visit her at home and explained it verbally, I don't think the purple book is that great to be honest."* MHO #6

Another policy interviewee thought that other media could be used to produce information for service users and carers:

> *"...If there were other materials available, I mean professionals don't have time so if there were a DVD or an interactive bit of the website that*

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[54] *'The Mental Health Act: A Guide To Named Persons'* has a purple cover.

would talk people through what the issues are and use some real life case
studies to get people thinking about it." POLICY #1

Verbal discussion appeared to promote understanding, after discussing the provisions (in the information sessions delivered by the researcher) several service users commented that they now had a clearer understanding and were motivated to make the decision and formalise a nomination.

There was a lack of clarity about which agencies or individuals completed nomination forms should be given to:

"I have the form filled in and ready to go but who do I give it to? It's not
clear. People have filled them in but don't know what to do with them. Are
you even sure that when people become unwell it's going to be available and
people will see it?" SERVICE USER #14

One carer who had been nominated a named person described how the social worker had taken the lead with distributing the forms:

"WHO TOOK THE FORMS?
The social worker, yes, she took them off and the GP's got a copy, the
hospital, I've got a copy, mum's got a copy. The social worker really
helped, maybe we got lucky with the social worker? But it's not supposed
to make more work because it saves trying to scrabble round when that
person's going off their head." CARER #4

6.2 Autonomy and Choice: Whom service users want to nominate as a named person

The service user interviewees were all considering using the named person provisions and a key part of that consideration was deciding whom they would choose to nominate as a named person. This chapter will describe whom service users said they would nominate, whether they were family or friends, and the reasons why they would choose that person. The choice of not nominating

anybody is described as well as the wish of some service users to nominate professionals, often due to social isolation.

All service user interviewees were asked whom they would nominate and if this person was also their nearest relative. Table 4 below shows whom service users said they wanted to nominate (or already had, if they had made the nomination).

Table 4: Whom service users planned to nominate as their named person

Relationship of (potential) named person to service user					
Friend	Partner	Parent	Child	Sibling	Do not know
7	4	2	2	1	4
Number that were also nearest relative under 2003 Act					
0	3	2	2	0	0

All those service users who had a partner said they were likely to nominate their partner (including one same-sex relationship); the majority of those who were single said it would be a friend. Of all those who did not know whom to nominate, none said they would nominate a relative. Of those who were nominating relatives four would be appointing their nearest relative who would have been appointed by default regardless. Overall, seven service users would be nominating their nearest relative, as defined under the 2003 Act

6.3 Reasons for nominating someone as a named person

Service users were asked to explain what was important to them when considering making a named person nomination. The reasons given fell into two categories: that the named person knew the service users' wishes; and that the named person would support actions in line with the service users' wishes.

The typical response, when asked whom they would nominate, referred to the closeness of the relationship the service user had with the potential named person:

> *"She's been a very good friend, she knows me really well… She's someone I can rely on, like the sister I never had."* SERVICE USER #14

Such statements were further reinforced by the interviewee saying how well their potential named person knew them:

> *"He knows me inside out."* SERVICE USER #8

This was only the case for those nominating partners and friends. Those nominating parents or children did not speak in these terms but with an assumption that the relative had historically taken responsibility for them:

> *"My mum's always been responsible for me, she's my mum, she's had to do it for years."* SERVICE USER #2

Service user interviewees felt very strongly that actions following their wishes should be supported by the named person, regardless of their own opinion. However, trusting the judgement of the named person was described as being important but only in circumstances when the service users' wishes were not known. There was a close relationship between people trusting the judgement of a named person if they felt the named person knew them well and already knew what their wishes would be:

> *"I would trust her judgement but I also know that she* [the named person] *would know how I would feel. She would empathise with my situation but she would also take a broad view of the situation."* SERVICE USER #15

The independent judgement of the named person was seen as only coming into effect when they had not previously expressed clear wishes to their named person and were no longer capable of making their own decisions:

"WHAT WOULD BE IMPORTANT TO YOU? [IN NOMINATING A NAMED PERSON]

For them to know what I wanted, or what I didn't want more importantly. SHOULD IT BE YOUR WISHES THAT ARE MORE IMPORTANT, OR THEIR JUDGEMENT?

The latter, as I would lack capacity to know whether they were right or wrong. There are some things I feel really strongly about and anyone who knows me would know about those things... but if it was a judgement call, it would have to be someone whose judgement I trusted." SERVICE USER #20

The concept was tested using a vignette (See Appendix 2) with service users to provide a clearer situation that they could relate to and comment on. The vignette described a situation where a named person disagreed with the wishes of a patient. Interviewees were asked to comment on what they thought the named person should do. They all thought that the named person should disregard their own opinion and support the wishes of the patient.

6.3.1 Nominating relatives

Three service users thought that family were the most appropriate people to be involved. All had positive experiences with their own families and all were nominating relatives:

"...It's better in the family. It should be kept in the family wherever possible." SERVICE USER #17

Most of the carers and service users described problems within either their own family of origin or, if they were partners, in that of the person the cared for:

"I know blood isn't thicker than water as I haven't spoken to my own immediate family since 1995 and to me friendship is something you build up and build up a trust for." CARER #10

One interviewee spoke of her lack of trust for her family of origin:

> *"SO NOT A FAMILY MEMBER?*
> *Absolutely not. Because what I find is a lot of the people I know, the relationship with the family has totally broken down, whether it be through aberrant behaviour over the years, anything could have happened and that relationship has broken down, there's no way… trust is a hugely important thing and I just wouldn't trust my family."* SERVICE USER #20

Another spoke of the additional factor of physical distance:

> *"I know my big sister X____, lives in England, she would jump at it* [being a named person] *but she lives down there. And me being in hospital is enough of a problem without her having to deal with how long I stay in, having to deal with my house when I'm in the hospital, how would she deal with it? She'd have to come up and that wouldn't be fair."* SERVICE USER #5

The issues of judgement and trust were often described in opposition to relationships with relatives, highlighting the importance for many service users of their family not being their named person:

> *"I wouldn't be too confident that they* [the family] *would follow my wishes. My instinct would be that a friend would be better at representing my wishes."* SERVICE USER #15

Half the service users said that they thought that relatives were less likely to act according to their wishes, often due to their role as carers over a number of years. This was discussed by several service users who thought that they had been infantilised by their families:

> *"Because they think they know what's best. It's the nature of illness. The family are so used to being the caretaker, the one who makes the decisions, you're never ever allowed to grow up. You get a sickly child role and friends have more respect for you than that and respect your*

boundaries and the decisions that you make… or why else would you have them as friends?" SERVICE USER #20

Sparing relatives responsibility

One way in which the named person provisions were being used by six service users were as a way of removing responsibility either from their family entirely, or from specific relatives:

"It's like my sister, she's so worried and upset by me as it is, I wouldn't want her to have that responsibility." SERVICE USER #15

One interviewee's nearest relative was her elderly parents:

"No I wouldn't want that as it would stress them as they don't keep too well." SERVICE USER #5

One service user was also concerned about asking her son to be her named person as she said he had *'gone through enough'*, a sentiment echoed by two other service users in relation to their (now adult) children.

A policy interviewee referred to the potential for service users not to want to impose a burden on relatives, especially if they were experiencing depression:

"If they're very, very depressed and don't feel they're worth anything and they don't want to bother anyone with all this, its all part and parcel of being depressed." POLICY #5

This was slightly different from the service user making a pre-planned choice to not wish to burden people though, as it is implied, it is the depression that is leading to the reluctance to make a nomination and would raise the question as to whether they were currently capable of making a nomination.

One of the carers explicitly spoke of her role as her mother's carer and named person changing the *'usual'* nature of these relationships. She thought that the

responsibility she felt for her mother had been imposed on her in the absence of anyone else to take responsibility. She spoke of how she looked at other people using their parents as a source of support with regret:

> *"You're supposed to be able to lean on your mum when you're having a crappy day, say: 'Come round and take the kids off me,' and I didn't have support from her when my daughter was ill in hospital so when I went through that I had to lean on my husband, as the person who could help was dependent on me."* CARER #4

6.3.2 Nominating friends and partners

The majority of the service users wanted to nominate partners or friends. Friends were often seen by service users as having greater insight than family into the wishes of the service user, due to both the likelihood of them having discussed treatment options and the greater equality of the relationship:

> *"DO YOU THINK IT IS EASIER FOR FAMILY TO OVERIDE PEOPLE'S WISHES?*
> *Yes, because they'll say they're acting in the best interests. Whereas it's probably something that friends will have had a conversation about. It's like ECT. I'll never consent to having it, never, and all my friends know that… But my sister would go straight for that if she was persuaded that would bring me out of it quicker, instead of trying anything else first. I think a friend would be more for trying other things first and would ensure that it was a last resort."* SERVICE USER #15

The discussions over the suitability of relatives in decision-making processes raised the further issue of who service users believed knew them best and with whom they discussed their true feelings:

> *"My friends understand me and know me inside and out. Family are different. You can feel embarrassed with your family, that you've let them down and it can make you more ill… with friends you're more equal. Family drag something up from 15 years ago, friends don't."* SERVICE USER #17

However, the friendship was also seen as a relationship that may breakdown, similar to a partnership:

> *"You might nominate a friend who you're very friendly with but they might turn out to be totally unsuitable... At least you're not stuck with someone who's against you and they can always be revoked."* SERVICE USER #3

The importance of being able to change a named person was highlighted here.

A quarter of the service users were planning on nominating a fellow service user as their named person. This raised the issue of not only the capacity of the service user to make decisions and contribute to the debate surrounding their treatment, but also, potentially, that of the named person. This was discussed with other service users through one of the vignettes, or as a topic that arose during the interview when discussing friendships within services. The attitudes towards the possibility of one service user acting for another was seen as an advantage by these service users due to the expertise that they thought another service user had gained by experience:

> *"Well, she's someone who's had her own problems so she knows what it's like to be in the system but she's keeping well these days. I trust her and she knows me very well and I'd do the same for her."* SERVICE USER #9

All those service users wanting to appoint fellow service users referred to the named person having to have the capacity to take on the role but did not view this as an impediment. This positive view was not taken by the remaining service users. Four people raised the issue of whether another service user would have the capacity to take on the role:

> *"I'd pick someone who wasn't ill too. They could get ill and couldn't cope with my illness too, so I'd pick someone who wasn't ill."* SERVICE USER #11

The same service user suggested that a service user acting as a named person may not be able to act independently from the service user for whom they were acting. They thought they may only carry out the service user's wishes:

> *"I think the named person, someone with the same illness or problems could be easily manipulated into doing what the patient wanted, they could be weak or unstable and that could be difficult."* SERVICE USER #11

One service user spoke of why he would not nominate a fellow service user as a named person as he thought her own agenda was too dominant:

> *"The obvious person is my friend X_____ but she's not very well herself. She's a Szaszian and she doesn't believe in psychiatrists… So she's the obvious person but I don't think she'd be too good as she thinks the system should be shut down!*
> *DO YOU THINK SHE WOULD PURSUE HER OWN AGENDA?*
> *I'm sure she'd act in my best interests, but in her own way."* SERVICE USER #3

One MHO also raised this potential difficulty, although he did acknowledge that no named person's behaviour could be guaranteed:

> *"I know one service user who would like to appoint himself to that role. He regularly counsels others and in many ways he'd be the worst person they could have… There are occasions when the other person could be quite meddlesome…. Although those criticisms equally lie with relatives."* MHO #4

Two service users thought that it was better if the named person was never a service user, whereas others did not feel as strongly. They still thought it was more suitable if the named person was not also a service user due to the potential for breakdowns in relationships that they had frequently witnessed in relations between service users. Two others referred to the potential for fluctuating capacity in another service user and the potential that they may not recognise illness in the other:

"Oh aye, there could be a problem with that. I would say so… If the person's ill the other might think the person's not ill and it could be awful." SERVICE USER #8

One service user expressed concern about thinking in this way:

"I've seen people be OK one day and then take a turn the other way, so I think there could be a problem there, that sounds bad doesn't it? It's like saying that people with mental health problems can't be trusted." SERVICE USER #7

Sixteen of the service users were asked if they themselves would consider acting as a named person (only 16 were asked as this question was only added after four interviews had been carried out, having been raised by a service user). The opinions were divided three ways; five service users said they would definitely take on the role for another service user and one interviewee had already agreed to act for two other service users:

"There are probably people I would turn down, that I don't know them that well. The two folks that have approached me I've known for a long time so that's different, plus the likelihood of getting called up is small. I can see myself being approached by others but it would depend on the situation." SERVICE USER #20

Those who said they would agree to be a named person often referred to their own mental health and the fact that they had been well for some time, which made them feel they were a suitable choice:

"Yes, I've got a caring nature and in here I work with people and do buddying but that's because I'm doing a lot better at the moment. It's like everything else once again; you don't know what will happen in the future. If I was nominated and then I was really ill myself of course that would be a different story, but being the way I am just now it would be OK." SERVICE USER #8

This was not the case for the rest of the service users. Five said they would take on the role but with reservations, the main one being concern about their own ability to represent somebody in the tribunal situation:

> *"Aye I would but I'd worry about having to speak out for them, I can be quite nervous, you know. Public things would make me anxious but I'd do it if they really wanted me to. It's a responsibility though, and it could be quite frightening knowing you have that responsibility for somebody and they're relying on you."* SERVICE USER #9

Another reservation from three service users was that they would have to know the service user very well before they would consider taking it on. A further six said they would definitely not take on the role as they would find it too stressful. However, within these six two did say that if it were for family they would feel obliged to do it and one service user said that additionally to family he would also do it if it were for a friend who had no one else to turn to. All MHOs were of the opinion that service users should be entitled to nominate a fellow service user if they wished to, however, their concerns were similar to the service users regarding the capacity of the person to act.

Of those nominating their partner, two were married and another had been cohabiting for more than five years so they would have already been treated as their nearest relative. However, one service user was in a same-sex relationship and they had not been cohabiting for more than five years. She also had a problematic relationship with her family and, thus, was particularly keen to make a nomination. The relationships between service users and their partners were described in different terms to those of the parents and children. There were fewer negative comments, and references made to both friendship and love. One service user described the friendship between herself and her husband:

> *"He's my best friend as well as my husband and we've been married 22 years and I wouldn't nominate anybody else."* SERVICE USER #14

Whereas another spoke of his caring being because of his love for his wife:

> *"I try my best, I try my best for her and I would like to think that I do the best for my wife, the person I love."* CARER #10

The one reservation expressed about partners was the potential for relationship breakdown, particularly if people were too quick to nominate partners:

> *"Because they* [the relationships] *might not last and then it's trouble. I mean, I was going out with someone in here and we split up. We're still friends, like, but I wouldn't want her in charge of anything!"* SERVICE USER #4

However, this criticism could equally apply to friends or relatives.

6.3.3 Nominating a professional as a named person and social isolation

Three of the service user interviewees said that they had wanted to nominate a mental health professional as their named person. One was in the process of making the nomination as the professional in question was no longer working in mental health services and he now saw her as a friend. The other two were unable to make the nominations due to organisational policy. One policy interviewee from a voluntary organisation thought that service users often saw staff as friends but the two roles were incompatible:

> *"…It can be quite difficult sometimes that people think of a professional as a friend and I think there have been circumstances, where workers have been asked if they can be the named person and they can't… unless they feel they have a personal commitment to that individual and if they have, they shouldn't be working with them…"* POLICY #4

The fact that service users may see staff as friends was seen as an illustration of the frequent isolation service users experienced:

"That's a sad indictment of society and it shows that the service user doesn't understand the named person role." POLICY #3

Several interviewees, particularly among the policy interviewees, spoke of the number of service users they had encountered who had nobody they could nominate. This was often described in terms of social isolation:

"One of the things I found quite shocking… [is] *the number of people who just don't have anybody to act* [as named person] *for them. A lot of people have said to me: 'Well, I've got a neighbour' or 'I've got a lawyer'... This is so sad and I found that quite a lot."* POLICY #7

An interviewee who had been a member of the Millan Committee said that the original assumption was that all patients would have someone in their life they could appoint as a named person and that this was possibly why the provisions for identifying a named person by default were less than satisfactory in some cases:

"…Because otherwise it just gets very silly and stops being about the person's best interests and starts being about obeying the letter of the law…. and at the end of the day is that going to help the individual? I would query whether it would. In a very silly way it was something that we didn't consider on Millan would be a possibility, that somebody could have that degree of isolation." POLICY #4

The isolation of many service users from wider society was seen as another reason why they may want to nominate a fellow service user, as they did not have any other people to choose from:

"A lot of people who are isolated don't have people who are outside the mental health world because they've lost all their friends from the past, so their friends are other service users." MHO #5

Those patients in the State Hospital[55] were referred to by several interviewees as being particularly isolated:

> *"I did some talks at the State Hospital where they were in the position of not having anyone, plus the stigma of being in the State Hospital and they hadn't had contact with friends or family for years and they really felt they were excluded."* POLICY #1

Interviewees discussed what should happen with service users in this position as it might make people feel more isolated if they were encouraged to appoint a named person and they did not have access to a suitable person:

> *"I mean how awful would that make you feel, you have to have a named person and to have to say:* 'Well, I don't have anyone.' *How sad is that?"* MHO #1

One interviewee thought that there were other situations in life where people simply do not have anybody to take on a non-professional but legal role and often there may be no solution.

> *"But if you've got no one to have that role then such is life and it's very unfortunate but that sometimes is the case, it's a fact of life. What if you need a welfare attorney? If there isn't anyone, you can't name one. There are lots of areas where those people are disadvantaged to a degree but it's part of their life, they're probably used to it anyway."* MHO #5

This chapter has presented the issues related to the autonomous choice of service users and the issues surrounding choosing particular people as a named person. The following chapter describes the inequality in relationships between service users, carers and professionals.

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[55] Scotland's high-security hospital.

Chapter Seven: Power Imbalances

On the face of it service users have the choice to make a nomination or not and those whom they nominate have a choice whether they accept the role. The actual situation is rarely as straightforward as this and there are a variety of power imbalances that influence the decisions made both by service users and carers. This chapter will examine interviewees' experiences of the imbalances of the relationship between carers and service users, and then the wider imbalance between both service users, carers and the mental health system, represented by professionals.

7.1 The relationship between service users and carers

If the service user has a carer there is a fundamental imbalance between them, with the service user dependent to some extent on the carer as well as on the duties under the 2003 Act to involve carers whether they have been appointed a named person or not. This was thought to make it very difficult for the service user to make a nomination for named person that might go against the wishes of the carer and it was thought that many service users might feel a pressure to nominate their carer or relatives. Service users had concerns about offending relatives and for carers the concerns were that the service user might not nominate a suitable person. Three service users spoke of the potential problems of choosing to appoint a friend rather than a relative or partner:

> *"SO COULD IT CAUSE TENSION IF YOU DON'T EVENTUALLY PICK YOUR PARTNER?*
> *Potentially, yes, and I could see myself doing it to take any pressure off her. If you've got a good relationship you should be able to say why you're doing it."* SERVICE USER #20

The majority of other interviewees also thought that the majority of service users with relatives who were either carers or with whom they were in regular contact would feel obliged to nominate them:

"You can imagine that you do have to be quite assertive if you're saying: 'No I don't want my mother, I want to appoint a friend'. You've got to be quite assertive to do that." POLICY #6

There was also a perception by carers that it may be hurtful to not be nominated:

"I think most carers would just feel hurt, it could be a real kick in the teeth." CARER #5

Service users recognised this potential for conflict and hurt feelings when discussing whether they would act as a named person for a friend. One referred back to relieving responsibility from the family or carer:

"You wouldn't want their family to be offended, so I think, if that was me, I'd want to talk with them and explain why they'd chosen me instead. You know, it's about taking the pressure off them and that could be beneficial for the family member as well, as they can be so busy caring." SERVICE USER #9

Carers were asked about how they would feel if the person they cared for chose someone other than themselves as a named person. Whilst none actually said that they would object, there was concern from some that the service user might not nominate somebody suitable:

"I suppose it would have depended on who she was going to go for. If it had been her best friend who's known my mum for 20 years and been a nurse for 30 years and knows what's gone on and is very level-headed, then I wouldn't have worried. But if it had been my sister who doesn't give a crap about anybody else, it wouldn't have benefited mum at the time." CARER #4

Carers often perceived themselves as the person who knew the service user best and had become very knowledgeable about their problems:

"HOW WOULD YOU HAVE FELT IF X____ HAD ASKED SOMEBODY ELSE AND NOT YOU?

If it was someone she was asking because they knew more than me, I wouldn't mind, but I know quite a lot about it all now so I don't know why she'd ask someone else. I've learnt a lot over the years with it all." CARER #1

It was further thought that the decisions the carer made when the service user was not competent were ones they would agree with:

ARE YOU CONFIDENT THAT YOU'RE SAYING AND DOING THINGS THAT SHE WOULD AGREE WITH, IF SHE WERE CAPABLE?
It's a hard one, it's really walking a thin line. Now, at the beginning it was very, very hard but now, after being together for ten years, I hope I've got the balance right." CARER #10

One carer and named person did not have these concerns. He had experienced nearly thirty years of his wife being regularly admitted to hospital under compulsory measures and took a more pragmatic view towards his previous involvement in these procedures. He described how he did not see his wife as *'herself'* when she was ill, which seemed to help him view the situation outside of their normal relationship:

"I knew that it wasn't her talking, just the illness making her like that, you know?" CARER #1

The passage of time in relation to knowing the service user well was referred to by several other carers.

Despite the perception that carers would want to be nominated as a named person, the carers interviewed were reluctant to participate in decision-making. A much older carer in her eighties caring for her son frequently spoke of the conflict she felt between treating him as an independent adult and looking after him:

"My daughters will say he should be on his own and I say he doesn't want to be on his own and I think that would be like putting him out, it would have to come from him… I say X____'s a man now and he has to make decisions of his own. Young people today are different, I'm 81 right enough." CARER #7

The carer may equally not be able to make a fully autonomous choice about becoming a named person as they may feel obliged to accept a nomination. Service user interviewees said that even though they did not want to become a named person they would agree to do so if the person was a relative or if they were a friend with nobody else to ask. To reject the role would require a written declaration to the local authority. One interviewee saw this as a potential rejection of the patient:

"…Then you get the awkward situation where the named person has to make the declaration to say 'I don't want to do this' which makes the person feel like they're giving up on their loved one. But it's because of the level of responsibility that the named person has." POLICY #7

The carers who were interviewed had all been keen to be involved in their relatives' care and support. It was service users who were asked whether they themselves would act as a named person who expressed concerns about not wanting the responsibility and the stressfulness of the role; something echoed by a policy interviewee who considered it:

"I don't think I'd be happy to be nominated as a named person by a friend or a family member because I'd be terrified that if I did disagree with them, what would I do?" POLICY #6

The formal nomination and witness process was seen as giving legitimacy to the nomination when relatives may have objected to the appointment:

"…Their relatives, they might not be very happy, me being a friend [and nominated named person]. *They would see it as their job, think that they*

know better. Here I am given this responsibility… It would be in writing though." SERVICE USER #13

One way thought to reduce the duress that a service user may feel to nominate a carer or relative was through investigation of the case by the person acting as a witness to the nomination. This was not currently thought to be a particularly inquisitorial process:

"Unless you set up an interview where the person who's the named person is there with the nominator and is interviewed by the witness then it's a responsibility for the witness. What happens to the witness if it goes pear shaped? I wouldn't do that without speaking to both of them first. I don't know what training they've been given, witnesses. My psychologist has never met my partner." SERVICE USER #20

There is currently no requirement of witnesses to interview the proposed named person, merely to testify that the service user is acting with capacity and not under duress, although this duress may be subtle and require an understanding of the service users' history and circumstances before it becomes apparent.

7.2 The relationship between service users and professionals

The relationship between the service user and potential patient and the mental health system, represented by professionals involved in detentions, is one where the service user holds least power. The fact that the service user can be declared incapable of making decisions and have their autonomy temporarily removed and that this has been the case for centuries means that there is frequently mistrust in the mental health detention system. One policy interviewee from the voluntary sector thought that it was this mistrust that meant people were not taking up the provisions of either advance statements or named persons, and this situation would take decades to change:

"I think we've got a couple of hundred years of mistrust in psychiatry for a start. I think that people see it as quite an oppressive system and psychiatry's got a long way to go to convince people that psychiatrists do

a good job and are on your side. So in terms of convincing service users that actually making an advance statement is going to help you and people are going to take notice of it… I'm not sure how convinced I am that if I was in a state of distress, how much notice a psychiatrist would take of something I'd written, especially if it were something they didn't agree with." POLICY #3

Although another interviewee felt the system had been improved due to the new act, giving the example of the introduction of tribunals:

"The real big thing that people hated was going to the place [the Sheriff Court]*, the stigma, the sitting around in the waiting room with criminals… The atmosphere of the place was not conducive to dealing with mental health… The big, big difference comes from the Act and the rights that the patients have and that it's taken seriously. Lots of people there who are there with a specific perspective that the tribunal must take account of, there's no longer any excuse for saying: 'Well, we've heard from Doctor A and we've heard from Doctor B, what else do we need to hear?' Which was very much the case in the Sheriff Court."* POLICY #8

However, regardless of these new rights awarded to service users there is still an inherent imbalance of power and one MHO felt that some service users would see the nomination of a named person as a futile act due to the essential paternalism of compulsory measures:

"But for a lot of people unfortunately I think that is the case: 'Do what you like as I can't stop you anyway because you've made the decisions and you're the professionals' and I think that does happen at times and I'm not saying that people don't act in the client's best interests but still it can be paternalistic. You don't want to generalise, but the power balance is always against the client and I'm sure they're very aware of that." MHO #1

Other MHOs thought that the imbalance of power between service users and professionals was further extended due to the potential dependency of the service user as a result of their mental health problems:

> "I do think there's a motivational thing as well. Do they do it [lack the motivation to take proactive decisions] in other aspects of their lives anyway or are they quite dependent and happy to let other people do it for them? So they might be the people who are like: 'I'm quite happy to let my nearest relative do it, I'll just carry on the way I've been doing it.' In that sense it is a wee bit difficult." MHO #5

Two interviewees further referred to class as playing an important role in the use of provisions:

> "Those tensions again around disadvantage, around class, race and gender come up and bite you. Have you seen the HUG[56] DVD which is a group of fantastically articulate middle-class people and I'm giving away some of my own political views, but there is a bit where the middle-class are incredibly adept at appropriating things for themselves." MHO #4

It was observed during the interviews with the service users and carers that many of those who had volunteered to be interviewed and had an interest in the named person provisions tended to be articulate and confident, with a clear sense of their rights and entitlements. The policy interviewees and MHOs were asked to comment on the observation that if it were those people who were most capable of asserting their opinions who were most likely to use the provisions, was there not a danger of the most vulnerable of service users not taking up the provisions. All the policy and MHO interviewees agreed that this was usually the case but thought it was inevitable:

> "Well, I mean, I think the more you're aware of your rights, the more you're going to take them up, so I don't think that's surprising in a way." POLICY #9

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[56] Highland Users' Group. A service user organisation that produce anti-stigma media.

This perceived inequity of accessing provisions under the 2003 Act had led to some services making concerted efforts to ensure the provisions were proactively introduced to all service users, particularly those unlikely to act proactively themselves:

> *"Yes, I certainly would say it is the case and one of the things we're trying to do to change services here is to try and work more assertively, have a more assertive outreach and to try and adopt that practice… My personal experience is that you keep going back and you keep going back until you can engage and I'm not saying you can do that with everybody and you need to put a lot of energy and effort into doing that. It pays off for that individual and it has happened, I've done it so it's not impossible."* MHO #1

However, this meant very much that the use of the right to appoint a named person was something that required promotion and support from a professional. The professional could have a role in explaining the provisions, advising the service user about who may be appropriate to nominate, supporting them by witnessing the nomination and then ensuring the nomination was recorded in all the required places. Those service users who had completed the forms without support were unsure how to get the nomination formally recorded.

Some professionals saw it as part of the professionals' role, particularly that of the CMHT, to encourage service users to use the provisions. Several MHOs described how they were trying to increase uptake amongst the service users they worked with regularly, by integrating discussion around the named person into standard assessment and review procedures:

> *"That's the way we've tried to tackle it, integrating it into assessment and care management and review meetings, and trying to get staff to be more aware and saying to people: 'What do you think about it?' Particularly if people have been subject to the Act on one occasion and maybe want to think about what they would want to be different."* MHO #7

Other interviewees felt that all contributors to the service users' care had a role to play in encouraging people to use the provisions and those with the most regular contact needed to be encouraged to raise making a nomination with service users:

> *"I think to a certain extent it's how it's sold to people, for example, if the people who are going to be most in contact with folk are nurses and they're not giving information about the benefits, they're just saying: 'You've got this right' and then not engaging with people, then maybe it's a training need for nurses and I don't want to dump it on them, but they often have that ongoing contact."* POLICY #4

The role of voluntary sector services was perceived as being slightly different and more about promoting service users' rights:

> *"I've been surprised, I'd imagined that advocacy would get quite involved in this but they don't seem to have done in our area."* MHO #7

Some of the policy interviewees were also senior managers of voluntary sector services. They reported that these services had all carried out awareness-raising work; one interviewee thought they were better placed to do this (if they were adequately resourced) as they could spend more time with service users than the statutory services:

> *"There are issues in the voluntary sector around resources and capacity, the same as in the statutory sector but there's definitely a role and we did some stuff at the time, we encouraged our services to have these discussions."* POLICY #1

However, one interviewee thought that those who did not use voluntary sector services and who might be more vulnerable would always be difficult to engage:

> *"It's always going to be limited, by the nature of the group."* POLICY #2

One interviewee thought that if there were enthusiastic professionals, they would increase service users' use of the provisions:

> "[A professional] *said she'd sat down with everybody and talked through advanced statements and named persons, and, without too much fuss and bother, she got everybody involved in drawing up an advance statement and nominating a named person. So I don't know, whether it's just a case of getting some dedicated person who really believes in it?"* POLICY #7

This further relies on a professional having the time and resources to *'champion'* the provisions which would certainly not have been possible for the MHO interviewees. However, there could be a downside to enthusiastic professionals using their influence to pressure service users into making nominations without fully understanding what this would involve and which may not actually be in their best interests, particularly in terms of information-sharing (as discussed below):

> *"I'm slightly worried about some of the stuff in the code of practice that encourages MHOs to go out and make sure people appoint. People have to be made fully aware of what the impact of this is in that they* [the named person] *might see confidential medical information."* POLICY #6

Other professionals were reported as being less likely to provide support, firstly, as some had negative attitudes, secondly, because they did not perceive it to be their role or they did not want to upset the service user by discussing relapse or create work for themselves. One policy interviewee told of witnessing negative and judgmental attitudes towards advance statements which they thought would equally apply to the named person provisions:

> *"I have been at a meeting where I was trying to train some nurses for something else when I heard someone saying 'Oh no, I'm not doing that advance statement stuff as schizophrenia is an insightless disease,' meaning that it's absolutely inappropriate to draw up an advance statement.*
> *WHO SAID THAT?*

One of the nurses... I thought 'Well, you know this is the kind of thing you're up against'." POLICY #7

A more complex situation was the opinion that the named person nomination should not be influenced and supported by professionals, and this was reinforced by the information provided about the named person that some MHOs thought implied that the use of the provisions would be service user led:

"...There could have been improvements, been clearer about speaking to the named person and a bit more guidance about what steps the person had to take. But I can understand why they didn't want to do that as they didn't want it to be professionally led." MHO #7

He further thought that this might have affected overall uptake:

"...Different areas had different views on the process. So I don't know whether that's influenced take up because some areas seem to be saying: 'We wouldn't be having a procedure because it's up to the person,' and I got the sense they were abdicating any responsibility and: 'Really, if the person wants to do it, fine, but we won't help them.' Maybe it was only a couple of people saying that, but I was thinking: 'If that's the message then you're not going to get a high take up.' You've got to be quite proactive to get people thinking about it." MHO #7

Some MHOs felt they should not be too involved with the named person nomination due to a conflict of interest if they provided support to the named person, other than written information:

"I think we do that in a very general way in as much as we give people written information, but, beyond that, I struggle to say how we would do that. Once you've set that in motion there's a conflict of interest." MHO #4

One thought that it was essentially a private arrangement between the service user and the named person:

"This is actually a contract between one individual and another individual, it's a personal contract, its not obligatory and it shouldn't be influenced. That's the big danger, if you go and talk to somebody about this you influence them either positively or negatively, because in one sense we can provide information but we shouldn't be influencing their point of view as to whether they want to take the role on or not because, as I say, it's a contract between those two individuals." MHO #5

One service user recognised the potential conflict of interest but thought it should be the responsibility of the key worker to discuss the named person with the service user, or at least refer on to another agency:

"I think something should be done as a matter of course now. All the CMHTs have caseloads, five minutes it would take to explain. The key worker or whoever they see the most. Point them in the direction of advocacy if you want to remain neutral, but do it." SERVICE USER #20

One interviewee thought that professionals were also concerned about making people uncomfortable by discussing potential relapse with them:

"I think professionals are a wee bit scared of signing off anything that's at all controversial and they're using the old: 'When I talk to people about it they're uncomfortable and don't want to be reminded of how unwell they were when they were first admitted' excuse." POLICY #7

One service user thought that professionals were not encouraging uptake as it would cause more work for them and the impetus would remain with the service user:

"I think they're afraid it'll create more work for them. There'll be big red stickers on medical records so all that fussy stuff they'll have to do. You're going to have to be the one that chases, the onus is on you but how can you ask the question if you don't know the information? If people don't have the information then how can they ask the questions? Where

do they get the forms? Who witnesses it? Where do they take the forms?"
SERVICE USER #20

This service user described the need for information before service users could act for themselves.

The tribunal hearing was the forum in which the service users' lack of power was exposed. Although the tribunal had been seen as an improvement on the previous hearing of cases in the Sheriff Court, it was still viewed as intimidating to the service user and the element of compulsion to attend was clear:

> *"I think the whole tribunal process can still be intimidating even though it's away from the courts, you've still got to go and there's these three people and you've got to give evidence and there's all sorts of things going on like that."* MHO #2

Even if the service user obtains and understands the information and makes a witnessed nomination for a named person, this choice can still be over-ruled by the tribunal and a different named person appointed in their place which undermines the autonomy of the decision.

7.3 The relationship between carers and professionals

The relationship between carers and professionals contains many imbalances that can influence the use of the named person provisions.

> *"You've got to have a really good relationship with somebody or you don't get anywhere."* CARER #4

 The experience of carers becoming named persons or wishing to become named persons in future was always referred to in the context of their previous relationships with mental health professionals, and many reported negative experiences with professionals. One carer had a negative opinion of physicians. She thought that they did not value the knowledge of the carer:

"Some doctors don't want the information from a carer. It's almost like a God complex that they get. They don't sometimes realise that they may know all the professional stuff about that illness, but they don't know about the everyday, like she's only eaten Shreddies[57] for six months, the other things that she would do, that go back twenty years so I think they have to see that carers are there not to do their job, but to help them do their job." CARER #4

The subject of physicians using medical terminology was raised by other carer and service user interviewees; one carer described how the social worker acted as an intermediary:

"Because she [the social worker] *can talk to doctors and then talk back to us, she can understand doctors' jargon and translate it back to us and put it in a way to make it easy for my daughter to understand. Sometimes they speak like they've got encyclopaedias in their mouths. Some of them I can understand but a lot just use jargon."* CARER #8

Other relationships were more positive and carers felt involved and included in the service users' care.

"The doctors talk to me you know, ask me how I think she's doing when she's in the hospital." CARER #1

Voluntary sector carers' support services were highly spoken of by all the carer interviewees:

"… If I need any information I just get on that 'phone and they're so helpful… I know if I need any information, they're at the end of the 'phone." CARER #9

However, as most of the carers were accessed through carers' services the sample is not representative.

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[57] Brand of breakfast cereal.

The formal title of *'carer'* was seen by one interviewee as leading to better relationships with professionals. Her adult son had not permitted information about himself to be given to her so she had started using the term *'carer'* rather than *'parent'* as she thought this gave her more rights with regard to information about her son:

> *"A* 'carer' *has more rights to information than a* 'parent' *per se. So when I write I always describe myself as his carer."*
> CARER #5

Carers can be dependent on their relationship with professionals to acquire support for both themselves and for the service user. However, there is no one professional who has responsibility for ensuring the named person receives information about the role. Support relating to becoming a named person had come from a CPN in one case and a carers' centre support worker in the others; no carers had accessed the MWC telephone support service. One policy interviewee thought that training should be available for named persons in addition to written information:

> *"I don't think there's enough information. We said there should be training available, there should be more training and there isn't any training.*
> *WHO SHOULD PROVIDE THE TRAINING?*
> *The Executive, because this is a new piece of legislation that the Executive are responsible for.*
> *TRAINING FOR WHOM?*
> *Named persons, it should be available for carers to tell them that there's a possibility that the person you care for might want a named person and this is what it involves."* POLICY #3

The main area where the carers' relationships with professionals was important was when decisions needed to be made. As described above, most carers wanted professionals to take responsibility for decisions and keep the carer at a distance in order to protect the long-term relationship between the service user and the carer. One interviewee and her mother's social worker had ensured that when

her mother was taken to hospital under compulsory measures that her daughter was kept distant from proceedings to avoid any conflict that may damage the relationship:

> *"The week after* [being admitted] *she decided she wasn't staying and she walked out and I knew exactly where she was because she'd just gone home. The hospital didn't want me involved as they didn't want me to be seen as the person who had brought her back into the hospital, so I had to give the keys to my husband. He drove down to my mum's and met a nurse and gave her the keys. The nurse got into the house and persuaded her back in."* CARER #4

There was a strong impression from all carer interviewees that they avoided conflict with the service user and, if difficult decisions had to be made, they preferred professionals to take responsibility for this, at least *prima facie*, to prevent the service user holding them responsible. Three carers, all parents, described how they would prefer professionals to lead in decision-making rather than it ever fall to them. One father of a daughter in her twenties thought that he had to trust professionals because of their specialist knowledge:

> *"I have to leave it to the professionals as I find it hard and these people understand and they know best.*
> *DO YOU TRUST THE PROFESSIONALS?*
> *You've no choice, you have to trust the professionals, you have to."*
> CARER #8

It was felt that pressure to accept the role of named person for the sake of the service user might be increased by the pressure the MHO felt to ensure that the named person had been identified. One policy interviewee agreed that the role might not be attractive to carers or relatives due to the responsibilities it involved, drawing similarities with the difficulties in appointing guardians:

> *"Like guardianship under the original* [1984] *Act, I think they had hoped more people would be guardians but local authorities found that people didn't want to be it. It was far too much responsibility and under Adults*

With Incapacity there are more welfare guardians but for people with very complex needs you often find nobody wants to take it on." POLICY #5

Despite the acknowledgement that it may not be a particularly desirable role to take on, several MHOs commented on the accountability they felt for identifying a named person:

"We've got paperwork to complete if we can't find a named person and it's placed more duties on us with regard to finding the named person and discussing with the named person… Previously nobody would hold us accountable, but now we have to prove why we haven't." MHO #5

However, there was awareness of the procedures to follow if there was not a candidate for named person:

We can declare it and there's a form that's completed that says: 'I have endeavoured to find someone but there is no one', so we actually can do that, but it's all the efforts we have to go to declare that." MHO #5

One MHO thought that the pressure was not solely on them to identify a named person but additionally to ensure they attended the tribunal:

"[Under the Act] The named person is encouraged to take part but there's no absolute mandate that they have to. When that doesn't happen, the chair [convenor] of the tribunal looks around the room and the social worker in the corner gets a very beady eye… They're quite an inquisitorial thing and it's like: 'Why's the named person not here?' and you're like: 'Well they're an autonomous adult'." MHO #4

There were several reasons why the potential named person might not attend the tribunal such as other commitments, lack of support, not wanting to disagree with the service user and the overall intimidating atmosphere. The practical elements of being a named person were raised by one policy interviewee who was particularly concerned about how a named person could

plan for a tribunal at short notice when they had other commitments, such as employment:

> *"When we talk about attendance at tribunals, especially because there's no notice these days, most people have jobs so it's one thing to take a day on leave but to be constantly going to tribunals and some have repeated sittings and interim orders and you've perhaps taken a day off to see the MHO and talk it through and the psychiatrist and the service user and you're stressed about it all and how much time off work can you have? And the tribunals say: 'Why do we have a low attendance?' and it's because people have real lives."* POLICY #5

There were reports of tribunals encouraging participation by taking evidence from named persons via telephone to encourage participation.

Another interviewee commented on the named person rarely having legal representation, even though they are entitled to appoint a lawyer, similar to the patient:

> *"Unfortunately some types of tribunal are very legalistic and you've got the poor old named person usually unrepresented, although they are entitled to be represented but nobody knows that. So they're sitting there unrepresented and there's quite an onus on named person testimony."* POLICY #7

The atmosphere of the tribunal could, again, be seen as off putting.

Several interviewees spoke of the difficulty faced by named persons who did not agree with the service user but did not want to voice this disagreement, fearing for the repercussions it may have on their relationship:

> *"Their care and friendship is with the person but they are certainly allowed to have an independent view and that is exactly why they don't want to go to the tribunal and say it to the person, for fear of the reaction."* POLICY #5

Situations such as this had led to named persons or relatives wanting to submit evidence to the tribunal privately, not wanting the patient to know that they had done so:

> *"Families can see their relative is unwell and will agree with you in relation to going for the detention. I had one case where the named person had written a letter about their relative and passed that to the tribunal as evidence, but didn't want to be in front of the tribunal and give evidence. The tribunal didn't allow that information to be given so I had to go back to the relative and ask if she minded the letter being copied to the service user, she said no* [that it could not be copied] *as she didn't want the relationship to be affected. And that tribunal process was affected anyway as the tribunal had already read it so had the information."* MHO #2

In this case the tribunal had not allowed the evidence to be submitted but had already seen the evidence while making this decision, so the named person had inadvertently managed to get the tribunal to see it regardless. One tribunal member and policy interviewee commented on the named persons who had managed to disagree with the patient without causing a breakdown in relations:

> *"Some people do come* [to the tribunal] *and I've been very impressed by how they've managed to state their view in a very diplomatic and sympathetic way in front of the patient, so some people can do that, but one can see that it's a difficult task, emotionally difficult."* POLICY #2

Similar to the previous involvement of relatives in the consent to admission and powers of discharge it seems that these situations will always have the potential for conflict.

This chapter has depicted the power imbalances between service users, carers and professionals. The next chapter relates the findings to the human rights issues of choice and information-sharing.

Chapter Eight: The named person provisions and human rights

Introduction

This chapter looks at the relationship between the named person provisions and human rights legislation, particularly when capacity is lost and a default named person is identified and appointed. This raises two specific issues, the lack of choice for the service user of the default named person being involved in their care and the sharing of confidential information with the named person.

8.1 The default named person provisions and human rights: Lack of choice

The identification of a named person by default is unique in Scots law and one policy interviewee drew parallels with other similar roles that do not have a default appointment:

> *"I think it's a very important role and should you really be defaulted into something with such ramifications? I mean, we wouldn't expect someone to become a guardian under Adults With Incapacity by default... maybe to become it by default when it's such a big responsibility is maybe wrong on reflection, yes."* POLICY #5

In the absence of a person to fulfil such legal roles (for example, guardian) the local authority usually takes on the responsibility. However, if the service user has not made an active nomination, their primary carer or nearest relative will be appointed their named person. There is currently no clear right to choose to have nobody appointed as a named person. Many interviewees felt that service users should be able to choose not to have a named person, even if there was somebody available to them. The 2003 Act allows a service user to make a declaration stating that they do not want a particular individual to be appointed their named person, but, if a service user were not to want any of the potential

people available as their named person, they would technically have to make a declaration for each one saying that they did not want them to be appointed. It is not possible to make a blanket declaration stating that no named person is to be appointed:

> *"…The law doesn't really allow people to reject it. Well, it does actually in making a declaration of rejection but the silly way that the law was written means you'd have to declare every person on the planet."* POLICY #9

A patient can choose not to appoint a lawyer or an independent advocate but cannot reject the named person. The subject was explored with service users using the same vignette as above that described a woman having no family who had refused to appoint a named person (See Appendix 2). Six service users thought that there should be a right to choose not to have a named person, rather than the MHO seeking to identify somebody in these situations:

> *"If it's the patient's right to name a named person than that's their right. If they say: 'I don't want anything to do with that,' then that's it. End of story."* SERVICE USER #3

The rest of the service users thought that although it was sometimes appropriate for the MHO to consult informally with others involved in a patients' care, it was not acceptable for anybody to become a named person by default. One service user thought particularly strongly about MHOs identifying named persons:

> *"No, it's not up to the social worker, she shouldn't, that's nosey parker business. Those two friends could be anyone, they could be from a cult for all she knows, so unless she really knows them, no, keep your neb[58] out! If she doesn't want to nominate a named person then she has that right."* SERVICE USER #20

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[58] Scots colloquial for 'nose'.

This view was echoed by the majority of the other interviewees:

> *"If the person is saying: 'I have no one to name or I have a distant cousin that I don't want to name as I don't have a close enough relationship with them' then I think the person, if they have the capacity to make that choice, should have that right."* MHO #5

One policy interviewee thought that it was a failing of the 2003 Act that it assumed every patient would have a named person and did not allow a declaration stating that it was not wanted:

> *"My own view is that, interestingly, if you study the provisions there's always an assumption that the patient will have a named person. But if the patient says 'I don't want my mother as my named person' and you go to the list of collaterals and the patient says 'Nope, I don't want my mother or my primary carer' the patient still has to have a named person. He must have the right to say 'I do not want a named person' but at the moment the Act doesn't allow for that."* POLICY #8

Another policy interviewee thought that if a patient had made a blanket declaration, a tribunal might accept it but there was no guarantee:

> *"We say if someone was saying that and it's witnessed and people are making an intelligent and informed decision then it's probably ok.*
> *DOES THAT MEAN THAT PEOPLE IN PRACTICE ARE ALLOWED TO MAKE BLANKET DECLARATIONS?*
> *I don't know, I think it varies, I really couldn't say, it depends on how it'd be viewed by the individual tribunals at the end of the day."* POLICY #9

A policy interviewee, from a legal background also thought that if a person had written a blanket declaration with full understanding and with capacity, a tribunal would be unlikely to overturn this decision and appoint a named person:

> *"...In theory, once you get to the end of that list the MHO can take it to the tribunal who can appoint somebody else. I mean that's never*

happened and I've taken the view that if the patient says: 'I don't want a named person' then the patient doesn't have to have a named person and until a higher court tells me I'm wrong, that's the way I'll go." POLICY #8

One interviewee thought that the absence of a provision to be able to choose not to have a named person was contrary to the principles of the 2003 Act and might even be seen as an additional source of information about the patient by the tribunal:

"There's some suggestion that they're [MHOs or the tribunal] *feeling they should nominate somebody, even if service users say they don't want one, and this seems to go against the principle of respect for the service users' wishes. If somebody has legal representation and an* [independent] *advocate and goodness knows what, I don't see why they would necessarily need someone and I worry that tribunals are seeing the named person as a source of extra information about the service user."* POLICY #6

The potential difficulty of a named person being appointed against the wishes of the patient were described:

"It's most awkward at the tribunal stage where there's tension between the user and the apparent named person, where the MHO has imposed one and, where that happens, there's still a great deal of bad feeling, I think, and it really doesn't seem to suit either party." POLICY #7

One policy interviewee thought that it was important to avoid the default situation for the reason that if an active nomination was made, the parties would be more likely to have discussed the situation and both have a greater understanding of the role:

"It's something that people could discuss and they could plan and they could discuss and say: 'Ok if I was your named person then what would happen if I disagreed with you?' and they might say: 'I'd never speak to you again', you know?" POLICY #3

Although, this is only possible with people who are already service users as opposed to first episode detentions.

Despite these potential problems most MHOs thought that in their experience the nearest relative had usually been the most appropriate person to take on the role of the named person:

> *"Yes, of the ones I've come across, there's no-one that I would have said that they wouldn't want their next of kin and there's been none where I've thought the next of kin isn't the best person. I've been quite happy with the default position."* MHO #5

Even if the patient had nominated a named person the tribunal retains the power to remove that person. One policy interviewee thought that there would have to be good reason for doing so and there might be grounds for a challenge under human rights legislation, similar to the difficulties with nearest relative provisions under the 1984 Act that the named person was intended to address:

> *"Even if I made a declaration saying I didn't want you* [as a named person] *the tribunal could appoint you, which is slightly bizarre.*
> *THEY WOULD HAVE TO TAKE THAT INTO CONSIDERATION THOUGH.*
> *They'd have to be able to justify it. I don't actually know why the provision giving the tribunal the power to appoint has been made because it's hard to envisage a situation… I think you'd be getting into human rights, the problem, the original problem."* POLICY #6

A solution to the problem of a named person being appointed whom the service user had not nominated would be to remove the default role. The patient would still retain the right to a lawyer and an independent advocate, and it was the view of some interviewees that it was these who offered the most robust protection of the patients' rights:

"…If they've got an [independent] *advocate that helps them speak up and these days most people have got a lawyer who is supposed to be challenging and questioning the material put forward."* POLICY #5

Additionally, one policy interviewee thought that although the named person could contribute personal information about the patient, the tribunal should find out about these issues regardless:

"I think all the issues that a named person would be alert to… that person could come along whether they're the named person or not. Any person the tribunal considers to have an interest, so if we knew this person who's not a named person was there, we'd want to hear from her anyway... If the principles are being adhered to and being applied, you should be picking up anything the named person would be concerned about anyway." POLICY #8

This interviewee acknowledged that a carer could participate in the tribunal without being appointed a named person. Another policy interviewee commented that the potential for wide variation in the abilities of named persons made it difficult to judge whether patients were at a disadvantage if they did not have a named person. If the named person was unwilling or unable to play a full part in the tribunal, then the patient was not gaining any benefit from the appointment:

"It's really difficult to say, isn't it? You might have a named person but… they've not wanted to participate." POLICY #1

8.2 Information-sharing and human rights

The named person has the right to receive information relating to the tribunal hearing which would usually be confidential to the patient and professionals. This was often thought not to be well understood by service users and one MHO thought that only when services users experienced the tribunal situation would they understand the level of information the named person received:

"…Unless they know what is involved in a CTO application how will they know how much information will be shared? They might have an indication about what might be involved, but unless they've been involved before, then they won't know in detail." MHO #5

Attitudes towards information-sharing were related to how well people perceived their potential named person to know them. Only two service users felt negatively about this; one was concerned about what might happen if the relationship broke down, the other could not think of a named person he would appoint, so was talking about how he would not want information shared with his family:

"I feel very, very strongly about that. It's not so much about the stigma attached to mental health, it's not that I'm afraid, if it helps them get close to me I'd have no problem, but it's simply because I'm not close to them, it's the confidential side of things." SERVICE USER #7

The majority of the service users thought that the person they would nominate as their named person would already know everything about their problems prior to receiving any information from a tribunal:

"Any friend that I would have nominated I've probably told them everything anyway. It's probably something that I've talked about." SERVICE USER #15

Several service users spoke of their relationships with their psychiatrists in relation to information-sharing. Only two service users thought they had told their psychiatrist things that they would not want their named person to know, but only if the named person was a child or parent. One spoke of information regarding her divorce from his father when the son was younger and the other did not want her mother to know of suicidal ideations she had discussed with her psychiatrist. Four service users spoke of the level of information they gave their psychiatrists as being on a need to know basis rather than confiding in them:

"I haven't told the psychiatrist a lot of things. I don't really tell them very much at all, just a quick how it's going and how's the medication, and this is why I think they're not always the best person to make a judgement about your situation." SERVICE USER #1

Those service users who had nominated a named person or who had a good idea whom they were nominating, were the least concerned about information about them being shared with their named person.

The MHOs thought that information-sharing would be less of a problem if the service user had been made fully aware of the level of information that would be passed to their named person before they had made the nomination:

"I've come across clients who don't understand the level of information and you say: 'They wont get access to your medical records they'll just be given info about this particular process, the detention et cetera, and the care plan' and most folk who've been concerned have understood that and been quite happy." MHO #6

One way to minimise problems occurring with information-sharing was for MHOs to temper the information going into the application documents of which the named person would receive a copy:

"We are watchful of what we put in reports and you're trying to observe and protect people's confidentiality throughout the course of their contact with services. Whilst if someone's under the Act there are stopping off points along the way where you have to rethink the sort of information and the amount you're sharing. I think it takes some managing." MHO #4

This relies on the MHO to protect the confidentiality of the patient rather than the actual formal structures.

One interviewee with both medical and a legal perspective raised the problem of the 2003 Act leaving a patient with fewer formal rights in this area than the

previous 1984 Act due to the assumption that patients would have actively nominated a named person:

> *"I think that, given that people knew the patient could nominate the named person, the role was so important that the patient should not have the right to block information going to the named person. But that actually took away a right they had in the 1984 Act where, for long-term and short term detention, the person had a right to say they didn't want information to go to the nearest relative."* POLICY #2

This was thought to leave the 2003 Act vulnerable to a challenge under human rights legislation:

> *"Now this is particularly a problem where it's a default named person, a nearest relative, because they may not want the nearest relative to know what's happening to them and, arguably, it's an infringement of their privacy and it'll be interesting to see if anyone brings up an Article Eight ECHR objection to that."* POLICY #2

This was particularly so because the default named person could potentially have already received information before the patient could raise an objection:

> *"I think Millan[59] thought the person could nominate somebody else if they didn't like the idea of information going to that person but that requires the formal route and of course there isn't time. If somebody is having a short-term detention or an application for a CTO and the first time they see the tribunal, the person's already been informed."* POLICY #2

One MHO was of the opinion that service users who were reluctant for information to be shared usually had valid reason for their concern:

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[59] The Millan Committee.

"I'm thinking of past situations where it had led to conflict and nine times out of ten the reasons for not wanting the information shared were valid." MHO #1

One interviewee thought it might lead to a service user not wanting a named person under any circumstances:

"Why shouldn't I be allowed to say: 'I don't want someone to act as I've got some ghastly thing that I'd sooner run the risk of losing my legal rights than reveal". POLICY #6

This comment further emphasises the fact that the service user cannot reject the role entirely.

An issue raised by a policy interviewee was that named persons themselves may not want the information about the patients:

"…One of the interesting things that has come up is that carers will get the full set of information at the tribunal and some don't want it. They don't want their sons' or daughters' full case notes, but by law that's what they have to get and they're given information that a) they would not want to be given in their caring role, and b) could be quite distressing." POLICY #4

This interviewee refers to *'full case notes'* which is not what the named person would actually receive, but rather standard application documentation and supporting reports, although these could still contain a large amount of confidential information.

When discussing the level of information given to the named person at a tribunal, two policy interviewees, one from the voluntary sector and another from the statutory sector, thought it should be limited. Another policy interviewee, again with a legal perspective thought that this was not necessary and that as long as the lawyer had all the information then the named person

could receive more limited information and the patients' rights still be protected:

> "…The information that goes to the named person, I don't know if that's essential. It's treating them like a solicitor.
> HOW CAN IT [THE TRIBUNAL] BE TRANSPARENT THOUGH?
> I think it can, people can contribute, of all that information, some of it won't be of any value and wouldn't be understood without the professional experience of others, and also some of the information may or may not be relevant to the purposes of the named person. Especially if the patient's legal representation has access to everything and the named person could have it through that solicitor." POLICY #9

A counter-argument made was that the named person had to have equity of access to the same information as the rest of the tribunal members in order to participate fully in the proceedings and to protect the patient's rights:

> "The named person has almost the same rights as the patient throughout the Act so legally, in my view, they should be treated as a party. If you have all the rights to appeal you need to be treated as a party." POLICY #8

It was further suggested that the role and access to information could be modified when the named person had been appointed by default, rather than by active nomination:

> "I would support looking at that and bringing in a provision whereby somebody could say that they didn't want information to go to a default named person, but not one that they'd actually chosen." POLICY #2

This 'stepped down' role of the default named person was further supported by another policy interviewee:

> "HOW USEFUL IS DEFAULT WHEN YOU THINK OF NEGATIVE ASPECTS, IS IT WORTH HAVING?

I don't know. It's an important basic thing that if you're being held against your will, there should be people who know about it on the outside, and the people you choose to know about it are the people who may help you do something about it. But the default though, whether the default person should have all those rights, given the other rights that are built into it, it might be over-egging it. It would be hard for us to go down that route and take that angle because it is an added element of protection but it does have problems, potentially, it works against their [the patient's] *interests."* POLICY #9

It is currently possible for information from the named person to be withheld from the patient and information about the patient to be withheld from the named person, but this is a decision made by the individual tribunal, if it is thought to be in the best interests of the patient or named person. One interviewee thought that there may be variation in what each tribunal saw as a valid withholding of information:

"Oh yes, there will be, you might get variations from one tribunal to the next as to what they'd accept as a good reason." POLICY #9

To change the information passed to a default or a nominated named person would require the creation of an amendment to the primary legislation which would give fewer rights to a default named person.

This chapter has completed the presentation of findings by relating them to the issues of choice and information-sharing. The next chapters go on to discuss the findings in relation to perceptions of the named person, autonomy and choice, power imbalances and human rights issues.

Chapter Nine: Discussion of methods and findings

The discussion of findings begins with a reflection of the method, including a personal reflection, consideration of the ethical issues, the resulting sample, interviewing process and analysis. This chapter then goes on to discuss part one of the findings with reference to overall opinions of the named person provisions, perceived advantages and reasons for the low take up.

The recommendations made in the discussion are further listed in the conclusion with corresponding page numbers.

9.1 Reflection on methods

The data was collected using a semi-structured interview with 20 mental health service users, ten carers, seven MHOs and nine policy influencers, a total of 46 interviews.

9.1.1 Reflections on personal influences on the research process

Whether explicitly acknowledged or not, all stages of the research process are shaped by the author's personal history, from which animating interests, habits of thought and methodological preferences emerge. This study is no different and a combination of study, employment and formal research training strongly influenced both the focus of the thesis and the general empirical approach.

The key themes of compulsory detention, autonomy and choice, and the social and legal context of care and treatment grew out of my employment experiences. My overall interest in mental illness began during my employment as a nursing auxiliary working with people with severe mental health problems who were often subject to mental health legislation. At the same time, I was undertaking undergraduate psychology courses with a focus on mental ill health. After graduating, I was employed in several voluntary sector community mental health projects. I found many service users to be isolated within their communities and estranged from their families, and I became particularly interested in how close relationships and everyday interaction could be affected by mental health problems. Further study allowed me to explore and develop these interests. I completed a part time Master of Community Care degree where my

dissertation explored the proposed use of compulsory treatment in the community. These experiences of providing direct care and simultaneous academic study resulted in an acute awareness of the potential impact mental health legislation could have on mental health service users. I felt that service users were poorly served by the 1984 Act at a time when mental health service ethos was attempting to widen service user involvement and participation, an area that I thought was of great importance.

This interest in advocacy for service users was further developed once I became an academic researcher. Studies included: an exploration of the experience of harassment of mental health service users living in the community; the impact of legislation on families of service users across Europe; and the social networks of service users. These studies attempted to maximise service user involvement, report service user experiences, and produce accessible findings which highlighted the stigma and exclusion experienced by research participants. As a result of these studies, I became particularly interested in the introduction of the named person provisions of the 2003 Act, and chose to carry out part time doctoral studies in that area.

My personal background and values shaped all stages of the research process, As described above, the initial choice of general study area and principal research questions were influenced by my previous experiences, with added motivation provided by the absence of any research on this significant change in the law and attendant procedures. The *a priori* themes were derived from the fact that law had changed, therefore interviewees' perceptions of these changes were key. This had the effect of the research becoming an administrative socio-legal study, with potential recommendations for policy and practice.

My interest in service user advocacy and experience was influential on the choice of a qualitative, interpretative approach that valued the lived experience of participants, *in vivo* expression, and allowed voices and themes to emerge. The sample size decisions came from experiences of what had proved achievable in terms of organisation of interviews and doable in terms of analysis. Previous experience influenced all stages of interview planning, including the decision to transcribe and analyse concurrently in order to promote iterative questioning and strong familiarity with the data. This ensured interviewing could continue for as long as necessary to gather significant new information without prejudging when fieldwork would be considered complete. Interview venues were organised to allow flexibility, which I have found to be important in previous research when people did not always want to be interviewed at service premises. The style of interviewing including duration, question order, use of vignettes,

knowing how to introduce and finish, and prompting, was heavily influenced by previous research experiences. The overall flexibility of approach aimed to let interviewees describe what was personally relevant to their lived experience.

My research training and experiences in academia meant I was personally uncomfortable with a dogmatic methods-driven approach. Furthermore, I held concerns that qualitative methods could often be poorly reported and lack transparency. I wanted to ensure that my methods for this research were as explicit as possible. I applied a general principal that conclusions must be grounded in the data but that the approach must be flexible enough to support both the deductive dimensions of the piece, while at the same time allowing unexpected ideas and themes to emerge inductively. Thematic analysis was selected as I thought that it had the flexibility to support both epistemological approaches while providing a transparent methodological framework.

The attempt to summarise and reflect on how data relates to the research questions is inevitably selective, and again influenced by researcher's values. Key discussion themes derived from several sources, including my interests in autonomy and wider relationships; and the power imbalances and human rights issues that emerged directly from interviewees' narratives. These *'anticipated'* and *'unanticipated'* themes show that I was sensitive to the possibility of rejecting my own assumptions and receptive to new ideas. My interests in advocacy, autonomy and choice inevitably shaped my critical conclusions and recommendations.

The extent to which a researcher's values do or should influence the research process is an essential subject for the social sciences and, historically, has been the cause for major and enduring methodological cleavage into broad epistemological and ontological camps, for example, qualitative and quantitative, interpretive and positivist, objectivist and social constructivist. It is beyond the scope of this research to contribute to these wider debates but I take the view that:

- all empirical observation is both theory and value impregnated
- one can inoculate oneself from the risks of a completely partial and biased account through thorough research training, peer-review and reflective practice
- it is the duty of the researcher to be explicit not only about their research questions and methods, but also the implicit values and assumptions that animate them.

This is what I have tried to address in this section.

9.1.2 Reflections on interviews

The interview was considered to have been the most appropriate method for all participants. For the service users, carers and policy influencers this was because they related differing experiences. The experiences of MHOs were the most similar but to have interviewed them as a group would have caused logistical problems and not allowed the flexibility of arrangements of the individual interview.

Mental health service user interviews

The interviews with service users were informal, carried out using a semi-structured schedule consisting of a list of topics (See Appendix 2). This allowed service users to speak freely about their experiences with prompt questions used as required. Feedback about the interview process from many interviewees was positive, with service users saying that they had enjoyed being listened to, they hoped their story was useful to the research, and they were glad their opinion had been sought. Due to the voluntary organisation group-based setting, other interviewees volunteered to take part after speaking to their peers who had reassured them that the interview was not a *'test'* but more like a conversation. Several interviewees said that they had been nervous about being *'interviewed'* but they had actually found the experience enjoyable, particularly discussing the vignettes. Many more service users attended the information session provided by the researcher than participated in an interview, it is thought this was as other service users had no experience of compulsory measures and, after learning about the named person provisions, did not think them personally relevant.

Because of this style of interviewing there were some subjects that were discussed at length with some interviewees and only briefly with others. A more structured interview might have ensured there was increased parity both within and across interviews (of all groups) of the subjects discussed, but time constraints would have prevented interviewees being able to talk at length about areas where they had the most knowledge and experience, which in turn produced the richest data. It was not thought that the removal of the nearest

relative power of discharge could have been easily discussed as the time was used discussing the present named person arrangements, and to have introduced another subject would have meant that the interviews became too long.

Many people with a history of mental health problems are used to telling their *'story'* as they have been through this process with a range of peers and professionals. This may have meant that some interviewees were better able to describe their experiences fluently and reflectively without experiencing visible distress. However, as anticipated, several interviewees did become distressed when discussing the break up of relationships and, therefore, were offered advice as to whom they could speak about these issues. If an interviewee became tearful it was considered important to acknowledge their distress and allow time for the interviewee to express how they were feeling, for them to feel that they were being listened to in a supportive manner, not merely to collect information. This approach can blur boundaries (Dickson-Swift *et al.*, 2006), but as the researcher had worked for many years in direct service provision prior to becoming a researcher, she was confident in her ability to negotiate these boundaries, understanding the similarities and differences of the therapeutic relationship and the role of the researcher. It was thought that to ignore an interviewee's distress would have appeared cold and given an unethical priority to the information gathering purpose of the interview. Ignoring distress may in turn have made the interviewee feel their experiences were being exploited, causing them to lose trust in the interviewer and, possibly, the wider research process.

No interviewee exhibited a level of distress that led the interviewer to feel the need to contact a member of support staff independently. However, on one occasion an interviewee contacted the researcher the day after an interview as she had been considering her options surrounding appointing a named person and wanted advice as to how to proceed (the information sheet gave the contact details for the researcher). The researcher was able to tell the interviewee to whom to speak at the service she used and then to contact that staff member to ask them to follow it up with the interviewee. This further demonstrates how the role of the researcher in this situation can easily become ambiguous. The interviewee had listened to the researcher provide information about the named

person and answer questions from other service users; this implied that a level of assistance and advice was available, which in relation to advice about the named person provisions, it was. This emphasised the importance that the researcher be prepared for how to refer interviewees on to access support from other sources.

The vignettes proved to be a useful tool in eliciting opinion. Service user interviewees often had strong views about the scenarios and frequently related them back to their own situations, sometimes bringing out contradictions in what they had originally said in relation to the independence of the named person. Interviewees sometimes asked if the vignette characters were real people saying there were similarities in the vignettes to people they knew. The placing of the vignettes at the end of the interview was considered to have been a success as this allowed some time for the interviewee to talk about people other than themselves and to begin to disengage from the interview process. Furthermore, the vignettes often seemed to provide light relief for the interviewee after talking about their own experiences. As the researcher had already described how the interview would progress, they played a further role in signifying that the interview was drawing to a close.

The one interview in which they were not a success was a situation where a service user interviewee said that she was unable to concentrate enough to take in the detail of the vignettes. The researcher offered to terminate the interview but the interviewee expressed a wish to continue, if the researcher could find another way to ask the questions. As an alternative, the researcher asked as simple questions as possible about the themes of the vignettes.

The audio-taping of interviews was of concern to only one service user interviewee who explicitly stated that being recorded would make him feel paranoid although he agreed instead to detailed notes being taken. Other interviewees were initially wary of the tape-recorder but when it was explained that audio-taping was quicker than the researcher taking notes and nobody would be identified by name on the tape, they soon appeared to forget the tape was there. Talking about how people do not like hearing themselves on a tape was often an icebreaker after the formality of the consent procedure.

The arrangements made where the researcher provided a series of presentations to groups, allowed a *quid pro quo* arrangement between the mental health service and the researcher. This method of *'getting in'* (Cassell, 1988) was thought to have been a success. Anecdotally, services said they felt they were over-consulted and over-researched, and this ensured that they were benefiting from taking part in the research in a direct way, rather than the more nebulous benefit of contributing to the greater sum of knowledge.

The researcher attending the service user meetings prior to speaking was also an important way of introducing herself to the potential interviewees. The coordinating staff member was clearly a respected and trusted figure within the group and, as such, acted as a *'patron'* (Lee, 1992) for the researcher, her inviting her to the group signifying that the researcher was not a threat and could be accepted by the wider group. Once the meeting was underway the researcher took care to contribute where it appeared appropriate and, equally, when not to contribute. This meant that by the time the researcher was called upon to speak about the named person, she had shown interest and involvement in the proceedings. After taking questions and distributing the invitations to potential interviewees, the researcher did not push attendees to take part but instead stayed for the social element of the meeting, for example, a buffet lunch. It was at this point that people often approached the researcher to say they were interested in taking part in an interview.

The perception of the researcher by the interviewees was thought to be important. The researcher introduced herself as both a part-time student, but also as a full-time professional researcher who worked in mental health research as she had encountered some of the service users previously through her employment as a researcher and wanted to avoid confusion. At all times the researcher aimed for a relaxed approach, dressing in a neutral way to reflect the casual surroundings of the service. When carrying out interviews the private room made available by each service was often a room that service users had used before so the setting was familiar to them. In these service settings the interviewee often assumed the role of the host, asking whether the researcher would like a cup of tea and the researcher was invited to join the interviewees

and other service users for lunch in the café. This approach of gaining access to participants was thought to have encouraged people to take part and for their participation to be a relaxed and even enjoyable experience.

The use of a £10 gift voucher as a token of thanks was thought to be well-received by the service users. A generic voucher was used that could be used at a wide range of high street shops so as to maximise choice, allowing people to spend it on either *'essentials'* or on a small gift for themselves. It was an adequate amount to be meaningful yet not considered enough to encourage people to take part against their better judgement.

Carer interviews

Carer interviews were, again, semi-structured to allow each person to tell their story. Many of the carers wanted to talk about their relationship with mental health services and the researcher decided to permit the relating of these experiences and of their relationships with professionals, as this gave the context to both their status as carers and might have influenced their perceptions of the named person. No carers showed any signs of distress during the interview and it was not thought necessary to offer any further sources of support, although encouragement to discuss the named person provisions with a professional was given to some interviewees.

As carer interviewees had been assured the interview would last for no longer than an hour, it was not possible to use the vignettes with all carers as originally planned. Only three carers were asked about them and these were the three interviewed face-to-face. This was because in two cases, the interviews had been short and there was time to spare, and in the third the interviewee was keen to hear them and requested the interview continued over the hour.

As carers were expecting the interview telephone call at a certain time and as they had already spoken with the researcher to receive information about the research and arrange a time, they generally sounded relaxed. Several carers said they had made a cup of tea and were going to sit down for an hour while they talked. Many commented that they had enjoyed the interview and as with

service users, that they were glad they were being listened to and hoped the information was of use. Carers showed no concerns about being audio-taped although it is thought that this is easier to accept over the telephone as the equipment is not visible and, as one carer commented, many commercial service providers routinely record telephone calls. It was less easy to move the interview back to the topics under discussion over the telephone, as it disbarred the use of non-verbal signals that could be used in face-to-face interviews. This was the only noted disadvantage of the telephone interview.

The access to carers did not go entirely as planned due to the reluctance of service users to invite their carers or potential named persons to take part in an interview. Only three carers were accessed in this way. This was thought to be because service users had concerns about being discussed themselves, although it was always made clear that this would not be the case. Of the three dyads, one was interviewed together which may have detracted from the openness of some of the responses, although it did not appear that way as their discussion of similar issues had the same, if not more detail, to the other dyads interviewed separately. The use of the carers' service to access carers was successful in recruiting the remainder of the carer interviewees, with them proactively contacting the researcher to volunteer to take part. As these carers had volunteered, there were not the same issues of gaining access to a closed group. Again, the receipt of a gift voucher was well received by carers with several emailing or sending a text message to the researcher to say thank you after receiving it.

MHO interviews

The interviews with MHOs were the most similar in both process and content, all interviewees raised subjects spontaneously, often before prompting was necessary and interviews mostly followed the natural course of conversation. In retrospect, it was thought that data saturation was probably reached after the first four interviews with MHOs all describing very similar experiences with the difficulties in promoting uptake of the named person provisions, the specific problems when compulsory measures were initiated, their experiences at the tribunal, and the difficulties of the default system. Carrying out the interviews

over the telephone allowed for more flexibility as several interviews were cancelled at no notice due to unplanned events and this meant that travel time and expense had not been wasted.

The access to MHOs used opportunistic sampling through the contact from a CMHT leader before the researcher had begun sampling procedures. This meant that, as with the service users, by providing an information and discussion session with the CMHT, there was a reciprocal arrangement. It was thought that MHOs agreed to take part as they had some strong opinions on the named person provisions that they wanted to share. For this reason it was thought important that confidentiality was assured and MHOs spoke candidly of their opinions.

Policy influencer interviews

This was the most disparate group of interviewees from a wide variety of backgrounds, although the subjects discussed and issues raised were very similar. These interviews tended to be the longest and most detailed with all lasting at least an hour. The interviewees had all been involved in the implementation of the 2003 Act to varying degrees, some from the beginning of renewal of the legislation and with involvement with the Millan Committee. There was a high level of knowledge about the named person provisions, with only one factual inaccuracy about the named person procedures detected in one interview and this from a person from a non-legal background. In their professional roles many of these people were also in regular contact with service users and carers, and, as such, could provide examples of cases they had encountered. As with the MHOs it took several attempts to actually carry out an interview with several of the policy interviewees due to unplanned events; this again, supported the choice of interviewing by telephone.

The use of the Mental Health Law Reference Group attendance list was judged to have been a successful way of accessing a range of key people with a continuing interest in the 2003 Act. Those who replied to the invitation had considered opinions of the named person provisions and, again, it was thought the assurance of confidentiality allowed the personal expression of views rather than the official organisational view. The snowball sampling generated through

the recommendations of interviewees proved useful in that these other key informants would not have been approached using only the list of reference group attendees. There was concern in some cases that the potential interviewee held a senior position of such a nature that would have meant it unlikely they would have found the time to speak to a student researcher. However, this method of sampling meant that the approach could be made stating that another interviewee had recommended the researcher approach them which served to provide an introduction and to verify that the research was pre-vetted and approved by their peers. One notable comment from several policy interviewees was the perceived low level of funding made available by the Scottish Executive for research into the 2003 Act and where it had been directed. This made them eager to take part in any research that was being carried out, whether funded by the Scottish Executive or not. There was a frequent and erroneous assumption by interviewees, when first invited, that this research was being funded by the Scottish Executive.

9.1.3 Reflections on ethical issues

The ethical issues raised by the research, identified prior to the fieldwork, are discussed in the light of the experiences of carrying out the interviews.

Capacity of mental health service users to provide informed consent

The application to the LREC proved to be problematic and ultimately prevented participants being accessed through NHS mental health services. The key issue for the committee was that of informed consent. The committee held the opinion that because a person used mental health services their capacity to take part in a research interview was likely to be diminished. The researcher held the view that in the absence of any evidence of reduced capacity (such as being subject to the Mental Health (Care and Treatment) (Scotland) Act 2003 or the AWISA 2000) the person should be assumed to have the capacity to consent. The researcher's view was consistent with both legal and GMC (2008) guidelines that presume global capacity unless there is evidence to the contrary. The service users who were sought were explicitly people who were not subject to any measures under either Act, although they might have been affected in the past.

Some psychiatric researchers have used a measure of capacity to judge whether a person is capable of taking part in research. This may possibly be appropriate for some clinical research with greater risks attached but it was thought that it was more likely to be both patronising and offensive to service users in this context. It was thought likely that it would also make people feel like they were being tested and reduce the number of service users who would take part.

This issue was raised by the researcher with the LREC in person. The researcher put to the committee that to assume that somebody was not capable of giving informed consent solely because they used a mental health service, despite them not being subject to any measures that could imply loss of capacity, was both stigmatising and discriminatory. She further stated that mental health service users are a particularly excluded group of people in general and that to prevent them taking part in non-clinical research with a trained and experienced interviewer in a supportive environment was further contributing to this exclusion. It is suggested that in instances like this the committee has a duty not only to protect potential participants from harm but also to provide a framework to empower them to be able to take part in research (Atkinson, J., 2007b). As the committee held the power the researcher had to concede to the committee's requirements in this instance. The LREC imposed conditions such as a lengthy and inaccessible letter of invitation, the opting in via post, with the further requirement that the clinician had to approve the service users' capacity to consent, a requirement challenged by a service user in Ulivi and colleagues' research (2009). These measures, predictably, led to no respondents being recruited through NHS services. It is suggested that LRECs might require clearer guidance surrounding the legal position as to the capacity to consent.

Lone working

Lone working can present risks and it is considered imperative that health and safety systems are used. However, the LREC recommendation that another person be present during interviews with service users was thought to be offensive and discriminatory. It is thought that for the interviewer to arrive at a person's home with another person would have made the service user feel that

they were being treated as a threat and would reinforce the stigma of the erroneous association of mental disorder and potential violence. The interviews that the researcher carried out in peoples' homes were treated by the interviewee much as a social visit. Interviewees made the researcher feel welcome and at no point did the researcher experience any sense of threat. The researcher's previous experience working in community mental health services was thought to be of value, with plenty of experience of visiting people at home and being alert to any sense of threat.

Confidentiality and data storage

Assurances of confidentiality were made to all interviewees. This seemed particularly welcome by MHOs and policy interviewees, in particular, the assurance that they were speaking personally and not on behalf of their employer. Nearly all the interviewees requested they be sent a summary of the research findings and several policy interviewers later contacted the researcher to inquire as to the progress of the research. Data storage was carried out as planned and presented no problems.

9.1.4 Sample bias

Due to the necessity of obtaining informed consent, none of the groups that make up the overall sample can be described as representative. Those people who volunteered to be interviewed were essentially those with an interest in the named person provisions. However, this means that the sample is uniquely placed to provide information about the concerns of service users considering using the named person provisions. To interview people with no experience of detention or compulsory treatment would not have provided any relevant information into the perception of the provisions for service users. Furthermore, the limited take up of the named person amongst service users indicated that many service users would be totally unaware of its existence and to interview those people would have not resulted in valuable opinions. Similarly, requesting volunteers from carers' groups resulted in carers interviewed also being those with an interest in the provisions.

A particular group who were not included in this research but who may have specific needs, in particular with information sharing surrounding the named person provisions, are forensic patients. There might be information revealed to a named person of a forensic patient concerning offences committed by the patient that might have been previously unknown. In these situations the importance of support to ensure full understanding of the role for both service user and potential named person may be of additional importance. To explore these issues would require specific research into this small but distinct group.

The MHOs who volunteered to be interviewed were again non-representative, but the similarity in experiences described, led the researcher to conclude that the views expressed and experiences described may well be typical of the wider group. The policy interviewees all had an interest in the named person and, due to their range of professional backgrounds and experiences, were the group providing the broadest range of topics during interview. It is thought that, because of the very specific focus of the research, there would have been no such thing as a representative sample of policy influencers.

9.1.5 Interview as method

Using an individual interview was thought to have been the only way to secure the necessary data. After completion of the service user and carer interviews, it was thought it would have proved impossible to collect these narratives and opinions in a focus group format. This was partly due to the personal nature of the disclosures and the time the interview allowed for discussion of the individual's thoughts. Likewise, the sheer amount of opinion and experience gathered from policy interviewees would not have been possible in a focus group and a great deal would have been missed. The only group with whom the focus group might have been effective was the MHOs due to the similarity of their experiences. However, this was not anticipated prior to the fieldwork so using interviews still allowed for the potential of greater variation of experience and opinion. Furthermore, due to the nature of their work, there would have been significant difficulties in gathering MHOs (or indeed policy interviewees) together at one time.

9.1.6 Data analysis

The use of thematic analysis aimed to provide a transparent and pragmatic method of analysis, clearly describing the process and not obscured by a particular theoretical framework. The explicit use of both inductive and deductive approaches to identifying themes allowed issues from the literature to be addressed as well as identifying novel themes in the data. The use of a thematic network allowed a visual representation of how the data fitted together within themes, and the identification of the links[60] that could be made across and within the groups of interviewees proved essential to structuring the findings in a coherent manner (Boyatzis, 1998).

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[60] See Appendix 4 for thematic analysis framework.

9.2 Discussion of findings

No interviewee questioned the need for mental health legislation itself. Service users appeared to be resigned to the fact that compulsory treatment should be possible and was on occasion necessary. Most interviewees referred back to their own experiences of compulsory treatment and considered the named person provisions in the light of this. Again, carers all accepted the need for compulsory treatment and some spoke of it as a means of respite for carers struggling to cope with a very ill service user.

9.2.1 Changes to the nearest relative and the introduction of the named person provisions

The named person provisions were a significant step in removing most of the rights of the relative acquired through biological closeness alone. There are still rights that remain for the nearest relative: the right to basic information when a person is detained or discharged, and the right to become a named person by default in the absence of both a nomination and a primary carer [s251(1)]. At the same time the 2003 Act widens the potential for other people to become involved in tribunal proceedings by the repeated use of the phrase *'any other person appearing to the tribunal to have an interest'* [s50(3)(i); s64(3)(j); s65(5)(c)] and of course, the potential for the service user to appoint a named person [s250]. The 2003 Act still uses a hierarchy to determine who is the nearest relative but, whilst this remains a legal position, there will inevitably need to be means of identifying it and this does now at least take into account same-sex partners in the same way that it changed over time to give gender parity and to acknowledge unmarried couples [s254(2)(a)].

The process of determining mental disorder has become increasingly medical from its origins as a purely legal process supported by medical evidence. This influence has now become an integral part of the legal process with the introduction of a medical member as part of the tribunals created by the 2003 Act [s21]. However, this introduction may be seen as being somewhat balanced by the introduction of a general member (with experience of mental health care either as a patient, carer or professional) who has equal weight in the tribunal,

leading to a more multi-disciplinary approach. The introduction of a general member is reminiscent of the jury that would have been summoned to provide judgement on a cognisance in the 18th Century, although the personal knowledge of a patient would now lead to a tribunal member having to declare a conflict of interest and not be viewed as the potential advantage it was then. This role of contributing the personal history of the patient now falls to the named person, carers or relatives. The one constant that has remained unchanged is the patient having the right to appeal decisions [s320].

The historical background to Scottish mental health legislation (Chapter Three) demonstrated that the role of the relative had remained largely unchanged over centuries until the 2003 Act. In the 18th Century the catch-all term *'friend'* was used for relative and friends of the patient, it became more defined as time went by and, although it has now broadened again with the introduction of the named person, the fundamental change is the right of the patient to choose who has these rights. Relatives have long had the right to information and could both admit and discharge a patient (although the origins of these rights have been closely linked to financial responsibility for the care of the patient, which has not applied since the advent of the NHS) but now only the right to some basic information remains for the nearest relative [s298(2)(ii); s38(4)(a)].

The rights of the nearest relative have been diminished over the 20th Century and the default named person can be seen as a vestige of those rights. The next renewal of mental health law may see the default position disappear completely in favour of full patient choice determining who is involved, supported by increased reliance on professional roles, perhaps even the mandatory appointment of a lawyer in all cases. The removal of these default roles may be seen as widening choice for the patient, but it may also be seen as a threat to the rights of the patient if it no longer ensures that another person is informed that the patient has been detained. This may be overcome by the appointment of a lawyer to represent the patient becoming mandatory, following due process rights in criminal law.

9.2.2 Interviewees' perceptions of the named person provisions

The overall opinion of the named person provisions was almost entirely positive, at least, in principle. No interviewee thought that the change had been a mistake or that it should revert back solely to the nearest relative, even those professionals who did not perceive a huge difference to their practice or had not encountered many problems with the nearest relative. Similar to the patients offered a crisis card (Sutherby & Szmukler, 1998), people described the potential to make decisions about involvement in their future care and treatment as empowering. The service user sample contained two people who spoke of having same-sex relationships. One was currently single so she did not speak of the issue at length but the other was cohabiting and, in addition, had negative family relationships which had potential parallels with the Kowalski case (Evans & Carter, 1995). Her appreciation of the change was evident in that she thought that a legal system could not have civil partnerships and strive for equality in other spheres, yet, not have the nearest relative hierarchy brought into line. This has at least, also been amended under the 2007 Act for England and Wales.

The Mental Health Bill in England and Wales originally had proposals similar to the named person which were then dropped when the new Act was abandoned and the 2007 Act amending the 1983 Act passed in its place. This Act allows the removal of the nearest relative in England and Wales only when there are grounds to do so and has to be approved by the Crown Court [s23]. This means that a patient has to have a provable reason why they do not want a person to act, rather than being able actively to choose who they think is the best person to carry out the role. It is suggested that once this system is implemented it may still be contrary to human rights legislation and may have to be amended further in future. The Mental Health Act 2007 is an amendment to the 1983 Act and may thus be seen as an interim measure rather than a full renewal of mental health law; the failure of the UK government to win the support of the service user movement, mental health professionals and other stakeholders meant that English and Welsh service users are denied a choice that their Scottish neighbours are beginning to value.

Although it may not immediately be seen as benefiting carers, the named person provision was widely welcomed by them overall. All recognised the importance of choice for the service user and thought that if they themselves were nominated as a named person it gave them additional rights. Although these rights only actually become legally enforceable once compulsory measures have been initiated, it seemed that this formalisation of the relationship meant carers who were also a named person may be more likely to be involved and consulted on the day-to-day care and support of the service user. The carer who was named person to her mother thought that it had strengthened the relationship she had with the social worker, although she still felt distant from medical staff.

Policy and MHO staff also welcomed the element of choice for people, especially the perceived minority of service users who would benefit most. This choice was seen as essential, not only to comply with human rights legislation but also as a fundamental right under a modern mental health act. There was no criticism of the use of the term *'named person'*. The similar *'nominated person'* proposed for England and Wales was criticised for being too loose a term (Andoh & Gogo, 2004), it is suggested that looseness can be a virtue to reflect the freedom of choice of the service user.

9.2.3 Advantages of the named person provisions for service users

Interviewees considered that the main disadvantage of a person not having a named person was their subsequently not having a presence at the tribunal who could contribute by giving information and opinion based on personal and historical knowledge. However, this information is not just available from a formal named person, the ability of any person with an interest in the patient to attend the tribunal allows this information to be given without it being through a named person. There may also be professionals involved with the patient who also have a longstanding knowledge of them and who can contribute this information to the tribunal. However, having a named person in itself does not guarantee that this personal information will be communicated to the tribunal. Interviewees spoke of named persons who did not attend the tribunal or if they did attend, were intimidated by proceedings and unlikely to actively contribute (discussed in Chapter Eleven). An additional point to consider is the principles

of the 2003 Act against which any decision must be tested [s1]. These go some way to ensure that the rights of the patient should remain at the fore. Some interviewees thought that this deficit was addressed in part by the presence of a solicitor and an independent advocate ensuring that the patient's views are heard and their rights upheld. However, a named person was also seen as providing an alternative view point if the patient's lawyer was not representing their best interests, for example, by opposing the CTO application. The overall opinion was that the patient was not placed at a substantial disadvantage by not having a named person.

9.2.4 Low uptake

A new mental health act requires a major change to practice and there is a vast amount of information required by professionals, service users and carers before an Act becomes fully operational. That very few of the service users had actually appointed named persons, or carers been appointed themselves, was not surprising within the context of confusion that surrounded the provisions at the time of fieldwork. Part of the reason why the researcher had been asked to provide information sessions was because services perceived that although there was interest amongst service users in using the provisions, there was a lack of clear information about what the named person was and how people should go about making a nomination. It is not possible to establish how many people have proactively nominated a named person at the time of writing but the reports from the MHOs and policy interviewees indicate that it is probably not a large number. There were several reasons interviewees thought contributed towards this low uptake; namely, a lack of awareness amongst services users, lack of clarity around the procedures for appointing (described in Chapter Six), a reluctance to acknowledge the potential for relapse, the acuity of situations when relapse occurs, and satisfaction with the default position (described in Chapter Five).

Acknowledging relapse

Service users commented that they did not like to acknowledge the potential to relapse when they were managing their mental health problems successfully.

Comparisons were often drawn with the lack of people who make wills despite the inevitability of death and the knowledge that every adult should have one. However, equally there can be reassurance gained from knowing that one has put into place all the necessary arrangements to communicate one's wishes should one become incapable. Sulmasy and colleagues' (1998) study of people with terminal illnesses showed that the presence of a terminal illness prompted discussion of forward-planning and the appointment of proxy decision-makers, so a high chance of relapse, and planning for such, may also increase the interest in appointing a named person in some patients.

Despite reluctance from some service users to do so, there is a focus on relapse management within mental health care and treatment, particularly for people with more severe problems and a history of admissions. Services are now likely to aim explicitly to manage relapse and promote self-management. People with multiple detentions are probably those who are most likely to have use of the named person provisions and nomination could be incorporated into discussions concerning relapse planning, framed as encouraging the service user to make full use of the rights available for him/her and ensuring that their views and wishes be discussed and recorded. If a similar level of interest as in previous research into similar provisions (Sutherby and Szmukler, 1998; Swanson *et al.*, 2003; Srebnik *et al.*, 2003) translated across the Scottish population, there would be many more people at risk from repeat admissions who could be supported to make a named person nomination than have currently done.

This kind of relapse management discussion naturally relates to the preparation of an advance statement, the two often being mentioned simultaneously by interviewees, and it was thought that those people preparing advance statements were also more likely to have completed a named person nomination. However, the two can be used independently of each other and it is a simpler process to nominate a named person than it is to prepare an advance statement; therefore, it is important that service users be made aware they are two separate provisions.

Acuity of circumstances when compulsory measures become necessary

The ideal situation as reported by MHOs and policy interviewees (that the service user had proactively made a nomination before he or she became subject to compulsory measures) appears only to occur in a small number of cases. When no nomination has been made and compulsory measures are initiated, there are further challenges due to the nature of the circumstances in which the provisions take effect, frequently involving the patient experiencing a crisis. This means that those who have not already nominated a named person face a major impediment, their mental illness may be such that they do not fully understand the consequences of making a nomination and, thus, the nomination cannot be witnessed. If there has been no awareness-raising with individuals within the mental health service, this crisis point may be the first time that a service user is informed of their right to nominate a named person, and may also be the first time it is communicated to a carer that they might become a named person. This emphasises the necessity of forward planning and general awareness-raising. However, awareness-raising must take care not to be alarmist for service users who are unlikely to ever be detained.

A situation where this forward planning is impossible is that of first episodes of mental illness that require compulsory measures. These may be completely unanticipated and the patient completely unknown to services. It can safely be assumed that this type of patient will have little understanding of their broader rights under the 2003 Act and is likely never to have heard of either the nearest relative or the named person provisions. In such cases the MHO will be expected to identify the named person, and, as there is no previous history of mental illness, there is unlikely to be a primary carer, so the named person is likely to be appointed using the nearest relative hierarchy. In these cases it is recommended that the patient and the named person are provided with as much support and information as possible, including referrals to legal and carers' services for support. Furthermore, the named person nomination should be revisited as soon as is possible to ensure that the patient is satisfied with the situation.

This chapter has discussed the methods used to collect the data and the findings surrounding the perception of the named person provisions. The following chapter will discuss the findings related to autonomy and choice.

Chapter Ten: Discussion of autonomy and choice

Introduction

To maximise the potential for service users' autonomous choice awareness and understanding of the named person provisions is required. This chapter discusses how this awareness and understanding can be increased and where the responsibilities for this may lie. It goes on to discuss the choices described by services users and the factors that influenced their choice of named person.

10.1 Autonomy: Understanding and information

10.1.1 Awareness and understanding of the named person provisions

The majority of service user interviewees had very little awareness of the named person provisions prior to coming to the information session. Rapaport (2004) described the lack of publicity surrounding the nearest relative role in England and Wales and there is no evidence to suggest the situation was otherwise in Scotland. It was suspected that awareness of the named person provisions outside mental health interest groups is probably very low, similar to the findings of Booth and colleagues (2004), where the only relative of an intensive care patient who was familiar with capacity legislation was also a social worker.

As well as lack of awareness, the interview data showed that amongst service users and carers there was a lack of understanding about aspects of the named person role, even amongst those who had made a nomination. This reinforces the need for better education and support for people making a nomination and for those who become named persons as a result. The findings have similarities to previous research into related areas. Summers and colleagues' (1999) research into the nearest relative in Scotland showed little understanding amongst people who had become nearest relatives under the 1984 Act and Marriott and colleagues (2001) recommended awareness-raising in relatives in order to strengthen the role of the nearest relative in England and Wales. Two US studies further indicate that this need for information about legal provisions is not only an issue in the UK (Backlar *et al.*, 2001; Peto *et al.*, 2004).

The lack of understanding is unsurprising so relatively early into the existence of the named person provisions, although that of the nearest relative remains little understood in Great Britain after nearly half a century of existence. Lessons can be learned from this in that a significant increase in knowledge and awareness does not appear to happen organically and measures are required to address this.

10.1.2 Increasing awareness and understanding

There may need to be several different stages of information provision and actual support for people using the named person provisions. It is not thought that it is a common enough situation to recommend wider public awareness as Booth and colleagues (2004) do with regard to capacity legislation. It is thought that many more people may have a relative who becomes at risk of incapacity due to diseases of old age or trauma, than are likely to have a relative detained under the 2003 Act. Therefore, the focus of awareness-raising should be aimed at the mental health service population generally, about what the named person is and how a nomination can be made. Two US studies showed that up to two thirds of service users with serious mental illness showed interest in completing psychiatric advance directives (Srebnik *et al.*, 2003; Swanson *et al.*, 2003). It might be the case that there are similar levels of interest in appointing a named person, if awareness is raised. This awareness-raising needs to be across several groups: service users, informal carers, relatives of service users, professionals within mental health services; and those professional groups who may be asked to witness a nomination, revocation or declaration. It is recommended that services run recurrent information sessions for service users, carers and professionals to ensure that as many of these people as possible are fully aware of the provisions. There may also be a contamination effect where users of voluntary organisations, who are in regular contact with other service users, discuss their experiences in nominating and using the named person provisions and this may mean that more people take it up. Meeker (2004) found that where there was experiential similarity between patients, they were more likely to appoint proxy decision-makers, having witnessed others do so.

In particular, those service users who are interested in appointing a named person or who are at risk of compulsory treatment, require support to ensure they understand the full impact of the role and what rights the nomination would award the named person. The potential named person also requires specific support and information to ensure that they know what rights and responsibilities they would have, for example, that they have the right of appeal against tribunal decisions, and in the light of this knowledge to decide whether they are willing to accept the role.

When no nomination has been made and compulsory measures are initiated, both service users and carers require support specifically relating to a default nomination. They should both receive information and support about what the role involves, what the implications are for both parties, and the named person be advised in how to reject the default role, should this be their choice. It has been shown in previous research that patients often do not understand their legal status as voluntary or involuntary patients (Monahan *et al.*, 1995) and it is suspected that there may be equivalent confusion over the named person role for those who have not been exposed to awareness-raising beforehand. If the primary carers or nearest relatives accept the default role, then they require support in understanding and actioning their rights. This is similar to the findings of Manthorpe and colleagues, who found that proxy decision-makers, who had willingly accepted the role in England and Wales under the Mental Capacity Act 2005, required support (Manthorpe *et al.,* 2008). Those who acquire a formal role by default may be even more likely to need it.

The Scottish Executive information booklet (Scottish Executive, 2004) was criticised by many interviewees as being too legalistic and too long. The booklet has a reading age of 14.5 (when measured by the Flesch-Kincaid Grade Level readability test) and it is recommended by the National Literacy Trust (2009) that for most people to be able to understand it, a booklet should have a reading age of 10 or below, which is also supported by publications looking at patient information leaflets (for example, Bradley *et al.,* 1994). However, it seems an impossible task to describe a complex piece of legislation with all the potential responsibilities in any other way. It may be that a shorter, more accessible leaflet to give people a very brief overview and to serve as an introduction to

the booklet could help serve to raise initial awareness in more people. Additionally, the booklet is aimed at service users rather than carers. It would appear to be a valuable resource to have written information targeted at carers parallel to that aimed at service users. Key points of information and advice could be highlighted in such literature. One such booklet called *'Guidance for Named Persons'* has been produced by a voluntary sector organisation in the South West of Scotland (User and Carer Involvement, undated). Although the reading age of their booklet is not significantly different from that of the Scottish Executive edition (14.1), supporting the suggestion that this may not be possible, it is at least aimed at carers.

Those service users who had gained the information and were keen to make a nomination experienced further difficulties during the nomination process. The Scottish Executive aim of not being overly directive about procedures had seemingly caused more confusion than a clear set of standard forms and guidelines would have done. The Scottish Executive information booklet (Scottish Executive, 2004) contained suggested sample forms which, although not the aim, appeared to have become the standard format. MHOs spoke of photocopying these to give to service users and they were perceived as a useful resource. It is argued that a standard format is more useful than merely a checklist of what must be included as then there is less chance of a nomination being invalid due to omissions in the statement. The use of a standard form would further be helpful for all people involved, including witnesses who could then quickly recognise a valid application. These forms could continue to be contained within the information booklet, as they are already and made publicly available on the Scottish Government website.

The act of having to put things into writing has been shown to be off-putting for detained patients in the England and Wales appeals process (Bradley *et al.*,1995) but there is no way around this if the nomination is to be both evidenced and communicated. This should be an area in which support should be offered, particularly for those service users and carers with literacy difficulties. There are jurisdictions where verbally communicated wishes are binding for professionals, for example in Arizona State (Arizona Secretary of State, 2009), although these will inevitably be less clear than written wishes.

There are challenges presented by the multi-agency environment in ensuring that everybody involved is aware of the nomination, plus any subsequent revocations. This was the experience of several service users who were unclear about what to do with the completed forms, although the booklet does advise that the service user give copies of the nomination to a list of specific people (Scottish Executive, 2004). It is thought that clearer guidelines are required for service users and professionals about where the nomination should be registered, particularly for those service users who may not currently be using services and thus not have an obvious contact. Ever-increasing numbers of electronic record systems may allow the named person to be centrally recorded but the ease of access to such systems, particularly in times of crisis is still questionable. There are examples, particularly in the US of web-based registers of living wills, for example, the national US Living Will Registry (2009) or state-wide, for example, the Washington State Living Will Registry (Washington State Department of Health, 2009). It may be argued that these are more likely to be able to be accessed in a crisis as all registered health care providers can access the database.

A patient-held record could offer a solution but again whether this would be easily accessed in a crisis remains to be seen. Relapse management cards were favoured by 40% of patients in Sutherby and Szmukler's research (1998), which may mean that cards may be acceptable to patients. However, the responsibility for preparing and updating them, and whether professionals would even look for them, is debatable, as found by Papageorgiou and colleagues (2004) where many psychiatrists, briefed that an advance statement had been placed on the front of patients' records, later reported they were not aware of its existence. However, in the absence of an entirely satisfactory solution, it may be that a card containing the details of a named person and confirming the presence of an advance statement may be of use to service users and professionals alike.

Although MHOs had a good awareness and understanding of the named person role, it may not be the MHO who has the most routine contact with the patient; it may be the GP, a CPN or a voluntary sector support worker. It is not known what the level of awareness is in other professionals but awareness-raising with

these groups may serve to increase uptake through their daily contact with service users, as found by Srebnik and colleagues (2003). It is recommended that the named person provisions be incorporated into the curricula of new mental health professionals and covered in continuing professional development for existing professionals, particularly those who may not be directly involved in activities under the 2003 Act but may be asked to witness a named person nomination. The role of the witness could be expanded for nominated named persons as the witness currently has no requirement to even ensure that the named person is aware of the nomination. It may be that a requirement could be placed on witnesses to provide information and to satisfy themselves that both parties understand the role before they sign the form.

10.1.3 Responsibility for supporting the promotion of understanding and awareness

It is proposed that the nature of the default role of the named person lead to a reciprocal duty to provide both parties with information and support.

The literature shows that there can be some confusion around who takes responsibility for encouraging uptake of provisions like the named person. The role of MHO is defined as having a responsibility to carrying out statutory responsibilities as required by the 2003 Act, which includes a duty to identify a named person [s255(2)(b)] and to provide information when compulsory measures are initiated, but not to encourage service users who are not imminently subject to compulsory measures to use the provisions. Those interviewees who had successfully made nominations had all had the support of an enthusiastic professional assisting and supporting their application, usually a social worker or CPN.

The attitudes of professionals towards provisions such as the named person can be important to increasing uptake, and their intervention, in the form of reminders from professionals was found to increase uptake of similar provisions to appoint proxy decision-makers (Dexter *et al.,* 1998) and psychiatric advance directives (Srebnik *et al.,* 2003). However, some MHOs spoke of the provisions being the responsibility of the service user rather than something the MHO

should steer them towards, with this seen as a conflict of interest. However, if the service user does not make a proactive nomination, then it falls to the MHO to identify the default named person, so, it is suggested they are more likely to have to play a role in the process if they (or their colleagues) have not encouraged the service user to make a nomination in the first place.

There was a suggestion from one policy interviewee that some professionals were not taking the named person provisions seriously, and that they did not believe that a person with a severe mental health problem had the insight to make a nomination. It is accepted that severity of mental illness might make it impossible for a small number of service users not to have the capacity to make a nomination, but even in these cases it could at least be used as an opportunity to explore whether the default named person would be seen as a suitable candidate.

Awareness-raising with professionals from all sectors may promote more positive attitudes and encourage support for service users in making nominations. In previous research looking at appointing proxies, the physicians required reminding to prompt patients to consider it (Dexter *et al.*, 1998). For patients in the care services system there will be regular reviews and these should be used as an opportunity to ensure that a nomination has been discussed. MHOs spoke of not having time to support people in making decisions and not having the ongoing relationship with service users to be able to support them adequately, supporting the findings of Grant (2004).

Voluntary sector organisations have traditionally taken the collective advocacy role with service users. These groups' history outwith traditional services may make them much more acceptable and seem to be more *'on side'* with both patients and carers, and this may mean that encouragement to make a nomination is better received from them, although it is acknowledged that in many areas such groups are becoming the major service providers. Where use of such organisations remains voluntary the obvious difficulty is that not all service users use them; indeed, it can appear that it is the more articulate and rights-aware service users who are the more likely to.

The nature of mental health services means that the key professional will vary from service user to service user; for some people it may be a CPN, for others a voluntary sector support worker. This means that the responsibility for supporting a service user in making a decision may fall between professionals rather than on to any one group. It is suggested that in this situation *'overkill'* is better than each professional assuming that another is offering information and support.

It is suggested that voluntary sector organisations such as carers' services are ideally placed to play a role in providing information, on the condition that additional resources be found to support such work. It was noted that taking part in the interview led several interviewees to say they were going to organise their nomination for their named person. This would support the method of personal face-to-face discussion about the subject as a way of increasing uptake, although a caveat must once again apply that this was a biased sample who may have done this anyway due to their initial interest in the provisions. Face-to-face support could be provided by carers' organisations or independent advocacy services, although, again, this would require additional resources from the Scottish Government. Independent advocates are familiar with the workings of the tribunal and the 2003 Act and each local service could provide information and assist named persons in clarifying their feelings about the application and a whether they wanted to appoint a solicitor.

10.2 Autonomy and choice: Whom service users want to nominate as a named person

The discussion of findings continues by considering whom the service user interviewees planned to nominate and why. The important factors in making a named person nomination are discussed and the issues concerned with parent, child, partner and friend relationships.

10.2.1 Important factors in making a named person nomination

The named person knowing the service user's wishes

Service users thought that two main factors were important when making a nomination; that the named person should know their wishes, usually by virtue of being somebody who knew them very well; and that they should act in such a way as to support these wishes. There was overwhelming support for substituted judgement rather than best interest decision-making. The UK government concern that patients would nominate someone to carry out their wishes rather than act in their best interests is supported by these findings (Hansard, 2001). There was, however, an acknowledgment from interviewees that best interest decisions should be made when there were no known prior wishes. This was a complex area to discuss with service users as it depended on them considering the overriding of wishes expressed after loss of capacity, and there was an assumption that their named person would be able to recognise when capacity had been lost in relation to a particular decision.

That a named person should know the patient very well could be taken as evidence that the service user planned to appoint somebody who had a thorough personal knowledge of them, in the manner of the ideal nearest relative. These findings are similar to those of Manthorpe and colleagues (2008), who when looking at people appointing attorneys under the England and Wales Capacity Act 2005, found that people wanted to appoint those people whom they trusted and who knew them well.

It was particularly important for the service users that they believe that the named person knew their wishes with regard to potential treatment. Despite the named person not strictly being a proxy decision-maker, the literature surrounding this area shows that patients often overestimate the extent to which a proxy decision-maker knows their wishes. Although some research has shown that accuracy of decision-making is not increased by discussion, the evidence from the dyads showed a clear understanding of why one interviewee did not want ECT, directly reflected in the interview with her husband who was also her named person. One area where proxy decision-making has been found to be the

least accurate is in dementia scenarios (Shalowitz *et al.,* 2006) and it may be extrapolated that any severe mental disorder may cause similar difficulties with communication and the expression of autonomous thoughts, thus making it hard for named persons to establish what the wishes of the patient are. This means that discussion about the future and perhaps the preparation of an advance statement should take place between the service user and their named person, similar to that recommended by Booth and colleagues (2004) regarding future decision-making.

Judgement of the named person

Service users generally stated that they would choose a named person whose judgement they trusted but, when this was tested with a vignette, they all said that the named person should advocate the patient's wishes rather than pursue their own opinion. This may be as a result of misunderstanding how the named person should operate or it may be because service users thought that, regardless of the right of the named person to act independently, they should support the patient's wishes. This issue is something that needs to be highlighted in support and information for both service users and carers.

Over half of the interviewees spoke of their named person respecting their wishes, which was borne out in the vignettes where the majority of service users thought that the known wishes of the patient should be acted on, rather than the opinion of the named person. Many service users spoke of trusting the judgement of the named person which seemed to indicate that the service users were aware that the named person could act independently from them in a number of ways, but this was not supported by the responses to the vignettes. Despite the reluctance of service users to approve of named persons making decisions, research has shown that patients discharged by their nearest relative, contrary to psychiatric advice, did no worse in relation to clinical outcomes (Shaw *et al.,* 2003). Discharging a patient is not now possible in Scotland but the named person could still present a case at the tribunal based on their personal knowledge and historical understanding of the patient.

The proxy decision-making literature showed that some proxies would prefer to make decisions by committee (for example, Hanson *et al.,* 1997; Pierce, 1999), reflected by some service user interviewees who thought that it should be possible to have two named persons. This seems to be a potentially complicated scenario that would leave the MHO or tribunal unsure about what lengths they should go to in contacting and involving *'named person A'* before they moved on to *'named person B'*. This appears to be a situation that could cause more problems than it would solve. Currently, if the named person is unable to act, then it reverts back to the tribunal to appoint a replacement, if there is one available, or for the patient to not have a named person. The named person cannot appoint a proxy as the nearest relative could under the 1984 Act. The removal of this right secures the choice of the service user that the named person provisions intended to promote.

10.3 Reasons for nominating different types of people as a named person

These findings show that under the previous nearest relative procedures twelve people would not have been happy with the resulting situation, over half the sample. However, this is a biased sample and it may be that people who had existing problems with the relationship with their nearest relative were more interested in taking part in the research. This was different to the carer sample where all but one of the carers either already were or would probably become their relatives' named person. The one relationship where this was not the case was a parent-child relationships which the parent carer described as being difficult. The majority of the interviewees with partners said they were going to nominate their partner with only one considering not doing so and even then only to spare her partner the responsibility. Following partners, friends were the most popular choice, with seven nominations and most of the friends being fellow service users. Biological relatives were the least frequently considered for nomination, although this may be due to the self-selecting nature of the interviewees.

10.3.1 Nominating relatives

The interview data showed variety in family relationships in that they could be very strong and supportive, or there could be difficulties to the extent that the service user was extremely keen that their relatives have no involvement in their care.

10.3.2 Considerations when nominating relatives

Amongst many interviewees, mostly those nominating friends, there was an assumption that family would not necessarily carry out their wishes as well as friends. It was not necessarily the case that they thought their family would abuse them deliberately, but rather that they did not understand them, infantilised them and assumed they, as carers, knew better.

Service user and carer interviewees expressed very strong views about their families of origin where relationships had broken down. Additionally, some referred to physical distance being taken into account when judging whether somebody would make an effective named person or not. Increased geographical mobility may mean that although there is a good relationship between the service user and a relative they are not the most appropriate choice for named person. However, tribunals can make use of telephone (as described by one MHO interviewee), or even as technology advances, web cameras to include physically distant relatives, especially if there is no other candidate.

Overall, there were few service user or carer interviewees who did not speak about some difficulty within the family and it would seem to be missing the opportunity to avoid potentially difficult future situations to not make full inquiries into this area with service users, preferably as standard, but particularly if compulsory measures seem likely. Carers did not discuss abuse from carers, as in the findings of Rapaport (2004) any mention of abusive carers or nearest relatives came from the other types of interviewee.

Advantages of family were difficult to draw out during the interviews. Only three interviewees thought that the role of the named person was best kept within the

family. It seemed that the attitude of these two interviewees was that family knew you best and would do what was best for you regardless of the situation.

10.3.3 Sparing relatives the responsibility

These finding show *'burden'* discussed somewhat differently that is usual. Many service users in the current research voiced concerns about sparing the responsibility to their relatives which is similar to the research on proxy decision-making where patients have expressed concern about the stress that becoming a proxy could cause for their relatives and whether they would be capable to act (Libbus and Russell, 1995; Jezewski, Meeker & Schrader, 2003). Manthorpe and colleagues (2008) also found that, indeed, not all carers would themselves have had the capacity to carry out the role of proxy. Service users were concerned about the imposition of this burden and were seeking to use the named person provisions to control and minimise this impact on relatives. The literature shows that carers are likely to be elderly parents who may be in poor health themselves (Rethink, 2003) so there is an increased chance that the nearest relative may be unsuitable to take on the role, which may become a cause for concern for service users. That they have no relative whom they consider suitable for the role may also be a rationale for a service user not to make a nomination at all.

The subject of taking on such roles being an unwanted burden for some carers has been discussed in earlier research (Rapaport, 2004). Most carers in this research did not speak of this being a burden, although both service users and professionals did. Only one carer spoke of her problems in balancing caring for her mother with working and caring for her young children, although she was the only carer who had young children.

Six service users were very conscious of the additional responsibilities their relatives had experienced as a result of the service users' mental health problems, particular concern was expressed for offspring who had had to take responsibility for their parents when they were children. It was thought that the parents and child carers in particular, felt they had little choice but to go on caring. It is thought that the nature of the sample and perhaps socially desirable

responses meant that information of this nature was unlikely to be provided by this particular sample.

The nature of the carer interviewees meant that these were people with enough interest in the provisions to agree to be interviewed which is far from representative of the general population of carers or potential carers.

10.3.4 Nominating a parent as a named person

The literature shows that the majority of carers are usually the parents of adult children as, for example, in Szmukler and colleagues (1996). Generational differences were evident in the interviewees with the older carers commenting about how they held different opinions to their children and MHOs describing how older relatives had different expectations of treatment. It may be that particular attention needs to be paid to explaining the provisions to older named persons in order to ensure that any outdated assumptions they may have are corrected.

Parents expressed similar emotions to those of the *'endless parenting'* described by Pejlert (2001), regret over the lack of independence of their adult child, and concern about what would happen after their death (Eakes, 1995), particularly the two parents who were in their 70s and 80s. Again, as in the literature, parents also spoke of the difficulty of being blamed by a child for their illness and the child not wanting contact with them when they were ill (Pejlert, 2001).

10.4 Not nominating a relative as a named person

There were three relationships discussed which were not of the biological family, those of the partner, the friend and the professional.

10.4.1 Nominating a partner as a named person

The nomination of a partner seemed to be less complex for service users and the parity awarded to same-sex partners was clearly welcomed. The temporal nature of many romantic relationships was referred to by a couple of interviewees, but it was thought that, as a nomination can be revoked, this

would prevent this from being too much of a problem, although only as long as nominations were kept up to date. It is thought unlikely that with proper advice a service user would want to nominate a short term romantic partner, although there was also no evidence of service users not wanting their long-term partners to be involved in their care, as was found by Henderson (2001). The two dyads that were interviewed showed no reluctance to be involved in their partner's care and treatment, and, as they had agreed to be interviewed in the first place, it can be assumed that they were happy to be involved.

10.4.2 Nominating a friend as a named person

The attitudes to friends seemed to be more favourable than those generally held towards relatives. This may be the nature of the sample, but it does go some way to support the literature describing the changing patterns of closeness amongst adults (Finch, 1989). Service users appeared to feel they had a more equal and honest relationship with friends, particularly those friends who were also service users. The experiential similarity seemed to be important as well as the knowledge of the mental health *'system'* or treatments. However, the issue of capacity loomed large over these discussions. The consensus was that it was probably not a wise choice to nominate a person with ongoing difficulties with their own mental health as they may not be relied upon to be able to provide support when it was required. Furthermore, it was recognised that mental health and illness can become a very emotive subject and service users can develop very strong views on what they think is right and wrong, and this may lead to the imposition of a personal agenda on another's situation.

It was generally agreed that it would be discriminatory to disbar a person from acting as a named person merely as a result of them having experienced mental ill health but it was interesting that service user interviewees in particular felt able to discriminate against other service users on that basis, with only one commenting that this was discriminatory. There is no guarantee that any named person might not turn out to have an individual agenda, or indeed even have capacity to carry out the role, regardless of whether they have ever had any contact with services themselves. Physical ill health can also strike at any time and may also render a named person incapable of acting. These are features of

the human condition that cannot be legislated or planned for, the only solution being to judge each case on its individual merits at the time in question. In this respect, it would be useful to create a situation where it is easier for a patient to have no named person, as then, if the nominated person were incapacitated for any reason, then the patient would simply not have their input, rather than a replacement being sought.

It was interesting that so few of the service users felt comfortable in taking on the role themselves, which may go some way to explain their reluctance to nominate another service user. They seemed to recognise the role as being both stressful and of great responsibility. They used the same standards to judge people as to whether they would act for others as they did in relation to their own nominations, *i.e.* they would have to know the person well. There seemed to be different standards in place for biological family with a number of service users saying they would act for family, but not for a friend, implying that they felt a stronger obligation to family members to care for each other. The service users with this attitude were also planning to nominate a relative as their named person.

10.4.3 Nominating a professional and the issue of social isolation

Three of the service users had wanted to nominate a professional. This was generally contrary to organisational rules and is advised against in the Code of Practice. The research looking at proxy decision-making has shown that patients often overestimate how accurate a professional would be at predicting their wishes, so it may be that the closeness of this relationship is overestimated. A further reason why this issue may become clouded is when there are people working in peer support roles. Should they be disbarred from acting as named persons for people they have only met through their employment, but not for those friends they may have in the mental health world outside of their employment? Many service users report their closest relationship as being with mental health professionals, often voluntary organisation support workers (Berzins, 2006), perhaps as they do not have the same potential control over aspects of the service user's life such as medication or initiating compulsory measures as a CPN or MHO might, but it is still a relationship that is not the

same as a friendship and does not have the reciprocal element. However, a professional providing support for a patient could still attend the tribunal regardless of assuming a formal position.

Unfortunately, a significant minority of service users will not have a named person available, as was the case for several interviewees, due to having no primary carer, no nearest relative and no friends whom they can appoint. Spencer and Skipworth's (2007) study of family involvement in compulsory treatment showed that the relatives of one fifth of patients undergoing assessment for compulsory treatment were unable to be consulted. The social support literature shows that this is not an uncommon situation for service users, (Nelson *et al.*, 1992; Webber & Huxley, 2004) and was reported as causing difficulties for MHOs who had to try and identify a named person regardless. It is suggested that it be made simpler in these situations to declare there to be no obvious candidate. It is recommended that in these and indeed all situations, the focus is shifted on promoting the use of independent advocacy to communicate the views of the patient and the use of a solicitor to take instruction from the patient. After all, there are many situations where a person can lose capacity and there be nobody available to act on their behalf, for example, the older person with dementia who has no relatives is still protected by the AWISA 2000 without a family member being there to assume the role of welfare attorney.

This chapter has discussed the findings surrounding autonomy underpinned by understanding and information, and the choice of named person. The next chapter discusses the power imbalances between service users, carers and professionals and the human rights implications of the named person provisions.

Chapter Eleven: Discussion of power imbalances and human rights

This chapter discusses the implications of the power imbalances between the different parties involved in the named person provisions and how this may affect the autonomy of choice of the service user in making a nomination and the carer or relative in accepting a nomination. It goes on to discuss the relationship between the named person and human rights legislation, with particular reference to choice and privacy before proposing a solution by the removal of the default named person provisions.

11.1 The relationship between service users and carers

The findings showed that there is the potential for an unequal relationship between service users and carers due to the services that a carer provides for the service user leading to reliance that can then, potentially, be exploited by the carer. The inequality may also work the other way round when a carer becomes afraid of conflict with the service user and does not want to disagree with them.

Some carers seemed less concerned about following the service user's wishes as they often spoke of times when the service user was unwell and they (the carer) had disagreed with their behaviour and had either found ways of persuading them to change their mind or openly disagreed with them. This can be very difficult for some people and can also have a lasting impact on the relationship afterwards. Some carer interviewees (most notably the elderly mother of a service user) spoke of standing back and not interfering, seeing their relative as having the right to do as they chose, even if they disagreed with their choices. One carer and named person saw the role as allowing her to become involved in her relative's care *'behind her back'* which may indicate that the role validates carers to take action independently.

The problem of the named person not wanting to disagree with the patient during the tribunal is a difficult one for which to offer a solution. It is known

that discussion about wishes may help a proxy to be aware of the patient's position, but this is not a proxy situation *per se*, the named person may be well aware of the patient's views yet still disagree, as is their right. It may be that better support of the nomination process would allow for discussion between the service user and named person so that disagreement would either be lessened or at least anticipated and discussed prior to the situation occurring. It is thought that without these opportunities it is probably more difficult for a default named person to openly disagree with a patient, which may mean that these people are the least likely to attend tribunals or make an active contribution.

MHO and policy interviewees thought that family would be offended if they were not nominated as a named person after the efforts they may have put into caring over the years. This was denied by the carers interviewed but there was commonly a questioning of whether there was anyone who knew the person as well as them, plus a wish to approve of the hypothetical person nominated in their place. It is thought that encouragement to make a nomination in the first place might lead service users to feel considerable pressure, particularly if the service user was otherwise socially isolated. Yeates (2005) commented that the primary carer and the nominated person being different people could become a potential source of friction within a family but this is not supported by this evidence. Essentially, it seems there could be friction in the family all round depending very much on the nature of the relationships of the individuals concerned, although confusion over specific roles could be clarified if there was support available to both service user and named person to ensure full understanding.

The named person does not make decisions on behalf of the patient but has the right to voice an opinion; to appeal decisions; to receive information; and to request certain procedures, for example, to request an assessment of needs. This means that decisions are made not on behalf of the patient but alongside. Discussion between the dyads who were couples showed that strongly felt wishes were known by the named person, although most of the other carers spoke of wanting difficult decisions to be made by professionals. Despite the research evidence showing that relatives have used their powers appropriately (Shaw *et al.,* 2003), these findings support those anecdotally reported by the Millan

Committee (Scottish Executive, 2001) that relatives prefer to leave difficult decisions, such as responsibility for consent to detention, to professionals. There was no evidence of carers expressing any wish to exert control over the service user, as in Perlick and colleagues' (1999) work, although such issues would probably not be expected to arise in a sample of carers who were interested in the named person provisions. It may be that those people who took part in research studies such as Shaw and colleagues' (2003) had had positive experiences of being the nearest relative which influenced their decision to take part in the research and it may be that the less active, or reluctant nearest relative would not participate. Research evidence aside, the court cases that resulted in the changes to the nearest relative procedures were example enough of the potential for harm to the autonomy of the patient from the role. The issue of decision-making within the named person provisions is not as straightforward as that of proxy decision-makers.

Another feature of the proxy decision-maker in the literature is the tendency for the proxy to act, rather than not act, if it is their right, regardless of what they actually believe. Although this is clearly conjecture, it may be that as the named person has the right to appeal against a judgement from the tribunal [s320(5)(b)], if the patient disagrees with the tribunal decision, the named person will feel obliged to appeal, even if they privately feel the judgement is in the best interests of the patient. To do nothing in the face of objection from the patient may lead to them being viewed as complicit with the tribunal and may damage the future relationship. This may be more the case if the named person is a friend, as they seemed to be expected to act on the patient's wishes more than family, and the friendship is likely to be less fixed and based on reciprocation rather than biological ties (Wellman, 1992).

It is suggested that the default named person places an obligation on the primary carer or nearest relative to become the named person. In previous research it was found that many nearest relatives did not know they could refuse to consent to an application for admission (for example, Summers *et al.*, 1999), this may the same with the appointment of the default named person. To reject the role they must communicate this in writing to the local authority [s250(6)(b)]. There may be many reasons why a primary carer or nearest relative

does not wish to become a default named person. They may not want to become formally involved in proceedings as it may have a negative impact on their subsequent relationship with the patient; they may also not feel capable of taking on the responsibility of what is a complex role at a time of crisis. Unlike the nearest relative under the 1984 Act they are not able to appoint a proxy to act in their place and as it has been suggested above, to allow this would seriously undermine the patient's autonomous choice of named person. However, at present for them to refuse the role in writing has the further possibility of being viewed as a rejection by the patient, who is likely to be experiencing serious mental illness.

11.2 The relationship between service users and professionals

The power imbalance can fall on either side between the service user and the carer but in contrast there is a unilateral imbalance of power between those people involved in the implementation of compulsory measures and the patient who is subject to them.

In this sample, the overall view of service users was that it was better to maximise the sharing of one's wishes and beliefs in the face of compulsory measures than not to. Although it must be noted again that a self-selecting sample such as this can be expected to have more favourable views than a wholly representative one. However, there was a sense from some service users and one policy interviewee, that widespread mistrust of the entire mental health system would affect the engagement of service users with the named person provisions. Service users were described as feeling futility in the face of compulsory measures to such an extent that there would be little point in them exerting their rights, and more than one interviewee referred to the ability of the tribunal to override the patient's nomination if it was deemed not in their best interests. However, it is difficult to argue for such a power to be removed; similarly, the Sheriff had the right under the 1984 Act to displace the nearest relative if they were deemed unsuitable [s56(1)]. This right to veto was found acceptable by the service users and carers in Manthorpe and colleagues' (2008) research of the England and Wales Mental Capacity Act 2005 and it provides reinforcement for a nomination that has been erroneously witnessed, or

remedies a situation when the relationship between the patient and the named person has suddenly deteriorated. It is also impossible to know how the named person will behave until the situation arises; they may not fulfil what is expected of them and behave in a way that is damaging for the patient. The patient may then lack capacity to revoke the nomination so there must remain an alternative option for this. This decision would only be made if there were clear reasons for the tribunal to remove a named person and the decision must adhere to the principles of the 2003 Act. However, there is the potential for challenge as to whether a tribunal should be able to actually remove and replace a named person against a service user's wishes. The decision-making capacity that is covered by the 2003 Act is that relating specifically to treatment decisions. It could be argued that a decision to appoint a named person, regardless of how unsuitable they may appear, remains the right of the patient as long as they have understood the implications of the nomination and not been subject to duress [s253(5)(b)].

The 2003 Act has clear principles that each decision made under it must be viewed in the light of [s1], there are also improvements in communication and information-sharing through the tribunal system, as well as the availability of independent advocates [s259(1)]. It may be that the introduction of these features and the increased transparency of the process provide greater reassurance for patients who become subject to compulsion. Unfortunately, the circumstances in which a service user may become a detained patient are unlikely to lead them to feel that their choices and decisions were to the fore, but this does not mean that these choices cannot be aired wherever possible and the reasons for them being overridden having to be transparent and clearly communicated. Research in England has found that 40% of patients who had been detained considered their dentention to be justified when interviewed one year later (Priebe & Katsakou, 2009). This substantial minority of patients may be those who are most interested in planning ahead in case of further admissions.

The tendency for MHO interviewees to distance themselves from the named person provisions, seeing them as something that the person can choose to use, is problematic. Although in theory this distancing reinforces the right of the

service user as an autonomous individual, there is the danger that this attitude will prevent awareness-raising with people who could benefit from making a nomination. It is argued that providing information is a way of supporting and maximising their autonomy, particularly if it is at risk of being diminished at a later date, either as a result of mental illness or the use of compulsory measures. It is not unduly influencing a service users' behaviour to provide them with comprehensive and accessible information about making a nomination. The making of a nomination has further benefits for the MHO and other members of the care team as it means that, in the event of compulsory measures taking effect, the MHO is not left with the task of identifying a named person in an acute and time limited situation.

The interviewees in this research who were appointing named persons were generally articulate and very aware of their rights, and several said they had been well for some years. The explicit protection of their *'rights'* was mentioned by nearly half of the service user interviewees. It is suggested that their involvement in voluntary sector mental health services with collective advocacy as an aim meant that this group were more *'rights-aware'* than other mental health service users might be. This may be a similar effect to the politicisation of same-sex relationships as suggested by Manthorpe (2003). It is not clear how much awareness less articulate and indeed more vulnerable service users, who have no contact with services except the required statutory ones, will have about their options regarding the named person. These people are likely to be those with least autonomy and possibly those more likely not to have contact with family and to have poor social support (Webber & Huxley, 2004). This group should be specifically targeted for discussions by professionals, even if it is to establish and record that there is no named person.

11.3 The relationship between carers and professionals

The relationship between carers and professionals is more complex. It may be seen that the professional is the stronger party but the carer has acquired a range of rights independently of the services the person they care for receives.

Many carers spoke of difficulties in their relationships with professionals. It is suggested that these problems arise from the unusual situation that carers find themselves in, that of assuming some responsibility for the service user but with rights as a carer themselves. The literature has also shown that carers have many complaints about communication with professionals, the problem of confidentiality often being central to these difficulties. All the carer interviewees except one (who by attending appointments with his wife had her implied consent to information being shared with him), spoke of difficulties with professionals with regard to information-sharing and general communication issues, but it seemed that those who had been appointed named persons were more satisfied with communication, and it may be that having this additional formal position means that professionals are more likely to make efforts to communicate with them. However, the named person role should not be seen as a means to improve communication with professionals. Carers have rights to consideration and support regardless of whether they are a named person or not, and professionals should be sensitive to their support and information needs regardless of their status under the 2003 Act, as encouraged by publications from the Royal College of Psychiatrists which provide good practice guidance on negotiating confidentiality with both service users and carers (Royal College of Psychiatrists, 2004)

Carers often spoke of being able to provide important contextual and historical information about the patient as well as day-to-day things that the patient may not reveal, and the literature has described information flowing both ways between carers and professionals with one concern, that the removal of the nearest relative in England and Wales would lead to the carer becoming a passive source of information (Yeates, 2005). It seems that this has been bypassed by the tribunal in Scotland as the carer can participate regardless of whether they are a named person or not, and, if they are additionally the nearest relative, they are still entitled to some basic information [s38(4)(a); s298(2)(ii)]. Furthermore there is the principle of the 2003 Act pledging consideration to the views of carers [s1(3)(b)(ii)]. Some carers may also be content to provide information without holding a formal position in proceedings as they may fear it could cause a problem with the patient and prefer someone else to have the role.

The advancement of carers' rights was reflected in that one parent carer had only started calling herself *'carer'* after realising that it opened more doors than using the term *'parent'*, supporting Szmukler's (1999) and Twigg and Atkin's (1994) findings and further demonstrating the greater currency that the term *'carer'* has assumed as a result of these policy and legislative shifts.

Several professional interviewees referred to the reluctance of named persons to attend tribunals and this was thought to be for several reasons. The first is the most difficult to overcome as tribunals are often adjourned and reconvened and it can be hard for somebody to arrange time off work and potential subsequent loss of wages, childcare or other commitments. The further reasons can be tied to the lack of support for the named person, some interviewees complained that the tribunal situation is still too intimidating to attend. There is little that can be recommended to lessen the gravity of the tribunal. It is a powerful agent and the formality ensures that due legal process is followed and in a transparent manner. However, the named person can be supported and adequately prepared for the tribunal, encouraged to clarify their feelings on various subjects that may be discussed, and appoint a lawyer to represent them. Making these provisions would be reliant on there being a point of support as discussed above. There is little that can be done about adjournments and delays, but there is room for named persons to receive better support and advice that may allow more people to fulfil the role.

There is a potential imbalance in the relationship between professionals and carers with regard to the default named person as, particularly in an acute situation, a carer or nearest relative may not know that they can choose not to become a named person by default. In order to avoid carers being pressured into accepting the role, it should be the MHO making the application who provides them with this information in the first instance and, preferably, should refer them on to a carers' support service for further information and independent support.

11.4 The named person provisions and human rights

The introduction of the named person originally sought to address problems with the nearest relative under the 1984 Act which specifically related to human rights. It is suggested that these problems have only partially been addressed by the 2003 Act due to limits to choice and a threat to privacy.

11.4.1 The default named person and human rights: lack of choice

It is thought that most existing patients becoming subject to compulsory measures have a named person appointed by default and this will almost always be the case for first episode patients. There are several unaddressed difficulties, the legality of one, it is suggested, may be open to challenge under human rights legislation.

Quality of relationship with the default named person

The first problem is that by using the hierarchy of nearest relative to identify a default named person, there is no consideration given to the quality of the relationship with the patient, the original problem with the nearest relative. This is particularly the case where there is neither primary carer or cohabitee. In these cases a patient may have a relative appointed who knows little about them and with whom they have little or a poor relationship. The repeal of the 1984 Act no longer allows the nearest relative to be changed, the service user can make a declaration preventing their nearest relative being appointed named person, but this relies on them having knowledge of this procedures and that will rarely be the case for first episode patients.

The quality of the relationship the first episode patient has with their nearest relative will be unknown to the MHO and to the ensuing tribunal panel. It can be assumed that in these situations the person identified as the named person will have little understanding of the named person role and may be too distressed by the crisis surrounding their relative to be able to fully accept their sudden responsibility. The usefulness of the default position here in both protecting the rights of the patient and the named person has to be questioned.

Lack of choice

There is currently no choice for the patient as to whether they have a named person or not. There is no mechanism that explicitly allows a service user to bar the appointment of any named person at all, they can only prevent named individuals from being appointed [s253(1)]. This seems contrary to human rights legislation as found by JT v UK[61] and may become subject to an eventual test case. It is also contrary to the limited research evidence in this area which has shown that one third of service users completing a psychiatric advance directive did not want to appoint a proxy decision-maker (Backlar *et al.*, 2001). It seems inconsistent that in the event of compulsory measures the patient is allowed to choose whether they use a solicitor or an independent advocate, yet they cannot prevent a named person being appointed. Of course, a solicitor or *curator ad litem* can be appointed on the behalf of the patient but this is appointing a person with specialist training and knowledge to ensure the patient's rights are protected. A named person *per se* has no special skills and may not have anything to contribute, especially if they do not know the patient particularly well which may well be the case when using the default provisions. Many interviewees thought that there should be the possibility to declare a universal rejection of a named person that would be binding for the tribunal. If a declaration of this sort were available, it was thought, by one policy interviewee with a legal background, unlikely to be overturned by the tribunal. This situation could be clarified by amending the 2003 Act to allow a declaration that no named person should be appointed in any circumstances, thus widening the patients' choice.

11.4.2 Information-sharing and human rights

Where there is a default named person identified and a tribunal is to take place, the default named person will receive the tribunal papers in advance from the tribunal. The MHO has no power to say that the default named person is unsuitable, only the tribunal can make this decision after an application stating

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[61] *JT v United Kingdom*, 1998 Application No. 26494/95

this perceived unsuitability, so even if the named person is known to be unsuitable they will still receive information about the patient, even though they may then be displaced when the tribunal sits [s257(2)]. This situation leaves the patient in a weaker situation than they were under the 1984 Act which specified that information could be withheld from the nearest relative if the patient requested it be [s110(4)]. This sequence of events could mean that an unsuitable default named person, by virtue of blood ties alone, could receive information about the application. This appears to be contrary to the ECHR ruling on privacy and medical records information[62], a concern also raised by the MWC in their most recent annual report (MWC, 2008b).

The issue of information sharing is particularly important as once the information has been passed to a default named person it cannot be retracted, the privacy cannot be restored. This has implications for the later relationship between the patient and the named person, for example, the information could be used against the patient in the future, for example to challenge custody of children as reported in Rappaport (2003).

It could be argued that no information be sent to any person, if the patient objects and particularly if this is written in an advance statement, but as was pointed out by a policy interviewee, if a person is detained against their will, it is imperative that, as one interviewee said: *'somebody on the outside'* be informed about what has happened. Another person being informed that a detention has taken place can be seen, as it was by the interviewee, as a civil right (de Stefano & Ducci, 2008) rather than a breach of confidentiality. Although automatic use of independent advocacy and a lawyer could offer protection in these cases. It is recommended that the situation be remedied and that the patient should be able to prevent information being sent to a default named person.

Despite this potential breach of confidentiality, the problem of information-sharing was not a concern to many service users as they thought that anything that may be detailed in an application for compulsory measures would already

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[62] *Z v Finland,* 1997 Application No. 22009/93.

be known to their named person, although, significantly, they were considering somebody they would have proactively chosen.

One interviewee spoke of carers not wanting to receive this level of information about the patient which would be avoided if they could more easily opt out of being the patient's default named person or the default situation was removed. Otherwise it is proposed that they cannot adequately fulfil the role if they do not receive the same level of information as the other tribunal members. There also appeared to be a level of misunderstanding of the level of information that is actually provided to the named person and the other tribunal members, and it has been reported that named persons and service users have been distressed by the level of disclosure after the fact (Smith, 2006). This is in the form of reports and applications rather than extracts of medical records or details of consultations with professionals. This is an issue that could form part of the information and awareness-raising as it is not currently clearly explained in the Scottish Executive Guide to Named Persons (Scottish Executive, 2004).

MHOs thought that they could be tactful about information put in reports for the tribunal and only that which was necessary would be there. However, it is suggested that the necessary could still be contentious and tempering of this information affects the integrity of the application and the transparency of the tribunal process. This issue would be less of a problem for MHOs if there was no provision for a default named person.

A Scottish Government report was published in February 2009 (Dawson *et al.*, 2009), too late to influence the research described in this thesis. The study was focused on professionals after difficulties recruiting service users and carers. The findings support those of this research with regard to perceived high levels of default appointments (thought to be due to a lack of knowledge and understanding about the role and the circumstances when the need arises causing difficulties); an over-emphasis on having to find someone to act as a named person and concerns about the amount of information sent to the named person.

11.5 Removal of the default named person role

There was general disapproval amongst service user interviewees as to the default appointment of a named person. Carers also did not think that named persons should be appointed by default; perhaps as carers themselves, they had a greater awareness of the responsibilities of the named person and they were less supportive of it being imposed on people by default. Policy interviewees spoke of the potential for a *'stepped down'* role for default appointments and MHOs felt it was often a similar situation to the previous nearest relative role, with the same associated problems. However, it is considered that a reduced role, perhaps where a default named person was not treated as a full *'party'* by the tribunal but had some rights, would prove complex to manage.

At this point it is interesting to note that the default appointment role was considered unnecessary by the Richardson Committee in England and Wales as anyone would have right of access to the tribunal to appeal the decision (Department of Health, 1999). It is argued here that the same is true under the Mental Health (Care and Treatment) (Scotland) Act 2003, any carer or *'any other person appearing to the tribunal to have an interest'* can attend and apply to the tribunal.

The named person as it currently stands is a legal anomaly. The nearest relative was for many years the only legal construct that allowed relatives decision-making rights over a relative (Twigg, 1994) but the named person has continued in this way via the default role. There is no other legal role such as this in which the role defaults, all other similar roles must be applied for and scrutinised, for example, welfare attorney provisions under the AWISA 2000 are registered with the Office of the Public Guardian [s22]. It is argued that it is a role that has emerged for historical reasons before patients had access to other forms of support to protect their rights such as independent advocates and solicitors. Now that they have these additional supports available and any person with an interest can attend the tribunal, the default role seems to have the potential to undermine patients' rights more than protect them. It has already been suggested, on the basis of anecdotal evidence, that it be reconsidered (Mental

Health Officers Newsletter Advisory Group, 2006) but in the light of the research evidence currently presented it is suggested that it be removed entirely.

11.6 An alternative system

One solution regarding lack of awareness and understanding of the role would be to remove the default appointment of a named person entirely solving the difficulties described above. It is proposed that an alternative provision would be as follows:

The process of nominating a named person would remain as it is, including the right to make a declaration preventing a person from being appointed named person by the tribunal. The default named person would be removed entirely. If a person had not made a nomination there would be no named person. Instead, any person with an interest could apply to the tribunal hearing to be appointed as the named person, similar to under the 1984 Act where a person could apply to become the nearest relative. The patient's views would be taken into account (and any declaration) and this person would then be appointed by the tribunal or by the patient, if they were judged to have capacity to make a nomination. If the patient later wished to revoke the named person they could.

There would be several advantages to applying this process: It would encourage patients to make an active nomination rather than leaving things to default, this in turn would ensure that they found out more information about what the role actually involved, would promote discussion between the patient and the named person and increase the chances that both parties have an understanding of what is involved. It would prevent MHOs from having to identify a named person in short time scales without being satisfied that the patient or named person fully understands the role. It would prevent confidential tribunal papers being sent to a default named person who may then be found to be unsuitable by the tribunal and subsequently removed. It would prevent patients becoming distressed that they had nobody to nominate as named person and not having choice as to who may be appointed by default. It would prevent a role being defaulted onto a relative who may find it stressful yet not want to formally reject the role for fear of upsetting the patient.

The nearest relative and primary carer would still be informed about the patient's detention and could attend the tribunal where they could apply to be appointed as the named person. At the point of a person being detained the MHO could pass information about the named person to the carer and / or nearest relative so that they can consider applying to take on the role.

It is thought that the active and involved named person provides the strongest support to the patient. The removal of the default would go some way to ensuring that the taking on of the named person role was always an active choice rather than a passive process.

The sole disadvantage is that fewer patients may subsequently have a named person than at present. However, the named persons that there were, would be more likely to understand their role, as would the service users who had appointed them. It has already been discussed that the patient has other means of protecting their rights than through the named person, so it is not thought that the patient would be put at a great disadvantage. Information that a named person could provide about the patient historically could still be sought from carers and relatives without them having the additional legal responsibilities.

There is a further, broader issue in that if a person's autonomy is compromised by illness and as a result societal structures deny them their freedom, checks must be built in and another person must be able to advocate on their behalf. It may be that the way round this is to strengthen the role of the independent advocate and the lawyer, and ensure that as many patients as possible have both representing them, although this of course relies on resourcing to provide adequate numbers of lawyers who can act for service users. Additionally, the MWC could be informed of cases were the patient did not have a named person and had refused both independent advocacy and a lawyer, in order to provide independent scrutiny.

In the light of these findings it can easily be seen how an actively involved named person, chosen by the service user can represent their interests in the

face of compulsory measures, however, it is difficult to see the benefit of an uninformed and even unwilling named person defaulted into the role.

This chapter has discussed the inequalities between service users, carers and professionals, and the potential difficulties caused by the lack of choice of default named person and the sharing of information, and proposed a solution. This concludes the discussion of findings, the next section draws conclusions and makes a series of recommendations arising from the findings.

Conclusion and recommendations

Conclusion

The 2003 Act and the named person provisions have greatly changed the way that people with mental disorder are treated under the law in Scotland, allowing people more choice about who is involved in decisions made about their care and treatment. This is the first research into the perceptions and use of the provisions to have been carried out with a range of stakeholders (Berzins & Atkinson, 2009).

The provisions allowing the nomination of a named person were seen as beneficial to service users by the majority of interviewees as they allowed a person chosen by the patient to protect their interests and to provide a personal and historical perspective of the patient's needs. The choice was particularly welcomed by those service users in same-sex relationships and where family relationships had broken down. Being appointed a named person is also valued by carers and may lead to improved relationships with professional carers. Despite the advantages of nominating a named person there appear to have been low numbers of proactive nominations for named persons made. This is thought to be as people are not always aware of the provisions, do not want to plan for relapse or are happy with the default scenario.

However, the majority of service user interviewees had used, or planned to use, the named person provisions although fewer than half were planning to nominate a biological relative and even fewer nominating their nearest relative, as defined by the 2003 Act. Although it must be remembered that this self-selecting sample may have been more likely not to want the involvement of their nearest relative. Some interviewees did not want their relatives to take on the role to spare them the burden of responsibility rather than due to hostility or disagreement. Advantages of family involvement included relatives knowing a person well and the greater perceived permanency of relationships. Others felt that their friends knew them better and often friends who were service users with similar experiences. The nomination of partners seemed the least difficult choice with all of those with partners wanting to nominate them. Only three of

the carer interviewees had been appointed named persons. Others hoped to become so in future although one felt her relative would not agree to this.

There was a distinct lack of understanding of the provisions amongst service users which undermined their ability to make a fully autonomous choice. This was most evident with service users not appearing to realise that a named person could act independently from themselves and did not have to represent their wishes. Further and ongoing support and awareness-raising was required with both service users, carers and professionals. This awareness-raising should be supported by accessible information for both service users and carers. The acquisition of information is further hampered by the readability of the available material from the Scottish Government. The role of promoting and supporting the use of the named person provisions by MHOs in particular was seen as problematic by some who feared a conflict of interest, although, where service users were making nominations independently, there were problems identified with actually processing the nomination and communicating it across the multi-disciplinary team.

Although service users can choose to make a nomination and those whom they nominate have a choice whether they accept the role, the actual situation is rarely as straightforward as this, and there are a variety of power imbalances that may influence the decisions made both by service users and carers. Service users may feel obliged to nominate carers and carers may feel obliged to accept the role. Professionals (witnesses in particular) could be of use in providing support in these situations. There is a further power imbalance between professionals and service users and carers, both of whom are dependent on professionals for support.

There are concerns regarding human rights with specific regard to the default named person, particularly when capacity is lost and a default named person (itself an anomaly in Scots law) is identified and appointed. This raises two specific issues, the lack of choice the service user has concerning the default appointment of a named person being involved in their care, and the sharing of confidential information with the named person. Service users' perceptions of named persons being appointed without their consent were negative. Some

MHOs reported difficulties with their responsibility to identify a default named person. The current lack of a right of a service user to reject having a named person restricts choice and autonomy and may place unwanted responsibilities on carers and relatives that are difficult to remove.

Information-sharing did not appear to be of great concern to service users, although this was usually spoken of in the context of a proactively nominated named person. The specific problem is that when a named person is appointed by default, they may receive confidential information about the patient (for example, an application for a CTO) prior to a tribunal, at which they may be removed from the role, for example, for not acting in the patient's best interests. The patient cannot stop this information being sent, as was possible under the 1984 Act.

One solution to these problems would be to remove the default named person, particularly as the advantages of having a named person seem largely dependent on the named person being proactively nominated. It is not thought that a service user is greatly disadvantaged by not having a named person, particularly a reluctant one appointed by default. In cases where no nomination has been made, a nomination could be made at a later time if the patient wished, and instead, a shift in focus to promoting the role of the independent advocate and lawyer is thought to better protect patients' rights.

Finally, a service user provided a concise summary of the named person provisions:

> *"In the past it was assumed that the nearest relative would have your interests at heart but sometimes it was the opposite and very often these people caused the trouble in your life. Or at least that may be thought by the person and it might be true as well. Just to casually assume that that was the right person was not a very sensible thing to do so to give the person the option to pick a person is an improvement."* SERVICE USER #6

Recommendations

The recommendations arising from this research are summarised as follows:

Awareness-raising and information

1. All service users at risk of compulsory measures should be encouraged to either make a nomination for a named person or a declaration to prevent the default appointment of an unwanted named person (Page 189).

2. To support this promotion, awareness-raising work should be carried out and evaluated with service users, carers and professionals (including those people who can act as witnesses and carer support services). This should focus on the amount of information shared with a named person and the independence of the named person (Page 192).

3. This awareness-raising work could benefit from the development of a more accessible introductory leaflet by the Scottish Government, about the named person to provide a broad overview and to direct service users and carers to the existing more detailed information (Page 193).

4. Information specifically for carers and relatives should be developed by the Scottish Government (Page 225).

5. Specific information should be provided for those who can act as witnesses ensuring that nominations are not made under duress and that service users understand the implications of their nomination (Page 192).

Access to direct support

6. Service users should be able to access support in making a nomination for named person from a professional or service (Page 225).

7. Carers should be able to access support either to fulfil their role as a named person or to reject the default role (Page 215).

Legal changes

8. The 2003 Act should be amended in order to permit a blanket declaration by the service user prohibiting the appointment of any named person (Page 216).

9. The 2003 Act should be amended to prevent tribunal papers being sent to a named person by default if it is contrary to the patient's wishes (Page 217).

10. The removal of the default named person provisions from the 2003 Act should be considered (Page 220).

Impact of the research

As a result of the research, the researcher was invited to participate in specialist training by the Law Society Scotland and the Royal College of Psychiatrists Scotland and to give evidence to an expert review of the 2003 Act, Scotland's Mental Health Act Review.

Appendices

Appendix 1: Participant information sheet, consent form and research protocol

Participant information sheet (service users and carers)

Mental Health Act 'Named person' research

My name is Kathryn Berzins, I am a PhD student at the University of Glasgow, Faculty of Medicine). I am inviting you to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it would involve. Please take time to read the following information carefully and discuss it with others if you wish. If you would like further information please get in touch with me. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of the study?

In 2003 the Scottish Parliament passed a new law, the Mental Health (Care and Treatment)(Scotland) Act 2003. It sets out how you can be treated if you have a mental illness and what your rights are. The Act created a new support role for mental health service users, the **'named person'**. A named person is somebody you can nominate to help to protect your interests if you have to be given care or treatment under the new Act. Your named person would have to be informed and consulted about aspects of your care, and can make applications to the Mental Health Tribunal for Scotland (set up by the Act to make decisions about the care and treatment of people with mental disorder). The named person is entitled to be given information concerning compulsory measures which have been taken, or are being applied for.

I am interested in what people affected by mental health legislation, their carers and mental health professionals think about these new provisions, whether they think they will be of help to people and in what ways.

Why have I been chosen?

You have been invited to take part either because you use a mental health service or care for someone who does, or you are a mental health professional. I aim to interview up to 50 people overall.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This research is not connected to the services you may use and these will not be affected if you do not take part.

What will happen to me if I take part?

You will take part in one interview, lasting no longer than one hour. This may be carried out over the telephone or it may be carried out face-to-face.

What do I have to do?

During the interview you will be asked for your opinions of the 'named person' role (You do not have to already know about this role, it will be explained to you and any questions you may have will be answered.)

I will ask service users what they think would be important if choosing a named person. You will be asked who it would be that you might choose to be your named person and the reasons why. You will be asked whether you think such provisions are helpful or unhelpful for people. You may be asked permission for that person to be contacted and invited to also take part in an interview. This interview will **not** be about you, but about their opinions of being a named person.

What are the possible disadvantages and risks of taking part?

Occasionally, some people can find talking about their experiences upsetting. If this were to be the case somebody you currently receive a service from (e.g. a Support Worker) would be told about this (with your permission) and could offer you support.

What are the possible benefits of taking part?
Many people enjoy taking part in this kind of research and enjoy having their experiences and opinions listened to. The information gained from this research may help services in the future to be more understanding of the needs of people with mental health problems. You may also find out more information about the role of the named person and where to go for further information and support.

Do I receive anything for taking part?
Each service user or carer who is interviewed will receive a £10 gift voucher from a choice of shops.

Will my taking part in this study be kept confidential?
All information which is collected about you during the interview will be kept strictly confidential. Any information about you will have your name and address removed so that you cannot be recognised from it. During the interview with the person you may ask to be your 'named person' you will **not** be discussed, they will be asked about their opinion of the role and how they would feel about carrying it out. The interview will be recorded so it can be typed up, all details identifying you will be removed at this point. Quotations may be used in the final report but anything that could link them to you will be removed.

What will happen to the results of the research study?
The results of the study will be used for a PhD thesis. A short summary of the findings will be available in 2008. You can ask for your name to be kept on file to receive a summary of the findings. This file will remain confidential, will not be passed to any other party and will be destroyed once the findings have been distributed.

Who is organising and funding the research?
The research is sponsored by the University of Glasgow. It is a self-funded PhD.

Who has reviewed the study?
The project has been reviewed by the Faculty of Medicine Ethics Committee.

Contact for Further Information

Kathryn Berzins, Public Health & Health Policy, University of Glasgow, 1, Lilybank Gardens, Glasgow, G12 8QQ.
Tel: 0141 330 2713
email: K.M.Berzins@clinmed.gla.ac.uk
Mobile: 07811 108537

If at any later time you feel at all unhappy about any aspect of your experience of taking part in this research, you have access to complaints procedures through contacting Dr Jacqueline Atkinson, Public Health and Health Policy, University of Glasgow, 0141 330 4039.

Thank you for taking part in this study!

Consent form

Participant identification number:_____

Project title: **Perceptions of the named person provisions under Mental Health Legislation**

Name of Researcher: **Kathryn Berzins**

UNIVERSITY
of
GLASGOW

Please initial box

1. I confirm that I have read and understand the information sheet dated........................... (version...........) for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care, any other support, or my legal rights being affected.

3. I agree to take part in the above study.

4. I would like to be kept informed about the findings of the study by being posted a summary of the research findings.

(If so, record postal address:
………
…………………………………………Postcode…………………)

_____   _____   _____

Name of interviewee   **Date**   **Signature**

_____   _____   _____

Researcher   **Date**   **Signature**

Protocol

Project title: Mental health service users', their (potential) nominees' and professionals' perceptions of the 'named person' role under the Mental Health (Care and Treatment) (Scotland) Act 2003

Name and address of researcher: Kathryn Berzins, PhD Student, Public Health and Health Policy, University of Glasgow, 1 Lilybank Gardens, Glasgow, G128RZ
Email: 9609867b@student.gla.ac.uk

Name of researcher's supervisor: Dr Jacqueline Atkinson, Senior Lecturer, Public Health and Health Policy, University of Glasgow, 1 Lilybank Gardens, Glasgow, G128RZ
Email: J.M.Atkinson@clinmed.gla.ac.uk

Fieldwork dates: October 2006 – February 2007

Fieldwork location: Across Scotland - as a result of opportunistic sampling

Qualifications and experience of the researcher:

The researcher is Kathryn Berzins who has a BA Hons and a Master of Community Care. She has seven years experience as a Research Associate within the Public Health and Health Policy Section and as such, has substantial experience in interviewing people who use mental health services. Prior to taking up research post she spent five years working directly with people with severe and enduring mental health problems.

Purpose of the research:

The purpose of this research is to explore the perceptions of mental health service users', their (potential) nominees' and mental health professionals' perceptions of the role of 'named person' under the Mental Health (Care and Treatment) (Scotland) Act 2003.

The research will seek to explore the understanding and perceptions of the named person provisions of the 2003 Act from the perspective of the (potential) patient and the (potential) named person, carers and mental health professionals involved in implementing the procedures (Mental Health Officers) and those involved in planning and policy.

It seeks to specifically explore:

- What are the views of stakeholders on the introduction of the named person provisions?

- What are the perceptions of the extent to which the named person provisions are being used by service users?

- What factors do service users consider when planning the nomination of a named person?

- What is the nature of the relationships between service users and their planned named person?

- What are stakeholders' opinions and experiences of the default named person provisions?

Participants:

A total of 40 participants will be sought from four groups:

1. People with mental health problems (20)
2. (Potential) Named persons (approximately 10)
3. Mental health professionals / policy makers (approximately 20)

Summary of the design and methodology of the project:

This is a qualitative study based on interview data from both face-to face and telephone interviews.

The research will be carried out Scotland-wide, wherever access can be gained to professionals, service users and carers through liaison with relevant non-NHS organisations. As these are new provisions there has not been consistent uptake across Scotland so it is necessary to be able to approach groups where interest is found to have emerged.

The research procedures as they affect the research participants:

Mental health service users:

The interviewees will be accessed through the independent sector organisations (this application is to approach people outwith the NHS).

Initial discussion will take place with relevant voluntary organisations to judge the potential interest. The researcher may also visit services, give a brief presentation of the issue under investigation, which both introduces people to the research and raises awareness of the issues. Service users will be given an information sheet about the research and if they wish to take part, be encouraged to advise a member of staff to pass their details to the researcher.

The staff member will pass the contact details of the potential interviewee to the researcher and a risk assessment will be carried out to ascertain whether there is any risk involved in the participant being interviewed. The researcher will contact the potential interviewee by telephone to ascertain whether they still wish to be interviewed and if so, arrange a date and location. Previous similar studies have shown that this will usually be at service premises but may occasionally be at another location, e.g. the interviewee's home. (An appropriate risk assessment in respect to the researcher's safety will be carried out and contact details will be left with a named person in the university)

Prior to the interview, if required (as many will already have a copy), each interviewee will be posted a short accessible booklet (Scottish Executive (2005) *The New Mental Health Act: A Guide to Named Persons* about the provisions. Immediately prior to the interview the interviewee will have the consent process explained and be asked to sign the consent forms. Interviewees will have the opportunity to withdraw their consent to take part at any stage in the process. The interview will then proceed.

Potential named persons:

This group will be accessed through the people using mental health services or independent organisations. After the interview each interviewee will be asked for permission to access the person they would (or may already have) nominate to act as their named person. The name and contact details of this person will be provided by the original interviewee and a risk assessment carried out as described above. The researcher will contact the potential interviewee by telephone to ascertain whether they would be interested in being interviewed, and if so, arrange a date and location.

Prior to the interview, if required, each interviewee will be posted the information booklet as above.

Immediately prior to the interview the interviewee will have the consent process explained and if they still wish to take part, be asked to sign the consent form or give verbal consent if the

interview is being carried out over the telephone. Interviewees will have the opportunity to withdraw their consent to take part at any stage in the process. The interview will then proceed.

Unconnected carers:

The interviewees will be accessed through independent sector organisations in Scotland.

Initial discussion will take place with relevant voluntary organisations to judge the potential interest. The researcher may also visit services, give a brief presentation of the issue under investigation, which both introduces people to the research and raises awareness of the issues. Carers' service users will be given an information sheet about the research and if they wish to take part, be encouraged to advise a member of staff to pass their details to the researcher.

The staff member will pass the contact details of the potential interviewee to the researcher and a risk assessment will be carried out to ascertain whether there is any risk involved in the participant being interviewed. The researcher will contact the potential interviewee by telephone to ascertain whether they still wish to be interviewed and if so, arrange a date and location. Previous similar studies have shown that this will usually be at service premises but may occasionally be at another location, e.g. the interviewee's home.

Prior to the interview, if required (as many will already have a copy), each interviewee will be posted a short accessible booklet (Scottish Executive (2005) *The New Mental Health Act: A Guide to Named Persons*) about the provisions. Immediately prior to the interview the interviewee will have the consent process explained and be asked to sign the consent forms or give verbal consent if the interview is being carried out over the telephone. Interviewees will have the opportunity to withdraw their consent to take part at any stage in the process. The interview will then proceed.

Mental Health Officers/ professionals involved in policy making:

If the interviewee is employed by a Local Authority Social Work Department the potential interviewees will be contacted after permission has been granted from the Association of Directors of Social Work and the employing Local Authority. If the potential interviewee is employed by an independent sector organisation they will be approached directly. Potential interviewees will be provided with an information sheet about the research and asked to contact the researcher if they would like to be interviewed. The interview with then be arranged for a convenient time and be carried out over the telephone. Immediately prior to the interview the interviewee will have the consent process explained and be asked to sign the consent forms or give verbal consent if the interview is being carried out over the telephone. Interviewees will have the opportunity to withdraw their consent to take part at any stage in the process. The interview will then proceed.

All interviewees will be asked for permission for the interview to be audio-taped for transcription. If this permission is not granted detailed notes will be taken instead.

Analysis:

The data generated from the interviews will be qualitative. Interviews will be transcribed and analysed using thematic analysis supported by Atlas ti.

Ethical considerations:

A study of mental health service users and their families and carers must be particularly alert to ensure that individuals have given their informed consent to participation in the study and that any research activity does not exacerbate any distress. All mental health service users invited to be included in the current study will be in contact with at least one specialist support service, and will be recruited through such agencies. This will ensure both that individuals are approached to participate in a supportive context and that, should any necessity for extra support emerge after the interview, resources will be on hand. Should any interviewee be felt to require additional support their consent will be sought before this is raised with a professional involved in their care, if they do not give consent they will be informed that the researcher's concerns will be communicated to the professional and what information will be communicated.

Experience suggests however that when respondents have chosen to participate in studies of this type, which give them an opportunity to discuss aspects of their lives in some depth, they can find it a valued experience.

The study will be conducted in a manner that ensures all ethical standards are met. Potential participants will have the study fully explained to them and will receive a copy of the project invitation / information leaflet. This will include assurances of confidentiality, explanation of how the data will be used, and their rights to withdraw from the project at any stage. Those agreeing to participate will be asked to indicate their informed consent either in writing or verbally and audio taped. Interviews will be conducted with sensitivity and care by an experienced researcher who will herself be within a supervision structure providing ongoing support and advice. Lone working can pose a risk to the health and safety of researchers and full procedures are in place to manage this risk.

All data will be anonymised as soon as the interview is completed and no names and contact details will be entered on the interview schedule except a unique identifier number. Participant's names and contact details will only be retained until the interview is completed, or their consent withdrawn, at which point they will be destroyed. Names and addresses will only be kept if the participant wishes to be kept informed as to the findings of the research in which case they will give consent (in the form of a signature on the consent form) for their details to be kept on a specific mailing list that will be destroyed after the findings have been disseminated and will not be used for any other purpose.

Access to data, confidentiality and data protection:

The researcher and her PhD supervisor will have access to the data which will be stored on a password protected computer. The researcher will store personal details on a password-protected computer until the interview has taken place or consent been withdrawn, whereupon the personal details will be withdrawn. If the interviewee wishes to be informed about the findings of the research their details will be kept on a specific mailing list until the summary report has been posted to them, at which point their details will be destroyed.

All respondents will be assigned a unique identifier number after the interview has been completed and data will be stored under this number in without any detail that could reveal the identity of the individual. Names will be recorded on the consent form which will be stored in a locked filing cabinet during the duration of the project, then securely archived as per University policy, before being destroyed following confidential waste procedures.

The analysis of the data will be carried out by the researcher and will be carried out on password protected computer equipment used exclusively by the researcher. It will take place within the researcher's office in the university and within her home. No analysis will be carried out on data that has not been fully anonymised. At the end of the project the data will be archived as per University procedure whereupon it will be removed from computers to CD data storage and interview schedules, consent forms and other related anonymised paperwork will be archived in a lockable data storage archive facility within the university. After the 7 year period it will be destroyed following confidential waste procedures.

Findings

The findings of this research will provide information about how people with mental health problems feel about the provisions put in place by the Act for their representation. This will contribute to the debate surrounding decision-making on behalf of others and will help services providing support to both mental health service users and their carers to ensure that they are aware of the concerns people are having over the use of this legislation. It will be of interest to all those working with the Act, particularly those who are involved in making decisions on the behalf of others.

Appendix 2: Interview schedules and vignettes

Interview schedule for service users

1. Introduction

First, some questions about the interviewee and their circumstances, and about their history. Then we will go on to talk about the named person provisions, what they think about them, whom they might choose and why. Then finally, to look at some examples of other people's situations and see what they think about them.

2. Introductory questions about the interviewee:

Demographic information, use of mental health services.

3. Understanding and perception of the named person provisions

Have you read the booklet?
Do you have any queries about the booklet?
What do you think in general of the provisions?
Had you heard of the provisions previous to becoming involved in the research?

4. Using the named person provisions

Do you think they will use the provisions?

Who might you like to be your named person?

What are your the reasons for this?

- Do they always agree with you?
- Do you feel they would act in your best interests or support your wishes?
- Have they given you advice they have valued in the past?

Vignettes

A. Family vs. Partner

Jim is in his 30s and lives with his mother, his partner Alison lives nearby. He has been with Alison for three years and they see each other almost every day, Alison also uses mental health services. Jim has recently appointed Alison to be his named person as he feels she knows him best. Jim's mother was not very happy about this as she feels she knows him best. Jim has made it very clear to Alison that if he becomes unwell, he wants to be treated in hospital as he feels safer there. Alison does not like Jim going into hospital as she thinks the last time he was in, it slowed his recovery. Jim becomes unwell and psychiatrist and MHO feel that he does not require to be admitted at the moment but can be treated in his own home with increased support. Alison agrees with them and wants Jim to remain at home. Jim wants to go into hospital as he feels distressed at home. Jim's mother also thinks he should go into hospital and has phoned the MHO and left a message to tell him this.

Should Alison press for Jim to be admitted? If so, why? If not, why not?
Should Jim's mother have a say in the matter?
Should the MHO phone her back and take into consideration her views?

B. Friend vs. Nobody

Marie is in her 40s, lives on her own and has no family contact. She has two close friends whom she has known for about seven years. The first, is Jean, whom she met through her church. She sees Jean regularly socially and they talk a lot and go out for lunch together. The second is Pat whom she met through a drop-in centre who helps her out at home and they often go to the supermarket together. Pat no longer experiences mental health problems. Marie has not shown any interest in nominating a named person and when asked by her psychiatrist if she wanted to do this, said she did not want the bother. She has recently become unwell and has been detained in hospital for the first time in about ten years. A tribunal is to be held to discuss Marie's care over the next few weeks. Her MHO is exploring who may be appointed Marie's named person; she knows about the two friends as they have been regular visitors to Marie since she was admitted and have shown concern for her well-being. They are surprised Marie has become this unwell as they both thought she was managing.

Should one of Marie's friends be approached and asked to act as her named person? Which one? Why?
Should Jean and/or Pat be consulted by the MHO about Marie's future but not asked to become her named person?
What difference do you think it would make to Marie if she didn't have a named person?

C. Friend vs. Family

Steven is in his 50's and has a close friend, Joe, whom he met in hospital 15 years ago. He and Joe see each other several times a week and often go to a drop in centre together. Steven lives near to his sister, Jean, and he sees her most days, although they are not that close. Steven has decided to appoint Jean as his named person as she was his nearest relative before. Steven has now been detained in hospital against his wishes; he feel he is better off at home with her and Joe visiting. A tribunal is planned and Steven has asked Joe if he will attend. Jean thinks Steven should be in hospital. Joe thinks that Steven is better supported at home with his support and he has told Jean this. Joe knows Jean will tell the tribunal that Steven should be in hospital but Joe wants to tell the tribunal he thinks Steven would be better off at home with increased support.

What should Joe do? Should he ask to appear at the tribunal or should he just leave it? Should Jean take into account Joe's views when she speaks to the tribunal?
Should Jean really be Steven's named person?

Interview schedule for carers

1. Introduction

First, some questions about the interviewee and their circumstances. Then we will go on to talk about the named person provisions, what they think about them, how they would feel if nominated, have they already been nominated? Then, finally, to look at some examples of other people's situations and see what they think about them.

2. Introductory questions about the interviewee:

- Demographic information, experience as a carer

3. Understanding and perception of named person provisions

- Have you read the booklet?
- Do you have any queries about the booklet?
- What do you think in general of the provisions?
- Had you heard of the provisions previously to becoming involved in the research?

4. Using the named person provisions

   a. Have you already been nominated? Might you be nominated or become a named person by default?
   b. How do you negotiate decision-making with the person they care for: do you act in their best interests or support your wishes?

5. Vignettes (as in service user interview schedule)

Interview schedule for MHOs and policy influencers

Introduction to research background and overview of interview.

- Overall impression of changes

- Level of uptake

- Nominating family versus friends

- Service users acting for each other

- Responsibilities of named person

- Sharing of information

- Named person acting independently

- MHOs identifying default named person

- Implementation issues

- Any other issues

Appendix 3:

Thematic analysis framework

LEVEL 3 THEMES	LEVEL 2 THEMES	LEVEL 1 THEMES	FINAL CODES
PERCEPTIONS AND UPTAKE OF NAMED PERSON PROVISIONS	PERCEPTIONS OF THE INTRODUCTION OF NAMED PERSON PROVISIONS	OVERALL ATTITUDES	SU - OVERALL OPINION NP - OVERALL OPINION MHO – OVERALL OPINION POL - OVERALL OPINION
	ADVANTAGES FOR SERVICE USERS AND CARERS	ADVANTAGES OF HAVING A NAMED PERSON ADVANTAGES OF BEING A NAMED PERSON TIRBUNAL ATTENDENCE	MHO - DISADVANTAGE HAVING NOBODY? NP - V2 DISADVANTAGE HAVING NOBODY? SU - V2 DISADVANTAGE HAVING NOBODY? NP - CARER AND PROS MHO – TRIBUNAL NP - TRIBUNAL POL – TRIBUNAL
	LOW UPTAKE	LOW UPTAKE PROMOTING UPTAKE MHO WORKLOAD ISSUES	SU - LOW UPTAKE NP - LOW UPTAKE MHO - LOW UPTAKE POL - LOW UPTAKE POL - PROMOTING UPTAKE MHO - WORKLOAD ISSUES
AUTONOMY: UNDERSTANDING AND INFORMATION	SERVICE USERS' AND CARERS' UNDERSTANDING OF THE NAMED PERSON PROVISIONS	SU UNDERSTANDNIG RESPONSIBILITY OF NP NP ACTING INDEPENDENTLY CONFUSION OF ROLES INFORMATION SHARING	MHO - SU UNDERSTANDING POL – SU UNDERSTANDING MHO - RESPONSIBILITY OF NP NP - RESPONSIBILITY OF NP POL - RESPONSIBILITY OF NP SU - NP ACTING INDEPENDANTLY MHO – NP ACTING INDEPENDANTLY POL - NP ACTING NDEPENDANTLY NP – NP ACTING INDEPENDANTLY POL - CONFUSION OF ROLES SU - INFORMATION SHARING NP - INFORMATION SHARING MHO - INFORMATION SHARING POL - INFORMATION SHARING
	SOURCES OF INFORMATION ABOUT THE NAMED PERSON PROVISIONS	SUPPORT FOR NP	NP - SUPPORT FOR NP POL - SUPPORT FOR NP

		HOW DID HEAR	SU - HOW HEARD OF NP NP - HOW DID HEAR
		PUBLICITY MATERIAL	SU - PUBLICITY MATERIAL NP - PUBLICITY MATERIAL POL - PUBLICITY MATERIALS MHO - PUBLICITY MATERIAL
	AUTONOMY AND CHOICE: WHOM SERVICE USERS WANT TO NOMINATE AS A NAMED PERSON	FAMILY VS FRIENDS	SU - WHO WOULD NOMINATE MHO - FAMILY VS FRIENDS NP - FAMILY VS FRIENDS SU - FAMILY VS FRIENDS POL - FAMILY VS FRIENDS SU - NEXT OF KIN REFERENCES
		PROBLEMS WITH BLOOD FAMILY RELATIONSHIPS	NP - PROBLEMS WITH BLOOD FAMILY RELATIONSHIPS SU - V1 MOTHER INVOLVED?
	REASONS FOR NOMINATING SOMEONE AS A NAMED PERSON	DECISION MAKING	SU - WHY WOULD NOMINATE
		V1 CARRY OUT WISHES	SU - V1 CARRY OUT HIS WISHES? NP – V1 CARRY OUT WISHES
	NOMINATING RELATIVES	FAMILY VS FRIENDS	MHO - FAMILY VS FRIENDS NP - FAMILY VS FRIENDS SU - FAMILY VS FRIENDS POL - FAMILY VS FRIENDS SU - V3 PICKED RELATIVE NP - V3 PICKING RELATIVE
	NOMINATING FRIENDS AND PARTNERS	SUS ACTING AS NP	SU - SUS ACTING AS NP MHO - SUS ACTING AS NP NP - SUS ACTING AS NP POL - SUS ACTING AS NP
		ACT AS NP THEIRSELVES?	SU - ACT AS NP THEMELVES?
		V2 APPOINTING FRIENDS	SU - V2 APPOINTING FRIENDS NP - V2 APPOINTING FRIENDS NP - V3 APPOINTING FRIENDS SU - V3 FRIEND ATTEND TRIBUNAL
	NOMINATING A PROFESSIONAL AND SOCIAL ISOLATION	STAFF AS NP	POL - STAFF AS NP
		HAVING NOBODY TO NOMINATE	SU – HAVING NO NP MHO - HAVING NO NP

			NP - HAVING NO NP
POWER IMBALANCES	THE RELATIONSHIP BETWEEN SERVICE USERS AND CARERS	INITIAL RESPONSES TO ILLNESS	NP - INITIAL RESPONSES TO ILLNESS
		DISAGREEMENT WITH PATIENT MAKING	NP - DISAGREEMENT WITH PATIENT NP – DECISION-MAKING
		DECISIONS FOR PATIENT	NP - DECISION MAKING NP - V1 MOTHER CONSULTED
		PATIENT CHOOSING OTHER THAN THEM?	NP - PATIENT CHOOSING OTHER THAN THEM?
		CONFLICT DUE TO SECTIONING INVOLVEMENT	NP - CONFLICT DUE TO SECTIONING INVOVEMENT
	THE RELATIONSHIP BETWEEN SERVICE USERS AND PROFESSIONALS	ARTICULACY	MHO – ARTICULACY POL - ARTICULACY
		TRIBUNAL APPOINTING	SU - TRIBUNAL APPOINTING POL - TRIBUNAL APPOINTING MHO - TRIBUNAL APPOINTING NP – TRIBUNAL APPOINTING
		PATERNALISM	MHO - PATERNALISM
		INFORMAL CONSULTATION	SU - V2 CONSULT INFORMALLY? NP - V2 CONSULT INFORMALLY
	THE RELATIONSHIP BETWEEN CARERS AND PROFESSIONALS	CARERS ISSUES	POL - CARERS ISSUES MHO - SUPPORT FOR NP
		CARER & PROS	NP – CARERS & PROS
		TRIBUNAL	MHO – TRIBUNAL NP - TRIBUNAL POL – TRIBUNAL
THE NAMED PERSON AND HUMAN RIGHTS	THE DEFAULT NAMED PERSON AND HUMAN RIGHTS: LACK OF CHOICE	DEFAULT NAMED PERSON	MHO - DEFAULT POSITION POL - DEFAULT POSITION SU - DEFAULT POSITION NP – DEFAULT POSITION
		CHOOSING NO NP	SU - ALLOWED TO HAVE NOBODY NP - ALLOWED TO HAVE NOBODY POL – ALLOWED TO HAVE NOBODY MHO - ALLOWED TO HAVE NOBODY
		DISADVANTAGE OF NOBODY	MHO - DISADVANTAGED HAVING NO NP NP - V2 DISADVANTAGED HAVING NO

			NP SU - V2 DISADVANTAGED HAVING NO NP
	INFORMATION-SHARING AND HUMAN RIGHTS	INFORMATION SHARING	SU - INFORMATION SHARING NP - INFORMATION SHARING MHO - INFORMATION SHARING POL - INFORMATION SHARING
		DIFFERENCES BETWEEN ACTS	POL - DIFFERENCES BETWEEN ACTS
		LEGISLATION CHANGE	MHO - CHANGE IN LEGISLATION POL - CHANGE IN LEGISLATION

Appendix 4: LREC correspondence and supporting documents

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26th September 2005

Full title of study:	Mental health service users and their (potential) nominee's perceptions of the 'named person' role under the Mental Health (Care and Treatment) Act (Scotland) 2003

REC reference number: **05/S0701/103**

Thank you for your letter dated 14th September which I received on 20th September.

I am writing to address the points raised in the Committee's recent review of the above study. The accompanying paperwork has been amended to take into account all changes (changes underlined and deletions crossed out). It has not been possible to indicate the changes on the COREC form but this has been fully amended to take into account all the amendments.

An additional invitation / information leaflet has been included for the additional sample of carers.

I will be attending Gartnavel at the Committee meeting time on 13th October and will thus be available to clarify in person any further points that may arise.

For clarity I have addressed each point as detailed in the committee's record of the review.

a) Recruitment – it is inappropriate to pass on patient details

The only details that would be passed to the Chief Investigator (CI) would be the contact details of the mental health service user and only then with their express consent. If the service user wishes to contact the CI directly they can do so but before an interview could be arranged the CI will request permission from the service user to contact the professional through whom the potential participant received the invitation. This will be to inform them that the service user has requested an interview and to ascertain that there are no risks involved, to either party, in the service user taking part in an interview. This risk is already minimised as professionals will be asked to give the invitation only to service users that they feel would not be put at risk by taking part in the research.

Amendment: These points have been clarified in the protocol (Exclusion criteria and Procedure),

Flowchart and Information / invitation leaflet.

b) It is unclear what the content of the interview with the patient would be

The interview will take the form of a structured conversation rather than a series of closed-response questions. This is as each participant's understanding of the role and previous

experiences will be different and the aim is that the interview can respond to this. The same subjects will be discussed, in the same order but the focus and length of time spent on each subject may differ depending on the participant, their views and experiences.

The procedure has been changed to post each interviewee from all three groups an accessible information leaflet on the named person provisions (the leaflet has been produced by the Scottish Executive). This will give each interviewee the chance to read about the provisions prior to the interview. They will, however, not be made to feel as if they have to have read the leaflet and are being tested on its contents. As part of the interview it will be ensured that, if participants have read the leaflet, they have understood the procedures and, if they have neither read the leaflet or not understood it, a full explanation will then be provided.

The content of the interview would cover the following areas:

- Initial questions about the interviewee and their circumstances.

- Discussion around the named person provisions based on the booklet the interviewee will have received, what they think about them, whom they might choose and why, and what the advantages and disadvantages of the provisions may be.

- Using vignettes to look at some examples of other people's situations and to generate discussion around them.

Amendment: These points have been clarified in the protocol (interviews), information / invitation leaflet, flowchart and the overview of anticipated questions.

c) **As far as the interview with the named person is concerned it is not clear what information would be given to these people to allow them to answer the questions that are proposed**

As detailed above the procedure has now been changed. Prior to the interview each participant will be posted a written accessible information booklet (Scottish Executive (2005) The New Mental Health Act: A Guide to Named Persons) about the role of named person.

Part of the interview would involve discussing the practicalities of the role with the interviewee and answering any queries they may have. If they have not read the leaflet a full discussion around the role, providing information and answering questions will take place.

Amendment: These points have been clarified in the protocol (Interviews), information / invitation leaflet, flowchart and the overview of anticipated questions.

d) **If there was no named person – how would these be identified and therefore how valid would the data be**

It is not expected that every mental health service user will be able to provide the name of a potential named person. In these cases an equivalent numbers of carers with experience of caring for a person who had been subject to compulsory measures would be drawn from a carers' support service. This would be a valid sample as these people are as likely to have the same (or more) previous experience of someone close to them experiencing compulsory measures as any person who may be nominated as a named person.

Amendment: These points have been clarified in the protocol (Participants and Procedure), flowchart and carers' information / invitation leaflet (new).

e) **The mechanics of notifying the healthcare professionals of the nominated person and the scrutiny of these nominated persons is not clear**

The healthcare professionals would not be informed of the details of the (potential) nominated named persons.

When the professional is being asked about the service user and whether there may be risks attached to them taking part in the interview they will be asked if they have any knowledge about whom the service user may nominate. It is thought that as this person will often be the

primary carer the professional may well know (of) them. If they do, they will be asked if they have concerns about this person. If the professional has no knowledge of such a person, the scrutiny of these nominated persons will be the sole responsibility of the CI who will follow the standard Health and Safety procedures followed when interviewing members of the general public.

I have carried out many interviews in people's homes, including cold-calling the general public. I am particularly aware and interested in aspects of Health and Safety issues in this kind of work and have provided training in Health and Safety in lone working for other researchers.

Amendment: These points have been clarified in the protocol (Interviewees).

f) **Would any of the potential participants be Secretary of State patients and how would the researcher be aware of this?**

No participants will be Secretary of State patients; only patients living in the community who are not subject to any orders will be approached. This has been clarified in the protocol and will be one of the exclusion criteria provided to professionals.

Amendment: These points have been clarified in the protocol (Interviewees).

g) **QA24 – there appeared to be some inconsistency in that if someone was detained they would not be approached but if under treatment order they would be approached**

This was originally included so as to not exclude people who may be living in the community and using community services but it has now been amended for consistency.

Amendment: This has been clarified in the protocol (Inclusion and exclusion criteria - People with mental health problems).

h) **Patients could be detained under old Act and if researcher speaks to them about new Act the researcher could actually be giving the patient the answers that they want**

Service users will not be currently detained under the 1984 Act, they will have previously been detained under the 1984 Act. I am fully aware of the different experiences people will have had, either under the old Act, or in preparation for the full implementation of the new Act and I am particularly alert to these differences. I will be explicitly giving the participants information about the new Act by posting them the named person information leaflet and discussing the practicalities of the role with them during the interview. I am not testing them on their knowledge of the new provisions or changes in the legislation. I do not perceive this as a difficulty; I am exploring the area and thus have no agenda to pursue, there are no responses that would be perceived as more desirable than others.

i) **The committee would require to see the vignettes**

The vignettes have not been written yet, as I have submitted MREC applications previously which have not required finalised research instruments to be submitted. I did not expect the committee to request them. I am still discussing and working on their content and I apologise that I have not been able to submit them at this point. I am keen to start arranging access to participants, but this will take some time during which the vignettes will be completed. I will be able to pass them to the committee for review when they have been completed prior to interviews commencing.

j) **Clarification required as to the intended number of participants – how was this arrived at?**

This number was decided upon as being more than adequate to provide enough data to allow for a rigorous qualitative analysis. As a qualitative study statistical power calculations do not apply.

Amendment: This has been clarified in the protocol (Participants)

k) Clarification required as to the patient's ability to provide valid consent

Legally there is a global assumption of capacity to consent unless proven otherwise. In Scotland to have been proven otherwise would mean the participant was subject to the Adults with Incapacity (Scotland) Act 2000; this has been added to the exclusion criteria of all three categories of participant.

It is not felt that being a user of mental health services or having previously been detained under mental health legislation removes a person's ability to consent to take part in a research interview.

The service user's suitability to take part in the research will be judged, initially, by the professional e.g. the psychiatrist and, secondly, by myself. If I perceived that prior to an interview the service user appeared unwell and I was not confident that they were capable of consenting to the interview, it would be cancelled.

Amendment: This has been clarified in the protocol ('Inclusion and exclusion criteria').

l) Clarification required as to what training in interviewing the researcher has had

There is not a formal qualification in interviewing that I am aware of. My training in the area has come from three sources, my formal academic background, my previous therapeutic work with people with mental health problems and my previous research work with people with mental health problems.

Formal academic background: I have completed formal research methods training over five years, including interviewing skills, as part of my two previous degrees (First degree with specific relation to psychological research and second degree more general social scientific research methods). These experiences have provided me with training in administering standard scales as well as conducting more qualitative guided conversations of the kind proposed for this study. I have read and written about different research methods, justifying their use in various projects and am aware of the benefits and costs of face-to-face interviewing. During the first year of my PhD I have attended research methods courses run by the Medical Faculty including the ethics of working with human subjects and qualitative research methods.

Previous therapeutic work with people with mental health problems: I spent a decade working in a variety of settings providing direct care and support to people with a wide range of mental health problems. I often used interviewing skills to assess needs and for care planning activities. I received training in Counselling Skills and Assessing Needs (during my years working in voluntary sector community mental health services, 1995-2000) and have found that these experiences have been valuable in later non-therapeutic interviewing. I feel strongly that interviewees should never feel intimidated or patronised by the interviewer, should feel in control and at ease and find the experience to be a positive one. The greatest benefit that I have gained from this experience has been my confidence in interacting with people with a variety of needs and difficulties which I feel has allowed my interviews to be a relaxed and enjoyable experience for many of my interviewees, despite the often sensitive subjects under discussion.

Research work with people with mental health problems: I have spent the last five years as a researcher within Public Health and Health Policy at the University of Glasgow. During this time I have undertaken many face-to-face interviews and focus groups, the majority of them with users of mental health services, including many with people experiencing severe and enduring mental health problems. Additionally, I have successfully carried out interviews with health and social care professionals, with carers of people with mental health problems and with the general public.

Through my employment I have line-management responsibilities for teams of Research Interviewers, providing on-going in the field supervision and support. I have responsibility for the design and delivery of training in interview skills and techniques through leading sessions and active learning strategies. I have produced policies, procedures and training material for research interviewers. I am particularly interested in the Health and Safety aspects of lone field-working and have developed and used procedures with my research interviewers in the University based on my experiences of lone working in a Home Support and Day Care context.

I am fully confident in my abilities to anticipate and manage situations as they arise and would never carry out an interview if I perceived any risk to the interviewee or myself.

m) Clarification required as to what healthcare training the researcher has had

I do not have vocational health-related qualification such as a degree in Nursing or Social Work. I have a first degree in Psychology and a Masters degree in Community Care, both of which covered many areas of health care (e.g. Psychology degree covering abnormal psychology, psychotropic medication and biological psychology; Master of Community Care covering ethics and values, care planning and multi-disciplinary working.)

Prior to my employment with the University of Glasgow, I worked for ten years in the direct care of people with adults of all ages with mental health problems and older people with dementia. Initially I worked for six years as a Nursing Auxiliary with older people with dementia (three years) and adults with severe and enduring mental health problems (three years) in high support nursing / residential settings. I then spent five years working in mental health services in the voluntary sector (Loretto Housing Association, Care Section) working first as a Support Worker, Senior Support Worker and finally Project Leader. I worked in Social Work Registered 24 hour Supported Accommodation projects for adults with severe and enduring mental health problems leaving long-stay hospital care and latterly within Home Support and Day Care services for adults with mental health problems living independently.

During the course of these ten years I completed many training courses run primarily by NHS agencies, as well as by independent consultants and in-house training including: Managing Aggression, Managing Challenging Behaviour, Medication, Counselling Skills, First Aid, Group-work Skills, Care and Support Planning and Management, Policy Development, Staff Development and Support in a Care Setting, SVQ Social Care Assessor.

My previous experience and training is such that I am fully confident in my abilities to judge a situation where intervention may be required and from where this intervention should come. The differential between the research and the therapeutic role means that researchers with a care background have to be very clear about the boundaries and limits of the research role.

n) PIS requires logos

Amendment: This has been added.

o) Audio and use of quotations should be in both information sheet and consent form

Amendment: This has been added to information / invitation leaflet, consent form and clarified in the protocol (Procedure).

p) PIS

q) Named person – this should be clarified and expanded

This has been done using the Scottish Executive introduction to the named person provisions as a guide.

Amendment: This has been added to the information / invitation leaflets.

r) A fuller explanation as to what the study is about is required

Amendment: This has been expanded on the information / invitation leaflets.

s) Simpler non technical language is required e.g. what is a tribunal?

This has been done using the Scottish Executive introduction to the new act as a guide.

Amendment: This has been added to the information / invitation leaflets.

t) **It is not appropriate to indicate that the Research Ethics Committee has approved the study – only that they have reviewed the study**

Amendment: This title in the protocol has been changed from 'Ethical approval'' to 'Ethical review'.

In conclusion, I hope that these amendments and clarifications address the Committee's concerns.

I look forward to hearing from you.

Kathryn Berzins

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12th December 2005

Full title of study:	Mental health service users and their (potential) nominee's perceptions of the 'named person' role under the Mental Health (Care and Treatment) Act (Scotland) 2003

REC reference number: **05/S0701/103**

Thank you for your letter dated 20th October.

I am writing to address the points raised in the Committee's recent review of the above study. The accompanying paperwork has been amended to take into account all changes (changes underlined and deletions crossed out). It has not been possible to indicate the changes on the COREC form but this has been fully amended to take into account all the amendments.

For clarity I have addressed each point as detailed in the committee's record of the review.

   a) **Recruitment process to be clarified:**
   i)   **How would the participant be recruited – it is not appropriate for the clinician to approach patients as there is already an existing relationship in place**

The recruitment procedures have been further revised. The clinician / key worker will be asked to pass an invitation letter to potential participants who meet the inclusion criteria. This would mean that people currently experiencing mental ill health or who may be distressed by taking part in an interview would be not be asked. The invitation letter will contain a return slip to allow the person to opt in, a stamped addressed envelope will be provided. The letter will ask for the contact details of the key worker / clinician.

   ii)   **How would the named person be identified – there is a data protection issue in names being given from a database? Named person could opt out.**

The potential named person will be identified through the patient during the interview. There is no database with the names of named persons on it. The potential named person will be contacted by letter and asked to consent to take part in an interview. This letter will be followed up by telephone call. Like all participants the potential named person can opt out at any point.

   b) **Administrators, with both their and the Consultant's permission could send out information to potential participant – this to include an opt in option for the participant to get back to the researcher – the participant should name their clinician. If the potential participant does not wish to name their clinician and**

consent for their clinician to be approached or there is no return then this person would be regarded as having opted out.

If the participant does not name their clinician / key worker and consent for them to be contacted they will be regarded as having opted out.

> **c) When clinician's contact details are known the researcher should contact them to ascertain whether there would be any risk in interviewing the participant.**

The researcher will contact the clinician / key worker to ascertain if there is any risk.

> **d) It is totally inappropriate to assume capacity to consent unless proven otherwise**

As all participants invited to take part in the interview will meet the following criteria as stated in the protocol:

"1. People with mental health problems

Inclusion: People who are in regular contact with at least one specialist support service (from any sector) for people experiencing mental health problems.

Participants must be aged 18 or over; there will be no upper age limit.

Participants must be living in the community.

Participants must have been affected in the past by compulsory admission and / or treatment under mental health legislation.

Exclusion: People suffering from dementia will not be included as it is felt this is a distinct group of people with specific needs and experiences. Although people with a dual diagnosis will not automatically be excluded, those with a primary problem of substance misuse will be excluded, again, due to them forming a distinct needs group and being specifically excluded from provisions under mental health legislation.

People who are currently experiencing a level of mental ill health such that the professional's judgement is that participation in such a study may pose a further risk.

People who are currently experiencing a level of mental ill health such that the professional's judgement is that the service user may not be able to give informed consent.

People who are currently detained or subject to a community based treatment order under mental health legislation will not be approached.

People who are subject to the Adults with Incapacity (Scotland) Act 2000"

As can be seen above, the exclusion criteria state that any person currently judged by the professional to be experiencing mental ill health that may reduce their capacity to consent will **not** be invited to participate. Only those considered capable of taking part by a professional involved in their care will be invited to take part. It is anticipated that the people interviewed will be living in the community, will have currently stable mental health will not be subject to any compulsory measures. They will **not** be currently subject to the Mental Health (Care and Treatment) Scotland Act 2003 or the Adults With Incapacity (Scotland) Act 2000.

> **e) Participant to be given the choice of venues for the interview e.g. either at home or at a resource centre. Mental health status of participant to be further ascertained from their key worker / clinician 2/3 days prior to the interview (this to be entered into the information sheet) and if deemed appropriate the researcher and another to be present at the interview / researcher to carry mobile phone with emergency number programmed into the phone.**

The participant will be given a choice of venues, previous experience has shown that most prefer to be interviewed at a resource centre but the option to be interviewed at home will remain. The protocol states that: "The interview will take place at a location of the participant's choice;

previous studies have shown this is most likely to be at local service premises or occasionally in their own home."

The mental health status of the participant will be ascertained several days prior to interview. Full health and safety procedures will be followed by the researcher, including carrying a mobile phone at all times or an other being present.

f) Committee require to see the vignettes

Proposed vignettes are enclosed.

In conclusion, I hope that these amendments and clarifications address the Committee's concerns.

I look forward to hearing from you.

Kathryn Berzins

Revised invitation letter

Dear Sir / Madam

'Named person' research

My name is Kathryn Berzins, I am a PhD student at the University of Glasgow, Faculty of Medicine). I am inviting you to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it would involve. Please take time to read the following information carefully and discuss it with others if you wish. If you would like further information please get in touch with me.

What is the research about?

In 2003 the Scottish Parliament passed a new law, the Mental Health (Care and Treatment)(Scotland) Act 2003. It sets out how you can be treated if you have a mental illness and what your rights are.

The Act has created a new support role for mental health service users, the **'named person'**. A named person is somebody you can nominate to help to protect your interests if you have to be given care or treatment under the new Act. Your named person would have to be informed and consulted about aspects of your care, and can make applications to the Mental Health Tribunal for Scotland (set up by the Act to make decisions about the care and treatment of people with mental disorder). The named person is entitled to be given information concerning compulsory measures which have been taken, or are being applied for. The named person and the patient are each entitled to act independently of the other, e.g. the named person can appeal a decision even if the patient does not.

I am interested in what people who have previously been affected by mental health legislation and their carers think about these new provisions, whether they think they will be of help to people and in what ways.

What does the research involve?

Thirty people living in Glasgow, who use mental health services and have been affected by Mental Health Legislation at some point in the past will be interviewed. Each of these people will be asked for permission to contact the person who they would like to be their named person to invite them to take part in an interview.

Do I receive anything for taking part?

Each person taking part in an interview will receive a £10 gift voucher from a choice of shops.

Why have I been invited?

You have been invited to take part because you use a mental health service and have been affected by the Mental Health Act in the past. It is entirely your decision; do not feel that you have to take part if you do not want to.

Is the research connected to service I may use?

This research is not connected to the services you may use and these will not be affected if you do not take part. If you do decide to take part, you will be asked to sign a consent form, although you can change your mind and withdraw from the study at any point and without giving a reason. Providing the name of a person you may choose to be your named person does not mean that they become your named person; that is a separate procedure that you will be given information about.

What will I asked questions about?

During the interview you will be asked for your opinions of the 'named person' role (You do not have to already know about this role, you will be posted a short booklet about it, it will be explained to you and any questions you may have will be answered.)

I am interested in how people who use mental health services feel about nominating somebody who could make decisions about their care and treatment. I want to find out what are the most important things that people would think about when making these decisions and in what ways they think it may affect their future care and treatment.

You will be asked who it would be that you would choose to be your named person and the reasons why. You will be asked whether you think such provisions are helpful for people and how it might have helped you in the past. You will be asked permission for that person to be contacted and invited to also take part in an interview. This interview will not be about you, but about their opinions of being a named person.

How will I be contacted?
If you choose to take part please fill in the enclose form and return it to the person who gave it to you using the envelope provided. You are asked for your name and contact details and to provide the name of your consultant or key worker. This is so that I can ask them if they think it is in your interests to take part in an interview. If you do not provide their name I will not be able to contact you. When I receive your form I will then arrange a suitable time and a place for you to be interviewed. This may be in your home or at a service you use; it is your choice.
How long will it take?

Each person will be interviewed once. The interview will take no longer than one hour.

What are the advantages and disadvantages of being interviewed?

Many people enjoy taking part in this kind of research and enjoy having their experiences and opinions listened to. The information gained from this research may help services in the future to be more understanding of the needs of people with mental health problems. Occasionally, some people can find talking about their experiences upsetting. If this were to be the case somebody you currently receive a service from (e.g. a CPN or Support Worker) would be told about this (with your permission) and could offer you support.

Will it be confidential?

All information which is collected about you during the interview will be kept strictly confidential. Any information about you will have your name and address removed so that you cannot be recognised from it. During the interview with the person you would ask to be your 'named person' you will **not** be discussed, they will be asked about their opinion of the role and how they would feel about carrying it out. The interview will be recorded so it can be typed up, all details identifying you will be removed at this point. Quotations may be used in the final report but anything that could link them to you will be removed.

What will the information be used for?
The results of the study will be used for a PhD thesis. A short summary of the findings will be available. The results will also be published in academic journals. This will be in 2008 at the earliest.
Can I be sent the findings?
You can ask for your name to be kept on file to receive a summary of the findings. This file will remain confidential and will not be passed to any other party and will be destroyed once the findings have been distributed.

How has the research been reviewed?This study has been reviewed by the Greater Glasgow NHS Local Research Ethics Committee.

What if I am not happy with the experience of being interviewed?

If at any later time you feel at all unhappy about any aspect of your experience of taking part in this research, you have access to complaints procedures through contacting Dr Jacqueline Atkinson, Public Health and Health Policy, University of Glasgow, 0141 330 4039.

If you would like to take part:

~~If you would like to take part please complete the form and return it to me in the envelope provided.~~

If you would like more information contact:

Kathryn Berzins, Public Health & Health Policy, University of Glasgow, 1, Lilybank Gardens, Glasgow, G12 8QQ. Tel: 0141 330 2713 email: K.M.Berzins@clinmed.gla.ac.uk

I would like to take part in an interview about my opinions of the named person role. I understand that my participation is voluntary and that I am free to withdraw without giving any reason, at any time, without my medical care and any other support, or legal rights being affected. I understand that any information I provide will be treated as confidential.

~~I am happy to be contacted using the following information:~~

YOUR NAME	
YOUR ADDRESS	
YOUR TELEPHONE NUMBER	
KEY WORKER'S NAME	
KEY WORKER'S TELEPHONE NUMBER	
WHERE IS YOUR KEY WORKER BASED?	

YOUR SIGNATURE……………………..…………………………………DATE…………………………..

RESEARCH PROTOCOL

Mental health service users and their (potential) nominee's perceptions of the 'named person' role under the Mental Health (Care and Treatment) Act (Scotland) 2003

INTRODUCTION

It is generally accepted that wherever possible patients should make their own decisions about the treatment they receive. These decisions are ideally made with the patient having full understanding of the facts of their situation, having taken into account the recommendations of their doctors and weighing up the options available to them, how these fit with their values and what impact they might have on their life. This is not always possible, illness and disability can affect a person's ability to make decisions about their care and treatment and when this is the case, careful consideration must be made before decisions are made on behalf of the patient.

Mental illness has the potential to affect a person's decision-making capacity. This has long been recognised by both the legal and medical professions and there is a history of both professions making decisions for people with mental illness spanning centuries. Alongside these two professional groups the individual's family has had an equally long history of involvement in these decision-making processes. Throughout history there has been (to varying degrees) an aim to protect the patient from decisions about them being taken against their best interest, whether that be from doctors, lawyers or their own family (Hoggett, 1996).

Despite this history of relatives having legal rights and responsibilities for a patient, it was first formalised (in Scotland) in the 1960 Mental Health (Scotland) Act, which established the concept of the 'nearest relative' based on a hierarchy of marriage and biological closeness. The nearest relative held certain rights including consent to compulsory admission to hospital, rights to certain information and power of discharge from hospital. These roles were modified in the Mental Health (Scotland) Act of 1984 as a result of the movement towards community care but the hierarchy remained.

Problems with the nearest relative role included its lack of consideration of the nature of the relationship between the mental health service user and their nearest relative, it discriminated against same sex couples and was found to be in breach of the European Convention on Human Rights. These difficulties were explored by the Millan review of the Mental Health (Scotland) Act 1984 and the introduction of a 'named person' was recommended, designed to address these problems (Scottish Executive, 2001).

The Mental Health (Care and Treatment) Scotland Act 2003 acted on the Millan recommendations and the provision of the 'named person' was introduced. It replaced the former role of the 'nearest relative' allowing the mental health service user to nominate a representative who is then given rights to carry out certain actions and be informed should compulsory measures be used. The nomination can be challenged by professionals involved in the patient's care and treatment if it is felt that the nominated person is inappropriate e.g. if the relationship between the patient and the nominated person is considered harmful to the patient.

The nearest relative still exists under the Mental Health (Care and Treatment) Scotland Act 2003, albeit in a much reduced role, they must be notified when an emergency detention takes place and if a patient has no named person or primary carer the nearest relative can be invited to act as the named person. The hierarchy for determining nearest relative has been amended to take into account cohabiting couples, including those that are same-sex.

There was very little research into the role of 'nearest relative' under the 1984 Act and only one report written in Scotland (Summers et al, 1999). There has been no research looking at service users' and their potential nominees' understanding and perceptions of the new role of named person. Mental health service users' understanding of the legislation may affect whom they choose to act as their named person. Mental health service users may not understand their rights and the rights of others under the legislation. Nothing is known about the factors that will be taken into consideration by service users when making a nomination for a named person or indeed, those service users who choose not to make such a nomination. The views and understanding of the role of the potential named person are unexplored, in particular whether they perceive the role as acting in the best interests of the service user or carrying out the service user's known wishes.

This research will show how service users perceive and understand the measures under the legislation and the factors they feel to be important when making a nomination. The views of potential nominees will show their level of understanding of the role and how they feel they would act within it, for example how will they balance wanting to act in what they think is the best interests of the patient if this goes against the patients wishes.

This research will provide information to those monitoring the new legislation surrounding how this important safeguard is being perceived. It will be of interest and use to professionals working with service users and their families affected by mental health legislation (for example, Psychiatrists and Mental Health Officers, voluntary organisations and advocacy services).

AIM

To explore mental health service users' and their (potential) nominees' perceptions of the role of 'named person' under the Mental Health (Care and Treatment) Scotland Act 2003

Research questions

How beneficial do interviewees perceive the 'named person' provisions to be?

What potential problems do interviewees perceive within the provisions?

What factors do mental health service users feel are most important when considering appointing a named person?

How do (potential) named persons perceive the prospect of acting for (and possibly independently from) the patient, what is the weight given to best interest over the patient's wishes?

METHODOLOGY

Location

The research will be carried out across Greater Glasgow NHS area.

Timescale

The research will be completed in 2008.

Participants

A total of 60 participants will be sought from three groups:

- People with mental health problems (30)
- (Potential) Named persons (approximately 20)
- (Unpaid) Carers of users of mental health services (approximately 10)

Sixty interviews will provide a substantial amount of data to allow for a rigorous qualitative analysis.

Inclusion and exclusion criteria

1. People with mental health problems

Inclusion: People who are in regular contact with at least one specialist support service (from any sector) for people experiencing mental health problems.

Participants must be aged 18 or over; there will be no upper age limit.

Participants must be living in the community.

Participants must have been affected in the past by compulsory admission and / or treatment under mental health legislation.

Exclusion: People suffering from dementia will not be included as it is felt this is a distinct group of people with specific needs and experiences. Although people with a dual diagnosis will not automatically be excluded, those with a primary problem of substance misuse will be excluded, again, due to them forming a distinct needs group and being specifically excluded from provisions under mental health legislation.

People who are currently experiencing a level of mental ill health such that the professional's judgement is that participation in such a study may pose a further risk.

People who are currently experiencing a level of mental ill health such that the professional's judgement is that the service user may not be able to give informed consent.

People who are currently detained or subject to a community treatment order under mental health legislation will not be approached.

People who are subject to the Adults with Incapacity (Scotland) Act 2000

2. (Potential) Named persons

Inclusion: People who would be (have been) nominated to act as a named person by a person with mental health problems as described above.

Participants must be aged 18 or over; there will be no upper age limit.

Exclusion: People who have themselves been involved in proceedings under Mental Health Legislation will be excluded as it is felt they will be unable to talk solely of their perceptions of the named persons role from the perspective of a (potential) named person.

Participants must not be currently experiencing major mental health problems themselves.

People who are subject to the Adults with Incapacity (Scotland) Act 2000

3. (Unpaid) Carers of users of mental health services

Inclusion: Participants must have been involved in the care of a relative who has been subject to compulsory admission and / or treatment under mental health legislation.

Participants must be aged 18 or over; there will be no upper age limit.

Exclusion: Participants must not themselves currently be affected, or have been affected in the past, by compulsory admission and / or treatment under mental health legislation.

Participants must not be currently experiencing major mental health problems themselves.

People who are subject to the Adults with Incapacity (Scotland) Act 2000

Ethical review

As part of the sample will be accessed through NHS sources, ethical review has been applied for by the Greater Glasgow NHS Primary Care Division Local Research Ethics Committee.

Procedure

1. People with mental health problems

The interviewees will be accessed through the following agencies:

- Community Mental Health Teams
- Primary Care Services
- Social Work Department services
- Independent sector organisations including people living in supported accommodation (some people with mental health problems prefer to use independent sector organisations and have minimal contact with statutory services; ensuring these organisations are sampled will allow access to these people).

Initial discussion will take place with several organisations and services in Greater Glasgow to judge the feasibility and willingness of the organisation to take part in the study. Previous research projects have shown that the most effective way to do this is for the researcher to visit services and arrange to attend local multi-disciplinary fora.

Professionals will be briefed on the research and asked to pass an invitation letter to take part in the research to their users who meet the criteria. approach to invite them to take part in the research. Potential participants will be given a letter of introduction containing details of the project and allowed as much time as they need to consider whether they wish to take part. If they choose to participate they will complete the reply slip and return it to the researcher in a freepost envelope provided. This form will ask for their contact details and those of their key worker / clinician. Any form returned without the details of the key worker / clinician provided will be treated as a nil return. The researcher will contact the key worker / clinician to ascertain whether there is any risk involved in the participant being interviewed. The clinician / key worker will be contacted three days prior to the interview to ensure that it is still appropriate for the interview to take place in order to take into account any recent changes in the participants mental health that may have occurred. either consent for their contact details to be passed to the Chief Investigator by the professional or they can opt to contact the Chief Investigator directly. If they contact the Chief Investigator directly the professional who gave them the invitation will be contacted to ensure that they do not perceive any risks to either the participant or researcher. Professionals will further be asked if they know who the interviewee is likely to nominate as their (potential) named person and if so they will be asked if they feel this person presents any risk. It is thought that as the (potential) named person will often be the primary carer the professional may well know (of) them through their contact with the service user. Prior to the interview each interviewee will be posted a short accessible booklet (Scottish Executive (2005) The New Mental Health Act: A Guide to Named Persons) about the role. They will then be contacted by the Chief Investigator for an interview to be arranged. The interview will take place at a location of the participant's choice; previous studies have shown this is most likely to be at local service premises or occasionally in their own home. Interviewees will have the opportunity to withdraw their consent to take part at any stage in the process. Interviews will be digitally recorded for transcription. All transcripts will be fully anonymised and any quotes subsequently used will have all identifying features removed. Audio files will be stored on a password protected computer in the charge of the Chief Investigator until the end of the project when they will be destroyed. Transcripts will be stored for a further five years following standard research procedures.

Interviewees will each be given a small token (£10 gift voucher) as an acknowledgement of them having given their time to participate in the study. This proved to be a well-received gesture in a previous study and does not risk interference with benefits payments.

2. Potential named persons

This group will be accessed through the people using mental health services. After the interview each interviewee will be asked for permission to access the person they would (or may already

have) nominate to act as their named person. The name and contact details of this person will be provided by the original interviewee. ~~The~~ This potential named person will be contacted and given an information leaflet and letter to take part in the project. Each interviewee will be posted a short accessible booklet (produced by the Scottish Executive in association with the Scottish Association for Mental Health) about the role prior to the interview. The interview will take part either at their own home or another location of their choice. Interviews will be digitally recorded for transcription as above. Interviewees will be able to withdraw consent at any point and will also receive a £10 gift voucher.

3. (Unpaid) Carers of users of mental health services

Where a mental health service user is unable to provide details of a person they would nominate as their named person a carer unconnected to them will be accessed through a specialist service (e.g. a carers' support group). This is to ensure equal numbers of mental health services users and those who (may) act as named persons. This group will be invited to take part through a professional at the service they attend, they will either consent to the professional passing their details on to the CI or they will contact the CI themselves. In these cases the CI will inform the professional at the service that the carer has elected to take part in an interview and ascertain whether there are any risks to either the carer or researcher. The carer will be posted the information leaflet about the role of named person. The interview will take part either at their home or another location of their choice. Interviews will be digitally recorded for transcription as above. Interviewees will be able to withdraw consent at any point and will also receive a £10 gift voucher.

Research instruments

Consultation Groups

During a series of four research consultation groups the issue under consideration was discussed with participants accessed through independent sector mental health organisations. It was generally felt that the subject was an important one for service users and those who provide informal support to them.

Interviews

Individuals with mental health problems

The interview has been selected as the most appropriate research method as the interview situation is the best placed to gain in-depth qualitative information about the interviewees' experiences (Brugha, 1988). The interview has the additional advantage of providing a safe and supportive environment to discuss the areas under investigation. This is of particular importance when interviewing potentially vulnerable participants. The interview will be reasonably unstructured, a guided conversation covering the subject under exploration but allowing it to respond to each participant's experience and situation.

The interview with mental health service users will begin with a discussion of the role of the Named Person which will be based on the information leaflet they will have been posted prior to the interview taking place. Their understanding of the role will be ascertained through discussion of this booklet and information provided where they may be unsure. If the participant has not read the booklet or does not understand the role a full explanation will be provided.

The second section will involve asking the interviewee for their opinions on how useful they feel the provisions will be. Whether they think that they would make use of them, who they would nominate and why.

The third and final part will use a series of vignettes to explore the potential situations where a named person could act on behalf of a mental health service user. Vignettes will be used as they allow the discussion of potentially sensitive subjects in a more detached manner. Questions will be asked in relation to each vignette surrounding how the person should act and what might influence them. The vignettes will be placed at the end of the interview as they can broaden the discussion and move it away from the personal and potentially sensitive to the more abstract.

The interview will aim to be relaxed and to put the participant at their ease. It has been noted in previous fieldwork that participants often expressed concern that they were being tested and did not 'know the correct answers'. The interview schedule, information / invitation leaflet and manner of the interviewer will aim to minimise these feelings.

(Potential) named persons and 'unconnected' carers

Similar to as described above, this interview will commence with an introductory section discussing the booklet they will have been posted and ascertaining their level of knowledge of the role. If they have not read or understood the booklet a full explanation will be provided and any questions they may have will be answered. Their feelings about undertaking such responsibilities will then be explored with reference to making decisions on behalf of others and the conflict that may occur between what the interviewee feels is best and what they know the other person would want. The same vignettes will be used to focus the interview around decision-making in a less personal context and allow comparison between the two groups.

These interviews will take place face-to-face wherever possible but if this is not possible (for example, if the person lives too far away) they will be carried out over the telephone.

All interviews will be digitally recorded for transcription with the interviewees' permission. If consent is not given detailed notes will be taken instead.

Data Analysis

The data generated by this study will be qualitative and will be analysed using ATLAS ti, a qualitative data analysis package that allows organisation of data so that key themes can be examined and links made between them.

Findings

The findings of this research will provide information about how people with mental health problems feel about the provisions put in place by the Act for their representation. This will contribute to the debate surrounding decision-making on behalf of others and will help services providing support to both mental health service users and their carers to ensure that they are aware of the concerns people are having over the use of this legislation. It will be of interest to all those working with the Act, particularly those who are involved in making decisions on the behalf of others.

Dissemination

Dissemination will be approached in the following ways:

- summary leaflet aimed at all interest groups
- articles in publications read by users of mental health services
- articles for the academic community
- presentations at national events for users of mental health services, policy makers and practitioners
- presentations at academic conferences.

References

Brugha, T. S. (1988) Social psychiatry. In: C Thompson (ed) The Instruments of Psychiatric Research. Chichester: Wiley. p. 253-70.

Hoggett, B. (1996) Mental Health Law, London: Sweet and Maxwell.

Scottish Executive (2001) New Directions: Report on the review of the Mental Health (Scotland) Act 1984, Edinburgh: Scottish Executive.

Scottish Executive (2005) The New Mental Health Act: A Guide to Named Persons, Edinburgh: Scottish Executive.

Summers, J. Mackay, K. Brown, K. and Rowlings, C. (1999) Relatives' consent under the Mental Health (Scotland) Act 1984 – A study of practice, relatives' experiences and effects on families (Final report to the Chief Scientist Office), Stirling: University of Stirling.

Acts

Mental Health (Care and Treatment) Act (Scotland) 2003
Mental Health (Scotland) Act 1984

Appendix 5: Application, supporting paperwork and correspondence with the University of Glasgow Faculty Of Medicine Sub Committee for Non Clinical Research Involving Human Subjects

UNIVERSITY OF GLASGOW

**FACULTY OF MEDICINE ETHICS COMMITTEE FOR NON CLINICAL
RESEARCH INVOLVING HUMAN SUBJECTS**

APPLICATION FORM FOR ETHICAL APPROVAL

NOTES:

THIS APPLICATION FORM SHOULD BE TYPED NOT HAND WRITTEN.

**ALL QUESTIONS MUST BE ANSWERED. "NOT APPLICABLE" IS A SATISFACTORY
ANSWER WHERE APPROPRIATE.**

FACULTY PROJECT CODE:

Project Title: Mental health service users', their (potential) nominees' and professionals' perceptions of the 'named person' role under the Mental Health (Care and Treatment) Act (Scotland) 2003

Date of submission: 5th October 2006

Name of all person(s) submitting research proposal: Kathryn Berzins

Position(s) held: Research Associate (PT PhD Student)

Department/Group/Institute/Centre: Public Health and Health Policy
Address for correspondence relating to this submission: Public Health and Health Policy, 1 Lilybank Gardens, Glasgow, G128RZ

Name of Principal Researcher (if different from above e.g., Student's Supervisor): Dr Jacqueline Atkinson

Position held: Senior Lecturer

Undergraduate student project: No

1.Describe the purposes of the research proposed.

The purpose of this research is to explore the perceptions of mental health service users', their (potential) nominees' and mental health professionals' perceptions of the role of 'named person' under the Mental Health (Care and Treatment) (Scotland) Act 2003.

This research was informed by discussion with mental health service users in a series of consultation groups. The service users felt that it was an important new change to the legislation and that it warranted investigation, particularly the level of understanding of the new provisions amongst those potentially subject to them.

The research will seek to explore the understanding and perceptions of the named person provisions of the 2003 Act from the perspective of the (potential) patient and the (potential) named person, carers and mental health professionals involved in implementing the procedures (Mental Health Officers) and those involved in planning and policy.

It seeks to specifically explore:

How beneficial do interviewees perceive the 'named person' provisions to be?

What potential problems do interviewees perceive within the 'named person' provisions?

What factors do mental health service users feel are most important when considering appointing a named person?

How do (potential) named persons perceive the prospect of acting as a 'named person' for (and possibly independently from) the patient?

What factors are important for professionals when supporting people in using the named person provisions?

What factors are important for those involved in the implementation of the named person provisions?

---

2. Please give a summary of the design and methodology of the project. Please also include in this section details of the proposed sample size, giving indications of the calculations used to determine the required sample size, including any assumptions you may have made. (If in doubt, please obtain statistical advice).

This is a qualitative study based on interview data from both face-to face and telephone interviews.

The research will be carried out Scotland-wide, wherever access can be gained to professionals, service users and carers through liaison with relevant non-NHS organisations. As these are new provisions there has not been consistent uptake across Scotland so it is necessary to be able to approach groups where interest is found to have emerged.

Participants: A total of 60 participants will be sought from four groups:
1.People with mental health problems (20)
2. (Potential) Named persons (approximately 10)
3. (Unpaid) Carers of users of mental health services (approximately 10)
4. Mental health professionals / policy makers (approximately 20)

Sixty interviews will provide a substantial amount of data to allow for a rigorous qualitative analysis.

Interviews will be transcribed and analysed using Atlas ti.

3. Describe the research procedures as they affect the research subject and any other parties involved.

1. People with mental health problems The interviewees will be accessed through the following agencies: Community Mental Health Teams in Greater Glasgow (Agreed procedures are already in place for accessing patients through NHS Greater Glasgow Community Mental Health Services and ethical approval has been granted for this by the Glasgow Primary Care LREC.) and independent sector organisations in other areas of Scotland (this application is to approach people outwith the NHS). It should be noted that day service in Glasgow and many other places in Scotland for people with mental health problems are provided by charities/voluntary organisations rather than the NHS and it is access to people in these services which is sought.

Initial discussion will take place with relevant voluntary organisations to judge the potential interest. The researcher may also visit services, give a brief presentation of the issue under investigation, which both introduces people to the research and raises awareness of the issues. Service users will be given an information sheet about the research and if they wish to take part, be encouraged to advise a member of staff to pass their details to the researcher.

The staff member will pass the contact details of the potential interviewee to the researcher and a risk assessment will be carried out to ascertain whether there is any risk involved in the participant being interviewed. The researcher will contact the potential interviewee by telephone to ascertain whether they still wish to be interviewed and if so, arrange a date and location. Previous similar studies have shown that this will usually be at service premises but may occasionally be at another location, e.g. the interviewee's home. (an appropriate risk assessment in respect to the researcher's safety will be carried out and contact details will be left with a named person in the Section, usually the researcher's supervisor.)

Prior to the interview, if required (as many will already have a copy), each interviewee will be posted a short accessible booklet (Scottish Executive (2005) The New Mental Health Act: A Guide to Named Persons about the provisions. Immediately prior to the interview the interviewee will have the consent process explained and be asked to sign the consent forms. The interview will then proceed.

2. Potential named persons This group will be accessed through the people using mental health services or independent organisations. After the interview each interviewee will be asked for permission to access the person they would (or may already have) nominate to act as their named person. The name and contact details of this person will be provided by the original interviewee and a risk assessment carried out as described above. The researcher will contact the potential interviewee by telephone to ascertain whether they would be interested in being interviewed, and if so, arrange a date and location.

Prior to the interview, if required, each interviewee will be posted the information booklet as above. Immediately prior to the interview the interviewee will have the consent process explained and be asked to sign the form if they still wish to take part. The interview will then proceed.

Interviewees will have the opportunity to withdraw their consent to take part at any stage in the process.

3. Unconnected carers The interviewees will be accessed through independent sector organisations in Scotland. Initial discussion will take place with relevant voluntary organisations to judge the potential interest. The researcher may also visit services, give a brief presentation of the issue under investigation, which both introduces people to the research and raises awareness of the issues. Carers' service users will be given an information sheet about the research and if they wish to take part, be encouraged to advise a member of staff to pass their details to the researcher.

The staff member will pass the contact details of the potential interviewee to the researcher and a risk assessment will be carried out to ascertain whether there is any risk involved in the participant being interviewed. The researcher will contact the potential interviewee by telephone to ascertain whether they still wish to be interviewed and if so, arrange a date and location. Previous similar studies have shown that this will usually be at service premises but may occasionally be at another location, e.g. the interviewee's home.

Prior to the interview, if required (as many will already have a copy), each interviewee will be posted a short accessible booklet (Scottish Executive (2005) The New Mental Health Act: A Guide to Named Persons) about the provisions. Immediately prior to the interview the interviewee will have the consent process explained and be asked to sign the consent forms. The interview will then proceed.

4. Mental Health Officers/ Mental health professionals involved in policy making If the interviewee is employed by a local authority Social Work Department the potential interviewees will be contacted after permission has been granted from the Association of Directors of Social Work and the employing local authority. If the potential interviewee is employed by an independent sector organisation they will be approached directly. Potential interviewees will be provided with an information sheet about the research and asked to contact the researcher if they would like to be interviewed. They will be posted a consent form and asked to return it to the researcher in a pre-paid envelope. The interview with then be arranged for a convenient time and be carried out over the telephone.

All interviewees will be interviewed on one occasion.

4. What in your opinion are the ethical considerations involved in this proposal? (You may wish for example to comment on issues to do with consent, confidentiality, risk to subjects, etc.)

A study of mental health service users and their families and carers must be particularly alert to ensure that individuals have given their informed consent to participation in the study and that any research activity does not exacerbate any distress. All mental health service users invited to be included in the current study will be in contact with at least one specialist support service, and will be recruited through such agencies. This will ensure both that individuals are approached to participate in a supportive context and that, should any necessity for extra support emerge after the interview, resources will be on hand. Experience suggests however that when respondents have chosen to participate in studies of this type, which give them an opportunity to discuss aspects of their lives in some depth, they can find it a valued experience.

The study will be conducted in a manner that ensures all ethical standards are met. Potential participants will have the study fully explained to them and will receive a copy of the project invitation / information leaflet. This will include assurances of confidentiality, explanation of how the data will be used, and their rights to withdraw from the project at any stage. Those agreeing to participate will be asked to indicate, by signature, their informed consent and they will retain a copy of this consent form. Interviews will be conducted with sensitivity and care by an experienced researcher who will herself be within a supervision structure providing ongoing support and advice. Lone working can pose a risk to the health and safety of researchers and full procedures are in place to manage this risk.

All data will be anonymised as soon as the interview is completed and no names and contact details will be entered on the interview schedule except a unique identifier number. Participant's names and contact details will only be retained until the interview is completed, or their consent withdrawn, at which point they will be destroyed. Names and addresses will only be kept if the participant wishes to be kept informed as to the findings of the research in which case they will give consent (in the form of a signature on the consent form) for their details to be kept on a specific mailing list that will be destroyed after the findings have been disseminated and will not be used for any other purpose.

5. Outline the reasons which lead you to be satisfied that the possible benefits to be gained from the project justify any risks or discomforts involved.

Experience suggests however that when respondents have chosen to participate in studies of this type which give them an opportunity to discuss aspects of their lives in some depth it can be a valued and therapeutic experience. There is the added benefit, on a wider level, that service providers can increase their understanding of the role social networks play in recovery from mental health problems and thus enhance their service provision.

6. Who are the investigators (including assistants) who will conduct the research and what are their qualifications and experience?

The lead and only researcher is the applicant. I have a BA Hons and a Master of Community Care which both contained elements of research. I have seven years experience as a Research Associate within the Public Health and Health Policy section and as such have substantial experience in interviewing people who use mental health services. Prior to taking up my research post I worked directly with people with severe and enduring mental health problems for five years.

7. Are arrangements for the provision of clinical facilities to handle emergencies necessary? If so, briefly describe the arrangements made.

As with all interviews about personal experiences there is the potential for interviewees to experience distress either during, or after, discussing negative experiences. Interviews will be conducted with sensitivity and care by the Chief Investigator who is an experienced researcher. Should the participant experience distress, procedures are in place to ensure they receive the appropriate follow on support. Service user and carer participants will be in contact with at least one service which will ensure both that individuals are approached to participate within a supportive context and that, should the need for extra support emerge, there will be a service that can be informed of this need, with the participant's consent.

8. In cases where subjects will be identified from information held by another party (for example, a doctor or hospital) describe the arrangements you intend to make to gain access to this information including, where

appropriate, which Multi Centre Research Ethics Committee or Local Research Ethics Committee will be applied to.

Where subjects may be accessed through NHS Community Mental Health services ethical review has been undertaken by Greater Glasgow NHS Primary Care Division Local Research Ethics Committee.

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9. Specify whether subjects will include students or others in a dependent relationship.

Not applicable.

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10. Specify whether the research will include children or people with mental illness, disability or handicap. If so, please explain the necessity of involving these individuals as research subjects.

The research will involve interviewing users of mental health services. As one of the aims of the project is to explore this group's perceptions and experiences this would not be possible without interviewing service users themselves.

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11. Will payment or any other incentive, such as a gift or free services, be made to any research subject? If so, please specify and state the level of payment to be made and/or the source of the funds/gift/free service to be used. Please explain the justification for offering payment or other incentive.

A £10 gift voucher for High Street stores will be given to each service user and carer that takes part in an interview. This has been offered as a small token of thanks in other studies and has always been well received. It is small enough to not interfere with benefits payments and not considered to be of an amount to incentivise people to agree to be interviewed against their best interests.

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12. Please give details of how consent is to be obtained. A copy of the proposed consent form, along with a separate information sheet, written in simple, non-technical language MUST ACCOMPANY THIS PROPOSAL FORM.

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1. People with mental health problems The interviewees will be accessed through independent sector organisations. (Agreed procedures are already in place for accessing patients through NHS Greater Glasgow Community Mental Health Services.) If a service user is interested in taking part in the research they will be given an information sheet / invitation letter. If they would like to be interviewed they will ask a staff member to pass their details to the researcher who will contact them by telephone to ascertain whether they still wish to be interviewed and if so, arrange a date and location. Immediately prior to the interview the interviewee will have the consent process explained and if they still wish to take part, be asked to sign the consent form. Interviewees will have the opportunity to withdraw their consent to take part at any stage in the process.

2. Potential named persons This group will be accessed through the people using mental health services. After the interview each interviewee will be asked for permission to access the person they would (or may already have) nominate to act as their named person. The name and contact details of this person may then be provided by the original interviewee and a risk assessment carried out as described above. The researcher will contact the potential interviewee by telephone to ascertain whether they would be interested in being interviewed, and if so, arrange a date and location. Immediately prior to the interview the interviewee will have the consent process explained and if they still wish to take part, be asked to sign the consent form. Interviewees will have the opportunity to withdraw their consent to take part at any stage in the process.

3. Unconnected carers The interviewees will be accessed through independent sector organisations for carers of people who use mental health services. If a carers' service user is interested in taking part in the research they will be given an information sheet / invitation letter. If they would like to be interviewed they will ask a staff member to pass their details to the researcher who will contact them by telephone to ascertain whether they still wish to be interviewed and if so, arrange a date and location. Immediately prior to the interview the interviewee will have the consent process explained and if they still wish to take part, be asked to sign the consent form or if the interview is being carried out over the telephone to give verbal consent to each element of the form. Interviewees will have the opportunity to withdraw their consent to take part at any stage in the process.

4 Mental Health Officers/Mental Health professionals involved in policy: If potential interviewees are employed by the local authority they will be contacted after permission has been granted by the Association of Directors of Social Work and their employer local authority. Other potential interviewees will be contacted directly e.g. directors of voluntary organisations. Potential interviewees will be provided with an information

sheet about the research and asked to contact the researcher if they would like to be interviewed. They will be posted a consent form and asked to return it to the researcher in a pre-paid envelope or if the interview is being carried out over the telephone give verbal consent to each element of the form. The interview with then be arranged for a convenient time and be carried out over the telephone. Interviewees will have the opportunity to withdraw their consent to take part at any stage in the process. Interviewees will be asked for permission for the interview to be audio-taped for transcription. If this permission is not granted detailed notes will be taken instead.

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13. Comment on any cultural, social or gender-based characteristics of the subject which have affected the design of the project or which may affect its conduct.

The interviews with service users and carers will take place face-to-face as this is felt most effective at putting people at their ease. Any specific requirements related to cultural, social or gender characteristics, will be organised, for example, if an interviewee preferred to have a person of their choosing sit in during the interview this would be arranged.

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14. Please state who will have access to the data and what measures which will be adopted to maintain the confidentiality of the research subject and to comply with data protection requirements e.g. will the data be anonymised?

The Chief Investigator and her PhD supervisor will have access to the data which will be stored on a password protected computer. The Chief Investigator will store personal details on a password-protected computer until the interview has taken place or consent been withdrawn, whereupon the personal details will be withdrawn. If the interviewee wishes to be informed about the findings of the research their details will be kept on a specific mailing list until the summary report has been posted to them, at which point their details will be destroyed.

All respondents will be assigned a unique identifier number after the interview has been completed and data will be stored under this number in without any detail that could reveal the identity of the individual.

Names will be recorded on the consent form which will be stored in a locked filing cabinet during the duration of the project, then securely archived as per University policy (7 years), before being destroyed following confidential waste procedures.

The analysis of the data will be carried out by the Chief Investigator and will be carried out using the software package Atlas ti on password protected computer equipment used exclusively by the Chief Investigator. It will take place within the Chief Investigator's office in the university and within their home. No analysis will be carried out on data that has not been fully anonymised.

At the end of the project the data will be archived as per University procedure whereupon it will be removed from computers to CD data storage and interview schedules, consent forms and other related anonymised paperwork will be archived in a lockable data storage archive facility within the university. After the 7 year period it will be destroyed following confidential waste procedures.

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16. Proposed starting date October 2006 (fieldwork)

   Completion date June 2007 (fieldwork) PhD to run until 2008.

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17. Please state location(s) where the project will be carried out.

Across Scotland, as a result of opportunistic sampling.

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18. Please state briefly any precautions being taken to protect the health and safety of researchers and others associated with the project (as distinct from the research subjects) e.g. where blood samples are being taken

Lone working can pose a risk to the health and safety of researchers and full procedures are in place to manage this risk. The address of any interviews and a start and finish time being left with a third party. The researcher carries a mobile phone at all times. Risk assessment is carried out with an involved professional

prior to visiting an interviewee at home. It is anticipated that the majority of interviews will be carried out within a service setting with other people nearby, or over the telephone.

Signed _____ Date _____
(Proposer of research)

Where the proposal is from a student, the Supervisor is asked to certify the accuracy of the above account.

Signed _____ Date _____
(Supervisor of student)

COMMENT FROM HEAD OF DEPARTMENT/GROUP/INSTITUTE/CENTRE

Signed _____ Date _____

(Head of Department/Group/Institute/Centre)

Send completed form to

Dr AM McNicol
Department of Pathology
Royal Infirmary
Castle St
Glasgow G4 0SF
A.M.McNicol@clinmed.gla.ac.uk

Faculty of Medicine Ethics Committee Review Form

Name: Kathryn Berzins	No: FM00206	Date: 30th Oct 06
Title: Mental health service users', their (potential) nominees' and professionals' perceptions of the 'named person' role under the Mental Health (Care and Treatment) Act (Scotland) 2003		

MAJOR RECOMMENDATIONS – amendments to be returned to reviewer for approval

Section no/name	

MINOR RECOMMENDATIONS – form need not be returned to reviewer

Section no/name	
	This is an interesting project, which has carefully been designed and thought out. The applicants appear to have the appropriate experience and qualifications to carry out this study. One minor comment relates to the individuals with mental health problems. Could I just check that there will be some mechanism put in place to ensure that these individuals are deemed competent and fully understand the nature of the study? Also will participants be informed that their help in this study is not part of their treatment programme?

ACTION:

Approve after comments have been addressed.

Kathryn Berzins

Response to comments from reviewer

'One minor comment relates to the individuals with mental health problems. Could I just check that there will be some mechanism put in place to ensure that these individuals are deemed competent and fully understand the nature of the study?'

Only individuals who are **not** currently subject to measures under either the Mental Health (Care and Treatment) (Scotland) Act 2003 or the Adults with Incapacity (Scotland) Act 2000 will be interviewed. Furthermore, any person felt to be experiencing a negative fluctuation in their mental health by a member of staff at the service they attend, or indeed by the interviewer, at the time of interview will also not be interviewed.

'Also will participants be informed that their help in this study is not part of their treatment programme?'

The consent form and information sheet both state that taking part in the interview is not connected with any treatment or support the person may be receiving and that a decision not to take part has no impact on this. However, this will be highlighted in discussion with the potential participant.

AMMcN/AMJG

Ms Kathryn Berzins
Public Health and Health Policy
1 Lilybank Gardens
Glasgow
G12 8RZ

17/07/2009

Dear Ms Berzins

Medical Faculty Ethics Committee

Project Title: Mental health service users', their (potential) nominees'
and professionals' perceptions of the 'named person' role under
the Mental Health (Care and Treatment) Act (Scotland) 2003

Project No.:   FM00206

The Faculty Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study. They are happy therefore to approve the project, subject to the following conditions:

- The research should be carried out only on the sites, and/or with the groups defined in the application.

- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.

- If the study does not start within three years of the date of this letter, the project should be resubmitted.

- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely,

Dr. Anne M McNicol
Faculty Ethics Officer

Appendix 6: Peer reviewed published paper

Berzins K. M. and Atkinson, J. M., 2009. Service users' and carers' views of the Named Person provisions under the Mental Health (Care and Treatment) (Scotland) Act 2003. *Journal of Mental Health,* 18 (3) pp. 207-215.

References

Alldridge, P., 2000. Relocating criminal law. Farnham: Ashgate.

Amnesty International, 2005. *Scotland: Apathy is stopping Scottish people making wills.* [Online] Available at: *http://www.amnesty.org.uk/news_details.asp?NewsID=16839* [Accessed May 2005]

Andoh, B. and Gogo, E., 2004. The nearest relative in mental health law. *Medicine, science and the law,* 44, pp.140-150.

Arizona Secretary of State, undated. Untitled. [Online] Available at: https://www.azsos.gov/Adv_Dir/HCD/Questions.htm [Accessed January 2009]

Atkinson, J., *1991.* Autonomy and mental health. In: P. Barker and S. Baldwin (Eds). *Ethical issues in mental health* (pp.103-126). London: Chapman and Hall.

Atkinson, J. M., 2007a. *Advance directives in mental health.* London: Jessica Kingsley Publishers.

Atkinson, J. M., 2007b. Protecting or empowering the vulnerable? Mental illness, communication and the research process, *Research Ethics Review,* 3 (4), pp.134-138.

Atkinson, J. M. and Coia, D. A., 1995. *Families Coping with Schizophrenia: A Practitioners' Guide to Family Groups.* Chichester: Wiley.

Atkinson, P., 1992. *Understanding Ethnographic Texts.* California: Sage.

Atlas ti, 2009. Berlin: Scientific Software Development.

Attride-Stirling, J., 2001. Thematic networks: an analytic tool for qualitative research. *Qualitative Research,* 1, pp.385-405.

Backlar, P., McFarland, B. H., Swanson, J. W. and Mahler, J., 2001. Consumer, provider, and informal caregiver opinions on psychiatric advance directives. *Administration and Policy in Mental Health,* 28 (6) pp.427-441.

Bailey, S., 2002. Decision Making in Health Care: limitations of the substituted judgement principle. *Nursing Ethics,* 9, pp.483-493.

Begum, M., Helliwell, R. and Mackay, A., 2004. Difficulties with use of the Mental Health (Scotland) Act 1984 by general practitioners in rural Scotland. *Psychiatric Bulletin,* 28, pp.248-250.

Berzins, K. M., 2006. *A World to Belong To - Social Networks of People with Mental Health Problems.* Glasgow: Scottish Association for Mental Health.

Berzins K. M. and Atkinson, J. M., 2009. Service users' and carers' views of the Named Person provisions under the Mental Health (Care and Treatment) (Scotland) Act 2003. *Journal of Mental Health,* 18 (3) pp. 207-215.

Berzins K. M., Petch, A. and Atkinson, J. M., 2003. Prevalence and experience of harassment of people with mental health problems living in the community. *British Journal of Psychiatry,* 183, pp.526-533.

BIDS, undated. Untitled. [Online] Available at: http://www.bids.ac.uk/ [Accessed October 2005]

Bielby, P., 2005. The Conflation of Competence and Capacity in English Medical Law: A Philosophical Critique. *Medicine, Health Care and Philosophy,* 8 (3), pp.357-369.

Birch, M. and Miller, T., 2000. Inviting intimacy: the interview as therapeutic opportunity. *International Journal of Social Research Methodology,* 3, pp.189-202.

Bloch, S., Szmukler, G. I., Herrman, H., Benson, A., and Colusa, S., 1995. Counseling Caregivers of Relatives with Schizophrenia: Themes, Interventions, and Caveats. *Family Process, 34,* pp.413-425.

Bogart, T. and Solomon, P., 1999. Procedures to Share Treatment Information Among Mental Health Providers, Consumers, and Families. *Psychiatric Services,* 50, pp.1321-1325.

Booth, M. G., Doherty, P., Fairgrieve, R., and Kinsella, J., 2004. Relatives' knowledge of decision making in intensive care. *British Medical Journal,* 30, pp.459-461.

Bowling, A., 1997. *Research Methods in Health. Investigating Health and Health Services.* Buckingham: Open University Press.

Boyatzis, R. E., 1998. *Transforming Qualitative Information: Thematic Analysis and Code Development.* London: Sage.

Bradford, B., McCann, S. and Mersky, H., 1986. A survey of involuntary patients' attitudes toward their commitment, *Psychiatric Journal of the University of Ottawa,* 11, pp.162–165.

Bradley B., Singleton, M. and Li Wan Po, A., 1994. Readability of patient information leaflets on over-the-counter (OTC) medicines. *Journal of Clinical Pharmacy and Therapeutics,* 19 (1), pp.7-15.

Bradley, C., Marshall, M. and Gath, D., 1995. Why do so few patients appeal against detention under Section 2 of the Mental Health Act? *British Medical Journal,* 310, pp.364-367.

Braun, V. and Clarke, V., 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology,* 3, pp.77- 101.

Buchanan, A. E. and Brock, D. W., 1990. *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge: Cambridge University Press.

Bulger, M. W., Wandersman, A. and Goldman, C. R., 1993. Burdens and gratifications of caregiving: appraisal of parental care of adults with schizophrenia. *American Journal of Orthopsychiatry,* 63, pp.255-265.

Bytheway, B. and Johnson, J., 1998. The social construction of carers. In: A. Symonds and A. Kelly (Eds) *The Social Construction of Community Care* (pp.241–253). Basingstoke: Macmillan.

Cassell, J., 1988. The relationship of observer to observed when studying up. In: R. G. Burgess (Ed). *Studies in Qualitative Methodology* (pp. 89-108). London: JAI Press.

Cho, N., 2002. Nearest Relatives of Gay and Lesbian Patients. *Journal of Mental Health Law,* December, pp.323-7.

Clausen, J. A. and Yarrow, M. R., 1955. The impact of mental illness on the family. *Journal of Social Issues,* 4, pp.6–10.

Coffey, A. and Atkinson, P., 1996. *Making Sense of Qualitative Data: Complementary Research Strategies*. California: Sage.

Cooke, F., Watkins, J. and Adams, C., 1994. Rescinding responsibilities as nearest relative and displacing the nearest relative. *Psychiatric Bulletin,* 18, pp.665-667.

Cornwall, P. L. and Scott, J., 1996. Burden of care, psychological distress and satisfaction with services in the relatives of acutely mentally disordered adults. *Social Psychiatry and Psychiatric Epidemiology,* 31, pp.345-348.

Cowles, K. V., 1988. Issues in Qualitative Research on Sensitive Topics. *Western Journal of Nursing Research, 10*, pp.163-179.

Crabtree, B. F. and Miller, W. L., 1999. *Doing Qualitative Research,* London: Sage.

Dawson, A., Ferguson, I., Mackay, K., and Maxwell, M., 2009. *An assessment of the operation of the named person role and its interaction with other forms of patient representation*. Edinburgh: Scottish Government.

Deering, A., 1994. Consent to emergency detention in Edinburgh. *Psychiatric Bulletin,* 18, pp.282-284.

Degrazia, D., 1988. Value theory and the best interests standard. *Hastings Center Report,* 18, pp.44-47.

Department of Health, 1999. *Report of the Expert Committee: Review of the Mental Health Act 1983*. London: Department of Health.

Department of Health for Scotland, 1959. *Second Report by a committee on mental health legislation*. Edinburgh: Department of health for Scotland.

DeSantis, L. and Ugarriza, D. N., 2000. The Concept of Theme as Used in Qualitative Nursing Research. *Western Journal of Nursing Research,* 22, pp.351-372.

Dexter, P. R., Wolinsky, F. D., Gramelspacher, G. P., Zhou, X., Eckert, G. J., Waisburd, M. and Tierney, W. M., 1998. Effectiveness of Computer-Generated Reminders for Increasing Discussions about Advance Directives and Completion of Advance Directive Forms: A Randomized, Controlled Trial. *Annals of Internal Medicine,* 128, pp.102-110.

Dickenson, D., 2001. Decision-making competence in adults: a philosopher's viewpoint. *Advances in Psychiatric Treatment,* 7, pp.381-387.

Dickson-Swift, V., James, E. L., Kippen, S. and Liamputtong, P., 2006. Blurring Boundaries in Qualitative Health Research on Sensitive Topics. Qualitative Health Research, 16, pp.853-871.

Ditto, P. H., Danks, J. H., Smucker, W. D., Bookwala, J., Coppola, K. M., Dresser, R., Fagerlin, A., Gready, R. M., Houts, R. M. Lockhart, L. K. and Zyzanski, S., 2001. Advance Directives as Acts of Communication: A Randomized Controlled Trial. Archives of Internal Medicine, 161, pp.421-430.

Domenici, N. and Griffin-Francell, C., 1993. The role of family education. *Journal of Clinical Psychiatry,* 54, pp.31-34.

Dono, J. E., Falbe, C. M., Kail, B. L., Litwak, E., Sherman, R. H. and Siegel, D., 1979. Primary Groups in Old Age: Structure and Function. Research on Aging, 1, pp.403-433.

Donovan, C., Heaphy, B. and Weeks, J., 1999. Citizenship and Same Sex Relationships. *Journal of Social Policy,* 28, pp.689-709.

Dunn, C., 1998. *Ethical Issues in Mental Illness.* Farnham: Ashgate.

Dworkin, G., 1998. *The Theory and Practice of Autonomy.* Cambridge: Cambridge University Press.

Eakes, G. G., 1995. Chronic sorrow: the lived experience of parents of chronically mentally ill individuals. *Archives of Psychiatric Nursing,* 9, pp.77-84.

Eastman, N., 2006. Reforming mental health law in England and Wales. *British Medical Journal,* 332, pp.737-738.

Elliott, W. A., Timbury, G. C. and Walker, M. M., 1979. Compulsory admission to hospital: an operational review of the Mental Health (Scotland) Act 1960. *British Journal of Psychiatry,* 135, pp.104-114.

Endnote, 2007. London: Thompson Scientific.

Evans, I. M., and Carter, J., 1995. The lesbian perspective on death and dying. In J. K. Parry and A. S. Ryan (Eds.), *A cross-cultural look at death, dying, and religion* (pp.131-144). Chicago: Nelson-Hall.

Fadden, G., Bebbington, P. and Kuipers, L., 1987a. The burden of care: the impact of functional psychiatric illness on the patient's family. The British Journal of Psychiatry, 150, pp.285-292.

Fadden, G., Bebbington, P. and Kuipers, L., 1987b. Caring and its burdens. A study of the spouses of depressed patients, *British Journal of Psychiatry*, 151, pp.660-667.

Feld, S., 1982. Social structural determinants of similarity among associates. *American Sociological Review*, 47, pp.797-801.

Fenig, S., Levav, I., Kohn, R., *and Yalin, N.,* 1993. Telephone vs face-to-face interviewing in a community psychiatric survey. *American Journal of Public Health,* 83, pp.896-898.

Fereday, J. and Muir-Cochrane, E., 2006. Demonstrating Rigor Using Thematic Analysis: A Hybrid Approach of Inductive and Deductive Coding and Theme Development. *International Journal of Qualitative Methods,* 5, pp.1-11.

Field, P. A. and Morse, J. M., 1985. *Nursing Research: The Application of Qualitative Approaches.* Cheltenham: Nelson Thornes.

Fielding, N., 1993. Qualitative interviewing. In N Gilbert (Ed.) *Researching Social Life* (pp 135-171) London: Sage.

Finch, J., 1989. *Family Obligations and Social Change.* Cambridge: Polity Press.

Foy, J., Macrae, A., Thom, A. and Macharouthu, A., 2007. Advance statements: survey of patients' views and understanding. *Psychiatric Bulletin,* 31, pp.339-341.

Gamble, E. R., McDonald, P. J. and Lichstein, P. R., 1991. Knowledge, attitudes, and behavior of elderly persons regarding living wills. *Archives of Internal Medicine,* 151, pp.277-280.

General Medical Council, 2008. *Consent: patients and doctors making decisions together.* [Online] Available at: http://www.gmc-uk.org/guidance/library/consent.asp [Accessed July 2008]

Gilbert, P., Price, J. and Allan, S., 1995. Social comparison, social attractiveness and evolution: How might they be related? *New Ideas in Psychology,* 13, pp.149-165.

Google Scholar, undated. Untitled. [Online] Available at: http://scholar.google.co.uk/ [Accessed October 2005]

Grant, S., 2004. *National Mental Health Services Assessment Towards implementation of the Mental Health (Care and Treatment) (Scotland) Act 2003 Final Report.* Edinburgh: Scottish Executive.

Great Britain Mental Health Act Commission, 2008. *Risk, rights, recovery: the Mental Health Act Commission twelfth biennial report 2005-2007.* London: The Stationery Office.

Greenberg, J.S., Greenley, J.R. and Benedict, P., 1994. Contributions of Persons with Serious Mental Illness to Their Families. *Hospital and Community Psychiatry* 45, pp.475-480.

Greenfield, T. K., Midanik, L. T. and Rogers, J. D., 2000. Effects of telephone versus face-to-face interview modes on reports of alcohol consumption. *Addiction,* 95, pp.277-284.

Hansard, 2001. 26th February, Column 1403.

Hansard, 2005a. Draft Mental Health Bill Session 2004-2005, HL Paper 79(1), HC Paper 95 (1) para 402.

Hansard, 2005b. Report of the Joint Committee on the Draft Mental Health Bill Session 2004-2005, HL Paper 79(1), HC Paper 95 (1) para 398.

Hanson, L. C., Tulsky, J. A. and Danis, M., 1997. Can Clinical Interventions Change Care at the End of Life? *Annals of Internal Medicine,* 126, pp.381-388.

Hare, J., Pratt, C. and Nelson, C., 1992. Agreement between patients and their self-selected surrogates on difficult medical decisions. *Archives of Internal Medicine,* 152, pp.1049-1054.

Henderson, J., 2001. "He" s not my carer-he" s my husband": personal and policy constructions of care in mental health. *Journal of Social Work Practice,* 15, pp.149-159.

Henderson, C., Flood, C., Leese, M., Thornicroft, G., Sutherby, K. and Szmukler, G., 2004. Effect of joint crisis plans on use of compulsory treatment in psychiatry: single blind randomised controlled trial. *British Medical Journal,* 329, 136.

Herring, J., 2007. Where are the carers in healthcare law and ethics? *Legal Studies,* 27, pp.51-73.

Hervey, N. and Ramsay, R., 2004. *Carers as partners in care.* London: Royal College of Psychiatrists.

Hewitt, D., 2007a. *The nearest relative handbook.* London: Jessica Kingsley Publishers.

Hewitt, D., 2007b. Relative Progress? *New Law Journal,* 157, pp.126-133.

Hill, R. G., Shepherd, G. and Hardy, P., 1998. In sickness and in health: The experiences of friends and relatives caring for people with manic depression. *Journal of Mental Health,* 7, pp.611-620.

Hirst, M., 2005. Carer distress: A prospective, population-based study. *Social Science and Medicine,* 61, pp.697-708.

Holloway, F., 2004. Confidentiality: threats and limits. *Psychiatry,* 3 (3), pp.11-13.

Horwitz, A. V., Reinhard, S. C. and Howell-White, S., 1996. Caregiving as Reciprocal Exchange in Families with Seriously Mentally Ill Members. *Journal of Health and Social Behavior,* 37, pp.149-162.

House of Lords, House of Commons, 2005. *Joint committee on the draft mental health bill.* London: The Stationery Office.

Houston, R., 2001a. Institutional care for the insane and idiots in Scotland before 1820: Part 1. *History of Psychiatry,* 12, pp.3-31.

Houston, R., 2001b. Institutional care for the insane and idiots in Scotland before 1820: part 2. *History of Psychiatry,* 12, pp.177-197.

Houston, R. A., 2003. Legal Protection of the Mentally Incapable in Early Modern Scotland. *Journal of Legal History,* 24, pp.165-186.

Howard, P. B., 1994. Lifelong maternal caregiving for children with schizophrenia. *Archives of Psychiatric Nursing,* 8, pp.107-114.

Howard, P. B., 1998. The experience of fathers of adult children with schizophrenia. *Issues in Mental Health Nursing,* 19, pp.399-413.

Hubbard, R. and Rossington, J., 1995. *As we grow older. A study of the housing and support needs of older Lesbians and Gay men.* London: Polari Housing Association.

I. S. D. Scotland, 2008. *Mental Health (Psychiatric) Hospital Activity Statistics.* Statistical Publication Notice 24th June 2008.

Inwald, A. C., Hippisley-Cox, J., Hippisley-Cox, S., and Hill-Smith, I., 1998. The only failure was the outcome. *BMJ,* 317:809.

Jezewski, M. A., Meeker, M. A. and Schrader, M., 2003. Voices of Oncology Nurses: What Is Needed to Assist Patients With Advance Directives. *Cancer Nursing,* 26, 105-112.

Jones, K., 1993. *Asylums and After: A Revised History of the Mental Health Services: From the Early 18th Century to the 1990s.* London: Athlone Press.

Keywood, K., 2003. Gatekeepers, proxies, advocates? The evolving role of carers under mental health and mental incapacity law reforms. *Journal of Social Welfare and Family Law,* 25, pp.355-368.

Kuipers, L., 1993. Family burden in schizophrenia: implications for services. *Social Psychiatry and Psychiatric Epidemiology,* 28, pp.207-210.

Lapadat, J. C. and Lindsay, A. C., 1999. Transcription in Research and Practice: From Standardization of Technique to Interpretive Positionings. *Qualitative Inquiry,* 5, 64-86.

Laurie, G., 2004. Commentary on Booth *et al., 2004. Medical Ethics,* 30, pp.461-462.

Layde, P. M., Beam, C. A., Broste, S. K., Connors, A. F., Desbiens, N., Lynn, J., Phillips, R. S., Reding, D., Teno, J., Vidaillet, H., and Wenger, N., 1995. Surrogates' predictions of seriously ill patients' resuscitation preferences. *Archives of Family Medicine,* 4, 518-23

Lee, R. M., 1993. Doing Research on Sensitive Topics. London: Sage.

Leff, J., Kuipers, L., Berkowitz, R. and Sturgeon, D., 1985. A controlled trial of social intervention in the families of schizophrenic patients: Two year follow-up. *British Journal of Psychiatry,* 146, pp.594-600.

Lefley, H. P., 1987. Aging Parents as Caregivers of Mentally Ill Adult Children: An Emerging Social Problem. *Psychiatric Services,* 38, pp.1063-1070.

LexisNexis, undated. Untitled. [Online] Available at: http://academic.lexisnexis.com/ [Accessed October 2005]

Link, B. G., Cullen, F. T., Frank, J., and Wozniak, J F., 1987. The Social Rejection of Former Mental Patients: Understanding Why Labels Matter. *American Journal of Sociology,* 92, 1461-1500.

Link, B. G., Mirotznik, J. and Cullen, F. T., 1991. The effectiveness of stigma coping orientations: Can negative consequences of mental illness labeling be avoided. *Journal of Health and Social Behavior,* 32, pp.302-320.

Mandelbrote, B. M. and Folkard, S., 1961. Some factors related to outcome and social adjustment in schizophrenia. *Acta Psychiatrica Scandinavica,* 37, pp.223-235.

Mannion, E., Mueser, K. and Solomon, P., 1994. Designing Psychoeducational Services for Spouses of Persons with Serious Mental Illness. *Community Mental Health Journal,* 30, 2, pp.177-190.

Manthorpe, J., 2003. Nearest and Dearest? The Neglect of Lesbians in Caring Relationships. *British Journal of Social Work,* 33, pp.753-768.

Manthorpe, J., Rapaport, J. and Stanley, N., 2008. Expertise and Experience: People with Experiences of Using Services and Carers' Views of the Mental Capacity Act 2005. British Journal of Social Work [*Advance* access, 1–17].

Marriott, S., Audini, B., Lelliott, P., Webb, Y. and Duffet, R., 2001. Research into the Mental Health Act: A qualitative study of the views of those using or affected by it. Journal of Mental Health, 10, pp.33-39.

Marsden, P. V., 1988. Homogeneity in confiding relations. *Social Networks,* 10, pp.57-76.

Marshall, T. B. and Solomon, P., 2000. Releasing information to families of persons with severe mental illness: A survey of NAMI members. *Psychiatric Services,* 51, pp.1006-1011.

Mason, J. K. M. S., R. A. and Laurie, G. T., 2003. *Law and Medical Ethics 6th Edition.* London: LexisNexis.

Matheis-Kraft, C. and Roberto, K. A., 1997. Influence of a values discussion on congruence between elderly women and their families on critical health care decisions. *Journal of Women and Aging,* 9, pp.5-22.

McCosker, H., Barnard, A. and Gerber, R., 2001. Undertaking Sensitive Research: Issues and Strategies for Meeting the Safety Needs of All Participants. *Forum Qualitative Sozialforschung / Forum Qualitative Social Research,* 2(1) Art. 22.

McCubbin, M. and Weisstub, D. N., 1998. Toward a pure best interests model of proxy decision making for incompetent psychiatric patients. *International Journal of Law and Psychiatry,* 21(1):pp.1-30.

McFarlane, W., Dixon, L. and Lukens, E., 2003. Family psychoeducation and schizophrenia: a review of the literature. *Journal of Marital and Family Therapy*, 29, 2, pp.223-245.

Meeker, M. A., 2004. Family Surrogate Decision Making at the End of Life: Seeing them Through with Care and Respect. *Qualitative Health Research,* 14, 204-225.

Meier, D. E., Fuss, B. R., O'Rourke, D., Baskin, S. A., Lewis, M., Morrison, R. S., 1996. Marked improvement in recognition and completion of health care proxies. A randomized controlled trial of counseling by hospital patient representatives. Archives of Internal Medicine, 156, pp.1227-1232.

Mental Health Officers Newsletter Advisory Group, 2006. MHO experiences of the new act and tribunals. *Newsletter for Mental Health Officers in Scotland,* 11, Spring, pp.6-8.

Mental Welfare Commission for Scotland, 2004. *Annual Report 2003-4.* Edinburgh: Mental Welfare Commission.

Mental Welfare Commission for Scotland, 2006. *Named Person – Guidance for practitioners.* Edinburgh: Mental Welfare Commission.

Mental Welfare Commission for Scotland, 2008a. *Our overview of mental welfare in Scotland 2007-8.* Edinburgh: Mental Welfare Commission for Scotland.

Mental Welfare Commission for Scotland, 2008b. *Our annual report 2007-8.* Edinburgh: Mental Welfare Commission for Scotland.

Mental Health Tribunal Scotland, undated. *A guide to travel / other expenses for named persons.* [Online] Available at: http://www.mhtscotland.gov.uk/mhts/522.1.193.html [Accessed February, 2009a]

Mental Health Tribunal Scotland, undated. *A guide for service users* [Online] Available at: http://www.mhtscotland.gov.uk/mhts/files/MHTS%20service%20users%20booklet.pdf [Accessed February, 2009b]

Merton, R. K., 1968. *Social Theory and Social Structure.* New York: The Free Press.

Michael, P. and Hirst, D., 1999. Establishing the rule of kindness: the foundation of the North Wales Asylum at Denbigh. *Insanity, Institutions and Society,* pp.159–179.

Mill, J. S., 1859 (1989) *On Liberty.* Cambridge: Cambridge University Press.

Miller, C., 1995. In-depth interviewing by telephone: some practical considerations. *Evaluation and Research in Education,* 9, pp.43-57.

Monahan, J., Hoge, S. K., Lidz, C., Roth, L. H., Bennett, N., Gardner, W. and Mulvey, E., 1995. Coercion and commitment Understanding involuntary mental hospital admission. International Journal of Law and Psychiatry, 18, pp.249-263.

Morris, F., 2003. Confidentiality and the Sharing of Information. *Journal of Mental Health Law,* July, pp.38-50.

National Literacy Trust, 2009. The Skills for Life Survey. [Online] Available at: http://www.literacytrust.org.uk/socialinclusion/adults/survey.html [Accessed June 2008]

Nelson, G., Hall, G. B., Squire, D., and Walsh-Bowers, R. T., 1992. Social network transactions of psychiatric patients. *Social Science and Medicine,* 34, pp.433-445.

NHS Scotland, undated. Untitled. [Online] Available at: www.confidentiality.scot.nhs.uk/publications/FRASER%20GUIDELINES.doc [Accessed June 2008]

Office for National Statistics, 2002. *Adults with a psychotic disorder living in private households, 2000.* London: The Stationery Office.

Ovid, undated. Untitled. [Online] Available at: http://ovidsp.uk.ovid.com/ [Accessed October 2005]

Oxford English Dictionary, undated. *Carers.* [Online] Available at: http://dictionary.oed.com/cgi/entry/50033454?single=1andquery_type=wordandqueryword=carerandfirst=1andmax_to_show=10 [Accessed February 2009]

Papageorgiou, A., Janmohamed, A., King, M. and Davidson, O., 2004. Advance directives for patients compulsorily admitted to hospital with serious mental disorders, *Journal of Mental Health,* 13 (4), pp.379–388.

Patrick, H., 2006. *Mental Health, Incapacity and the Law in Scotland.* Edinburgh: Tottel Publishing Ltd.

Pejlert, A., 2001. Being a parent of an adult son or daughter with severe mental illness receiving professional care: parents' narratives. *Health and Social Care in the Community,* 9, pp.194-204.

Percy Commission, 1957. *Report of the Royal Commission on the Law Relating to Mental Disorder 1954-1957.* Cmnd 169, London: HMSO.

Perlick, D., Clarkin, J. F., Sirey, J., Raue, P., Greenfield, S., Struening, E. and Rosenheck, R., 1999. Burden experienced by care-givers of persons with bipolar affective disorder. *The British Journal of Psychiatry,* 175, pp.56-62.

Peto, T., Srebnik, D., Zick, E. and Russo, J. 2004. Support needed to create psychiatric advance directives. *Administration and Policy in Mental Health,* 31 (5), pp.409-419.

Pierce, S. F., 1999. Allowing and assisting patients to die: the perspectives of oncology practitioners. *Journal of Advanced Nursing,* 30, pp.616-622.

Pilgrim, D., 2006. New 'Mental Health' Legislation for England and Wales: Some Aspects of Consensus and Conflict. *Journal of Social Policy,* 36, pp.79-95.

Quam, J. K., 1997. *Social Services for Senior Gay Men and Lesbians.* Binghampton: Haworth Press.

Ramsay, R., 2001. *Mental Illness: A Handbook for Carers.* London: Jessica Kingsley Publishers.

Rapaport, J., 2003. Ghost of the Nearest Relative under the Mental Health Act 1983-Past, Present and Future. *Journal of Mental Health Law,* August, pp.1-65.

Rapaport, J., 2004. A Matter of Principle: the Nearest Relative under the Mental Health Act 1983 and Proposals for Legislative Reform. *Journal of Social Welfare and Family Law,* 26, pp.377-396.

Rapaport, J., Bellringer, S., Pinfold, V., and Huxley, P., 2006. Carers and confidentiality in mental health care: considering the role of the carer's assessment: a study of service users', carers' and practitioners' views. *Health and Social Care in the Community,* 14, pp.357-365.

Rapaport J. and Manthorpe, J., 2008. Family Matters: Developments Concerning the Role of the Nearest Relative and Social Worker under Mental Health Law in England and Wales. *British Journal of Social Work,* 38(6), pp.1115-1131.

Rethink, 2003. *Under Pressure.* London: Rethink.

Robinson, A. D. T., 1989. Dorothea Dix: When will we see your like again in Scotland? *Psychiatric Bulletin,* 13, 305-307.

Robinson, R. and Scott-Moncrieff, L., 2005. Making Sense of Bournewood. *Journal of Mental Health Law,* May, pp.17-25.

Rook, K. S., 1984. The negative side of social interaction: Impact on psychological well-being. *Journal of Personality and Social Psychology,* 46, pp.1097-1108.

Rosenfield, S. and Wenzel, S., 1997. Social Networks and Chronic Mental Illness: A Test of Four Perspectives. *Social Problems,* 44, pp.200-216.

Rossi, A. S. and Rossi, P. H., 1990. *Of Human Bonding: Parent-child Relations Across the Life Course.* New Jersey: Aldine Transaction.

Rubin, S. M., Strull, W. M., Fialkow, M. F., Weiss, S. J., and Lo, B., 1994. Increasing the completion of the durable power of attorney for health care. A randomized, controlled trial. *Journal of the American Medical Association,* 271, pp.209-212.

Rutz, W., 1995. The need for psychiatric professionalism-an integrative view. *Nordic Journal of Psychiatry,* 49, pp.17-23.

Sandelowski, M., 1995. On the Aesthetics of Qualitative Research. *Journal of Nursing Scholarship,* 27, pp.205-209.

Scottish Executive, 1999. *Strategy for carers in Scotland.* Edinburgh: Scottish Executive.

Scottish Executive, 2001. *New Directions A Report on the Review of the Mental Health (Scotland) Act 1984.* Edinburgh: Scottish Executive.

Scottish Executive Equality Unit and Public Health Division, 2001. *User consultation on the Millan report summary.* Edinburgh: Scottish Executive.

Scottish Executive, 2003. *Partnership for care.* Edinburgh: Scottish Executive.

Scottish Executive, 2004. *The New Mental Health Act: A Guide to Named Persons.* Edinburgh: Scottish Executive.

Scottish Executive, 2005. *Mental Health (Care and Treatment) (Scotland) Act 2003, Code of Practice Volumes 1-3.* Edinburgh: Scottish Executive.

Seckler, A. B., Meier, D. E., Mulvihill, M., and Paris, B. E., 1991. Substituted judgment: how accurate are proxy predictions? *Annals of Internal Medicine,* 115, pp.92-98.

Shalowitz, D. I., Garrett-Mayer, E. and Wendler, D., 2006. The Accuracy of Surrogate Decision Makers A Systematic Review. *Archives of Internal Medicine,* 166, pp.493-497.

Shaw, P., Hotopf, M. and Davies, A., 2003. In relative danger? The outcome of patients discharged by their nearest relative from sections 2 and 3 of the Mental Health Act. *Psychiatric Bulletin,* 27, pp.50-54.

Singleton, J. and Mclaren, S., 1995. *Ethical Foundations of Health Care: Responsibilities in Decision-making.* London: Mosby.

Smith, S., 2006. The first 12 months of the mental health tribunal service. Newsletter for Mental Health Officers in Scotland. *Newsletter for mental health officers in Scotland,* 13, Autumn. pp.18-19.

Spencer, G. and Skipworth, J., 2007. Forcing family involvement in patient care: legislative and clinical issues. *Australasian Psychiatry,* 15, pp.396-401.

Srebnik, D. S., Russo, J., Sage, J., Peto, T. and Zick, E., 2003. Interest in Psychiatric Advance Directives Among High Users of Crisis Services and Hospitalization. *Psychiatric Services,* 54 (7), pp.981-986.

Stevenson, G. S., 2003. Emergency psychiatric detentions in a Scottish health region—the use of Sections 24 and 25 of the Mental Health (Scotland) Act 1984. *International Journal of Law and Psychiatry,* 26, pp.257-267.

Stewart, A., 2006. Nine months on, how is the 2003 Act's implementation being experienced by MHOs? *Newsletter for mental health officers in Scotland,* 12, Summer, pp.9-10.

Sturges, J. E. and Hanrahan, K. J., 2004. Comparing Telephone and Face-to-Face Qualitative Interviewing: a Research Note. *Qualitative Research,* 4, pp.107-118.

Suitor, J. J., Pillemer, K. and Keeton, S., 1994. When Experience Counts: The Effects of Experiential and Structural Similarity on Patterns of Support and Interpersonal Stress. *Social Forces,* 73, pp.1573 -1588.

Sulh, J., Simons, P., Reedy, T., and Garrick, T., 1994. Myth of substituted judgment. *Archives of Internal Medicine,* 154, pp.90-96.

Sulmasy, D. P., Haller, K. and Terry, P. B., 1994. More talk, less paper: predicting the accuracy of substituted judgments. *American Journal of Medicine,* 96, pp.432-438.

Sulmasy, D. P., Terry, P. B., Weisman, C. S., and Miller, D. J., Stallings, R. Y., Vettese, M. A. and Haller, K. B., 1998. The Accuracy of Substituted Judgments in Patients with Terminal Diagnoses. *Annals of Internal Medicine,* 128, pp.621-629.

Summers, J. M., K, Brown, K. and Rowlings, C., 1999. *Relatives' consent under the mental Health (Scotland) Act 1984 - A study of practice, relatives' experience and effects on families.* Stirling: University of Stirling.

Sutherby, K. and Szmukler, G., 1998. Crisis cards and self-help crisis initiatives. *Psychiatric Bulletin,* 22, pp.4-7.

Swanson, J. W., Swartz, M. S., Hannon, M. J., Elbogen, E. B., Wagner, H. R., McCauley, B. J. and Butterfield, M. I., 2003. Psychiatric Advance Directives: A Survey of Persons With Schizophrenia, Family Members, and Treatment Providers. *International Journal of Forensic Mental Health,* 2(1), pp.73-86.

Swigart, V., Lidz, C., Butterworth, V., and Arnold, R., 1996. Letting go: Family willingness to forgo life support. *Heart and Lung: Journal of Acute and Critical Care,* 25, 483-494.

Szmukler, G., 1999. Ethics in community psychiatry. *Australian and New Zealand Journal of Psychiatry,* 33, pp.328-338.

Szmukler, G. I. and Bloch, S., 1997. Family involvement in the care of people with psychoses. An ethical argument. *British Journal of Psychiatry,* 171, pp.401-405.

Szmukler, G. I., Burgess, P., Herrman, H., Bloch, S., Benson, A., and Colusa, S., 1996. Caring for relatives with serious mental illness: the development of the Experience of Caregiving Inventory. Social Psychiatry and Psychiatric Epidemiology, 31, pp.137-148.

Tausig, J. E. and Freeman, E. W., 1988. The next best thing to being there: conducting the clinical research interview by telephone. *American Journal of Orthopsychiatry,* 58, pp.418-427.

Taylor, J. R. and Idris, K. B., 2003. Use of the Mental Health Scotland Act 1984 in south Glasgow. *Psychiatric Bulletin,* 27, pp.141-144.

Thomson, L. D. G., 2005. The Mental Health (Care and Treatment) (Scotland) Act 2003: civil legislation. *Psychiatric Bulletin,* 29, 381-384, pp.381-384.

Tilden, V. P., Tolle, S. W., Garland, M. J., and Nelson, C. A., 1995. Decisions about life-sustaining treatment. Impact of physicians' behaviors on the family. *Archives of Internal Medicine,* 155, pp.633-638.

Toews, J., el-Guebaly, N., Leckie, A. and Harper D., 1984. Patients' attitudes at the time of their commitment. *Canadian Journal of Psychiatry,* 29(7), pp.590-5.

Tomlinson, T., Howe, K., Notman, M., *and* Rossmiller, D., 1990. An empirical study of proxy consent for elderly persons. *The Gerontologist,* 30, pp.54-64.

Tuck, I., du Mont, P., Evans, G., and Shupe, J.,1997. The experience of caring for an adult child with schizophrenia. *Archives of Psychiatric Nursing,* 11, pp.118-125.

Tuckett, A. G., 2005. Applying thematic analysis theory to practice: A researcher's experience. *Contemporary Nurse,* 19, pp.74-87.

Twigg, J., 1994. Carers, families, relatives: Socio-legal conceptions of care-giving relationships. *Journal of Social Welfare and Family Law,* 16, pp.279-298.

Twigg, J. and Atkin, K., 1994. *Carers perceived: policy and practice in informal care.* Buckingham: Open University Press.

Uhlmann, R. F., Pearlman, R. A. and Cain, K. C., 1988. Physicians' and spouses' predictions of elderly patients' resuscitation preferences. *Journal of Gerontology,* 43, pp.115-121.

Ulivi, G., Reilly, J. and Atkinson, J. M., 2009. Protection or empowerment: Mental health service users' views on access and consent for non-therapeutic research, *Journal of Mental Health,* [*First* access].

User and Carer Involvement, undated. *Guidance for Named Persons.* Dumfries: User and Carer Involvement.

US Living Will Registry, undated. Untitled. [Online] Available at: http://www.uslivingwillregistry.com/default.asp [Accessed January 2009]

Washington State Department of Health, undated. Untitled. [Online] Available at: http://www.doh.wa.gov/livingwill/ [Accessed January 2009]

Webber, M. and Huxley, P., 2004. Social exclusion and risk of emergency compulsory admission. A case-control study. *Social Psychiatry and Psychiatric Epidemiology,* 39, pp.1000-1009.

Wellman, B., 1992. Which types of ties and networks give what kinds of social support. *Advances in Group Processes,* 9, pp.207-235.

World Health Organization, 1996. *Mental health care law: Ten basic principles.* Geneva: World Health Organization.

World Health Organization, 2005. *ICD-10 2nd Edition International Statistical Classification of Diseases and Health Related Problems, 10th Revision, Second Edition.* Geneva: World Health Organization.

World Medical Association, 2004. *Declaration of Helsinki* [Online] Available at: http://www.wma.net/e/policy/b3.htm [Accessed April 2008]

Wrigley, A., 2007. Personal Identity, Autonomy and Advance Statements, *Journal of Applied Philosophy,* 24, pp.381-396.

Yeates, V., 2005. Death of the Nearest Relative? Carers' and Families' RIghts to Challenge Compulsion under Current and Proposed Mental Health Legislation. *Journal of Mental Health Law,* November, pp.123-137.

Zalta, E. N., 2002. *Stanford Encyclopedia of Philosophy.* [Online] Available at: http://www.seop.leeds.ac.uk/contents.html [Accessed March 2006]