The Genetics of Prenatal Diagnosis, c.1950-1990: The Case of Malcolm Ferguson-Smith

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Abstract:

In the present day, the fetus is a well-studied entity, with both physical appearance and genetic constitution able to be determined prior to birth. However, this is a relatively new phenomenon, that has been made possible due to developments which have occurred in the field of prenatal testing in the last fifty or so years. Prior to the implementation of antenatal testing technologies, the fetus was surrounded by mystery, accessed through information passed on by the pregnant woman. This thesis examines the developments that have occurred in the prenatal testing field within the time period 1950 to 1990, which have made it possible to characterise the physical and genetic structure of the fetus prior to birth. An analysis is made of the development of relevant prenatal testing technologies, including amniocentesis, chorionic villus sampling, and ultrasound, with a consideration of their role in making the fetus an accessible entity during pregnancy.

To examine how these technologies have been implemented into clinical care, this thesis focuses on the development of prenatal testing and screening programmes in the West of Scotland. Within this region, the city of Glasgow presents an interesting case study for analysis. Work in this city was led by Malcolm Ferguson-Smith, who is widely regarded as one of the most eminent British medical geneticists of recent decades. This thesis studies the role which Ferguson-Smith and his colleagues played in the development and implementation of prenatal testing and screening programmes in the West of Scotland, particularly for chromosome disorders and neural tube defects. It will be shown that the group played a central role in bringing prenatal testing to residents of Glasgow, with the majority of screening programmes proving to be popular with pregnant women in the region.

Whilst prenatal testing became technically feasible due to advances in technology and science, the field presents a particularly interesting area for analysis, due to the ethical questions which prenatal diagnosis raises. There are no medical treatments available for the majority of conditions which can be detected, and after a positive prenatal diagnosis, many women choose to terminate their pregnancies. The importance of the development

of permissive abortion legislation is therefore important to consider within the context of this thesis. With prenatal testing being linked to termination of pregnancy, it can be seen that it has the potential to cause conflict between those who manage and participate in the prenatal testing programmes, and those who oppose abortion, such as certain religious groups. This thesis examines how the two largest religious organisations that were present in Glasgow during the time period of this study, the Church of Scotland and the Roman Catholic Church, responded to permissive abortion legislation in the form of the Abortion Act 1967. The views of both the Church of Scotland and the Roman Catholic Church on abortion following prenatal diagnosis will also be considered, and it will be argued that remarkably few discussions were taking place on this subject. This has created a complex situation whereby the expected conflict between prenatal testing and religion did not seem to be overly prominent during the time period of this study; this is reflected in a lack of direct correlation between prenatal decision making and religious affiliation.

Glasgow presents a particularly interesting area for examining the interplay of the technical and social aspects of prenatal diagnosis. In the city there was a focus on prenatal testing amongst the group led by Ferguson-Smith, whilst concurrently the Roman Catholic population in the region were openly voicing their opposition to abortion. This thesis provides a detailed picture of the interaction of the technical and social influences in this geographical region. To achieve this, a wide variety of sources have been examined, including archival material, published scientific papers, and newspapers and magazines. A number of oral history interviews have also been carried out. As a result of the analysis of these sources, what emerges is an in-depth account of the development of prenatal testing in the West of Scotland.

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Abbreviations:

AChE – Acetylcholinesterase

ACMR – Advisory Committee for Medical Research

ALRA – Abortion Law Reform Association

AFP – Alpha-fetoprotein (α-fetoprotein)

BMA – British Medical Association

BMJ – *British Medical Journal*

BSE – Bovine spongiform encephalopathy

CVS – Chorionic villus sampling

DHSS – Department of Health and Social Security

GP – General Practitioner

ILPA – Infant Life Preservation Act

M.P. – Member of Parliament

NIPT – Non-invasive prenatal testing

NHS – National Health Service

NTDs – Neural tube defects

MRC – Medical Research Council

msAFP – Maternal serum alpha-fetoprotein (α-fetoprotein)

RCOG – Royal College of Obstetricians and Gynaecologists

RMPA – Royal Medico-Psychological Association

SCO – *Scottish Catholic Observer*

SHHD – Scottish Home and Health Department

SPUC – Society for the Protection of Unborn Children

WHO – World Health Organisation

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I would like to thank my supervisors, Professor Malcolm Nicolson, Professor Kevin O'Dell, and Professor Callum Brown, who have been there for every step of this project. It has been a fantastic opportunity to learn from all three of you, and I hope that I can take away knowledge from each of your varied fields. You have all provided me with such encouragement and support over the last few years, and it has been a privilege to work alongside you. Thank you for everything.

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A great deal of the research for this PhD centred round archives, and I am particularly indebted to the archive services of the University of Glasgow. Special thanks to Moira Rankin, who was a great source of help, and who was always interested to hear about how the project was progressing. A large amount of time was also spent at the Mitchell Library in Glasgow, working with newspaper and magazine collections. All of the staff were exceptionally helpful and accommodating, which made the long months of document checking that bit easier. The same can be said for the staff of the NHS Greater Glasgow and Clyde archive, also based in the Mitchell Library, who assisted me in my use of the Ian Donald archive. Special thanks also go to Dr Ian Jessiman, from the Scottish Catholic Medical Association, who carried out the arduous task of sifting through several decades of publications of the Catholic Medical Association journal on my behalf. In the absence of an available archive, you were an invaluable source of help, and I appreciate you giving up your time so freely to assist with the project.

This thesis would not have been possible without the participation of all of my interviewees, who were so generous with their time and memories. Special thanks to Professor Malcolm Ferguson-Smith, and Marie Ferguson-Smith, who welcomed me into their home in Cambridge, and shared their stories over the course of a few days at the very beginning of my research. These conversations helped me track down many others who had worked in the prenatal testing field in Glasgow, who were an invaluable source of information. Through all of my interviewees I was able to step back in time, and get a real sense of how the department worked. Whilst I may not have included all of your testimony, you had a key role in shaping the direction of the project, and I will be forever grateful for your kind reception. Thanks also go to the many other individuals who I have interacted with throughout the course of my research on a more informal basis, at conferences, seminars, and other networking events. All of these discussions encouraged me to think about my research on a deeper level, and have influenced how I view the world of prenatal testing.

I would also like to offer my heartfelt thanks to my friends, who have been an invaluable source of support over the last few years. You have been so important in motivating me throughout the entire research and writing process, and are always there to listen to and support me. This also applies to my colleagues in Lilybank House, who have provided an important support network to exchange ideas with, and have made my PhD journey such a positive one. Special thanks to Maëlle Duchemin-Pelletier for taking the time to proof-read my thesis, which was gratefully appreciated.

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Declaration:

I declare that, except where explicit reference is made to the contribution of others, that this dissertation is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Paula Blair

Introduction

> Prenatal diagnosis is a highly atypical diagnostic approach. Usually the aim of diagnosis of a pathological condition is to treat it, prevent it, or both. The main consequence – at least, for now – of the prenatal diagnosis of a major fetal anomaly is to allow the pregnant woman to choose to end the pregnancy. In that case, the "prevention" of an impairment is the prevention of the birth of a human being with that impairment, a unique and, for many, a highly problematic solution.[1] – Ilana Löwy

I. Introduction

Prenatal testing has contributed to the study of the fetus in utero, and has made it possible to detect fetal anomalies prior to birth, providing women with the option to terminate an affected pregnancy if they choose to do so. Prenatal diagnosis enables the detection of a number of conditions in the fetus, including chromosome disorders such as Down's syndrome,[2] and a variety of neural tube defects, including anencephaly and spina bifida.[3] As highlighted in the quote above by Löwy, the nature of research into the detection of these and other genetic anomalies, enabling elective termination of affected pregnancies, has raised ethical issues which challenge the views of a number of groups and individuals who oppose abortion, including religious organisations. Prenatal testing involves the use of invasive diagnostic techniques including amniocentesis and chorionic villus sampling, alongside visual technologies such as obstetric ultrasound, to gain information about both the genetic constitution and physical structure of the fetus.[4]

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[1] Ilana Löwy, *Imperfect Pregnancies: A History of Birth Defects and Prenatal Diagnosis*, (Baltimore: Johns Hopkins University Press, 2017), p. vii.

[2] Down's syndrome is caused by an extra copy of chromosome 21 inside the cells of the body. The condition is characterised by Down's Syndrome Scotland as being 'the most frequently recognised form of learning disability'. For more information on the condition see 'What is Down's Syndrome?', *Down's Syndrome Scotland* <https://www.dsscotland.org.uk/new-parents/what-is-downs-syndrome/> [accessed 18th July 2018].

[3] In spina bifida the spinal column does not develop properly, resulting in a gap in its formation. The condition can be on a spectrum from mild to severe, and symptoms can range from leg weakness to paralysis. Many babies with the condition will also develop hydrocephaly, a condition caused by excess fluid on the brain. Anencephaly is a more severe condition in which babies are born missing part of the brain or skull. It results in ante- or neo-natal death.

[4] Detailed descriptions of the development of these technologies and their uses will be given in chapter one. Briefly, amniocentesis involves the insertion of a needle into the amniotic sac, to remove a small volume of amniotic fluid for analysis. Chorionic villus sampling involves removing a small number of cells from the placenta for analysis, and ultrasound is a visual technology which uses high-frequency sound waves to create an image of the fetus for visual examination.

For the majority of pregnant women today, prenatal screening programmes and diagnostic testing are both accepted and expected aspects of antenatal care.[5] However, the ability to examine the fetus has only been possible since the 1950s. As Nicolson and Fleming have noted in *Imaging and Imagining the Fetus: The Development of Obstetric Ultrasound*, 'Fifty years ago, the unborn human being was hidden, enveloped within the female abdomen, away from the medical gaze. The fetus made its presence known largely by its effects on the pregnant woman's body, and many of its activities and characteristics were understood by doctors only through the medium of her verbal testimony.'[6] Prior to the advent of prenatal testing, the pregnant woman was the main source of information about the developing fetus, and doctors and midwives required close physical contact with the pregnant woman to gain access to the fetus. As described by Rothman, midwives and doctors had to use their hands to palpate the abdomen of the woman, which enabled them to 'feel the recognizable shape of the baby' and 'feel its movements against their own hands through the mother'.[7] This is a contrast to the current situation, whereby the fetus is accessed as a separate entity by clinicians, both through the visual use of ultrasound where it can be seen as an individual, and in the characterising of genetic information of the fetus, which differs from that of the pregnant woman. Löwy argues that the generalisation of prenatal diagnosis 'has transformed the understanding of pregnancy, childbirth, and human reproduction' and has produced 'a technoscientific entity; "the scrutinized fetus"'.[8]

The technical developments which made prenatal diagnosis clinically feasible were also affected by the social and cultural context of the time and place in which they occurred. The aim of this thesis is to examine the scientific and technical developments which were occurring in prenatal diagnosis in the West of Scotland between 1950 and 1990,

[5] Prenatal screening involves large-scale programmes which are targeted at all pregnant women. They aim to detect women who have an increased chance of having a fetus affected by the screened-for condition, to refer them on for further diagnostic testing. Termination of pregnancy would not be offered based on an increased chance result at the screening stage, and would require confirmation of the diagnosis using an invasive diagnostic test, such as amniocentesis or chorionic villus sampling.
[6] Malcolm Nicolson and John E.E. Fleming, *Imaging and Imagining the Fetus: The Development of Obstetric Ultrasound* (Baltimore: The Johns Hopkins University Press, 2013), p. 1.
[7] Barbara Katz Rothman, *The Tentative Pregnancy: Amniocentesis and the Sexual Politics of Motherhood*, 2nd Edition, (London: Pandora, 1994), p. 113.
[8] Löwy, *Imperfect Pregnancies*, p. 4.

and to place these alongside wider national developments. To analyse the developments in prenatal diagnosis in detail, this thesis will utilise the case study of an individual who was centrally involved in the field, Malcolm Ferguson-Smith, who helped to develop and implement prenatal testing in the West of Scotland from the 1960s to the late 1980s.

Malcolm Ferguson-Smith was the key figure involved in bringing medical genetics to the West of Scotland, and was the driving force for approximately 30 years behind the scientific and clinical work which led to prenatal testing and screening programmes in the region. Ferguson-Smith graduated with his medical degree in 1955, which was immediately before many of the crucial discoveries were made which would enable the creation of the field of prenatal testing, and only a few years after the structure of DNA had been identified. In the space of only a few decades, the field of medical genetics was created and expanded a great deal – it moved from a scenario where the correct chromosome number in humans was not known, to being able to map genes on specific chromosomes. Peter Harper has commented that the field expanded 'so rapidly and extensively over a period of little more than 50 years', and that the changes happened so quickly that 'there has been little time for those directly involved to reflect on this process of development'.[9] To provide a sense of the huge expansion of medical genetics in the few years after Ferguson-Smith graduated, some key events which were occurring in the prenatal field can be highlighted here.[10] In 1956 the correct chromosome number in humans was identified by Tjio and Levan, and in the same year Fuchs and Riis would use amniocentesis to determine fetal sex. In 1959, the year that Ferguson-Smith travelled out to the United States to begin his own medical genetics training, the previously unknown chromosome constitutions were determined in Down's syndrome, Turner's syndrome, and Klinefelter's syndrome. 1960 led to the identification of both trisomy 13 and trisomy 18,[11] and 1966 was the year where Steele and Breg announced that the cells in amniotic fluid could be cultured and their chromosome constitution analysed, thus opening up the possibility of the entire field of prenatal testing. Ferguson-Smith was beginning his career in the midst of all of these developments, and

[9] Peter S. Harper, *A Short History of Medical Genetics*, (Oxford: Oxford University Press, 2008), p. 3.
[10] All of these events will be discussed in detail in chapter one, with references provided for each in that chapter.
[11] Trisomic conditions are characterised by an extra copy of a chromosome, for example, in cases of trisomy 13, the individual would have three copies of chromosome 13, as opposed to two copies.

his early training was with Victor McKusick, a senior clinician and researcher whose contributions and influence in medical genetics have been described by Harper as 'probably greater than those of any other single individual', partly due to his role in training others who would go on to set up their own medical genetics units throughout the world.[12] Ferguson-Smith would be one of these individuals.

Thus, Ferguson-Smith was starting out on his career at a time when the entire field of medical genetics was showing promise, with discoveries following closely one after another over a period of a few short years. Ferguson-Smith himself would go on to implement huge change in this area in Glasgow, becoming the first Lecturer in Medical Genetics at the University of Glasgow.[13] He was responsible for bringing medical genetics, particularly clinical services, to Glasgow and the West of Scotland, where no provision had previously been available. When he began his role as lecturer, the region had no chromosome diagnostic testing programmes in place, and Ferguson-Smith campaigned to rectify this situation. He became responsible for establishing a chromosome diagnostic service which would become available to many families through genetic clinics, and to thousands of pregnant women through prenatal testing. For the first time in the city it became possible, through the work of Ferguson-Smith and his colleagues, to test pregnant women for conditions such as Down's syndrome in the fetus, and offer a termination of pregnancy. The work led by Ferguson-Smith on chromosomes also examined, to name but a few areas, the role of maternal age effect on chromosome disorders in the fetus, mapping genes to specific chromosomes, and campaigning for better understanding of sex chromosome disorders.

Ferguson-Smith also led a huge campaign of screening for neural tube defects, with the aim of detecting these conditions in pregnancy. The scale of the screening programme was in the thousands, and completely changed the way in which pregnant women in the region could receive information on their fetus during pregnancy. The department run by Ferguson-Smith were also centrally involved in the clinical trials looking at the use of folic acid supplements to prevent the formation of neural tube defects, hence

[12] Harper, *A Short History of Medical Genetics*, p. 285.
[13] Full details of this will be provided in chapter two.

obviating the need to offer termination of affected pregnancies. Additionally, Ferguson-Smith was responsible for sourcing the funding and creating the Duncan Guthrie Institute of Medical Genetics, which would bring together scientists, clinicians, nurses and various other staff members under the one roof. This Institute was at the helm of modern medical genetics practice, enabling close work and collaboration between all these different staffing groups. The Institute made it possible for thousands of families in the West of Scotland to seek genetic advice, and greatly expanded medical genetics services, including prenatal testing, to the wider public in the region.

Ferguson-Smith contributed a great deal to medical genetics. Under his leadership, prenatal testing and then prenatal screening programmes became implemented in the West of Scotland for a number of different conditions. Ferguson-Smith himself has described how his department's publication on prenatal chromosome analysis in 1971 was the first in the United Kingdom to report on a prospective study of prenatal diagnosis, and that his department also made the first prenatal diagnosis of spina bifida from amniotic fluid alpha-fetoprotein in 1972.[14] In addition to providing diagnostic services, the staff working in his team were involved in key research projects, including work on sex chromosome anomalies, and gene mapping projects, to name only a few. The formation of the Duncan Guthrie Institute meant that more patients could access genetics services, and that these services were located in one building – a system that would go on to be seen as an example of best practice, and central in fostering the development and collaboration of staff members, and improving the care of patients. In the thirty-two years between Ferguson-Smith's graduation, and his departure from medical genetics in Glasgow, he developed a department from one which had no

[14] These comments were made by Ferguson-Smith in the following article: Malcolm A. Ferguson-Smith, 'Putting Medical Genetics into Practice', *Annual Review of Genomics and Human Genetics*, 12:1 (2011), pp. 9-10. It should be noted that the original work linking alpha-fetoprotein and neural tube defects was carried out by Brock and Sutcliffe, based in Edinburgh. Further information will be provided on this in chapter one.
For the 1971 publication, see M.E. Ferguson-Smith, M.A. Ferguson-Smith, N.C. Nevin and M. Stone, 'Chromosome Analysis Before Birth and its Value in Genetic Counselling', *British Medical Journal*, 4:5779 (1971), pp. 69-74.
For the 1972 work which resulted in a 1973 publication, see Lindsey D. Allan, M.A. Ferguson-Smith, Ian Donald, Elizabeth M. Sweet and A.A.M. Gibson, 'Amniotic-fluid Alpha-fetoprotein in the Antenatal Diagnosis of Spina Bifida', *The Lancet*, 302:7828 (1973), pp. 522-525.

diagnostic capabilities, to one which contributed a significant amount to clinical practice and research in the medical genetics field.

Having such a department ensured that the West of Scotland was not left behind in providing a medical genetics service to patients, and contributing important research data. Many of the other centres which were established that provided such services were based in England, particularly in the London region.[15] For example, one of the most renowned figures in genetics, Lionel Penrose, headed up the Galton Laboratory in London. The Galton has been described by Harper as playing a 'pivotal role in the development of human genetics worldwide', with 'almost all students and visiting workers' at the Galton finding that it had 'a profound and lasting influence on their later careers and on their thinking'.[16] Those based in London benefitted from the close proximity to one another, and several key figures were located here. These included Paul Polani (who had studied genetics with Penrose) who in 1960 opened up the first full medical genetics institute in the UK, the Paediatric Research Unit at Guy's Hospital, which was 'clearly established from the outset as a specific medical genetics institute, with a focus on research into developmental genetic disorders'.[17] Polani was also able to develop the service aspects of a medical genetics department, and received NHS funding to 'support diagnostic cytogenetics and biochemical genetics', creating an 'integrated institute, unique in the world at that time'.[18] A third centre was located at London's Great Ormond Street Hospital for Sick Children, where John Fraser Roberts established a genetic counselling clinic in 1946, and where Cedric Carter would go on to become the director, from 1964 until 1982, of the MRC-funded Clinical Genetics Research Unit.[19]

[15] Details of Lionel Penrose, John Fraser Roberts, Cedric Carter, and Paul Polani can all be found in the Witness Seminar on Clinical Genetics. Further information will be given on this Witness Seminar in the literature review. See L A Reynolds and E M Tansey, (eds) (2010) *Clinical Genetics in Britain: Origins and Development*. Wellcome Witnesses to Twentieth Century Medicine, vol. 39. (London: Wellcome Trust Centre for the History of Medicine at UCL).
[16] Harper, *A Short History of Medical Genetics*, p. 235.
[17] Ibid., p. 294.
[18] Ibid., p. 295.
[19] Ibid., p. 296.

The result of the proximity of these sites to each other has led Harper to comment that 'medical genetics was well developed in the three centers described by the mid-1960s', but that 'it was largely absent from the rest of the country'.[20] Whilst other geneticists were based throughout the United Kingdom, such as Alan Stevenson in Oxford, Cyril Clarke in Liverpool, Rodney Harris in Manchester, Alan Emery in Edinburgh, and John Edwards in Birmingham,[21] there was no comparable figure in the West of Scotland until Ferguson-Smith became involved in expanding medical genetics in that region. As can be seen from the above descriptions, in London there was a genetic counselling clinic established as early as the 1940s, with a genetics institute following in 1960. Thus, the lack of medical genetics services out with the London area cannot purely be linked to time-sensitive developments in the field, such as the expansion of cytogenetics. The role that Ferguson-Smith played in developing and implementing medical genetics services becomes more crucial in light of the above information, as it can be seen that other patients throughout the United Kingdom were able to access genetics services when these were not yet available in Glasgow. Key individuals built up services around them in London, as did Ferguson-Smith for the West of Scotland, the specific details of which will be explored in chapters two to four of this thesis.

In addition to examining the technical developments which were occurring within the department led by Ferguson-Smith, it will be argued that key social changes were essential for the establishment of prenatal diagnosis as a routine part of antenatal care. This thesis will emphasise the importance of the implementation of the Abortion Act 1967, which made termination of pregnancy legal for a number of reasons, including following a diagnosis of fetal anomaly. Without the development of permissive legislation, prenatal testing would have been able to provide information only. Whilst that is the aim of some women accessing prenatal testing, in Scotland, between 2000 and 2011, 85.2% of women terminated pregnancies after a diagnosis of a trisomy

[20] Ibid., p. 297.

[21] Details of Alan Stevenson, Cyril Clarke, Rodney Harris, and Alan Emery can all be found in the Clinical Genetics Witness Seminar. See Reynolds and Tansey, *Clinical Genetics in Britain: Origins and Development*.
Further details on John Edwards can be found in D A Christie and E M Tansey, (eds) (2003) *Genetic Testing*. Wellcome Witnesses to Twentieth Century Medicine, vol. 17. (London: Wellcome Trust Centre for the History of Medicine at UCL), p. 19.

condition.[22] This highlights that the majority of women are not using prenatal services solely as an information gathering exercise, and are instead making use of abortion legislation to end their pregnancies should they be given a diagnosis of fetal anomaly.

That a specific fetal anomaly clause was included in the Abortion Act 1967 is therefore of importance, and will be considered within this thesis. This will be examined in several ways, including by looking at the ways in which fetal anomaly was discussed within the debates surrounding the legislation. It will be argued that abortion for fetal anomaly was often viewed as acceptable by the wider public, even when terminations for other reasons were not. In addition, campaigns against more liberal abortion legislation did not often focus on the fetal anomaly clause. Whilst there were attempts to alter or remove this clause, they generally seemed to be put forward by small groups of individuals who were opposed to more liberal abortion legislation in a broader sense.

The thesis will also examine the ways in which medical professionals viewed termination for fetal anomaly, as it was they who would be responsible for carrying out abortion procedures. In addition to considering the viewpoints of some of the key professional medical bodies and figures, the specific views of Ian Donald towards abortion for fetal anomaly are investigated. Donald was often seen as a key figure in the anti-abortion movement, and played a central role in restricting access to abortion services in the West of Scotland. By way of contrast to liberal medical figures such as Dugald Baird, who was based in Aberdeen, and who was centrally involved in ensuring women could safely access abortion services in that region, Donald was proud of the low numbers of abortions which took place in the Glasgow region. One area, however, where Donald was willing to carry out terminations in very specific circumstances, was in cases of fetal anomaly. This thesis adds a contribution to the literature by examining in more detail this facet of Donald's personality, and also looks at the role that Ferguson-Smith may have had in influencing the development of these views.

[22] Myrthe Jacobs, Sally-Ann Cooper, Ruth McGowan, Scott M. Nelson and Jill P. Pell, 'Pregnancy Outcome Following Prenatal Diagnosis of Chromosomal Anomaly: A Record Linkage Study of 26,261 Pregnancies', *PLOS ONE*, 11:12 (2016), p. 7.

What becomes apparent when considering the roles that individuals such as Baird and Donald had on the availability of abortion services within their regions, is that inequality was prevalent. Such variances in access to abortions dependent upon postcode were apparent not only in Scotland, but more broadly throughout the United Kingdom, and were noted as an area of concern amongst the medical profession. This thesis will look at the responses of various medical professional bodies to the Report published by the Lane Committee, which was set up to examine the working of the Abortion Act. Examining responses by Scottish medical professionals and religious groups based within the region, provides an insight into the ongoing debates which surrounded abortion legislation after it had been implemented.

As the majority of positive prenatal diagnoses result in a termination of pregnancy, it is possible to see that a conflict could exist between those who provide prenatal testing and those who oppose abortion. Some of the key groups in this category are a variety of religious organisations. Within this thesis, this potential conflict between religious organisations and prenatal testing will be examined, focusing on the viewpoints of two of the main religious groups that were prominent in the West of Scotland during the time period of the study, the Roman Catholic Church and the Church of Scotland. Their specific views on termination after a diagnosis of fetal anomaly will be considered, in the context of a wider examination of their broader views towards abortion. The complex interactions of faith and prenatal testing will also be considered by looking at the ways in which women correlate religious views with termination decisions. Considering the views of religious organisations and the impact religion can have on decision making helps to place the medical developments occurring in prenatal diagnosis in a wider social context. By specifically examining these views for the West of Scotland, a more nuanced analysis can be achieved.

The examination of a smaller regional area can provide a detailed insight into the development of new technologies and the reaction to their implementation, but as will be shown throughout the literature review in a later section of this introduction, the majority of studies which have considered the history of prenatal testing have

concentrated more on a national context, with perhaps a few local case studies interspersed into the narrative. With the exception of Nicolson and Fleming's book *Imaging and Imagining the Fetus*, which charts the development of obstetric ultrasound, with a focus on Glasgow where the technology was pioneered, very few studies have considered the wider Scottish perspective on the development of prenatal testing. This creates a gap in the literature, which is particularly important to examine, given the central role that a number of scientists and clinicians who were based in Scotland played in developing and implementing prenatal testing. Thus, a great deal of the significance of this research is aligned with its configuration; the particular groups and their views have never before been analysed with regards to prenatal testing in this geographical area. By examining this variety of scientific developments and the responses to them, it is envisaged that a detailed picture will emerge of the medical and social factors involved in the development of the field of prenatal testing.

II. Literature Review – Published Texts on Prenatal Diagnosis

There were a number of scientific and technical developments which led to the formation of prenatal diagnosis as a clinical service, which will be examined in detail throughout the chapters of this thesis. Although it is clear that there is a lack of published data on these developments in the West of Scotland, there are a number of publications which discuss the evolution of the field of prenatal testing more widely. It is important to give consideration to published works which discuss these technological developments, and those which discuss the wider social issues associated with them. One of the first texts to examine the development of prenatal technologies was *The Captured Womb: A History of the Medical Care of Pregnant Women* by Ann Oakley, published in 1984. The book set out to 'write the history of the care pregnant women receive in preparation for childbirth and motherhood',[23] which included a chapter titled 'Getting to Know the Fetus', incorporating a detailed study of the development of ultrasound technology. Oakley argued that the new technology was 'revolutionary', as it enabled obstetricians to 'make direct contact with the fetus, and to acquire a quite detailed knowledge of her or his physiology and personality before the moment of the

[23] Ann Oakley, *The Captured Womb: A History of the Medical Care of Pregnant Women*, (Oxford: Basil Blackwell Publisher Ltd, 1984), p. 1.

official transition to personhood – the time of birth'.[24] It is unclear why Oakley commented that ultrasound could gain an insight into the personality of the fetus, as this is not possible from the testing; perhaps it stemmed from the visual accessibility of the fetus, which would have showed the fetus moving around, thus potentially giving an impression of how active the fetus was. Oakley's account of the development of ultrasound is particularly interesting, as she interviewed Ian Donald, the clinical pioneer for ultrasound. The contributions of Ian Donald will be discussed in detail throughout this thesis, both from a technological and a social point of view. Oakley's descriptions of the development of ultrasound are interspersed with direct quotations from Donald, and also of photographs showing Donald working early ultrasound machines, which provide a more personal insight into the development of this technology. As will be described later in the introduction, a similar approach is taken within this thesis through the examination of a local case study, which incorporates these personal insights.

Such an approach is also taken by Malcolm Nicolson and John Fleming in their book *Imaging and Imagining the Fetus*. Whilst Oakley dedicated only part of a chapter to the development of ultrasound, Nicolson and Fleming chart the story in detail throughout the entirety of their publication. The use of the Ian Donald archive throughout the book adds a much greater level of detail than prior publications on the history of ultrasound; the use of archival documents to create such a detailed analysis will also be used throughout this thesis. Although a great deal of the book focuses on describing the development of ultrasound in Glasgow by Donald, this work is placed into context by considering others who played important roles in the story of ultrasound. Developments which were occurring in Glasgow are also placed in a wider geographical context, and both technological and social factors are considered throughout the text. Nicolson and Fleming have described their historiographical approach to the book as posthumanist, which 'with its symmetrical handling of the natural, the social, and the technological, allows us to provide a more precise and convincing account of the origins of human actions, by placing them in their fullest context'.[25] Indeed, consideration is given to the impact that Donald's religious views had on his willingness to terminate pregnancies; this subject is examined in detail throughout chapter five of this thesis. Building on

[24] Ibid., p. 155.
[25] Nicolson and Fleming, *Imaging and Imagining*, p. 11.

Nicolson and Fleming's work, this thesis considers Donald's views in an in-depth manner, and adds original material to the subject by specifically examining Donald's views with regards to termination for fetal anomaly. Whilst Nicolson and Fleming consider Donald's views on this subject, this thesis provides original archival material which gives a more detailed insight into this area, and specifically considers how Donald's friendship with Ferguson-Smith could have further impacted his views. Thus, it could be said that a similar 'posthumanist' approach as taken by Nicolson and Fleming has been shown throughout this thesis, whereby an examination of both the technical and social developments which have impacted prenatal diagnosis are considered in detail.

Whilst ultrasound is a central component of antenatal care today, invasive testing in the form of amniocentesis is also commonly used to diagnose chromosome conditions and neural tube defects. As amniocentesis gives a definitive diagnosis and is an invasive procedure, it is perhaps not surprising that it has been the focus of a number of studies into its uses. Two of the most detailed are *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America* by Rayna Rapp, and *The Tentative Pregnancy: Amniocentesis and the Sexual Politics of Motherhood* by Barbara Katz Rothman. Both of these publications explore the impact that amniocentesis has had on the women who underwent the procedure, and both authors have carried out interviews to gain this insight, resulting in an authoritative analysis of the development and implementation effects of amniocentesis. The inspiration for Rapp's book *Testing Women, Testing the Fetus* came from her own experience of prenatal testing in 1983, where she had an amniocentesis test at the age of 36, and her fetus was diagnosed with Down's syndrome. After terminating the pregnancy, Rapp sought out information in medical libraries to try and help her recover from the experience, only to discover that the voices of medical experts 'dominated the discourse on prenatal diagnosis', with most of these experts being male, 'highly educated, and overwhelmingly white'.[26] She became convinced that 'the complex topic of prenatal testing and abortion begged for a woman-centered

[26] Rayna Rapp, *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America*, (New York: Routledge, 2000), pp. 3-4.

analysis', and thus began interviewing other women about their experiences in late 1983.[27]

Rapp's research methodology was multi-faceted, involving interviews with women who underwent and who turned down amniocentesis, observation of medical genetics departments in a variety of healthcare settings, and interviews with families who had children with Down's syndrome, amongst other approaches.[28] Rapp's book covers a whole host of factors involved with prenatal testing, including how the technical processes are carried out within a laboratory (she spent time observing the technicians at work), the reactions of women to being offered testing, the reasoning behind those women who turn it down, and the decision to terminate or continue a pregnancy after a diagnosis of fetal anomaly. Running throughout all of these chapters are the women's voices themselves, which frequently highlight the complex nature of prenatal diagnosis. Rapp describes these women as 'moral pioneers', none of whom entered the 'decision to undergo amniocentesis trivially' or 'aborted for superficial reasons'.[29] She concluded that 'Women are both constrained and empowered through technologies like amniocentesis … At once held accountable at the individual level for a cascade of broadly social factors which shape the health outcome of each pregnancy, and individually empowered to decide whether and when there are limits on voluntary parenthood.'[30]

Whilst Rapp argues that the complexities of prenatal testing can be both limiting and empowering for women, throughout *The Tentative Pregnancy*, Rothman seems to be more critical of the testing. Rothman interviewed over 120 women to gather their thoughts on how prenatal testing impacted their pregnancy experiences, and also spent time observing and interviewing genetic counsellors, who guide women through the process of prenatal testing. Describing amniocentesis as 'the fulcrum on which the reproductive revolution turns', Rothman argues consistently that the procedure is changing how many women experience pregnancy, and is causing society 'to confront

[27] Ibid., p. 4.
[28] Ibid., pp. 6-8.
[29] Ibid., pp. 306-307.
[30] Ibid., pp. 317-318.

the very meaning of motherhood'.[31] For Rothman, the use of amniocentesis is leading to what she terms 'tentative pregnancies', whereby a 'woman's commitment to her pregnancy under the conditions imposed by amniocentesis can only be tentative. She cannot ignore it, but neither can she wholeheartedly embrace it.'[32]

Rothman believes that women are waiting on the results of amniocentesis tests before being able to fully commit to their pregnancy. For this theory she presents several arguments, including that women who are undergoing amniocentesis choose to begin wearing maternity clothes later in their pregnancy. This was confirmed by one of her interviewees, who stated that '"There was a definite feeling of resisting buying maternity clothes until the results came back."'[33] Rothman also hypothesised that women undergoing amniocentesis do not feel movement of the fetus until later in the pregnancy than those women who opt not to have the testing done, which she argues is a 'response to a "tentative pregnancy"'.[34] For women who have undergone prenatal testing, the feeling of fetal movement does not provide reassurance that all is well with their pregnancy, in the way that it did for women who have not had the testing. Instead, Rothman argues, the reassurance comes from the amniocentesis test results, resulting in two very different experiences, as for 'women who had amniocentesis, reassurance came from medical science and authoritative reports. For the women who refused amniocentesis, reassurance came from the experience of their own bodies and from their developing relationship with their babies.'[35] This parallels both Löwy's ideas of the changing experience of pregnancy as a result of prenatal testing, whereby the fetus is seen as a separate 'technoscientific' entity from the pregnant woman, and Nicolson and Fleming's comments that the advent of prenatal testing has changed the role that pregnant women play in providing information about the fetus. Throughout the book, Rothman argues against the proclaimed benefits of prenatal testing, instead contesting that the technology is 'being used to give the illusion of choice'.[36] This choice, she argues, only really benefits those 'who want what the society wants them to want',

[31] Rothman, *The Tentative Pregnancy*, p. 3.
[32] Ibid., p. 101.
[33] Ibid., p. 99.
[34] Ibid., p. 105.
[35] Ibid., p. 108.
[36] Ibid., p. 14.

which, she puts forward, is prenatal testing followed by selective termination of pregnancy.[37]

However, not all of those who have examined the impact of prenatal testing have come to such conclusions. In *Heredity and Hope: The Case for Genetic Screening*, Ruth Schwartz Cowan argues that 'Genetic screening increases reproductive choice, and it also provides hope … of having, not a perfect child, but a child who, at least at the start of life, is free of devastating disease or overwhelming disability.'[38] In the introduction, Cowan details how she struggled with many of the ethical and moral dilemmas surrounding prenatal testing. Questioning whether prenatal diagnosis discriminated against the disabled, and whether medical geneticists were 'inherently evil' and their patients 'inherently deluded' as some of her feminist friends believed, she turned to history to 'resolve such dilemmas, because the discipline of history teaches us to examine the particular, not the universal; we try, in other words, to uncover the very particular interests of very different people who are interacting in very particular situations'. She further described how 'Once that is understood, we can begin thinking not only about the moral content of those interests but also about how they can be balanced so that no set of interests is allowed to dominate over the others.'[39] This approach has also been taken throughout this thesis, whereby the interests of specific people working in defined situations can provide an insight into the development of prenatal testing, which can then be expanded to comment on the wider moral questions which surround the field.

Throughout the text Cowan examines prenatal diagnosis as a socio-technical system, an approach which she argues 'allows me to explain that, for example, changes in abortion law were as important in the diffusion of amniocentesis as changes in laboratory techniques and discoveries in classical genetics'.[40] The examination of these developments as part of a socio-technical system is reflective of the approach which is

[37] Ibid.
[38] Ruth Schwartz Cowan, *Heredity and Hope: The Case for Genetic Screening*, (Massachusetts: Harvard University Press, 2008), p. 245.
[39] Ibid., pp. 8-9.
[40] Ibid., p. 10.

taken throughout this thesis, whereby social and technical influences are both considered in detail, with their importance highlighted in the relevant descriptive chapters. In *Heredity and Hope*, Cowan covers a number of key themes which are also reflected in this thesis, including the development of genetic techniques which made prenatal testing possible, the uses of amniocentesis and ultrasound, and the importance of the Thalidomide crisis and the rubella epidemic for impacting abortion legislation.[41] However, one area of difference is that Cowan is arguing in favour of prenatal testing, whilst this thesis retains a neutral view on whether the testing is inherently 'right' or 'wrong'. For Cowan, those who choose to undergo prenatal testing should not be made to feel 'unnecessarily guilty about their fundamentally wise and moral behaviour', highlighting her approval of the prenatal diagnosis technologies which are available.[42]

Other authors, such as Andrew Hogan, have also charted the detailed development and implementation of invasive testing, with Hogan writing an informative piece on the history of chorionic villus sampling. Similar to the approach taken by Nicolson and Fleming in *Imaging and Imagining the Fetus*, Hogan has written a detailed description of the development of the technology, including information on the different prototypes which existed, and how researchers worked to improve these. Hogan also undertook a detailed analysis of the social circumstances which surrounded the development and implementation of prenatal testing using chorionic villus sampling, some of which are specific to the United States of America, such as the impact that the Food and Drug Association had on limiting access to the devices used to carry out the testing.[43] However, Hogan also covers wider social issues including those associated with uptake of new prenatal testing methods, highlighting the problems created by devising/designing these new tests without the input of the women who will use them,

[41] Thalidomide was a drug given to pregnant women to help with morning sickness. However, it resulted in a number of babies being born with limbs which were shortened, or incompletely formed. Rubella can affect the fetus in several ways, including causing problems with the developing brain. Both Thalidomide and rubella will be discussed in detail in chapter five of this thesis.
[42] Cowan, *Heredity and Hope*, p. 245.
[43] Andrew J. Hogan, 'Set Adrift in the Prenatal Diagnostic Marketplace: Analyzing the Role of Users and Mediators in the History of a Medical Technology', *Technology and Culture*, 54:1 (2013), pp. 71-74.

and also the impact that the 'fetal limb defect' controversy had on uptake, which will also be discussed in this thesis.[44]

The above information highlights the importance of both technical and social factors for the development of prenatal testing which involved scientific and technological changes, mediated by a variety of scientific researchers and clinicians, all of which were situated amongst the wider social and cultural context of the 1960s onwards. One of the key publications which ties all of these issues together for prenatal diagnosis is Ilana Löwy's 2017 publication, *Imperfect Pregnancies: A History of Birth Defects and Prenatal Diagnosis*. This book has many parallels to this thesis, and discusses in detail the technical developments of invasive and non-invasive prenatal testing methods, and the stories of some of the individuals who were involved.[45] Whilst the thesis does have similarities to Löwy's work, there are several areas where the texts differ from one another, and a discussion of the distinctions of Löwy's work and this thesis will follow.

Chapter one of Löwy's publication follows the origins of the concept of 'birth defects', before the development of prenatal diagnosis. Much of the chapter considers a time period prior to the primary focus of this thesis, charting the histories of individuals who worked in areas surrounding birth defects, which provides useful background of the early work on fetal anomaly. For some of these individuals, but not all, the aim of preventing birth defects had a eugenic focus. [46] Throughout *Imperfect Pregnancies*, Löwy discusses what some see as the linked history between prenatal testing and the eugenics movement. This is one of the key differences between Löwy's book and this thesis, which does not examine these eugenic links. Whilst there is some brief discussion in chapters five and six about the views of some individuals who associate eugenics and prenatal testing, this is not a focus of this thesis. One of the reasons for

[44] Ibid., pp. 76-78 discusses the fetal limb defect controversy, and pp. 81-83 considers some of the issues associated with lower than expected uptake rates.

[45] Löwy's work was not available to view when the research for this thesis was being planned and undertaken. The book was published when much of the analysis and writing for this thesis was already concluded.

[46] For example, Löwy spends much time in this chapter discussing the history of Lionel Penrose, who was a strong opponent of eugenics, but also presents information about Alfred Frank Tredgold, who she describes as 'an enthusiastic advocate of eugenic measures' (Löwy, *Imperfect Pregnancies*, p. 26).

this is that Ferguson-Smith himself has specifically distanced himself from any eugenic agenda. Throughout the years he has maintained that it was always his aim, and that of his colleagues, to provide women with the opportunity to have healthy children. In many cases, Ferguson-Smith has argued, the provision of prenatal testing led to women having children who had previously refused to do so, due to their concerns of the child being born with certain genetic conditions. These points by Ferguson-Smith will be highlighted later in this thesis, but it is important to mention here that Löwy's discussion of the eugenic implications of prenatal testing is not replicated in this thesis.

Chapter two of Löwy's book is titled 'Karyotypes', and focuses on the study of human chromosomes and prenatal diagnosis. As would perhaps be expected, there is crossover between the material in that chapter and the work contained within this thesis, particularly chapter one of this thesis. However, although the early history of the development of the field of cytogenetics is covered in both, there are also marked differences. Löwy looks at the study of dermatoglyphs, metabolic studies (including the work on the discovery of phenylketonuria) and also the development of genetic counselling, three areas which this thesis does not cover at all.

Chapter three of Löwy's book examines the link between rubella and Thalidomide changing attitudes towards abortion, which is a key theme discussed particularly in chapter five of this thesis. However, Löwy also focuses on areas such as the development of the field of teratology, dysmorphology and fetal pathology, in addition to a discussion of the use of birth defect registries. Whilst these areas are of interest, they are not considered within the scope of this thesis, which has a more specific focus. Interestingly, in this chapter Löwy does discuss the history and use of ultrasound, but only briefly over the course of a few pages. She does, however, highlight that there is a lack of literature on the diagnostic uses of this technology by social scientists, who tend to focus on 'the transformation of the intimate experience of pregnancy by the production of fetal images, and on the social, political, economic, and cultural roles of

such images'.[47] It is hoped that this thesis can help to address this issue, as the diagnostic uses of ultrasound are discussed throughout this work.

By way of contrast, chapter four of Löwy's book shares a focus with this thesis, as it looks at the movement from diagnostic prenatal testing towards wide-scale prenatal screening programmes. Löwy considers particularly the development of prenatal screening programmes for Down's syndrome, and the discussions which were taking place at the time around the cost-effectiveness of implementing such policies. Malcolm Ferguson-Smith is mentioned by name twice in this chapter – once to highlight his role as the head of the Working Party of the Clinical Genetic Society when they published their report recommending the introduction of alpha-fetoprotein screening for the detection of neural tube defects,[48] and again when she discusses Ferguson-Smith's views that an abnormal alpha-fetoprotein result should be relied upon more closely than an ultrasound scan for the detection of neural tube defects during pregnancy.[49] Whilst no more details are given of the work which was taking place in the department led by Ferguson-Smith, that his views are highlighted in Löwy's book lends support to the view that he was seen as a central figure within the development of the prenatal testing field.

Chapters five and six of *Imperfect Pregnancies* contain far fewer direct links with this thesis, as they focus on the history of sex chromosome anomalies and the new developments in fetal DNA, including non-invasive prenatal testing (NIPT), respectively. Whilst this thesis briefly considers conditions such as Turner's and Klinefelter's syndromes, Löwy charts a far more detailed history of the discovery of these conditions. Whilst NIPT is highlighted in chapter three of this thesis, a discussion of its developing impact was unable to be covered within the scope of this thesis.

[47] Löwy, *Imperfect Pregnancies*, p. 89.
[48] Ibid., p. 107.
[49] Ibid., p. 109.

Thus, it can be seen from the above discussion, that whilst there is crossover between the material that Löwy covers within *Imperfect Pregnancies* and the material covered within this thesis, there are also distinct differences. Löwy's text is far-ranging and covers a wide range of topics, whilst this thesis has a more specific temporal and geographic focus. However, both texts are written from a similar standpoint, whereby the interaction between scientific and social factors are both seen as being of central importance to gain an insight into the development of the prenatal testing field.

Löwy discusses the interaction of technical and social factors, which have led to the development of what she terms the '"prenatal diagnosis dispositif"'.[50] The term "dispositif", Löwy explains, was 'coined by the philosopher Michel Foucault to describe an entity that combines a certain "regime of truth" with the practices and institutional forms that make it a bona fide site of knowledge/power'.[51] For Löwy, the "prenatal diagnosis dispositif" emphasises that prenatal diagnosis was 'developed thanks to a partly fortuitous combination of several medical technologies: amniocentesis, the culture of fetal cells, the study of human chromosomes, and obstetrical ultrasound', which along with the 'professional practices, and institutional and legal arrangements' formed the '"prenatal diagnosis dispositif"'.[52] That the development of medical technologies and the social elements linked to prenatal testing are both of central importance is a key concept running throughout this thesis.

The quote below by Rayna Rapp about her approach in her book *Testing Women, Testing the Fetus* further highlights these complexities, where she argues that both social and technological aspects need to be given consideration when examining the development of prenatal diagnosis:

> At the center of this account lies my conviction that the technologies of prenatal diagnosis, like all technologies, are produced at multiple intersections where the work of particular scientists, research clinicians, and health service providers engages social relations far beyond the

[50] Ibid., p. 2.
[51] Ibid.
[52] Ibid.

> purview of their laboratories, clinics and consulting rooms. What come to count as the technologies of prenatal diagnosis, now and in the past, are shaped by large-scale transformations of biomedical knowledge, our legal structure, widely shared and sometimes contested cultural values, and the social identities within which service providers and patients encounter one another. In other words, I will argue that an understanding of the history and ongoing evolution of this biomedical technology requires us to see how its developers, because of and despite their individual expertise and achievements, became enrolled in larger social projects to which their scientific accomplishments were conscripted.[53]

To provide an example of the intersection of scientific and social factors in the development of amniocentesis, Rapp considers the differences that having a national health service can have on the availability of, and access to, amniocentesis. Emphasising that 'larger, more complex social transformations are also at work' in the development of prenatal diagnostic technology than just the medical progress which is simultaneously occurring, Rapp compares the 'experience' of prenatal diagnosis in Great Britain, with that of the United States.[54] She discusses her view that the impact of a commitment to providing some form of national health service has led to a higher minimum age for amniocentesis being implemented in Britain, as opposed to the United States, where a 'free market economy in health care' has led to a much lower age limit.[55] Without an understanding of the different social contexts in which amniocentesis was developing in these countries, the slightly different trajectories that the testing followed may not be known. However, by considering the social aspects alongside the scientific and clinical developments which were occurring, a fuller and more complex picture emerges, which implicitly links funding to the resources and choices available to the women undergoing the testing.

This thesis is written from a similar standpoint to Rapp's work, whereby the scientific, technical, social and cultural changes which were occurring throughout the decades in which prenatal diagnosis was being developed and implemented, are all viewed as being of equal importance. This approach is particularly important for understanding the history of prenatal diagnosis, where a mere description of the technologies and scientific

[53] Rapp, *Testing Women, Testing the Fetus*, p. 24.
[54] Ibid., p. 32.
[55] Ibid., pp. 32-33.

techniques not placed alongside a relevant social context, could result in what Pickstone has described as 'mere chronicles of progress, or scientific biographies which do little to illuminate either the science or the society in which it as produced, let alone their subtle interactions'.[56] In a similar manner to Rapp, this thesis therefore aims to examine the technical and scientific aspects of prenatal diagnosis, including the development of amniocentesis, chorionic villus sampling and ultrasound, and will later place these developments alongside the social circumstances in which they were being devised. The specific impact of the Abortion Act 1967 will be considered, alongside religious responses to the more permissive abortion legislation, and prenatal testing more specifically. These will provide an insight into the cultural context amongst which the developments were occurring.

III. Literature on Abortion

It can be seen that work has been undertaken by scholars to chart the development of the prenatal testing field. However, as described above, inextricably linked to prenatal testing is abortion, with many women choosing to terminate a pregnancy upon receiving a diagnosis of an anomaly in their fetus. It is therefore important to consider the literature on abortion, as this will be the subject of chapters five and six.

One of the key texts on the subject is *Abortion Law Reformed*, published in 1971 by Keith Hindell and Madeleine Simms.[57] The book considers a wide range of issues regarding abortion. There is also a foreword by David Steel, who introduced the private member's Bill which became the Abortion Act 1967. The authors of the text were in favour of abortion law reform, with Madeline Simms one of the most prominent members of the Abortion Law Reform Association (ALRA). This should be kept in mind when analysing the text.

[56] John V. Pickstone, 'Series Editor's Introduction', in *Medical Innovations in Historical Perspective*, ed. by John V. Pickstone, (London: Macmillan Press Ltd., 1992), p. ix.
[57] Keith Hindell and Madeleine Simms, *Abortion Law Reformed*, (London: Peter Owen Ltd., 1971)

Some of the key material within *Abortion Law Reformed* examines the links between religious organisations and opposition to legislative change. The chapter titled 'Religion and Reform' discusses the many ways in which religious groups attempted to prevent more permissive abortion legislation being passed prior to Steel's Bill, and also provides an in-depth look at the formation and role of the Society for the Protection of Unborn Children (SPUC), which campaigned strongly against abortion. The role that groups such as SPUC played will be considered in chapter six, and the detailed overview provided by Hindell and Simms is of use in understanding the workings of this group, and its contributions to the abortion debate. Hindell and Simms also examine the role of the Roman Catholic Church more broadly, which is again useful for the discussion which takes place on this organisation in chapter six.

Fetal anomaly is also an important theme within *Abortion Law Reformed*, and is of particular interest for this thesis. Hindell and Simms place it as a central reason by which the ALRA was 'reinvigorated' to campaign strongly for abortion law reform, after a time of being less active.[58] They specifically link the Thalidomide scandal to the increase in the membership of the ALRA in the early 1960s. The importance of factors such as rubella and Thalidomide in impacting the perception of abortion for reasons of fetal anomaly will be considered within chapter five. This discussion will form part of a larger narrative of fetal anomaly terminations being viewed as different to terminations for other reasons by many people, and Hindell and Simms provide useful background information on this subject.

Fetal anomaly is also considered by others, notably Kate Gleeson. In her article 'Persuading Parliament: Abortion Law Reform in the UK', Gleeson examines the role that fetal anomaly played in influencing legislative change, and the impact of medical practitioners on abortion law reform.[59] Throughout Gleeson's article, fetal anomaly is placed as a central feature, and she states that 'crucially, it was the argument for eugenic terminations that secured supposedly 'liberal' law reform in 1967'.[60] Gleeson discusses

[58] Ibid., p. 108.
[59] Kate Gleeson, 'Persuading Parliament: Abortion Law Reform in the UK', *Australasian Parliamentary Review*, 22:2 (2007), pp. 23-42.
[60] Ibid., p. 24.

how concerns about the low population rate meant that abortion was not a legal focus in the early part of the twentieth century. However, the specific cases of rubella and Thalidomide would impact public perception of termination of pregnancy in the years that followed. In a similar manner to Hindell and Simms, Gleeson identifies Thalidomide as important in the campaign to alter abortion legislation, stating that abortion law reform 'might have stagnated entirely' had it not been for Thalidomide.[61] Previously, it was cases resulting from rubella infection that garnered sympathy amongst members of the public for allowing termination in cases of fetal anomaly. However, this increased sympathy was not enough to result in legislative change. Gleeson argues that the Thalidomide scandal, combined with a rubella epidemic in 1964-1965, reinvigorated the ALRA's abortion campaign.

The way in which fetal anomaly was viewed within the abortion debate will be examined throughout chapter five of this thesis, with a discussion of attempts to alter or remove the fetal anomaly clause from legislation. Some of these issues have been examined by Gleeson, who argues that those who opposed the fetal anomaly clause within Steel's Bill tended to be those who opposed abortion more generally, including the Catholic M.P. Norman St. John-Stevas, who was a key figure in the fight against abortion reform, and whose role will be discussed in chapters five and six.[62] As highlighted above, it will be argued that termination as a result of fetal anomaly was viewed more favourably by many of those who discussed abortion. Gleeson highlights that the ALRA were publishing data which showed high levels of public support for terminations for fetal anomaly. However, as Gleeson points out, correspondence in *The Times* newspaper paints a slightly different story, with a difference of opinion evident between those who agreed with terminations in a case of fetal anomaly and those who disagreed. Similarly, magazines and newspapers will be examined within chapter six to chart opinions on the subject of abortion.

One of the major groups involved in the abortion debate were the medical profession, and the role they played in influencing Steel is considered by several commentators.

[61] Ibid., p. 30.
[62] Ibid., p. 35.

One author who considers the medical profession in-depth is MacIntyre, whose article 'The Medical Profession and the 1967 Abortion Act in Britain' is a detailed examination of the part they played within the abortion debate.[63] MacIntyre highlights that clinicians had a variety of viewpoints, with some showing 'extreme repugnance' of abortion, whilst others viewed abortion as the ending of one life for the sake of another.[64] Whereas some doctors argued that the sanctity of life was of the utmost importance, others viewed the overall health of the patient i.e. the woman, as being the most important factor. MacIntyre highlights that some doctors viewed health as a holistic concept, which involved taking social considerations into account. Dugald Baird's views are discussed by MacIntyre in this context; a further examination of Baird and his opinions will take place in chapter five.

MacIntyre also analyses the viewpoints of the professional medical groups who publicly discussed abortion. One of MacIntyre's key arguments is that each group were professing views which would maintain their own professional standing. For the Royal Medico-Psychological Association (RMPA), this was arguing for a wide view of health, which would take into account more than just physical illness, whilst for the Royal College of Obstetricians and Gynaecologists (RCOG), this was trying to have abortion decisions and procedures kept under the control of gynaecologists. On both sides of the abortion debate, doctors were concerned with maintaining their professional freedom, and there was discussion about whether this would best be achieved with or without Steel's Bill. Regardless of the differing viewpoints, the vast majority of the medical profession wanted to retain their control over who could have an abortion. As will be discussed in this thesis, the Abortion Act 1967 kept abortion decisions firmly in the hands of the medical profession, which could go on to hugely impact the women who were seeking terminations of pregnancy. As will be shown in chapter five, the area in which a woman lived could influence the likelihood of her securing a termination of pregnancy if requested, which as MacIntyre states 'can have enormous implications both for individual women and for society as a whole'.[65] These issues will be

[63] S.J. MacIntyre, 'The Medical Profession and the 1967 Abortion Act in Britain', *Social Science and Medicine*, 7:2 (1973), pp. 121-134.
[64] Ibid., p. 123.
[65] Ibid., p. 132.

specifically considered within the Glasgow region for this thesis, examining the case of Ian Donald.

In his book *Abortion, Doctors and the Law. Some Aspects of the Legal Regulation of Abortion in England from 1803 to 1982*, John Keown examines the legislation which has been in place to cover abortion for more than a century, and considers the views of the medical profession to it.[66] In a similar manner to MacIntyre, Keown outlines the views of some of the professional bodies who attempted to influence the legislation, including the RCOG, the British Medical Association (BMA), and the RMPA. Interestingly, Keown highlights that discussion by these medical professionals often did not centre only on the medical aspects of abortion, but also 'on the desirability of reform, the appropriate scope of the Bill, and the wording of particular provisions'.[67] A similar argument will be made in chapter five of this thesis, where the attempts by medical professionals to impact the changing abortion legislation will be considered. It will be seen that the views which were being aired by professional medical groups and also by individuals such as Baird and Donald, focused far more on the issue of the acceptability of abortion, as opposed to concerns with the safety of the procedure itself.

Keown also examines how the Abortion Act 1967 has been interpreted by different medical professionals. Of interest to this thesis is the data indicating that high percentages of varied medical professional groups would support termination for reasons of fetal anomaly.[68] These figures provide evidence for the general widespread acceptability of termination for reasons of fetal anomaly, a concept which, as noted above, will be discussed within this thesis.

As can be seen from the above discussion, much of the literature which has been published on abortion has focused on Britain more broadly, without considering a specific regional view towards the changing legislation. However, two key scholars

[66] John Keown, *Abortion, Doctors and the Law. Some Aspects of the Legal Regulation of Abortion in England from 1803 to 1982*, (Cambridge: Cambridge University Press, 1988)
[67] Ibid., p. 109.
[68] Ibid., p. 120.

have examined the abortion context from a Scottish perspective, investigating the specific nuances which existed. The work by Gayle Davis and Roger Davidson is of central importance to this thesis, as it helps to provide the geographical context of Scotland with regards to abortion legislation. A main focus of their work is on examining the role of two medical professionals who worked in Scotland, Ian Donald and Dugald Baird. As already noted, Baird and Donald held starkly contrasting views on the acceptability of abortion, with Baird holding a liberal viewpoint, whilst Donald had a highly restricted attitude. Their opinions would permeate throughout the regions in which they worked. Davis and Davidson also examine other important aspects of the abortion debates, looking at the broader influence of medical professionals and their response to the new abortion legislation, and also the different abortion laws which were in place for Scotland and England prior to the Abortion Act 1967. Their work will be examined within the next section of this literature review.

As well as her work with Davidson, Gayle Davis has published several independent pieces, two of which will be considered here. In her chapter 'The Medical Community and Abortion Law Reform: Scotland in National Context, c1960–1980', Davis looks at the role of different medical groups, noting that most of the current literature has considered England and that 'Scotland has been largely omitted', a situation which she describes as 'a particular shortcoming'.[69] As this thesis considers developments occurring in the West of Scotland surrounding prenatal testing and abortion, it is hoped that it goes some way towards addressing this gap in the literature. Davis looks closely at the differences which existed in legislation between Scotland and England prior to 1967, emphasising that the legislation which governed England, such as the Offences Against the Person Act and the Infant Life Preservation Act, did not apply in Scotland, where abortion was a common law offence.[70] Davis highlights the differences in the definition of what constituted criminal abortion in Scotland and England, and discusses the different ways in which suspected cases were investigated. Davis describes how abortion law had the potential to be interpreted in a more liberal manner in Scotland

[69] Gayle Davis, 'The Medical Community and Abortion Law Reform: Scotland in National Context, c1960–1980', in *Lawyers' Medicine: The Legislature, the Courts and Medical Practice, 1760–2000*, ed. by Imogen Goold and Catherine Kelly (Oxford: Hart Publishing, 2009), p. 144.

[70] The specific differences between the legislation which applied to each country will be considered in chapter three of this thesis.

than in England. However, she argues that the possibilities of liberal interpretations of the legislation were not utilised by most doctors in Scotland prior to 1967. It is likely that illegal abortions were carried out in as high numbers in Scotland as in England.[71]

Davis also discusses the movement towards the passing of the Abortion Act 1967, the various ways in which Scottish medical professionals were involved, and the responses of medical groups in Scotland to the Act when it had come into force. Of interest for this thesis is Davis' discussion of the Lane Committee, which will be discussed in chapter five. Davis considers the differences in the concerns over the working of the Act between Scotland and England, which again highlights the importance of considering issues from a Scottish perspective.

Within her online publication 'The Great Divide: The Policy and Practice of Abortion in 1960s Scotland', Davis carries out a further examination of the influence that Baird and Donald had on abortion legislation and services within their respective regions.[72] A key theme is that certain individuals were able to massively impact the working of the Abortion Act 1967. Davis outlines Baird's early career, including a conflict he had with a Catholic priest in Glasgow over terminating the pregnancy of a woman who would otherwise have died, and charts the reasons behind his move to Aberdeen, which had a more liberal societal composition. The role of the Catholic Church in attempting to influence abortion legislation in the region of Glasgow will be considered in chapter six of this thesis, illustrating that these conservative attitudes remained in the decades after Baird moved to Aberdeen. Baird was unusual at the time, being willing to exploit the liberal interpretations of Scots common law unlike most of his colleagues.

Ian Donald held completely opposing views to Baird, and was willing to make his anti-abortion views known. Davis highlights Donald's unwillingness to carry out terminations of pregnancy except in very limited circumstances. This thesis considers

[71] Davis, 'The Medical Community and Abortion Law Reform: Scotland in National Context', p. 147.
[72] Gayle Davis, 'The Great Divide: The Policy and Practice of Abortion in 1960s Scotland', online publication, *Royal College of Physicians of Edinburgh*, (2005) <https://www.rcpe.ac.uk/heritage/great-divide-policy-and-practice-abortion-1960s-scotland> [accessed 9th August 2018]

the role of Donald but advances our understanding of his anti-abortion stance, exploring the situations in which Donald was willing to carry out terminations of pregnancy, and examines whether Ferguson-Smith influenced him in these situations. This adds a new dimension to the published literature on the subject, which does not currently consider these nuances in Donald's practice.

Davidson and Davis also compare the two clinicians within their book *The Sexual State*. They investigate Baird's move into the political sphere and specifically highlight ways in which he influenced Steel when it came to designing the abortion legislation.[73] Interactions between individuals could affect important changes, as will be explored within chapter five. Davidson and Davis also look at the response of various religious groups to attempts to alter abortion legislation. They highlight that Steel was influenced by both the Church of England and the Church of Scotland's writings about abortion, and also consider two of the main attempts to make abortion more restrictive once the legislation was in place, those by White and Corrie.

The above themes are further developed in Davis and Davidson's article '"A Fifth Freedom" or "Hideous Atheistic Expediency"? The Medical Community and Abortion Law Reform in Scotland, c.1960-1975'.[74] The authors look at some of the differences which existed in the response to the Abortion Act 1967, and highlight that the same concerns were not always prevalent in Scotland as in England. They take this analysis further, by examining responses to the Lane Committee Report in their article ''Big White Chief', 'Pontius Pilate', and the 'Plumber': The Impact of the 1967 Abortion Act on the Scottish Medical Community, c.1967-1980'.[75] This examination of the evidence submitted to the Lane Committee, and the responses to it, links to chapter five of this thesis, whereby by Davis and Davidson's work on this subject is considered in the light of further archival research.

[73] Roger Davidson and Gayle Davis, *The Sexual State*, (Edinburgh: Edinburgh University Press, 2012), pp. 104-105.
[74] Gayle Davis and Roger Davidson, '"A Fifth Freedom" or "Hideous Atheistic Expediency"? The Medical Community and Abortion Law Reform in Scotland, c.1960-1975', *Medical History*, 50:1 (2006), pp. 29-48.
[75] Gayle Davis and Roger Davidson, ''Big White Chief', 'Pontius Pilate', and the 'Plumber': The Impact of the 1967 Abortion Act on the Scottish Medical Community, c.1967-1980', *Social History of Medicine*, 18:2 (2005), pp. 283-306

Davis and Davidson have categorised medical professionals as fitting into one of three groups immediately following the passing of the Abortion Act – those who believed women should be deciding for themselves about abortion, those who believed there were social as well as medical indications for abortion (but within this group some held ideas about women who were more 'deserving' of abortion), and those who interpreted the Act strictly and would only terminate if the mother's life was in danger or the fetus 'grossly deformed'.[76] As will be shown throughout this thesis, within the Glasgow region there were doctors who fitted into each of these categories.

Davis and Davidson highlight some of the strategies employed by medical professionals to cope with the changes in legislation which fundamentally impacted their practice, including utilisation of the conscience clause, and trying to shift the focus to prevention of terminations through promotion of the importance of contraception education. A key part of their paper also involves examining the ways in which the medical profession utilised psychiatrists to try and deflect their own involvement with the changing abortion legislation. To discuss this, Davis and Davidson utilise an article which was written by the psychiatrist Ingram, titled 'Abortion Games: An Inquiry into the Working of the Act', which was published in 1971 when the new abortion legislation was in force.[77] Ingram was based at the Southern General Hospital in Glasgow, and it is possible that he recognised many of the key figures involved in providing abortion services in the city as being responsible for taking part in the 'games' he goes on to discuss. Ingram's article and the discussion within it were based on the book *Games People Play* by Berne, and within the article Ingram discusses a number of different games which he believes clinicians involved in delivering the Abortion Act 1967 were playing; the key groups he considers are general practitioners (GPs), gynaecologists, and psychiatrists. He also discusses the games that women seeking abortions were taking part in, as a result of the games being played by the medical practitioners in the above groups. Davis and Davidson take this original publication by Ingram and present their own extension of it, by specifically naming individuals and situations which they

[76] Ibid., pp. 292-293.
[77] I. M. Ingram, 'Abortion Games: An Inquiry into the Working of the Act', *The Lancet*, 298:7731 (1971), pp. 969-970.

could identify as having arisen in Scotland as a result of such 'games'. Their analysis will be examined in chapter five of this thesis, alongside the presentation of primary source materials which provide a deeper insight into the specific situation occurring in the West of Scotland.

In addition to considering the role of the medical profession in impacting abortion legislation, this thesis will also examine the views of religious organisations. One of the key publications which provides an insight into religious perspectives on the abortion debate is *Abortion An Ethical Discussion*. Published by The Church Assembly Board for Social Responsibility of the Church of England in October 1965, it provides a detailed analysis of their perspective towards the rightfulness of abortion.[78] Of most importance for this thesis is the section which considers termination due to suspected fetal anomaly. Whilst the Church Assembly Board view fetal anomaly as a potentially acceptable reason for a termination, they acknowledge the impact continuation of the pregnancy might have on the woman concerned. This is of central importance, as fetal anomaly on its own is not viewed as a suitable reason for abortion by the Church Assembly Board – it would have to be shown that the suspected fetal anomaly would have a negative effect on the pregnant woman. The Church of England highlight that a pregnant woman upon learning of such an instance may 'suffer such acute anxiety that her health is seriously impaired', but that this situation results in the interests of the woman and the fetus being opposing.[79] The difficulties with knowing if a pregnancy will be affected by a condition are explored, stating 'Until it becomes possible – if it ever does – to diagnose with certainty the severe deformities despite which and with which the child will live, we are bound to accept this prognostic uncertainty as the inescapable context in which the decisions, moral and medical, have to be taken.'[80] This quote highlights the very different situations which existed prior to and after the development of areas such as the detection of chromosome disorders in the fetus. As discussed in chapter five, with the advent of prenatal testing, the diagnosis of fetal anomaly would be seen as sufficient reasoning for a termination of pregnancy.

[78] Church Assembly Board for Social Responsibility, *Abortion An Ethical Discussion*, 3rd Edition, (London: Church Information Office, 1973)
[79] Ibid., p. 37.
[80] Ibid., p. 38.

The key publication for the Church of Scotland is *Abortion in Debate*, which was published on behalf of their Board of Social Responsibility, and is presented in a format which is reflective of the differing viewpoints which exist within the church. [81] The preface affirms that 'No issue has been discussed by the Church in recent years with more vigour and strength of feeling than that of abortion'.[82] Each chapter has two contributors writing from different views. Both authors are then provided with the opportunity to reply, thus providing a 'debate' on paper. A variety of aspects of abortion are considered, including looking at abortion from the viewpoint of a doctor who won't perform terminations of pregnancy. Another article examines the wider issues facing the medical profession surrounding abortion. Of use in this thesis are the chapters on the Church's teaching on abortion issues – one author covers the subject of traditional teaching, whilst the other highlights the differing viewpoints which have existed within Christianity on the subject, providing an insight into the more static Catholic viewpoint when compared to the Protestant stance. The changing views of the Church of Scotland on the subject of abortion make for an interesting study, however, there is no detailed information on this available in published literature. This thesis therefore aims to address this gap in the literature, discussing the viewpoints that have existed within the Church of Scotland on the subject over the course of two decades. This will be an important addition to the knowledge base on attitudes towards abortion within religious organisations in Scotland.

The views of religious organisations towards abortion have also been discussed more broadly by other commentators. Colin Francome, in his book *Abortion Freedom: A Worldwide Movement*, looks from a more international perspective at the development of abortion legislation, but also dedicates two chapters of his book to the specific changes which took place in Britain.[83] Of particular use in examining religious responses to abortion is Francome's description of campaigns such as that by the ALRA, and also the opposition which was raised by the Catholic Church, and groups

[81] Church of Scotland's Board of Social Responsibility, *Abortion in Debate*, (Edinburgh: Saint Andrew's Press, 1987)
[82] Ibid., p. 6.
[83] Colin Francome, *Abortion Freedom: A Worldwide Movement*, (London: George Allan & Unwin, 1984)

including SPUC. Whilst it does not specifically deal with the West of Scotland, it provides a useful framework on which to build the original primary research of this thesis concerned with the perspectives of different religious groups. Francome also devotes a chapter to detailing the debate which occurred in Britain post-1967, after the Abortion Act had been passed. This is of interest for this thesis, which will argue that a great deal of the opposition to abortion, particularly by the Catholic Church, was actually monopolised after the legislation had been passed.

Others have also written from a religious perspective on the ethics and morality of the subject. Gilbert Meilaender has covered abortion and prenatal testing in his book *Bioethics A Primer for Christians*.[84] In his chapter on prenatal testing, Meilaender states that Christians 'ought to set themselves against prenatal screening',[85] and that they 'could do the world a considerable favor and could bear substantial witness to the meaning of God's own love for the world if they would simply say no to routinized prenatal screening'.[86] However, as will be discussed in this thesis, the reality of accepting or rejecting prenatal screening and testing is far more complex for people of a Christian faith.

Anthony Fisher, in *Catholic Bioethics for a New Millenium*, examines similar issues to Meilaender, but covers these in a more in-depth and complex manner. Describing himself as someone who writes 'as a Catholic moral theologian and Bishop', Fisher frequently refers to scripture throughout his publication.[87] Of interest for this thesis is Fisher's examination of prenatal testing, which he views as having mainly negative consequences. Fisher links this to his perspective that prenatal testing will not be used therapeutically in the majority of cases. As will be shown throughout this thesis, this viewpoint can be seen to be consistent with published data, which shows that for certain conditions, the majority of women will choose to terminate a pregnancy after a positive

[84] Gilbert Meilaender, *Bioethics A Primer for Christians*, 3rd edition, (Cambridge: William B. Eerdmans Publishing Company, 2013)
[85] Ibid., p. 50.
[86] Ibid., p. 56.
[87] Anthony Fisher, *Catholic Bioethics for a New Millennium*, (Cambridge: Cambridge University Press, 2012), p. 1.

prenatal diagnosis. It is interesting to note that Fisher states that those who disagree with abortion more broadly also view 'genetic and other antenatal testing with a view to possible termination of pregnancy' as 'also unethical'.[88] However, as will be shown, this viewpoint does not seem to translate exactly into decision making, with religion shown to be only one of many factors influencing whether to terminate or continue with a pregnancy.

IV. Witness Seminars

In addition to the sources discussed above, a number of Witness Seminars have been undertaken by the History of Modern Biomedicine Research Group (which originated as the Wellcome Trust's History of Twentieth Century Medicine Group), funded by the Wellcome Trust, on different areas in the history of genetics. The group define a Witness Seminar as 'a particularly specialized form of oral history, where several people associated with a particular set of circumstances or events are invited to come together to discuss, debate, and agree or disagree about their memories'.[89] Some of these Witness Seminars discuss events linked to prenatal testing, which are of use for this thesis. One of these Witness Seminars, titled *Genetic Testing*, took place in London in July 2001, with Malcolm Ferguson-Smith acting as one of the participants. A number of different themes were covered, including the development of cytogenetics. Ferguson-Smith contributed his own testimony describing how he became involved in this field.[90] A more detailed description of his movement into the field is provided within this thesis. A number of other related themes are also covered within this Seminar, including linkage studies, biochemical genetics, and prenatal testing of metabolic disorders. There is also a detailed discussion of efforts to shift diagnosis further back in pregnancy – from second-trimester to first-trimester prenatal testing, and then on to pre-implantation genetic diagnosis for some conditions. The Witness Seminar provides a useful overview of the main individuals who were involved in the field, and also gives an insight into the interactions they had with one another. These interactions, Ferguson-Smith contends, are 'special to the UK', and he believes that the success of genetics in the UK 'was made possible by each of us knowing one another, and deciding on sharing and having

[88] Ibid., p. 164.
[89] Christie and Tansey, *Genetic Testing*, p. xi.
[90] Ibid., pp. 16-17.

common interests and common meetings'.[91] The Witness Seminar helps to provide an overview of this network, and the impact that it had.

Another Witness Seminar which has relevance for this thesis took place in London in September 2008, and was titled *Clinical Genetics in Britain: Origins and Development*. Many topics were covered, including the scientific work which was behind the development of clinical genetics as a field, and some of the key individuals who first worked as medical geneticists throughout Britain. It also considered the role that other bodies had played in the development of the field, including the Department of Health, and the Clinical Genetics Society, which became the British Society for Human Genetics. The development of the field of genetic counselling is also considered, with some of the key individuals who were centrally involved in setting up this area taking part in the discussions. One of the key areas discussed is the importance of the field of cytogenetics for the expansion of medical genetics more broadly. This argument is supported throughout this thesis, with much of the innovation in the prenatal testing field developing from the ability to detect when chromosome numbers differed from the standard 46 in humans. As John Bell states, 'It was a time when the first laboratory function, cytogenetics, created the distinctive capabilities of the field that ultimately allowed the specialty to develop a unique position among the medical specialties.'[92]

Useful information is also provided on several of the individuals who acted as pioneers in the field of clinical genetics. As previously highlighted, several of these were based in London at different periods throughout time (Lionel Penrose, John Fraser Roberts, Cedric Carter, and Paul Polani), whilst others were based elsewhere in the United Kingdom (Alan Stevenson in Oxford, Cyril Clarke in Liverpool, Rodney Harris in Manchester, and Alan Emery in Edinburgh). Interestingly, there is no real discussion about the work which was going on in Glasgow. It can be seen in the published text of the Witness Seminar that both Malcolm Ferguson-Smith and his successor Michael Connor sent their apologies for the event, which could explain this absence. However, with much of the discussion centring around developments which were occurring in

[91] Ibid., p. 68.
[92] Reynolds and Tansey, *Clinical Genetics in Britain: Origins and Development*, p. xix.

England, the particular situation in the West of Scotland is missing from this perspective. Indeed, Alan Emery, who spent much of his career in Edinburgh, highlights these differences between London and other areas within the Witness Seminar, stating that 'One tends to forget where you're coming from: if you're in inner London and you've been with all these very famous people, of course the scene is set, but if you were outside it was very different.'[93] This highlights the importance of regional perspectives in the development of a field, which was not linear in all areas throughout the United Kingdom.

This can be seen in the example of discussing the importance of having specialists together in one field. Rodney Harris details that in the late 1980s a topic 'that exercised us a great deal at that time was the question of getting clinicians and laboratory people to work closely together. It's hard to believe now, but there was quite a lot of struggle going on over who controlled laboratories. The idea of it all being 'under one roof' took hold. Now, it was not literally under one roof, but it was spiritually under one roof.'[94] In Glasgow, the Duncan Guthrie Institute had been opened in the early 1980s, with clinicians and scientists all working together in the one building. Throughout this thesis it is contended that working together in the one building was of key importance for enabling staff to carry out their work to a high standard, and for the passing of ideas between them. Therefore, the experience that Rodney Harris and perhaps others were facing in the late 1980s of clinicians and scientists being encouraged to work together, had already been occurring in Glasgow from the early years of the same decade. Thus, this Witness Seminar on the origins and development of clinical genetics in Britain, acts as a useful tool to consider the broader development of the field. It also provides an insight into some of the areas where similarities existed between different regions, and where differences were also developing over time.

Another Witness Seminar was held in London in 2013, focusing on *Clinical Molecular Genetics in the UK c.1975-c.2000*. There was only a very limited amount of molecular genetics work happening in the medical genetics department in Glasgow during the time

[93] Ibid., p. 40.
[94] Ibid., p. 49.

period of this thesis, and accordingly it is not covered here.[95] Despite this, the Witness Seminar on molecular genetics contains information which would be useful for a wider study of some elements of prenatal diagnosis, notably the work which was going on to detect haemoglobinopathies. Bernadette Modell gives a detailed account of the development of prenatal testing for thalassaemia major, and whilst this specific condition is not relevant to the foci of this thesis, many parallels emerge with the milestones and challenges which were encountered in developing prenatal testing methods for this disease.[96] A key theme, which Modell refers to several times, is the importance of the role of patients in driving the development of the testing, with many being 'afraid' to risk having another child with the condition.[97] Modell gives a few specific examples, including one of a patient who wanted to be sterilised, but Modell encouraged them to wait as prenatal testing might become possible.[98] This example exemplifies what many of those working on developing prenatal tests have argued, that the testing actually encouraged women to have more children, not fewer.

However, it should be noted that, if a woman became pregnant prior to a prenatal test becoming available, she would have had to face the decision to continue or terminate the pregnancy without a diagnosis. Modell provides an example of a woman who

[95] Professor Connor himself stated in his interview that there was no provision for molecular genetics within the Duncan Guthrie Institute when he moved to Glasgow in 1982, as molecular 'didn't exist as a diagnostic subject' at that time. Specific space had not been set aside in the Duncan Guthrie, and molecular was therefore fitted in physically as best as possible in the Duncan Guthrie Institute, and the work expanded from the mid-1980s onwards. As the majority of the molecular work expanded into clinical practice after Ferguson-Smith had moved to Cambridge, the decision was taken not to focus on this as a specific area within this thesis. See MC interview, DS300143, p. 5. Interview with Mike Connor, 3rd March 2016. Mike Connor completed his medical degree in Liverpool, before spending time working at Johns Hopkins University in Baltimore. He began working in the Department of Medical Genetics in Glasgow in 1982, and replaced Malcolm Ferguson-Smith as the Burton Chair of Medical Genetics when Ferguson-Smith moved to Cambridge in 1987.
Further evidence showing the lack of established facilities for molecular genetics at that time in Scotland is given in the report *Clinical Genetic Services in Scotland*, published by the Working Group of the National Medical Consultative Committee in 1986. It was highlighted that at the time of writing the report, there were 'no facilities in Scotland for providing patients and their families with DNA diagnosis other than through research support'. See National Records of Scotland, HH98/602, Report titled 'Clinical Genetic Services in Scotland Report of the Working Group Established by the National Medical Consultative Committee', p. 57.
[96] E M Jones and E M Tansey, (eds) (2014) *Clinical Molecular Genetics in the UK c.1975–c.2000.* Wellcome Witnesses to Contemporary Medicine, vol. 48. (London: Queen Mary, University of London), pp. 21-26.
[97] Ibid., p. 23.
[98] Ibid., p. 24.

wanted prenatal testing, but there was not yet a technique available for obtaining fetal blood. Despite being told this, the patient wanted Modell's team to try prenatal diagnosis, as she stated that the 'worst' they could do was cause a miscarriage, and that she would terminate the pregnancy if they couldn't try prenatal testing.[99] Modell comments that 'the patients really pushed the pace'.[100] As will be seen in chapter two, Ferguson-Smith expressed similar views.

Another witness seminar which was relevant to this thesis was *Looking at the Unborn: Historical Aspects of Obstetric Ultrasound*, which took place in March 1998 at the Wellcome Institute for the History of Medicine in London. This Witness Seminar focused on the development of ultrasound technology, with the key work in this field by Ian Donald a major focus throughout. Much of the discussion focuses on specific clinical developments and applications, with Stuart Campbell recalling the process by which he developed techniques to measure the fetus, and also his work on diagnosing anencephaly via ultrasound. Campbell was the first in the field to be able to make a diagnosis at an early enough stage that a woman could request a termination of pregnancy following an ultrasound diagnosis of anencephaly,[101] and this will be discussed later in this thesis. Charles Whitfield describes some of the other key uses of ultrasound which are directly linked to prenatal testing, including using ultrasound to improve the safety of amniocentesis.[102] He discusses the role that ultrasound played in biochemical screening programmes, by helping to date pregnancies and check for multiple pregnancies, etc.[103] All of these themes will be covered within this thesis when the development of biochemical screening programmes is considered. Indeed, this thesis will highlight that the development of ultrasound in Glasgow, alongside the close working relationship of Ian Donald and Malcolm Ferguson-Smith, were contributory factors in Glasgow's ability to implement large scale biochemical screening programmes in pregnancy.

[99] Ibid., p. 25.
[100] Ibid., p. 25.
[101] E M Tansey and D A Christie, (eds) (2000) *Looking at the Unborn: Historical Aspects of Obstetric Ultrasound*. Wellcome Witnesses to Twentieth Century Medicine, vol. 5. (London: Wellcome Trust), pp. 54-55.
[102] Ibid., p. 61.
[103] Ibid., pp. 62-63.

Thus, several of the Witness Seminars listed above provide further information on the development of the medical genetics field, and can help to give a broader geographical overview of much of the expansion which was occurring.[104] They highlight the importance of recording individual's memories to chart the work which was happening in a field, an approach which was taken throughout this thesis to record the experiences of those who worked in Glasgow. The group methodology of the Witness Seminars compliments the interview methodology employed in research for this thesis.

V. The Importance of Local Case Studies

It can be seen from the above discussion of the current literature, that material is available which provides information of the development of the prenatal testing field, and the permissive abortion legislation which enabled it to be widely applied. However, it is clear that much of the available literature covers Britain more broadly, with less material available on Scotland. As previously highlighted, to analyse the developments in prenatal diagnosis in detail, this thesis will utilise the case study of the region of the West of Scotland. This will enable a detailed study of both the development of the scientific and clinical aspects of the testing, alongside the response of medical professionals and religious organisations. To analyse the medical development of prenatal diagnosis, the life and work of Malcolm Ferguson-Smith and his colleagues will be examined. As has been discussed, Ferguson-Smith and his co-workers were at the forefront of many of the developments in prenatal testing. However, despite Ferguson-Smith's contributions, very few papers have been published on his input into

[104] Several other Witness Seminars have been considered to analyse their importance for this thesis, but were found to contain less material of direct use, including that titled *Human Gene Mapping Workshops c.1973-c.1991*. Whilst the mapping of the human chromosomes, and the wider human genome mapping project are of central importance in the history of the broader field of genetics, this work has fewer links with this thesis. Despite this, the Witness Seminar on the human gene mapping workshops may hold interesting material for scholars more widely interested in the development of the field of genetics. Other Witness Seminars fall into a similar category, such as *Medical Genetics: Development of Ethical Dimensions in Clinical Practice and Research*, which provides a great deal of information about the ethics involved in medical genetics more broadly, some of which was at a later time period than this thesis has considered. However, it would be a useful resource for considering the many ethical issues which can arise in this field. Similarly, the Witness Seminar *Clinical Cancer Genetics: Polyposis and Familial Colorectal Cancer c.1975-c.2010* gives a detailed overview of a completely different aspect of genetic testing, this time for cancer, which could be of use to individuals looking at a wider history of genetic testing. Details of all of these publications can be found in the bibliography.

prenatal testing in the West of Scotland.[105] A key feature of these published papers are that they tend to be celebratory in nature, and have been written as tributes. One of these, titled 'A Tribute to Malcolm Ferguson-Smith, Founding Editor of Prenatal Diagnosis' was written in 2006 to mark his retirement as editor-in-chief of the journal *Prenatal Diagnosis*.[106] The article is only two pages in length, and lists some of Ferguson-Smith's key achievements throughout his career. As would be expected with such an article, it is not a critical analysis of his life and work, and is instead a brief overview including main dates and events. Another paper which has been written about Ferguson-Smith is an article for the 'Distinguished Cytogeneticist' section of the journal *Cytogenetic and Genome Research*.[107] This article is three pages long, and again provides more of an overview of some of Ferguson-Smith's key contributions to the field of genetics. The article does, however, provide a Curriculum Vitae of Ferguson-Smith, and also lists fifty selected publications. The other sources which provide an insight into Ferguson-Smith's life and career include an article written by himself, titled 'Putting Medical Genetics into Practice', which is understandably a personal account,[108] webpages on the University of Glasgow website, and the Wellcome Trust website,[109] and an in-depth interview with Ferguson-Smith, carried out by a fellow geneticist, Peter

[105] Malcolm Ferguson-Smith's contribution to the development of the prenatal diagnosis field was the subject of my dissertation for my taught MSc in History with an emphasis on the History of Medicine (the dissertation was titled 'Malcolm Ferguson-Smith and the Development of Prenatal Diagnosis' and was submitted in September 2015). However, this dissertation was a far smaller piece of work, which focused mainly on the work of Ferguson-Smith in a local context, and less on placing these developments in a national setting. The main focus was on the work which was happening in Glasgow, with a small consideration of Ferguson-Smith's role in the wider research community. The dissertation used mainly sources from the Ferguson-Smith archive alongside published papers by Ferguson-Smith and his colleagues, and involved no oral history interviews with any of those involved in the field. Therefore, this PhD thesis is a vast expansion on this work, particularly as it involved several oral history interviews, and also considers the wider social circumstances that the developments in prenatal testing were situated amongst. As the dissertation formed part of a taught Master's course, it has not been published, and is therefore not available to view publicly.

[106] Diana W. Bianchi and Charles H. Rodeck, 'A Tribute to Malcolm Ferguson-Smith, Founding Editor of Prenatal Diagnosis', *Prenatal Diagnosis*, 27:9 (2007), pp. 854-855.

[107] Peter Pearson, 'Distinguished Cytogeneticist – Malcolm Ferguson-Smith', *Cytogenetic and Genome Research*, 111:1 (2005), pp. 2-4.

[108] Ferguson-Smith, 'Putting Medical Genetics', pp. 1-23.

[109] For the Wellcome Trust see:
'Codebreakers: Makers of Modern Genetics', *Wellcome Library*
<http://wellcomelibrary.org/collections/digital-collections/makers-of-modern-genetics/> [accessed 22nd June 2018].
For the University see:
'Malcolm Ferguson-Smith', *The University of Glasgow Story*
<https://www.universitystory.gla.ac.uk/biography/?id=WH2412&type=P> [accessed 12th July 2018].

Harper.[110] For an individual who was responsible for the establishment of one of the first medical genetics institutes in the United Kingdom, this is surprisingly little material. Despite this lack of published material, there are a number of benefits to exploring the wider changes occurring in the prenatal testing field through the examination of a local region. Local case studies have been utilised by several scholars, whose approaches will be detailed below.

Exploring the uses of biography, Hankins argues that examining an individual's life and career 'gives us a way to tie together the parallel currents of history at the level where the ideas and events occur'.[111] This has been possible for this thesis through the examination of the Ferguson-Smith archive, and oral history interviews with Ferguson-Smith and his colleagues, which provide a perspective on the regional developments occurring in the prenatal testing field. Another benefit of focusing on a specific actor in a particular location is that the volume of archival documents is more manageable, enabling a detailed analysis to be carried out, where all relevant documents can be studied. Lindee has highlighted that the volume of archival documents which exist for 'post-1945 science are quite frankly too rich, voluminous, dispersed, and complicated to be easily tamed', however the use of 'focused case studies' can 'facilitate broader pictures'.[112]

The individual case-study approach has been taken by a number of researchers, when examining a larger topic of historical interest. In his chapter 'What is the Use of Writing Lives of Recent Scientists?' in *The Historiography of Contemporary Science, Technology, and Medicine*, Thomas Söderqvist charts his own experience of writing the biography of the immunologist Niels Jerne. Whilst initially setting out to write the

[110] Peter Harper, 'Interview with Malcolm Ferguson-Smith, 2003.' *Interviews with Human and Medical Geneticists series* <http://www.genmedhist.info/interviews/Ferguson%20Smith> [accessed 12th July 2018].
[111] Thomas L. Hankins, 'In Defence of Biography: The Use of Biography in the History of Science', *History of Science*, 17:1 (1979), p. 5.
[112] Susan Lindee, 'Human Genetics After the Bomb: Archives, Clinics, Proving Grounds and Board Rooms', *Studies in History and Philosophy of Biological and Biomedical Sciences*, 55 (2016), p. 45.

biography of an 'interesting person' without a specific subject in mind,[113] working on Jerne's story led Söderqvist to become interested in the wider development of the field of immunology. The correspondence between Jerne and others in the emerging field, alongside the detailed notes that Jerne had taken at scientific meetings, led Söderqvist to believe that Jerne had been at the 'epicenter' of many of the key developments, and that the story of Jerne's life and work could be used for 'contextual-historical purposes'.[114] As Söderqvist has detailed, 'The Jerne collection thus functioned as a lens into these exciting years of the new cellular and molecular immunology; he was the single package that wrapped up these currents.'[115] Whilst this thesis does not contend that Ferguson-Smith was the 'single package' in relation to prenatal testing, Söderqvist's ideas that an individual can act as a lens to provide an insight into new developments is a central component of this thesis.

Other researchers have incorporated case studies of medical genetics into larger projects, including Ilana Löwy. In her recent book *Imperfect Pregnancies*, which is discussed in detail above, she dedicates a small section to charting the process of studying chromosomes at the University of Wisconsin in the 1960s, using the geneticist Klaus Patau as a central feature.[116] By utilising published papers and correspondence between Patau and others, she examines the developments which occurred in chromosome studies in his department and further afield. She highlights that studies of 'Patau and his collaborators at the University of Wisconsin illustrate the dilemmas and hopes of pioneers of studies of chromosomal anomalies'.[117] Examining the development of prenatal testing in the West of Scotland under the leadership of Ferguson-Smith provides a similar illustration, with both the aims of his department, and the setbacks they faced, able to be analysed in detail. Indeed, similarities can be discerned between the work being carried out by Patau, and that of Ferguson-Smith. Löwy discusses a case where a geneticist from another department advised the mother of a child with Down's

[113] Thomas Söderqvist, 'What is the Use of Writing Lives of Recent Scientists?', in *The Historiography of Contemporary Science, Technology and Medicine. Writing Recent Science*, ed. by Ronald E. Doel and Thomas Söderqvist, (Oxon: Routledge, 2006), p. 100.
[114] Ibid., p. 107.
[115] Ibid.
[116] Trisomy 13 is also known as Patau's syndrome, and is named after Klaus Patau. He was responsible for discovering that the condition was caused by an extra copy of chromosome 13.
[117] Löwy, *Imperfect Pregnancies*, p. 49.

syndrome to ask Patau to carry out a chromosome test on her son. However Patau replied to state that their lab 'dealt with basic research only', and that he believed there was no need for a specialised laboratory dealing with 'routine chromosome analyses'.[118] As will be seen later in this thesis, Ferguson-Smith also faced restrictions due to the head of the genetics department in Glasgow stating that they focused on research and not clinical diagnoses. In contrast to Patau, Ferguson-Smith felt there was a real need for a laboratory specialising in providing these routine chromosome analyses. Looking at a small case study in both of these examples provides an insight into some of the issues which were arising, and how individuals might have viewed these developments in a far different manner from one another.

Alexandra Stern's book *Telling Genes: The Story of Genetic Counseling in America* takes this approach further, whereby she uses a variety of case studies to explore the development of genetic counselling in America. Similar sources to this thesis are used, including archival research and oral history testimonies.[119] One chapter of the book is particularly useful for this thesis, as it charts the development of prenatal diagnosis at Johns Hopkins University in Baltimore, in the United States of America. Stern guides the reader through the various stages of prenatal diagnosis development and implementation within the Prenatal Diagnostic Center at Johns Hopkins, telling the stories of a variety of individuals who were involved. By utilising this specific centre as a case study, it is possible for Stern to discuss the twists and turns which are linked to the development of such a new enterprise, including the changing number of patient referrals, and the specific results of prenatal tests for these patients.[120] This approach is taken in this thesis, whereby the analysis of the Department of Medical Genetics in Glasgow also incorporates such information. These details are not usually present in larger scale studies of prenatal diagnosis, which chart the development of the technologies and their implementation overall, meaning that local nuances in testing patterns are often missed.

[118] Ibid., p. 56.
[119] Alexandra Minna Stern, *Telling Genes: The Story of Genetic Counseling in America*, (Baltimore: Johns Hopkins University Press, 2012), p. 3.
[120] Ibid., pp. 146-169.

Perhaps the publication which follows the most similar path to this thesis is a study of the origins of prenatal testing in Madrid, written by María Jesús Santesmases. Santesmases follows the story of two clinicians, Andrés Sánchez Cascos and Emilia Barreiro, who established a laboratory for chromosome diagnosis in Madrid in the 1960s.[121] Many parallels can be seen in their story to Ferguson-Smith's early career, which will be discussed in chapter two, including time spent abroad to learn the necessary skills to set up such a department,[122] and their small beginnings in a single room which only had a centrifuge, a microscope and a heater.[123] By focusing on the case study of these individuals, Santesmases is able to go in to a great deal of detail about the exact processes which were followed by the pair when carrying out chromosome analysis. The laboratory skills required for culturing chromosomes were initially learned whilst working on blood samples from adult patients, and Santesmases describes the entire process from the collection of a 15-20ml blood sample, right through to the viewing and photographing of chromosomes under the microscope.[124] These skills could then later be adapted for analysing the chromosome constitution of the fetus, using the cells found in amniotic fluid. This level of detail is an important source of information for the historical record, and many of the interviewees for this thesis went in to a similar descriptive mode when asked about the techniques and laboratory tests they had regularly carried out.

By focusing on a local area, key differences can also be highlighted with other regions. Perhaps most importantly for the clinicians involved in Santesmases' study was the lack of permissive abortion legislation which existed in Spain during the time period of the charted developments. This meant that, in contrast to Scotland, prenatal testing could be used for information-gathering purposes only. However, Santesmases discussed how women who had the financial means would go abroad to have a termination of pregnancy.[125] Again, in contrast to the situation in Glasgow, those clinicians in Madrid who carried out amniocentesis were 'publicly criticised … for merely mentioning the

[121] María Jesús Santesmases, 'The Human Autonomous Karyotype and the Origins of Prenatal Testing: Children, Pregnant Women and Early Down's Syndrome Cytogenetics, Madrid 1962-1975', *Studies in History and Philosophy of Biological and Biomedical Sciences*, 47 (2014), p. 142.
[122] Ibid.
[123] Ibid., p. 145.
[124] Ibid., pp. 145-146.
[125] Ibid., pp. 149-150.

technique at public conferences and for doing prenatal tests'.[126] It is clear from Santesmases' study that utilising the case study of individuals involved in setting up a department which carried out prenatal testing, can provide a detailed insight into the science and clinical practice which was taking place, but which can also give information about the wider social context these individuals were placed amongst. This approach is particularly useful for the study of the situation in Glasgow, whereby scientific developments in prenatal testing were occurring in the department led by Ferguson-Smith, despite the outspoken opposition to abortion by the Catholic Church.

A similar approach has been taken by Peter Coventry and John Pickstone, who have examined the emergence of genetics as a medical specialism in the city of Manchester in England. Although looking at the wider field of genetics, Coventry and Pickstone contend that their study of a specific city uses 'a local focus to bring together many levels of phenomena – from laboratory tests to NHS reforms, from the politics of medical specialisms to the workings of the Abortion Act'.[127] This thesis aims to follow a similar path, using the case study of Glasgow to analyse the mix of scientific, social and cultural factors which impacted on the development of prenatal diagnosis in the region. Within their paper, Coventry and Pickstone chart the work which was occurring in the field of genetics in Manchester both prior to and after the implementation of prenatal diagnostic techniques, outlining some of the key figures and departments involved in a variety of research and clinical practice. A useful parallel emerges in the article with the description of the development of medical genetics under the consultant Rodney Harris. Coventry and Pickstone describe the increasing demand from the early 1970s onwards for chromosome diagnosis for Down's syndrome, which led to staffing and resourcing issues.[128] As the demand for prenatal diagnosis increased throughout the 1970s, calls were made for more staff and resources to be made available, and Harris himself was writing to the health board to express his concerns about the clinical and legal dangers which could result from such a situation. As will be seen later in this thesis, this situation is almost an exact replica of the challenges which were being faced

[126] Ibid., p. 150.
[127] Peter A. Coventry and John V. Pickstone, 'From What and Why Did Genetics Emerge as a Medical Specialism in the 1970s in the UK? A Case-history of Research, Policy and Services in the Manchester Region of the NHS', *Social Science and Medicine*, 49:9 (1999), p. 1228.
[128] Ibid., p. 1233.

in Glasgow by Ferguson-Smith and his colleagues.[129] By focusing on a local area these specific problems become noticeable. Whilst these issues may be lost in a larger history of a field, they are essential to understanding the development of a new medical specialism, and highlight the less than straightforward trajectory which is often characteristic of the implementation of prenatal testing programmes.

In addition to the parallels which can be drawn between the development of genetics in Manchester and Glasgow, within their article Coventry and Pickstone specifically mention the work of Ferguson-Smith, and the 'key site' that was run in Glasgow by him.[130] In the 'Concluding observations' section of their paper, they highlight the need for more research to be carried out which would give a similar insight into the development of other regional genetics centres throughout the United Kingdom, and they were especially keen for work to be carried out on the development of genetics in Scotland. They highlight the close ties which existed in the cities of both Glasgow and Edinburgh between the teaching hospitals and the regional services; within this thesis these ties become clear within Glasgow, when examining the relationship between Ferguson-Smith and Ian Donald. The Department of Medical Genetics in Glasgow was located in close proximity to two of the most prominent hospitals in the city, and Ferguson-Smith and Ian Donald had a working relationship which was key to many of the developments in the prenatal testing field in Glasgow. Thus, these close ties, as Coventry and Pickstone have suggested, had an impact on the expansion of prenatal work which was occurring in the West of Scotland. It is hoped that this thesis will contribute to the body of work that Coventry and Pickstone felt was lacking on the development of other regional centres of genetics, and will also lend support to their opinion that 'a focus on local services' is important 'not just because they are constitutive of wider changes, but because they allow detailed study of the range of factors and contingencies that are involved in the development of medicine'.[131]

[129] Ibid., pp. 1233-1234.
[130] Ibid., p. 1232.
[131] Ibid., p. 1236.

VI. Research Questions

As can be seen from the information presented above, there are scholars who have undertaken work to chart the history of the prenatal diagnosis field, and the changing abortion legislation. Whilst these studies provide a useful framework for placing further research on the history of prenatal testing against, it has been shown that they tend to focus on the development and/or implementation effects of prenatal testing technologies and social change spread over large regions. As has been emphasised above, it can be argued that there are several benefits to analysing these developments in a specific geographical region, which can then be expanded to analyse greater social issues. This introduction has argued that the West of Scotland presents a unique set of circumstances which have yet to be studied in detail with regards to prenatal testing. The technical developments and social responses occurring within the region merit investigation, which they are currently lacking. This thesis will therefore consider the following research questions:

I) How did invasive and non-invasive prenatal testing techniques develop from the 1950s through to the late 1980s?

II) What role did Ferguson-Smith and his colleagues in the West of Scotland play in these developments, particularly with regards to testing for chromosome conditions and neural tube defects?

III) How was fetal anomaly viewed within debates on changing abortion legislation, and was the fetal anomaly clause in the Abortion Act 1967 seen as acceptable by members of the medical profession, including in the West of Scotland? Additionally, how did the medical profession in Scotland respond to the implementation of the Abortion Act more broadly?

IV) How did religious organisations, namely the Church of Scotland and the Roman Catholic Church, respond to the Abortion Act 1967, and also to the advent of prenatal testing?

These questions will be considered using a variety of sources, which will be discussed in detail in the following section on methodology.

VII. Methodology

Söderqvist, writing on the historiography of recent and contemporary technoscience, highlighted a number of key methodological challenges which could face the researcher. These included a lack of available archives, the sheer volume of publications available for analysis, the issues associated with using oral history for projects, and the difficulties of writing about scientific subjects in detail, when not scientifically trained.[132] Despite the potential drawbacks of studying contemporary science, all of these challenges were successfully overcome when carrying out research for this thesis, as will be discussed throughout this section. A variety of sources have been used throughout this project to enable the analysis of the scientific, clinical and social developments which occurred in prenatal testing from the 1950s to the late 1980s, including archival sources, oral history interviews, and published newspapers, magazines and journal articles.

Contrary to Söderqvist's concerns about the lack of available archives, one of the key sources which formed the initial basis for the development of this research project was the Malcolm Ferguson-Smith archive, which is housed at the University of Glasgow Archives. This archive is vast but highly accessible, largely due to the fact that it has been catalogued and digitised as part of the Wellcome Trust funded Codebreakers: Makers of Modern Genetics project.[133] The digitisation of the archive has resulted in the majority of information being available in PDF format, circumventing the concerns Comfort has raised about limitations of access in archives, with researchers only being able to access 'one box, folder, or even letter at a time – each text under analysis is

[132] Thomas Söderqvist, 'Who Will Sort Out the Hundred or More Paul Ehrlichs? Remarks on the Historiography of Recent and Contemporary Technoscience', in *The Historiography of Contemporary Science and Technology*, ed by. Thomas Söderqvist, (Amsterdam: Overseas Publishers Association, 1997), pp. 1-12.

[133] 'Codebreakers: Makers of Modern Genetics', *Wellcome Library* <http://wellcomelibrary.org/collections/digital-collections/makers-of-modern-genetics/> [accessed 22nd June 2018].

surgically isolated to prevent cross-contamination'.[134] The archive contains a wide range of resources from the period 1957-2008, including material relating to medical genetics, details of publications, and a vast array of correspondence. It was possible to have several PDF files open simultaneously, enabling a more in-depth analysis of the sources. All relevant documents in the archive were examined, and the correspondence section proved to be very insightful for this thesis. It was possible to chart some of the professional relationships and friendships that Ferguson-Smith had with others, both within and outside the medical and scientific fields, through his letter writing. A sense of Ferguson-Smith's personality also emerged through the reading of these letters, and it became clear how involved he was with the medical genetics field more widely, and how his clinical opinions were sought with increasing frequency as his academic career advanced.

Whilst the archive was a very useful source for the project, as with any curated documents, there can be issues related to the collection. It is highly unlikely that the archive itself contains a full record of all the documents Ferguson-Smith possessed throughout his career. Particularly within the correspondence section, it is likely that letters that were sent and received are missing, perhaps as a result of being misplaced over time. Within any archival collection, source bias is also an important consideration, both from the perspective of the individual who the records belong to, and the institution where the archival documents are being made available. From the perspective of the individual, there is the possibility that items have been deliberately excluded, perhaps because they did not view them as being of importance, or because they do not wish them to be made publicly available, either for a set period of time or permanently. From an institutional perspective, archival collections have to be organised and ordered into subsets within the wider collection, which could result in documents being categorised differently than the way the individual intended them to be catalogued. Items may also not be accepted by archives when presented by an individual, or they may not be included within a wider collection because they are deemed as not belonging to a certain category within which they have been assigned. Additionally, for data protection reasons some material is unavailable to scholars, as is

[134] Nathaniel Comfort, 'When Your Sources Talk Back: Toward a Multimodal Approach to Scientific Biography', *Journal of the History of Biology*, 44:4 (2011), p. 666.

the case with the records which exist on Malcolm Ferguson-Smith at the University of Cambridge. Thus, there is a human element involved in the collection and curation of archival material, alongside accessibility issues, which can lead to a lack of a complete picture forming if archive documents alone are used as source material.

In the case of the Ferguson-Smith archive, the vast majority of the collection is made up of typed or hand-written sources, with only a small number of items in other formats, including video and photographic material. Whilst such sources are exceptionally valuable, they will fail to capture the nuances of conversations and relationships that exist within a working department. It became particularly clear when analysing the archive that a key group of individuals were missing from the written record – Ferguson-Smith's colleagues. That this group was not recorded in the archive was understandable; Ferguson-Smith and his colleagues worked in the same building as one another and were able to discuss ideas in person, rather than writing letters to one another. However, these members of staff were centrally involved in the running of the department, carrying out the prenatal testing and screening programmes, and it seemed important that their recollections should be recorded. This led to the decision to carry out a number of oral history interviews with a variety of staff members who had played different roles in medical genetics in Glasgow.[135]

From the beginning of the research project it was recognised that it was important to interview Malcolm Ferguson-Smith and his wife Marie Ferguson-Smith, who had worked side-by-side. However, the decision to expand the oral history aspect of the project gave many others, such as technicians and research scientists, an opportunity to tell their stories, which greatly influenced the direction of the project. Key work by Tansey has highlighted the importance of recording the voices of technicians, a group she argues play 'key roles in both the routine maintenance and innovative research work of a laboratory … metaphorically – and quite literally in some circumstances – they keep alive the very 'culture' of a laboratory'.[136] Despite the importance of technicians

[135] Details of each of the interviewees can be found in Appendix 3.
[136] E.M. Tansey, 'Keeping the Culture Alive: The Laboratory Technician in Mid-Twentieth-Century British Medical Research', *Notes & Records of the Royal Society*, 62:1 (2008), p. 78.

for the central running of a laboratory, they are distinctly lacking in the historical record. As Tansey has reported, they 'have proved a difficult group to trace historically. They rarely leave material records in archives, write reminiscences or receive obituaries. They can be troublesome to track via published staff lists … and are frequently not even acknowledged in the scientific papers to which they contribute'.[137] Whilst in the department run by Ferguson-Smith, technicians did appear on staff lists and received credit on publications, as noted above, none of them have left behind records in the archives. However, as Paul Thompson has described, a 'cumulative process of transformation is set in motion' when new evidence is brought forward by groups of people who have traditionally been ignored in history, which he argues results in 'historical writing itself' becoming 'enlarged and enriched'.[138] This was certainly the case for this thesis, where the department members interviewed added a great deal of useful information to the project. The decision to track down, interview and include these individuals supports Thompson's argument that 'By giving a central place in its writing and presentation to people of all kinds, history gains immensely.'[139] The specific details of the interview process will be discussed in the following section.

Interviewees for this project comprised several different groups, including those who, as described above, had worked in medical genetics in Glasgow. Other groups included people who had worked in prenatal testing in other regions, and religious figures including priests, and a midwife who was strong in her Catholic faith. These participants were recruited in a number of ways for this research project. During my initial interviews with Malcolm and Marie Ferguson-Smith, they mentioned colleagues who had been centrally involved in the work of the medical genetics department throughout the time period of this thesis. Some of these individuals were still working in the current medical genetics department in Glasgow, and were therefore contacted by myself via email to enquire about their willingness to take part in the project. Others could not be contacted directly, due to changes in their circumstances, such as that they had retired or changed job role. To ensure confidentiality was maintained, the current

[137] Ibid.
[138] Paul Thompson, *The Voice of the Past: Oral History*, 3rd Edition, (Oxford: Oxford University Press, 2000), pp. 8-9.
[139] Ibid., p. 12.

head of the medical genetics department agreed to pass on letters to these individuals where address details were available. The letters were written and put in stamped envelopes by myself, and address details were added by the current head. Also, a number of individuals contacted me directly, having heard about the project from others, who were keen to be involved and tell their stories. One interviewee was suggested by a current staff member of a medical genetics department in Edinburgh, and others became involved after hearing presentations about this project at seminars and events. Both priests were recruited directly by email; one was suggested by a personal contact as he had studied medicine before entering the priesthood, the other was suggested by his fellow priest, who knew that his colleague had an interest in bioethics. Thus, a broader pool of interviewees was gathered, which ensured that not all those interviewed had been chosen by the Ferguson-Smith family.

Once contact had been established with an interviewee, and they had confirmed that they would be interested in participating in the project, a suitable interview date and time was agreed upon. Interviews took place in a number of locations, as decided by the interviewees themselves. Locations included in the homes of the interviewees, at their place of work, in meeting rooms at the University of Glasgow, and one in a public café, at the request of the interviewee. Each interviewee had been made aware prior to meeting what the focus of this PhD research was, and upon meeting were given a copy of the Participant Information Sheet to read, and the consent form to sign (see Appendix 1 and 2). They were also informed that the transcript of their interview would be available to view, and edits to the transcript would be permitted. Interviews were unstructured, but with similar themes covered throughout, such as education, work history, and personal recollections of stories related to prenatal testing and medical genetics more widely. The content of the interview and the time spent discussing a variety of subjects was different for each interviewee, due to the unstructured nature of the interviews. Interviews were recorded using an Olympus digital recorder, and all interviewees were made aware that the recorder could be paused at any time.

After the interviews were completed, all were transcribed using verbatim transcription style as closely as possible. The completed transcript was then sent by email or post to

the interviewee, who was able to read through the interview, and make changes as they deemed fit. Interviewees were made aware that the verbatim style had been used to closely reflect the spoken word, and preserve dialect characteristics etc. However, some interviewees chose to edit their transcript to read in a more grammatically correct manner. No edits to any transcripts were made by myself. The questions and discussion points raised by me are completely unedited in all transcripts. All completed transcripts were stored in a locked filing cabinet in my office in the University of Glasgow, alongside the digital sound recordings of the interview. The completed and approved transcripts from each interviewee were the material consulted to select quotes for this thesis. On a few occasions, interviewees had not edited their transcript for a variety of reasons, despite intending to do so. In these instances, only specific quotes were used, and only after the interviewee gave their full consent for these particular quotes to be included.

After returning a completed transcript, the interviewee played no further role in the interview process, including the selection of quotes. This process was completed by myself. None of the interviewees, including Malcolm Ferguson-Smith, had knowledge of the quotes which had been chosen, or the context in which they were presented, such as having access to draft chapters. This decision was made to minimise the influence that any interviewee could have on the project with regards to selection of material for inclusion in this thesis. Particularly in the case of Malcolm Ferguson-Smith, it was hoped that this would reduce the potential for his curating his own biography through the interview process. In many cases, the interview material which was incorporated was selected as it provided information on an aspect not available through archival or other published documents. Personal recollections of the medical genetics department were also viewed as being of importance for inclusion. As well as providing illustrative quotations, the interviews broadened my understanding of the functioning of many aspects of the medical genetics department, particularly laboratory work and service provision. The interviews also enabled me to develop a sense of the place that the medical genetics department was, and the relationships which existed between the staff members working there.

The use of oral history in this project was therefore multi-faceted, and was not solely used to record the voices and memories of those who worked in the prenatal field. Lynn Abrams has highlighted that there are three models of oral history usage when it comes to interpreting the interviews, and two of these were used throughout the project. The first she describes as the 'reminiscence and community model' which involves 'undertaking oral history interviews for the sole purpose of recovering voices and placing them on the historical record'.[140] Whilst it was not the sole aim of the interviews I carried out, it was part of the reason for interviewing such a wide range of individuals, to ensure that their names and stories were collected for the historical record. However, Abrams also describes a second model, which she terms 'evidential', which 'encompasses the application of oral history for evidence gathering, the use of oral testimony as data, providing information to support an argument and illustrative material for publication'.[141] This was also a central use of the oral history testimonies I gathered, which helped to provide more information than could be found in published scientific papers and archive documents. The oral testimony became a source of data in itself, which could be used to support or dispute published historical accounts. The approach I took throughout this thesis to the use of oral history is reflective of Thompson's view that oral histories have a 'triple potential', which include 'to explore and develop new interpretations, to establish or confirm an interpretation of past patterns or changes, and to express what it felt like'.[142] This last potential, the expression of feelings, was particularly important throughout the project, as prenatal testing is an emotive subject. I wanted to find out the details of what was not in the published record from my interviewees, and how they felt in respect of a number of developments in the field.

Hoddeson has commented that 'Oral history interviews can breathe life into the research and writing of recent history. By filling in the nerves and connective tissue (motives, inspirations, fears, obsessions, etc.) that link actions with each other, participant accounts can animate a narrative with details not found in documents, shade it with

[140] Lynn Abrams, *Oral History Theory*, (Oxon: Routledge, 2010), p. 25.
[141] Ibid.
[142] Thompson, *The Voice of the Past*, p. 265.

nuances, and vitalize interpretations with insights into diverse points of view.'[143] It is a firm belief that oral history had this effect on the project, helping me to gain a better understanding of the individuals who were involved in medical genetics in the West of Scotland, and how they interacted with their job role, and with one another. However, whilst oral history added a great deal to this project, as mentioned by Söderqvist, it is not without nuances, which should be addressed. Abrams has spoken of the interpersonal relationship between an interviewer and an interviewee, and how the interviewer 'by word, deed and gesture in the interview solicits a narrative from the narrator; a different interviewer would solicit different words, perhaps even a very different story or version of it'.[144] This is particularly fitting for considering my own scientific background, which the interviewees were made aware of. It is possible that knowing I had spent time in a laboratory and understood a number of scientific techniques would have altered the details presented by some interviewees. When many of them discovered that I had undertaken a scientific undergraduate degree they were comfortable going in to detail about procedures and techniques they had used in the laboratory over the years, knowing that I would understand the language. This helped to circumvent the methodological challenge of lack of scientific training which was highlighted by Söderqvist at the beginning of this section. My own beliefs that technicians and those scientists carrying out the work on a daily basis are essential for the running of a department would most likely have been picked up on by those I was interviewing, and perhaps could have impacted their stories.

In addition to my own background, interviewees were also aware of the focus of my project, which involved using Malcolm Ferguson-Smith as a case study. The Participant Information Sheet clearly described that the focus of the project was Malcolm Ferguson-Smith, and that transcripts would be housed in his archive at the University of Glasgow, if permission was given to do so. Abrams has described how 'There are two people involved in an interview, which means two worlds, or subjectivities, are colliding'.[145] However, I would also argue that within my interviews there was often the

[143] Lillian Hoddeson, 'The Conflicts of Memories and Documents. Dilemmas and Pragmatics of Oral History', in *The Historiography of Contemporary Science, Technology and Medicine. Writing Recent Science*, ed. by Ronald E. Doel and Thomas Söderqvist, (Oxon: Routledge, 2006), p. 187.
[144] Abrams, *Oral History Theory*, p. 64.
[145] Ibid., p. 21.

presence not only of myself and the interviewee, but of Ferguson-Smith himself. Whilst not physically present at any interviews except for those carried out between myself and him, all those I interviewed for the project were aware that Ferguson-Smith knew about the project and was supportive of it, and that their testimonies would eventually be deposited in the Ferguson-Smith archive if they agreed to do so.

It could therefore be argued that the framing of this project had the potential to influence the pool of interviewees. Given the nature of the project, it is likely that those who agreed to be involved held positive memories of their time working in the medical genetics department under the leadership of Ferguson-Smith, as they were often keen to give up their time to speak in detail about their experiences. Employees who only worked in the department for a short time were unlikely to be suggested as potential interviewees, and it is also less likely that their forwarding address details would have been available. Thus, if there were individuals who worked in the department for shorter periods and perhaps did not have as positive an experience, they would have been hard to locate and invite to take part in the project. That the interviewees were made aware of the focus of the project prior to the interview could have impacted the response to the invitation to interview – if an individual did not wish to speak about their time in the department, they were under no obligation to reply to communications inviting them to do so. Additionally, due to the small numbers of staff who worked in the department at certain time periods, it was not possible to anonymise transcripts – identification would be possible by reading the stories they told which would often contain references to time frames, even if names had been redacted. Again, this is likely to have impacted the information that interviewees would have contributed whilst recounting the history of the department from their own perspective, as they would be aware that their colleagues could access their interview transcripts in the future.

All interviewees were given the option to read their completed transcript, and make changes to this document. Whilst from an ethical standpoint this was the correct path to follow, it also gave interviewees a chance to self-censor the information they had volunteered during the interview process. However, as highlighted above, the vast majority of the interviewees used the editing process to tidy up their grammar, and in

some cases, to clarify details, such as names and dates etc. that they felt were unclear from the transcript, as opposed to removing specific information. Some interviewees made several changes, whilst others made none at all. For Ferguson-Smith himself, there was likely to be an understanding of his place in the history books, and this could have impacted the events he discussed. He would likely have been more aware than many of the other interviewees that what he said in our discussions would form a lasting legacy, both within the University of Glasgow archives, and further afield. This could possibly lead to a more censored interview, which would perhaps provide more information on material which Ferguson-Smith knew was already available in the public record, as opposed to more personal recollections. As Ferguson-Smith had already taken part in a detailed oral history interview with Peter Harper in the past, it is likely that he had some experience with sorting his memories into a narrative that he was comfortable sharing. Being given an opportunity to edit the transcript potentially furthered this process. However, as with the other interviewees discussed above, Ferguson-Smith mainly focused on editing the grammar in the transcript, to reflect that of a more traditional text document, as opposed to a verbatim style transcription. He also utilised the opportunity to clarify details within the text itself, as some of the others did.

That this sort of historical awareness could cause problems has been discussed by other scholars, as highlighted by Söderqvist when detailing his project writing the biography of the immunologist Niels Jerne. He described how himself and Jerne 'became involved in a subtle continuous negotiation over the control of the story' over a period of four years, with Jerne expressing concerns about how Söderqvist would manage to understand all of the science involved with the project, having no scientific training.[146] This highlights a difficulty which can be encountered when writing the history of an individual who is aware of their historical presence. For Ferguson-Smith, this could have been reflected in the individuals that he suggested would be important people to interview as part of this project. It is unlikely that he would have recommended speaking to individuals that he had not formed a working relationship with, or who were not centrally involved in some aspect of the department. As Ferguson-Smith would have played a key role in shaping the careers of many of these individuals, this could have

[146] Söderqvist, 'What is the Use of Writing Lives of Recent Scientists?', p. 103.

led to a pool of interviewees who were more likely to speak positively about Ferguson-Smith, and the department more broadly. However, as mentioned earlier in the methodology section, there were several interviewees who were not directly suggested by or linked to Ferguson-Smith; it is hoped that their testimonies help to alleviate possible concerns about the ability of Ferguson-Smith to curate his own biography through this project.

All of the issues raised above link to the question of the reliability of oral history testimony for providing an accurate historical picture. Whilst there are issues involved in interviewing on an individual basis, it does provide the interviewee with the opportunity to provide a detailed account of their recollections. However, the reliability of these recollections is a source of discussion with regards to oral history; memory is known to be unreliable, and time can alter the perception of events. Thompson has highlighted how with interviews which stretch further back in time there is the 'added possibility of distortions influenced by subsequent changes in values and norms, which may perhaps quite unconsciously alter perceptions'.[147] As many of those interviewed have now retired, it is possible that looking back on their working careers as an overall experience would have coloured their view, with the small everyday frustrations being forgotten, in favour of the key events they recalled as being of particular importance. As all of the interviewees knew of the subject matter prior to the interview taking place, it is likely that they would have been actively thinking back over their career, selecting key events which would end up forming their narrative. It is also possible that memories of events are changed over time, however these distortions are of interest in themselves. Why one interviewee remembered an event in a slightly different manner from another serves to highlight the importance of the people involved in this work, and helps to form a more vivid picture of how these individuals worked together whilst retaining their sense of self. These nuances bring an added dimension to the story being told throughout this thesis, which paper documents alone could not achieve.

[147] Thompson, *The Voice of the Past*, pp. 128-129.

Whilst it was clear that the particular developments which were occurring in the area of prenatal testing in Glasgow could be accessed through archival documents and oral history interviews, as has been discussed above, relying solely on these sources could result in a biased account being written. There is therefore a need for information to be gathered from other sources which could provide a different perspective on the developments which were occurring in the medical genetics department in Glasgow, and for these developments to be placed in a national and international scientific and medical context. To enable analysis of how the work in Glasgow compared to the situation in other geographical areas, a number of scientific and clinical publications were examined. The challenge of interpreting a vast amount of publications as a caveat of contemporary scientific history which was highlighted by Söderqvist, was apparent when researching the material for this thesis, and so the decision was taken to choose key sources to analyse in detail. Two of the main sources used were the medical journals *The Lancet* and the *British Medical Journal*. Every issue of these journals from 1950 to 1990 were examined, and all relevant articles on prenatal testing and abortion were considered. This led to a far more enriched understanding of how the field of medical genetics and prenatal testing were developing more widely, and where the work of Ferguson-Smith and his colleagues fitted in. A number of other medical and scientific journals were also examined, including the *British Journal of Obstetrics and Gynaecology*, *Prenatal Diagnosis*, *Clinical Genetics*, the *Journal of Medical Genetics*, the *Journal of Medical Ethics*, and the *Scottish Medical Journal*. Again, each of these played a key role in enabling the work happening in the West of Scotland to be situated in a wider context.

By examining these varying journals, it also became possible to gain an insight into the wider social circumstances which were surrounding prenatal testing, including debates on the ethics and morality of termination of pregnancy. Both *The Lancet* and the *British Medical Journal* were particularly insightful for this purpose, as both contained large correspondence sections in each issue, which were often the site of heated debates amongst clinicians surrounding abortion issues. All relevant articles on abortion from all of the journals listed above were examined in detail, and assisted in the understanding of the changing social landscape in the 1960s surrounding termination of pregnancy.

As a key aim of this thesis is to examine the wider social response to prenatal testing, particularly of religious organisations, sources other than scientific and clinical journals were also examined to further aid understanding. As noted above, to build up a picture of how religious organisations in Scotland responded to prenatal testing, the views of two of the main groups at that time were considered, the Church of Scotland and the Roman Catholic Church. It was felt that newspaper and magazine publications by these organisations and their followers would provide an important insight into how they were responding to the development of prenatal testing. Two key publications for the Roman Catholic Church were considered for the period 1966 to 1987, *The Tablet* and the *Scottish Catholic Observer*, both of which were weekly newspapers. For the Church of Scotland the weekly Protestant newspaper publication *The British Weekly* was examined, alongside the monthly magazine publication of the Church of Scotland, *Life and Work*, both also from 1966 to 1987. Upon examination of these sources it became clear that *Life and Work* and the *Scottish Catholic Observer* would provide the best insight into the situation in Scotland. Both *The Tablet* and *The British Weekly* focused more on developments occurring throughout the United Kingdom more widely, often in England, which did not always reflect the situation in Scotland. It was therefore decided that *Life and Work* and the *Scottish Catholic Observer* would be the key sources of material for consideration of religious perspectives, and both publications were analysed for any discussion on abortion and/or prenatal testing.

The archive of Ian Donald was also considered. This is housed at the Mitchell Library in Glasgow, and was a useful source for providing an insight into the specific situation in the city whereby accessibility to abortion services was linked to the views of senior medical professionals. As highlighted above, interviews were also carried out with two Catholic priests and a Catholic midwife, to gain an understanding of the current perspective on prenatal testing and abortion within the Catholic Church. They were able to discuss religious teachings from the time period being examined, to highlight how these have impacted current beliefs. A number of the interviews I carried out with staff who had worked within the medical genetics field in the West of Scotland also discussed the subject of religion, specifically linked to prenatal testing and abortion. A

theme which emerged was whether or not religious identification impacted prenatal decision making, as this was discussed by a number of interviewees. To examine this interaction further, journal articles and books from a variety of authors were considered. These sources were examined to discern whether a link did exist between the choices that individuals made when faced with prenatal testing, and whether their religious identification, or more concisely, their religious adherence, played a role in their decision-making process. This information was gathered by considering material found in articles published at the beginning of the study time period, all the way through to current publications.

By utilising a number of different sources for this project, a complex and detailed understanding of the changes in the field of prenatal testing has developed. Utilising archives and oral history enabled the voices of those involved in the story from a Glasgow perspective to be told, and added a greater personal slant to the research. Due to the vast nature of the Ferguson-Smith archive, and his role as a key figure, the decision was taken to focus on this as the main archival source. Due to the quantity of documents in his archive, a great deal of time was required to analyse them in sufficient detail to ensure academic rigour. There are items contained within his archive, such as reports, which are related to the entire department, and not solely his person recollections. The inclusion of such items further highlights this archive as the most relevant source to be studied.

Another potential archive source which was considered for examination was the University of Cambridge archives, to elucidate if any resources were available which would provide further insight into Ferguson-Smith's move there. However, whilst it was confirmed that files do exist on Ferguson-Smith in that archive, as mentioned above, they are all closed to scholars due to data protection legislation. Therefore, these documents could not be accessed. Due to the vast volume of data which was present in the Ferguson-Smith archive, and the large numbers of oral history interviews which were carried out for this thesis, comparative archive studies were not carried out at other institutions, such as the University of Edinburgh. However, this could be an interesting

resource if a future study was carried out which compared the development of prenatal testing services in the East and West of Scotland.

As the scientific and medical discoveries which were occurring in the prenatal field coincided with a period of major social change in the United Kingdom with the implementation of the Abortion Act 1967, it was essential also to consider social responses to the testing. The response of the medical profession and religious organisations needed to be considered in detail, and this was achieved through the use of newspapers, magazines, journal articles and oral history interviews. The examination of material from the National Records of Scotland provided an insight into the views of the medical profession and those involved in the debates surrounding changing abortion legislation, including towards fetal anomaly. The Ian Donald archive also provided primary source material which was useful to analyse the specific impact that he had on the region of Glasgow. The high number of newspaper and magazine articles which were available for study required careful consideration, with each analysed in detail to glean any relevant information for this thesis.

Combining all of these sources highlights the importance of the scientific and medical developments which were occurring, but also shows that these developments were being driven by human agency. The implementation and spread of prenatal testing was a combined result of technical advances, and of individuals and society pushing them forward.

VIII. Chapter Outline

Chapter one focuses on the scientific and clinical developments which occurred throughout the 1950s to 1980s, which contributed towards making prenatal testing possible. It will examine the development of amniocentesis, and will argue that the discovery of the chromosome number in humans was essential to the formation of the prenatal testing field. The risks surrounding invasive prenatal testing methods will be examined, and it will also consider the move towards developing first trimester testing in the form of chorionic villus sampling. It will argue that the increased risk of

miscarriage associated with amniocentesis and chorionic villus sampling led researchers and clinicians to work on creating new screening programmes which changed the field of prenatal testing entirely. [148] These large-scale screening programmes opened up prenatal detection of a number of conditions to all pregnant women, and not just those who were known to have an increased chance of having a fetus with an anomaly. One of these less invasive testing methods was ultrasound, and it will argue that the diagnostic application of this technology owed a great deal to the individuals who developed its use in Glasgow. Consideration of the various technologies and techniques which resulted in the development of the prenatal testing field is essential for the chapters which will follow, which analyse the running of prenatal services for conditions such as chromosome anomalies and neural tube defects. Without an understanding of the development of the invasive and non-invasive testing methods, and the scientific discoveries which enabled them, it would not be possible to analyse the development and running of prenatal services in Glasgow and other locations.

To examine the development of prenatal services in Glasgow and the West of Scotland, the case study of the Glaswegian geneticist Malcolm Ferguson-Smith is being used as a conduit to explore these processes throughout this thesis. Chapter two will focus on the development of medical genetics in Glasgow, under the leadership of Ferguson-Smith. This chapter will consider several decades of Ferguson-Smith's life, c. 1950 to c. 1990, but will mainly focus on the time period of 1955 to 1987. 1955 is the year that Ferguson-Smith graduated with his medical degree, and 1987 is the year that he left his

[148] The language surrounding pregnancy loss has changed over time, with the term 'miscarriage' currently the recommended term by the Royal College of Obstetricians and Gynaecologists (RCOG). This term was initially suggested in 1997, as part of the recommendations from the 33rd RCOG Study Group. Under the 'Recommendations for health education and health policy' section of their report, the study group stated that 'the term 'abortion' should be replaced', and more specifically that '*Spontaneous abortion* should be replaced by *miscarriage*'. See Royal College of Obstetricians and Gynaecologists 33rd Study Group, 'Recommendations from the 33rd RCOG Study Group', in *Problems in Early Pregnancy: Advances in Diagnosis and Management*, ed. by J.G. Grudzinskas and P.M.S. O'Brien (London: RCOG Press, 1997), p. 330. These recommendations were taken up for use by the RCOG in 2006, and information on the recommended terminology can be found in their Green-top Guideline published in that year. See Royal College of Obstetricians and Gynaecologists, 'The Management of Early Pregnancy Loss', Green-top Guideline, no. 25, (2006), pp. 1-2. As noted above, the changing movement towards the use of the word 'miscarriage' occurred throughout the 1990s and 2000s, which is after the study period of this thesis. Therefore, throughout the time period of this PhD thesis other terms were frequently used, including 'spontaneous abortion'. To ensure historical accuracy, where necessary the original term will be used in direct quotes. Outside of such examples, the term 'miscarriage' will be used where possible.

position at the University of Glasgow. These dates therefore provide an overview of his career at the University of Glasgow. His early education and career will be considered, to trace his interest in the field of genetics, and how he became involved in studying chromosomes. It will be argued that a lack of interest in human chromosome research from others working in the field of genetics at the University of Glasgow led to Ferguson-Smith moving to the United States to pursue his chromosome research further, where he would develop a number of skills which would be essential for a career in medical genetics. This chapter will emphasise the strong connection that Ferguson-Smith felt to his home city, and how this influenced his decision to return to Glasgow to set up his own department. The expansion of medical genetics services under his leadership will be considered, and the financial challenges that the department faced over several decades will be highlighted. His move to the University of Cambridge in 1987 will also be discussed, alongside the impact this had on the running of the department, and how his departure affected his colleagues.

By considering the development of medical genetics in the West of Scotland, a detailed picture emerges of the expansion of prenatal testing in the region during this period. Throughout the time that Ferguson-Smith was leading medical genetics in Glasgow, one of the key antenatal testing programmes carried out by the department aimed at detecting chromosome disorders in the fetus. Chapter three will therefore examine the changes which occurred in the investigations into chromosome anomalies, not only in Glasgow, but also nationally and internationally. This chapter will begin with a consideration of the early work of researchers who were focused on analysing patterns of heredity for chromosome conditions before prenatal testing was possible. It will be argued that the development of amniocentesis, combined with the Abortion Act 1967, led to the expansion of the detection of chromosome anomalies in the fetus. The experience of the department led by Ferguson-Smith in implementing testing programmes for these conditions will be considered, and will be compared with that of other departments to highlight the similarities and differences between them. The technical issues and the debates surrounding the maternal age effect which were happening within the scientific and medical community will be examined, which will emphasise the difficulties associated with implementing a new form of medical testing. These difficulties were not only seen in the discussions taking place in medical journals

but, for some regions, were also reflected in lower than expected uptake rates of prenatal testing programmes. Some of the reasons behind these low uptake rates will be considered, and it will be argued that the development of serum screening programmes for chromosome anomalies had an impact on increasing the number of women participating in prenatal testing.

Chapter four will have a similar structure to chapter three, however it will focus on the development of testing for neural tube defects in the fetus. Beginning with an analysis of the discoveries which led to the testing becoming a clinical reality, it will then examine how the testing for these conditions developed in the West of Scotland within the medical genetics team led by Ferguson-Smith. The prenatal detection of neural tube defects became possible when a linkage was found between the conditions, and a molecule known as alpha-fetoprotein. This finding was published in 1972 by two researchers based in Edinburgh, David Brock and Roger Sutcliffe. As a key function of the medical genetics department in Glasgow was carrying out prenatal testing, the detection of neural tube defects formed a central component of the department's workload, despite the majority of neural tube defects not being linked to a genetic cause. As with chapter three, the experiences of the Ferguson-Smith group in the detection of these conditions will be considered, alongside reports from other clinical and scientific research teams, both throughout the United Kingdom and further afield. Some of the technical issues will be highlighted, and the work by researchers to develop ways of moving to less invasive testing for neural tube defects will be examined. The formation of serum screening programmes will be discussed in detail, and the regional disparities which emerged with their formation will be analysed. One key area where the research into neural tube defects differed from that of chromosome disorders, was the work which began in the 1970s and 1980s that suggested that vitamin supplementation could possibly prevent the formation of neural tube defects in the fetus. These findings caused many debates within the scientific and medical communities, and the ethics of clinical trials to either substantiate or disprove these findings will be discussed at length.

The possibility of preventing the formation of neural tube defects in the fetus, as opposed to terminating a pregnancy found to be affected, had the potential to greatly impact the prenatal testing field. It circumvented the issues associated with termination of pregnancy, to which a number of moral, religious and/or ethical objections were voiced. Chapters five and six will move away from considering scientific and clinical developments, and will instead examine the social context in which prenatal testing was situated. As highlighted in chapter two, the implementation of the Abortion Act 1967 was crucial for the development of prenatal testing, and chapter five will examine the processes which led to this legislation. It will consider early attempts to make abortion legislation more liberal, and will examine some of the key groups involved in these processes. A central argument of this chapter will be that fetal anomaly played an important role in impacting abortion legislation, and it will be argued that many medical professionals and members of the public viewed abortion for fetal anomaly as more acceptable than abortion for other reasons. How fetal anomaly was discussed within debates on the legislation will be examined, and it will be highlighted that some of the key concerns which were raised were related to the uncertainty of a diagnosis. Many of these debates on the fetal anomaly clause took place prior to the widespread implementation of prenatal testing, whereby it was far more difficult to correctly diagnose a condition prenatally in the fetus. It will be argued that by the time Steel's Bill was progressing, the fetal anomaly clause was widely accepted, with few individuals opposing this part of the legislation, or attempting to amend it.

The perspectives of several key professional medical bodies towards the subject of abortion will also be discussed within this chapter, and it will be suggested that each of these groups worked in such a way as to protect their own professional autonomy when campaigning either for or against changes to the abortion legislation. As much of this thesis focuses on the development of prenatal testing in Scotland, the views of two of the key obstetricians/gynaecologists in the country, Ian Donald and Dugald Baird, will be examined in detail. This analysis is particularly detailed in this chapter for Donald, as he was based in Glasgow and worked together with Ferguson-Smith on clinical cases and research projects. Other academics, such as Gayle Davis and Roger Davidson, and also Malcolm Nicolson, have examined the views of Ian Donald prior to this thesis. However, a key aim of this chapter is to further develop this work, by considering

Donald's views on termination of pregnancy for fetal anomaly, and the potential impact that his friendship with Malcolm Ferguson-Smith had on his clinical practice. This chapter will also consider the responses of several medical and religious groups to the publication of the Lane Report.

It was, however, not only those in the medical profession who could impact abortion legislation, and one of the key sets of groups who were keen to voice their opinions were religious organisations. Within chapter six, a more detailed examination will take place of the viewpoints of the Roman Catholic Church and the Church of Scotland. This chapter will begin with a broad overview of the views of these religions to the subject of abortion, and will then consider what efforts were made by both of these groups to influence abortion legislation when it was being drafted. It will argue that whilst the Church of Scotland were working to influence the exact wording of David Steel's Bill, the Catholic Church were unprepared for the fight against abortion. The perspectives of the Church of Scotland and the Catholic Church in the two decades following the implementation of the Abortion Act 1967 will be examined, with a consideration of whether they supported or opposed the more permissive abortion legislation. The next section of this chapter will consider whether religious identification and/or belief impacts decision making in prenatal testing situations. Whilst it might be expected that there would be a conflict between the teaching of the Catholic Church and prenatal testing, that might result in a termination of pregnancy, it will be shown that such tension does not seem to be completely reflected in decision making. It will be argued that many factors including religious observation can impact prenatal decision making. The decisions surrounding prenatal testing are multi-faceted and complex for each woman, and cannot be linked, solely or directly, to religious identification in the majority of cases.

Chapter One – The Development of Invasive and Non-Invasive Prenatal Testing Techniques

I. Introduction

For the majority of women who have been pregnant in recent decades, prenatal diagnostic testing has become a frequently offered procedure for the detection of fetal anomalies during pregnancy. From non-invasive methods, such as visualising the fetus by ultrasound, through to invasive tests including amniocentesis and chorionic villus sampling (CVS), prenatal testing has become centrally involved in the clinical care of pregnant women. Despite this integration, prenatal diagnosis has had a relatively short history. Whilst it had long been recognised that many medical conditions were inherited, it was not until the late 1950s that it became possible to identify any specific genetic conditions during pregnancy using prenatal testing methods. It has only been in the past few decades that the mysteries of fetal development have begun to be unravelled.

To analyse these changes in antenatal care, it is important to consider the historical development of the techniques and methods which made prenatal diagnosis possible. An understanding of these developments is essential for the reading of this thesis, as the use of amniocentesis, CVS and ultrasound formed the key components of prenatal testing in the medical genetics clinics and laboratories in Glasgow and beyond. This chapter will therefore provide a comprehensive history of these three key methods, to enable a detailed analysis to be made of prenatal testing programmes in future chapters.

This chapter will firstly examine the development of amniocentesis, considering a number of scientific and clinical events which highlighted its potential for use in detecting conditions prenatally. It will then examine the use of amniocentesis in testing for both chromosome anomalies and neural tube defects, arguing that for chromosome anomalies, the identification of the correct chromosome number in humans was essential for the testing to become clinically useful. It will also consider some of the main drawbacks associated with the testing, including the increased miscarriage rate

linked to the procedure, and the importance of clinician experience in reducing the number of fetal losses in this manner. The development of CVS will then be considered, including the rationale behind developing a test which could take place in the first trimester of pregnancy. It will argue that the increased miscarriage rate associated with this procedure when compared to amniocentesis resulted in the test being less popular with pregnant women than expected, highlighting the unpredictable nature of uptake rates of new testing methods.

The chapter will then argue that the increased miscarriage rate associated with both amniocentesis and CVS encouraged researchers to develop less invasive prenatal screening programmes, which could be used on the entire pregnant population with less risk of miscarriage. The development of screening programmes using biochemical markers will be outlined, as these programmes will form a central focus of future chapters, particularly chapter four, examining neural tube defects. The history of ultrasound and the move towards using it as a tool in prenatal testing will also be examined, outlining how ultrasound became centrally involved in directly detecting structural anomalies in the fetus, and also improved the safety of invasive testing methods such as amniocentesis.

II. The History of Amniocentesis

Amniocentesis is described by Sutton as the 'mainstay of prenatal diagnosis',[1] so it is fitting to begin this chapter with a discussion of its development. Amniocentesis is an invasive prenatal diagnostic technique which can test for a variety of conditions including chromosome disorders, single gene defects, and neural tube defects.[2] The transabdominal amniocentesis procedure is shown in Figure 1.1:

[1] Agneta Sutton, *Prenatal Diagnosis: Confronting the Ethical Issues*, (London: The Linacre Centre, 1990), p. 23.
[2] Ibid., p. 20.

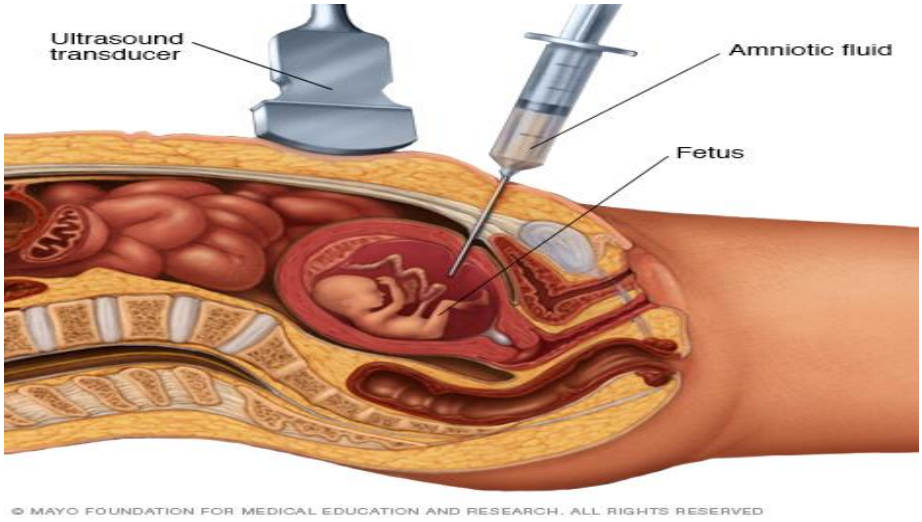

Figure 1.1 – Showing the transabdominal procedure of amniocentesis, which involves the insertion of a needle into the amniotic sac, through the abdominal wall, to remove amniotic fluid.[3]

Amniocentesis is typically carried out in the second trimester, at 15 to 17 weeks of pregnancy, and involves the removal of 20-30ml of amniotic fluid, to harvest fetal cells (amniocytes).[4] The use of amniocentesis as a diagnostic tool during pregnancy was described in 1952 by Douglas Bevis, a researcher based in Manchester. He studied amniotic fluid to assess the possibility of predicting the severity of haemolytic disease in fetuses of a Rhesus negative mother sensitised to the Rhesus antigen.[5] Bevis used the amniotic fluid to measure the concentrations of iron and urobilinogen, and showed that the 'results of analysis of the liquor amnii taken at various times in pregnancy indicate that the concentrations of non-haematin iron and urobilinogen offer a reliable guide to the outcome for the fetus'.[6] Dependent upon the result of the test, clinicians would

[3] 'Amniocentesis', *Mayo Clinic* <http://www.mayoclinic.org/tests-procedures/amniocentesis/multimedia/amniocentesis/img-20008561> [accessed 8th May 2018].
Transabdominal amniocentesis is the method currently used by clinicians. Transvaginal amniocentesis was performed in the past, however this was not widely adopted due to concerns about sepsis and the procedure inducing abortions. See A.C. Turnbull and I.Z. Mackenzie, 'Second-Trimester Amniocentesis and Termination of Pregnancy', *British Medical Bulletin*, 39:4 (1983), p. 1.
[4] Lynn B. Jorde, John C. Carey and Michael J. Bamshad, *Medical Genetics*, 4th Edition, (Philadelphia: Elsevier, 2010), p. 267.
[5] D.C.A. Bevis, 'The Antenatal Prediction of Haemolytic Disease of the Newborn', *The Lancet*, 259:6704 (1952), p. 395.
[6] Ibid., p. 397.

either induce birth, and/or give a blood transfusion as soon as the baby was born, with the main aim of saving the life of the baby.[7]

Bevis had shown that analysis of amniotic fluid could enable the prediction of the effects of a medical condition on a fetus before it was born, and also influence the outcome of the birth. It was a few years later that one of the next key developments using amniocentesis occurred, when in 1956 two Danish researchers, Fritz Fuchs and Povl Riis, showed that amniocentesis could be used for fetal sexing. They collected amniotic fluid in the middle of pregnancy or at term, and found that the sex of the fetus could be identified by the presence of sex chromatin, which is found in female cells but not in male cells.[8] Determining the sex of the fetus enabled parents who were carriers of sex-linked genetic conditions to select against having a child with the condition, through termination of possibly affected fetuses. For example, in the case of haemophilia, a woman who is a carrier of the condition has a 50% chance of passing this gene onto her children. As outlined in Figure 1.2, if the affected gene is passed to her son then he would have haemophilia, and if it is passed to her daughter then she would be a carrier. Whilst the carrier daughter would be unaffected, she could herself pass the condition onto the next generation. Thus, the pregnant woman could choose to terminate a male pregnancy to avoid having a child who was directly affected by the condition.

[7] Ilana Löwy, 'Prenatal Diagnosis: The Irresistible Rise of the 'visible fetus'', *Studies in History and Philosophy of Biological and Biomedical Sciences*, 47 (2014), p. 291.
[8] Fritz Fuchs and Povl Riis, 'Antenatal Sex Determination', *Nature*, 177:4503 (1956), p. 330.

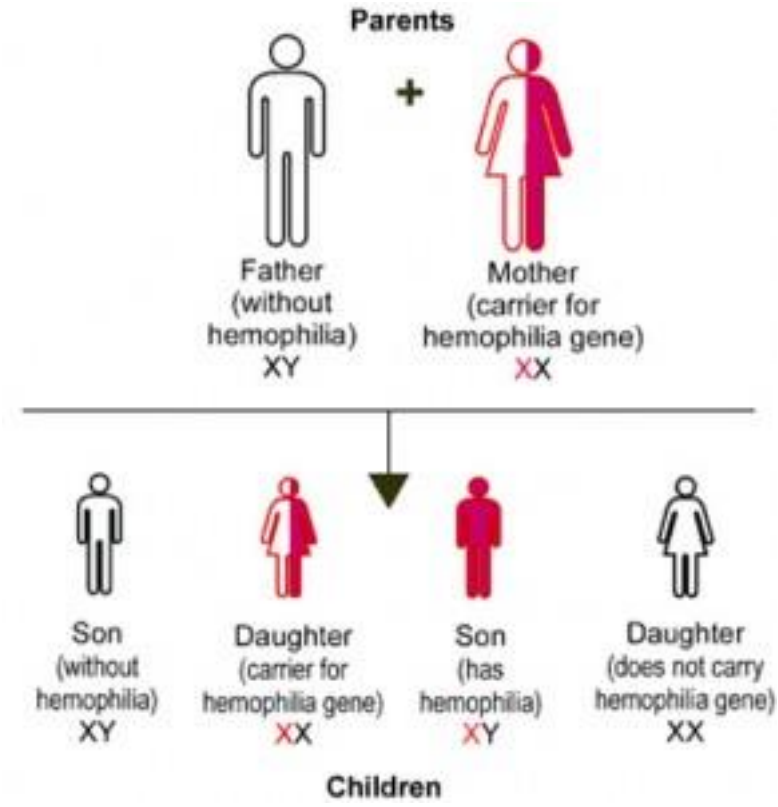

Figure 1.2 – Showing the patterns of haemophilia inheritance. The black X represents the unaffected gene, and the red X represents the affected gene. If the affected gene is passed on to the daughter then she will become a carrier, and if passed on to the son then he will be affected by the condition.[9]

Löwy has discussed the work of Fuchs and Riis in the context of a 1956 Danish Act, the Pregnancy Act, which permitted termination of pregnancy for a fetus which might be affected by a hereditary disease.[10] She has stated that the law was 'unmistakably eugenic'.[11] However, the case of a patient seen by Fuchs and Riis highlights the difference which can arise between the overall character of a law, and the individual application of it. The patient of Fuchs and Riis was a known carrier of haemophilia and had previously given birth to a son who had haemorrhaged and died within a few hours of his birth. When the woman discovered she was pregnant again, she had decided to terminate until she found out there was the option to determine the sex of the fetus. The

[9] 'Hemophilia A and B', *Indiana Hemophilia & Thrombosis Center, Inc.* <https://www.ihtc.org/patient/blood-disorders/bleeding-disorders/hemophilia-a-and-b/> [accessed 7th August 2018] (section titled 'Causes of Hemophilia').
[10] Löwy, 'Prenatal Diagnosis: The Irresistible Rise of the 'visible fetus'', p. 291.
[11] Ibid.

fetus turned out to be female and she opted to continue with the pregnancy, and went on to have a healthy baby girl.[12] Thus knowing the sex of her baby actually led her to choose to continue with a pregnancy which she would have otherwise terminated. The testing could therefore lead to increased numbers of continuing pregnancies in women who were carriers of sex-linked conditions.

Whilst Bevis, Fuchs and Riis used amniocentesis to gain general information about the fetus, it was not until the mid-1960s that it became possible to analyse the fetus on an individual level to gain information about its genetic constitution. These developments occurred as a result of advances in the field of cytogenetics, which involves the study of the structure and function of chromosomes. A critical moment in the discipline of cytogenetics occurred in 1956, when the correct chromosome number in humans was identified as 46 by Joe-Hin Tjio and Albert Levan of the Institute of Genetics in Lund, Sweden. Smeets has stated that this discovery 'paved the way for the start of a new era of clinical cytogenetics'[13] and Garcia-Sagredo attributes the 'birth of modern human cytogenetics' to the publication of the information 'that the diploid number of chromosomes in humans is 46'.[14] The story of the discovery of the correct human chromosome number has been discussed in detail by Kottler. He has described how human chromosomes were first observed in the 1870s and counted in the 1890s, with estimates of the chromosome number varying between 8 and 50.[15] Whilst most reports placed the number of diploid chromosomes at around 24, cytologist Hans de Winiwarter disagreed with these findings. He had studied chromosomes for several decades, and published a paper in 1912 which reported human chromosome numbers of 47 in spermatogonia and 48 in oogonia.[16] Human chromosome research was furthered in the 1920s when Theophilus Painter began working on mammalian chromosomes and was able to confirm Winiwarter's findings that the human chromosome number was in the 40s. Painter was sure the chromosome number was either 46 or 48, but could not decide

[12] Ibid.
[13] Dominique F.C.M. Smeets, 'Historical Prospective of Human Cytogenetics: From Microscope to Microarray', *Clinical Biochemistry*, 37:6 (2004), p. 440.
[14] J.M. Garcia-Sagredo, 'Fifty Years of Cytogenetics: A Parallel View of the Evolution of Cytogenetics and Genotoxicology', *Biochimica et Biophysica Acta*, 1779:6 (2008), p. 363.
[15] Malcolm Jay Kottler, 'From 48 to 46: Cytological Technique, Preconception, and the Counting of Human Chromosomes', *Bulletin of the History of Medicine*, 48:4 (1974), p. 467.
[16] Ibid., p. 469.

which of these figures was correct.[17] Despite his own comment that 'in the clearest equatorial plates so far studied only 46 chromosomes have been found' he eventually settled on 48 as the definitive number. [18] Kottler has theorised that Painter was influenced by Winiwarter's work, and as Painter was sure that Winiwarter had definitively shown the existence of a minimum of 47 chromosomes, this impacted on his decision to put the chromosome count at 48.[19]

It took several decades for technical advances to occur which would lead to the challenge of this figure. These advances began in the area of tissue cell culture as a result of work carried out in 1951 and 1952 by T.C. Hsu. Hsu found that altering the tonicity of the balanced salt solution which was used to rinse tissue cell cultures enabled chromosomes to be clearly visualised. Until this point chromosomes had been notoriously difficult to see, so this discovery was a 'turning point of critical significance'.[20] Despite these improved visualisation techniques, Hsu and others continued to put the chromosome number at 48. Whilst Hsu himself found it difficult to fit his own findings to the proposed number, it was so entrenched in the scientific literature that he felt it had to be correct. When necessary Hsu even 'reinterpreted long chromosomes as two shorter chromosomes aligned end-to-end in order to raise lower counts to the expected 48'.[21] Kottler has argued that this shows the 'reigning strength' of preconceived ideas in science, and Hsu himself believed that if he had analysed his cells without these preconceptions then he would have been the one to discover the correct chromosome number in humans.[22]

Advanced cell preparation techniques enabled clearer visualisation of human chromosomes, and two of the researchers in this field, Tjio and Levan, worked to exploit these developments. These techniques included using a hypotonic solution to rinse the cells, as discovered by Hsu, and also adding colchicine to cell cultures.

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[17] Theophilus S. Painter, 'The Y Chromosome in Mammals', *Science*, 53:1378 (1921), pp. 503-504.
[18] Ibid., p. 503.
[19] Kottler, 'From 48 to 46', p. 475.
[20] T. C. Hsu, *Human and Mammalian Cytogenetics An Historical Perspective*, (New York: Springer-Verlag, 1979), p. 21.
[21] Kottler, 'From 48 to 46', p. 491.
[22] Ibid.

Colchicine causes the cells to be arrested in the metaphase stage of mitosis, where they can then be examined with more ease.[23] Tjio counted 46 human chromosomes in a clear preparation which could not be doubted. The findings were published by Tjio and Levan in 1956, who ended the main body of their paper with the cautious but rational note that 'we do not wish to generalise our present findings into a statement that the chromosome number of man is 2n=46, but it is hard to avoid the conclusion that this would be the most natural explanation of our observations.'[24] The observations of 46 chromosomes were quickly confirmed by others including Ford and Hamerton.[25] As shown in Figure 1.3, the 46 chromosomes in humans are made up of 23 pairs – 22 of these pairs are autosomes, which are ordered numerically by size and are the same in both males and females. The 23rd pair are the sex chromosomes, composed of X and Y chromosomes, where biological males are XY and biological females are XX.

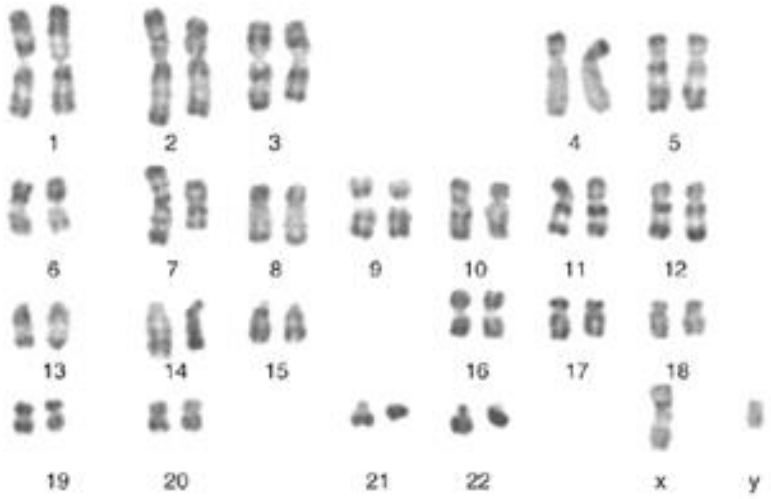

Figure 1.3 – Showing the human chromosome karyotype. All autosomes are shown as pairs, and the sex chromosomes are that of a genetic male.[26]

[23] Clare O'Connor, 'Mitosis and Cell Division', *Scitable by Nature Education* <https://www.nature.com/scitable/topicpage/mitosis-and-cell-division-205> [accessed 8th May 2018] (section titled 'Metaphase').
[24] Joe Hin Tjio and Albert Levan, 'The Chromosome Number of Man', *Hereditas*, 42:1-2 (1956), p. 5.
[25] C.E. Ford and J. L. Hamerton, 'The Chromosomes of Man', *Nature*, 178:4541 (1956), p. 1021.
[26] 'A Karyotype of Human Chromosomes', *Scitable by Nature Education* <https://www.nature.com/scitable/content/a-karyotype-of-human-chromosomes-6873458> [accessed 7th August 2018].

Ferguson-Smith has commented that Tjio and Levan 'heralded in the modern era of human cytogenetics' with their findings.[27] However, it was a combination of these discoveries with the finding that chromosomes could be analysed from amniotic fluid which would have such a big impact on prenatal testing. This discovery occurred in 1966, when Steele and Breg showed that some cells taken from human amniotic fluid were not only viable, but could be grown in culture and also karyotyped. Their neat summary statement that 'chromosome analysis of the fetus in utero is therefore feasible'[28] gives little clue that their findings would assist in the creation of a new field of medical testing.

With the human chromosome count having been established as 46, it quickly became possible to identify chromosome anomalies that diverged from this number, which changed previously held beliefs about certain conditions. For example, in 1952 Ursula Mittwoch had examined a Down's syndrome testicular sample and found the chromosome count to be 47 or 48. As the chromosome number at that time was thought to be 48, the conclusion was reached that the chromosome counts were the same as in those without the condition.[29] It was not until 1959 that a paper published by Jerome Lejeune, Marthe Gautier and Raymond Turpin confirmed that those affected by Down's syndrome had 47, rather than 46 chromosomes, which we now know is the result of an extra chromosome 21.[30] With knowledge of the extra chromosome number in Down's syndrome combined with Steele and Breg's discovery, it became possible to test pregnant women to see if they were carrying a fetus which had the condition. Other chromosome disorders were also being researched, including sex chromosome anomalies. Polani, working collaboratively with Ford, showed that patients with Turner's syndrome had only 45 chromosomes, including only one X chromosome and no Y chromosome,[31] and Jacobs showed that patients with Klinefelter's syndrome had

[27] Malcolm A. Ferguson-Smith, 'Cytogenetics and the Evolution of Medical Genetics', *Genetics in Medicine*, 10:8 (2008), p. 554.
[28] Mark W. Steele and W. Roy Breg, Jr., 'Chromosome Analysis of Human Amniotic-Fluid Cells', *The Lancet*, 287:7434 (1966), p. 385.
[29] Peter S. Harper, *A Short History of Medical Genetics*, (Oxford: Oxford University Press, 2008), p. 152.
[30] Peter S. Harper, *Landmarks in Medical Genetics*, (Oxford: Oxford University Press, 2004), pp. 72-73.
[31] C.E. Ford, K.W. Jones, P.E. Polani, J.C. De Almeida and J.H. Briggs, 'A Sex-Chromosome Anomaly in a Case of Gonadal Dysgenesis (Turner's syndrome)', *The Lancet*, 273:7075 (1959), p. 711.

47 chromosomes – two X chromosomes and one Y chromosome.[32] All of these studies were of great relevance to prenatal testing; having the knowledge of the genetic mechanisms underpinning numerous conditions allowed for diagnosis of these conditions in the fetuses of pregnant women when prenatal testing facilities became available. The ability to diagnose chromosome anomalies also became easier from 1968 onwards, when new staining techniques became available, using quinacrine dihydrochloride (Q-banding). When chromosomes were exposed to quinacrine, bands of different fluorescence showed up, which were distinct for each chromosome.[33] This made it much easier to identify which chromosome an anomaly was on, thus aiding diagnosis.

The diagnostic application of amniocentesis was expanded in 1972 by two researchers based in Edinburgh, David Brock and Roger Sutcliffe. They showed that analysis of amniotic fluid could also be used to detect neural tube defects (NTDs) in the fetus, such as spina bifida and anencephaly. Brock and Sutcliffe were interested in the analysis of biochemical markers for NTDs in amniotic fluid, and after researching and discounting the role of several molecules, they discovered that alpha-fetoprotein (AFP) could be used as a marker for fetuses with anencephaly and spina bifida. They found that levels of this protein were greatly raised in pregnancies affected by these conditions, and suggested that measuring AFP would be 'valuable in the early antenatal diagnosis of anencephaly and spina bifida and will enable termination of these pregnancies'.[34] This suggestion proved to be correct, and it became possible to detect a number of fetuses with neural tube defects in this manner.

Although the development of amniocentesis as a medical tool to detect chromosome anomalies and neural tube defects was a major scientific and medical breakthrough, the procedure was affected by a number of clinical, technical and ethical issues. The

[32] Patricia A. Jacobs and J.A. Strong, 'A Case of Human Intersexuality Having a Possible XXY Sex-Determining Mechanism', *Nature*, 183:4657 (1959), p. 302.
[33] Susan Lindee, *Moments of Truth in Genetic Medicine*, (Baltimore: The Johns Hopkins University Press, 2005), p. 118.
[34] D.J.H. Brock and R.G. Sutcliffe, 'Alpha-fetoprotein in the Antenatal Diagnosis of Anencephaly and Spina Bifida', *The Lancet*, 300:7770 (1972), p. 197.

technical and ethical issues will be discussed in subsequent chapters, but it is important to consider here the clinical implications of fetal loss that were associated with the testing. Whilst amniocentesis is currently linked to a 0.5-1% increase in miscarriage rate when carried out after 15 weeks gestation, [35] when the technique was first developed the potential risks to the pregnant woman and her fetus were unknown. Clinicians worked on learning the skills required for successful amniotic fluid sampling by carrying out the procedure on women who were seeking termination of pregnancy (these terminations usually being sought for social reasons). Several papers highlight this practice, with Nelson and Emery describing carrying out amniocentesis 'before installation of hypertonic solutions for induction of abortion',[36] and Hasholt collecting 'amniotic fluid obtained from normal pregnancies by transvaginal amniocentesis before inducing abortion'.[37] However, those working in the medical genetics field were acutely aware of the need to demonstrate risk figures associated with amniocentesis, relative to pregnancies which were not being terminated either immediately or shortly after the procedure was carried out.

A number of published studies appeared in the 1970s and 1980s from departments across the world, with varying fetal loss rates being quoted. In 1977 Philip and Bang published results of a study in which 0.3-0.7% of the 'spontaneous abortions' which occurred may have resulted from amniocentesis.[38] Others found similar fetal loss rates, with Munk-Andersen and colleagues reporting that the 'risk of abortion after amniocentesis apparently does not greatly exceed the spontaneous abortion risk for the same gestational age'.[39] These findings are consistent with the results of two larger-scale collaborative studies, one carried out by the National Institute of Child Health and Development in the United States of 1040 women undergoing diagnostic amniocentesis, and one collaborative study carried out in Canada which involved monitoring 1223 mid-

[35] 'Amniocentesis – Risks', *NHS Choices* <https://www.nhs.uk/conditions/amniocentesis/risks/> [accessed 28th May 2018] (section titled Risks).
[36] Matilda M. Nelson and A.E.H. Emery, 'Amniotic Fluid Cell Cultures', *Journal of Medical Genetics*, 10:1 (1973), p. 19.
[37] Lis Hasholt, 'Behaviour of Cell Cultures from Human Amniotic Fluid', *Journal of Medical Genetics*, 13:1 (1976), p. 34.
[38] John Philip and Jens Bang, 'Outcome of Pregnancy after Amniocentesis for Chromosome Analysis', *British Medical Journal*, 2:6146 (1978), pp. 1183-1184.
[39] Ebbe Munk-Andersen, Jan Weber and Margareta Mikkelsen, 'Amniocentesis in Prenatal Diagnosis. A Controlled Series of 78 Cases', *Clinical Genetics*, 11:1 (1977), p. 23.

trimester amniocentesis.[40] In both of these studies no difference was found between the amniocentesis group and control groups with regard to obstetric outcome. A slightly higher fetal loss rate was reported in a large study published in 1978 by the Medical Research Council (MRC) in the United Kingdom, where 2428 women undergoing amniocentesis were studied. The MRC trial found that the fetal loss rate was 2.6% in women undergoing amniocentesis, compared to only 1.1% in the control group, leading to a difference in fetal loss of 1.5%.[41] Similar findings of increased loss rates were reported by Webb and colleagues in 1980 (a risk of 1 to 1.5%),[42] and Tabor and colleagues in 1986 also found there were more miscarriages in their amniocentesis group (1.7%) compared to their control group (0.7%).[43]

The differences in these findings could result from a number of reasons, including the methodological designs of these studies. Adequate matching of controls and subjects is of clear importance if fetal loss rates are to be accurately compared between the two groups. However even a study as large and collaborative as the MRC report had difficulties in correctly matching women. As described by Turnbull, 'it sometimes took weeks or even months to find a suitable control. As the main study proceeded, analysis revealed that the incidence of abortion was higher in subjects than in controls, and the possibility was raised that this might result from controls being entered later into the study than the subjects, thus providing a control group at lesser risk of abortion'.[44] The chance of miscarriage decreases as a pregnancy progresses, which could lead to skewed results. It was discovered that, in one centre, if the pregnancy of a control miscarried,

[40] Barbara J. Culliton and Wallace K. Waterfall, 'Consensus Development – Amniocentesis', *British Medical Journal*, 2:6192 (1979), p. 723.
[41] Author Unknown, 'Editorial – The Risk of Amniocentesis', *The Lancet*, 312:8103 (1978), p. 1287.
[42] Tessa Webb, J H Edwards, A H Cameron, J Margaret Crawley, Maj Hulten, D I Rushton and R A Thompson, 'Amniocentesis in the West Midlands: Report on 1000 Births', *Journal of Medical Genetics*, 17:2 (1980), p. 86.
[43] Ann Tabor, John Philip, Mette Madsen, Jens Bang, Erik B. Obel and Bent Nørgaard-Pedersen, 'Randomised Controlled Trial of Genetic Amniocentesis in 4606 Low-Risk Women', *The Lancet*, 327:8493 (1986), p. 1291.
[44] A.C. Turnbull, 'Amniocentesis – The Medical Research Council Study', in *The Diagnosis and Management of Neural Tube Defects A Scientific Meeting of the Royal College of Obstetricians and Gynaecologists*, ed. by J.A. Jordan and E.M. Symonds (London: The Royal College of Obstetricians and Gynaecologists, 1978), p. 15.

then this person would be replaced by a control with a continuing pregnancy, thus leading to the lowering of the miscarriage rates in the control group.[45]

Another area which is important to consider when examining varying fetal loss rates is the impact of experience of the technique and availability of modern obstetric equipment, such as ultrasound, to improve pregnancy outcomes. In a formal discussion on the subject Ferguson-Smith highlighted that many people in the field were 'very anxious about the forthcoming results of this MRC trial' as it 'lumps together a great deal of information from different centres of different quality'.[46] As more amniocenteses were carried out by obstetricians, their skill level in carrying out the procedure improved, and this is correlated in some studies with a declining fetal loss rate. Leschot, Verjaal and Treffers analysed the number of fetal deaths and miscarriages which were associated with different amniocentesis numbers, having carried out 3000 amniocenteses in total. Of these 3000, between the 1st and 500th procedure the fetal death rate was 2.0%, this dropped to 1.3% between the 501st and 1500th, and 0.5% from the 1501st to the 3000th amniocenteses carried out. This highlights a declining fetal loss rate as experience is gained with the technique. They also considered whether the individual experience of the obstetrician could impact fetal loss rate, and found that in obstetricians who had carried out fewer than 10 amniocenteses, the loss rate was 3.7%. This decreased to 1.8% when obstetricians had carried out between 11 and 50 amniocenteses, and 0.3% when more than 50 had been carried out.[47] As different obstetric departments may have gained experience with amniocentesis at differing paces, the fetal loss rate could have changed at a non-uniform rate across various centres. As the risk of miscarriage as a result of amniocentesis is still quoted as 0.5-1%, these early studies were generally quite accurate in assessing risk of fetal loss. Despite this risk, amniocentesis is still used to diagnose a number of conditions prenatally today,

[45] Ibid.
[46] Comments made by Ferguson-Smith in the Discussion section of Turnbull, 'Amniocentesis – The Medical Research Council Study', p. 36.
[47] N.J. Leschot, M. Verjaal and P.E. Treffers, 'Risk of Midtrimester Amniocentesis; Assessment in 3000 Pregnancies', *British Journal of Obstetrics and Gynaecology*, 92:8 (1985), pp. 805-806.

including Down's syndrome and other chromosome disorders, in addition to conditions such as cystic fibrosis and muscular dystrophy.[48]

III. The Importance of Early Diagnosis – The Implementation of Chorionic Villus Sampling

Whilst amniocentesis played a key role in providing prospective parents with greater reproductive choice, it had the drawback of taking place in the second trimester of pregnancy. By this stage most women had felt the baby move and were bonding with their child, in addition to being visibly pregnant. Löwy has highlighted that in the early days of prenatal testing 'many physicians were not aware of the distress produced by a termination of pregnancy for foetal indications' and 'viewed the abnormal foetus as a 'problem' and its removal as a 'solution''.[49] However, over time it became recognised that the decision to terminate a longed for pregnancy was not easy, and to do so in the second trimester was thought by some to be particularly difficult for many parents. A study by White-Van Mourik and colleagues of couples who had undergone a termination in their second trimester as a result of a positive prenatal diagnosis showed an array of emotions felt by those affected, including depression, guilt and shame.[50] Second trimester termination of pregnancy is also more medically challenging and those working in the field at this time were aware of the 'grave complications'[51] that could accompany such terminations, and the benefits of replacing this with 'early termination by suction curettage … carrying a much lesser risk to the mother'.[52] A technology which allowed prenatal diagnosis to be undertaken earlier in pregnancy was highly sought after, and work began on developing an appropriate technique in the late 1960s. However, it was not until the 1980s that this goal was achieved and implemented into clinical practice, in the form of chorionic villus sampling (CVS). CVS involves the use

[48] 'Amniocentesis – Why it's Offered', *NHS Choices* <https://www.nhs.uk/conditions/amniocentesis/why-its-done/> [accessed 22nd April 2019].
[49] Ilana Löwy, 'How Genetics Came to the Unborn: 1960-2000', *Studies in History and Philosophy of Biological and Biomedical Sciences*, 47 (2014), p. 157.
[50] M.C.A. White-Van Mourik, J.M. Connor and M.A. Ferguson-Smith, 'The Psychosocial Sequelae of a Second Trimester Termination of Pregnancy for Fetal Abnormality', *Prenatal Diagnosis*, 12:3 (1992), p. 194.
[51] Z. Kazy, I.S. Rozovsky and V.A. Bakharev, 'Chorion Biopsy in Early Pregnancy: A Method of Early Prenatal Diagnosis for Inherited Disorders', *Prenatal Diagnosis,* 2:1 (1982), p. 41.
[52] Steen Smidt-Jensen and Niels Hahnemann, 'Transabdominal Fine Needle Biopsy from Chorionic Villi in the First Trimester', *Prenatal Diagnosis*, 4:3 (1984), p. 163.

of a catheter to extract several milligrams of fetal trophoblastic tissue for genetic analysis, using either a transcervical or transabdominal approach, approximately ten or eleven weeks into the pregnancy.[53] These two approaches are shown in Figure 1.4 and Figure 1.5:

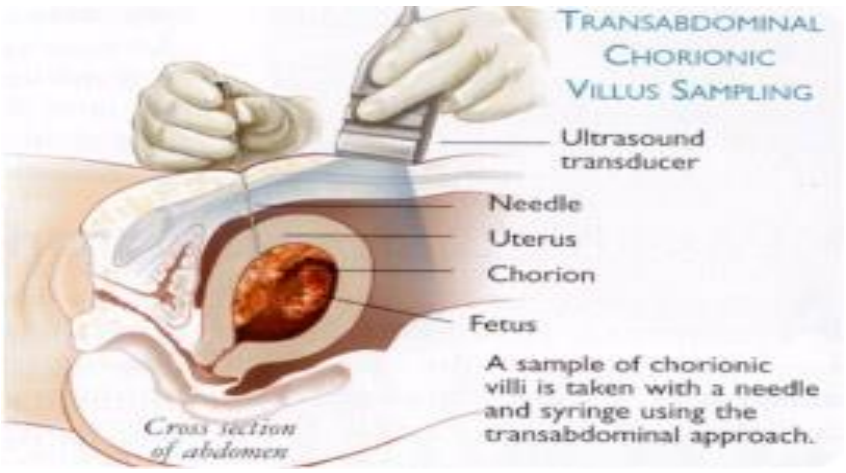

Figure 1.4 – Transabdominal CVS. A fine needle is guided through the wall of the abdomen into the placenta, under ultrasound control, and a biopsy of the placental tissue is taken.[54]

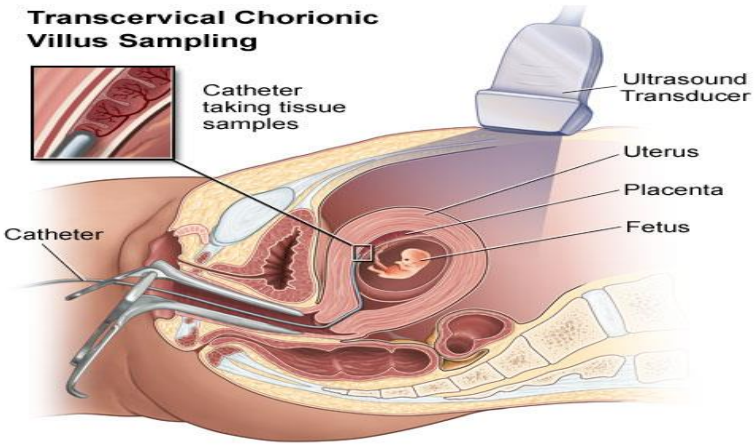

Figure 1.5 – Transcervical CVS. A catheter is inserted through the vagina and cervix, and guided towards the placenta using the ultrasound scanner. The catheter will then collect tissue samples from the placenta.[55]

[53] Jorde, Carey and Bamshad, *Medical Genetics*, p. 269.
[54] 'Chorionic Villus Sampling', *Ultrasound Care* <https://www.ultrasoundcare.com.au/services/prenatal-chorionic-villus-sampling.html> [accessed 8th May 2018].
[55] 'Chorionic Villus Sampling', *Stanford Children's Health* <http://www.stanfordchildrens.org/en/topic/default?id=chorionic-villus-sampling-90-P02442> [accessed 8th May 2018].

Two of the first researchers to work on CVS in the 1960s were Mohr and Hahnemann, who were based at the Aalborg Hospital in Denmark. In 1968 Mohr described the use of an instrument to 'cut off and collect any foetal membrane tissue' which he hoped could be analysed to enable the diagnosis of genetic conditions in the early stages of pregnancy.[56] In collaboration with his colleague Hahnemann, Mohr designed a more specialised instrument that was 6mm in diameter and contained a fibre optic device to allow direct visualisation of the chorion. Hahnemann trialled CVS on 94 women who were about to undergo an abortion, either immediately following the CVS procedure (67 cases) or 8 days after the procedure to allow for observation (27 cases).[57] Only 38% of the biopsies were successful, and in the outpatient group where CVS was performed several days prior to termination, '42% of studies would have entailed termination of pregnancy even if this had not already been planned i.e. the complications of the study were not consistent with continued pregnancy'.[58] A similar study of transcervical placental biopsies was published by Kullander and Sandahl in 1973 who also trialled the procedure on 39 women undergoing termination of pregnancy. Two fetal losses were recorded as a result of infection, and of the 39 biopsy samples taken, only 20 were able to be successfully cultured to gain knowledge about the fetal karyotype.[59] The high fetal loss rate experienced by Hahnemann, and the low culture success of Kullander, highlighted that, although CVS had promise, further work would be needed to improve the technique to a standard that was suitable for clinical practice.

The first successful CVS case was reported in 1975, by a team of Chinese researchers who had used a simple instrument with no fibre optic capacity to characterise the sex of fetuses. They used an aspiration technique to obtain fetal tissue from 100 women and reported four miscarriages.[60] However, research teams in the United States were unable

[56] Jan Mohr, 'Foetal Genetic Diagnosis: Development of Techniques for Early Sampling of Foetal Cells', *Acta Pathologica et Microbiologica Scandinavica*, 73:1 (1968), p. 77.
[57] Niels Hahnemann, 'Early Prenatal Diagnosis; A Study of Biopsy Techniques and Cell Culturing from Extraembryonic Membranes', *Clinical Genetics*, 6:4 (1974), p. 295.
[58] Ibid., p. 303.
[59] S. Kullander and B. Sandahl, 'Fetal Chromosome Analysis After Transcervical Placental Biopsy During Early Pregnancy', *Acta Obstetricia et Gynecologica Scandinavica*, 52:4 (1973), pp. 356-357.
[60] Laird Jackson, 'Prenatal Genetic Diagnosis by Chorionic Villus Sampling (CVS)', *Seminars in Perinatology*, 9:3 (1985), p. 209.

to replicate their results, with their efforts hindered by contamination of samples with maternal cells.[61] After these attempts, the idea of prenatal diagnosis in the first trimester of pregnancy lay dormant for a number of years.[62] It was not until 1982 that Kazy et al. published their report in *Prenatal Diagnosis* detailing the success of 165 biopsies carried out at 6 to 12 weeks of pregnancy using a needle of 1.7mm in diameter. They reported no miscarriages, and all women who chose to continue their pregnancy delivered the child as expected.[63] In December of 1982 several reports appeared in *The Lancet* of successful uses of CVS, highlighting the applicability of the technique. Gosden and colleagues demonstrated that fetal sex could be determined from chorionic biopsy samples taken from the fetus in the first trimester of pregnancy,[64] and Old et al. successfully diagnosed β-thalassaemia, a blood disorder that reduces the production of haemoglobin, from a fetal tissue sample obtained via a chorionic villus biopsy.[65] In 1983 Brambati and Simoni used the technique to diagnose a case of Down's syndrome at 11 weeks of pregnancy,[66] and Simoni also showed that it was possible to gain information on the fetal karyotype in just a few hours using a 'direct prep' method. This method did not involve the traditional cell culture techniques used previously, which resulted in long waiting times for results.[67]

Whilst CVS was becoming technically feasible, concerns were beginning to emerge about the fetal loss rate associated with the procedure. The data presented a confusing picture, with fetal loss rates varying amongst studies; for example, Muggah et al.

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[61] Neil S. Silverman and Ronald J. Wapner, 'Chorionic Villus Sampling', in *Prenatal Diagnosis and Screening*, ed. by David J.H. Brock, Charles H. Rodeck and Malcolm A. Ferguson-Smith (Edinburgh: Churchill Livingstone, 1992), p. 25.
[62] Joseph Woo, 'A Short History of Amniocentesis, Fetoscopy and Chorionic Villus Sampling', *Obstetric Ultrasound* <http://www.ob-ultrasound.net/amniocentesis.html> [accessed 20th April 2017].
[63] Kazy, Rozovsky and Bakharev, 'Chorion Biopsy in Early Pregnancy', pp. 41-45.
[64] J. R. Gosden, A.R. Mitchell, C.M. Gosden, C.H. Rodeck and J.M. Morsman, 'Direct Vision Chorion Biopsy and Chromosome-Specific DNA probes for Determination of Fetal Sex in First-Trimester Prenatal Diagnosis', *The Lancet*, 320:8313 (1982), pp. 1416-1418.
[65] J.M. Old, R.H.T. Ward, M. Petrou, F. Karagozlū, B. Modell and D.J. Weatherall, 'First-Trimester Fetal Diagnosis for Haemoglobinopathies: Three Cases', *The Lancet*, 320:8313 (1982), p. 1415.
[66] B. Brambati and G. Simoni, 'Letters – Diagnosis of Fetal Trisomy 21 in First Trimester', *The Lancet*, 321:8324 (1983), p. 586.
[67] G. Simoni, B. Brambati, C. Danesino, F. Rossella, G. L. Terzoli, M. Ferrari and M. Fraccaro, 'Efficient Direct Chromosome Analyses and Enzyme Determinations from Chorionic Villi Samples in the First Trimester of Pregnancy', *Human Genetics*, 63:4 (1983), p. 349.

reported a post-CVS miscarriage rate of 6.3%,[68] whilst Jackson and colleagues reported a 2.2% miscarriage rate.[69] Larger scale studies included the Report of a World Health Organisation (WHO) consultation on the risk evaluation of CVS, which pooled data from three large centres, and found that the fetal loss rate was 3.4% in the first few hundred cases in each centre, which fell to 1.7% as the CVS programme progressed.[70] This highlights that, in a similar manner to amniocentesis, as operator experience improved, fetal loss rates dropped. The WHO report concluded that when 'corrected for background losses obviously unrelated to CVS, the incidence of fetal loss following CVS appears to be no greater than 0.7 per cent'.[71] However, a similar large scale study carried out by the MRC in Europe evaluated the safety of CVS compared to amniocentesis in a study of around 3000 women, and found less reassuring results. It was found that 'chorion villus sampling in the first trimester reduces the chances of a successful pregnancy outcome by 4.6%' when compared to second-trimester amniocentesis.[72] The current miscarriage risk rate as a result of CVS is given as 1-2%, which is higher than the amniocentesis miscarriage risk rate of 0.5-1%, but current National Health Service guidance also states that it is unclear how many of these miscarriages would have occurred without a CVS procedure being undertaken.[73]

Whilst researchers and clinicians had been keen to develop CVS for first trimester testing, it is interesting to note that CVS did not become as popular a choice for women as the medical profession expected. The development of CVS co-existed with a belief that women would be keen to find out about anomalies earlier in pregnancy, but it seems that this did not occur in practice. As Hogan discusses, many women preferred to remain with amniocentesis due to the slightly lower risk to the fetus associated with this

[68] Henry Muggah, Alasdair G.W. Hunter, Brian Ivey and David M. Cox, 'Difficulties Encountered in a Randomization Trial of CVS versus Amniocentesis for Prenatal Diagnosis', *Clinical Genetics*, 32:4 (1987), p. 238.
[69] L.G. Jackson, R.A. Wapner and M.A. Barr, 'Letters – Safety of Chorionic Villus Biopsy', *The Lancet*, 327:8482 (1986), p. 674.
[70] Report of a WHO Consultation on First Trimester Fetal Diagnosis, 1 June 1985, 'Special Report – Risk Evaluation in Chorionic Villus Sampling', *Prenatal Diagnosis*, 6:6 (1986), p. 451.
[71] Ibid., p. 452.
[72] MRC Working Party on the Evaluation of Chorion Villus Sampling, 'Medical Research Council European Trial of Chorion Villus Sampling', *The Lancet*, 337:8756 (1991), p. 1496.
[73] 'Chorionic Villus Sampling – Risks', *NHS Choices* <http://www.nhs.uk/Conditions/Chorionic-Villus-sampling/Pages/Risks.aspx> [accessed 13th April 2017] (section titled Miscarriage).

procedure.[74] The exception to this trend seemed to be women who had an increased chance of having a fetus affected by a genetic condition, possibly one that the woman herself was a carrier for. This group seemed to be more willing to accept the higher risk associated with CVS in favour of receiving earlier results, possibly because of heightened awareness of the likelihood of their fetus having an anomaly.[75] In addition to concerns about the miscarriage rate, the premise around which CVS was developed, that termination of pregnancy at an earlier gestation would be psychologically 'easier' on a woman, did not prove to be applicable in many cases. A study carried out by Kolker in 1993, which investigated the experiences of women who had a termination of pregnancy for fetal anomaly after either amniocentesis or CVS, found that whilst 'late terminations are physically and emotionally traumatic, first-trimester abortions for abnormality carry a burden of their own', which they felt was 'largely unrecognized by caregivers and society at large'.[76] They interviewed a number of genetic counsellors whose views supported these findings. One described how it was 'devastating' for families to receive a diagnosis of anomaly, and that it 'hurts just as much whether they are at 12 weeks or 18 weeks … because they wanted that baby'.[77] Whilst termination in the first trimester may be 'simpler, cheaper, and safer for the woman', it does not necessarily mean it is emotionally easier;[78] it is 'wanted-ness, not gestational age' which is the 'critical factor'.[79] Rothman has also argued this point in *The Tentative Pregnancy*, where she states that 'The meaning of the abortion lies in the meanings the pregnancy holds for the woman … if the fetus is to be her child, if she has chosen to have this baby … then she considers that fetus to be a person. It is her baby. She means it to be her baby. To abort an accident is one thing. To abort your baby, even your very imperfect baby, is something else again.'[80]

[74] Andrew J. Hogan, 'Set Adrift in the Prenatal Diagnostic Marketplace: Analyzing the Role of Users and Mediators in the History of a Medical Technology', *Technology and Culture*, 54:1 (2013), p. 76.
[75] Ibid., p. 83.
[76] Aliza Kolker and B. Meredith Burke, 'Grieving the Wanted Child: Ramifications of Abortion After Prenatal Diagnosis of Abnormality', *Health Care for Women International*, 14:6 (1993), p. 514.
[77] Ibid., pp. 518-519.
[78] Ibid., p. 518.
[79] Ibid., p. 520.
[80] Barbara Katz Rothman, *The Tentative Pregnancy: Amniocentesis and the Sexual Politics of Motherhood*, 2nd Edition, (London: Pandora, 1994), pp. 5-6.

Other studies have shown that the severity of the condition is a more important factor in a woman's decision to terminate a pregnancy than her stage of gestation, with her decision 'focused on the severity of the disorder and only marginally influenced by when in gestation the decision is made'.[81] These varying opinions highlight the importance of providing women with a number of options for prenatal testing, and emphasise that medical tests are often developed in the absence of consultation with the groups who will be utilising them, and that these tests may prove not to be as popular as expected.

In addition to the higher fetal loss rate associated with CVS, the testing has also faced other issues which could have affected uptake rates, with one of the most important being the 'fetal limb defect controversy'.[82] Described in detail by Hogan, this controversy began in the early 1990s when reports began to surface linking CVS with defects in the form of missing fingers, toes and limbs in fetuses that had undergone the testing. The key paper describing these limb defects appeared in *The Lancet* in March 1991, by Firth and colleagues, which reported that among 289 pregnancies where CVS was carried out at 56-66 days' gestation, 5 babies with severe limb abnormalities were identified.[83] The authors concluded their paper with a note that they were aware the findings may have occurred by chance, but that they were concerned that CVS could have been a cause of the abnormalities found, and encouraged others in the field to examine their own experience for similar cases. In the months that followed, others from around the world, including researchers in Italy and China, wrote in to *The Lancet* with their own experiences, some of which seemed to further implicate CVS as a possible cause of limb defects. Mastroiacovo and Cavalcanti reported 4 cases of limb defect in their own study, and stated that their findings 'suggest an increased risk for transverse limb-reduction defect associated with CVS at any gestational age'.[84] Hsieh

[81] Mark I. Evans, Michelle A. Sobiecki, Eric L. Krivchenia, Debra A. Duquette, Arie Drugan, Roderick F. Hume, Jr., and Mark P. Johnson, 'Parental Decisions to Terminate/Continue Following Abnormal Cytogenetic Prenatal Diagnosis: "What" Is Still More Important Than "When"', *American Journal of Medical Genetics*, 61:4 (1996), p. 353.
[82] Hogan, 'Set Adrift in the Prenatal Diagnostic Marketplace', p. 76.
[83] Use of the term 'babies' as used by the original authors. H.V. Firth, P.A. Boyd, P. Chamberlain, I.Z. MacKenzie, R.H. Lindenbaum and S.M. Huson, 'Severe Limb Abnormalities After Chorionic Villus Sampling at 56-66 Days' Gestation', *The Lancet*, 337:8744 (1991), p. 762.
[84] Pierpaolo Mastroiacovo and Denise Pontes Cavalcanti, 'Letters – Limb-reduction Defects and Chorion Villus Sampling', *The Lancet*, 337:8749 (1991), p. 1091.

and colleagues also reported 4 fetal limb-reduction defects in their CVS cases, and concluded that 'limb defects cannot easily be dismissed as a possible complication of CVS'.[85] However, others working in the field were not as convinced, citing their own data that limb abnormalities did not seem to be increased in babies where their mothers had undergone CVS.[86] Despite uncertainty about the role of CVS in limb defects, stories linking the procedure and outcome began to appear in the press, interest in CVS reportedly began to decline amongst women, and some medical professionals suggested that women should not be offered the testing until this link could be examined in detail.[87] An investigation into this link was carried out and the results of just under 139,000 CVS tests were published in 1996 which showed that the number of limb defects did not differ significantly in fetuses that had undergone CVS than what would be expected in the general population.[88] Whilst this may have put an end to the controversy, it is reasonable to believe that this could have had an impact on the uptake of the testing during this time period. Indeed, the George Washington University Medical Center, reported that their annual number of CVS procedures had dropped by half between 1991 and 1992.[89]

IV. The Development of Non-Invasive Screening Programmes

The previous sections have considered two invasive testing methods for prenatal diagnosis, but as discussed above, some women would choose to forego testing if they felt that the risk to the fetus was too high. As a result of the risks involved, when prenatal diagnosis was developing it was mainly offered to those who were perceived as having a high chance of carrying a fetus with an anomaly, either because they had previously had a child with one of the conditions which could be tested for, or because of advanced maternal age, which is linked with an increased likelihood of chromosome anomaly in the fetus. However, offering testing to these small numbers of women did

[85] Fon-Jou Hsieh, Dar Chen, Li-Hui Tseng, Chien-Nan Lee, Tsang-Ming Ko, Sou-Ming Chuang and His-Yao Chen, 'Letters – Limb-reduction Defects and Chorion Villus Sampling', *The Lancet*, 337:8749 (1991), pp. 1091-1092.
[86] Giovani Monni, Rosa Maria Ibba, Rosalba Lai, Giovanni Olla and Antonio Cao, 'Letters – Limb-reduction Defects and Chorion Villus Sampling', *The Lancet*, 337:8749 (1991), p. 1091 and Maurice J. Mahoney, 'Limb Abnormalities and Chorionic Villus Sampling', *The Lancet*, 337:8754 (1991), pp. 1422-1423.
[87] Hogan, 'Set Adrift in the Prenatal Diagnostic Marketplace', pp. 76-77.
[88] Ibid., pp. 77-78.
[89] Ibid., p. 77.

not result in high detection rates in the overall pregnant population, as the majority of chromosome disorders and neural tube defects occur in the pregnancies of women who have not had previous experiences with either of these conditions. For example, in the case of neural tube defects, only 5% of cases have a previous history of such conditions, so the use of amniocentesis in women known to be at risk 'cannot reduce significantly the overall incidence of affected fetuses born in the community'.[90] As a result of the lack of 'success' of many prenatal testing programmes, researchers were keen to increase the number of fetal anomalies which were detected, and the potential implications of prenatal screening programmes began to be explored.[91]

Screening programmes were designed to detect members of the pregnant population who had a higher chance of having a fetus with certain conditions, such as neural tube defects, to provide them with the option of further diagnostic testing. One of the first screening programmes that was developed involved the use of alpha-fetoprotein (AFP), which had been found in raised quantities in the amniotic fluid if the fetus had a neural tube defect. Continued research by Brock showed in 1973 that it was possible to diagnose anencephaly through increased concentrations of AFP in maternal serum, as AFP migrates across the placenta.[92] This procedure circumvented the risk of the invasive amniocentesis procedure as it only required a blood sample from the pregnant woman, paving the way for genetic screening of the pregnant population. However, although the screening programmes could identify women who had an increased likelihood of their fetus having a NTD, they could not offer a definitive diagnosis, and clinicians were not willing to terminate pregnancies on the basis of a high chance screening result. It was therefore essential that amniocentesis testing was offered to those with raised levels of AFP in the maternal serum to confirm a diagnosis and lead to a termination of the pregnancy if requested.

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[90] Hugh P. Robinson, Valerie D. Hood, A. Hunter Adam, Angus A.M. Gibson and Malcolm A. Ferguson-Smith, 'Diagnostic Ultrasound: Early Detection of Fetal Neural Tube Defects', *Obstetrics and Gynecology*, 56:6 (1980), p. 705.

[91] The success of prenatal testing is a very subjective concept. For individuals who disagree with abortion, prenatal testing resulting in increased terminations of pregnancy would not be a 'success' story. However, for those who set out to reduce the number of babies born with these conditions, in their eyes the programmes which resulted in high detection and termination rates would perhaps be seen as successful.

[92] D.J.H. Brock, A.E. Bolton and J.M. Monaghan, 'Prenatal Diagnosis of Anencephaly Through Maternal Serum-Alphafetoprotein Measurement', *The Lancet*, 302:7835 (1973), p. 923.

The detection rates and acceptability of such screening programmes differed greatly between departments and regions throughout the United Kingdom, and the specific details of the testing and the issues associated with it will be discussed in chapter four. Briefly, in areas with a high incidence of neural tube defects the screening was seen as being widely 'successful', decreasing the number of babies born with anencephaly and spina bifida.[93] For example, in the West of Scotland, maternal serum AFP screening followed by ultrasound and amniocentesis was associated with a decrease of liveborn babies with neural tube defects from 4.3 per 1000 in 1976 to 1.7 per 1000 in 1981. [94,95] In contrast, a maternal serum AFP screening programme was carried out in Norfolk for two years, but was then discontinued as it did not fulfil the expectations held by staff there that it would 'prevent the birth of most live babies with neural tube defects'.[96]

As time progressed, other screening programmes began to develop, and AFP was also found to be a useful diagnostic marker for Down's syndrome. In 1984 Merkatz and his co-workers found that maternal serum AFP levels were around 25% lower in pregnancies affected by Down's syndrome than in pregnancies which did not have the condition.[97] Until this point, advanced maternal age and prior pregnancies with genetic anomalies had been the key indicators for amniocentesis to test for Down's syndrome, but testing of serum AFP levels allowed many more women to be screened for the condition, and offered amniocentesis when deemed appropriate by their clinician. Over time several other markers were found to aid in the screening for Down's syndrome, including human chorionic gonadotrophin and unconjugated oestriol.[98] A new screening

[93] As above, the success of these programmes is a very subjective one.
[94] Both nutrition and the standard of living were improving in the West of Scotland during this time period, which could have also contributed to this decrease.
[95] M.A. Ferguson-Smith, 'The Reduction of Anencephalic and Spina Bifida Births by Maternal Serum Alphafetoprotein Screening', *British Medical Bulletin*, 39:4 (1983), p. 371.
[96] Susan J. Standing, M.J. Brindle, A.P. MacDonald and R.W. Lacey, 'Maternal Alpha-fetoprotein Screening: Two Years' Experience in a Low Risk District', *British Medical Journal*, 283:6293 (1981), p. 707.
[97] Irwin R. Merkatz, Harold M. Nitowsky, James N. Macri, and Walter E. Johnson, 'An Association Between Low Maternal Serum α-fetoprotein and Fetal Chromosomal Abnormalities', *American Journal of Obstetrics and Gynecology*, 148:7 (1984), p. 886.
[98] For human chorionic gonadotrophin, see Mark H. Bogart, M.R. Pandian and O.W. Jones, 'Abnormal Maternal Serum Chorionic Gonadotrophin Levels in Pregnancies with Fetal Chromosome Abnormalities', *Prenatal Diagnosis*, 7:9 (1987), pp. 623-630.
For unconjugated oestriol, see N.J. Wald, H.S. Cuckle, J.W. Densem, K. Nanchahal, J.A. Canick, J.E. Haddow, G.J. Knight and G.E. Palomaki, 'Maternal Serum Unconjugated Oestriol as an Antenatal

strategy was developed which combined these markers with maternal serum AFP and maternal age to provide a likely probability of Down's syndrome in the fetus. These discoveries changed the field of prenatal diagnosis in an unprecedented manner, facilitating mass screening of the pregnant population.

V. The Importance of Ultrasound

Although screening opened up the possibility that many more women could have prenatal testing if required, it was still necessary for pregnant women to undergo an invasive amniocentesis to confirm or disprove the suspected diagnosis. Exceptions to this rule began to emerge with the development of ultrasound, perhaps the most well-known non-invasive prenatal testing method. Pioneered in Glasgow by Ian Donald and Tom Brown, ultrasound made it possible for the first time to safely visualise the fetus inside the womb. Thus, whilst amniocentesis and CVS enabled clinicians to analyse the genetic constitution of the fetus, ultrasound permitted them to examine the fetus for physical anomalies.

Although the technology was not implemented in routine prenatal testing until the 1970s, it was around 1954 that Donald developed a serious interest in examining the medical possibilities of ultrasound. This interest first began when Donald served as a Medical Officer in the Royal Air Force during the Second World War,[99] and was further piqued by reading the textbook *Ultrasonics*, which described the physics of ultrasound.[100] In 1955 Donald began to turn this interest into something tangible when he was introduced to a director at Babcock and Wilcox, an industrial fabrication company in Glasgow. This meeting was arranged after Donald operated on a female patient whose husband was a research director at the firm.[101] He was taken on a tour of

Screening Test for Down's Syndrome', *British Journal of Obstetrics and Gynaecology*, 95:4 (1988), pp. 334-341.

[99] 'Ian Donald', *The University of Glasgow Story* <http://www.universitystory.gla.ac.uk/biography/?id=WH2489&type=P&o=&start=0&max=20&l=> [accessed 20th April 2017] (para. 2 and 3).

[100] Malcolm Nicolson and John E.E. Fleming, *Imaging and Imagining the Fetus: The Development of Obstetric Ultrasound*, (Baltimore: The Johns Hopkins University Press, 2013), p. 88.

[101] Ann Oakley, *The Captured Womb: A History of the Medical Care of Pregnant Women*, (Oxford: Basil Blackwell Publisher Ltd, 1984), p. 158.

the factory, and whilst there he encountered ultrasound being applied to biological material, in the form of ultrasound technicians testing their ultrasonic flaw detectors on their thumbs. Echo spikes appeared in the oscilloscope screens of their machines when they did so, and if these were of the correct size then the technicians knew that the settings and sensitivity of the machines were configured correctly.[102]

Donald was keen to investigate whether the metal flaw detection equipment used at Babcock and Wilcox could be used for a clinical purpose, and after gaining permission to use their machines he took a number of specimens to the factory to be examined in July 1955. Donald wanted to determine if the metal flaw detector could distinguish between a cyst and a fibroid, and to his delight the difference was clear. In *The Captured Womb*, Oakley describes how Donald's enthusiasm shows through in his description of the events of that day, when he stated: 'I shall never forget it, because that was when I realised we'd struck oil … this was it. There was no getting away from it.'[103] Despite the success of these tests, it took another three years before ultrasound was shown to have a use in the detection of pregnancy, and it was in 1958 that the first image of the fetus as visualised by ultrasound was published in a paper by Donald, Brown and MacVicar. Their image showing the uterus of a woman fourteen weeks into her pregnancy was poignant not only because it showed the fetus at such an early stage, but also because the woman had been scanned for a suspected fibroid.[104] Thus ultrasound could be used to 'diagnose' pregnancy.

Over the next few years ultrasound was implemented in Glasgow, and in 1963 Donald and his team made an unexpected discovery which led to even better visualisation of the fetus. Patients were instructed to empty their bladder before the scan, but one woman was kept waiting for her appointment and hers filled up. She was too nervous to ask to use the bathroom, and went in for her appointment with a full bladder;[105] the examining obstetricians found that the sound waves of the ultrasound went straight through the

[102] Nicolson and Fleming, *Imaging and Imagining*, p. 90.
[103] Oakley, *The Captured Womb*, p. 158.
[104] Ian Donald, J. MacVicar and T.G. Brown, 'Investigation of Abdominal Masses by Pulsed Ultrasound', *The Lancet*, 271:7032 (1958), pp. 1192-1193.
[105] Nicolson and Fleming, *Imaging and Imagining*, p. 177.

liquid and provided a 'window into the pelvis' which allowed a view of the uterus in 'all its outlines, contours, length, dimensions, the lot'.[106] Donald himself described it as a 'beautiful view', and it formed the basis of the full bladder test to allow clearer visualisation of the uterus.[107]

It was evident that ultrasound could be of great use in the clinical care of pregnant women by enabling visualisation of the fetus. It had the potential to be of particular use in the detection of neural tube defects. This was realised in 1972 by Stuart Campbell and colleagues who diagnosed an anencephalic pregnancy at 17 weeks gestation which led to an elective termination of the pregnancy.[108] This was the first time that ultrasound had been used to detect a medical condition in the fetus early enough to enable termination. As experience was gained using ultrasound a number of other conditions could also be detected prenatally, including spina bifida and microcephaly,[109] alongside other non-neural conditions such as renal tract anomalies.[110] In some cases termination of pregnancy was carried out after diagnosis of such anomalies by ultrasound, without further invasive testing.

Alongside direct detection of fetal anomalies such as anencephaly, ultrasound also played less direct roles in the screening of neural tube defects. The maternal serum AFP screening programmes which were being implemented throughout the United Kingdom benefitted greatly from having ultrasound available to them, as false positive and negative screening results were often caused by factors which could be ruled out by ultrasound. Some of the most common reasons for a maternal AFP figure which did not correlate with the expected outcome of the pregnancy included an incorrect estimation

[106] Oakley, *The Captured Womb*, p. 161.
[107] Ibid.
[108] Stuart Campbell, F.D. Johnstone, E.M. Holt and Pamela May, 'Anencephaly: Early Ultrasonic Diagnosis and Active Management', *The Lancet*, 300:7789 (1972), p. 1226.
[109] Microcephaly is a condition where the fetus/baby has a smaller head than expected. This can occur because the brain has not developed properly during pregnancy, or has stopped growing after birth. 'Facts about Microcephaly', *Centers for Disease Control and Prevention – Birth Defects* <https://www.cdc.gov/ncbddd/birthdefects/microcephaly.html> [accessed 20th April 2017] (para. 2).
[110] S. Campbell and C. Rodeck, 'The Role of Ultrasound and Fetoscopy in the Diagnosis of Neural Tube Defects and Other Abnormalities', in *The Diagnosis and Management of Neural Tube Defects A Scientific Meeting of the Royal College of Obstetricians and Gynaecologists*, ed. by J.A. Jordan and E.M. Symonds (London: The Royal College of Obstetricians and Gynaecologists, 1978), pp. 88-95.

of gestational age, undetected multiple pregnancies, and missed 'abortions' (miscarriages).[111] As stated by Campbell 'AFP varies in maternal blood and in amniotic fluid with gestational age and values can only be correctly interpreted if the gestational age has been accurately determined by ultrasonic fetal measurements.'[112] Thus suitable ultrasound machinery was essential to ensure the accuracy of a serum test, leading in turn 'to the avoidance of unnecessary amniocentesis'.[113] Ultrasound could also be used to investigate the likelihood that a raised AFP level was truly indicative of a neural tube defect by examining the fetus for physical anomalies, thereby potentially avoiding the termination of pregnancies as a result of a false positive AFP test.[114] The view of some medical genetics centres, including that run by Ferguson-Smith in the West of Scotland, was that staff with experience of obstetric ultrasound were vital for AFP screening programmes.[115]

The use of ultrasound to detect fetal conditions was taken further in the 1990s, when it became possible to screen for Down's syndrome using ultrasound. A number of studies had shown a link between the collection of fluid behind the fetal neck (nuchal translucency) and chromosomal anomalies.[116] Nicolaides and colleagues used ultrasound in 1992 to visualise nuchal translucency thickness in the first trimester of pregnancy, and showed that the incidence of chromosomal anomalies was linked to nuchal translucency of greater than 3mm. They found that only 1% of fetuses with a nuchal translucency of less than 3mm were found to have chromosomal anomalies compared to 35% of those in which it was greater than 3mm.[117] In 1994 they carried out

[111] Robinson, Hood, Adam, Gibson and Ferguson-Smith, 'Diagnostic Ultrasound: Early Detection of Fetal Neural Tube Defects', p. 705.
[112] Campbell and Rodeck, 'The Role of Ultrasound and Fetoscopy', p. 87.
[113] Ibid.
[114] Ibid., p. 90.
[115] M.A. Ferguson-Smith, H.A. Rawlinson, H.M. May, P.N.C. Gent and J.G. Ratcliffe, 'Maternal Serum Alphafetoprotein in Prenatal Screening for Open Neural Tube Defects', in *The Diagnosis and Management of Neural Tube Defects A Scientific Meeting of the Royal College of Obstetricians and Gynaecologists*, ed. by J.A. Jordan and E.M. Symonds (London: The Royal College of Obstetricians and Gynaecologists, 1978), p. 64.
[116] K. H. Nicolaides, M.L. Brizot and R.J.M. Snijders, 'Fetal Nuchal Translucency: Ultrasound Screening for Fetal Trisomy in the First Trimester of Pregnancy', *British Journal of Obstetrics and Gynaecology*, 101:9 (1994), p. 782.
[117] K H Nicolaides, G Azar, D Byrne, C Mansur and K Marks, 'Fetal Nuchal Translucency: Ultrasound Screening for Chromosomal Defects in First Trimester of Pregnancy', *British Medical Journal*, 304:6831 (1992), p. 868.

a study on 1273 pregnant women, examining them with ultrasound between ten and thirteen weeks of pregnancy to measure fetal nuchal translucency thickness. They found that 84% of trisomy 21 fetuses had nuchal translucency of greater than 3mm, compared to only 4.5% of chromosomally unaffected fetuses.[118]

In addition to providing direct diagnoses, ultrasound was also beginning to improve the safety of invasive prenatal testing methods. This is shown in the 1972 publication by Bang and Northeved, based in Copenhagen, which described ultrasound-guided amniocentesis. Before ultrasound was used in amniocentesis, the procedure had been carried out blind, with the puncture site located by external palpation of the uterus in the abdomen.[119] By using ultrasound to assist with amniocentesis, practitioners could use a one-dimensional A-mode ultrasound scan to visualise a free pocket of amniotic fluid and mark the point of entry for the needle on the abdomen, thereby minimising the injury risk to the placenta. This increased safety was reported by Harrison et al. in 1972 who showed that the incidence of fetomaternal transfusion, which is caused by damage to the placenta, was halved when using ultrasound-guided amniocentesis.[120]

Several technical innovations have helped to further enhance the use of ultrasound in prenatal testing. For instance, the addition of grey-scaling enhanced the imaging of soft tissue structure. Ultrasound can now be used to diagnose multiple pregnancies, determine the size and age of the fetus or fetuses, and recognise a range of structural fetal anomalies including problems with limb formation. The development of quicker, portable ultrasound scanners further assisted with their incorporation into antenatal care.

[118] Nicolaides, Brizot and Snijders, 'Fetal Nuchal Translucency: Ultrasound Screening for Fetal Trisomy', p. 785.
[119] Woo, 'A Short History of Amniocentesis, Fetoscopy and Chorionic Villus Sampling'.
[120] Robert Harrison, Stuart Campbell and Ian Craft, 'Risks of Fetomaternal Hemorrhage Resulting from Amniocentesis With and Without Ultrasound Placental Localisation', *Journal of Obstetrics and Gynecology*, 46:4 (1975), p. 391.

VI. Conclusion

The field of prenatal testing has developed at a rapid pace since its inception in the 1950s, with many of the techniques being quickly incorporated into clinical practice. The development of amniocentesis and CVS enabled in-depth genetic analysis of the fetus before it was born, but neither tests were without risk. Despite the increased chance of miscarriage associated with both amniocentesis and CVS, many women were still keen to undergo the testing to plan for their future. This demonstrates the demand for knowledge about the fetus which exists amongst many women, and also shows the impact that prenatal diagnosis has had on the female population, who now have the option to find out information about the fetus prior to birth.

This chapter has highlighted how the interactions between laboratory research and clinical developments paved the way for invasive prenatal testing to become an established aspect of antenatal care, using amniocentesis and CVS as examples. Whilst there was considerable uptake of these tests, those involved in prenatal testing were keen to develop alternative methods which carried less risk of miscarriage. This drive, it has been argued, led to the development of non-invasive prenatal screening programmes, such as those involving biochemical markers in the maternal serum. However, even these screening programmes were not truly non-invasive, as an amniocentesis or CVS procedure was still required to confirm diagnosis of the suspected anomaly before termination could take place. It could therefore be argued that the only truly non-invasive prenatal method is that of ultrasound, which made it possible to visualise physical anomalies of the fetus in utero. Ultrasound also played an essential role in improving the efficiency of maternal serum screening programmes and the safety of amniocentesis, placing it in a central role in the provision of antenatal care.

The technical developments discussed in this chapter have resulted in more information for prospective parents to enable them to make decisions regarding their reproductive future. However, it is important to note that there are members of society who do not view the testing and information it provides as a positive development – their views will be discussed in chapters five and six in this thesis. The next chapter of this thesis will examine the development of the medical genetics field in Glasgow under the leadership

of Malcolm Ferguson-Smith, followed by a chapter on the detection of chromosome anomalies, and one on the detection of neural tube defects, respectively. Within all of these chapters the use of the invasive and non-invasive prenatal testing methods will be discussed in detail, emphasising the important nature of the developments presented in this chapter.

Chapter Two – The Formation and Expansion of Medical Genetics in Glasgow, Under the Leadership of Malcolm Ferguson-Smith

I. Introduction

As shown in the previous chapter, the field of genetics has progressed at a fast pace over the last few decades, with a key development being the advent of prenatal diagnostic testing. This development has been of great significance, as previously the information which was available about the health of a fetus before birth was limited. One of the key aims of this thesis is to understand how prenatal testing developed in the specific geographical region of the West of Scotland. This is of importance, as the major developments occurring in this area have never been examined in detail. This research will look at the period between 1950 and 1990, using the case study of a local Glaswegian geneticist, Malcolm Ferguson-Smith. Described as both 'eminent'[1] and a 'pioneer of methods for prenatal diagnosis of genetic disease',[2] Ferguson-Smith was the key figure who helped to develop and implement prenatal testing in the West of Scotland. To gain a greater understanding of the contributions made by Ferguson-Smith, it is important to consider a biography of his life and career, as this provides an insight into the circumstances which led to his involvement in this area.

This chapter will begin by exploring Ferguson-Smith's education and early career, examining some of the key events and contacts that stimulated his interest in genetics as a subject area, particularly with regards to chromosome studies. It will highlight how a lack of interest in human chromosome work in Glasgow led to Ferguson-Smith moving to Johns Hopkins University in Baltimore, where the opportunity to develop skills in analysing chromosomes was responded to with enthusiasm. This chapter will then argue that a sense of loyalty to his home city led Ferguson-Smith to return to Glasgow, and will detail the difficulties faced when trying to establish medical genetics there.

[1] Malcolm Nicolson and John E.E. Fleming, *Imaging and Imagining the Fetus: The Development of Obstetric Ultrasound*, (Baltimore: The Johns Hopkins University Press, 2013), p. 223.
[2] 'Malcolm Ferguson-Smith', *The Royal Society* <https://royalsociety.org/people/malcolm-ferguson-smith-11429/> [accessed 31st August 2019] (Biography section).

The next area for analysis will be the expansion of medical genetics in Glasgow under the leadership of Ferguson-Smith, including the establishment of a regional genetics service, and the increasing number of tests which were being carried out within the laboratories and clinics. These increased numbers of tests led to a need for more space, and the process of the planning and development of the Duncan Guthrie Institute of Medical Genetics will be examined. Finally, Ferguson-Smith's surprise move to the University of Cambridge will be considered, and his rationale behind this decision discussed. The impact of this decision on the staff working for Ferguson-Smith will be examined, as will, briefly, his later career in Cambridge.

II. Education and Early Career of Malcolm Ferguson-Smith

Malcolm Ferguson-Smith was born on the 5th September 1931 in Glasgow, the youngest of four siblings, all of whom would go on to pursue careers in medicine.[3,4] These career choices were perhaps not a great surprise, as the Ferguson-Smith family were well entrenched in the medical sphere. Ferguson-Smith's father was the distinguished dermatologist John Ferguson-Smith, Consultant Physician in Diseases of the Skin at the Glasgow Royal Infirmary, and Lecturer in Dermatology at the University of Glasgow.[5] Malcolm Ferguson-Smith was surrounded by medical influences from a young age – his family home in Woodside Place in the city was the house in which Lister had lived whilst he was developing his antiseptic techniques in Glasgow, and his father ran a medical consulting practice from home in the afternoons, which his mother helped to maintain.[6] Ferguson-Smith recalled that the area of Glasgow they lived in was so full of medics that it was 'known locally as "the valley of the shadow of death"'.[7]

[3] All interview file names begin with 'DS' followed by a number, except for those carried out with KM and MEFS. Interviews have been transcribed and will be stored in the Ferguson-Smith archive at the University of Glasgow upon completion of the PhD.
[4] MAFS interview, DS300114, p. 1. Interviews with Malcolm Ferguson-Smith, 12th and 13th November 2015. The career of Malcolm Ferguson-Smith will be discussed throughout this chapter.
[5] 'John Ferguson Smith', *The University of Glasgow Story* <http://www.universitystory.gla.ac.uk/biography/?id=WH22014&type=P&o=&start=0&max=20&l=> [accessed 9th February 2016] (para. 3).
[6] MAFS interview, DS300114, p. 1.
[7] Ibid.

Despite being surrounded by strong academic influences, Ferguson-Smith's early education did not get off to a remarkable start. He was educated at Glasgow High School from the age of five until ten, before his father decided to withdraw him from the school as he did not think he was working hard enough.[8] Ferguson-Smith recalled that he 'hadn't been doing very well during wartime' and 'was said to be lazy and badly behaved in class' and his father therefore decided to send him to Craigflower Preparatory School in Fife.[9] Once at this preparatory school his academic progress improved and at the age of thirteen he passed his common entrance exams and moved to Stowe Boarding School in Buckinghamshire, where he would remain until 1949.[10] He recalled that it 'was not a particularly exciting time for me at school although it was a lovely place'. However, his educational experiences at Craigflower and Stowe stimulated his interest in biology, and whilst at Stowe he won a biology prize for his dissection of a dogfish.[11] Ferguson-Smith recalled with some humour that his biology teacher at school 'never thought I'd ever become a doctor' because he 'thought I wasn't working hard enough', but at the end of his school career he secured admission to study medicine at the University of Glasgow.[12]

Ferguson-Smith began his medical studies in 1949 and throughout his time at the university he was a successful student who was awarded prizes in Clinical Surgery and Medical Paediatrics.[13] After graduating in 1955 he completed two residencies; one as a House Physician with Dr William Snodgrass, and the other as a House Surgeon with Sir Charles Illingworth.[14] He had great respect for Snodgrass, but 'crossed swords' with Illingworth for several reasons, one of which was that Illingworth 'didn't think much of

[8] Ibid.
[9] Ibid.
[10] Ibid.
[11] Ibid.
[12] Ibid.
[13] The Malcolm Andrew Ferguson-Smith archive is held at the University of Glasgow and has been catalogued and digitised as part of the Wellcome Trust funded Codebreakers: Makers of Modern Genetics collection. All archival documents referenced in this chapter have been downloaded from the Wellcome Trust website; page numbers refer to the PDF page number of the document.
University of Glasgow Archives, Papers of Malcolm Andrew Ferguson-Smith, UGC 188/1/2/1, Material relating to job applications, p. 4.
[14] MAFS interview, DS300114, p. 2.

genetics'.[15] Although Ferguson-Smith was not yet working in genetics, this highlights that his passion for the subject was already developed and that this was an area he felt strongly about. After completing his degree and residencies Ferguson-Smith wanted to specialise in general medicine, and decided that the best way to gain knowledge of this field was to apply for a job in pathology, as he felt that if 'one understood the science of disease then one would be better placed as a physician'.[16] In 1956 he was appointed Senior House Officer in Pathology at the Western Infirmary in Glasgow, under Professor Dan Cappell.[17] His time spent here influenced his career in such a notable way. Whilst he was based in the department the esteemed pathologist Bernard Lennox was looking for a trainee to help him with a nuclear sexing project; upon visiting the workroom of the trainees, Lennox found Ferguson-Smith at his microscope and commented 'something to the effect that as I did not appear to be overworked would I be interested in joining him in a nuclear sex project'.[18] After reading one of Lennox's editorials Ferguson-Smith was 'hooked', and thus began his extended interest in chromosome disorders.[19]

Lennox was interested in studying Klinefelter's syndrome, a chromosomal disorder which affects male physical and cognitive development, and which we now know is due to the presence of an extra X chromosome. However, at that time it was proposed that Klinefelter's was a sex chromosome anomaly disorder in which males had 'female' nuclear sex, so Lennox suggested that Ferguson-Smith should begin by looking for sex chromatin (present in females but not in males) in male children with undescended testes.[20] Lennox thought that these children were 'the most likely source' of patients with Klinefelter's,[21] but despite Ferguson-Smith studying 115 males, no cases of Klinefelter's were found.[22] A key figure involved in this work was Mr Mack, the

[15] Ibid.
[16] Peter Harper, 'Interview with Malcolm Ferguson-Smith, 2003.' *Interviews with Human and Medical Geneticists series* <http://www.genmedhist.info/interviews/Ferguson%20Smith> [accessed 12th July 2018], p. 3.
[17] UGC 188/1/2/1, Material relating to job applications, p. 4.
[18] UGC 188/1/1/4, Correspondence between Ferguson-Smith with Professor John Anderson on the history of genetics at Glasgow, p. 4 (letter dated 18th August 1992).
[19] Ibid.
[20] Malcolm A. Ferguson-Smith, 'Putting Medical Genetics into Practice', *Annual Review of Genomics and Human Genetics*, 12:1 (2011), p. 2.
[21] MAFS interview, DS300115, p. 2.
[22] Ferguson-Smith, 'Putting Medical Genetics', p. 2.

surgeon in charge of urology at the Western Infirmary in Glasgow, who gave Ferguson-Smith access to patients and samples for testing, and allowed him to collect testicular biopsy samples from patients who were infertile.[23] Ferguson-Smith recalled the process of these first studies into Klinefelter's syndrome, and the subsequent work on infertile males which followed this, in great detail during his interview:

> So I looked at a whole series of Mr Mack's patients with undescended testes and didn't find a single Klinefelter. But having been with Mr Mack and having read up about Klinefelter's syndrome I knew they were all infertile so I asked him if he had seen any of these patients at his infertility clinic. He said no he hadn't and I said (off my own bat) would you mind if I went into the infertility clinic and looked for them there. The eighth person I tested for the sex chromatin body was a Klinefelter and there were soon others. And that resulted in the first paper I wrote with Dr Lennox on the frequency of Klinefelter's syndrome among subfertile patients with either no sperm in their semen samples or with very few. About 11% of these patients had Klinefelter's syndrome. I became very interested in these patients with Klinefelter's syndrome and took careful histories.[24]

It was thought at this time that patients with Klinefelter's were sex-reversed females with two X chromosomes, but studying the testicular biopsy of one of Mr Mack's patients made Ferguson-Smith query this presumption:

> And then another patient was referred to Mr Mack with query Klinefelter's syndrome. He was a young man who had been examined for his army medical and found to have small testicles. Mr Mack did a testicular biopsy on this man and I got the biopsy to examine and sure enough he was a Klinefelter. But when I looked at the testicular biopsy it was very unusual because I found one tubule that had complete spermatogenesis with mature sperm.[25]

This finding convinced Ferguson-Smith of the need to study these chromosomes in greater detail to gain a better understanding of the condition. Whilst these findings were of great interest, his enthusiasm was not reflected by others working in Glasgow during this time period. Upon approaching the head of genetics, Guido Pontecorvo, with his

[23] MAFS interview, DS300110, p. 1.
[24] MAFS interview, DS300115, pp. 1-2.
[25] Ibid., p. 3.

findings, Ferguson-Smith found him to be not 'the least bit interested, he said "we don't look at chromosomes here as we are more interested in biochemical genetics"'.[26] However, he suggested that Ferguson-Smith contact Charles Elliott, the person most interested in chromosome research in Glasgow.[27] Elliot was working on the chromosomes of a fungus, *Aspergillus*, but he put Ferguson-Smith in touch with Charles Ford, an expert on mammalian chromosomes who was based at the Medical Research Council Radiobiological Research Unit in Harwell.[28] Ford informed Ferguson-Smith about a bone marrow preparation technique he was developing to visualise chromosomes; Ferguson-Smith attempted to replicate this technique, but had little success.

III. The Move to Johns Hopkins University

One of the reasons behind this lack of success was that Ferguson-Smith was working to develop the technique in his free time in the evenings and at weekends, and was unable to dedicate time during his working schedule to advance his skills in this area. It was suggested by Professor Cappell that he would benefit from undertaking a fellowship elsewhere, where he could focus on developing his chromosome visualisation techniques.[29] Ferguson-Smith was put in touch with Victor McKusick of Johns Hopkins University in Baltimore in the United States, who was setting up a medical genetics laboratory. After an interview in Liverpool, arrangements were made for Ferguson-Smith to join McKusick to work on developing the bone marrow preparation technique to enable analysis of the chromosomes in Klinefelter's.[30] A letter to Ferguson-Smith on the 6th October 1958 confirmed that Johns Hopkins were able to offer him a place as a Research Fellow to start as soon as was suitable, with a salary of $325 per month.[31]

[26] Ibid.
[27] Ibid.
[28] Harper, 'Interview with Malcolm Ferguson-Smith', p. 4.
[29] MAFS interview, DS300115, p. 4.
[30] UGC 188/1/1/4, Correspondence between Ferguson-Smith with Professor John Anderson, p. 5 (letter dated 18th August 1992).
[31] UGC 188/1/2/2, Correspondence between Ferguson-Smith and Dr Victor Almon McKusick regarding appointment as Fellow in Medicine, Johns Hopkins University, p. 7 (letter dated 6th October 1958).

Ferguson-Smith travelled to Baltimore in February 1959,[32] and his arrival coincided with one of the most prominent chromosome discoveries, the finding that Down's syndrome was caused by an extra copy of chromosome 21. It is reasonable to postulate that such a discovery would have had an impact on Ferguson-Smith – whilst he was just beginning his own career examining chromosomes and had not managed to garner any interest in the subject area back in Glasgow, other researchers were showing that the field held real possibilities for scientific and clinical discoveries. Ferguson-Smith himself has described how it seemed that he had 'arrived in the USA at a most opportune time for studying human chromosomes'.[33] However, upon his arrival at Johns Hopkins, Ferguson-Smith found that his laboratory consisted of nothing more than a cupboard off the secretary's office, which had no equipment.[34] Despite this, he was keen to persevere; he 'tentatively suggested' that his new department purchase a microscope for his work, and wrote to Lennox that 'you may imagine my surprise when the latest model actually materialised'.[35] That Ferguson-Smith was surprised at such a development is perhaps reflective of the different financial climate for research and medical genetics in the United States when compared with Glasgow. This was a difference which would be seen to be pronounced when Ferguson-Smith contemplated moving back to Glasgow from Hopkins and the financial difficulties he faced, both regarding a drastic cut to his salary and in securing funding to set up his own laboratory in Scotland. These issues will be highlighted later in the chapter.

Whilst he was based at Johns Hopkins, Ferguson-Smith made a 'fortunate' contact in the form of Lawson Wilkins, who was second in command of the Department of Paediatrics. Ferguson-Smith attended Wilkins' clinic regularly, which led to him seeing patients with various sex anomalies, including Klinefelter's and Turner's syndrome.[36] Wilkins was keen for Ferguson-Smith to study the chromosomes of his patients and this

[32] Ibid., p. 16 (letter dated 5th January 1959).
[33] Malcolm A. Ferguson-Smith, 'Cytogenetics and Early Days at the Moore Clinic with Victor McKusick', in *Victor McKusick and the History of Medical Genetics*, ed. by Krishna Dronamraju and Clair Francomano (New York: Springer, 2012), p. 56.
[34] Harper, 'Interview with Malcolm Ferguson-Smith', p. 6.
[35] UGC 188/1/2/3, Correspondence between Ferguson-Smith and Professor Daniel Fowler Cappell, Dr Bernard Lennox, Dr Tom N Fraser, Dr James Harrison Renwick, Dr J SS Stewart and family members about a variety of career issues, p. 10 (undated, probably May 1959).
[36] Ibid., p. 11 (undated, probably May 1959).

gave Ferguson-Smith a great deal of data to work with: this arrangement highlights the impact that genetic laboratory research could have on clinical practice if the two disciplines worked together. Ferguson-Smith also made key contacts with several other geneticists including T.C. Hsu and Albert Levan. In the spring of 1959, he spent four days at the Texas Medical Center in Houston with Hsu and Levan, learning tissue culture and chromosome photography techniques. Hsu wrote to Ferguson-Smith in May of 1959 to thank him for visiting, and spoke of the 'great stir' it had caused amongst the local clinicians, who were 'fascinated' by his talk.[37] For Ferguson-Smith, the visit compounded the belief he had been forming over the last few years that he wanted to follow the 'fascinating path' of genetic research 'as far as I am able'.[38] Within two weeks of spending time with Tsu and Levan and 'benefitting from their advice', Ferguson-Smith was able to obtain good chromosome samples from bone marrow, and draw diagrams of these using his new microscope.[39]

Lack of space became a problem for McKusick's department as the field of chromosome work expanded, and in the summer of 1959 permission was given to convert a nearby men's bathroom into a cytogenetics laboratory and photographic dark room.[40] Ferguson-Smith helped with the design of both of these rooms, which would have been a very useful learning experience for his future work designing his own laboratories in Glasgow. Despite intending to stay for only one year at Johns Hopkins, by October of 1959 Ferguson-Smith had been offered an extension of his contract to continue with his chromosome research,[41] an offer he had accepted by the start of 1960.[42] By January of 1961 Ferguson-Smith had written to Levan to say that he would be 'astonished to see us in our new little laboratory designed carefully by me to make the most use of space' and spoke of the expanding department which consisted of more research fellows, technicians, and even a research student.[43] Ferguson-Smith remained at Hopkins until October of 1961, and by the time he left to return to Glasgow as a

[37] UGC 188/3/1/4/3, Ferguson-Smith Correspondence with Dr T C Hsu, p. 3 (letter dated 27th May 1959).
[38] Ibid., p. 11 (letter dated 20th May 1959).
[39] Ferguson-Smith, 'Cytogenetics and Early Days at the Moore Clinic with Victor McKusick', p. 56.
[40] Ibid., pp. 56-57.
[41] UGC 188/1/2/3, Correspondence about a variety of career issues, p. 52 (undated, probably October 1959).
[42] Ibid., p. 67 (letter dated 7th January 1960).
[43] UGC 188/3/2/8/7, Ferguson-Smith Correspondence La-Li, p. 18 (letter dated 23rd January 1961).

Lecturer in Medical Genetics, the laboratory he was part of had become the first diagnostic laboratory in the United States, receiving patient samples for chromosome analysis from several states.[44]

IV. The Return to Glasgow as Lecturer in Medical Genetics

Ferguson-Smith's return to Glasgow was bittersweet. Whilst he felt he owed 'Glasgow, and particularly the Western Infirmary Pathology Department, a tremendous debt', and this was one of his 'major reasons' for turning down the offer of an Assistant Professorship in Medicine at Johns Hopkins Hospital,[45] he was aware of the issues facing the University of Glasgow including lack of research space, and he was 'very anxious not to leave a situation where I am productive for a post however attractive, where my studies are arrested due to a temporary lack of facilities'.[46] His time spent at Hopkins made him determined that it was part of his 'future mission to put medical genetics into practice in Glasgow',[47] and it was this that influenced his decision to return home. He recalled how he 'was going from a place like Hopkins back to Glasgow to try and bring what I'd learned back to help Glasgow medicine. Why else should I come back to earn one third of my Baltimore salary to a place that doesn't know anything about medical genetics?'[48] Despite his reservations, Ferguson-Smith recognised the opportunity that a move back to Glasgow could provide. In a recent interview he stated that 'it was very good for me because I was the one person in Glasgow who was doing anything to do with this. So I had the ball at my feet, everybody was interested and supportive and there was no opposition [laughs].'[49]

The decision to return to Glasgow was, however, initially hindered by a lack of funding available to set up the department Ferguson-Smith had envisaged. A number of communication issues arose as a result of the geographical distance between Ferguson-

[44] Harper, 'Interview with Malcolm Ferguson-Smith', p. 9.
[45] UGC 188/1/2/4, Correspondence concerning Ferguson-Smith's appointment to the lectureship in Medical Genetics at the University of Glasgow, p. 88.
[46] UGC 188/1/2/5, Correspondence concerning the establishment of the lectureship in Medical Genetics which was established in 1961 for Ferguson-Smith, p. 5.
[47] MAFS interview, DS300116, p. 1.
[48] Ibid., p. 2.
[49] Ibid.

Smith, still based in Baltimore, and his supervisors and co-workers in Glasgow. Communication was by written letter, sent via air mail, which could take long periods to arrive, resulting in a misunderstanding which contributed towards Ferguson-Smith having a grant application rejected by the Medical Research Council (MRC), who were thought to be the most likely to fund the establishment of a medical genetics department.[50] Guido Pontecorvo, the head of the Department of Genetics where Ferguson-Smith was to be based upon his return, had advised Ferguson-Smith that if he wished to apply to the MRC for funds then he should write to them directly to obtain an application form.[51] Pontecorvo had been in touch with an individual at the MRC 'who gave him the impression that the chance of getting funds might be very good'.[52] However, Ferguson-Smith then received a letter from his other supervisor, Professor Dan Cappell, based in pathology, who advised him to submit a funding application to the Advisory Committee for Medical Research (ACMR).[53] Assuming that Professors Pontecorvo and Cappell had come to an agreement that he should apply to the ACMR, Ferguson-Smith did not send off an application to the MRC, only to receive a letter from Pontecorvo querying why they had not received the application.[54] Ferguson-Smith wrote of it being 'most frustrating for me not to be on the spot in Glasgow where such a situation would so easily have been avoided',[55] and of his feeling 'greatly the disadvantage of the distance between Baltimore and Glasgow'.[56] Funding applications were subsequently submitted to both the MRC and ACMR. Neither were successful, with the amount of money requested being deemed too large by both groups.[57]

Ferguson-Smith's immediate response to the news that these funding applications were unsuccessful 'was one of extreme disappointment, particularly as I had been led to believe by Professor Pontecorvo that my chances were exceedingly high because all the preliminary arrangements for the favourable reception of the application had been made

[50] UGC 188/1/2/5, Correspondence concerning the establishment of the lectureship in Medical Genetics, pp. 23-24 (letters dated 3rd August 1961 and 26th July 1961).
[51] Ibid., p. 13 (letter dated 13th March 1961).
[52] UGC 188/1/2/4, Correspondence concerning Ferguson-Smith's appointment to the lectureship in Medical Genetics at the University of Glasgow, p. 54 (letter dated 30th May 1961).
[53] Ibid., p. 35 (letter dated 3rd May 1961).
[54] Ibid., p. 52 (letter dated 30th May 1961).
[55] Ibid.
[56] Ibid., p. 54 (letter dated 30th May 1961).
[57] Ibid., pp. 83-84 (letter dated 13th June 1961) and pp. 86-87 (letter dated 5th August 1961).

in advance'.[58] He wrote once again of the frustration he felt at the geographical divide 'by being so far away and being thus so entirely dependent on others who have other and more important things to take up their time'.[59] He was also concerned that by putting in an application for such a large sum of money that he had given the MRC 'the impression that I am a spoilt boy from the United States – an impression which will be hard to overcome in the future'.[60] The application had been sent to the MRC with no corrections made by more senior members of staff, and so Ferguson-Smith had mistakenly included the costs for everything he would need, unaware that this was not following protocol. However, determination by all those involved in the process resulted in funds being found from the University of Glasgow for his work, and Ferguson-Smith returned to Glasgow in 1961 as the first Lecturer in Medical Genetics appointed in the city. His vision of returning to a well-developed laboratory had not come to fruition, but he was provided with one room within the university, and had access to communal laboratory facilities such as a room for washing glassware. Funding was found for basic equipment such as microscopes, and the University also agreed to pay the salary of a science graduate, Patricia Ellis, who would assist Ferguson-Smith with the work.[61]

The above description highlights the issues that Ferguson-Smith faced upon his return to Scotland from the United States. Problems with funding and lack of space would be recurrent throughout his career, as they are for many researchers. That Ferguson-Smith was trying to establish a new department accounted for a large proportion of this, and it is possible to imagine his frustration at a number of these administrative hurdles which were detracting from his work. It is of interest to consider whether his desire as a Glaswegian to return to his home city played a part in his determination to succeed in bringing medical genetics to the region. Prior to his return to Scotland he had expressed his 'sincere desire to set up in Glasgow as good a cytogenetics unit as possible' as he was 'convinced that there is a great future in this line, and I don't see why Glasgow shouldn't play a bigger part in its development'.[62] As highlighted previously, he was

[58] Ibid., pp. 88-89 (letter dated 14th August 1961).
[59] Ibid.
[60] Ibid.
[61] Ibid., pp. 99-100 (letter dated 29th August 1961).
[62] Ibid., p. 7 (letter dated 28th November 1960).

returning to a city which knew nothing about his field and was being paid a far smaller salary; it is difficult to envisage an academic leaving an established post where funding was guaranteed, to return to these problems unless they have a strong connection with the region. Throughout all of his discussions surrounding his return to Glasgow, he was keen to emphasise that he specifically wanted to return to the region, writing in one letter that this was for 'personal, family, and academic reasons'.[63] It therefore seems likely that this decision was due to his connection to Glasgow – he extended his stay at Johns Hopkins and his work was progressing well, and there is no hint in any of the archive documents that his desire to return to Glasgow was due to him wanting to leave Johns Hopkins. Indeed, Ferguson-Smith was happy to stay at Johns Hopkins until 'suitable conditions' could be found for his return to Glasgow, which would enable him to continue his research.[64] He has also described how he was 'incredibly lucky' to get to spend time at Johns Hopkins, an institution he described as 'world class'.[65] He discussed being 'tempted' to stay in the United States, however he felt he had an 'obligation' to return to Glasgow, and bring his developing medical genetics expertise with him.[66] Whilst it cannot be known if medical genetics would have developed into such a strong field in the West of Scotland if an individual other than Ferguson-Smith had been involved, it is clear to see that he played a central role in this process. That Ferguson-Smith had personal ties to the West of Scotland, and was driven to bring medical genetics to the region, resulted in the establishment of a whole new area of clinical and scientific medicine in Glasgow.

V. The Expansion of Medical Genetics in Glasgow

With Ferguson-Smith's appointment in 1961, the first medical genetics unit was informally established in Glasgow in the form of a small human cytology research department, comprising one room within the university.[67] The human cytology department was focused on research and teaching only, and had no responsibility for providing diagnostic services, an arrangement Ferguson-Smith felt was 'decidedly

[63] Ibid., p. 8 (letter dated 28th November 1960).
[64] Ibid.
[65] MAFS interview, DS300116, p. 1.
[66] Ibid., p. 2.
[67] UGC 188/1/2/5, Correspondence concerning the establishment of the lectureship in Medical Genetics, p. 34.

unfavourable to the clinical and more strictly genetic aspects of human cytogenetic research'.[68] Between 1961 and 1963 the Western Infirmary Pathology Department was responsible for providing nuclear sexing and chromosome analysis services. However, despite a close working relationship between pathology and medical genetics, the high number of cases meant that patient samples were often not seen by a geneticist. Ferguson-Smith was based in the Department of Genetics, and not the Department of Pathology, and Pontecorvo stressed that 'the Department of Genetics is not a clinical department, and we are in no way connected with the National Health Service'.[69] Pontecorvo did however permit Ferguson-Smith to investigate 'cases in which he may decide that the research interest is sufficient to warrant the labour and cost of an investigation'.[70]

Ferguson-Smith felt that merely being permitted to investigate cases of research interest was not sufficient. He was keen to develop a more 'clinically-orientated Medical Genetics Unit', and he wrote in 1964 that he had been 'fighting here (without any sign of success) for the past few years' for the establishment of such a unit.[71] He considered that it was a 'most important deficiency' that many cases were not seen by a geneticist, and he proposed that this could be remedied by the formation of a combined diagnostic and research unit in human cytogenetics.[72] A proposal for such a service was written up by Ferguson-Smith on the 22nd July 1964, and subsequently submitted to the Western Regional Hospital Board for consideration. By this time, the demand for diagnostic services had gone 'well beyond the stage' where it could be handled through an informal arrangement between pathology and medical genetics. It was therefore suggested that a diagnostic chromosome laboratory should be established 'within one of the hospitals of the region, physically distinct from the University Research Laboratory but supervised by the Lecturer in Medical Genetics'.[73]

[68] Ibid., pp. 36-37.
[69] UGC 188/3/2/3/2, Ferguson-Smith Correspondence Ca-Cu, p. 6 (letter dated 9th May 1963).
[70] Ibid.
[71] UGC 188/3/2/3/3, Ferguson-Smith Correspondence with Dr Ronald G Davidson, p. 11 (letter dated 24th November 1964)
[72] UGC 188/1/2/5, Correspondence concerning the establishment of the lectureship in Medical Genetics, p. 37.
[73] Ibid., p. 51.

Temporary accommodation was arranged for the laboratory in the Queen Mother's Hospital in Glasgow by the Professor of Child Health, James Hutchison. Hutchison was interested in chromosome disorders,[74] and provided Ferguson-Smith with access to the 'examination of selected patients' for his work.[75] In 1965 the Chromosome Diagnostic Service was established by the Western Regional Hospital Board,[76] directed by Ferguson-Smith, with weekly genetics clinics held in the accommodation provided by Hutchison in the Queen Mother's Hospital. After a number of years working to achieve this, Ferguson-Smith was pleased with the outcome, which he hoped would enable him to play 'a slightly more clinical role once more', as his appointment would become a joint one in the Departments of Child Health and Genetics.[77]

Between 1965, when the Chromosome Diagnostic Service was established, and 1970, when it moved into specialised laboratory accommodation, the demand for services continued to grow. In 1966 there were only 25 clinic consultations, rising to 125 in 1970. In 1969 the first amniotic fluid samples were tested within the laboratory.[78] The new purpose built accommodation, which replaced the laboratories in the Queen Mother's Hospital, opened on the 11th May 1970 at the Royal Hospital for Sick Children, Glasgow.[79] Figure 2.1 shows the geographical locations of these buildings in relation to one another:

[74] Ibid., p. 52.
[75] Ibid., p. 46.
[76] UGC 188/2/2/2/5, Memoranda on 'Department of Medical Genetics, Yorkhill Hospitals. Current Status and Future Development' 1977, and 'Medical Genetics at Glasgow University' 1979, p. 9.
[77] UGC 188/3/2/5/2, Ferguson-Smith Correspondence with Dr Richard E Goodman, p. 2 (letter dated 23rd August 1965).
[78] UGC 188/2/2/2/5, Memoranda on 'Department of Medical Genetics, Yorkhill Hospitals. Current Status and Future Development' 1977, and 'Medical Genetics at Glasgow University' 1979, p. 20.
[79] The site which housed both the Queen Mother's Hospital, and the Royal Hospital for Sick Children, was known locally as the Yorkhill site.

Figure 2.1 – Showing the locations of the Queen Mother's Hospital, and the Royal Hospital for Sick Children in Glasgow.[80]

The Royal Hospital for Sick Children housed a number of different departments, including the medical genetics unit.[81] The laboratory increased in size considerably, from 128 square feet in 1965, to 646 square feet in 1970. Staffing levels also grew, with the number of scientific officers increasing from 1 in 1965 to 5 in 1970.[82] Ferguson-Smith was promoted to Senior Lecturer in 1965, and was given an honorary consultant contract 'in respect of his clinical responsibilities at the Royal Hospital for Sick

[80] "Glasgow - 1960s. National Grid Tile NS5666SW" [JPG map], Scale 1:1000, Ordnance Survey National Grid 1:1250, National Survey 1943-1993 [TIFF geospatial data], Published: Year 1969, Landmark Information Group, Using: EDINA Historic Digimap Service, <http://digimap.edina.ac.uk/>, Created: August 2018.
[81] UGC 188/2/2/2/3, Correspondence and papers on the development of the Department of Medical Genetics (1970-1972), p. 20.
[82] UGC 188/2/2/2/5, Memoranda on 'Department of Medical Genetics, Yorkhill Hospitals. Current Status and Future Development' 1977, and 'Medical Genetics at Glasgow University' 1979, p. 20.

Children'.[83] In a report to the University Court for the session 1969-70, Ferguson-Smith commented that it was believed that this was 'the first time special accommodation for Medical Genetics has been provided in a hospital by the Health Service', which emphasises the pioneering role that the West of Scotland was playing in providing chromosome diagnostic services.[84]

In a letter written in October 1970, Ferguson-Smith outlined the main activities underway in medical genetics in Glasgow at that time. He was still 'the sole practitioner of Medical Genetics in Glasgow and the West of Scotland', and his clinical duties included 'providing a Genetic Counselling Service and a Chromosome Diagnostic Service for Glasgow and the West of Scotland'.[85] He was involved in teaching, and had ongoing research projects, including one on chromosome mapping.[86] During this time period, when the department was increasing in size, Ferguson-Smith had several people working with him who would remain in his department for a number of decades. One of these individuals was Elizabeth Boyd, who had done doctoral research under the supervision of Bernard Lennox, and subsequently worked with Ferguson-Smith. She recalled in an interview that she remembered feeling that she had 'got as far as I could with the subject in pathology and that it would be much better to go down to genetics', where she was to be based in the diagnostic side of the department.[87] It would appear

[83] Ibid., p. 9.
[84] UGC 188/2/2/2/3, Correspondence and papers on the development of the Department of Medical Genetics (1970-1972), p. 20.
It was Ferguson-Smith's belief that no comparable space existed in another hospital, funded by the NHS, to accommodate medical genetics. The closest comparable space is the Paediatric Research Unit established by Paul Polani in 1960, at Guy's Hospital in London. This unit was, however, initially funded by a small charity (The National Spastics Society, as it was known then) with the remit of undertaking research in development using 'genetic approaches'. It was only later that in the Guy's Unit there would be the 'transfer of areas that were initiated as research into diagnostic services that could be funded by the rapidly developing National Health Service'. See Peter S. Harper, 'Paul Polani and the Development of Medical Genetics', *Human Genetics*, 120:5 (2007), pp. 727-729.
It is therefore unclear whether there would have been overlap of the timeframes in which these events occurred between Glasgow and London. As the medical genetics space in Glasgow was specifically funded by the NHS in their premises, it can perhaps be viewed as different to the involvement of NHS funding for the Paediatric Research Unit, who had initially been funded by a different source altogether.
[85] UGC 188/3/3/8/5, Ferguson-Smith Correspondence with Peter S Harper, p. 7 (letter dated 28th October 1970).
[86] Ibid., p. 8 (letter dated 28th October 1970).
[87] EB interview, DS300135, p. 3. Interview with Elizabeth and Anne Boyd, 25th February 2016. Elizabeth Boyd completed her PhD on human cytogenetics under the supervision of Bernard Lennox, and began working with Malcolm Ferguson-Smith upon his return from Johns Hopkins.

that this was a positive decision, as she would go on to spend her full career in the Department of Medical Genetics, where she continued to work in diagnostics, using blood and bone marrow samples to analyse the chromosome constitutions of patients.[88] Having a staff member to work in this role would have ensured that the patient samples, which were often not seen by a geneticist when the chromosome service was run by pathology, were now being analysed with a genetic perspective in mind.

Another individual who was centrally involved during this time period was Marie Gzowska,[89] who would go on to become known as Marie Ferguson-Smith, after marrying Malcolm in July 1960.[90] They met at Johns Hopkins University, where Marie had a summer job working for Victor McKusick while undertaking a degree in history and economics.[91] She was assigned to help Malcolm Ferguson-Smith with administrative and clerical duties on one of his research projects, but later discovered she was good at photographing chromosomes.[92] She also began carrying out some laboratory work, setting up and working with microscopes, in addition to discovering a talent for culturing cells in the laboratory.[93] She became certain that her key interest lay not in history and economics, but in genetics, and decided that any further study she would do would be in this field.[94] It is interesting to note that both Malcolm and Marie Ferguson-Smith became certain that they would pursue careers in genetics as a result of their time spent at Hopkins, where medical genetics under McKusick was a flourishing field.

The expansion of the number of staff members in the department which occurred from 1965 onwards, and the move into larger, more specialised accommodation in 1970, took place at a crucial time point for the development of prenatal diagnostic services.

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[88] EB interview, DS300139, p. 1.
[89] Ferguson-Smith, 'Cytogenetics and Early Days at the Moore Clinic with Victor McKusick', p. 56.
[90] MAFS interview, DS300116, p. 2.
[91] MEFS interview, Transcript 1, p. 2. Interviews with Marie Ferguson-Smith, 12th and 13th November 2015. Marie Ferguson-Smith worked in medical genetics in Glasgow from its inception, and would go on to lead the cytogenetics division of the prenatal testing section. She remained in Glasgow until she moved to Cambridge in 1987 with Malcolm Ferguson-Smith.
[92] Ibid.
[93] Ibid., p. 3.
[94] Ibid., p. 2.

Prenatal diagnostic testing was first carried out in Glasgow in 1969, and the demand for the service grew dramatically over the following years. Ferguson-Smith and his colleagues were at the forefront of many of the developments in prenatal diagnostic testing, and were key contributors towards the implementation of tests for spina bifida and other conditions. When the laboratory first began using amniocentesis as a prenatal diagnostic tool in 1969, it was with the aim 'of saving pregnancies which would otherwise be terminated on the grounds of substantial risk of foetal abnormality'.[95] This links back to the idea presented in the introduction, that for many of those involved in the early days of prenatal testing, the intention was to increase the number of children born, as opposed to terminating on what some argued were eugenic grounds. Indeed, Ferguson-Smith has emphasised that in the majority of cases, women were able to be reassured that the fetus did not have the condition being tested for, and could continue with their pregnancy. He has highlighted that many of the women who had prenatal testing would not have considered another pregnancy without the option of the testing.[96]

As the technology advanced, so too did the workload, and by 1973 there were 240 clinic consultations and 101 amniotic fluid samples processed. Many of these patients and samples were coming from outside the Yorkhill Hospital group, including more than two thirds of the samples for genetic analysis, and around 70% of the patients being referred to the clinic. Those involved in medical genetics felt that this should be recognised, and so proposed to the Western Regional Hospital Board in February of 1973 that the Department of Medical Genetics should be formally designated as the "Regional Genetic Advisory Service".[97] This proposal was agreed upon on the 16th October, 1973,[98] shortly after Ferguson-Smith was awarded the newly created Burton Chair of Medical Genetics in the same year.

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[95] UGC 188/2/2/2/3, Correspondence and papers on the development of the Department of Medical Genetics (1970-1972), p. 20.

[96] History of Modern Biomedicine Research Group (Interview Questions by Ms Emma M. Jones, transcribed by Mrs Debra Gee, and edited by Professor Tilli Tansey and Mr Alan Yabsley), 'Ferguson Smith, Malcolm 06 Scotland, Genetic Counselling, Religious Objections', *YouTube* <https://www.youtube.com/watch?v=DzH-Mrh9Lrw> [accessed 20th July 2018]. 2 minutes 20 seconds to 3 minutes 15 seconds.

[97] UGC 188/2/2/2/4, Correspondence and papers on the development of the Department of Medical Genetics (1973-1974), p. 2 (letter dated 14th February 1973).

[98] Ibid., p. 8 (letter dated 16th October 1973).

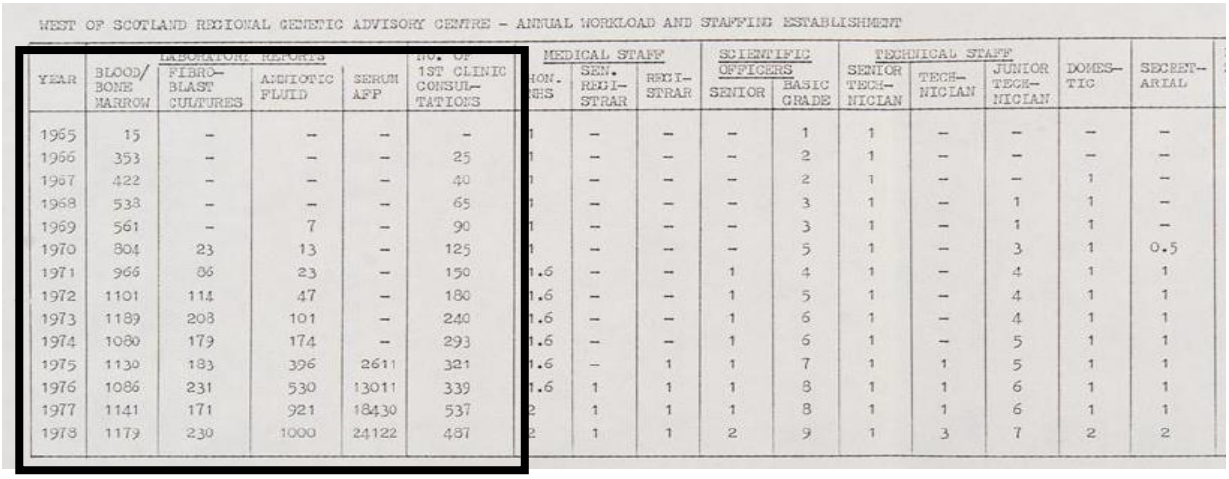
VI. The Duncan Guthrie Institute of Medical Genetics

With the demand for genetic services continuing to increase, it became apparent that the laboratory facilities available to the Regional Genetic Advisory Service were inadequate. The department was still based on the Yorkhill site for its clinical work, but due to an increased need for space the staff were partially housed in 'Transline' temporary accommodation units.[99] Their research laboratories were still based in the University Department of Genetics, which was in a separate building in Church Street in Glasgow, located away from the Yorkhill hospital site,[100] as shown in Figure 2.2:

Figure 2.2 – Showing the different geographical locations of the Queen Mother's Hospital and the Royal Hospital for Sick Children, located at Yorkhill, and marked with the blue circle, and the research laboratories in Church Street, marked by the orange diamond.[101]

[99] UGC 188/2/2/2/6, Memoranda on 'The New Institute of Medical Genetics at Yorkhill' and 'Regional Genetic Advisory Services', p. 10.
[100] UGC 188/2/2/7/2, 'The Duncan Guthrie Institute of Medical Genetics', p. 7.
[101] "Glasgow - 1960s. National Grid Tile NS5666" [JPG map], Scale 1:2500, Ordnance Survey National Grid 1:2500, National Survey 1943-1995 [TIFF geospatial data], Published: Year 1968, Landmark

After being appointed Burton Chair of Medical Genetics, Ferguson-Smith approached the founder of the National Fund for Research into Crippling Diseases, Duncan Guthrie, to enquire about a possible grant to build some new portacabins to expand medical genetics further. The National Fund offered to help out with the costs, not for more temporary accommodation, but for the building of an entire institute for medical genetics if Ferguson-Smith could also secure equal funding from the University of Glasgow and the Greater Glasgow Health Board.[102] The need for this extra accommodation is evident when the work which was going on in the department is considered. Research areas included chromosome mapping, the use of banding techniques to analyse chromosome anomalies in more detail, studies of sex chromosome disorders, and analysis of recurrent miscarriage, amongst other areas of work.[103] This was in addition to the clinical diagnostic services that were also being provided. As shown in Figure 2.3, the number of laboratory tests which were being carried out from 1970 onwards increased dramatically:



WEST OF SCOTLAND REGIONAL GENETIC ADVISORY CENTRE – ANNUAL WORKLOAD AND STAFFING ESTABLISHMENT

YEAR	LABORATORY REPORTS: BLOOD/BONE MARROW	LABORATORY REPORTS: FIBRO-BLAST CULTURES	LABORATORY REPORTS: AMNIOTIC FLUID	LABORATORY REPORTS: SERUM AFP	NO. OF 1ST CLINIC CONSULTATIONS	MEDICAL STAFF: HON. [illegible]	MEDICAL STAFF: SEN. REGISTRAR	MEDICAL STAFF: REGISTRAR	SCIENTIFIC OFFICERS: SENIOR	SCIENTIFIC OFFICERS: BASIC GRADE	TECHNICAL STAFF: SENIOR TECHNICIAN	TECHNICAL STAFF: TECHNICIAN	TECHNICAL STAFF: JUNIOR TECHNICIAN	DOMESTIC	SECRETARIAL
1965	15	–	–	–	–	1	–	–	–	1	1	–	–	–	–
1966	353	–	–	–	25	1	–	–	–	2	1	–	–	–	–
1967	422	–	–	–	40	1	–	–	–	2	1	–	–	1	–
1968	538	–	–	–	65	1	–	–	–	3	1	–	1	1	–
1969	561	–	7	–	90	1	–	–	–	3	1	–	1	1	–
1970	804	23	13	–	125	1	–	–	–	5	1	–	3	1	0.5
1971	966	86	23	–	150	1.6	–	–	1	4	1	–	4	1	1
1972	1101	114	47	–	180	1.6	–	–	1	5	1	–	4	1	1
1973	1189	208	101	–	240	1.6	–	–	1	6	1	–	4	1	1
1974	1080	179	174	–	293	1.6	–	–	1	6	1	–	5	1	1
1975	1130	183	396	2611	321	1.6	–	1	1	7	1	1	5	1	1
1976	1086	231	530	13011	339	1.6	1	1	1	8	1	1	6	1	1
1977	1141	171	921	18430	537	2	1	1	1	8	1	1	6	1	1
1978	1179	230	1000	24122	487	2	1	1	2	9	1	3	7	2	2

Figure 2.3 – Showing the annual workload from 1965 to 1978, with the number of tests highlighted with a black box. Tests shown include number of amniotic fluid and serum AFP samples processed each year.[104]

Information Group, Using: EDINA Historic Digimap Service, <http://digimap.edina.ac.uk/>, Created: August 2018.

[102] UGC 188/2/2/7/4, Correspondence and papers regarding the Duncan Guthrie Institute's mural titled, 'Medical Genetics in the Prevention of Handicap' by the Artists' Collective, pp. 16-17.

[103] UGC 188/2/2/2/4, Correspondence and papers on the development of the Department of Medical Genetics (1973-1974), pp. 9-11.

[104] UGC 188/2/2/2/5, Memoranda on 'Department of Medical Genetics, Yorkhill Hospitals. Current status and future development' 1977, and 'Medical Genetics at Glasgow University' 1979, p. 20.

In 1977 Ferguson-Smith wrote of how 'very hectic' their laboratory had become – in one year they were culturing around 850 amniotic fluid cultures, 200 other fibroblast cultures, 1000 blood cultures, and 17,000 serum samples.[105] He hoped that 'perhaps in three years time we will have a better building and adequate staff for this work. Meanwhile, it is rather a struggle.'[106] This struggle would however be the driving force behind several years of work to raise the appropriate funds. After approaching both the University and the Health Board, Ferguson-Smith found that 'astonishingly' everyone agreed with the proposals to split the costs.[107] Upon returning to the Health Board with details of the required funds in 1976, Ferguson-Smith was informed that the initial costs he had been provided with were not correct, and that in order to fund the building it would have to be reduced in size by 30%.[108] He later recalled how the department were 'totally despondent' upon receiving this news, and that they had been told that research laboratories were not essential.[109] Despite these setbacks, the project was saved by a large donation from the Hugh Fraser Foundation and building work began. The end result was the Duncan Guthrie Institute of Medical Genetics, which opened in Glasgow in October 1980.

At the inauguration of the building Ferguson-Smith did not shy away from the trouble that these financial difficulties had caused. He outlined the monetary problems the project had faced, and how it had been saved by the large grant from the Hugh Fraser Foundation.[110] He also spoke of the more general atmosphere of recession which was pervading, with mention of the 'rather modest inauguration' where due to 'hard times, tea has to serve for champagne'.[111] In another document he commented that amongst 'the depressing environment of remedial works and in an atmosphere of recession and general reduction of services to patients', it was positive to see the 'growth and new

[105] UGC 188/3/4/48/5, Ferguson-Smith Correspondence, Lo-Ly, p. 14 (letter dated 3rd June 1977).
[106] Ibid.
[107] UGC 188/3/6/1/1, Ferguson-Smith Correspondence with Professor G C Arneil, p. 12.
[108] UGC 188/2/2/7/1, Inauguration of the Duncan Guthrie Institute, July 1981, p. 11.
[109] UGC 188/3/6/1/1, Ferguson-Smith Correspondence with Professor G C Arneil, p. 12.
[110] UGC 188/2/2/7/1, Inauguration of the Duncan Guthrie Institute, July 1981, p. 11.
[111] Ibid., p. 9.

development' of the Duncan Guthrie Institute at Yorkhill.[112] Ferguson-Smith and his colleagues were 'enthusiastic and excited about the potential of the new facilities for our future work', but felt that there remained 'considerable anxiety about the future stemming from the national recession in general and the economies being forced on the National Health Service in particular'. They raised concerns that there would not be enough staff and equipment to realise the full potential of the new Institute.[113]

These concerns were not unfounded, as over the next few years the financial climate continued to impact the new Institute. A number of letters commented on cuts to services and financial difficulties over the following years, with one from a Doctor Stewart based in Ayrshire who was unhappy with the length of time it was taking to receive results from amniocentesis.[114] Ferguson-Smith replied to him in February 1980 commenting that 'In recent times, like everyone else, we have suffered from the freeze on development and have been unable to employ the staff which it is recognised is required for our work load', and that the 'standard of service is directly related to the number and quality of staff we are allowed to employ'.[115] These problems appeared to continue as, in 1981, Ferguson-Smith wrote to a colleague in Australia, outlining that the recession was 'hitting the development of services very hard'.[116] By 1982 there were still financial troubles, with Ferguson-Smith thanking a fundraiser by letter, informing him that 'In these times when the recession is biting even deeper each month, we rely more and more on the support of generous donations like yours to carry on this work. My colleagues and I are therefore deeply grateful to you for this generous gift.'[117]

These monetary struggles can also be seen in the loss of a lectureship position for the department, which had been funded by the University of Glasgow. In 1981 Ferguson-Smith stated his case to the 'Faculty of Medicine Academic Development Committee' to fill the post of Lectureship in Medical Genetics, which was to become vacant with

[112] UGC 188/3/4/77/1, Ferguson-Smith Correspondence with A D Reith, p. 14 (document dated October 1980).
[113] Ibid., pp. 18-19 (document dated October 1980).
[114] UGC 188/3/4/82/4, Ferguson-Smith Correspondence St, pp. 8-9 (letter dated 9th October 1979).
[115] Ibid., pp. 10-11 (letter dated 25th February 1980).
[116] UGC 188/3/5/3/5, Ferguson-Smith Correspondence B, p. 14 (letter dated 17th February 1981).
[117] UGC 188/3/5/4/3, Ferguson-Smith Correspondence Ba-Bl, p. 13 (letter dated 20th May 1982).

the early retirement of the staff member Jean Patrick.[118] The document stated that 'If the Lecturer post were abolished the total responsibility for the work of 58 people, including all teaching, provision of genetic consultations and other genetic services to a population of 3 million and supervision of several major research projects would remain with the Professor. In the event of his leave of absence, illness or death there would be no one qualified to deputise for him.'[119] Even with these implications, the lectureship was not renewed, and from September 1981 'the entire responsibility for teaching, clinical work, laboratory reports and research projects remained with the Professor', Ferguson-Smith, until August of 1982.[120]

However, the situation did begin to improve from 1982 onwards. Several new staff members were recruited over the following few years, including Mike Connor, appointed as a National Health Service (NHS) Consultant in Medical Genetics in 1982, and Nabeel Affara, awarded a Lectureship post in Human Molecular Genetics.[121] A number of my interviewees also began their careers in the early 1980s, and have provided an insight into life working in the Institute. The Duncan Guthrie Institute was believed to be 'the first of its kind in the U.K.', 'designed and built to provide the community with comprehensive genetic services and to provide facilities for teaching and research in Medical Genetics'.[122] It housed both clinical and scientific staff in the one building, and, alongside providing diagnostic services, the staff were also involved in research. Having scientific and clinical staff housed together in the same accommodation was very unusual at this time in medical genetics. However, many of the interviewees commented on how positive this arrangement was. As one clinician recalled, 'Where Malcolm had really excelled was he had the vision to build the first integrated NHS clinical, NHS diagnostic and university research genetics Institute in Britain. It was just incredible to be working in that kind of hot-bed with all these different specialties within the one place and we could communicate together very

[118] UGC 188/2/2/2/7, Memoranda on the vacant lectureship in Medical Genetics, p. 2.
[119] Ibid., p. 4.
[120] UGC 188/2/2/8, University of Glasgow Department of Medical Genetics Report for 1980-1984, pp. 9-10.
[121] Ibid., p. 10.
[122] UGC 188/2/2/7/4, Correspondence and papers regarding the Duncan Guthrie Institute's mural titled, 'Medical Genetics in the Prevention of Handicap' by the Artists' Collective, p. 17.

easily, it was a very exciting time.'[123] Others also commented on the importance of this ease of communication, whereby 'you could go up a stair and talk to somebody, it was a huge area and there was a lot of cross-collaboration that went on',[124] which resulted in a 'very close community' and 'cross-fertilisation of staff and ideas'.[125] This model, where clinical and research services were integrated, would end up being 'adopted across the world',[126] and several visiting scientists and clinicians would come to undertake training there. As one interviewee commented, 'there can't be many departments in the country that don't have someone who's been through the Duncan Guthrie'.[127]

This close communication can be clearly seen in the weekly Wednesday meetings which were held within the department, which many interviewees recalled as being a central feature of their week. The entire staff of the Institute would come together to discuss the work which was going on in the different departments, on both the clinical and research fronts. Ferguson-Smith would 'send someone round to go and get people … because there was no excuse' and if you had laboratory work which would need attended to during the time of the meeting then 'you couldn't start it, because it was very important'.[128] Whilst several of the attendees at the meetings recalled that it was 'torturous' to sit through them as they involved the reporting of so many figures, they were appreciative of how educational these could be. The importance of the meetings was highlighted by two of the interviewees, with one explaining how they used to have 'a weekly Wednesday meeting, Wednesday lunchtime, and every part of the department reported back and we used to sit and go through everything from a month before. So

[123] DW Interview, DS300142, p. 3. Interview with Douglas Wilcox, 1st March 2016. Wilcox graduated with his intercalated medical and science degree in 1979, and after two years of rotations in the medical wards, began working in the Department of Medical Genetics in 1982. He became an Honorary Consultant in the department, and was heavily involved in the teaching and organising of the medical genetics course at the University of Glasgow. He spent his entire career in the department.
[124] GG Interview, DS300134, p. 2. Interview with Gordon Graham, 18th February 2016. Gordon Graham obtained his biology degree in 1979, and worked in biochemistry for 18 months, before moving to the Department of Medical Genetics in 1981. He remained in the department throughout the rest of his career, completing a PhD in the early 1990s.
[125] Ibid., p. 9.
[126] DW Interview, DS300142, p. 20.
[127] JL Interview, DS300179, p. 9. Interview with Jennifer Lambert, 16th November 2016. Jennifer Lambert completed an honours degree in biochemistry in 1976, and began working in the Department of Biochemistry in Glasgow after her graduation. She worked at the Beatson Institute in Glasgow for several years, before moving to the Department of Medical Genetics in Glasgow in 1984.
[128] Ibid., p. 2.

we'd sit and we'd talk about all the cases we've counted X number of bloods and we found these abnormalities and we've found so many prenatals and we've found these abnormalities and we listed them and we talked about some of them and someone would present.'[129] Although he recalled that the 'figures were just dreadful', the meetings were useful because 'it really helped you learn and you would find out about things that were going on elsewhere'.[130] He also recalled Ferguson-Smith's ongoing interest in sex chromosome disorders, and how, when those working in cytogenetics found such anomalies and presented details of them at the weekly meetings, Ferguson-Smith would 'jump up in interest' and there was 'real interest and scrutiny' surrounding such cases.[131] The interests that first propelled Ferguson-Smith into studying chromosomes remained with him throughout his career.

Another member of the department has commented that they also thought the meetings were 'a way of Professor Ferguson-Smith keeping in touch with everything, he liked to have his finger on all the areas of the department'.[132] When the overall workload for the department is considered, it is perhaps not surprising that Ferguson-Smith was keen to arrange these meetings to remain informed about the work which was going on. Figures 2.4 and 2.5 show the many research grants which Ferguson-Smith had been awarded, highlighting the vast numbers of projects which were occurring within the department:

[129] SI Interview, DS300173, p. 1. Interview with Stuart Imrie, 13th July 2016. Stuart Imrie graduated with a degree in genetics in 1983, and began working in the Department of Medical Genetics in Glasgow shortly after graduating. He is still currently based within the department.
[130] Ibid.
[131] Ibid.
[132] SC Interview, DS300158, p. 6. Interview with Alexander (Sandy) Cooke, 21st April 2016. Sandy Cooke completed a degree in molecular biology, before going on to undertake a PhD and a post-doctoral research post. He began working in the Department of Medical Genetics in Glasgow in December 1980.

Appendix II. Research Grants in Medical Genetics, 1965-1984

	Granting Body	Award No. and Year	Amount	Awarded to	Type of Grant	Duration Years	Title
1	MRC	G965/67/C 1965	£ 6,479	M.A. Ferguson-Smith	Project	3	A study into possible factors predisposing to non-disjunction in man, with particular emphasis on Klinefelter's syndrome
2	British Empire Cancer Campaign for Research	SP/1254 1966	£ 5,032	M.A. Ferguson-Smith J.H. Renwick	Project	2	The genetics of self-healing squamous epithelioma
3	SHERT	SHERT 292 1968	£ 33,898	M.A. Ferguson-Smith	Project	5	The use of chromosomal aberrations in gene localisation
4	MRC	G973/676/C 1973	£ 11,458	M.A. Ferguson-Smith	Project	4	Assessment of the risks of amniocentesis in the first half of pregnancy
5	National Fund for Research into Crippling Disease	G/C/A8/795 1975	£150,000	M.A. Ferguson-Smith	Capital	-	The reduction of congenital defects by prenatal diagnosis and the identification of pregnancies at risk
6	MRC	G975/411/C 1975	£ 40,226	M.A. Ferguson-Smith	Project	3	The development of techniques of human ribosomal and globin gene localisation
7	DHSS	Welsh Office 1976	£ 3,000	P.S. Harper M.A. Ferguson-Smith	Small Grant	2	Genetic linkage studies in Huntington's Chorea
8	MRC	G978/535/C 1979	£ 21,834	S. Malcolm R. Williamson M.A. Ferguson-Smith	Project	2.75	Use of in situ hybridisation for human gene localisation
9	NFRCD	A/8/1057 1979	£ 25,009	M.A. Ferguson-Smith	Project	3	Intrachromosomal identification of structural genes using molecular hybridisation techniques in interspecific cell hybrids
10	SHHD	K/MRS/50/C123 1979	£ 77,606	M.A. Ferguson-Smith J. Stevenson J.G. Ratcliffe	Project	5	Neonatal screening for congenital hypothyroidism

Figure 2.4 – Research grants awarded between 1965 and 1979.[133]

Appendix II. (Continued)

	Granting Body	Award No. and Year	Amount	Awarded to	Type of Grant	Duration Years	Title
11	NFRCD	A/8/795A1 1980-1982	£155,508	M.A. Ferguson-Smith	Equipment Grant	-	Towards first equipping of the Duncan Guthrie Institute (including £80,000 grant towards Fluorescence Activated Cell Sorter)
12	NFRCD	A/8/795A2 1980	£ 20,264	M.A. Ferguson-Smith	Project	3	The application of recombinant DNA technology to the detection of genetic abnormalities in fetal cells
13	GGHB Research Support Grant	18/5/1-13/N1 1982	£ 2,234	M.A. Ferguson-Smith W.R. Chatfield J.E. Duke	Equipment Grant	-	Prenatal diagnosis in the first trimester by chorion biopsy
14	MRC	SPG8215054 1982	£ 21,370	M.A. Ferguson-Smith M.C. Macnaughton	Multicentre Study	3	MRC randomised clinical trial of folate and other vitamin supplementation in the prevention of neural tube defects
15	Muscular Dystrophy Group of GB	RA3/127(RMC) 1982	£ 60,680	M.A. Ferguson-Smith	Project	3	A study of muscular dystrophy in the West of Scotland
16	GGHB Research Support Group	Project 1983	£ 9,163	A.M. Wallace G.H. Beastall R.W.A. Girdwood M.A. Ferguson-Smith	Project	1	Neonatal screening for congenital adrenal hyperplasia
17	MRC	G8327373 1983	£ 15,000	N. Affara	Setting-up Grant	-	Cloning of the steroid sulphatase gene to investigate X-inactivation and X-Y interchange
18	SHHD	K/MRS/50/C548 1983	£ 29,643	M.A. Ferguson-Smith	Project	3	Evaluation of the use of cloned DNA probes in X-linked disease
19	Cystic Fibrosis Research Trust	Project 231 1983	£ 67,377	M.A. Ferguson-Smith	Project	3	The production of a monoclonal antibody to cystic fibrosis protein
20	Wellcome Research Foundation	13096/1.25 1984	£ 5,000	J.M. Connor	Project	5	The use of DNA probes in carrier detection of X-linked mental retardation and haemophilia

Figure 2.5 – Research grants awarded between 1980 and 1984.[134]

[133] UGC 188/2/2/8, University of Glasgow Department of Medical Genetics Report for 1980-1984, p. 37.
[134] Ibid., p. 38.

In addition to these research grants, Ferguson-Smith was responsible for overseeing the work of all the staff in the department, which had grown to 78 members by 1984.[135] The department was also providing a clinical service in peripheral genetics clinics in the community.

VII. The Move to Cambridge

This intense workload would continue expanding until 1987, when Ferguson-Smith moved from Glasgow to Cambridge to take up the post of Chair of Pathology. The move was an unexpected one for him, as he had not actually applied for the job. In a recent interview he recalled the moment he received the news:

> It was in the early summer of 1986 that I received a phone call from Richard Adrian the Vice-Chancellor of the University of Cambridge telling me that I'd been elected Professor of Pathology in Cambridge. I was exceedingly surprised and I laughed and said this must be a mistake as I hadn't applied for the job, I didn't know it existed and in any case I'm not a pathologist; although I've trained in pathology my specialty is in medical genetics. And he said oh well I don't know anything about that, but I know that you've just been elected by our Board of Electors. So I pulled myself together and said I'd be happy to come down and discuss this with you and with the department and learn to what I've been elected.[136]

Despite having 'no thought of moving from Glasgow', he realised that this could be an important career move for him.[137] After several meetings and an array of correspondence, it was agreed that the University of Cambridge would purchase the equipment Ferguson-Smith felt was essential for the department, and would find job roles for two of his key staff,[138] which surprised Ferguson-Smith as he had 'fought for years to try and get one lectureship position in Glasgow'.[139] Alongside these incentives, another key factor in his decision to accept the job was the realisation that he was also being asked to set up a medical genetics department in Cambridge; he was aware that no

[135] Ibid., pp. 35-36.
[136] MAFS interview, DS300127, p. 1.
[137] Ibid.
[138] Ibid., pp. 1-2.
[139] Ibid., p. 2.

regional genetics service existed in the area, and was keen to remedy this. Notes for one of his trips to Cambridge outlined plans to establish an East Anglia Regional Genetic Service, which would provide a chromosome diagnostic service, amongst other plans.[140] Ferguson-Smith felt that this was an opportunity 'to make a greater impact on helping to get medical genetics more recognised in medicine, which was one of the main aims of my career. I felt that I should take this opportunity seriously.'[141] He expressed his formal interest in the post to the Vice-Chancellor of the University of Cambridge in July 1986, citing as one of his reasons that he believed he could 'help to introduce the modern developments of molecular genetics into clinical practice in East Anglia'.[142]

In his letter of resignation to the Principal of the University of Glasgow on the 12th March 1987, Ferguson-Smith stated that 'I shall always look back with great pleasure on my 26 years association with Glasgow University as a member of staff. It has been a great privilege to have the opportunity of helping to pioneer Medical Genetics here.'[143] It was not an easy decision to leave, and Ferguson-Smith recounted that, when he was first contacted about the job in 1986, 'it had only been six years since the Duncan Guthrie Institute had been opened and had been my work, helped by my wife … since we'd come to Glasgow. And of course we'd been by that time twenty-five years in Glasgow, and had worked very hard to develop the Institute and get it going, and I had no particular plans to leave.'[144] It is therefore perhaps not surprising that many of the staff members working in the Duncan Guthrie Institute did not foresee such a move. Several of Ferguson-Smith's colleagues whom I interviewed recalled how they felt when they found out that Ferguson-Smith was to leave the department. One commented that 'Surprise was the first thing I think everyone was really amazed that he was leaving because we thought that he had obviously built up that department. It was his – he had built it up from scratch and it was his creation and the thought that he was going to leave just seemed so unexpected. I think that was the main thing.'[145] This theme that he

[140] UGC 188/1/2/10/1, Visit to Cambridge, July 1986, p. 5.
[141] MAFS interview, DS300127, p. 1.
[142] UGC 188/1/2/10/2, Correspondence regarding possible move to Cambridge arising from visit, p. 7 (letter dated 11th July 1986).
[143] UGC 188/1/2/10/3, Correspondence regarding Ferguson-Smith's move to Cambridge, including formal acceptance, p. 9 (letter dated 12th March 1987).
[144] MAFS interview, DS300127, p. 1.
[145] SC interview, DS300158, p. 7.

was leaving behind his 'creation' was echoed by another interviewee: 'I think it was quite keenly felt by the whole department because it was essentially Malcolm's baby and he set it all up and he was quite a driving force. But yeah it was keenly felt, definitely keenly felt.'[146] The second interviewee quoted here emphasised the strong, founding role that Ferguson-Smith had played in the department, as he felt when he left that it was 'like losing your dad basically'.[147] This individual spent all but a few years of his career in medical genetics, beginning work with Ferguson-Smith when he was a young man, and progressed through the ranks under his supervision.

The man who replaced Ferguson-Smith as the Burton Chair of Medical Genetics was Professor Michael (Mike) Connor, who had been working with Ferguson-Smith since 1982. He had followed a similar career path to Ferguson-Smith, working at the Moore Clinic with Victor McKusick in Johns Hopkins University,[148] and was appointed the first NHS Consultant in Genetics in Scotland in Ferguson-Smith's department.[149] However, Connor recalled with some humour during his interview that the prospect of taking over the role was 'scary'. He was already responsible for the clinical aspects of genetics within the department, but his new role would require him to take over the running of both the research and university side of the job in addition to this. Several different areas would be brought in or expanded under his leadership, including molecular genetics, newborn screening, and cancer genetics.[150] He became the head of a department with over 100 staff, but received no induction or training, and recalled a moment of panic when he first looked through the account books for the department and thought they were not even financially solvent, only to be reassured by the university accounts staff that all was well.[151]

The view of the majority of those I interviewed was that Connor adapted to the role well, with one describing how in his opinion Connor 'carried on where Malcolm left off

[146] GG interview, DS300134, p. 18.
[147] Ibid.
[148] MC interview, DS300143, p. 1.
[149] Ibid., p. 3.
[150] Ibid., p. 8.
[151] Ibid., pp. 7-8.

basically and it was seamless, absolutely seamless'.[152] Another recalled that they could not think of anything 'that was particularly different' when Connor took over.[153] One interviewee commented that, whilst of course there was a 'personality change' with the move from Ferguson-Smith to Connor, the department continued to grow in size and scope under his leadership.[154] Some did, however, feel that the working environment under Connor was less rigorous than it had been when Ferguson-Smith was running the department. One commented 'We still had the Wednesday meetings although they weren't quite as demanding shall we say. But they then kind of petered out really and we didn't have them.'[155] Professor Connor did however give weekly talks on a variety of relevant subjects, and also took employees round the hospital wards so that they could appreciate the clinical implications of their work.[156]

One interviewee voiced his concerns that the department 'wasn't as intense a place, it was a more relaxed atmosphere', and he felt that the research aspect of the department deteriorated after Ferguson-Smith left.[157] This is an assertion that Ferguson-Smith agrees with. He described how when he left the department was 'flourishing, and in fact it was probably the most active genetics service in the United Kingdom. It certainly was the biggest and was working extremely well. Perhaps it's a good time to leave a job when it's flourishing because the momentum would hopefully carry it on. I'm sorry to say that the research fell off quite a lot when I left but the service continued unabated, they have always provided a first class service and that was a good legacy to leave when I moved to Cambridge.'[158] Thus, it can be seen that the research and the service aspects of the medical genetics department were viewed as distinct entities by Ferguson-Smith. That Connor continued to expand the service element is clear, but for some interviewees, the research aspects and projects of the department decreased after Ferguson-Smith left. However, for others within the department, Ferguson-Smith's move allowed them to step up and take on more responsibility within their role. For

[152] GG interview, DS300134, p. 19.
[153] JL interview, DS300179, p. 5.
[154] SI interview, DS300173, p. 4.
[155] JL interview, DS300179, p. 5.
[156] Weekly talks described in JL interview, DS300179, p. 5. Hospital rounds described in SI interview, DS300173, p. 2.
[157] SC interview, DS300158, pp. 6-8.
[158] MAFS interview, DS300127, p. 3.

Gordon Graham, this was linked to the stage of his career when the change in leadership happened. He has described how he found that for him personally, the research aspect was better under Connor, however he attributed this to being 'in a position to take advantage of it'.[159] He described how 'in the seven years I knew Malcolm I was still a kind of wet behind the ears and young and still learning my trade in the service side of it and it wasn't really until Mike took over in the 80s that I kind of was more involved in doing other things and at that point extending into research'.[160] The experience differed for individuals, dependent on their particular roles and career stages.

Thus, whilst the research aspect of the department may have been seen by some to have diminished under Connor's leadership, it seems that there is agreement that the service aspect of the department continued to develop. This is seen in Coventry and Pickstone's comment that after Ferguson-Smith's departure, Connor 'has since established the department at Glasgow as the largest medical genetic service in Europe serving some 3 to 5 million people'.[161] Interestingly, one interviewee commented that in present day the department is definitely more 'service based', linking this to factors such as accreditation.[162] Thus, from this perspective, the move away from research was partly as a result of the formalisation of procedures and testing within medical genetics laboratories, which were not as prevalent throughout the 1960s and 1970s. Douglas Wilcox has also noted that Mike Connor 'oversaw a huge expansion in the department both in terms of patients seen and in numbers of staff', emphasising Connor's commitment to continue to expand the medical genetics service.[163]

One of the most crucial areas which developed under Connor's leadership was the service work in molecular genetics. As discussed in the introduction, prior to his move to Cambridge, Ferguson-Smith had been involved in putting in a funding bid for a molecular genetics consortium to run in Scotland. It was the later 1980s before

[159] GG interview, DS300134, p. 19.
[160] Ibid.
[161] Peter A. Coventry and John V. Pickstone, 'From What and Why Did Genetics Emerge as a Medical Specialism in the 1970s in the UK? A Case-history of Research, Policy and Services in the Manchester Region of the NHS', *Social Science and Medicine*, 49:9 (1999), p. 1232.
[162] GG interview, DS300134, p. 19.
[163] DW interview, DS300142, p. 10.

molecular genetics began to be implemented as a clinical service, with much of the work prior to this focusing on research.[164] Connor played a key role in developing this service, building upon the early research work in molecular genetics which had been done in Glasgow under Ferguson-Smith.

Another area that Connor developed was the MSc course in Medical Genetics, which had been set up by Ferguson-Smith. Upon Ferguson-Smith's departure, the course numbers fell to one student, and Connor approached Douglas Wilcox to enquire if he would be interested in taking on the course and developing it. Wilcox readily agreed, and throughout the years that Wilcox taught on the course, there were over 700 graduates.[165] Others within the team recalled that the MSc course 'expanded a great deal under Professor Connor and grew and grew' but that the course 'didn't involve sort of innovative research to any great extent'.[166]

For Ferguson-Smith, the process of taking over a new department upon his move to Cambridge was not without its challenges. He was appointed as the Director of the East Anglia Regional Genetics Service, and drew on his experience from setting up the regional service in the West of Scotland to implement a similar scheme in East Anglia. This was a large undertaking as when he arrived in Cambridge in 1987 there was little medical genetics work happening. There was only one cytogenetics lab which was staffed with around four or five scientists, which Ferguson-Smith deemed to be 'really inadequate' for the running of a regional service.[167] Whilst keen to implement such a regional service for the area, he found the experience differed greatly from his work to achieve the same outcome in Scotland. Many of the obstetricians in the towns which surrounded Cambridge were reluctant to get involved, mainly, he felt, because he was a 'new guy coming to Cambridge from Scotland trying to impose this programme'.[168] He recalled how he tried to get his colleagues 'to think in terms of a network of regional centres in England to share out the load of tests. This was how we got the system to

[164] As highlighted in the discussion of the Witness Seminar in the introduction of this thesis.
[165] Ibid.
[166] SC interview, DS300158, p. 7.
[167] MAFS interview, DS300127, p. 2.
[168] MAFS interview, DS300128, p. 2.

work in Scotland. We established a consortium of labs in which each of the four centres provided tests for an agreed number of different conditions and posted the patient samples to each other. Each received enough samples to develop sufficient expertise in a particular condition. It worked well in Scotland, but it took a long time before the individual groups in England worked together as a network.'[169] Despite these setbacks the regional service did become established and grew greatly over the years which followed, becoming instrumental in offering prenatal diagnostic testing and screening for a variety of conditions.

In addition to the diagnostic work, Ferguson-Smith and his colleagues were also involved in a wide range of research, including gene mapping, comparative genomics and research to improve prenatal testing methods. Whilst working in Cambridge Ferguson-Smith was asked by the Government to be the scientist on the inquiry into bovine spongiform encephalopathy (BSE). This began in late 1997 and it was expected to take up one day a week of Ferguson-Smith's time for a year, but instead was almost a full-time job which lasted for three years.[170] At the beginning of the inquiry Ferguson-Smith was still the Chair of Pathology, and so was required to train up the other members of the inquiry to give them the required knowledge about BSE. He organised lectures in the Department of Pathology for them, and despite retiring from his chair in pathology in 1998 he maintained his involvement with the inquiry, seeing it through to completion.[171]

When retiring from the Chair of Pathology post he remained active in research, and moved to the Veterinary School in Cambridge to work on comparative genomics in greater detail. He took the members of his research team who were working on flow cytometry in pathology to the Veterinary School to assist in this work,[172] and the group formed the Cambridge Resource Centre for Comparative Genomics. Their current work in the Centre involves comparative analysis of chromosomes from a variety of species, and the group also provide chromosome specific DNA from over 150 species to

[169] Ibid., pp. 4-5.
[170] Ibid., p. 6.
[171] Ibid.
[172] Ibid., p. 5.

researchers around the world. This work is enabling studies on comparative genetics and evolutionary biology, and it has the potential to provide an insight into which genes are essential for life and have been conserved amongst species.

VIII. Conclusion

It is clear that Ferguson-Smith was a critical figure in the development of medical genetics in the West of Scotland. Beginning with his interest in chromosomes at the early stage of his career, through to the move to Johns Hopkins to further develop his skills, medical genetics remained a key focus of his priorities throughout. The expansion of the medical genetics department in Glasgow was aligned with the wider developments which were occurring in the prenatal field, such as the use of amniocentesis, CVS and ultrasound, combined with the increased demand for testing from pregnant women. The department grew from one room within the University of Glasgow to an entire Institute for medical genetics, in the form of the Duncan Guthrie Institute. The details of the running of the department highlight the collaborative nature of the work which was going on, with many staff members listing ease of communication as central to departmental functioning. Whilst Ferguson-Smith's move to Cambridge may have been a surprise for his staff members, it shows his continuing commitment to expand medical genetics and make it more accessible to the public. That the department continued to thrive under the leadership of Professor Connor is reflective of the nature of the staff who worked there, who were keen to continue developing and expanding medical genetics further.

Thus, it can be seen that whilst there was change which took place with the move from Ferguson-Smith to Connor running the department, much of this followed on from earlier work implemented by Ferguson-Smith. Both the clinical service and the MSc work were established by Ferguson-Smith, but expanded and continued to develop under Connor's management. In addition, the molecular genetics work which was mainly at the research stage in Glasgow when Ferguson-Smith left, became entrenched in the molecular genetics' consortium for Scotland, with the clinical molecular service flourishing with Connor running the department. Whilst some members of the department, including Ferguson-Smith himself, felt that the research culture stagnated

after Ferguson-Smith's departure, this can perhaps be seen in a wider movement towards becoming more service focused over time. Ferguson-Smith himself has continued to leave a legacy in this area in Glasgow, with his contribution to the early days of medical genetics still recognised. This was shown in 2004, when the new clinical genetics centre opened in the West of Scotland, and was called the 'Ferguson-Smith Centre for Clinical Genetics'.

By using the case study of Ferguson-Smith to explore how medical genetics advanced in the specific region of the West of Scotland, it is possible to build up a comprehensive understanding of the staff and facilities which were involved. Examining the development of medical genetics in Glasgow in this manner allows for a detailed picture to emerge of how the department was structured, both in terms of physical space and under the leadership of Ferguson-Smith. Having an understanding of these features will enable an in-depth analysis of how the prenatal testing programmes were run within the department. Two of these key programmes, namely testing for chromosome disorders and neural tube defects, will be the focus of chapters three and four. In both of these chapters the material presented here on the development of medical genetics in Glasgow will combine with the information from chapter one on prenatal testing techniques, to enable detailed examination of these prenatal services in the West of Scotland.

Chapter Three – Prenatal Diagnosis of Chromosome Anomalies: Development, Implementation, and Uptake

I. Introduction

At the First International Congress of Human Genetics held in 1956 in Copenhagen, data was presented by Tjio of Sweden, and by Ford and Hamerton of London, showing that the chromosome number in humans was 46, and not 48 as had been previously theorised.[1] This discovery opened up the field of chromosome research to the detection of many chromosome anomalies, and a number of associated chromosome disorders would be identified over the following years. An editorial published in *The Lancet* in April 1959 highlighted that the 'chromosomes of man, as of other mammals, are very hard to study', but that strides were being made in the detection of chromosome disorders, exemplified by findings such as those by Lejeune, Gauthier and Turpin that 47 chromosomes were present in cases of Down's syndrome.[2] These discoveries, when situated amongst those made by others such as Steele and Breg, would go on to make prenatal testing feasible. As highlighted in previous chapters, one of the key focus areas for those working in the prenatal testing field was the detection of fetal chromosome anomalies. This chapter will examine how the detection of chromosome disorders in the fetus evolved, giving consideration to both the work carried out in the West of Scotland by Ferguson-Smith and his colleagues, and also other research teams throughout the rest of the world.

The first section of this chapter will consider the early research work into chromosome anomalies, which was focused not on antenatal detection of these conditions, but instead centred on trying to understand hereditary patterns. Discussion will then highlight how the timing of the work by Steele and Breg alongside the implementation of more permissive abortion legislation would combine to provide women with the option to terminate affected pregnancies after a diagnosis of fetal anomaly, thus opening up the whole field of prenatal testing. Early attempts at diagnosis of chromosome anomalies in

[1] Author Unknown, 'Conferences and Congresses – International Congress of Human Genetics', *The Lancet*, 268:6938 (1956), p. 350.
[2] Author Unknown 'Leading Article – The Chromosomes of Man', *The Lancet*, 273:7075 (1959), p. 716.

the fetus by Ferguson-Smith and his colleagues at Glasgow will be considered, followed by a detailed description of the expansion of prenatal testing in the region. The running of prenatal testing programmes by other research groups will also be examined, as will key technical issues associated with prenatal testing.

A major area of interest for Ferguson-Smith was the link between maternal age and chromosome anomalies, and the debates surrounding the discrepancies between prenatal and live-born rates of chromosome disorders will be discussed in detail. The uptake rates of prenatal testing programmes for chromosome disorders will also be considered, with the differing numbers experienced by various research groups discussed. Finally, the attempts to develop screening programmes for Down's syndrome using maternal serum AFP levels will be examined, exemplifying the continued drive by researchers to move towards less invasive testing methods.

II. Early Chromosome Research to Predict Patterns of Heredity

Despite the key publication in 1960 by Fuchs and Riis, which showed that amniocentesis could be used for fetal sexing, the main focus of chromosome research in the early 1960s was not on developing chromosome work to be used in prenatal testing. Those involved in studying chromosomes were instead keen to understand more about the different types of chromosome anomalies, and how these could be inherited. They were hopeful that this information could then be used to predict the likelihood of recurrence of conditions in families who were seeking genetic advice. By 1961 it had been identified that 'the recently described human chromosome abnormalities are of 2 main types', with the first group comprising 'individuals who have an irregular number of chromosomes, a situation called aneuploidy' and the second group comprised of individuals where the 'chromosome anomaly involves the structure of the individual chromosomes'.[3] These structural aberrations can include deletions, where a section of the chromosome is missing which results in the loss of genetic material, and translocations, where part of one chromosome becomes attached to another

[3] Malcolm A. Ferguson-Smith, 'Chromosome Abnormalities with Congenital Disease', *Modern Medicine*, 29:5 (1961), p. 80.

chromosome.[4] These structural aberrations are shown in Figure 3.1, alongside an inversion and a duplication of a section of a chromosome:

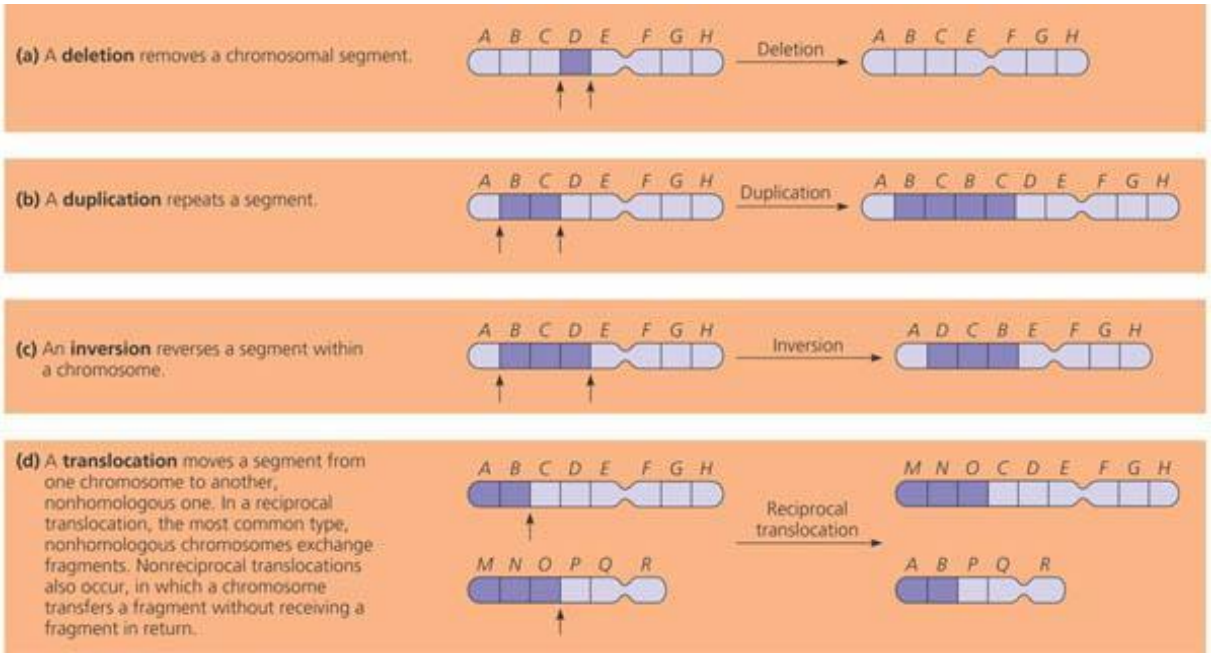


Figure 3.1 – Showing a variety of alterations which can occur, which impact chromosome structure.[5]

In March 1961 the Royal College of Physicians of London held a conference on the 'Clinical Aspects of Genetics', where topics included the description of human chromosomes and the methods available to identify them. Discussions also focused on the sex chromosome anomalies, and trisomic conditions such as Down's syndrome.[6] Work was also presented on new trisomy syndromes which were in the process of being identified – these would later go on to be classified as trisomy 13 and trisomy 18.[7] A conference held in November 1961 in Glasgow on 'Diseases of Genetic Aetiology' covered similar subjects, with sex chromosome disorders, Down's syndrome and other

[4] 'Chromosomal Abnormalities – Structural Rearrangements', *Virtual Genetics Education Centre University of Leicester* <http://www2.le.ac.uk/projects/vgec/healthprof/topics/patterns-of-inheritance/chromosomal-abnormalities#structural-aberrations> [accessed 17th August 2017].
[5] Neil A. Campbell and Jane B. Reece, *Biology*, 7th Edition, (San Francisco: Pearson Education, Inc., publishing as Benjamin Cummings, 2005), p. 286.
[6] Author Unknown, 'Conferences – Clinical Aspects of Genetics', *The Lancet*, 277:7178 (1961), pp. 663-664.
[7] Ibid., p. 664.

trisomy syndromes discussed.[8] Whilst there was a brief discussion on the 'present knowledge and future prospects in the field of human cytology', there is no recorded mention of hoping to develop these techniques for prenatal testing – instead the speaker 'looked forward to the day when he could map genes on human chromosomes'.[9]

A key aim of understanding how chromosomes worked was to utilise this knowledge to provide genetic advice to families. In October 1961 several papers were published in *The Lancet* which assessed the possible increased chance of having a second child with Down's syndrome subsequent to having had an affected child. As described by Carter and Evans:

> Three questions are very important for genetic counselling in relation to Down's syndrome. First, if parents have had one child with the syndrome, is there an increased risk of their having a second child similarly affected, and is the increase dependent on maternal age? Secondly, if the answer is Yes, is the increase limited to a minority of the parents? Thirdly, if the answer is again Yes, can these parents be identified cytologically?[10]

This quote highlights the many questions which still remained unanswered about chromosome disorders in the early 1960s.[11] Whilst researchers were becoming aware that recurrence rates of chromosome conditions could be higher in families who had an affected child, there was still uncertainty surrounding whether these conditions could be identified in families prior to future pregnancies. By December 1962 it seemed that advances had been made. The *British Medical Journal* stated that 'the value of the new techniques of studying chromosomes is now firmly established', and that an 'important practical application in relation to Down's syndrome is in predicting the chances of the

[8] Author Unknown, 'Conferences – Diseases of Genetic Aetiology Conference at Glasgow', *British Medical Journal*, 2:5266 (1961), pp. 1559-1560.
[9] Ibid., p. 1560.
[10] C.O. Carter and K.A. Evans, 'Risk of Parents Who Have Had One Child with Down's Syndrome (Mongolism) Having Another Child Similarly Affected', *The Lancet*, 278:7206 (1961), p. 785.
[11] It should be noted here that the term 'mongolism' was still commonly used in the early 1960s to describe Down's syndrome. I strongly oppose the use of this terminology, however to retain historical accuracy the term 'mongolism' will be used in this thesis in direct quotes.

parents' having a second similarly affected child'.[12] It was thought to be 'advisable to test the parents and child before offering advice on the risk of recurrence of mongolism in later pregnancies'.[13] This could be achieved by testing the chromosomes of the parents to see if they had a chromosome translocation which could lead to future children having an increased chance of inheriting the condition.[14] By 1963 this seemed to be becoming a more common testing practice, with a report published in the *British Medical Journal* from the 'Second Symposium on Mental Subnormality', held at the University of Birmingham, stating that 'chromosomal investigation should now be part of the routine laboratory service of a children's teaching hospital'.[15] This was the case in the Birmingham region, where 'all cases of mongols born to mothers under the age of 30, both parents, and when convenient the child, were seen immediately'.[16] In Glasgow, the medical genetics unit also accepted cases of parents 'who have had more than one mongol child', young mothers 'who have had one mongol child and contemplate a further pregnancy (possibly 20% of such cases carry a chromosome translocation)' and parents 'who have had one mongol child and have a history of mongolism in other members of the family'.[17]

III. The Emerging Possibility of Prenatal Testing

Although it was becoming possible to determine the recurrence of Down's syndrome, it seemed doubtful to some that there would ever be the possibility of detecting this and other chromosomal conditions in the fetus early enough during pregnancy to enable termination prior to birth. The samples which were being tested were from children and adults, with no attempts being made to characterise fetal chromosomes. Ferguson-Smith himself wrote in 1964 of it being 'doubtful if foetal chromosome analysis from

[12] Author Unknown, 'Leading Article – Chromosomes in Medicine', *British Medical Journal*, 2:5317 (1962), p. 1453.
[13] Ibid.
[14] Translocation Down's syndrome is rare, and involves the breaking off of the long arm of chromosome 21 and its re-attachment to the long arm of another chromosome – for example chromosome 14. A parent can have a translocation but be unaware because of a complete lack of Down's syndrome characteristics. If a child receives the typical two copies of chromosome 21 (one from each parent) along with the copy of chromosome 14 with the added long arm of chromosome 21, then they will have three copies of the long arm of chromosome 21, leading to Down's syndrome.
[15] Author Unknown, 'Special Report – Mongolism', *British Medical Journal*, 1:5325 (1963), p. 248.
[16] Ibid.
[17] University of Glasgow Archives, Papers of Malcolm Andrew Ferguson-Smith, UGC 188/3/2/3/7, Ferguson-Smith Correspondence Da-Du, pp. 19-20 (letter dated May 30th 1963).

embryonic cell cultures could be completed early enough in pregnancy to make therapeutic abortion possible'.[18] However, the publication of the previously discussed key paper by Steele and Breg in 1966 would go on to refute these doubts. They showed that cells taken from human amniotic fluid were not only viable, but could be grown in culture and also karyotyped. They concluded that 'chromosome analysis of the fetus in utero is therefore feasible'.[19] This would prove to be correct, with the discovery acting as the stimulus to develop the field of prenatal testing.

To enable these discoveries surrounding chromosome knowledge to become clinically applicable, however, would require changes to abortion legislation. This would occur in 1967, with the passing of the Abortion Act, which specifically detailed that termination of pregnancy could be carried out after a diagnosis of fetal anomaly. Prior to the implementation of the Abortion Act 1967, there had been a number of legal prohibitions on abortion, but these did not cover Scotland and England together. Whilst in England there was specific legislation in place prohibiting termination of pregnancy, in Scotland abortion was a 'common law offence without strictly defined limits' which meant that 'it was possible to interpret it more elastically than English statute law'.[20,21] Whilst abortion was defined in Scottish legal textbooks as being illegal, it was stated that it could be carried out when 'certain medical criteria relating to the life and health of the

[18] M.A. Ferguson-Smith, 'Avoiding Serious Birth Defects by Prenatal Diagnosis: Current Effects on Birth Incidence', in *Changing Patterns of Conception and Fertility*, ed. by D.F. Roberts and R. Chester, (London: Academic Press Inc. (London) Ltd., 1981), p. 121.
[19] Mark W. Steele and W. Roy Breg Jr., 'Chromosome Analysis of Human Amniotic-Fluid Cells', *The Lancet*, 287:7434 (1966), p. 385.
[20] Gayle Davis and Roger Davidson, '"A Fifth Freedom" or "Hideous Atheistic Expediency"? The Medical Community and Abortion Law Reform in Scotland, c.1960-1975', *Medical History*, 50:1 (2006), p. 31.
[21] In England legislation such as the Offences Against the Person Act of 1837 prohibited abortion entirely, but this was succeeded in 1929 by the Infant Life Preservation Act (ILPA). The ILPA made termination of pregnancy legal when the abortion was carried out for the purpose of preserving the life of the pregnant woman. (See Stephen Brooke, 'Abortion Law Reform 1929-68', in *Witness Seminar The Abortion Act 1967*, ed. by Michael D. Kandiah and Gillian Staerck, Institute of Contemporary British History, 2002, p. 15.) Despite the ILPA, it was not clear from a legal perspective when it would be deemed suitable for a medical practitioner to carry out an abortion. The legal position at that time was put to the test in 1938 by Alec Bourne, a London-based gynaecologist who carried out an abortion on a 14 year old girl who had become pregnant after being raped by several soldiers. Bourne's case went to trial but he was acquitted, and the ruling set the precedent for a belief that abortions could be carried out under certain circumstances to preserve the life of the pregnant woman. See James Owen Drife, 'Historical Perspective on Induced Abortion Through the Ages and its Links with Maternal Mortality', *Best Practice & Research Clinical Obstetrics and Gynaecology*, 24:4 (2010), p. 437 and John Keown, *Abortion, Doctors and the Law. Some Aspects of the Legal Regulation of Abortion in England from 1803 to 1982*, (Cambridge: Cambridge University Press, 1988), p. 51.

mother were satisfied'.[22] Thus a doctor could carry out a termination of pregnancy if they had assessed the case of the patient, and felt that an abortion would be the best outcome to maintain their health or welfare. The advances made in chromosome knowledge in the 1960s, combined with the implementation of the Abortion Act 1967, made it possible to not only detect fetal anomalies prior to birth, but to provide women with the option to terminate affected pregnancies if they chose to do so. For Marie Ferguson-Smith these two developments were inextricably linked in the development of practical prenatal decision-making:

> And in 1967, debate started about updating the 1921 abortion law. The amendment to the law was being looked at and it was introduced in Parliament by David Steel. And that was to allow women selective termination in certain circumstances with the signature of two doctors and so on. That was passed. And at the same time, scientists in United States were discovering that they could grow amniotic fluid cells. So putting the two things together suddenly you had the potential to give a practical choice in genetics. Because until then, until prenatal diagnosis, clinical genetics was consultative and there was nothing tangible on offer. You gave patients risks but you couldn't do a bloody thing about it. There was little choice.[23]

This lack of choice would change swiftly after the Abortion Act 1967 was officially implemented in April 1968.[24] Only a few months after this the medical genetics unit in Glasgow was attempting to culture amniotic fluid cells, with Malcolm Ferguson-Smith stating that he was 'particularly interested in the application of these cultures for the antenatal diagnosis of chromosome aberrations' as he had 'recently seen two pregnant women who are both translocation carriers' and was therefore keen 'to establish a reliable technique as soon as possible'.[25] Ferguson-Smith wrote to colleagues in Wisconsin and Boston to seek their advice on how best to develop the technique,

[22] Davis and Davidson, '"A Fifth Freedom"', p. 31.
[23] MEFS Interview, Transcript 2, p. 4.
[24] Stephen Brooke, 'Abortion Law Reform 1929-68', in *Witness Seminar The Abortion Act 1967*, ed. by Michael D. Kandiah and Gillian Staerck, Institute of Contemporary British History, 2002, p. 19.
[25] UGC 188/3/3/15/6, Ferguson-Smith Correspondence Na-Ne, p. 2 (letter dated October 21st 1968).

updating them on their progress and setbacks, highlighting the knowledge sharing network which was widespread amongst those working in medical genetics.[26]

A key reason that the group in Glasgow were able to start working on culturing amniotic fluid cells so soon after Steele and Breg's publication was that they were already involved in working with samples of placenta, culturing these for chromosome analysis. This was to help understand the cause of multiple miscarriages or stillbirths, which was a research focus for the department as early as 1963.[27] As the group had a laboratory in the Queen Mother's Hospital in Glasgow, they were working closely with the obstetrics and paediatrics teams, and Marie Ferguson-Smith has recalled how these experiences helped her to develop skills for tissue culture:

> Our lab was based in a maternity hospital with neonatal paediatrics ward. Ian Donald was Professor of Midwifery,[28] and he and the paediatricians wanted some chromosome analysis done on stillbirths and spontaneous abortions. I found that I could actually do it and I was quite good, successful at it. I could basically grow any tissue that was given to me. Our local paediatric pathologist Angus Gibson tutored me on selecting the correct placental tissues, a totally neglected but genetically informative material, and I started to develop tissue culture techniques to get chromosome preparations for clinical diagnosis. I started working very closely with the firms that were producing media, and the two firms that worked in Scotland were Gibco Bio-cult, and Flow, to improve tissue culture methods.[29]

Whilst the group were working with placental tissues prior to the publication by Steele and Breg, after 1966 they began to consider how they could utilise their existing knowledge and skills to develop tissues cultures from amniotic fluid. Malcolm Ferguson-Smith has recalled the steps which led to these advances, which interestingly derived from receiving amniotic fluid samples from pregnant women whose fetus had

[26] Letters to Wisconsin – UGC 188/3/3/19/14, Ferguson-Smith Correspondence Sa, pp. 9-10 (letters dated October 21st 1968 and November 13th 1968).
Letters to Boston – UGC 188/3/3/12/12, Ferguson-Smith Correspondence Li-Lo, pp. 12-13 (letters dated October 21st 1968 and November 19th 1968).
[27] UGC 188/3/2/3/7, Ferguson-Smith Correspondence Da-Du, pp. 19-20 (letter dated May 30th 1963).
[28] This title given to Donald was a particular one in Scotland, with the Professor of Midwifery essentially a Professor in Obstetrics and Gynaecology. Donald himself was an obstetrician.
[29] MEFS Interview, Transcript 2, p. 3.

haemolytic disease due to Rhesus incompatibility. Haemolytic disease of the fetus and newborn is also known as Rhesus disease, and as shown in Figure 3.2, occurs in women who have Rhesus negative blood, if their fetus has Rhesus positive blood:

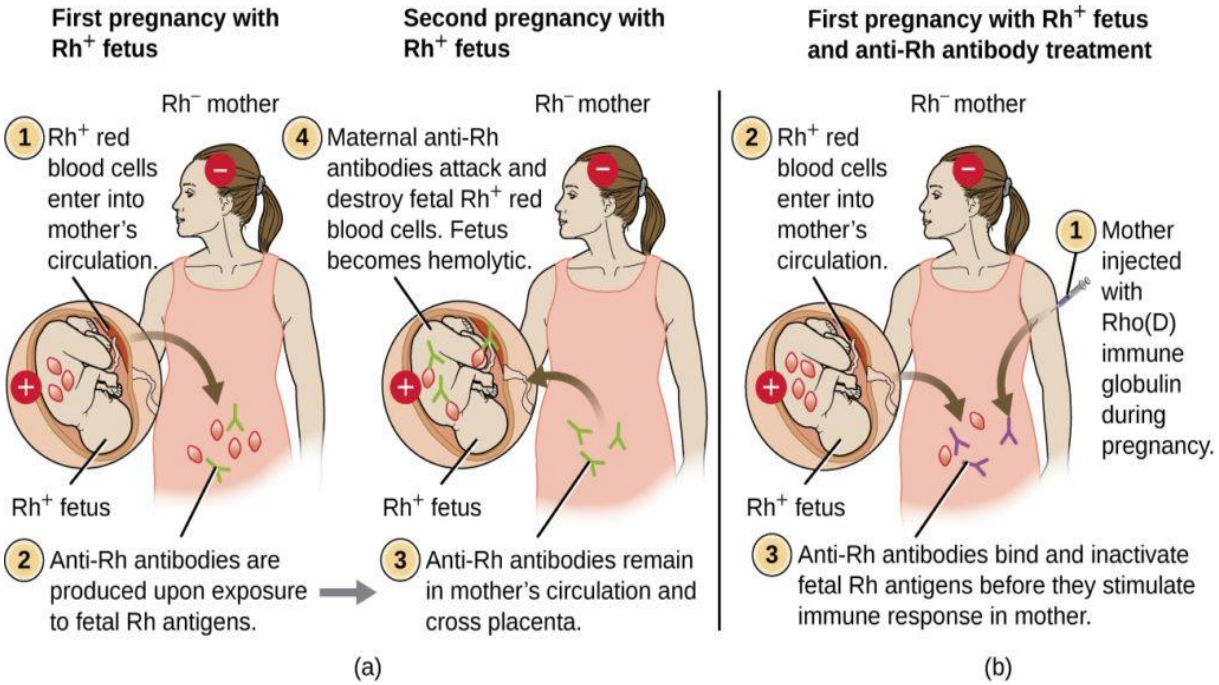


Figure 3.2 – Showing the Rhesus interaction between a Rhesus negative woman, and her Rhesus positive fetus. The pregnant woman must have already been exposed to Rhesus positive blood (most usually in a previous pregnancy), and her body goes on to produce antibodies against the Rhesus antigen. If her immune system encounters the Rhesus antigen again (for example in a subsequent pregnancy) then the antibodies it had produced will cross the placenta and attack and destroy the red blood cells of the fetus. It can continue to attack these red blood cells even after birth. The condition is now fairly uncommon due to injections which can be given to the pregnant woman, which help to remove the fetal blood cells which are Rhesus positive before the mother becomes sensitised.[30]

[30] 'Hypersensitivities', *Lumen Microbiology* <https://courses.lumenlearning.com/microbiology/chapter/hypersensitivities/> [accessed 7th August 2018] (section titled Rh Factors).
For more information on Rhesus, see 'Rhesus Disease – Overview', *NHS Choices* <http://www.nhs.uk/conditions/Rhesus-disease/Pages/Introduction.aspx> [accessed 16th August 2017].

Marie Ferguson-Smith 'was growing up placental cells at the time and of course that's where the amnion comes from. So we thought about what material we needed to get practice for making amniotic cell cultures. We got samples of amniotic fluid from patients who had had their amniotic fluid tested because the fetus had haemolytic disease due to Rhesus incompatibility'.[31] This was the material which would form the basis of much of the testing:

> In these cases the obstetricians were taking samples of amniotic fluid to test for bilirubin[32] in the amniotic fluid and I wanted the amniotic cells that were being discarded. So these were some of the samples that we got to practice with. We got another lot of samples from pregnant patients that had to have their uterus removed because of obstetric problems. The whole pregnancy was removed in those cases, it's called a hysterotomy. Ian Donald and his team told us when they had such cases and gave us the samples so that we could collect the amniotic fluid and grow the cells. That's what Marie started working on.[33]

This prior experience in tissue culture would go on to benefit the medical genetics unit over the following years. In November 1968 Malcolm Ferguson-Smith wrote to a colleague in Boston in the United States updating him on their progress, declaring that they were 'nearly at the stage of making chromosomes' and that this was partly due to the fact they were now getting amniotic fluid samples from much earlier in pregnancy, in cases of therapeutic abortion. The group had discovered that trying to culture cells from the amniotic fluid of pregnancies at a more advanced gestation was not as successful, such as in cases of Rhesus incompatibility.[34] As mentioned in chapter two, the group first began offering amniocentesis for the purposes of prenatal diagnosis in 1969. Some of the first people to undergo the testing were people that Ferguson-Smith

[31] MAFS Interview, DS300117, p. 2.
[32] Rhesus disease causes a build-up of excessive amounts of bilirubin, which can lead to neurological damage.
'Rhesus Disease – Complications', *NHS Choices*
<http://www.nhs.uk/Conditions/Rhesus-disease/Pages/Complications.aspx> [accessed 16th August 2017].
[33] MAFS Interview, DS300117, p. 2.
[34] UGC 188/3/3/12/12, Ferguson-Smith Correspondence Li-Lo, p. 13 (letter dated 19th November 1968).

knew, such as friends and wives of colleagues with an understanding of the tests, but it was quickly made available to the general public.[35]

After testing several individuals, by 1971 the Glasgow medical genetics unit were publishing results of their work in the area. In the *British Medical Journal* in October of that year, they highlighted the importance of the Abortion Act 1967 in giving 'mothers with a substantial risk of bearing a seriously handicapped child the choice of having the pregnancy terminated', and described that 'as chromosome aberrations are numerically the most important indication for antenatal diagnosis our efforts have been directed particularly at the chromosome analysis of cultured amniotic fluid cells'.[36] They carried out amniocentesis on 30 pregnant women who had been referred for genetic counselling, and they successfully determined the chromosome constitution in all but one of the fetuses, resulting in 29 fetal karyotypes for analysis. A second amniotic sample was required in 5 of the patients, bringing the success rate of the procedure to 83%.[37] Of the 29 fetuses that had their karyotype successfully determined, one was subsequently terminated. This was due to the finding that the fetus was male, in a pregnancy which was at risk of X-linked granulomatous disease, a condition which impairs the immune system and is passed from mother to son.[38]

Over the following years the demand for prenatal chromosome analysis increased in the West of Scotland, with the majority of patients being referred through Malcolm Ferguson-Smith's genetics clinics. He recalled that the group did not advertise the prenatal service at this stage as they were so busy with the work they had, and that they 'wanted to go carefully to know what we are doing, are we causing abortions or causing difficulties for the fetus. I mean was there a danger to the fetus in any kind of way.'[39] These concerns were reasonable, especially as awareness was growing amongst clinicians of the link between amniocentesis and miscarriage.[40] However, referrals did

[35] MAFS Interview, DS300117, p. 3.
[36] M.E. Ferguson-Smith, M.A. Ferguson-Smith, N.C. Nevin and M. Stone, 'Chromosome Analysis Before Birth and its Value in Genetic Counselling', *British Medical Journal*, 4:5779 (1971), p. 69.
[37] Ibid., p. 70.
[38] Ibid.
[39] Abortions in this context is referring to miscarriages. MAFS Interview, DS300117, p. 4.
[40] These risks are discussed in detail in chapter one on the history of prenatal testing.

increase, and the main indications for testing were 'parental chromosomal translocation or mosaicism where the risk of fetal chromosome abnormality is about 20%, pregnancies in mothers over the age of 40 years where there is a 2.6% risk of Down's syndrome, and pregnancies in mothers who have had a previous child affected with Down's syndrome'.[41]

134 cases were referred to the Glasgow and West of Scotland Genetic Counselling Service for chromosome analysis between 1969 and 1973, and 90% of these cases were successfully analysed.[42] There was one false negative in this testing group; the cell culture showed an unaffected female karyotype, maternal cells having been cultured in error, and a chromosome anomaly was not predicted.[43] Ferguson-Smith noted the details of this case in 1976 when completing a questionnaire about the prenatal testing service in Glasgow. He stated that the 'trisomy-21 fetus was missed early on in our series. A normal female karyotype was diagnosed from our culture dish of fibroblast-like cells. A female infant with Down's syndrome was born at term. Clearly maternal cells and not fetal cells were grown.'[44] The group were aware of the problems that maternal cell contamination could cause, referring to it as 'undoubtedly the major hazard in fetal chromosome analysis'.[45] The group were keen to minimise this risk, and worked on several techniques to reduce the chance of diagnostic error. They noted that it was most likely that the maternal cells were 'included in the sample either during insertion of the needle or during withdrawal when negative pressure is applied to the syringe. It is therefore essential to use a stiletto with the needle and to discard the first and last few drops of amniotic fluid withdrawn into the needle.'[46] Marie Ferguson-Smith also recalled working with John Paul, an eminent research scientist based at the Beatson

[41] M.A. Ferguson-Smith, 'Prenatal Diagnosis of Chromosome Anomalies', *Proceedings of the Royal Society of Medicine*, 67:12 Pt. 1 (1974), p. 1256
[42] Ibid.
[43] Ibid.
[44] UGC 188/3/4/57/2, Ferguson-Smith Correspondence M, pp. 11-15 (letter accompanying questionnaire dated 8th November 1976).
[45] M.A. Ferguson-Smith and M.E. Ferguson-Smith, 'Screening for Fetal Chromosome Aberrations in Early Pregnancy', *Journal of Clinical Pathology*, 29:Suppl. 10 (1976), p. 175.
[46] Ibid.

Institute in Glasgow,[47] to learn how to identify different cell types and ensure they were growing fetal and not maternal cells:

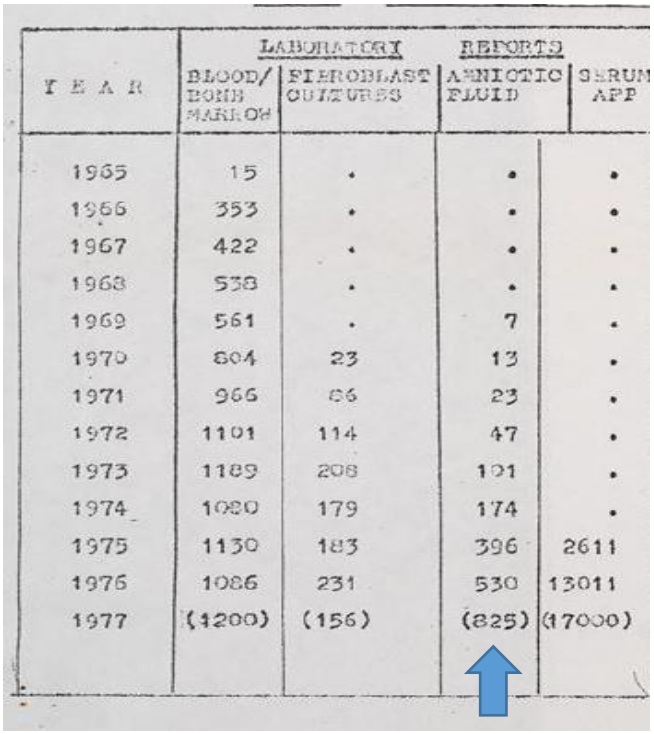
> I learned a lot from John Paul, who was in Beatson and the guru in tissue culture. He was exceedingly helpful because the other technical difficulty was to make absolutely sure that we were growing fetal cells and not maternal cells. So very early on we had to be very aware of what type of cell line became established. Now this is where people like John Paul were fantastic, because I took my specimens to him. At one point he actually came to our lab and held my hand so to speak while we identified the different cell lines. So then we knew that if we had a fibroblast cell line from amniotic fluid it had to be skin and not fetal. We were able to differentiate between epithelial cells which were fetal and fibroblast which were suspect … Every step of the process was recorded. Each sample had a case note, each culture dish had its own identifying letter and each step of growing was recorded in detail. We could go over our notes, analyse each step, learn from it and get better results.[48]

This focus on improving laboratory techniques to ensure correct results was of great importance, especially as the number of women undergoing prenatal testing increased dramatically over the following years. By 1975, 353 pregnant women had been tested, because of an increased chance of chromosomal anomaly in the fetus. A further 363 women were tested to exclude a chromosomal disorder, despite their initial referral to the genetic counsellor being for a non-chromosomal factor, such as a previous pregnancy affected by a neural tube defect.[49] One of the main reasons for referral for chromosome analysis was pregnancies with a maternal age of over 40, as a number of chromosome disorders in the fetus become more frequent with advanced maternal age. 121 women underwent amniocentesis as they were over 40 years of age, and 8 of these pregnancies were diagnosed with chromosomal anomaly, giving a high anomaly rate of 6.6%. The aberrations included seven cases of Down's syndrome and one of XXY Klinefelter's syndrome.[50] In addition, 1 of 72 cases tested in women aged 35-39 had a

[47] The Beatson was originally a cancer hospital which opened in 1890, with a research department formed at the facility in 1912. Under the directorship of Dr John Paul, the distinguished scientist noted above, in 1967 the department became the Beatson Institute for Cancer Research. See 'History', *Cancer Research UK Beatson Institute* <http://www.beatson.gla.ac.uk/About/history.html> [accessed 7th August 2018].
[48] MEFS Interview, Transcript 4, p. 2.
[49] M.A. Ferguson-Smith and M.E. Ferguson-Smith, 'Screening for Fetal Chromosome Aberrations', p. 166.
[50] Ibid., p. 167.

chromosome anomaly (rate of 1.4%).[51] Among 363 women offered amniocentesis for reasons other than a potential chromosomal disorder, two cases of chromosome aberration were diagnosed, one of Down's syndrome, and one in which a female fetus had an extra X chromosome (triple X syndrome).[52] All 11 of these diagnoses led to termination of the affected fetus. 1 case of Down's syndrome was missed throughout the testing period (the above-mentioned case due to maternal cell contamination).[53]

The number of amniotic fluid samples being tested continued to grow, as shown in Figure 3.3 (relevant column highlighted with a blue arrow).



YEAR	LABORATORY REPORTS			
	BLOOD/ BONE MARROW	FIBROBLAST CULTURES	AMNIOTIC FLUID	SERUM AFP
1965	15	.	.	.
1966	353	.	.	.
1967	422	.	.	.
1968	538	.	.	.
1969	561	.	7	.
1970	604	23	13	.
1971	966	66	23	.
1972	1101	114	47	.
1973	1189	208	101	.
1974	1080	179	174	.
1975	1130	183	396	2611
1976	1086	231	530	13011
1977	(1200)	(156)	(825)	(17000)

Figure 3.3 – Detailing the number of amniotic fluid samples tested per year.[54]

[51] Ibid.
[52] Ibid., pp. 170-171.
[53] Ibid., p. 166.
[54] UGC 188/3/4/2/1, Ferguson-Smith Correspondence with G C Arneil, p. 9.

In 1976 there were 530 amniotic fluid samples tested, but by November 1977 around 100 amniotic fluid samples were being received for testing each month.[55] Despite these increasing numbers, Ferguson-Smith felt that they did not represent the actual need for the testing in the region, which he estimated to be 'at least four times the number received'.[56]

As prenatal testing for fetal chromosome anomalies was becoming well established in Glasgow, reports of successful attempts at chromosome analysis from amniotic fluid were also being described from other groups around the world. Ebbin and colleagues in California reported their experience in 1973 of diagnosing a translocation between chromosomes 9 and 18 in a fetus at 17 weeks gestation. The pregnancy was terminated and the fetus was found upon pathological examination to have several anomalies.[57] In 1974 Gordon and colleagues in Edinburgh reported their experience of diagnosing a case of trisomy 18 in the fetus of a forty-one year old woman. They took an initial amniotic fluid sample by amniocentesis at 16 weeks but the cells failed to grow in culture, so the procedure was repeated at 19 weeks gestation. The second sample of cells grew and showed trisomy 18, and the pregnancy was subsequently terminated.[58] The group commented that they felt the case illustrated 'the value of antenatal diagnosis of fetal abnormality when this can be followed by abortion'.[59] Results from larger scale trials were also starting to emerge, with Wahlström and colleagues reporting their findings from a study of prenatal chromosome analysis carried out on 219 women. Overall 97.8% of women in their study received chromosome information about the fetus, and the frequency of miscarriage after the procedure was 2.3%.[60] Three cases of fetal chromosome anomaly were diagnosed, all of which led to termination of the pregnancies.[61] The group concluded that 'prenatal chromosome determination is a

[55] Ibid., p. 4.
[56] UGC 188/3/4/5/3, Ferguson-Smith Correspondence B, p. 34 (letter dated 15th March 1977).
[57] Allan J. Ebbin, Miriam G. Wilson, Joseph W. Towner and James P. Slaughter, 'Prenatal Diagnosis of an Inherited Translocation Between Chromosomes No. 9 and 18', *Journal of Medical Genetics*, 10:1 (1973), pp. 65-67.
[58] George Gordon, Grant R. Sutherland, Rhona Bauld and A. Douglas Bain, 'The Antenatal Diagnosis of Trisomy 18', *Clinical Genetics*, 5:2 (1974), p. 110.
[59] Ibid., p. 111.
[60] J. Wahlström, F.K. Bartsch and J. Lundberg, 'Prenatal Chromosome Determination. A Study of 219 Cases', *Clinical Genetics*, 6:3 (1974), pp. 186-187.
[61] Ibid., pp. 188-189.

reliable and safe method, allowing as it does, the diagnosis of invalidating diseases during pregnancy'.[62]

IV. The Technical Issue of Mosaicism Associated with Prenatal Testing

Whilst prenatal testing programmes were becoming established in various centres throughout the world, it was perhaps inevitable that potential concerns would arise. One such issue was mosaicism, where a mixture of cells would be encountered after amniocentesis, with some of the cells having 46 chromosomes, whilst other cells showed a different chromosome count. These cases presented difficulties for counselling, as clinicians were unsure of the impact such a cell mixture could have on fetal development. Expectant parents were therefore placed in a very difficult situation, whereby they were unsure of what the outcome of mosaicism would be, and were having to make decisions to terminate or continue with their pregnancies based on very limited information. For example, some cases of fetal mosaicism which were detected prenatally led to the birth of children with an unaffected karyotype, displaying no physical signs of any chromosome anomaly. Such a case was reported by Atkins, Milunsky and Shahood in 1974. Following amniocentesis one cell line showed a male karyotype, 46,XY, and the other cell line had 47 chromosomes, including two abnormal X chromosomes and a normal Y chromosome. The pregnancy continued, and studies after birth showed a 46,XY male karyotype.[63]

Reports were also emerging of cases where terminations of pregnancy occurred as a result of a diagnosis of mosaicism, only for the fetus to be found not to have the expected anomalies upon pathological examination. Kardon and colleagues reported a case where a 45,X fetus was diagnosed as a result of amniocentesis, but the terminated fetus was found to be male, with a 46,XY chromosome complement.[64] It was thought that this was a case of 45,X/46,XY mosaicism. As the authors highlighted, if the 46,XY chromosome complement had been discovered initially then the mosaicism would not

[62] Ibid., p. 190.
[63] Leonard Atkins, Aubrey Milunsky and Jacqueline M. Shahood, 'Prenatal Diagnosis: Detailed Chromosomal Analysis in 500 Cases', *Clinical Genetics*, 6:4 (1974), p. 318.
[64] N.B. Kardon, P.R. Chernay, L.Y.F. Hsu, J.L. Martin and K. Hirschhorn, 'Problems in Prenatal Diagnosis Resulting from Chromosomal Mosaicism', *Clinical Genetics*, 3:2 (1972), p. 83.

have been diagnosed. It is therefore unlikely that a termination of pregnancy would have taken place. Another case of 45,X/46,XY mosaicism was reported by the same laboratory in 1976. A prenatal diagnosis of 45,X/46,XY mosaicism was made at 22 and a half weeks gestation, and the mosaic cell line was found from two different cultured flasks of amniotic fluid cells. The parents were counselled about the range of physical manifestations which could occur as a result of this mosaicism, ranging from 'relative normality to sexual maldevelopment' and they opted to continue with the pregnancy. The infant was born phenotypically male, and by the time the paper had gone to print was still developing normally, however the mosaic cell line was confirmed postnatally in both blood and skin cultures.[65] These cases highlight one of the many difficult decisions faced by pregnant women undergoing prenatal diagnosis. Whilst the testing could offer an insight into the chromosome constitution of a fetus, it could not necessarily predict the effect this would have on the mental and physical development of the fetus if the pregnancy continued.

Trisomy 20 mosaicism was also diagnosed relatively frequently following amniocentesis. In these cases, a mixture of cells would be found, some of which had 46 chromosomes, and others which had 47 chromosomes, due to an extra copy of chromosome 20. Recognising that postnatal outcome of this condition was unknown, in 1978 Rodriguez commented that 'confronted with a situation of undetermined significance and risk, counselors and parents alike have so far considered termination of pregnancy as the only acceptable solution'.[66] In the cases reported by Rodriguez and colleagues, two observations of trisomy 20 mosaicism were made; one couple opted to terminate their pregnancy, whilst the other chose to continue 'in spite of the uncertainty associated with the prenatal finding'.[67] In the terminated fetus 'no external or internal abnormalities of any organ or tissue' were found upon pathological examination, and tissue cultures of skin showed no evidence of extra copies of chromosome 20.[68] Similarly, in the case of the couple who opted to continue with their pregnancy, no

[65] Lillian Y.F. Hsu, Hyon J. Kim, Richard Hausknecht and Kurt Hirschhorn, 'Prenatal Diagnosis of 45,X/46,XY Mosaicism with Postnatal Confirmation in a Phenotypically Normal Male Infant', *Clinical Genetics*, 10:4 (1976), p. 233.
[66] M.L. Rodriguez, D. Luthy, J.G. Hall, T.H. Norwood and H. Hoehn, 'Amniotic Fluid Cell Mosaicism for Presumptive Trisomy 20', *Clinical Genetics*, 13:2 (1978), p. 164.
[67] Ibid.
[68] Ibid., p. 165.

physical anomalies were found when the baby was born. By 2 months of age all 'physical and developmental landmarks were completely normal', and analysis of the tissues of the infant after birth ruled out mosaicism for trisomy 20.[69] The authors in the discussion section of their paper pondered whether it would turn out that trisomy 20 'might yet reflect just another peculiarity of amniotic fluid cells in culture'.[70]

Several other groups also published similar findings. Kardon and colleagues reported three instances where trisomy 20 mosaicism was detected prenatally. Two couples opted to continue with their pregnancies and phenotypically unaffected infants were born, both of whom had 46 chromosomes.[71] The third couple opted to terminate their pregnancy and upon pathological examination the fetus was found to be a phenotypically unaffected female. In this instance, cells from the aborted fetus failed to grow in culture, so it was not possible to confirm or refute a diagnosis of mosaicism.[72] Nevin and colleagues reported a similar case where a 25 year old woman was referred for amniocentesis due to a history of neural tube defects in her husband's family.[73] After undergoing amniocentesis three separate chromosome cultures were set up from the amniotic fluid, and a total of 41 cells were analysed from these. 22 cells had a 46,XX chromosome constitution, and 19 cells had a 47,XX+20 constitution. Although 'the difficulty of interpreting the mosaicism were explained to the parents' they opted to terminate the pregnancy. The aborted fetus was found to be physically unaffected, and post-abortion chromosome analyses from several tissues were all found to be 46,XX.[74]

In the cases listed above it is clear that terminations took place in a number of pregnancies where the fetus was found after abortion to be phenotypically and chromosomally unaffected. Mosaicism therefore presented a real difficulty for genetic counselling – what advice should be given to pregnant women when such anomalies

[69] Ibid., p. 166.
[70] Ibid., p. 167.
[71] Nataline B. Kardon, Ernest Lieber, Jessica G. Davis and Lillian Y.F. Hsu, 'Prenatal Diagnosis of Trisomy 20 Mosaicism', *Clinical Genetics*, 15:3 (1979), pp. 267-268.
[72] Ibid., p. 269.
[73] N.C. Nevin, J. Nevin and W. Thompson, 'Trisomy 20 Mosaicism in Amniotic Fluid Cell Culture', *Clinical Genetics*, 15:5 (1979), p. 440.
[74] Ibid., p. 441.

were found? In most of the cases quoted above, women and couples were given the information that there could be a potential anomaly but that the outcome of this was unknown. It is perhaps not surprising that several women in this situation opted to terminate their pregnancies. However, the impact of this upon finding out the fetus was physically and chromosomally unaffected after abortion must have been great, if the women were told of these findings. These cases raise wider questions of whether having more knowledge of the condition of a fetus prenatally is actually beneficial to a woman and/or couple, especially in cases where medical professionals are unable to offer a great deal of insight into the impact this may have on fetal and child development.

V. Debate Surrounding Maternal Age Effect

The above section highlights some of the main issues linked to decision making following prenatal testing. For some pregnant women, such as those faced with the possibility of mosaicism in the fetus, they had only limited information upon which they had to make decisions about continuing or ending their pregnancy. Uncertainties about how prenatal findings would influence postnatal development were a real concern for researchers, as they were aware of the impact such information could have on decisions surrounding termination of pregnancy. However, mosaicism was not the only area where discrepancies between prenatal and postnatal data were beginning to emerge. One of the key debates centered on the inconsistency of pre- and post-natal risk estimates of chromosomal anomalies at varying maternal ages. [75] This was an area in which Ferguson-Smith had a keen interest, and he was involved in a number of discussions on this subject. The group he led were keen to provide 'accurate estimates of the risks associated with increased maternal age' to enable patients to make 'informed decisions about whether or not to have amniocentesis'.[76]

[75] 'Risk' was the term commonly used to describe the likelihood of pregnancies having certain chromosomal or other anomalies. There is a current movement amongst parents, advocates, and individuals with Down's syndrome to change the use of the term 'risk' to that of 'chance', due to the negative connotations that the word 'risk' entails. Where possible in this thesis I have used the term 'chance', however in this particular section the word 'risk' will be used to be maintain historical accuracy, as many descriptions are quoted or paraphrased from publications which use 'risk'.
[76] M.A. Ferguson-Smith, 'Letters – Prospective Data on Risk of Down Syndrome in Relation to Maternal Age', *The Lancet*, 308:7979 (1976), p. 252.

However, this area of research was not without controversy, as a number of research groups disagreed on what the correct risk estimates for Down's syndrome should be. In *The Lancet* in 1976 Ferguson-Smith presented the case for Down's syndrome rates being a great deal higher than previously thought. Most patients at this time were counselled based on risks from retrospective studies of live births, which gave much lower risk rates of Down's syndrome than amniocentesis did. For example, in a retrospective study carried out by Dr Ernest Hook in New York, the risk of having a child with Down's syndrome was 0.4% in mothers aged 35-39, and 1.3% in mothers aged 40-44.[77] In contrast, the study presented by Ferguson-Smith of 283 pregnancies tested by amniocentesis found the risk of carrying a fetus with Down's syndrome to be 0.8% in women aged 35-39 years, and 4.6% in women 40 years or over.[78] Ferguson-Smith argued that the 'differences between the risk calculated from the prospective and retrospective data appear to be too great to be accounted for solely by the loss (through spontaneous abortion and stillbirth) of Down syndrome pregnancies between the time of amniocentesis and delivery'. He concluded that 'the risks associated with increased maternal age … have been substantially underestimated in the past', and that 'the most important consideration is to ensure that patients and their obstetricians take account of the prospective data so that they may make informed decisions about whether or not to have amniocentesis'.[79] Other researchers based in Edinburgh wrote to *The Lancet* supporting Ferguson-Smith's letter. Their own data had shown that women aged 35-39 had a 1.3% risk of having a fetus with Down's syndrome, and that in women aged 40 years and over this was 3.4%.[80] The Edinburgh group concluded that they wished to add 'our support to Professor Ferguson-Smith's opinion that amniocentesis results provide the preferred basis for clinical and actuarial judgements regarding prenatal screening'.[81]

However, these opinions sparked a debate amongst the scientific and medical community. In a reply to Ferguson-Smith's paper Hook described his opinion as being

[77] Ernest B. Hook, 'Estimates of Maternal Age-Specific Risks of a Down-Syndrome Birth in Women Aged 34-41', *The Lancet*, 308:7975 (1976), p. 33.
[78] Ferguson-Smith, 'Prospective Data on Risk of Down Syndrome', p. 252.
[79] Ibid.
[80] A. Douglas Bain, Ian I. Smith, Rhona Bauld, Susan Bowser Riley and Janet Watson, 'Letters – Prenatal Diagnosis, Stillbirths, and the Macerated Fetus', *The Lancet*, 308:7981 (1976), p. 375.
[81] Ibid.

'erroneous on several counts'.[82] Hook believed that there were 'no grounds' for Ferguson-Smith's claim 'that my study or the other retrospective studies cited have grossly underestimated the true rates'. He argued that the discrepancies in the rates could be explained partly by the high rate of fetal loss which occurs late in pregnancies with fetal anomalies, and partly by the fact that Ferguson-Smith had grouped ages together (such as 35-39 and 40 and over) when the age estimates, in Hook's opinion, should be analysed by each individual year.[83] Hook concluded that 'data derived from studies of amniotic fluid obtained in the second trimester cannot be used to estimate rates of cytogenetic abnormalities among live births' and that 'those doing genetic counselling should carefully distinguish the risk of an abnormality in a live birth from the risk of an abnormality detectable in mid-pregnancy'.[84]

The Paediatric Research Unit at Guy's Hospital in London also wrote to *The Lancet* with their thoughts on the matter. Whilst they found that their amniocentesis figures 'show a similar increase in the frequency of chromosomally abnormal offspring in women of 35 years and older, and the risk for Down syndrome specifically is about double that usually indicated by postnatal studies', they thought that it 'should not be assumed that the amniocentesis figures necessarily represent the true risk figures which should be applied to the population as a whole'.[85] Previous research by their department had shown that of fetuses with Down's syndrome roughly 13.6% aborted, 6.4% were stillborn, and 80% were liveborn, leading them to conclude that the discrepancy between the prenatal and liveborn figures was unlikely to be wholly accounted for by 'fetal wastage'. The group suggested that one reason for the discrepancies could be that women referred for amniocentesis have a known poor obstetric or family history, and so represent a group who were already high-risk. The group believed that instead of assuming that 'the data gathered prenatally are correct and the postnatal incorrect, we believe that the discrepancy between the two could stimulate a fruitful search for

[82] Ernest B. Hook, 'Letters – Risk of Down Syndrome in Relation to Maternal Age', *The Lancet*, 308:7983 (1976), p. 465.
[83] Ibid.
[84] Ibid.
[85] P.E. Polani, E. Alberman, A.C. Berry, S. Blunt and J.D. Singer, 'Letters – Chromosome Abnormalities and Maternal Age', *The Lancet*, 308:7984 (1976), p. 516.

information which might allow the definition of further risk factors, so that appropriately weighted counselling could be given to individuals'.[86]

As different groups were publishing a variety of findings in quick succession, the research community had the difficult task of trying to reach a consensus on which were the correct figures for a number of conditions, to allow this information to be translated into clinical practice. An editorial in *The Lancet* in 1978 suggested that perhaps the 'correct course of action is to advise the older mother of the unresolved discrepancies between liveborn and amniocentesis rates of Down's syndrome, to acquaint them with the possible complications of amniocentesis itself, and to allow them to use their own judgement of which risks pose the greater threat'.[87] This would allow women to weigh up the chance of miscarriage associated with amniocentesis versus the chance of the fetus having a chromosomal anomaly, and make their own decision about whether to undergo testing. However, the reality was not quite as simple as this, with many women unable to access prenatal testing facilities due to their age. Different centres throughout the world had varying age cut-off points at which they would offer amniocentesis, with some centres offering the testing from 35 onwards, whilst others would only make it available to women over the age of 40.

In Edinburgh the policy was to 'offer amniocentesis to patients of 38 years or over and to make the procedure available on request to those aged 35-37'.[88] Data presented by the Edinburgh group showed that between 1975 and 1977, of the 404 pregnancies tested, with a maternal age between 35 and 39, 1.98% of these pregnancies were found to have chromosomal anomalies. 195 pregnancies were tested with a maternal age over 40, and 6.15% of these were found to have chromosome anomalies. This 'relatively high' prevalence of chromosome anomalies in the younger age bracket led the group to conclude that their results 'highlight the necessity for more widespread application of amniocentesis in the 35 and over age group'. However they felt that 'the ultimate

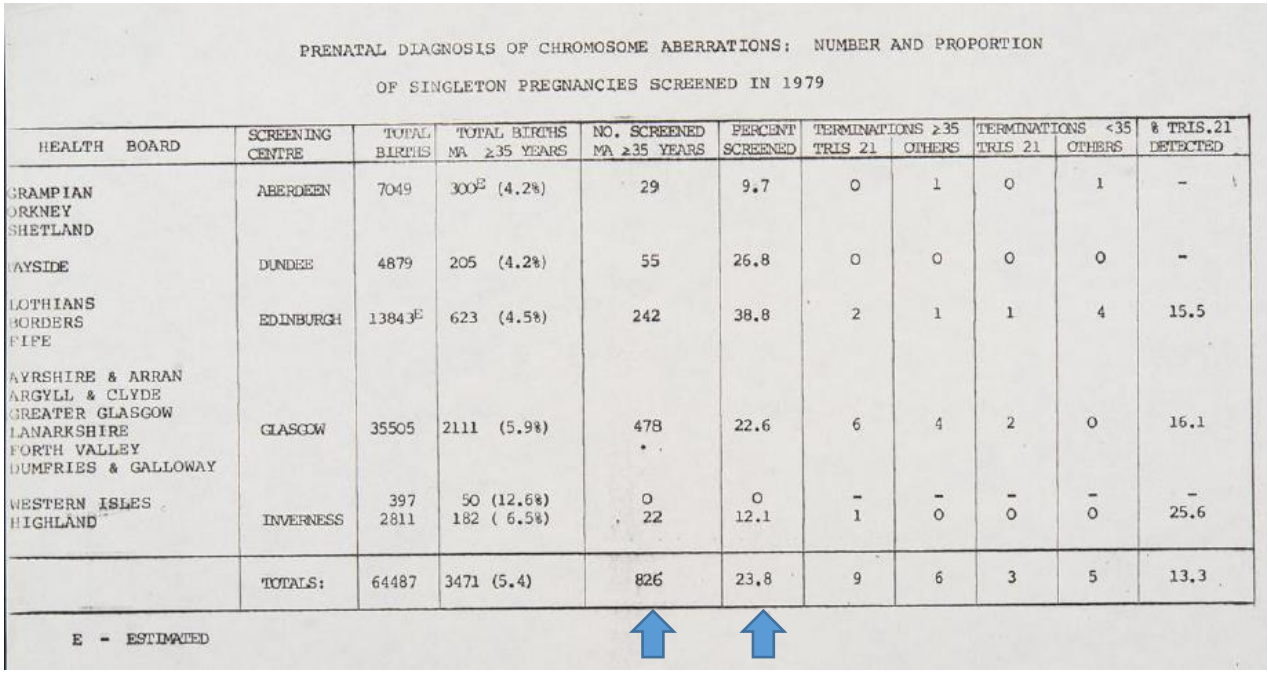
[86] Ibid., pp. 516-517.
[87] Author Unknown, 'Editorial – Maternal Age and Down's Syndrome', *The Lancet*, 312:8079 (1978), p. 25.
[88] J.D. Steven and J.B. Scrimgeour, 'Letters – Should the Indications for Prenatal Chromosome Analysis Be Changed?', *British Medical Journal*, 1:6108 (1978), p. 301.

decision should rest with the parents and the availability of clinical and laboratory expertise'.[89]

Research into maternal age effects became a key focus for Ferguson-Smith, and for several years he worked on furthering his knowledge in this area. He was certain that if those working in the field wanted to reduce the number of babies born with Down's syndrome, then amniocentesis would have to be offered to younger women, in his opinion those aged 35 and over. In July 1978 he wrote to *The Lancet*, again querying the discrepancies between live-birth and prenatal rates of Down's syndrome, and the impact these would have on younger women. Data presented at the 3rd European Prenatal Diagnosis Conference had shown that the expected rate of Down's syndrome in pregnancies in the 35-39 year age group was 0.84%, which was 37% above the expected rate from live born studies.[90] Ferguson-Smith felt that it seemed likely that 'many obstetricians are deterred from offering amniocentesis to their patients in the 35-39 years age group because they use obsolete and incomplete information and believe the risk of a fetal chromosome abnormality may not be sufficiently different from the risk of fetal loss after amniocentesis to justify the procedure'.[91] By November 1980 he was working to convince his own obstetrics colleagues in Glasgow that offering women amniocentesis from the age of 35 would reduce the number of Down's syndrome births further. He wrote to Doctor Rob Chatfield of the Department of Obstetrics and Gynaecology in the Queen Mother's Hospital outlining that 'about 50% of mothers 40 years of age and over are being tested in Glasgow, but, although the risk to these mothers is high, the numbers of affected births avoided are small. If all such pregnancies were tested the reduction in Down's syndrome would be 10%, whereas the reduction would be 37% if all mothers 35 years of age and over were tested.'[92] He presented data showing that, in 1979, different health board regions were varying a

[89] A Douglas Bain, Susan M Bowser-Riley, Ian I Smith and J B Scrimgeour, 'Letters – Amniocentesis for the 35s and Over', *British Medical Journal*, 1:6120 (1978), p. 1141.
[90] M.A. Ferguson-Smith, 'Letters – Maternal Age and Down Syndrome', *The Lancet*, 312:8082 (1978), p. 213.
[91] Ibid.
[92] UGC 188/3/4/14/3, Ferguson-Smith Correspondence with W R Chatfield, p. 7 (letter dated 17th November 1980).

great deal in the number of pregnancies in women over the age of 35 who were tested, as shown in Figure 3.4 (relevant columns designated with a blue arrow):



PRENATAL DIAGNOSIS OF CHROMOSOME ABERRATIONS: NUMBER AND PROPORTION OF SINGLETON PREGNANCIES SCREENED IN 1979

HEALTH BOARD	SCREENING CENTRE	TOTAL BIRTHS	TOTAL BIRTHS MA ≥35 YEARS	NO. SCREENED MA ≥35 YEARS	PERCENT SCREENED	TERMINATIONS ≥35 TRIS 21	TERMINATIONS ≥35 OTHERS	TERMINATIONS <35 TRIS 21	TERMINATIONS <35 OTHERS	% TRIS.21 DETECTED
GRAMPIAN ORKNEY SHETLAND	ABERDEEN	7049	300[E] (4.2%)	29	9.7	0	1	0	1	-
TAYSIDE	DUNDEE	4879	205 (4.2%)	55	26.8	0	0	0	0	-
LOTHIANS BORDERS FIFE	EDINBURGH	13843[E]	623 (4.5%)	242	38.8	2	1	1	4	15.5
AYRSHIRE & ARRAN ARGYLL & CLYDE GREATER GLASGOW LANARKSHIRE FORTH VALLEY DUMFRIES & GALLOWAY	GLASGOW	35505	2111 (5.9%)	478	22.6	6	4	2	0	16.1
WESTERN ISLES HIGHLAND	INVERNESS	397 2811	50 (12.6%) 182 (6.5%)	0 22	0 12.1	- 1	- 0	- 0	- 0	- 25.6
	TOTALS:	64487	3471 (5.4)	826	23.8	9	6	3	5	13.3

E - ESTIMATED

Figure 3.4 – Showing the varying numbers of pregnancies in women aged 35 and over which were tested by amniocentesis in different health boards.[93]

Some of the health boards which tested the highest number of pregnancies were those associated with the Edinburgh screening centre (38.8%), the Dundee screening centre (26.8%) and the Glasgow screening centre (22.6%). In stark contrast, the Western Isles health board tested no pregnancies, highlighting the huge variety in access to services dependent upon geographical location. A potential reason for these discrepancies could be a lack of suitable facilities and trained staff in the more remote geographical region of the Western Isles, as even in Glasgow there were concerns being raised about the possible burden on staff involved in carrying out amniocentesis if the age was dropped to 35 years. In November 1980, Professor Whitfield, Head of the Department of Obstetrics at the Queen Mother's Hospital wrote of his concerns that the 'ultrasonically trained staff are overstretched at the moment' and that work was now having to be done after normal working hours and at the weekend. Whilst he confirmed that he would

[93] Ibid., p. 8 (letter dated 17th November 1980).

'discuss with the ultrasounders the (at present) hypothetical implications of reducing the age for Down's syndrome screening to 35 years' he felt that 'my own view remains that 37 years is the right age to begin offering this screening to mothers, and I base this on my own balancing of relative risks rather than on logistic or staffing factors'.[94]

By December 1980 it had been confirmed by the Executive Committee of the Division of Obstetrics that, in fact, the policy of the Queen Mother's Hospital was 'to offer amniocentesis to all women of 35 years of age or over, and while this may not be the practice in the rest of the West of Scotland it has been the policy of the Hospital since the innovation of amniocentesis'.[95] It is noteworthy that an important member of staff, Professor Whitfield, if sticking to his view that amniocentesis should be offered from the age of 37 onwards, would not have been following official hospital policy on this matter. A group led by Hamerton and Boué seemed to have similar reservations to Whitfield, concluding that a 'centre's decision to set a lower limit at which it will recommend amniocentesis for maternal age will depend on the balance between a number of factors' including, amongst others, the resources available to the centre. The group recommended that 'highest priority for this service should be given to mothers aged 40 and above. Furthermore *all* mothers aged 40 and over should be informed about the test and offered this service if they so wish. High priority for amniocentesis should be given to mothers between ages 37 and 39 who have a moderately high risk. If sufficient resources are available, all mothers in this age group should be informed about the test and offered the service. Mothers in the 35-36 age group may enter this programme if facilities are available.'[96]

These concerns about staffing commitments, resources, and risk of miscarriage continued to cause discrepancies between policy and practice for a number of years. In 1985, Ferguson-Smith wrote to Professor Beard, who was based in the Department of

[94] UGC 188/3/4/93/2, Ferguson-Smith Correspondence with C R Whitfield, p. 10 (letter dated 21st November 1980).
[95] UGC 18/3/4/14/3, Ferguson-Smith Correspondence with W R Chatfield, p. 11 (letter dated 3rd December 1980).
[96] Emphasis in original text. J.L. Hamerton, A. Boué, M.M. Cohen, A. De La Chapelle, L.Y. Hsu, J. Lindsten, M. Mikkelsen, A. Robinson, D. Stengel-Rutkowski, T. Webb, A. Wiley and R. Worton, 'Section 2: Chromosome Disease', *Prenatal Diagnosis*, 1:5 (1981), p. 11.

Obstetrics and Gynaecology, Saint Mary's Hospital Medical School in London, highlighting that, although the policy in Glasgow was to offer amniocentesis to women aged 35 and over, his 'obstetric colleagues show no uniformity in their policy'. He believed that 'the majority now adopt the lower age of 35 years, although some of my older colleagues still use 37. In the past, many were influenced by the rather high fetal loss rate obtained in the MRC Study into the hazards of amniocentesis'.[97] These hazards were of course of importance, as obstetricians had to weigh up the potential risk of miscarriage associated with amniocentesis against the chance that a fetus would have a chromosome anomaly. With the miscarriage risk not known in the early days of prenatal testing it is understandable that the teams would have proceeded with caution, however it seems that some obstetricians continued with this viewpoint even once the testing was safer and well established.

Research into the referring practices of 173 Western New York State obstetricians found that between 1974 and 1978, 47.4% of this group did not refer a single patient for amniocentesis.[98] Of those obstetricians who did refer patients for the testing procedure, their demographic showed that they were younger, worked in rural areas, were associated with university hospitals and tended to be non-Catholic.[99] A study in Canada found that women expected that the testing would be offered to them if their physician thought it was necessary, however women were frequently not offered any testing. This led the authors to conclude that 'professional reticence has the practical effect of blocking access to prenatal diagnosis, especially for the youngest eligible age group (35-38 years)'.[100] These studies highlight that the obstetrician could play a central role in limiting access to prenatal testing, and the impact of the views of key clinicians in Scotland will be discussed in chapter five of this thesis.[101]

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[97] UGC 188/3/6/2/5, Ferguson-Smith Correspondence Be, p. 6 (letter dated 15th March 1985).
[98] Barbara A. Bernhardt and Robin M. Bannerman, 'The Influence of Obstetricians on the Utilisation of Amniocentesis', *Prenatal Diagnosis*, 2:2 (1982), p. 117.
[99] Ibid., p. 120.
[100] Abby Lippman-Hand and Martha Piper, 'Prenatal Diagnosis for the Detection of Down Syndrome: Why Are So Few Eligible Women Tested?', *Prenatal Diagnosis*, 1:4 (1981), p. 256.
[101] A similar situation was occurring in the West of Scotland, where the Professor of Midwifery, Ian Donald, was limiting access to terminations of pregnancy at the Queen Mother's Hospital in the city of Glasgow. General Practitioners were aware that if they wanted to refer a woman for a termination of pregnancy then she should not be referred to Donald. This will be discussed in further detail in chapter five on the social aspects of prenatal testing.

Ferguson-Smith remained focused on researching the impact of maternal age on chromosome anomalies, and one of his key contributions to the field was a study with John Yates, who was also based at the Duncan Guthrie Institute, of 52,965 amniocenteses from across Europe. The study was the largest of its kind, and aimed to analyse the influence of maternal age for a number of chromosome disorders including trisomies 13, 18 and 21, Turner's syndrome and Klinefelter's syndrome. Of the 52,965 pregnancies tested, 1200 chromosome aberrations were found, and an analysis of their frequency carried out.[102] Trisomy 21 (Down's syndrome) was responsible for 51.1% of the aberrations, trisomy 18 (Edward's syndrome) for 10.1%, XXY (Klinefelter's syndrome) for 7.2%, triple X syndrome for 5.4%, trisomy 13 (Patau's syndrome) for 3.2%, 45,X (Turner's syndrome) for 2.0%, and XYY syndrome for 1.5%.[103]

The data from this study strengthened the hypothesis that trisomy 21 was increased in older mothers, but interestingly it showed that the condition rose 'exponentially from age 35'.[104] This finding supported Ferguson-Smith's argument that testing for the condition via amniocentesis should be offered to women from the age of 35 onwards if a decline in Down's syndrome births was the desired outcome of the testing programmes. The research also showed that the rise in cases of trisomy 21 was not sustained past the age of 46 years; Ferguson-Smith and Yates hypothesised that this was due to the inability of older mothers to maintain a fetus with a chromosome anomaly in utero, which would result in an increased miscarriage rate prior to amniocentesis.[105] Similar figures were observed for both trisomy 18 and 13, although the incidence rate for both conditions was lower than for trisomy 21. In trisomy 18 the rates rose exponentially up to age 43, and in trisomy 13 up to age 42, but then declined in both;[106] it was hypothesised that rates were lower for both of these conditions than for trisomy

[102] M.A. Ferguson-Smith and J.R.W. Yates, 'Maternal Age Specific Rates for Chromosome Aberrations and Factors Influencing Them: Report of a Collaborative European Study on 52965 Amniocenteses', *Prenatal Diagnosis*, 4:7 (1984), p. 9.
[103] Ibid., p. 12.
[104] Ibid., p. 29.
[105] Ibid.
[106] Ibid.

21 due to their lower viability, which resulted in greater difficulty in maintaining the fetus in an older mother.[107]

In contrast, slightly different findings were noted in the majority of the sex chromosome anomalies. For both triple X and XXY Klinefelter's syndromes there was an increase above a maternal age of 38, but this level did not decrease with advancing maternal age. This was thought to be due to the lesser impact these conditions would have on the viability of a fetus.[108] In the case of 45,X Turner's syndrome, the mean maternal age for the chromosome anomaly was 38 years, notably lower than for triple X syndrome (40.8 years) and Klinefelter's syndrome (41.1 years).[109] Turner's syndrome showed an inverse relationship with increasing maternal age, and again this was thought to be due to the decreased viability of the fetus, which would lead to earlier miscarriages in older mothers.[110] The findings of this study were clinically significant, as they presented a case for lowering the age at which prenatal testing was offered to 35. They were also important for providing data to prospective mothers which highlighted the increasing chance of having a child with a fetal anomaly as maternal age progressed, potentially influencing the decision of whether or not to accept the risk of miscarriage associated with amniocentesis.

VI. Uptake Rates of Prenatal Testing

Whilst testing for chromosomal disorders had the potential to drastically reduce the number of babies born with chromosome anomalies, the testing was not as popular as would perhaps have been expected. This could have been for several reasons, including concerns about the safety of the procedure, objections to termination of pregnancy, and a lack of clinicians who were willing to refer patients for the testing, amongst others. The safety issues were discussed in chapter one, and the issues surrounding clinician referrals and social reasons for objecting to the testing will be discussed in detail in chapters five and six. Much of the data which follows focuses on detection and

[107] Ibid., pp. 29-30.
[108] Ibid., p. 31.
[109] Ibid., p. 18.
[110] Ibid., pp. 31-32.

termination rates for Down's syndrome, but other chromosome anomalies were also being tested for. However, at the time much of this data was being published, it was thought that the prevention of Down's syndrome was the most important in terms of public health initiatives and funding. Cases of Down's syndrome were numerically the highest, and people with Down's syndrome can have a number of other health concerns linked to the condition, such as heart problems, which require medical attention. Due to medical advances many individuals with Down's syndrome were starting to live into adulthood and progressing through education systems, and social support systems were needed to support these individuals through each of these life stages. By way of contrast, at this time the majority of individuals with trisomy 13 and trisomy 18 were not expected to live past their first year, and so the financial and longer-term health implications were perhaps not seen as being quite as important.[111]

The longer-term health implications of sex chromosome anomalies were also not seen as being of the same severity as those associated with Down's syndrome by some clinicians and pregnant women. As described by Holmes-Siedle and colleagues, 'Sex chromosome abnormality is far less damaging to the phenotype; most types are compatible with a normal life expectancy, and are often undiagnosed.'[112] This is reflected in the lower termination rates for pregnancies with sex chromosome anomalies when compared to pregnancies with Down's syndrome, as shown in a study by Verp et al. published in 1988. 87.5% of pregnancies with autosomal aneuploidy ended with termination (this group was composed of cases of trisomy 21, trisomy 18 and trisomy 13), but only 41.2% of cases of sex chromosome anomaly resulted in elective termination of the pregnancy.[113]

[111] It is now known that individuals with trisomy 13 and trisomy 18 can survive for much longer than was previously thought. Documented cases include that of Elaine Fagan, who had trisomy 18 and lived until the age of 25:
'Elaine Fagan', *Every Life Counts* <https://www.everylifecounts.ie/stories/elaine-fagan/> [accessed 29th August 2017].

[112] M. Holmes-Siedle, M. Ryynanen and R.H. Lindenbaum, 'Parental Decisions Regarding Termination of Pregnancy Following Prenatal Detection of Sex Chromosome Abnormality', *Prenatal Diagnosis*, 7:4 (1987), p. 239.

[113] Marion S. Verp, Allan T. Bombard, Joe Leigh Simpson and Sherman Elias, 'Parental Decision Following Prenatal Diagnosis of Fetal Chromosome Abnormality', *American Journal of Medical Genetics*, 29:3 (1988), p. 616.

Between 1976 and 1981, 2700 women aged 35 or over were tested for chromosome aberrations in the West of Scotland; these women were offered the testing due to their advanced maternal age.[114] This represented only 20.8% of women over 35 who were pregnant during this period. Down's syndrome births in the West of Scotland were reduced by 8.8% during this period. However, this figure did not take into account the 30% of Down's syndrome fetuses which were thought to be lost between amniocentesis and birth, so the real impact of the testing was thought to be as low as 5.8%. Ferguson-Smith felt that this 'must be regarded as disappointing when it is considered that an estimated 35% reduction might be achieved in the region if all women 35 years of age or over had amniocentesis'.[115] There were several reasons that women did not attend for amniocentesis in this age range; whilst 16% of women refused amniocentesis as they objected to termination on religious or moral grounds, the majority (50%) did not have amniocentesis because their obstetrician did not offer them the procedure, believing the risks outweighed the benefits.[116] These attitudes are reflected in a survey carried out in 1976 by the Clinical Genetics Society, who found that ten regional health authorities tested less than 1% of all their pregnancies.[117]

Several other centres also reported lower than expected uptake of their prenatal diagnosis programmes. Bell and colleagues found that in women aged over 35 years in Queensland, Australia, the uptake of prenatal diagnostic testing was only on average 15.5% between 1981 and 1983.[118] This was despite women in the region having access to amniocentesis since 1974.[119] Youings, Gregson and Jacobs found that in Wessex the uptake of prenatal diagnosis amongst eligible women was 36% (mean proportion) with figures ranging from only 16% uptake in women aged 35, to 50% uptake in women aged 37 and over.[120] With these uptake rates, corrected for the expected 30% loss of

[114] M.A. Ferguson-Smith, 'Prenatal Chromosome Analysis and its Impact on the Birth Incidence of Chromosome Disorders', *British Medical Bulletin*, 39:4 (1983), p. 358.
[115] Ibid., pp. 358-359.
[116] Ibid., p. 359.
[117] Ferguson-Smith, 'Avoiding Serious Birth Defects by Prenatal Diagnosis', pp. 123-124.
[118] Judith Bell, Jørgen Hilden, Francis Bowling, John Pearn, Arthur Brownlea and Nicole Martin, 'The Impact of Prenatal Diagnosis on the Occurrence of Chromosome Abnormalities', *Prenatal Diagnosis*, 6:1 (1986), p. 4.
[119] Ibid., pp. 1-2.
[120] Sheila Youings, Nina Gregson and Patricia Jacobs, 'The Efficacy of Maternal Age Screening for Down's Syndrome in Wessex', *Prenatal Diagnosis*, 11:7 (1991), pp. 423-424.

fetuses with Down's syndrome between prenatal diagnosis and birth, the group surmised that they had detected around 53% of cases of Down's syndrome using prenatal testing. However, they thought it was likely that this figure would be an overestimate, as they could not ascertain all the livebirths of babies with Down's syndrome which had occurred in the region.[121] Data from the Mersey Region and North Wales showed a higher uptake of testing in women over the age of 35, with the percentage of women tested increasing steadily, rising from 26.65% in 1978, to 44.13% in 1983.[122] The detection rate for Down's syndrome between 1978 and 1984 was 15.06% (taking into account the expected 30% loss of Down's syndrome fetuses).[123] Whilst the number of pregnancies being tested in this region was higher than in the West of Scotland, less than a quarter of Down's syndrome cases were detected.

VII. The Development of Maternal Serum Screening Programmes

A potential means to test the pregnancies of more women was however being developed during this time period, as a result once again of alpha-fetoprotein (AFP). As previously described, this protein was found in increased quantities in pregnancies in which the fetus had a neural tube defect. It migrated across the placenta and was detectable at low levels in blood taken from pregnant women. This discovery opened up the entire field of screening for neural tube defects, enabling a maternal blood test to determine whether the likelihood of the fetus having a neural tube defect was increased. A similar discovery would change the process of testing for chromosome disorders, as Merkatz et al. noted in 1984 that there was an association between low maternal serum alpha-fetoprotein (msAFP) levels and autosomal trisomies, such as Down's syndrome.[124]

This work by Merkatz prompted others to begin investigating the use of msAFP as a marker for Down's syndrome and other chromosome anomalies, with one of the first papers being published by Cuckle, Wald and Lindenbaum in April 1984. They analysed

[121] Ibid., p. 424.
[122] S. Walker and P.J. Howard, 'Cytogenetic Prenatal Diagnosis and its Relative Effectiveness in the Mersey Region and North Wales', *Prenatal Diagnosis*, 6:1 (1986), p. 14.
[123] Ibid., p. 22.
[124] Irwin R. Merkatz, Harold M. Nitowsky, James N. Macri, and Walter E. Johnson, 'An Association Between Low Maternal Serum α-fetoprotein and Fetal Chromosomal Abnormalities', *American Journal of Obstetrics and Gynecology*, 148:7 (1984), pp. 886-894.

records from their AFP screening service (which had been running since 1975 to test for neural tube defects) and found 61 pregnancies in which the fetus had Down's syndrome and msAFP results were available. Overall they found that msAFP levels were significantly lower for pregnancies where the fetus had Down's syndrome, compared to normal pregnancies.[125] Although this data was retrospective, they concluded that 'Maternal serum AFP levels are significantly lower in pregnancies associated with Down syndrome than in unaffected pregnancies and sufficiently so to form the basis of a screening test.'[126] Noting that msAFP levels and maternal age were independent measures of the chance of Down's syndrome, they proposed that the use of both of these parameters together would result in more successful screening.[127] They postulated that an effective screening policy would be to offer amniocentesis to all women above a certain age (suggested age 38) and then to those of younger maternal ages, whose msAFP levels were low enough to suggest Down's syndrome. Implementing a screening policy such as this would result in 40% of Down's syndrome pregnancies and 6.8% of unaffected pregnancies being selected for further testing by amniocentesis.[128]

Their paper was not however met with overwhelming support, with several authors writing in to *The Lancet* shortly after its publication to voice their concerns. Houlsby, based in the Department of Paediatrics in Sheffield, calculated that Cuckle and colleagues estimate of 6.8% of unaffected pregnancies being selected for amniocentesis would result in 44,404 unaffected pregnancies undergoing amniocentesis in one year in England and Wales. Houlsby wrote that this 'alarming number of false positives with consequent parental distress, taken in conjunction with the number of miscarriages that would result from the amniocenteses performed' led them to conclude that it was 'not acceptable to offer amniocentesis to over 6% of pregnant women on the basis of this

[125] Howard S. Cuckle, Nicholas J. Wald and Richard H. Lindenbaum, 'Maternal Serum Alpha-fetoprotein Measurement: A Screening Test for Down Syndrome', *The Lancet*, 323:8383 (1984), p. 927.
[126] The terms Down's syndrome and Down syndrome are often used when describing the condition. Generally, Down's syndrome is the term used in Britain, whilst Down syndrome is often used in other countries including the United States. See 'About Down's Syndrome: Terminology Guide', *Down's Syndrome Association* <https://www.downs-syndrome.org.uk/about/terminology-guide/> [accessed 1st November 2019].
[127] As discussed in previous chapters, the idea of whether or not a screening programme was successful was a very subjective one.
[128] Cuckle, Wald and Lindenbaum, 'Maternal Serum Alpha-fetoprotein Measurement', p. 929.

proposed screening policy'.[129] Others such as Seller raised concerns about the potential emotional cost to pregnant women, especially as, when their data was analysed, between 400 and 500 amniocenteses would have had to have been carried out to detect 1 case of Down's syndrome. Seller emphasised that screening programmes caused a greater level of anxiety for women who had no reason to suspect a chromosome anomaly in their fetus, than for women who expect their pregnancy may have a higher chance of a chromosome disorder, possibly due to family history or advanced maternal age. She concluded that 'It is possible that, with a yield of around 1 in 450, the price could be too high in emotional terms, even if the test were proved to be cost-effective' and that more counselling facilities would need to be provided to support women through the screening process.[130] Others, such as Cowchock and Ruch, reported that, although there seemed to be a link between decreased levels of msAFP and Down's syndrome, the difference was not great enough when compared to pregnancies where the fetus did not have the condition for them to confirm the findings by Cuckle and others. They concluded that 'At this time the suggestion that low maternal serum AFP levels could be used as a screening test for fetal trisomies or Down syndrome may be premature.'[131]

There were however some groups who found similar results to Cuckle, including Fuhrmann and colleagues who were based in Germany. By analysing retrospective data from their msAFP screening programme (which was in place to detect neural tube defects), they found that they would have had to carry out 1361 amniocenteses to detect 9 of the cases of Down's syndrome in their study, giving a rate of 150 amniocenteses carried out for every 1 case of Down's syndrome detected.[132] A prospective study was started in July 1984 in the State of Connecticut in the United States, and detected a number of cases of Down's syndrome which would have otherwise been missed, particularly in women who were not of advanced maternal age. They looked at msAFP

[129] W. T. Houlsby, 'Letters – Maternal Serum AFP as Screening Test for Down Syndrome', *The Lancet*, 323:8386 (1984), p. 1127.
[130] Mary J. Seller, 'Letters – Prenatal Screening for Down Syndrome', *The Lancet*, 323:8390 (1984), p. 1359.
[131] F. Susan Cowchock and Denise A. Ruch, 'Letters – Low Maternal Serum AFP and Down Syndrome', *The Lancet*, 324:8395 (1984), pp. 161-162.
[132] Walter Fuhrmann, Peter Wendt and Hans K. Weitzel, 'Letters – Maternal Serum-AFP as Screening Test for Down Syndrome', *The Lancet*, 324:8399 (1984), p. 413.

levels, maternal age, and maternal weight to create a formula to calculate the likelihood of the fetus having Down's syndrome, and offered amniocentesis testing to women where the chance was at least 1 in 250.[133] Their initial screening programme (carried out for a year) 'has yielded 4.9% of women less than 35 years of age at increased risk for trisomy. To date, 7 cases of trisomy have been found in the screened population.' This led them to conclude that these 'initial results strongly support a continued evaluation of prospective screening for trisomy in women who, by reason of their age, would not ordinarily have been considered for amniocentesis'.[134] Another large scale prospective study was carried out in an eight-centre New England collaborative project, limited to women under the age of 35, and data was published in 1986 of the results gathered between January and August 1986. 51,141 women were screened and 1050 (2.1%) were offered amniocentesis, of which 807 accepted. After amniocentesis 10 cases of Down's syndrome and 4 cases of trisomy 18 were detected, leading the group to conclude that 21% of estimated cases of Down's syndrome were detected (48 cases were predicted in the age group of women screened). They felt that their experience indicated that msAFP screening for Down's syndrome on a larger scale was feasible.[135]

The Glasgow group led by Ferguson-Smith were also one of the teams exploring the use of msAFP in the detection of chromosome anomalies.[136] Ferguson-Smith and colleagues began a retrospective study of pregnancies diagnosed with Down's syndrome or other trisomies between April 1982 and May 1987.[137] They investigated the possibility of combining maternal age and maternal serum alpha-fetoprotein levels as risk estimates for fetal autosomal trisomies, as this combination detected more at risk pregnancies.[138] This increased detection rate would allow for more targeted testing using amniocentesis

[133] Adjustments for maternal weight were required as pregnant women of a higher weight have lower levels of msAFP than women of a lighter weight.
[134] A. Baumgarten, M. Schoenfeld, M. J. Mahoney, R.M. Greenstein and H.M. Saal, 'Letters – Prospective Screening for Down Syndrome Using Maternal Serum AFP', *The Lancet*, 325:8440 (1985), pp. 1280-1281.
[135] Glenn E. Palomaki, 'Collaborative Study of Down Syndrome Screening Using Maternal Serum Alpha-fetoprotein and Maternal Age', *The Lancet*, 328:8521-8522 (1986), p. 1460.
[136] Throughout this section, and the remainder of the chapter, the term 'detection' refers to identifying pregnancies at a higher chance of having a chromosome disorder to refer the women on for further testing, and does not refer to directly diagnosing an affected pregnancy.
[137] M. Zeitune, D.A. Aitken, J.A. Crossley, J.R.W. Yates, A. Cooke and M.A. Ferguson-Smith, 'Estimating the Risk of a Fetal Autosomal Trisomy at Mid-Trimester Using Maternal Serum Alpha-fetoprotein and Age: A Retrospective Study of 142 Pregnancies', *Prenatal Diagnosis*, 11:11 (1991), p. 848.
[138] Again, the term 'risk' will be used in this section to maintain historical accuracy.

and CVS in those higher risk individuals. msAFP levels were available for 142 pregnancies with chromosomal anomalies – 114 with trisomy 21, 19 with trisomy 18, and 9 with trisomy 13, whilst msAFP levels from 113,045 unaffected pregnancies tested during the same time period were used as the control group.[139] The results showed that msAFP levels were significantly lower in pregnancies which had a chromosomal anomaly when compared to unaffected pregnancies, with 79.6% of the msAFP levels below the median of the general population of pregnant women in affected pregnancies.[140]

It was estimated that the use of both maternal age and msAFP combined would detect 37% of autosomal trisomies, compared to only 30% when using the risk factor of maternal age over 35 alone.[141] The inclusion of msAFP levels decreased the screening age to 25, and the percentage of trisomies detected varied greatly between age groups, with only 12% of autosomal trisomies detected in the age group 25-29 years, compared to 100% detection in those aged over 40 years.[142] Whilst these figures are low for the younger age groups, if risk estimates were based purely on maternal age alone, it is likely that none of these cases would have been detected. These results led the group to conclude that 'significantly improved detection of aneuploid pregnancies can be achieved for no increase in the amniocentesis rate by utilising the existing information available from MSAFP screening programmes'.[143]

Screening using msAFP for Down's syndrome was implemented in Glasgow in 1987. The process was recalled by a scientist working in the group as being one of the major changes that occurred in the laboratory in the late 1980s:

> But the biggest change was the shift with low serum being found for women with Down syndrome … and effectively what it did was it brought the age range down a bit so it meant some younger mothers were included

[139] Zeitune, Aitken, Crossley, Yates, Cooke and Ferguson-Smith, 'Estimating the Risk of a Fetal Autosomal Trisomy', p. 848.
[140] Ibid.
[141] Ibid., pp. 851-852.
[142] Ibid., pp. 852-853.
[143] Ibid., p. 848.

> … so you got a better pick up rate. And so we started to, we were still doing the raised serum for the neural tubes but we were also starting to look at low serum. And still looking quite a lot at maternal age patients but also younger patients, younger mothers were being included in the Down's risk group … I think the cut off at the time was taken at about 1 in 220 or 1 in 250 risk of Down syndrome. So if you were given a risk in that figure you would then go and have, be offered an amniocentesis or a CVS.[144]

Whilst from the scientific perspective the implementation of the test seemed a straight-forward progression, for the midwife who worked closely with both the obstetricians and medical genetics department, this was not entirely the case. She had seen the initial difficulties involved in ensuring all wider staff members and patients had an understanding of the testing process and the interpretation of the results:

> My impression of that at the time was that there could have been more discussion between the medical genetics department and the obstetricians in general about the introduction of Down's syndrome screening because many of the obstetricians and many of the midwives in the antenatal clinic started to get reports that said there was a higher risk of a baby having Down's syndrome but really didn't fully understand how this information had come about, what it meant and I think that there was a period where there was, confusion is maybe too strong a word but just a bit of anxiety about how to convey this information, what the options are.[145]

This insight into the initial implementation of screening procedures highlights the difficulties that several groups of staff can face when new protocols are implemented. It is interesting to note that the midwife recalled the testing being implemented in March 1987, which was the same month that Ferguson-Smith accepted the Chair of Pathology post in Cambridge, and that may have contributed to the initial difficulties encountered. Another key area where difficulties were noted was amongst the parents undergoing screening and testing, who experienced anxiety upon finding out test results:

[144] SI Interview, DS300172, p. 3.

[145] KM Interview, Transcript 1, p. 4. Interview with Karen McIntosh, 26th October 2016. Karen McIntosh initially trained as a nurse, before undertaking her midwifery qualifications. She began working as a midwife in the Department of Medical Genetics in Glasgow in 1984. She remained closely involved with the department throughout her career, despite her official role being as a specialist midwife in fetal medicine.

> And you can imagine also the impact it had on parents. I think today not all but most parents are aware of the option of screening, of prenatal diagnosis, not all but it is certainly more out there and known about. But you can imagine then, "what do you mean the blood test is saying that my baby has Down's syndrome", well no that's not actually what it's saying, but the anxiety that it caused was huge until it kind of settled down and we managed it much better. So for parents it caused a lot of anxiety.[146]

This corresponds to the concerns that were raised by others, such as Seller, when the screening was first being discussed in *The Lancet.*[147] The problems with implementation were however resolved relatively quickly, due to the role that the midwife played in the department:

> As the midwife at that time I took a lot of that on board so in fact it came to pass reasonably quickly I think that the higher chance results came back to me, I would then contact the patient to let them know that they had a higher chance result, they would come back and speak to me about that, I would give them the option of amniocentesis so again you know sort of starting at the very beginning and following them through.[148]

This highlights the importance of having proper communication when new screening and testing programmes were being implemented, and also of having dedicated staff members who played key roles in supporting parents through these new procedures. Ensuring that staff were up to date with changing techniques would also be significant over the years which followed, as other markers would be identified which made the testing more specific. In 1988 Wald and colleagues published a detailed study on the use of maternal serum unconjugated oestriol as a screening test for Down's syndrome, which they found in significantly lower levels in pregnancies where the fetus was affected, compared to pregnancies where the fetus was not.[149] Using a combined screening test involving maternal age, msAFP and unconjugated oestriol levels was more effective at detecting pregnancies with an increased chance of the fetus having

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[146] Ibid.

[147] Seller, 'Letters – Prenatal Screening for Down Syndrome', p. 1359.

[148] KM Interview, Transcript 1, p. 4.

[149] N.J. Wald, H.S. Cuckle, J.W. Densem, K. Nanchahal, J.A. Canick, J.E. Haddow, G.J. Knight and G.E. Palomaki, 'Maternal Serum Unconjugated Oestriol as an Antenatal Screening Test for Down's Syndrome', *British Journal of Obstetrics and Gynaecology*, 95:4 (1988), p. 334.

Down's syndrome, than using any of the measures alone.[150] Further work confirmed these results.[151] Another marker, human chorionic gonadotrophin, was also found to be associated with pregnancies where the fetus had a chromosome anomaly, although in this case it was found in raised, rather than decreased, concentrations in the maternal serum.[152]

The new 'triple test' as it would become known, involving the measurement of maternal serum levels of AFP, unconjugated oestriol, and human chorionic gonadotrophin, alongside maternal age, was found to be more reliable than testing using maternal age alone. Researchers based in Denmark found that using what became known as the 'triple test' – combined measurements of msAFP, unconjugated oestriol and human chorionic gonadotrophin – together with maternal age would result in the detection of 57.6% of pregnancies with Down's syndrome with a 7.3% false positive rate, whilst only using msAFP and maternal age would detect 53% of Down's syndrome pregnancies for a false positive rate of 9.4%.[153] A research group in Italy also found that combining the triple test with maternal age gave the highest detection rate and lowest false-positive rate. They concluded that their results, when considered alongside the other reported cases in the literature, 'provide sufficient evidence that DS screening using maternal serum markers is an effective complementary strategy', which they were offering to women through their genetic counselling clinics.[154]

First and second trimester screening programmes are now firmly established in the prenatal field in the National Health Service, with all women being offered access to such programmes. First trimester screening is now being refined further, with the development of non-invasive prenatal testing (NIPT). NIPT involves taking a blood

[150] Ibid., pp. 338-340.
[151] J.A. Canick, G.J. Knight, G.E. Palomaki, J.E. Haddow, H.S. Cuckle and N.J. Wald, 'Low Second Trimester Maternal Serum Unconjugated Oestriol in Pregnancies with Down's Syndrome', *British Journal of Obstetrics and Gynaecology*, 95:4 (1988), p. 332.
[152] Mark H. Bogart, M.R. Pandian and O.W. Jones, 'Abnormal Maternal Serum Chorionic Gonadotrophin Levels in Pregnancies with Fetal Chromosome Abnormalities', *Prenatal Diagnosis*, 7:9 (1987), p. 627.
[153] Bent Nørgaard-Pedersen, Severin Olesen Larsen, Jørgen Arends, Birgit Svenstrup and Ann Tabor, 'Maternal Serum Markers in Screening for Down Syndrome', *Clinical Genetics*, 37:1 (1990), p. 39.
[154] Giuliana Mancini, Marco Perona, Daniela Dall'Amico, Carla Bollati, Fulvia Albano, Raffaela Mazzone, Maria Rosso and Angelo Oscar Carbonara, 'Screening for Fetal Down's Syndrome with Maternal Serum Markers – An Experience in Italy', *Prenatal Diagnosis*, 11:4 (1991), pp. 250-251.

sample from the pregnant woman to analyse DNA fragments present in the maternal plasma during pregnancy, known as cell-free DNA. Whilst the majority of the cell-free DNA comes from the mother, around 10-20% of it is fetal. If there are a greater number of fetal DNA sequences which map to chromosome 21 than would be expected in the sample, then the woman is likely to be at a higher chance of carrying a fetus which has Down's syndrome. Whilst research has shown that this testing can detect around 98% of fetuses with Down's syndrome, the test only provides a chance factor and does not provide a definitive diagnosis. A woman who received a high chance result would still be required to have the diagnosis confirmed by an invasive test, such as amniocentesis.[155]

VIII. Conclusion

The move towards NIPT highlights the continued interest which has now existed for several decades in detecting a number of chromosome disorders prior to birth. Although technology has advanced to enable the analysis of fetal DNA, all screening programmes still rely on the diagnostic testing methods of amniocentesis and CVS. The work carried out by groups such as that led by Ferguson-Smith to increase the detection rates of chromosome anomalies and decrease the number of incorrect results was therefore of central importance to such programmes becoming established.

As can be seen at the beginning of this chapter, for researchers studying chromosomes in the early 1960s, the priority was on detecting patterns of heredity. There was uncertainty that analysis of chromosomes would ever be available early enough in pregnancy to enable termination, with Ferguson-Smith himself skeptical of such possibilities. However, the work of scientists and clinicians throughout the 1950s and 1960s which showed that amniotic fluid cells could be cultured and their chromosome constitution analysed, combined with the implementation of the Abortion Act 1967, paved the way for prenatal testing to become a central component of antenatal care.

[155] All information on NIPT from:
'NIPT for Down Syndrome A Guide For Patients and Healthcare Professionals', *The NHS Rapid Project* <http://www.rapid.nhs.uk/guides-to-nipd-nipt/nipt-for-down-syndrome/> [accessed 29th August 2017].

By analysing the developments which were occurring at both local and national/international perspectives, it is possible to build up a detailed picture of how chromosome analysis in prenatal testing developed. The early testing was broadly successful in being able to correctly detect chromosome anomalies, and in the case of the group run by Ferguson-Smith, enough women were coming forward for such tests to enable the staff to refine their skills. However, as can be seen by the discussion on mosaicism, the testing was not without technical difficulties, some of which would have life-long consequences for the women involved. The debates surrounding what information should be given to pregnant women were exemplified in the discussion on maternal age effects, whereby different research groups struggled to reach a consensus. Whilst academic debate continued, women were making decisions on whether or not to undergo invasive testing based on the information being supplied to them by their clinicians. The risks associated with invasive testing for chromosome anomalies resulted in some obstetricians showing an unwillingness to refer women for the testing, and some women themselves opting out due to the miscarriage risk. It is perhaps not surprising that when faced with these issues, researchers were keen to develop less invasive screening programmes.

The main screening programme for chromosome anomalies used msAFP, which was also linked to the detection of neural tube defects. The next chapter will consider the development of testing for neural tube defects, which followed a similar path to that of chromosome anomalies – invasive testing followed by the development of large-scale screening programmes.

Chapter Four – Research into Neural Tube Defects: Alpha-fetoprotein, Screening Programmes, and the Impact of Vitamins

I. Introduction

With the advent of prenatal diagnosis in the 1960s, it became clear that testing for a variety of chromosome disorders was feasible, and could provide women with the option to terminate affected pregnancies. However, there was an awareness amongst researchers and clinicians that prenatal testing might be developed to assist in detecting other conditions before birth, such as anencephaly and spina bifida, both neural tube defects (NTDs). Anencephaly results in a lack of formation of the cranial vault; skin also fails to develop, resulting in exposure of the nervous tissue to the amniotic fluid, which causes degeneration. The outcome of this condition is either stillbirth or post-partum death.[1] In spina bifida, part of the spinal column remains open, and the condition varies in severity dependent upon the location of the lesion and whether or not it is covered by skin. Symptoms range from leg weakness through to full paralysis, neurological difficulties, and a short life span in severe cases.[2] Both of these NTDs are often associated with poor clinical prognosis due to their severity, and the possibility of reducing the number of children born with these conditions through the utilisation of prenatal testing was viewed positively by the majority of geneticists.[3]

This chapter will consider the development of testing programmes for neural tube defects, both in the West of Scotland and wider afield. The central role that alpha-fetoprotein (AFP) played as a marker for neural tube defects in the fetus during pregnancy will be examined, and the limitations of testing using AFP alone will be discussed. As with chapter three on chromosome research, researchers were keen to move to less invasive screening methods for NTDs. The move towards screening using

[1] Michael Connor and Malcolm Ferguson-Smith, *Essential Medical Genetics*, 5th Edition, (Oxford: Blackwell Science Ltd, 1997), p. 180.
[2] Lachlan de Crespigny and Rhonda Dredge, *Which Tests for My Unborn Baby?*, (Australia: Oxford University Press, 1991), pp. 95-96.
[3] This is shown in the high number of geneticists who were working on tests to detect these conditions. The work of various individuals and groups developing these tests will be discussed in detail throughout this chapter.

maternal serum AFP (msAFP) will be discussed, with the experiences of different research and clinical groups considered. The regional variations which existed within these screening programmes will be analysed, and the debate surrounding the suitability of msAFP will be examined. The final section of this chapter will look at the attempts to elucidate the role that vitamin supplementation could play in preventing the formation of neural tube defects in the fetus. The issues associated with trying to assess the impact that vitamins could play will be considered, alongside the key role that pregnant women played in taking part in clinical trials. By considering all of these aspects, the timeline of testing for NTDs will become apparent, with the focus for researchers moving from invasive testing to prevention attempts over a short period of time.

II. The Role of Alpha-fetoprotein

Throughout the time period of this study, 1950 to 1990, the rate of NTDs varied across the United Kingdom. In the high prevalence area of the West of Scotland, NTDs occurred in approximately six per thousand births.[4] Prior to the discovery of the role that AFP could play in detecting NTDs, a leading clinician in this region, Professor Malcolm MacNaughton, expressed his hopes that it would be possible in the future to 'detect conditions like spina bifida by some similar technical method' as was currently being used to detect chromosome anomalies, as the condition was becoming 'quite a problem'.[5] It was only four months after MacNaughton wrote this letter to Ferguson-Smith that Brock and Sutcliffe published their now renowned paper in *The Lancet* titled 'Alpha-fetoprotein in the Antenatal Diagnosis of Anencephaly and Spina Bifida'. They described the measurement of AFP in the amniotic fluid of a number of pregnancies which had led to anencephaly, spina bifida or hydrocephaly,[6] and found that the level of AFP was raised in cases of anencephaly and spina bifida. They concluded that the

[4] M.A. Ferguson-Smith, H.A. Rawlinson, H.M. May, P.N.C. Gent and J.G. Ratcliffe, 'Maternal Serum Alphafetoprotein in Prenatal Screening for Open Neural Tube Defects', in *The Diagnosis and Management of Neural Tube Defects A Scientific Meeting of the Royal College of Obstetricians and Gynaecologists*, ed. by J.A. Jordan and E.M. Symonds (London: The Royal College of Obstetricians and Gynaecologists, 1978), p. 55.

[5] University of Glasgow Archives, Papers of Malcolm Andrew Ferguson-Smith, UGC 188/3/3/13/6, Ferguson-Smith Correspondence with M Callum MacNaughton, p. 2 (letter dated 1st March 1972).

[6] Hydrocephalus is a build-up of fluid on the brain, which can lead to brain damage due to the pressure caused by the excess fluid.
'Hydrocephalus', *NHS Choices* <http://www.nhs.uk/conditions/hydrocephalus/Pages/Introduction.aspx> [accessed 26th April 2017] (para. 1).

results suggested that 'amniotic-fluid AFP measurements will be valuable in the early antenatal diagnosis of anencephaly and spina bifida' and that the prenatal detection of these conditions would 'enable termination of these pregnancies'.[7]

Sandy Raeburn, a clinician who began working in the same department as Brock shortly after this discovery, has described how the finding that AFP was raised in pregnancies with NTDs was both a 'brilliant bit of planning' by Brock, but also a bit of a 'fishing trip'.[8] Raeburn described how a recurrence rate of roughly 1 in 20 was known for women who had previously had a child with a NTD, but it was not yet possible to detect those subsequent affected pregnancies. For many of the women a 1 in 20 recurrence rate was too high for them to consider continuing with the pregnancy, and so they opted to have a termination. Prior to or during the termination a sample of amniotic fluid would be taken, and the outcome of these pregnancies could therefore be monitored. The fetus was examined pathologically for the presence of a neural tube defect, and the amniotic fluid studied to detect if certain proteins were raised in these pregnancies. As Raeburn recalls, around 25 proteins were examined but it was 'alpha-fetoprotein that did it', highlighting that this was not just a fortuitous finding, but the result of a study of several potentially relevant proteins.[9]

The publication of Brock and Sutcliffe's findings led others in the medical genetics field to begin examining the possibility that AFP could be used as a diagnostic marker. Brock reported another case, this time along with Scrimgeour, of raised AFP in an anencephalic fetus,[10] and Lorber and colleagues also found greatly increased AFP levels in the amniotic fluid of a woman who was pregnant with an anencephalic fetus.[11] Ferguson-Smith and his colleagues were some of the first to begin analysing

[7] D.J.H. Brock and R.G. Sutcliffe, 'Alpha-fetoprotein in the Antenatal Diagnosis of Anencephaly and Spina Bifida', *The Lancet*, 300:7770 (1972), p. 197.
[8] SR and AR interview, DS300150, p. 13. Interview with Sandy and Arlene Raeburn, 13th April 2016. Sandy Raeburn completed a medical degree, and was appointed a Senior Lecturer in Medical Genetics in Edinburgh in May 1973. He worked in several medical genetics roles throughout his career, and spent six months on sabbatical at the Duncan Guthrie Institute in Glasgow.
[9] Ibid.
[10] D.J.H. Brock and J.B. Scrimgeour, 'Letters – Early Prenatal Diagnosis of Anencephaly', *The Lancet*, 300:7789 (1972), pp. 1252-1253.
[11] J. Lorber, C.R. Stewart and A. Milford Ward, 'Letters – Alpha-fetoprotein in Antenatal Diagnosis of Anencephaly and Spina Bifida', *The Lancet*, 301:7813 (1973), p. 1187.

retrospective samples of amniotic fluid, which had been stored from previous pregnancies after chromosome analysis was carried out on the samples, to measure AFP levels. That the amniotic fluid samples were stored and not discarded highlights the forward-thinking nature of the department, and it was this initiative which enabled them to offer the testing to relevant patients shortly after Brock and Sutcliffe's work was published. Records of this are detailed in several correspondence documents in the Ferguson-Smith archive, which shows the initial caution expressed about the reliability of the testing, followed by its rapid diffusion from research into clinical practice.

In February 1973 Jack Insley, a Consultant Paediatrician in Birmingham, wrote to Ferguson-Smith to enquire if the department in Glasgow would be willing to test samples of amniotic fluid for increased AFP levels in patients from Birmingham.[12] Ferguson-Smith replied that he would be happy to test samples, but only if the patients were aware that the results could not be guaranteed, as the reliability of the test 'had by no means been proved and must await the results of a large series'. At this point in time, March 1973, the department in Glasgow had tested 125 retrospective amniotic fluid samples, and found raised levels of AFP in three abortus specimens, all of which had central nervous system malformations.[13] In April 1973 Rodney Harris, Director of the Department of Medical Genetics in Manchester, wrote to Ferguson-Smith asking for details of the AFP work going on in Glasgow, as he had heard from a student that Ferguson-Smith had found raised levels of AFP in a fetus with spina bifida.[14] Ferguson-Smith replied detailing the current situation in Glasgow, where they were offering the testing as a clinical service to patients who had previously had one or more children with major central nervous system malformations, with the aim of detecting fetal anomalies. Ferguson-Smith was keen to stress that the testing was not offered until they had carried out AFP analysis on 150 retrospective amniotic fluid samples, and had found no false positive or false negative results.[15] By May 1973 they had carried out amniocentesis on 14 women; of these only 1 exhibited markedly raised levels of alpha-

[12] UGC/188/3/3/9/1, Ferguson-Smith Correspondence with Jack Insley, p. 15 (letter dated 28th February 1973).
[13] Ibid., p. 14 (letter dated 15th March 1973).
[14] UGC 188/3/3/8/6, Ferguson-Smith Correspondence with Rodney Harris, p. 12 (letter dated 13th April 1973).
[15] Ibid., p. 13 (letter dated 17th May 1973).

fetoprotein at both 15 and 18 weeks gestation, but the department were 'very concerned by this case as ultrasound showed a normal sized head'.[16] After an X-ray at 18 weeks showed a short trunk the woman opted for a termination and those involved in the testing were 'very relieved' when the patient delivered a fetus with physical anomalies.[17] This termination was the first to be carried out in ten years at the Queen Mother's Hospital,[18] and was a major milestone as the head obstetrician at the time was Ian Donald, who as previously discussed, was morally opposed to the majority of terminations.[19] Harris replied in June 1973 that he now knew of three spina bifida fetuses which had raised AFP levels, and concluded that it 'rather looks as though there is something in it!'[20]

This prediction by Harris would prove to be true, and in September 1973 the Glasgow group published the findings of the case of spina bifida reported to Harris. The paper was an investigation into the use of amniotic fluid alpha-fetoprotein in the diagnosis of NTDs, and was one of the first studies of this kind in the United Kingdom.[21] They used AFP values from 140 samples from unaffected pregnancies, which helped to form their control group for the experiments,[22] and also undertook amniocentesis on 20 patients who had an increased chance of having a fetus affected by a NTD.[23] 18 of the 20 patients had normal alpha-fetoprotein levels, and by the time the paper went to print, six of these had delivered healthy children. Of the two who had high levels of AFP, both chose to terminate their pregnancies, and both had a fetus with anomalies.[24] As both

[16] Ibid.
[17] Ibid.
[18] Ibid.
[19] Malcolm Nicolson and John E.E. Fleming, *Imaging and Imagining the Fetus: The Development of Obstetric Ultrasound*, (Baltimore: The Johns Hopkins University Press, 2013), pp. 238-239. As discussed in the introduction, the views of Ian Donald and others will be discussed in detail in chapter five, which examines the social response to prenatal testing.
[20] UGC 188/3/3/8/6, Ferguson-Smith Correspondence with Rodney Harris, p. 15 (letter dated 5th June 1973).
[21] It should be emphasised here that although the work published by Ferguson-Smith was one of the earliest publications showing the clinical applicability of the alpha-fetoprotein test, the original work which showed the link between neural tube defects and alpha-fetoprotein was carried out by Brock and Sutcliffe in Edinburgh.
[22] 10 samples were excluded from the main analysis as they came from 'spontaneous abortions', and were found to have very high levels of AFP.
[23] Lindsey D. Allan, M.A. Ferguson-Smith, Ian Donald, Elizabeth M. Sweet and A.A.M. Gibson, 'Amniotic-fluid Alpha-fetoprotein in the Antenatal Diagnosis of Spina Bifida', *The Lancet*, 302:7828 (1973), p. 524.
[24] Ibid., pp. 523-524.

cases of NTDs were detected and there were no false positive readings, the group concluded that 'A.F.P. estimation in amniotic fluid may be used to detect open neural-tube defects early enough in pregnancy to allow termination' and that their results were 'sufficiently promising to justify a more widespread screening of pregnancies in women who have had one or more children with a neural-tube defect'.[25] These results were of importance as they not only confirmed the use of AFP as a marker for NTDs, but they also enabled women to receive the diagnosis early enough to terminate the affected pregnancy.

Other reports from around the United Kingdom and further afield began to surface in the early 1970s, supporting the association between raised AFP and NTDs. Seller and colleagues diagnosed a case of anencephaly on the basis of increased AFP, which was confirmed by ultrasound. This diagnosis occurred at 18 weeks gestation, which was early enough to enable termination. The group linked their findings with that of Brock and Scrimgeour, and concluded in their paper, published in July 1973, that, to their knowledge, 'this is the first report of its practical application'.[26] In October 1973, Field and colleagues from Australia reported another case of raised AFP in a pregnancy where the fetus was anencephalic. Neither ultrasound nor X-ray could confirm the presence or absence of a fetal head, so the decision to terminate the pregnancy was based on the raised AFP level. Although they felt that 'more experience' was required to confirm the validity of the technique, they were confident that the present research 'suggests that a very high amniotic alpha-fetoprotein is diagnostic of anencephaly to the extent of influencing a decision to terminate'.[27] Connon also used AFP measurement alongside ultrasound to rule out a recurrence of spina bifida in 12 patients, and noted that the relief for these women 'once the fear of another spina bifida baby has been removed has been impressive and has made the second halves of their pregnancies a time of happy expectancy'.[28]

[25] Ibid., pp. 524-525.
[26] Mary J. Seller, Stuart Campbell, T.M. Coltart and J.D. Singer, 'Early Termination of Anencephalic Pregnancy After Detection by Raised Alpha-fetoprotein Levels', *The Lancet*, 302:7820 (1973), p. 73.
[27] Barbara Field, Gillian Mitchell, W. Garrett and Charles Kerr, 'Letters – Amniotic Alpha-fetoprotein Levels and Anencephaly', *The Lancet*, 302:7832 (1973), p. 798.
[28] Aileen F. Connon, 'Antenatal Diagnosis of Spina Bifida', *The Journal of Obstetrics and Gynaecology of the British Commonwealth*, 81:10 (1974), p. 754 and p. 756.

III. Problems Associated with Closed Lesions

It was becoming clear that increased levels of AFP were linked to anencephaly in the fetus, and some cases of increased AFP in cases of open spina bifida were also being reported. However, data began to emerge which showed that closed spina bifida lesions might not be associated with an increased level of AFP, and would therefore potentially remain undetected. Closed spina bifida lesions are usually characterised by skin covering the affected area – the most common form is known as Occulta, with the name, derived from the Latin 'hidden', reflective of the closed lesion. The symptoms associated with a closed spina bifida lesion vary greatly – whilst some people show no symptoms, others are affected by paralysis, and/or bowel and urinary problems.[29] Laurence and colleagues reported a case in 1973, where AFP levels tested by amniocentesis at 16 weeks of pregnancy were within the normal range, but when the baby was stillborn later in the pregnancy it was found to have a closed spinal lesion. They concluded that their case 'confirms that some affected children will be missed even though they may have disabling neural-tube defects compatible with survival', and speculated that this missed diagnosis could be due to the AFP not diffusing as easily into the amniotic fluid when the lesion is closed.[30] A similar case was reported by Stewart and colleagues who tested several hundred pregnancies and had one false negative result, whereby a closed spinal lesion was not associated with raised levels of AFP, which they felt added 'further confirmation to the thesis that this technique will not be of value in the diagnosis of "closed" lesions'.[31]

These results were also being found in the West of Scotland, where two closed lesions had been missed by the middle of 1974. Correspondence between the Director of the Birth Defects Treatment Center in Johns Hopkins University in Baltimore and Ferguson-Smith provides more information on these cases. Asked to provide an update

[29] 'What Are the Different Types of Spina Bifida?', *My Child Without Limits* <http://www.mychildwithoutlimits.org/understand/spina-bifida/how-is-spina-bifida-diagnosed/types-of-spina-bifida/> [accessed 9th August 2018].
[30] K.M. Laurence, A.C. Turnbull, R. Harris, R.F. Jennison, E. Ruoslahti and M. Seppälä, 'Letters – Antenatal Diagnosis of Spina Bifida', *The Lancet*, 302:7833 (1973), p. 860.
[31] C.R. Stewart, A. Milford Ward and J. Lorber, 'Amniotic Fluid $\alpha_1$fetoprotein in the Diagnosis of Neural Tract Malformations', *British Journal of Obstetrics and Gynaecology*, 82:4 (1975), p. 261.

on the AFP testing programme,[32] Ferguson-Smith described the testing of 71 women who had previously had one or more children with a NTD. Of the 33 women who had presented with normal AFP levels during pregnancy, two had delivered babies with closed defects. Although both babies were treated surgically, one had mild signs of neurological damage.[33] This case highlights the fallible nature of prenatal testing; whilst correct in the majority of cases, an incorrect diagnosis could have a major impact on the family of an affected child. Many of the women undergoing the testing could not contemplate another pregnancy after having an affected child, and only began conceiving again once a test for NTDs was in use. For a woman to experience the relief of a negative diagnosis when she was extremely concerned about the recurrence of a condition, to then give birth and find the baby was subsequently affected, would be difficult to process. Whilst those involved in the testing stressed the imperfect nature of prenatal diagnosis, it would not have made an incorrect diagnosis any easier on those involved.

Whilst cases of 'false negative' diagnoses were beginning to disseminate in the literature, concerns were also being raised about the possibility of 'false positive' diagnoses, whereby an unaffected fetus would be terminated as a result of an incorrect AFP reading. Campbell and colleagues reported such a case in *The Lancet* in May 1975. A woman who had previously had an anencephalic baby was tested by amniocentesis, and very high levels of AFP were found, but ultrasound examination could show no anomalies in either the fetal head or spine. When further AFP tests continued to show raised levels, a termination of pregnancy was decided upon. Pathological examination of the fetus revealed no anomalies.[34] This case highlights the key role that ultrasound could play in detecting structural fetal anomalies, as if the ultrasound findings had been relied upon then a termination of pregnancy could have been avoided, which would have presumably resulted in the birth of an unaffected baby. A similar case was reported by Field and Kerr from Australia, who found raised levels of AFP in a woman who had spina bifida herself, and had previously given birth to a baby with anencephaly. Raised

[32] UGC/188/3/3/6/8, Ferguson-Smith Correspondence Fr, p. 33 (letter dated 15th April 1974).
[33] Ibid., p. 34 (letter dated 23rd May 1974).
[34] S. Campbell, J. Pryse-Davies, T.M. Coltart, Mary J. Seller and Jack D. Singer, 'Ultrasound in the Diagnosis of Spina Bifida', *The Lancet*, 305:7915 (1975), p. 1066-1067.

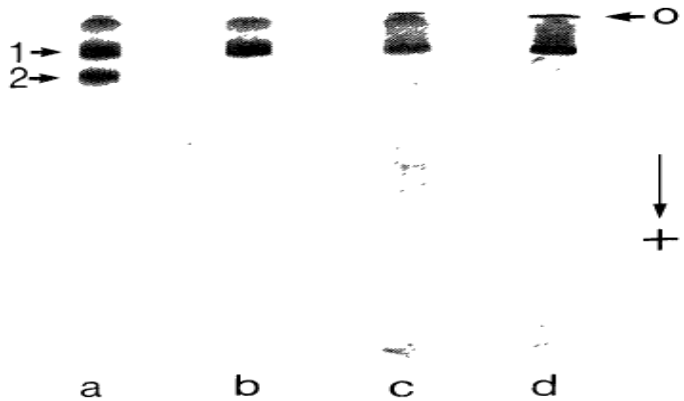
AFP levels were found in the amniotic fluid, but similar to the Campbell case, no anomalies were noted on the ultrasound scan. In this case the parents elected not to terminate the pregnancy, and a healthy baby girl was born with no spinal malformations.[35]

In 1976 Ferguson-Smith responded to a questionnaire from Dr Milunsky which requested information on various aspects of the prenatal diagnosis service in Glasgow and the West of Scotland. He emphasised that in the 1030 amniotic fluid AFP samples that the department had tested they had only had one false positive result. A raised AFP level was found after amniocentesis at 18 weeks gestation, and another sample taken one week later was similarly increased. However, after termination of the pregnancy the fetus was 'apparently normal', highlighting that even in experienced departments, incorrect diagnoses could still occur.[36]

Explanations were sought about causes of raised AFP levels in unaffected pregnancies, and it was noted by the Ferguson-Smith group that, when more than one amniotic fluid sample was submitted after amniocentesis, and one was more blood-stained than the other, the blood-stained sample had higher levels of AFP.[37] Similar findings were reported by Brock, who noted that even a small amount of fetal blood in the amniotic fluid sample could result in a 'grossly elevated A.F.P. value'.[38] By discarding any samples in which there was a substantial amount of fetal blood present, they were able to achieve a 0% false positive rate in their own AFP diagnostic procedure.[39] In addition, the discovery in 1979 that another marker, acetylcholinesterase (AChE), could be found in the amniotic fluid of pregnancies affected by NTDs was also increasing the

[35] Barbara Field and Charles Kerr, 'Letters – Antenatal Diagnosis of Neural-Tube Defects', *The Lancet*, 306:7929 (1975), pp. 324-325.
[36] UGC 188/3/4/57/2, Ferguson-Smith Correspondence M, p. 15 (letter to Dr Milunsky dated 8th November 1976).
[37] Allan, Ferguson-Smith, Donald, Sweet and Gibson, 'Amniotic Fluid Alpha-fetoprotein', p. 525.
[38] D.J.H. Brock, 'Letters – Antenatal Misdiagnosis of Neural-Tube Defects', *The Lancet*, 306:7933 (1975), p. 495.
[39] Theirs was a study of 997 cases; AFP values were raised in 45 cases. In 12 cases the AFP levels were raised due to blood contamination and were therefore discarded, a variety of NTDs were diagnosed in the remaining 33 cases.
See D.J.H. Brock and J.B. Scrimgeour, 'Letters – Alphafetoprotein Assay in All Amniocentesis Samples', *The Lancet*, 307:7974 (1976), p. 1404.

specificity of testing. When inhibited by a specific reagent, AChE would show up as a distinct band on an electrophoresis gel, making it possible to distinguish between pregnancies in which the fetus was affected or unaffected. These distinct bands are shown in Figure 4.1:



Gel electrophoresis of amniotic fluid, showing bands of reaction product formed by hydrolysis of acetylthiocholine.

Samples from:
(a) Spina-bifida pregnancy.
(b) Same as (a) but incubated with the specific inhibitor of AChE (BW284C51 at 10^{-4} mol/l), showing that band 2 is due to AChE.
(c) Pregnancy without a neural-tube defect, showing only a single major band (1), due to non-specific cholinesterase.
(d) Pregnancy without a neural-tube defect, showing reaction product on the origin (O), indicating that the AChE was of a different molecular form fron that in band 2. This pregnancy (AChE level 8·6 munits/ml) resulted in a miscarriage.

Figure 4.1 – Showing the bands associated with a NTD pregnancy on an electrophoresis gel. When amniotic fluid samples were run through an electrophoresis gel, two bands would appear in the gel in pregnancies associated with a NTD, whilst only one band would appear in pregnancies where the fetus did not have a NTD. This is exemplified in the photograph – lane A shows the two bands associated with a NTD pregnancy, in this instance a case of spina bifida, compared to lane C which shows only one band, and was a sample from an unaffected pregnancy.[40]

A collaborative group was set up to analyse the usefulness of AChE as an adjunct to testing AFP in amniotic fluid, and they published their results in August 1981. The Collaborative Acetylcholinesterase Study pooled data from 15 centres to examine the impact testing amniotic fluid samples could have on the specificity of results. 99.6% of

[40] A.D. Smith, N.J. Wald, H.S. Cuckle, G.M. Stirrat, M. Bobrow and H. Lagercrantz, 'Amniotic-Fluid Acetylcholinesterase as a Possible Diagnostic Test for Neural-Tube Defects in Early Pregnancy', *The Lancet*, 313:8118 (1979), p. 687.

pregnancies affected by anencephaly had positive AChE results, as did 99.4% of pregnancies with open spina bifida.[41] The test could therefore be useful if used in addition to traditional AFP testing. A raised level of AFP in the amniotic fluid combined with two bands on an AChE gel would be a more reliable indicator of a NTD in the fetus than a raised AFP level alone. It would be particularly useful in cases where the AFP level was borderline between a raised and normal level – a borderline result combined with one band on an AChE gel was a likely indicator that the fetus did not have a NTD.

Utilising knowledge such as this, alongside implementing other methods of prenatal diagnosis including ultrasound, to confirm a diagnosis of neural tube defect, could decrease the false positive rates in testing programmes. However, despite these improvements, amniocentesis was still required to provide a diagnosis, and as it was associated with a 1% increased miscarriage rate the testing was only offered to those who had an increased chance of having a fetus with a NTD. As described previously, the discovery by Brock that AFP could also be found in the maternal serum, albeit in much lower quantities, would entirely change the target group of women for prenatal examination, and would pave the way for mass prenatal screening for NTDs.

IV. The Move Toward Less Invasive Screening Using Maternal Serum Alpha-fetoprotein

The majority of cases of NTD occur in women with no prior history, and so only testing those known to have a higher chance of NTD in their pregnancy would therefore not diagnose a number of affected fetuses. However, the ability to detect AFP in maternal serum opened up the possibility of screening the pregnant population to uncover those pregnancies where the fetus had a higher chance of a NTD, and referring these women on for further diagnostic testing. Brock and colleagues published the findings of their research on the maternal serum levels of AFP in *The Lancet* in October 1973, presenting details of a case of anencephaly. The woman in their study had previously given birth to

[41] Report of the Collaborative Acetylcholinesterase Study, 'Amniotic Fluid Acetylcholinesterase Electrophoresis as a Secondary Test in the Diagnosis of Anencephaly and Open Spina Bifida in Early Pregnancy', *The Lancet*, 318:8242 (1981), pp. 322-323.

a baby with anencephaly, and during the subsequent pregnancy she had blood taken at 16 and 21 weeks gestation to test the maternal serum alpha-fetoprotein (msAFP) levels. These were found to be greatly increased at both gestation periods when compared with controls. Amniocentesis was carried out and the amniotic fluid AFP level was also raised; further examination by ultrasound and X-ray showed that the woman was carrying another fetus with anencephaly, and the pregnancy was terminated.[42] Whilst the group were aware that this result 'raises the possibility of screening pregnancies through a determination made on a small amount of maternal blood', they felt that it would be 'unwise to suggest that maternal serum A.F.P. alone could be used to diagnose anencephaly or spina bifida early in pregnancy'.[43] They were concerned about the potential number of false positive or false negative results, and were aware that as more samples were tested the level at which msAFP levels would be deemed as normal or raised might change.

In a similar manner to the discovery of raised AFP in amniotic fluid, after the report by Brock on msAFP, others working in the prenatal field began to explore the potential uses and drawbacks of the technique. Seller and colleagues in London examined levels of msAFP in women who had an increased chance of having a fetus with a NTD, and found that in those pregnancies where the fetus had a NTD the msAFP levels were raised. In some cases the rise was noticeable, for example, at 19-24 weeks gestation an msAFP level of 450ng. per ml. was found in a woman carrying a fetus with a NTD, the highest level in the control group being around 90ng. per ml. However, in other cases, such as one recorded in the group at 13-18 weeks gestation, the msAFP level was actually lower in a pregnant woman carrying a fetus with a NTD than the highest levels recorded in the controls (350ng. per ml. in the control, versus 300ng. per ml. in the woman carrying the affected fetus).[44] It was concluded that, whilst msAFP testing could potentially lead to the detection of NTDs in affected fetuses, there was a risk of 'error' and the test was not as clear-cut as it was for the detection of raised AFP in amniotic

[42] D.J.H. Brock, A.E. Bolton and J.M. Monaghan, 'Prenatal Diagnosis of Anencephaly through Maternal Serum-Alphafetoprotein Measurement', *The Lancet*, 302:7835 (1973), p. 923.
[43] Ibid., pp. 923-924.
[44] Mary J. Seller, J.D. Singer, T.M. Coltart and S. Campbell, 'Maternal Serum-Alpha-fetoprotein Levels and Prenatal Diagnosis of Neural-Tube Defects', *The Lancet*, 303:7855 (1974), pp. 428-429.

fluid.[45] Harris and colleagues reported far less promising results, with eight of the nine pregnancies affected by a NTD that they tested showing msAFP values in the normal range, leading them to conclude that msAFP screening of the wider pregnant population was not advisable.[46] However, Wald and Bonnar in Oxford, working collaboratively with Brock in Edinburgh, published details of seven cases of NTD (five of spina bifida and two of anencephaly) where the msAFP levels were raised when compared to control pregnancies.[47]

Debate continued throughout the following months on the usefulness of msAFP screening, with the need for a pilot study to test this on a large scale becoming apparent. The UK Collaborative Study on Alpha-fetoprotein in Relation to Neural-Tube Defects was set up in January 1975, with the aim of determining the efficiency of msAFP screening to select members of the pregnant population for further diagnostic testing. Nineteen centres provided data for the study and the results were published in 1977, with 18,684 non-NTD pregnancies acting as the control group, and 301 NTD pregnancies forming the study cohort.[48] The study was mainly retrospective, with many samples tested after the outcome of the pregnancy was already known. However, the results showed that, if serum samples were taken at 16-18 weeks of pregnancy, then 88% of cases of anencephaly and 79% of open spina bifida cases could be detected using the msAFP screening assay.[49]

Whilst the results showed that a high number of cases of NTD could be detected, several other factors would impact the outcome rates of such a screening programme, including having adequate laboratory facilities such as space and equipment to run such a large project, and ensuring that women presented early enough in pregnancy to be

[45] Ibid., p. 428.
[46] R. Harris, R.F. Jennison, A.J. Barson, K.M. Laurence, E. Ruoslahti and M. Seppälä, 'Comparison of Amniotic-Fluid and Maternal Serum Alpha-fetoprotein Levels in the Early Antenatal Diagnosis of Spina Bifida and Anencephaly', *The Lancet*, 303:7855 (1974), p. 431.
[47] N.J. Wald, D.J.H. Brock and J. Bonnar, 'Prenatal Diagnosis of Spina Bifida and Anencephaly by Maternal Serum-Alpha-fetoprotein Measurement. A Controlled Study', *The Lancet*, 303:7861 (1974), p. 765.
[48] Report of U.K. Collaborative Study on Alpha-fetoprotein in Relation to Neural-Tube Defects, 'Maternal Serum-alpha-fetoprotein Measurement in Antenatal Screening for Anencephaly and Spina Bifida in Early Pregnancy', *The Lancet*, 309:8026 (1977), p. 1325.
[49] Ibid., p. 1323.

screened. Levels of msAFP rise from 13 weeks' gestation and peak at around 32 weeks, changing on a weekly basis.[50] Ensuring that the correct gestational date is being compared against the equivalent control level is therefore of vital importance in msAFP screening. However, many women who presented with a pregnancy were unsure when they had conceived. The UK Collaborative Study felt that 16-18 weeks was the optimum time for blood samples to be taken for screening, however in practice many groups increased this time limit to include from 16 to 20 weeks' gestation. This would ensure that higher numbers of women would be able to participate in the screening programmes, whilst still allowing time for repeat samples to be taken and amniocentesis and ultrasound examinations to be carried out if required. This was the case in the West of Scotland screening programme, where samples were screened between these time periods; testing any earlier than 16 weeks could lead to incorrect diagnoses, as even an anencephalic fetus could have normal msAFP levels at 15 weeks gestation, and it was thought that beginning the screening procedure after 20 weeks would lead to termination very late in the pregnancy which would cause additional distress for the women involved.[51] It was therefore of vital importance that ultrasound technology was developing throughout the same time period that prenatal screening programmes were expanding. Ultrasound scanning was now capable of accurately determining gestational age, and well-trained staff were involved in the screening programmes, who were competent and confident in using such technology. Ultrasound was also of key importance in the direct visualisation of the fetus. Structural anomalies such as anencephaly could be detected, in addition to several of the other reasons for raised msAFP levels which could lead to false positive results, such as multiple pregnancies and missed abortions.[52]

Since ultrasound was to be of key importance, it is perhaps not surprising that Glasgow contributed a great deal to the development of msAFP screening, as ultrasound facilities were well developed in the city. Ian Donald had pioneered the technology and

[50] M.A. Ferguson-Smith, 'The Reduction of Anencephalic and Spina Bifida Births by Maternal Serum Alphafetoprotein Screening', *British Medical Bulletin*, 39:4 (1983), pp. 365-366.
[51] Ibid., p. 366.
[52] Ibid., p. 367 for detection of anencephaly using ultrasound, and Ibid., p. 366 for information on twin pregnancies and missed abortions. Missed abortion was the term used in the original paper, and has been kept here to retain historical accuracy.

implemented it in Glasgow, and many of the clinicians and researchers working within this region therefore had an awareness of the uses of ultrasound. In addition, Donald worked with Ferguson-Smith in a clinical and research capacity, and knew him personally as both a neighbour and friend.[53] Glasgow contributed the highest number of NTD pregnancies to the UK Collaborative Study, and under the leadership of Ferguson-Smith, would go on to run one of the largest prenatal screening studies for NTD over the following years. Perhaps the particular set of circumstances which was occurring in the West of Scotland at that time played a key role in this contribution. The high rate of NTD in the region in addition to the work of Ian Donald ensured that the patients and technology were in place. Combined with Ferguson-Smith's drive to offer relevant testing to any women who wished to utilise it, and the growing laboratory facilities and expertise under his leadership, the elements required for further study of msAFP screening were in place. Ferguson-Smith commented in 1975 that Scotland seemed to be particularly well placed to carry out such studies. As much of the original research on the subject had stemmed from Scotland, there were a number of experienced personnel working in the field, and there was a real interest from many others in the profession.[54] Indeed, as early as June 1974 Ferguson-Smith was in discussion with the Scottish Spina Bifida Association about the pilot study the department had begun.[55] This work involved determining the normal range of AFP in the maternal serum. Several of the reagents were supplied by other researchers to assist with the project, including Nishi in Japan and Leek in London, highlighting the many collaborations which were required in the early stages of such a project to develop a workable technique.

In November 1974 Ferguson-Smith wrote to Nishi to thank him for providing reagents and to update him on the progress of the research in Glasgow. At this stage the group had not had any false positive results, as all raised msAFP levels could be linked to either intrauterine fetal death, multiple pregnancies, or NTDs.[56] These initial results

[53] MAFS interview, DS300130, p. 1.
[54] UGC 188/3/3/1/6, Ferguson-Smith Correspondence with Michael Ashely-Miller, pp. 10-11 (document dated 6th March 1975).
[55] UGC 188/3/3/13/4, Ferguson-Smith Correspondence with Gwendoline B McIntyre, p. 6 (letter dated 24th June 1974).
[56] UGC 188/3/3/15/5, Ferguson-Smith Correspondence with Shinzo Nishi, p. 5 (letter dated 20th November 1974).

were encouraging and the department became involved in another larger pilot study to test the impact of msAFP screening for NTDs in the West of Scotland. The first two phases of the study ran from 20th May 1975 to 30th June 1977, and screened a total of 17,707 women who were 15-20 weeks pregnant.[57] In phase one, which ran until 30th June 1976, a total of 6122 pregnancies were tested between 15 and 20 weeks gestation to measure their msAFP levels. The levels were checked against the normal distribution of msAFP levels, which had been measured in a control group composed of 948 samples from pregnancies which had resulted in the delivery of a healthy baby.[58] The intervention point which was used as a cut-off score for increased msAFP levels was the 99th percentile of the levels estimated from the control samples. The msAFP levels were found to be increased above the intervention point in 87.5% of pregnancies with an anencephalic fetus, and in 71.4% with an open spina bifida fetus.[59] If a pregnancy was found to have increased msAFP levels, another sample was taken and the test repeated. If the result still showed increased levels then clinical examination by ultrasound was carried out. If ultrasound did not reveal a reason for the increased msAFP level then the next step was amniocentesis to confirm a clinical diagnosis. A number of women whose increased alpha-fetoprotein levels were detected during the screening programme opted to undergo terminations as a result of a positive diagnosis; the overall impact of the programme in phase one was thus 'to reduce the birth frequency of open neural-tube defects in 6122 pregnancies by 63.3%'.[60]

Whilst these results looked promising to the researchers involved, a small number of anomalies which should have been detected were missed during phase one. False-negative msAFP results were given in six pregnancies, two of which were anencephalic fetuses, and four of which were fetuses with open spina bifida.[61] In both of the anencephalic and two of the open spina bifida cases, the serum levels had been measured at 15 weeks gestation. This fell outside the 16-20 weeks gestation screening period which the group determined later in this study as being the ideal time period for

[57] M.A. Ferguson-Smith, H.A. Rawlinson, H.M. May, H.A. Tait, J.D. Vince, A.A.M. Gibson, H.P. Robinson and J.G. Ratcliffe, 'Avoidance of Anencephalic and Spina Bifida Births by Maternal Serum-alphafetoprotein Screening', *The Lancet*, 311:8078 (1978), p. 1330.
[58] Ibid.
[59] Ibid., p. 1331.
[60] Ibid.
[61] Ibid.

screening.[62] In the remaining two cases of open spina bifida the serum levels were taken at 18 weeks, but the intervention threshold which had been used for this stage of pregnancy was too high, and the cases were therefore not identified.[63] In another five pregnancies high msAFP levels were detected, but further testing did not consistently confirm these results, which led to continuation of the pregnancy through to the birth of an affected baby. In one of these cases the woman was pregnant with an undiagnosed twin pregnancy, which was discordant for anencephaly, with one fetus affected by the condition and the other fetus unaffected.[64] After a high msAFP level was detected during screening, the woman proceeded to amniocentesis. As the twin pregnancy had not been diagnosed, amniotic fluid was only taken from one fetus. By chance, the amniotic fluid sampled was that of the unaffected fetus, giving a false negative result.[65] One other patient did not return for any further testing after the initial elevated msAFP level was detected, and continued on to have a fetus with spina bifida. In another case a diagnosis of open spina bifida was missed as the gestation was overestimated by four weeks.[66] Two further pregnancies with spina bifida were missed as, despite having initial raised levels of msAFP, their second msAFP test showed levels which were thought to be within the normal range. These samples were taken at 18 weeks, and as previously mentioned, the intervention threshold used for this stage was too high, which resulted in the misinterpretation of the samples as having normal levels of msAFP.[67] These results show that the testing was not without problems, and that incorrect diagnoses could be made which affected the outcome of pregnancies. They also highlight once again the importance of ultrasound for correctly dating pregnancies and visualising multiple pregnancies and structural anomalies.

[62] Ibid.
[63] Ibid.
[64] Details of this case published in *The Lancet* state that 'considerable technical difficulty' was encountered during the ultrasound examination, but that multiple pregnancy were not suspected. No further details are given to explain why the twin pregnancy was not diagnosed. See J.D. Vince, H. Rawlinson, H.A. Tait, T.J. McManus, M.A. Ferguson-Smith, J.O. Struthers and J.G. Ratcliffe, 'Maternal Serum-A.F.P. in Twin Pregnancy Discordant for Anencephaly', *The Lancet*, 309:8001 (1977), p. 43.
[65] Ferguson-Smith, Rawlinson, May, Tait, Vince, Gibson, Robinson and Ratcliffe, 'Avoidance of Anencephalic and Spina Bifida Births', p. 1331.
[66] Ibid.
[67] Ibid.

Phase two of the study ran from 1st July 1976 until 30th June 1977, during which 11,585 pregnancies were screened between 16-20 weeks gestation.[68] As the laboratory had, by this time, developed facilities for the testing of a higher number of specimens, and due to a number of missed detections when the intervention point was the 99th percentile, the intervention point was now dropped to the 97th percentile. Whilst this increased the number of amniocentesis tests required, it also improved the detection rate for NTDs – 100% of anencephalic and 81.2% of open spina bifida fetuses were detected by checking msAFP levels.[69] As in phase one, a number of women chose to undergo terminations after further clinical examination and a positive diagnosis, and the result was a reduction in the 'birth incidence of open neural tube defects in 11,585 pregnancies by 81.4%'.[70] In phase two, seven cases of open spina bifida were not detected; in three of these cases the msAFP levels were below the intervention point, and in the other four cases levels were above the intervention point but were not detected for a number of reasons.[71] In one case the msAFP level was incorrectly interpreted as being normal, whilst in another, amniocentesis gave a false negative result.[72] Another case was incorrectly diagnosed as being a twin pregnancy and this was thought to explain the raised alpha-fetoprotein levels. No further checks took place, and the woman delivered a single child with spina bifida. In the remaining case amniocentesis was not repeated after a first unsuccessful attempt, so a prenatal diagnosis was not possible.[73]

The screening test detected a high number of anomalies overall. The group therefore believed that their work strongly supported 'the case for the introduction of a voluntary national screening programme for neural-tube defects along the general strategy outlined in phase II of this study'.[74] Ferguson-Smith was keen to highlight that screening programmes should be introduced gradually, with high cut-off rates for increased levels of msAFP used initially. This would enable screening programmes to be developed in conjunction with obstetric departments to ensure that the resources to

[68] Ibid., p. 1330.
[69] Ibid., p. 1332.
[70] Ibid.
[71] Ibid.
[72] Ibid.
[73] Ibid.
[74] Ibid., p. 1333.

meet the demand for the increased number of ultrasound examinations and amniocentesis tests that would be required would be available. As confidence grew in using these techniques, the intervention point for raised msAFP could be lowered, increasing the detection rates for NTDs.[75] These pilot studies showed that implementing a screening programme for msAFP levels could greatly reduce the number of babies born with NTDs. Brock and Gosden, writing to the *British Medical Journal*, commented on the 'dramatic decrease in the birth incidence of both spina bifida and anencephaly since the introduction of screening into the Strathclyde region', which they felt justified 'the hopes that many of us have held out for a real reduction in incidence of these appalling disorders as soon as anyone had courage to apply the AFP test on the scale for which it was designed'.[76]

V. Regional Variations in Maternal Serum Alpha-fetoprotein Screening Programmes

The results of programmes run by other groups were also emerging, with Clarke and colleagues screening 5539 pregnant women at three maternity units in London. Whilst Clarke found that the screening led to diagnosis of NTDs in a number of women who had no previous history for the conditions, only a quarter of the women presented to their medical practitioner during the ideal time period for the blood test to be taken, and there were a number of issues with false positive and false negative results during the programme. 300 women who booked before 23 weeks gestation had a raised msAFP level, however in 204 of these women no explanation could be found for the elevation.[77] Not all of these women progressed on to amniocentesis, but if they had then this could have resulted in a number of miscarriages as a result of the procedure. A number of diagnoses were also missed due to women booking too late for the test to be reliable, or because gestational age was incorrectly estimated.[78] This illustrates the differing detection rates in varying regional areas, and emphasises the importance of having the infrastructure in place to run such a screening programme. Changing patterns in

[75] M.A. Ferguson-Smith and J.G. Ratcliffe, 'Letters – Screening for Neural-Tube Defects', *The Lancet*, 312:8085 (1978), p. 374.
[76] D.J.H. Brock and Christine Gosden, 'Letters – Alpha-fetoprotein in Antenatal Diagnosis of Neural Tube Defects', *British Medical Journal*, 2:6103 (1977), p. 1669.
[77] P.C. Clarke, Y.B. Gordon, M.J. Kitau, T. Chard and A.T. Letchworth, 'Screening for Fetal Neural Tube Defects by Maternal Plasma Alpha-fetoprotein Determination', *British Journal of Obstetrics and Gynaecology*, 84:8 (1977), pp. 569-570.
[78] Ibid., p. 571.

antenatal attendance were needed for such tests, with women being referred at appropriate weeks of their pregnancy. This required publicity to encourage women to inform their own doctors about their pregnancy at an early stage, and also for clinicians to ensure that blood samples were being taken at appropriate time periods. In addition, developed ultrasound technology and instruments, and the ability to use them, were required for accurate dating of gestational age; as seen in this study, inaccurate gestational dating led to a number of false results.

Bennett and colleagues also found that their experience with false negative and false positive results made them 'cautious' about implementing a screening programme using msAFP. They measured msAFP levels in over 6000 women and had a detection rate of 74.5%.[79] One case of open spina bifida was missed as the msAFP level was not raised, and one 'morphologically normal' fetus was terminated after two serum samples and an amniotic fluid sample all showed raised levels of msAFP and AFP respectively.[80] Bennett raised an important issue in the paper, highlighting the impact that false negative diagnoses can have on women. Whilst a lack of false positive results is often detailed in these studies as it entailed that there were no unnecessary terminations of pregnancy, the impact of false negative diagnoses is often not discussed. However, Bennett comments on the case of one woman who had several tests including msAFP screening followed by ultrasound and amniocentesis, which all showed no increased chance of NTD, but the woman then went on to deliver an affected baby. The effect on the woman is described as 'disastrous', with the parents rejecting the baby after the birth, and continuing to do so four months later.[81] In contrast, a screening programme carried out in Edinburgh on 6377 women had a detection rate for open NTDs of 83%.[82] Although eight fetuses with spina bifida (four open and four closed) were missed in the study, this high detection rate led Brock and colleagues to conclude that 'facilities and

[79] M.J. Bennett, K. Blau, R.D. Johnson and G.V.P. Chamberlain, 'Some Problems of Alpha-fetoprotein Screening', *The Lancet*, 312:8103 (1978), pp. 1296-1297.
[80] Ibid.
[81] Ibid., p. 1297.
[82] D.J.H. Brock, J.B. Scrimgeour, J. Steven, Lilias Barron and Muriel Watt, 'Maternal Plasma Alpha-fetoprotein Screening for Fetal Neural Tube Defects', *British Journal of Obstetrics and Gynaecology*, 85:8 (1978), p. 575.

finance should be found to provide an antenatal maternal plasma AFP screening service'.[83]

The experience of different departments in several regions was clearly variable, and there was uncertainty about whether or not screening programmes should be implemented. To this end, the Working Group on Screening for Neural Tube Defects was set up by the Standing Medical Advisory Committee in 1978, with the aim of advising on 'what guidance might be given to health authorities on the introduction into routine antenatal care of a service to detect neural tube defects'.[84] The report covered a number of areas including the balance between benefits and risks of a screening programme, and the financial and staffing implications. At the beginning of the report, the group outlined four 'strategic options'. These were:

> (i) Discourage, or at most fail to encourage, development of the screening programme. This might be dangerous, leading to the establishment of a large number of local centres, many of which might fall below acceptable standards.
>
> (ii) Encourage the development, including the monitoring, of existing centres.
>
> (iii) Support the development, including the monitoring, of screening facilities in areas which at present do not have them.
>
> (iv) Make the service generally available as soon as resources permit.[85]

Of these four, the Working Group felt that 'Option (i) is probably untenable, and rapid progress towards Option (iv) may be unwise, in view of some remaining uncertainties on the merits of the programme and the costs entailed in implementing it rapidly. Options (ii) and (iii) are not mutually exclusive, and in the longer term might in fact lead to Option (iv).'[86] It is of interest to note that the Working Group had concerns around the quality of the service provided by local centres, but were also keen to avoid

[83] Ibid., p. 580.
[84] Standing Medical Advisory Committee, *Report by the Working Group on Screening for Neural Tube Defects*, (London: Department of Health and Social Security, 1979), p. 1.
[85] Ibid., p. 4.
[86] Ibid.

wider rapid implementation without adequate resources. That the Working Group specifically mention monitoring of programmes in options ii and iii seems to suggest that they wished to proceed cautiously, with monitoring being a key feature of any screening programmes being implemented.

The Working Group set out twelve recommendations at the end of their report, the first of which was that 'There should be co-ordination and planning of screening for neural tube defects at all levels of the service, locally, regionally and nationally, using the existing committee structure. No screening programme should be established without extensive discussion with all staff involved.'[87] This recommendation shows the need for widespread involvement in screening programmes, and seems to link to the first strategic outcome that the Working Group discussed at the start of the report, regarding the development of centres on a local basis. Several other recommendations were made, including the need for women to be encouraged to attend antenatal appointments as early as possible to enable screening to take place, the requirement for ultrasound facilities to be available, that screening should be organised to minimise unnecessary amniocenteses, and that laboratories should take part in the National Quality Control Scheme to ensure that measurements of maternal serum alpha-fetoprotein were precise and within an acceptable standard.[88] The Working Group also stressed the importance of patients being given sufficient information to ensure that they could make a decision about whether or not to take part in a screening programme.[89]

Overall, the report carefully weighed up the potential areas of concern surrounding implementing screening programmes, but also considered that screening programmes could work with careful planning and monitoring. Despite the Working Group expressing concerns that local services could fall below recommended standards, and that there should be co-ordination and planning at a national level, regional variations did develop, and continued to exist for a number of years after the publication of the report. A key example is the experience of Standing and colleagues, who carried out a

[87] Ibid., p. 60.
[88] Ibid.
[89] Ibid., p. 61.

screening programme for two years in the King's Lynn Health District, which had a low incidence of NTD. They screened 3479 pregnant women, and eight of these women had pregnancies affected by NTDs.[90] Four of these fetuses had anencephaly, and four had other forms of open NTDs. Of the four with other forms, one was detected by msAFP screening and the finding of raised AFP confirmed in amniotic fluid, one had raised msAFP levels but had normal AFP levels upon amniocentesis, and two cases were missed entirely.[91] The outcome of the anencephalic pregnancies is not described, however it is likely that they were terminated; this was the most common decision made by pregnant women in this situation, as no treatment was available for anencephaly. The screening programme had been implemented 'with the expectation that it would prevent the birth of most live babies with open neural tube defects', but after just two years the group felt that 'these expectations had not been fulfilled and, with the agreement of all those connected with the maternity service, the screening programme was discontinued'.[92]

A number of clinicians and researchers questioned the decision to end the King's Lynn screening programme after only two years, with many feeling that Standing's conclusion that 'the correlation between concentrations of maternal serum alpha-fetoprotein and fetal open neural tube defect, anencephaly apart, is insufficiently close to justify this type of screening' was very different from their own findings.[93] The South Wales Anencephaly and Spina Bifida Screening Group thought that the conclusions of their own study were 'not likely to be so pessimistic',[94] and Wald and colleagues felt that there was 'no sound basis for the screening programme to be abandoned' as Standing's results were based on small numbers.[95] Others working in low-incidence areas in London expressed similar concerns, with Enticknap and colleagues reporting their screening results of over 6000 women, where no non-NTD pregnancies were

[90] Susan J. Standing, M.J. Brindle, A.P. MacDonald and R.W. Lacey, 'Maternal Alpha-fetoprotein Screening: Two Years' Experience in a Low Risk District', *British Medical Journal*, 283:6293 (1981), p. 705.
[91] Ibid., p. 707.
[92] Ibid.
[93] Ibid.
[94] Bryan Hibbard and C.J. Roberts, 'Letters – Maternal Alphafetoprotein Screening', *British Medical Journal*, 283:6298 (1981), pp. 1053-1054.
[95] Nicholas Wald, Howard Cuckle, Gordon Stirrat and John Lorber, 'Letters – Maternal Alphafetoprotein Screening', *British Medical Journal*, 283:6298 (1981), p. 1054.

terminated, and only one case of closed spina bifida was missed.[96] Seller, also based in London, reported their own 'disappointments' as a result of a screening programme, in which several cases of NTD were missed, but felt that two years was far too short a time period to truly test the applicability of such programmes.[97] A report by Ward and colleagues on their four years' experience of running a msAFP screening service at University College Hospital in London, from the initial stages of research through to providing it as a routine service, detailed that it took them two and a half years to establish a normal range for serum AFP levels, and that the majority of their undetected cases happened early in the study.[98] This highlights the initial difficulties associated with screening programmes of this kind, which measure 'amounts' of something, and often require adjustments in the first few years, as was the case in the studies led by Ferguson-Smith.

Perhaps the study by Standing could have benefitted from longer term analysis and adjustments, instead of being stopped after such a comparatively short time period. Screening programmes can take time to develop, as can be seen in the case of the West of Scotland, where the uptake of screening increased over time, from 34.1% of pregnant women undergoing screening in 1977 to 77.4% in 1982.[99] By the end of 1982, 238 pregnancies in which the fetus had anencephaly, and 157 pregnancies where the fetus had spina bifida, had been terminated as a result of being initially identified by the screening programme. Despite seven pregnancies being terminated as a result of a false positive diagnosis, it was felt that the screening programme was important enough to maintain. As previously discussed in chapter one, the increased participation of women in the screening process contributed to a notable decrease in the total birth rate for neural tube defects, which declined from 4.3 per 1000 in 1976 to 1.7 per 1000 in 1981 in the West of Scotland.[100] By 1985 220,000 pregnancies had been screened, and the

[96] J.B. Enticknap, M. Faigen and B. Piatkus, 'Letters – Maternal Alpha-fetoprotein Screening: Two Years' Experience in a Low-Risk District', *British Medical Journal*, 283:6301 (1981), pp. 1261-1262.
[97] Mary J. Seller, 'Letters – Maternal Alpha-fetoprotein Screening: Two Years' Experience in a Low-Risk District', *British Medical Journal*, 283:6301 (1981), p. 1262.
[98] The group tested 7315 pregnancies over a period of four years. See R.H.T. Ward, D.V.I. Fairweather, G.A. Whyley, I.M. Shirley and M. Lucas, 'Four Years' Experience of Maternal Alpha-fetoprotein Screening and its Effect on the Pattern of Antenatal Care', *Prenatal Diagnosis*, 1:2 (1981), pp. 99-100.
[99] Ferguson-Smith, 'The Reduction of Anencephalic and Spina Bifida Births', p. 369.
[100] Ibid., p. 371.

programme was linked to a 72% reduction in the birth incidence of NTDs in the West of Scotland.[101] Brock commented that this was the largest screening programme attempted, and that 'no other prenatal screening programme can claim figures anywhere near this'.[102]

Regional differences were therefore apparent, with some health districts offering screening programmes whilst others did not, and great variations were occurring in the detection rates of NTDs. Whilst it was clear that screening programmes could play a role in decreasing the number of babies born with NTDs, there were clear benefits to preventing the occurrence of NTDs, rather than only terminating affected pregnancies. At the same time as work was going on to implement screening programmes, other clinicians and researchers were investigating the underlying causes of NTDs, in the hope that this knowledge could be used to prevent the occurrence of affected fetuses in the future.

VI. Vitamin Studies and Folic Acid in the Prevention of Neural Tube Defects

For several years prior to the finding that AFP could be used in the detection of NTDs, there was an understanding that vitamins could impact the development of the embryo, and that a lack of vitamins within the pregnant woman could negatively affect fetal growth. In 1956 Woollam and Millen wrote of how 'the effect of a vitamin deficiency during the first stage (corresponding to the first three months of pregnancy in the human) will be to interfere with the development of vital organs, such as the heart and brain, which are then in a critical stage of their development. The result will be the birth of a foetus with a congenital malformation which represents a form of arrested or abnormal growth.'[103] Despite this awareness, the specific factors leading to conditions such as anencephaly and spina bifida were unknown; however both conditions had been induced in animal models by causing a deficiency of folic acid during the affected

[101] D.J.H. Brock, 'Satellite Meeting: Alphafetoprotein in Diagnosis and Screening', *Journal of Medical Genetics*, 24:2 (1987), p. 124.
[102] Ibid.
[103] D.H.M. Woollam and J.W. Millen, 'Role of Vitamins in Embryonic Development', *British Medical Journal*, 1:4978 (1956), p. 1262.

pregnancies, suggesting that dietary factors could influence their occurrence.[104] Work in the late 1960s and early 1970s did consider the role of vitamins, but research findings were mixed. In 1969 Emery and colleagues reported their study in which they measured serum folate levels in parents who had children with either anencephaly and/or spina bifida, and found no difference between these parents and controls. They concluded that 'the results suggest that, in man, a deficiency of folic acid may not be directly related to the pathogenesis of spina bifida and anencephaly'.[105]

Research continued into the potential causes of NTDs and a complex picture began to emerge, showing that a number of factors such as genetic susceptibility, environmental influences, and social class could play a role in their incidence. Renwick's potato blight hypothesis was proposed in 1972, suggesting that 'a teratogenic substance in potatoes afflicted by the potato blight fungus, *Phytophthora infestans*' was responsible for causing NTDs.[106] Despite Renwick's insistence that this could be the causative factor, little evidence was found by others to confirm this, with groups in Edinburgh[107] and the United States[108] finding no correlation. Folic acid continued to be investigated as a possible factor, and whilst studies from Aberdeen[109] and Edinburgh[110] continued to question the role it played, larger studies by Hibbard and Smithells showed that there might be a correlation. Hibbard examined 805 women early in their pregnancies and found that the rate of fetal malformation was four times greater in women who had red-cell folate concentrations of less than 130ng/ml, compared to women who had levels greater than 130ng/ml.[111] Smithells examined 900 women in the first trimester of pregnancy and found that the mean red-cell folate levels of the women who went on to give birth to a child with a NTD were 141ng/ml, compared to 228ng/ml in the control

[104] A.E.H. Emery, J. Timson and E.J. Watson-Williams, 'Letters – Pathogenesis of Spina Bifida', *The Lancet*, 294:7626 (1969), p. 909.
[105] Ibid., p. 910.
[106] Author Unknown, 'Editorial – Neural Tubers', *The Lancet*, 300:7770 (1972), p. 222.
[107] C. Smith, Muriel Watt, A.E.W. Boyd and J.C. Holmes, 'Letters – Anencephaly, Spina Bifida, and Potato Blight in the Edinburgh Area', *The Lancet*, 301:7797 (1973), p. 269.
[108] B. MacMahon, S. Yen and K.J. Rothman, 'Letters – Potato Blight and Neural Tube Defects', *The Lancet*, 301:7803 (1973), p. 599.
[109] Marion H. Hall, 'Letters – Folates and the Fetus', *The Lancet*, 309:8012 (1977), pp. 648-649.
[110] Alan E.H. Emery, 'Letters – Folates and Fetal Central-Nervous-System Malformations', *The Lancet*, 309:8013 (1977), p. 703.
[111] Author Unknown, 'Editorial – Folates and the Fetus', *The Lancet*, 309:8009 (1977), p. 462.

group.[112] It was suggested that the next logical step would be to determine the causality directly by supplementing mothers who had an increased chance of having children with NTDs prior to conception.

Smithells and colleagues duly initiated a study of pre-conception supplementation, and in February 1980 they reported their results. A number of different departments contributed patients to the study, including Leeds, London, Belfast, Manchester and Chester; women were recruited both through genetic counselling clinics and by obstetricians, and all women who had previously had a child with a NTD and who were not already pregnant were invited to join the study. Those women who were already pregnant or declined to join the study formed the control group.[113] Women in the study group were given one multivitamin and iron preparation tablet (Pregnavite Forte F) three times a day 'for not less than 28 days before conception and continuing at least until the date of the second missed period – i.e., until well after the time of neural-tube closure'.[114] Overall the provisional recurrence rate[115] in the supplemented group was 0.6%, compared to 5.0% in the non-supplemented control group.[116] Whilst these results seemed to suggest that supplementation prior to pregnancy could impact recurrence rates of NTDs, the authors were keen to stress that this was not a definite conclusion, and that other factors could have affected the results. However, they hoped that their data would encourage others to carry out similar studies to gain further insight into this possible link.[117]

Almost immediately after the publication by Smithells and colleagues, criticisms were voiced regarding the design of the study. As previously mentioned, NTD rates varied throughout the country and concerns were raised about bias in the study and control groups. David Stone, at the University of Glasgow, wrote in to *The Lancet* expressing

[112] Ibid.
[113] R.W. Smithells, S. Sheppard, C.J. Schorah, M.J. Seller, N.C. Nevin, R. Harris, A.P. Read and D.W. Fielding, 'Possible Prevention of Neural-Tube Defects by Periconceptional Vitamin Supplementation', *The Lancet*, 315:8164 (1980), p. 339.
[114] Ibid.
[115] Provisional as not all pregnancies had gone to term at the time of publication.
[116] Smithells, Sheppard, Schorah, Seller, Nevin, Harris, Read and Fielding, 'Possible Prevention of Neural-Tube Defects', p. 340.
[117] Ibid.

his view that it was 'clear' that the supplemented group lived mainly in low-incidence areas, whereas the control group were formed of those living in high-incidence regions. He found it 'hardly surprising' that the recurrence rate was higher in the control group than in the supplemented group.[118] Stone also raised further concerns about the design of the study, querying why Smithells and his colleagues did not 'evaluate their interesting hypothesis by means of a randomised controlled trial, which would have been eminently practicable, would have minimised selection bias, and would have been more likely to convince the sceptics'.[119] This question would go on to cause an intense debate in the scientific and medical community, as Smithells replied to Stone stating that their intention has been to carry out a 'double-blind controlled study for which placebo tablets had already been prepared, but that the protocol was rejected by three separate hospital research ethics committees, and we had to resort to a less satisfactory design'.[120]

An editorial in May 1980 in *The Lancet* framed the situation well, questioning if it would be ethical for clinicians to ignore the result of Smithells' study because it was not based on random selection criteria, knowing that this could potentially lead to more NTD births, or if, on the other hand, it would be ethical to prescribe vitamins when their exact impact was unknown.[121,122] The editorial also argued that ethics committees should have to answer questions about their decision to decline permission for a randomised trial. Clearly the best way to test the data presented by Smithells and colleagues would be in a large randomised trial, but as Smithells' work had shown a potential correlation between supplementation and NTDs, it was even less likely that ethics committees, knowing this, would now approve such a study.[123] Criticism of the ethics committees was fierce amongst some readers, with Kirke likening the decision of

[118] David H. Stone, 'Letters – Possible Prevention of Neural-Tube Defects by Periconceptional Vitamin Supplementation', *The Lancet*, 315:8169 (1980), p. 647.
[119] Ibid.
[120] R.W. Smithells and S. Sheppard, 'Letters – Possible Prevention of Neural-Tube Defects by Periconceptional Vitamin Supplementation', *The Lancet*, 315:8169 (1980), p. 647.
[121] Author Unknown, 'Editorial – Vitamins, Neural-Tube Defects, and Ethics Committees', *The Lancet*, 315:8177 (1980), pp. 1061-1062.
[122] Queries had been raised about the potential impact of vitamin A, as this was known to be teratogenic in rodents. Robert Sharpe, 'Letters – Vitamins and Neural-Tube Defects', *The Lancet*, 315:8181 (1980), p. 1301.
[123] Author Unknown, 'Editorial – Vitamins, Neural-Tube Defects, and Ethics Committees', pp. 1061-1062.

the ethics committees to 'sanctioning what amounts to a situation of uncontrolled experimentation on mothers and their babies',[124] and Freed commenting that the 'sorry situation' had resulted in risks being undertaken without the end result of any real answers.[125]

Throughout 1981 and 1982 debate continued on the subject, with further work by Laurence and colleagues corroborating the impact of folic acid supplementation on recurrence rates of NTDs. Among the 44 women in their trial who received folate supplementation there were no recurrences of NTDs, compared to 6 recurrences in the 67 women who did not receive supplements.[126] Smithells and colleagues discussed the sense of urgency which now surrounded the study of folic acid, as due to the publicity accorded to their findings, it could not be guaranteed for much longer that women who were in control groups in trials were not self-supplementing with vitamin preparations bought over the counter, which could skew results.[127] The study by Laurence prompted further discussion of whether it was ethically justifiable to continue randomised trials when more data seemed to be pointing to a beneficial effect of folic acid supplementation.[128] Some commentators went so far as to state that it was 'clear that all women who have an affected child should receive supplementation for further pregnancies'.[129] In the United States the American Spina Bifida Association would not endorse a trial for NTDs if it involved a placebo drug, as they felt it was unethical.[130] However, not all clinicians and researchers were convinced, with Stirrat expressing concerns that women's hopes could be raised unnecessarily if supplementation did not

[124] Peadar N. Kirke, 'Letters – Vitamins, Neural Tube Defects, and Ethics Committees', *The Lancet*, 315:8181 (1980), pp. 1300-1301.
[125] David L.J. Freed, 'Letters – Vitamins, Neural Tube Defects, and Ethics Committees', *The Lancet*, 315:8181 (1980), p. 1301.
[126] K.M. Laurence, Nansi James, Mary H. Miller, G.B. Tennant and H. Campbell, 'Double-blind Randomised Controlled Trial of Folate Treatment before Conception to Prevent Recurrence of Neural-Tube Defects', *British Medical Journal*, 282:6275 (1981), pp. 1510-1511.
[127] R.W. Smithells, Sheila Sheppard, C.J. Schorah, N.C. Nevin and Mary J. Seller, 'Letters – Trial of Folate Treatment to Prevent Recurrence of Neural Tube Defects', *British Medical Journal*, 282:6278 (1981), p. 1793.
[128] R. Mamtani and Stephen J. Watkins, 'Letters – Trial of Folate Treatment to Prevent Recurrence of Neural Tube Defects', *British Medical Journal*, 282:6281 (1981), pp. 2056-2057.
[129] J.H. Edwards, 'Letters – Vitamin Supplementation and Neural Tube Defects', *The Lancet*, 319:8266 (1982), p. 275.
[130] David E. Walsh, 'Letters – Vitamin Supplements to Prevent Neural Tube Defects', *The Lancet*, 319:8280 (1982), p. 1075.

prove to be effective,[131] and Meier questioning if other avenues of research would be shelved in favour of supplementation programmes which might prove to be ineffective.[132]

In the end it was the side of caution which was firmly erred on, with the Medical Research Council (MRC) in the United Kingdom announcing in 1982 that they would carry out a long-term study to analyse the effects of vitamin and folic acid supplementation. The study proposed four separate 'categories' into which women would be placed – one group would receive minerals and multivitamins, another would receive minerals, vitamins and folate, a third group would receive minerals and folate, and a final group would receive minerals alone; this fourth group who would only receive minerals would act as the placebo group within the study.[133] The Steering Committee of the trial wrote to *The Lancet* in 1983 stating that the trial was being carried out because many doctors remained uncertain about what they should be advising their patients, and that there remained doubts about the impact vitamin supplementation had on recurrence rates of NTDs.[134] The response to the proposed study by the wider medical population was mixed, with some strongly in favour of the trial. Wald and Polani, two key figures in medical genetics based, respectively, at St Bartholemew's Hospital and Guy's Medical School in London, felt that 'though suggestive, the evidence is so inconclusive that it does not justify offering extra vitamins to all women who are at risk'.[135] They felt that the potential harmful effects of prescribing supplementation had to be considered alongside the benefit of providing these vitamins, and that a large, randomised trial would be the most appropriate method of truly examining the safety and efficacy of such preparations. However, it should be noted that they were both members of the Steering Committee for the trial, and so were evidently in favour of the trial being carried out. Interestingly, in contrast to the United

[131] G.M. Stirrat, 'Letters – Vitamin Supplementation and Neural Tube Defects', *The Lancet*, 319:8272 (1982), pp. 625-626.
[132] Paul Meier, 'Letters – Vitamins to Prevent Neural Tube Defects', *The Lancet*, 319:8276 (1982), p. 859.
[133] Author Unknown, 'Editorial – Vitamins to Prevent Neural Tube Defects', *The Lancet*, 320:8310 (1982), p. 1255.
[134] G. Rose, I.D. Cooke, P.E. Polani and N.J. Wald, 'Letters – Vitamin Supplementation for Prevention of Neural Tube Defect Recurrences', *The Lancet*, 321:8334 (1983), p. 1165.
[135] Nicholas J. Wald and Paul E. Polani, 'Neural-Tube Defects and Vitamins: The Need for a Randomised Clinical Trial', *British Journal of Obstetrics and Gynaecology*, 91:6 (1984), p. 516.

States, in the United Kingdom the Association for Spina Bifida and Hydrocephalus was in favour of the MRC trial.[136]

Others working in medical genetics, such as Harris and Read in Manchester, were in favour of the trial but raised concerns about how it could be proved that self-supplementation did not take place. In their region around three quarters of obstetricians offered some kind of vitamin supplementation to women with a previous child with NTDs, and for this reason Harris and Read decided not to take part in the study. However, they did not have concerns about the ethics of a randomised trial.[137] Lorber in Sheffield thought the whole trial was 'regrettable' and questioned how it could be ethical at that time, when it had not been deemed so when Smithells and colleagues were carrying out their original work.[138] Similar sentiments were echoed by Leck, who theorised that many women would decline to participate when fully informed that vitamin supplementation may reduce the chance of recurrence of NTDs, and that it was likely that their family doctor would support their decision.[139]

Whilst the debate about the ethics of the MRC trial continued, more research was published which corroborated the relation between vitamin supplementation and NTDs. Smithells and colleagues looked at another cohort of women, and found there were recurrences of NTDs in 0.9% of supplemented women, compared to a 5.1% recurrence rate in un-supplemented mothers.[140] Seller and Nevin looked at the impact of vitamin supplementation in two areas which varied greatly in their incidence of NTDs – the south-east of England, which was a low-incidence area, and Northern Ireland, a high incidence area. They found that vitamin supplementation produced a slightly less than two-fold reduction in the recurrence rate in south-east England, and a greater than three-

[136] Ibid., p. 522.
[137] Rodney Harris and A.P. Read, 'Letters – Spina Bifida and Vitamins', *British Medical Journal*, 285:6355 (1982), p. 1651.
[138] John Lorber, 'Letters – Vitamins to Prevent Neural Tube Defects', *The Lancet*, 320:8313 (1982), p. 1458.
[139] Ian Leck, 'Spina Bifida and Anencephaly: Fewer Patients, More Problems', *British Medical Journal*, 286:6379 (1983), p. 1680.
[140] R.W. Smithells, N.C. Nevin, M.J. Seller, S. Sheppard, R. Harris, A.P. Read, D.W. Fielding, S. Walker, C.J. Schorah and J. Wild, 'Further Experience of Vitamin Supplementation for Prevention of Neural Tube Defect Recurrences', *The Lancet*, 321:8332 (1983), p. 1027.

fold reduction in Northern Ireland.[141] These findings indicated that vitamin supplementation might have varying impacts depending on the incidence status of the region in which it is being trialled. Other cases provided more information specifically about folic acid, with Blank and colleagues reporting a case where a woman took a vitamin supplementation which lacked folic acid, and had a recurrence of NTD. Although they were keen to stress that one case could not provide a definitive answer about the role of folic acid, they thought it might suggest that folic acid is indeed of importance.[142] A study into the effects of folic acid in Cuba examined a larger number of women, and found no recurrences of NTDs in the 81 women who had been fully supplemented with folic acid, or the 20 women who had only been partially supplemented, but reported 4 recurrences of NTDs in the 114 women who became pregnant without taking any form of folic acid supplementation.[143]

Despite reservations by some that women would not wish to take part in the MRC trial, the number of women recruited increased steadily over several years, and the results of the study were published in July, 1991. It had initially been envisaged that 2000 subjects would be required for the trial, but it was stopped after the results of 1195 pregnancies were determined, as it became clear that folic acid was having an impact in preventing NTDs. In the groups given folic acid there were only 6 recurrences of NTD, compared to 21 recurrences in the groups which did not take folic acid.[144] The relative risk estimate for the folic acid group was 0.28 compared to the control groups, linking folic acid to the prevention of 72% of NTDs.[145] The study comprised data from 33 centres around the world, the greatest number of participants being drawn Glasgow.[146]

[141] Mary J. Seller and Norman C. Nevin, 'Periconceptional Vitamin Supplementation and the Prevention of Neural Tube Defects in South-East England and Northern Ireland', *Journal of Medical Genetics*, 21:5 (1984), p. 325.
[142] C.E. Blank, D. Kumar and M. Johnson, 'Letters – Multivitamins and Prevention of Neural Tube Defects: A Need for Detailed Counselling', *The Lancet*, 323:8371 (1984), p. 291.
[143] R.G. Vergel, L.R. Sanchez, B.L. Heredero, P.L. Rodriguez and A.J. Martinez, 'Primary Prevention of Neural Tube Defects with Folic Acid Supplementation: Cuban Experience', *Prenatal Diagnosis*, 10:3 (1990), p. 150.
[144] MRC Vitamin Study Research Group, 'Prevention of Neural Tube Defects: Results of the Medical Research Council Vitamin Study', *The Lancet*, 338:8760 (1991), p. 131.
[145] Ibid., p. 135.
[146] Ibid., p. 132.

As the West of Scotland had such a high rate of NTDs Ferguson-Smith and others were keen to participate in trials from the earliest possible stage, with correspondence on a proposed trial covering several geographical regions as far back as 1980. Dr Michael Hill, Chairman of the Division of Obstetrics in the Forth Park Maternity Hospital, Kirkcaldy, had written to Professor Whitfield in Glasgow informing him that the Fife region had hoped to begin a study on the role of vitamin supplementation, but had been advised that the geographical area was too small to sustain a meaningful study. The hospital in Kirkcaldy was located around 60 miles away from Glasgow and was in a separate council area, however Hill asked if Glasgow would be interested in joining such a trial together with Fife to ensure sufficient numbers of women could be enrolled.[147] In a letter written to Dr Chatfield, based in the Division of Obstetrics in the Queen Mother's Hospital in Glasgow, Ferguson-Smith detailed that he would be keen to take part in such a trial, highlighting the 'considerable concern' surrounding the design of the initial trial by Smithells and colleagues. Ferguson-Smith felt that Glasgow would be excellently placed to contribute patients to a multi-vitamin trial in the region, as the success of the msAFP screening programme had brought suitable subjects to the attention of the medical genetics department. Ferguson-Smith proposed that the fairest way to carry out a randomised trial was to contact half the women known to the department who had previously had one or more children with NTDs, and ask them to take part in the trial. Those who agreed would be given vitamin supplements and would form the subject group, and those who were not contacted would have any future pregnancies followed up as a control group. Ferguson-Smith felt that this was 'perhaps the only ethical way' that such a trial could be carried out, given the 'major uncertainty that vitamin deficiency plays any role whatsoever in the aetiology of N.T.D.'[148]

However, it was decided that the department would participate in the large-scale MRC trial, which had a different design from that outlined above by Ferguson-Smith. The role that folic acid played in the prevention of NTDs became a main focus for the medical genetics department in Glasgow, with one staff member describing it as 'one of the single biggest research and development programmes' occurring in the mid-1980s in the

[147] UGC/188/3/4/14/3, Ferguson-Smith Correspondence with W R Chatfield, p. 4 (letter from Dr Hill dated 16th September 1980).
[148] Ibid., p. 5 (letter from Ferguson-Smith dated 24th September 1980).

department.[149] He recalled how 'huge' the scheme was, and that Glasgow were playing an important role as they were 'supplying patients and tests and staff over the course of about 6 or 7 years'.[150] The department hired a co-ordinator specifically for the programme, Margaretha van Mourik, who began working in the department in 1982. Van Mourik recalled seeing the advertisement for a Research Assistant post in the Department of Medical Genetics led by Ferguson-Smith, and being told about the MRC Vitamin Trial during her interview in June of 1982. She was involved in the trial, covering the West of Scotland, from the beginning of her employment, which she described as a 'well defined' project.[151] The trial was double-blind, so neither van Mourik nor the patients knew if the patients were receiving vitamin or folic acid supplements, which were handed out as dark red capsules.

Van Mourik recalled in detail visiting the patients in their homes to discuss the research project to ensure the women had an informed understanding of what it would entail. Participation in the study was entirely voluntary, and van Mourik recalled informing the women that they were able to obtain the vitamin supplements from their own doctors if they did not feel they could participate in the trial. Despite many of the women struggling with 'enormous sadness' and 'raw' emotions as a result of previously terminating a pregnancy following a diagnosis of NTD, the majority she visited were keen to take part in the trial. This level of participation was contradictory to what many expected when the MRC trial was announced. However, several of the women involved in the study run by the Glasgow centre emphasised that they would take part as they did not want another woman to go through what they had – an attitude that made van Mourik 'fiercely loyal' to these women.[152] Patients enrolled in the trial were visited every three months and urine and blood samples were taken for analysis. At each visit any tablets the patients had not used were collected and taken back to the laboratory, to monitor rates of non-compliance. The Glasgow centre contributed information on 287

[149] GG interview, DS300134, p. 11.
[150] Ibid.
[151] MvM interview, DS300167, p. 1. Interview with Margaretha van Mourik, 14th June 2016. Margaretha van Mourik undertook her nursing and midwifery qualifications in the Netherlands. She joined the Department of Medical Genetics in Glasgow in 1982, where she has remained for 36 years, and she was the first Consultant Genetic Counsellor in Scotland.
[152] Ibid.

'informative' pregnancies to the MRC study, where the outcome of the birth was known.[153]

As previously mentioned the MRC study was stopped in the early 1990s. Van Mourik recalled the 'enormous difference' folic acid supplementation made in decreasing NTD births.[154] She stressed that the people researchers should be most grateful to were the women who opted to take part in a double-blind trial to aid scientific discovery, and whose contribution is often underestimated, as their names do not appear on scientific papers.[155] More than a decade on from the original research by Smithells, the MRC trial showed that folic acid supplementation could reduce the chance of NTDs, and supplementation is still recommended by the NHS. Women not known to be at an increased chance for NTDs are advised to take a 400 microgram tablet per day prior to conception and up until 12 weeks of pregnancy, and those with a high chance are advised to take a 5 milligram tablet per day for the same time period.[156] This illustrates the lasting impact that this research has had, and is indicative of the move from termination of affected fetuses to the prevention of the condition in the wider population.

VII. Conclusion

In many ways the development of prenatal tests for NTDs followed the same path of prenatal testing for chromosome disorders, moving from invasive testing to large scale screening programmes. Testing for NTDs began after it became possible to detect conditions such as anencephaly and spina bifida prenatally using AFP, which had been shown to be a useful marker by Brock and Sutcliffe. This discovery would go on to be utilised by research groups throughout the world, including the team led by Ferguson-Smith. As highlighted in this chapter, they were one of the first groups to analyse amniotic fluid samples for a retrospective link between AFP and NTDs, as they had

[153] MRC Vitamin Study Research Group, 'Prevention of Neural Tube Defects', p. 132.
[154] MvM interview, DS300169, p. 1.
[155] Ibid.
[156] 'Pregnancy and Baby – Vitamins, Supplements and Nutrition in Pregnancy', *NHS Choices* <http://www.nhs.uk/conditions/pregnancy-and-baby/pages/vitamins-minerals-supplements-pregnant.aspx#Folic> [accessed 5th May 2017] (section titled 'Folic acid before and during pregnancy').

amniotic fluid samples stored from prior pregnancies of a number of women. Whilst a link between AFP and NTDs was established fairly quickly by the research community, the testing was not without issue, and there were a number of false negative and false positive results reported. It was also found that closed lesions could not be detected, meaning that AFP was only a reliable marker for open NTDs. The introduction of AChE helped to reduce the chance of an incorrect diagnosis, but there was still a focus amongst researchers and clinicians on moving towards less invasive testing. This was achieved in the form of a screening programme, which measured the levels of AFP in the maternal serum of pregnant women. Whilst the group led by Ferguson-Smith ran a large scale trial which seemed to show a link between increased levels of msAFP and NTDs, many other research groups were not convinced of the suitability of such screening programmes. As Löwy has summarised, these large scale prenatal screening programmes could not 'guarantee the absence of false negatives and false positives', and they could also be responsible for generating 'false reassurance for some people' and 'an unnecessary, costly, and distressing diagnostic odyssey for others'.[157] In addition to the issues associated with false positive and false negative results, data also began to emerge that showed regional variations in the detection rates of NTDs using msAFP, and in some geographical areas the screening programmes were stopped altogether. This illustrates the impact that the views of certain individuals in different locations could have on availability of prenatal testing resources.

Perhaps the area where testing for NTDs differs most from that of detection of chromosome disorders, was the discovery that folic acid could play a role in preventing NTDs forming in the fetus. Instead of being able to detect conditions prenatally and then offer a termination of pregnancy, it became possible to prevent the formation of NTDs in around 70% of women by offering them folic acid supplementation. Despite the various debates and controversies which surrounded this discovery, the overall result was that over time these findings would be incorporated into antenatal care. This reduced the number of terminations which would take place for fetuses with NTDs, and was seen as an acceptable antenatal intervention by the majority of women. The option to prevent NTD formation as opposed to terminating an affected pregnancy would be

[157] Ilana Löwy, *Imperfect Pregnancies: A History of Birth Defects and Prenatal Diagnosis*, (Baltimore: Johns Hopkins University Press, 2017), p. 181.

particularly welcome for those women who disagreed with termination. The next two chapters of this thesis will consider the perspective of the various groups who were opposed to termination of pregnancy, for a variety of reasons such as moral or religious beliefs.

Chapter Five – The Abortion Act 1967: Development, Discussion, and the Views of the Medical Profession

I. Introduction

The previous chapters of this thesis have examined the scientific and clinical developments which were occurring in the field of prenatal testing between 1950 and 1990. However, it is also important to consider the social time period and circumstances that these developments were situated amongst, particularly the 1960s, which was a decade of major social and cultural change. Whilst prenatal testing offered the diagnosis of fetal anomaly during pregnancy, without permissive abortion legislation this information could not be legally acted upon. The implementation of the Abortion Act 1967, with its specific clause for fetal anomaly, would change this situation entirely, providing a clear legal basis for carrying out terminations after a diagnosis by prenatal testing.

The Abortion Act of 1967 was the culmination of a great number of debates on the subject which had spanned several decades, but found a footing amongst the many social changes which were occurring in Britain in the 1960s. Stephen Brooke has suggested that since its implementation the Act has 'accrued profound symbolic meaning', which alongside the abolishment of the death penalty and the decriminalisation of homosexuality, 'signalled a more liberal approach to moral and sexual questions' in Britain.[1] The nature of research into the detection of conditions such as chromosome disorders and neural tube defects, enabling elective termination of affected pregnancies, raised a number of ethical issues for society to contemplate. Running throughout this chapter will be a consideration of the way in which fetal anomaly was considered within the changing abortion legislation, which links the work in medical genetics in Glasgow with the wider social context in which it was occurring.

[1] Stephen Brooke, 'Abortion Law Reform 1929-68', in *Witness Seminar The Abortion Act 1967*, ed. by Michael D. Kandiah and Gillian Staerck, Institute of Contemporary British History, 2002, p. 15.

This chapter will examine the debates surrounding the Abortion Act 1967, and the response of those within various medical professions to the new legislation. It will begin by examining the legal situation in Scotland surrounding termination of pregnancy, prior to the implementation of the Abortion Act 1967. It will then consider the movement towards the development of new legislation, which would permit termination of pregnancy under specific circumstances, analysing the role that groups such as the Abortion Law Reform Association (ALRA) played in this campaign. It will go on to argue that one of the most crucial areas of the debate focused on the permissibility of abortion for fetal anomaly, and will emphasise that for many of those involved in campaigning both for and against abortion, fetal anomaly was a central topic for discussion. The argument here will be that fetal anomaly was often viewed as different to abortions which were taking place for other reasons, and that despite objections to a fetal anomaly clause in the early 1960s, by the time of Steel's Bill, this clause had become less contentious and was not the subject of a great deal of debate, with broad acceptance of its provisions.

This chapter will also consider the views of the medical profession towards the legislation, and the divisions that existed on the subject. The opinions of some of the key professional medical bodies will be discussed, including their views on fetal anomaly, and the role they played in trying to influence the content of the legislation will be examined. To analyse the impact that the views of medical figures could have on access to abortion services, the case of two key figures in Scotland will be considered, Dugald Baird and Ian Donald. The opinions and actions of Donald are particularly important, as he was based in Glasgow and had both a working relationship and personal friendship with Malcolm Ferguson-Smith. Analysing their perspectives will give an insight into how those in positions of medical power could impact abortion services in the regions in which they worked. Specifically, for Donald, the way in which he viewed terminations for fetal anomaly, as opposed to abortion more broadly, will be considered.

The passing of the Abortion Act 1967 did not result in unanimous acceptance of the new legislation, and this chapter will therefore consider the response to the Report of

the Lane Committee, which was set up in 1971, to examine the working of the 1967 abortion legislation in practice. This will provide an insight into the implementation of the new legislation, and highlight the differing viewpoints which remained on the subject after the Act was in place, with a particular focus on Scotland. Some of the groups who will be considered within this section will be religious and associated organisations, who are the central focus of chapter six. This chapter therefore plays an important role in providing background knowledge of the changing abortion landscape, which is essential for understanding the perspectives of the religious groups who will be considered in the next chapter.

II. Early Legislation and the Development of the Abortion Act 1967

There is a wealth of published literature available on the development of abortion legislation, much of which was discussed within the literature review. It is important, however, to examine some of this literature here, to help provide a detailed overview of the development of the Abortion Act. This will provide a framework on which to place section three of this chapter, which will examine the specific views which existed towards termination for fetal anomaly, analysing primary sources to build up a comprehensive picture of these circumstances.

As discussed in chapter three, before the development of the Abortion Act 1967, there had been a number of legal prohibitions on abortion, but these varied between Scotland and England. Whilst in England termination of pregnancy was prohibited by specific legislation, in Scotland abortion was a common law offence, which meant that it could be interpreted in a more flexible manner than English legislation on the subject. In addition to the legal ambiguities surrounding abortion in Scotland, Nicolson has described how the Scottish police were reluctant to become involved in investigating abortion cases in hospitals. This meant that 'as far as the performance of abortion by qualified medical practitioners was concerned, the matter was left to the conscience of individual doctors'.[2] In Scotland proof was also required that the woman had been

[2] Malcolm Nicolson, 'Letters – Abortion Shouldn't Become a Postcode Lottery', *The Guardian* <https://www.theguardian.com/world/2017/oct/29/abortion-shouldnt-become-a-postcode-lottery> [accessed 22nd May 2018].

pregnant before any conviction could be made; the victim in Scots law was 'the potential child … if there was no potential child there was no crime'.[3] As Davis and Davidson have discussed, gathering enough proof to secure a conviction was difficult in Scotland. There would have to be evidence that the woman had been pregnant, and usually the pregnant woman and her family would be keen to conceal the pregnancy, as would the person who had carried out the abortion. These factors are reflected in the prosecution rates; between 1945 and 1966 there was not one prosecution in Scotland against a registered medical practitioner when it had been argued that the abortion was carried out to perhaps save the life or benefit the health of the pregnant woman.[4]

Whilst abortion may have been a common law offence in Scotland with a low prosecution rate, many in the medical profession were still wary of aborting pregnancies without clear legal guidelines. It would take until 1967 before updated legislation was produced in the form of the Abortion Act, which was a culmination of the efforts of the M.P. David Steel, and numerous pro- and anti-abortion campaigners who worked to influence the exact wording of the Act. One of the key groups involved were the ALRA, who campaigned strongly for women to have access to abortion services. Founded by feminist figures and members of the legal profession, the group's aim was the removal of restrictions on abortion. They felt that women should have access to abortions for a variety of social, economic and psychological reasons; these included risk to the physical or mental health of the woman, in cases of pregnancy following rape, if a woman's ability to act as a mother was in question, or if the baby was likely to be born with severe disabilities.[5] The ALRA campaigned initially outside of Parliament, but frustrated with the lack of progress they were making, began looking at ways to change the laws on abortion in the House of Commons.[6] It is perhaps unsurprising that no political party was keen to take on the contentious subject of abortion as a main party issue. However, the ALRA got round this by working with a number of individual parliamentarians who were keen to see abortion laws liberalised, including Renee Short

[3] Gayle Davis and Roger Davidson, '"A Fifth Freedom" or "Hideous Atheistic Expediency"? The Medical Community and Abortion Law Reform in Scotland, c.1960-1975', *Medical History*, 50:1 (2006), p. 32.
[4] Ibid.
[5] Sylvie Pomies-Marechal and Matthew Leggett, 'The Abortion Act 1967 A Fundamental Change?', in *Preserving the Sixties Britain and the Decade of Protest*, ed. by Monia Carla O'Brien Castro and Trevor Harris (Basingstoke: Palgrave Macmillan, 2014) p. 52.
[6] Brooke, 'Abortion Law Reform 1929-68', p. 16.

and Lord Silkin.[7] Short and Silkin both introduced Bills with a view to liberalisation in 1965, and although neither were passed, they were discussed in much greater detail than any legislation on the subject had been previously, leading some to argue that 'the climate at Westminster was warming to the liberalisation of abortion law'.[8]

Perhaps contributing to this more liberal climate was the fact that a number of young M.P.s from various political parties were elected in 1966, whom Pomies-Marechal and Leggett have stated were 'open-minded' and 'more attuned to the expectation of 1960s Britain'.[9] Amongst these M.P.s was David Steel, a 28 year old lawyer, who came third in the ballot for Private Members Bills for 1966-67. He was approached by a number of pressure groups to take forward their campaigns, including the ALRA, and he decided to act on the issue of abortion. A key reason for this was his strong disagreement with the situation that financial status affected access to abortion services. Women who were financially well off could access medically safer terminations when compared to those who were poorer, who were having to resort to 'back-street abortions' and all the risks these carried.[10] After consultation with the ALRA, Lord Silkin, Renee Short, and Dugald Baird, amongst others, Steel published his 'Medical Termination of Pregnancy Bill' on the 15th of June 1966. It proposed four criteria under which legal abortions could be carried out, if they had been agreed upon by two doctors. These included a risk to the life or mental or physical health of the mother; if the baby was likely to be born with 'abnormalities'; if the pregnant woman's capability as a mother would be severely overstretched by the care of this child; or if the pregnant woman was a 'defective', had been raped, or was under the age of 16.[11]

III. The Importance of Fetal Anomaly in Impacting Abortion Legislation

Whilst there have been a great number of reasons suggested for the successful passing of the Abortion Act in 1967 when a number of previous attempts at similar legislation

[7] Madeleine Simms, 'Abortion Law and Medical Freedom', *British Journal of Criminology*, 14:2 (1974), p. 121.
[8] Brooke, 'Abortion Law Reform 1929-68', p. 16.
[9] Pomies-Marechal and Leggett, 'The Abortion Act 1967', p. 55.
[10] Ibid., p. 56.
[11] Brooke, 'Abortion Law Reform 1929-68', p. 18.

failed, it is widely believed that the fetal anomaly clause played a key role. Indeed, a number of those writing on the subject of the Act, including Gleeson, and Davis and Davidson, place it as a central factor around which the legislation was designed.[12] As this thesis is concerned with prenatal testing, the impact of fetal anomaly in influencing legislative change will be examined in detail, looking particularly at the influence of Thalidomide and rubella. Löwy has argued that these 'widely publicized events – the thalidomide scandal of 1961 and the German measles epidemic of 1962-1964 – brought to the fore the role of environmental teratogens (agents that produce fetal malformations) and contributed to an important shift in the perception of abortion'.[13]

In her article 'Persuading Parliament: Abortion Law Reform in the UK', Gleeson outlines how in the 1940s Australian scientists had shown that the viral infection rubella was responsible for babies being born with congenital anomalies,[14] including hearing loss, brain damage and heart problems.[15] Gleeson describes how, despite the effects of rubella being well known, an attempt to introduce an abortion Bill into the British Parliament in 1954 failed. The Bill had been drafted by Glanville Williams of the ALRA (who was a leading academic expert on English criminal law), and would have allowed termination on grounds of anomaly. Gleeson describes how Williams had persuaded Lord Amulree to introduce the Bill, but that the Bill 'was not debated, however, because Lord Amulree was so 'alarmed' by the clause that at the last hour he declined to introduce the entire Bill'.[16] Gleeson's example illustrates that it was not a straightforward trajectory between recognising the impact of fetal anomaly and implementing legislation which would enable termination on these grounds. However, by 1964 attitudes towards termination for anomaly seemed to have relaxed, and it was claimed by Williams that it had become 'quite standard practice in a number of hospitals to terminate pregnancy on eugenic grounds where the woman has caught German Measles (rubella) during the first trimester', despite it being technically illegal

[12] See Kate Gleeson, 'Persuading Parliament: Abortion Law Reform in the UK', *Australasian Parliamentary Review*, 22:2 (2007), p. 30, and Davis and Davidson, '"A Fifth Freedom"', pp. 35-36.
[13] Ilana Löwy, *Imperfect Pregnancies: A History of Birth Defects and Prenatal Diagnosis*, (Baltimore: Johns Hopkins University Press, 2017), p. 75.
[14] Gleeson, 'Persuading Parliament', p. 29.
[15] 'Rubella', *NHS Choices Website* <http://www.nhs.uk/chq/Pages/1104.aspx?CategoryID=54> [accessed 23rd March 2018] (section titled Rubella and Pregnancy).
[16] Gleeson, 'Persuading Parliament', p. 29.

in England and Wales.[17] In 1964, the editor of the *British Medical Journal* (*BMJ*), responding to a letter querying the ethics of aborting a fetus after a maternal rubella infection, stated that 'It is difficult to justify risking the birth of a deformed baby where this is preventable and where it seems certain that the mother can subsequently give birth to a normal baby.'[18] That the editor of such a prominent medical journal was speaking out in favour of abortion in cases of fetal anomaly highlights the seemingly more widespread acceptability of terminations for women who found themselves in this situation.

It is also of interest to consider the statements which were being made by various professional bodies on the subject of abortion for fetal anomaly, to gain further insight into the views of the medical profession. As early as 1938 a report by the British Medical Association (BMA) stated that abortion was permissible if there was a reasonable certainty that 'serious hereditary risk' would be transferred to the child.[19] They had also favoured clarification of the law of the position of a doctor who carried out a termination 'due to "handicap"'.[20] By the time the BMA released a subsequent report in 1966, they had strengthened this argument further, stating that:

> In the intervening period a considerable amount of knowledge has accumulated about foetal abnormalities. Prediction can now be made with some certainty in the case of certain genetically determined disease, chromosomal anomalies, and maternal rubella. Furthermore, the possibility of damage to the health of the mother and environmental factors may need to be considered in reaching a medical opinion on the desirability of termination. Accordingly it is important that the law should not attempt to define too precisely the circumstances in which pregnancy may be terminated in such cases. We recommend that the law be amended to provide that the risk of serious foetal abnormality may be taken into account in deciding whether or not to recommend termination of pregnancy.[21]

[17] Glanville Williams, 'Legal and Illegal Abortion', *The British Journal of Criminology*, 4:6 (1964), p. 563.
[18] Author Unknown. Editorial reply to original letter by Eugene G. Laforet, 'Letters – Embryo, Foetus, or Child?', *British Medical Journal*, 2:5413 (1964), p. 878.
[19] Sheelagh McGuinness, 'Law, Reproduction, and Disability: Fatally 'Handicapped'?', *Medical Law Review*, 21:2 (2013), p. 221.
[20] Gleeson, 'Persuading Parliament', p. 31.
[21] Report by B.M.A. Special Committee, 'Therapeutic Abortion', *British Medical Journal*, 2:5504 (1966), p. 40.

Another of the professional groups in favour of legalising abortion for fetal anomaly was the Royal Medico-Psychological Association (RMPA), which dedicated four paragraphs of an eleven-paragraph memorandum to the subject. They provided a number of examples to support their view that legislation on this subject could be beneficial to society, including the increased likelihood that women would go on to have further children if they terminated a pregnancy likely to result in fetal anomaly, whilst the converse was true if they continued with the pregnancy.[22] As has been shown earlier in this thesis, there were women who agreed with this sentiment, and who would not contemplate another pregnancy until prenatal detection of the condition which affected their family was possible. In a similar manner to the RMPA, the Royal College of Obstetricians and Gynaecologists (RCOG) published a report in 1966 in which they stated that it was 'the view of Council that the great majority of gynaecologists would find it possible to work to an Abortion Act which contained the following provisions', one of which was where the pregnancy would 'involve substantial risk that the child if born would suffer from such physical or mental abnormalities as to deprive it of any prospect of reasonable enjoyment of life'.[23]

Several medical professionals also wrote to journals such as *The Lancet* and the *British Medical Journal* on the subject. Views put forward by those who were in favour of termination on the grounds of fetal anomaly included that it would 'surely be tyrannical to hold that the law forces a woman against her strong revulsion to give birth to a child that will probably be born seriously deformed or mentally subnormal'.[24] Likewise, a study of NHS doctors carried out in the London area in 1964 found that '70% approved the liberalising of the abortion law to make statutory the termination of pregnancy, not only when the woman's mental or physical health is at stake, but also when "there is a serious risk of a defective child being born"'.[25]

[22] The Royal Medico-Psychological Association, 'The Royal Medico-Psychological Association's Memorandum on Therapeutic Abortion', *British Journal of Psychiatry*, 112:491 (1966), p. 1072.
[23] Council of the Royal College of Obstetricians and Gynaecologists, 'Legalized Abortion: Report by the Council of the Royal College of Obstetricians and Gynaecologists', *British Medical Journal*, 1:5491 (1966), p. 853.
[24] Williams, 'Legal and Illegal Abortion', p. 564.
[25] Evelyn Fisher, 'Letters – Legalising Abortion', *The Lancet*, 288:7472 (1966), p. 1077.

However, objections to legislation on the grounds of anomaly were also voiced. Stacpoole-Ryding wrote to the *BMJ* in 1963 stating his belief that 'The taking of innocent human life is opposed because it is wrong' and queried why 'If it is moral to destroy children with congenital defects, why is it immoral to destroy adults with acquired defects?'[26] Concerns were also raised in an editorial in the *BMJ* in 1965 about how easy it would be to reliably predict the impact exposure of agents such as maternal rubella might have on the fetus, and that 'Evidence of the date of conception and of the actual risk which the foetus had run might not be easy to obtain in some cases.'[27] Others queried how difficult it would become to justify preserving the life of premature babies, or carrying out surgery on 'deformed newborn babies which will still leave them permanently crippled'. The same correspondent felt that, if the abortion laws were to be liberalised, it would 'spell the end of the code of ethics on which Western medicine has been built' and that doctors would have to 'find a new code which will include the right to decide on who lives and who dies'.[28] The Medical Women's Federation published their memorandum on the subject of 'Abortion Law Reform' in December 1966, where they stated that, despite agreeing that the present abortion law needed revising, the committee did not consider 'that the risk of an abnormal child being born should be listed as a categorical indication'.[29]

Whilst the problems associated with rubella ignited some level of support for abortion in cases of fetal anomaly, it was not strong enough to lead to legislative change. However, it has been argued that the impact of Thalidomide, a drug which was given to pregnant women in the 1950s and early 1960s to help with morning sickness, but which resulted in the birth of babies with shortened limbs, 'contributed to the climate of public and medical sympathy for women seeking abortion'.[30] Indeed, Gleeson goes as far as to say that 'Law reform might have stagnated entirely had it not been for Thalidomide.'[31]

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[26] F. Stacpoole-Ryding, 'Letters – Abortion Law Reform', *British Medical Journal*, 2:5354 (1963), p. 444.
[27] Author Unknown, 'Leading Article – Abortion Law', *British Medical Journal*, 1:5441 (1965), p. 1010.
[28] H.J. Liebeschuetz, 'Letters – Abortion Law Reform', *British Medical Journal*, 1:5499 (1966), p. 1359.
[29] Medical Women's Federation, 'Abortion Law Reform. Memorandum Prepared by a Subcommittee of the Medical Women's Federation', *British Medical Journal*, 2:5528 (1966), p. 1512.
[30] Davis and Davidson, '"A Fifth Freedom"', p. 35.
[31] Gleeson, 'Persuading Parliament', p. 30.

An international rubella epidemic in 1964-65 coincided with the Thalidomide scandal becoming well publicised, and the combination is thought to have 'secured heightened sympathy' for women seeking abortion due to fetal anomaly.[32] Many members of the ALRA have directly linked their involvement in the campaign for the Abortion Act to the 'thalidomide tragedy',[33] and Hindell and Simms have described it as 'the motor that reinvigorated the Abortion Law Reform Association and which paved the way for reform'.[34] Likewise, in her book *Heredity and Hope*, Ruth Schwartz Cowan links Thalidomide and rubella as key catalysts for change in the abortion movement. Cowan argues that 'All successful social movements – and abortion reform was indeed very successful – are galvanized by one or two crucial events, the kind that recruit more activists to the cause at the same time as they alter the receptivity of people with the power to make the desired reform.'[35]

This is reflected in the stories of some of the key campaigners for changes to abortion legislation. In his book *Abortion Freedom: A Worldwide Movement*, Francome described how Diane Munday, a leading figure in the ALRA, recounted that she had been given a prescription for Thalidomide from her doctor.[36] Her realisation that 'if I had taken that drug, and had developed a handicapped fetus, I would have wanted an abortion' was key in her decision to join the ALRA and work for a change in the law.[37] Others had stronger views, including Madeleine Simms, a key campaigner within the ALRA, who thought it was 'so appalling that there were people around who were actually prepared to compel women to have handicapped babies when this could be avoided'.[38] She had a family friend who had a brain-damaged son, and in her opinion it 'devastated' the life of the mother, and she believed that people 'do not always understand what the implications are for the mother and the whole family'.[39] She went

[32] Gleeson, 'Persuading Parliament', p. 30.
[33] Interview with Madeleine Simms, 'Abortion Law Reformers: Pioneers of Change', ed. by Ann Furedi and Mick Hume, British Pregnancy Advisory Service, 2007, p. 15.
[34] Keith Hindell and Madeleine Simms, *Abortion Law Reformed*, (London: Peter Owen Ltd., 1971), p. 108.
[35] Ruth Schwartz Cowan, *Heredity and Hope: The Case for Genetic Screening*, (Massachusetts: Harvard University Press, 2008), p. 108.
[36] Colin Francome, *Abortion Freedom: A Worldwide Movement*, (London: George Allan & Unwin, 1984), pp. 81-82.
[37] Interview with Diane Munday, 'Abortion Law Reformers: Pioneers of Change', ed. by Ann Furedi and Mick Hume, British Pregnancy Advisory Service, 2007, p. 8.
[38] Interview with Madeleine Simms, 'Abortion Law Reformers', p. 15.
[39] Ibid.

as far as to dedicate her book *Abortion Law Reformed*, co-written with Keith Hindell, 'To the thalidomide mothers for whom reform came too late'.[40]

These views were not limited to those directly involved in the ALRA. Löwy discusses the case of a 'white, middle-class, educated, devoted mother of four children and the animator of a popular children's TV show' from Arizona, Sherri Finkbine, who had taken Thalidomide early in her pregnancy and was subsequently granted an abortion on medical grounds. However, when she took her story to the general public to warn other women about the dangers of Thalidomide, the hospital which had been scheduled to carry out her abortion cancelled the procedure as they were afraid of negative reactions. Finkbine was eventually forced to travel to Sweden to have a termination. Löwy argues that Finkbine's case 'was an ideal vehicle for the claim that abortion may be justified in certain cases', and that she was 'very different from the stereotypical image of an immoral and irresponsible lower-class woman who seeks an illegal abortion'. [41]

Whilst this case happened in the United States, there also seemed to be a move within the United Kingdom towards viewing termination for fetal anomaly as a separate category. Ferguson-Smith himself made this distinction. Despite being one of the main advocates for prenatal testing, he disagreed with abortion for social reasons, which shows that these circumstances were often viewed differently, even by those involved in the medical field.[42] Cowan has argued that 'Public opinion polls have revealed, over and over again, that the majority of people, even some who have their doubts about the wisdom of abortion for other indications, believe that it is better to terminate a pregnancy than to bring someone who is doomed to suffer with a serious disease or disability into the world.'[43] This view was reflected in a national opinion poll carried out by the *Daily Mail* newspaper in 1962 which showed that 73% of the British public

[40] Hindell and Simms, *Abortion Law Reformed*, dedication page.
[41] Löwy, *Imperfect Pregnancies*, pp. 75-76.
[42] History of Modern Biomedicine Research Group (Interview Questions by Ms Emma M. Jones, transcribed by Mrs Debra Gee, and edited by Professor Tilli Tansey and Mr Alan Yabsley), 'Ferguson Smith, Malcolm 06 Scotland, Genetic Counselling, Religious Objections', *YouTube* <https://www.youtube.com/watch?v=DzH-Mrh9Lrw> [accessed 20th July 2018]. 4 minutes 30 seconds to 4 minutes 44 seconds.
[43] Cowan, *Heredity and Hope*, p. 6.

were in favour of abortion where a child might be born 'deformed',[44] and by 1966-67 this figure had risen to 91%.[45] As the *Daily Mail* has traditionally been seen as a right-wing, conservative newspaper, these findings are perhaps quite surprising, but provide an insight into the wider cultural shift happening within the United Kingdom surrounding abortion attitudes. The *Report of the Committee on the Working of the Abortion Act*, also noted that, when the general public were asked if they agreed with abortion in women who had contracted rubella in the first trimester or who were at 'risk' of having a 'deformed baby', support increased over time – from 58% in 1965 to 91% in 1966.[46] It also appears that the prosecuting authorities were not keen to be involved in cases involving licensed doctors who had carried out terminations on the grounds of fetal anomaly in good faith. As Gleeson has pointed out, there is 'no record of prosecution of a doctor for performing an abortion on a woman who had taken Thalidomide', despite concern within the medical profession about the legality of these procedures.[47]

As this chapter has shown, for many, termination of pregnancy as a result of fetal anomaly was viewed differently from termination for social reasons. The following section will consider how a fetal anomaly clause was discussed when attempts to alter abortion legislation were being considered. One of the areas of discussion that are most prominent when examining attitudes towards termination for fetal anomaly before the advent of prenatal testing, is that of diagnostic certainty. While fetal anomaly was being specifically considered within changing abortion legislation in the early 1960s, much of the discussion focused around the uncertainty of the diagnosis of conditions prenatally. Indeed, in a discussion of his draft Bill in the House of Commons in February 1961, Kenneth Robinson specifically mentioned rubella infection as a situation which it may be suitable for termination to take place under. However, Mr Renton, also participating in the discussion, voiced his concerns regarding the surety of diagnosis. He stated that 'although medical science has made considerable strides since 1938, when the Departmental Committee sat, it is still not possible to predict with any confidence in any

[44] Davis and Davidson, '"A Fifth Freedom"', p. 36.
[45] Pomies-Marechal and Leggett, 'The Abortion Act 1967', p. 59.
[46] The Hon. Mrs. Justice Lane, D.B.E. *Report of the Committee on the Working of the Abortion Act – Volume II Statistical Volume*, (London: Her Majesty's Stationery Office, 1974), p. 30.
[47] Gleeson, 'Persuading Parliament', pp. 30-31.

particular case whether a child will exhibit some form of abnormality or how severe that abnormality will be'.[48] That diagnosis of fetal anomaly, or its severity, could not be made definitively during pregnancy was also raised by several other commentators. In a draft version of a note in response to Robinson's Bill, it was stated that additional criteria such as fetal anomaly were 'open to strong objection' and that a diagnosis could not be made with 'sufficient certainty'.[49] Others commented that 'Congenital deformity is so unpredictable that the only related justification for medical termination of pregnancy springs not from the ascertainable degree of risk but from the mother's state of apprehension', leading to the conclusion that there was no need for a separate fetal anomaly clause, as a medical professional could proceed to termination in this instance under existing legislation.[50] These examples indicate that the concerns surrounding a fetal anomaly clause in the early 1960s, prior to Steel's Bill, focused on how one could be sure that fetal anomaly was present.

However, by the time Steel's Bill was put forward, there seemed to be clear support for a fetal anomaly clause. It was reported that Steel himself felt that any 'revised' wording of his abortion Bill which 'did not contain an express reference to abnormality' would be 'unacceptable'.[51] Support was also voiced more widely, including by individuals who were happy to make their views known. David Primrose, a consultant working with 'mental deficiency', wrote to the Minister of Health, expressing his approval of the abortion Bill overall, but specifically emphasising his support for termination where there was 'the possibility of serious physical or mental abnormality in the foetus'.[52] A survey carried out by the National Opinion Poll on behalf of the ALRA showed the high levels of acceptability for terminations as a result of fetal anomaly. 80.5% of respondents answered positively when asked the question 'Do you think abortion should also be legal if there is serious risk that the child would be born deformed?', which was

[48] National Records of Scotland, HH41/1329, Medical Termination of Pregnancy Bill (dated 10th February 1961).
[49] National Records of Scotland, HH41/1329, Legislation Committee, Private Member's Bills, Mr. Kenneth Robinson's Bill on the Medical Termination of Pregnancy, Note by the Home Secretary, p. 2.
[50] National Records of Scotland, HH41/1329, Letter from T.B. Williamson to R.R. Pittam, p. 1 (letter dated 17th January 1961).
[51] National Records of Scotland, AD63/759/2, Report titled 'Medical Termination of Pregnancy Bill', p. 6 (report written by J.K.T. Jones, dated 27th April 1967).
[52] National Records of Scotland, HH41/1821, Letter from David Primrose to The Minister of Health, p. 2 (letter dated 22nd May 1967).

the same percentage who agreed that abortion should be legal in cases where the woman had become pregnant as a result of rape.[53] These high levels of acceptability seem to reflect that, in general, there was widespread support for abortion in cases of fetal anomaly. Even some individuals who were campaigning against abortion law reform more broadly, such as Norman Wylie, M.P.,[54] were willing to allow an exception in such circumstances. Wylie commented that '"There might be arguments in favour of abortion to avoid the birth of a seriously handicapped child, but the rest of the Bill is thoroughly bad"'.[55]

However, not all of those who were politically involved in the discussion of the proposed abortion legislation were supportive of the fetal anomaly clause. There were those who supported attempts to change the language within the clause, and those who wanted its removal altogether. With regards to the language, discussion focused a great deal around the wording which dealt with the likelihood of fetal anomaly, including terms such as 'substantial risk'. The Bill proposed that abortion would be allowed 'on the ground that there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped'. The Viscount Dilhorne proposed an amendment to the Bill to leave out the phrase ("there is a substantial risk") and insert ("it is more likely than not") in its place. He also wanted to leave out the term ("seriously handicapped") and insert ("deprived of reasonable enjoyment of life") as its substitution.[56] However, opposition was raised to both of these suggestions. The idea that a clinician should be responsible for determining what would constitute 'reasonable enjoyment of life' was not seen as viable. It was pointed out that many different factors combine to influence enjoyment of life 'which may be independent of any physical or mental abnormality', including personality, 'which it

[53] National Records of Scotland, HH41/1822, Survey on Abortion, Report of a Survey carried out by National Opinion Polls Limited for The Abortion Law Reform Association, information in Table 2 and Table 3 of the document.
[54] Norman Wylie (1923-2005) was a member of the Scottish Conservative and Unionist Party, and was an M.P. for Edinburgh Pentlands. Prior to this he had been the Solicitor General for Scotland, and later became Lord Advocate.
[55] National Records of Scotland, HH41/1820, Newspaper article in the *Glasgow Herald* titled 'Abortion Bill Meets Scottish Opposition' (published 14th July 1966).
[56] National Records of Scotland, AD63/759/9, Abortion (No. 2) Bill Lords Report 1/1/20 and 1/1/22, p. 1.

would be impossible for the doctor to assess or even form an opinion on in the case of an unborn child'.[57]

If the proposed phrase 'more likely than not' was introduced, it would require certainty by the medical profession that there was a greater than 50 per cent chance that anomaly would be present. However, critics of this suggested wording change, argued that 'it is evident that the degree of risk demanded by the amendment can rarely be identified'.[58] It was highlighted that 'developments in medical research may in the years to come make more accurate prognostication of abnormality possible, but it is doubtful whether it is right to legislate now for this eventuality'.[59] The amendments were proposed prior to the more widespread use of prenatal testing for conditions such as chromosome anomalies, where a diagnosis could be made with greater confidence, and thus there was resistance to limiting the clause to grounds which would make it too specific to be utilised in clinical practice.

Whilst there were some concerns raised over the fetal anomaly clause being made too restrictive by proposed wording changes, others were arguing for further restrictions to be put in place, or for the clause to be removed altogether. Two of the key figures involved were the M.P.s Jill Knight and Norman St. John-Stevas. St. John-Stevas's campaign against the Abortion Act 1967 will be discussed in chapter six in the context of opposition on religious grounds. However, his attempts to limit fetal anomaly legislation will be described briefly here. Both Knight and St. John-Stevas proposed amendments which would have required both the 'mother' and the 'father' to provide 'written consent' before a termination for fetal anomaly could be carried out, with a statement that 'the degree of risk and the seriousness of the handicap have been fully explained … by a registered medical practitioner'.[60] Opponents of the amendment expressed concern that difficulties would arise from such a requirement, including that the precise estimate of risk for anomaly might not be available for the doctor to provide,

[57] Ibid., pp. 3-4
[58] Ibid., p. 2.
[59] Ibid.
[60] National Records of Scotland, AD63/759/11, Medical Termination of Pregnancy Bill Commons Report 1/1/17 (54), p. 1.

and that conflict could arise between the pregnant woman and the male involved, with the male potentially refusing to provide consent for the termination.[61]

Amendments were also proposed to remove the fetal anomaly clause as a whole. These were put forward by various groups of individuals, but were defeated each time. One of these groups was composed of the Earl of Dundee, the Baroness Emmet of Amberley, and the Lord Bishop of Exeter. Another group consisted of Jill Knight, Norman St. John-Stevas, James Dunn and William Wells.[62] The main line of argument presented against inclusion of the fetal anomaly clause was that the 'unborn child is a member of the human race … and that it is wrong to deprive it of life solely because it may be seriously handicapped', a standpoint which was viewed as being 'Roman Catholic'.[63] These ideas will be discussed further in chapter six, when considering the Catholic view towards prenatal testing and termination for fetal anomaly. Another reason given for the removal of the fetal anomaly clause related to the previously discussed concept of uncertainty, with it being contested that 'with present medical knowledge it is impossible to forecast with any certainty whether there will be serious disability or abnormality in a particular case'.[64] In the consideration of both of these proposed amendments, however, other members noted that there was 'a good deal of public sympathy' for abortion in cases of fetal anomaly, and that people 'who support this reform do not see themselves as passing judgement on a child's fitness to live but as exercising compassion for the potential child and its parents'.[65]

[61] National Records of Scotland, AD63/759/11, Medical Termination of Pregnancy Bill Commons Report 1/1/20 (24), p. 3.
[62] Information on the amendments proposed by the group consisting of the Earl of Dundee, the Baroness Emmet of Amberley, and the Lord Bishop of Exeter, can be found in National Records of Scotland, AD63/759/10, Medical Termination of Pregnancy Bill Lords Committee 1/1/17 (11). Information on the amendments proposed by the group consisting of Jill Knight, Norman St. John-Stevas, James Dunn and William Wells can be found in National Records of Scotland, AD63/759/11, Medical Termination of Pregnancy Bill Commons Report 1/1/18 (18).
[63] National Records of Scotland, AD63/759/10, Medical Termination of Pregnancy Bill Lords Committee 1/1/17 (11), p. 1.
[64] Ibid.
[65] National Records of Scotland, AD63/759/11, Medical Termination of Pregnancy Bill Commons Report 1/1/18 (18), p. 2.

Whilst issues relating to fetal anomaly did feature in discussions surrounding abortion legislation, there was widespread acceptance of the inclusion of this clause within Steel's Bill. Whilst clauses such as allowing abortions for social reasons were subject to fierce debate, and ended up being removed prior to the legislation being passed as the Abortion Act 1967, the clause relating to fetal anomaly remained, despite a small number of individuals opposing it. It is of interest to note that much of the debate surrounded a lack of certainty over a positive diagnosis of anomaly during pregnancy, a situation which would decrease with the implementation of prenatal diagnosis. Despite this uncertainty, most people were still willing to support abortion on these grounds, and accept that some pregnancies which were unaffected by fetal anomaly, could be terminated as a result.

IV. The Perspectives of the Professional Medical Bodies

As we have seen, Steel's Bill aimed to make abortion available for a number of different reasons, including to preserve a woman's physical or mental health. The medical profession, who would shoulder the responsibility for the implementation of the law, were heavily involved in debating the potential changes. Abortion law reform was a very contentious issue within the profession, with conflicting views existing amongst many of the key professional bodies, including the RCOG, the BMA and the RMPA. Prior to the implementation of the Abortion Act 1967 the RCOG and the BMA had expressed the view that the current law did not need changing. As late as 1966, in the middle of many ongoing debates on the subject, the BMA 'noted that there "remains a body of medical opinion which takes the view that the law does not need amendment in that all the accepted medical indications for therapeutic abortion are covered by the law"'.[66] In the same year, a report by the RCOG stated that 'The present situation commends itself to most gynaecologists … in that it leaves them free to act in what they consider to be the best interests of each individual patient.'[67] This contrasts strongly with the view put forward by the RMPA that many in the medical profession 'are inhibited in advising on, or carrying out, termination of pregnancy for fear that they

[66] Gleeson, 'Persuading Parliament', pp. 26-27.
[67] Simms, 'Abortion Law and Medical Freedom', p. 124.

might have to face legal consequences or because their professional reputation might be endangered'.[68]

However, as MacIntyre has argued, each of the professional bodies were acting in such a way as to protect their own interests. In the case of the RMPA they had a vested interest in health being viewed as a combination of physical and mental wellbeing; otherwise, MacIntyre argues, 'to put it crudely, they would be out of business if the concept of health were restricted to that of absence of biological pathology'.[69] Those involved in the psychology and psychiatry fields were generally held to have more liberal views towards abortion, and in a survey carried out of members of the Society of Clinical Psychiatrists in 1967, 80% were found to be in favour of progressive legislation.[70] However, those with a more conservative attitude towards termination dissented from the views of the psychiatrists, and some went as far as to state their belief that there was no such thing as psychiatric indications for pregnancy termination.[71] By way of contrast, the RCOG were in favour of clarification of the law, but wanted to restrict reform as much as possible. Once they realised that legal changes were going to occur despite their objections, they became closely involved in trying to influence the Act, in conjunction with the BMA. The RCOG recommended that termination should only be carried out under the supervision of a consultant gynaecologist. There were 460 of these consultants in Britain at this time, and so there would be a major problem with the supply and demand balance for the procedure.[72] The RCOG were also against specific indications being included in any legislation, arguing instead that it should be the general health of the mother which was taken into account, and the gynaecologist should be the one to make a decision on her health. These combined clauses were designed, MacIntyre argues, to ensure that the RCOG maintained authority in this medical sphere.[73] In the end, the BMA persuaded the

[68] The Royal Medico-Psychological Association, 'The Royal Medico-Psychological Association's Memorandum on Therapeutic Abortion', p. 1071.
[69] S.J. MacIntyre, 'The Medical Profession and the 1967 Abortion Act in Britain', *Social Science and Medicine*, 7:2 (1973), p. 127.
[70] John G. Howells, 'Letters – Legalising Abortion', *The Lancet*, 289:7492 (1967), p. 728.
[71] D.G. Wilson Clyne, 'Letters – Abortion Law Reform', *British Medical Journal*, 1:5501 (1966), pp. 1482-1483.
[72] Gleeson, 'Persuading Parliament', p. 39.
[73] MacIntyre, 'The Medical Profession and the 1967 Abortion Act', p. 127.

RCOG that it was impractical to only have consultants carrying out the operation. However, both the BMA and RCOG combined to argue strongly that two or more doctors should be required to decide upon a termination.[74] The BMA were similarly disposed to the RCOG as regards to specific indications being excluded from the legislation, and argued that doctors should be able to maintain their professional autonomy and decide for themselves whether or not a termination should take place. Both the BMA and RCOG emphasised that their organisations would not put any pressure on doctors to terminate a pregnancy, including if it had occurred as the result of a sexual assault.[75]

Whilst a number of issues in the legislation were debated during the various stages of the Bill, the possibility of the inclusion of a social clause proved to be the most contentious and highly debated subject. A clause which would permit women to have abortions based on social, rather than strictly medical, grounds, was one that the ALRA had campaigned strongly for. The RMPA also favoured that social circumstances should be taken into account,[76] whilst both the RCOG and BMA were strongly opposed to their inclusion.[77] The RMPA released a memorandum on therapeutic abortion in 1966, stating that 'The Royal Medico-Psychological Association approaches the problem of therapeutic abortion with the firm view that, in addition to traditionally accepted medical and psychiatric criteria, all social circumstances should be taken into account. If, after considering all these factors, a psychiatrist should form the opinion that the mental health of the mother and the whole family would be promoted by termination, then it should be lawful for him to recommend it.'[78] As Keown has discussed, the RCOG and BMA objected to a social clause as they felt that these indications were not medical, and they were concerned that it would lead to an 'excessive demand for termination on social grounds, and this would be unacceptable to the medical profession'.[79]

[74] Gleeson, 'Persuading Parliament', p. 39.
[75] Simms, 'Abortion Law and Medical Freedom', p. 124.
[76] Ibid., p. 125.
[77] John Keown, *Abortion, Doctors and the Law. Some Aspects of the Legal Regulation of Abortion in England from 1803 to 1982*, (Cambridge: Cambridge University Press, 1988), pp. 96-97.
[78] The Royal Medico-Psychological Association, 'The Royal Medico-Psychological Association's Memorandum on Therapeutic Abortion', p. 1071.
[79] Keown, *Abortion, Doctors and the Law,* pp. 96-97.

The views of the medical profession impacted the legislation for the Abortion Act 1967. Steel was aware that support of the medical organisations was essential for the Bill to be passed, and it became clear to him that in order to secure the agreement of the medical profession, the social clause would have to be removed. In December 1966, Steel withdrew the clauses relating to the woman's capability as a mother, and the criteria of being a 'defective', having been raped, or being under sixteen.[80] Instead, medical practitioners were able to take into account the physical and mental health of the pregnant woman, and her current and foreseeable future environment. The specific clause for fetal anomaly remained within Steel's Bill. A conscience clause was also inserted into the Bill, ensuring that medical practitioners were able to opt out of taking part in abortions. After the committee stages the Bill passed its third reading in the House of Commons on the 14th of July 1967, with 262 to 181 votes.[81] After being passed by the House of Lords on the 24th of October 1967, the Bill received the Royal Assent on the 27th of October 1967, and was officially implemented on the 27th of April 1968.[82] It was the first time that abortion legislation had covered Great Britain, rather than Scotland and England and Wales separately.[83]

V. The Views of Senior Obstetricians/Gynaecologists – The Case of Dugald Baird and Ian Donald

Although abortion legislation changed with the passing of the Abortion Act 1967, there continued to be disagreements amongst various groups on the subject. Vast regional differences existed for both the availability of, and access to, abortion services, and it has been argued that in a number of cases, this was down to the beliefs of the senior obstetricians/gynaecologists who were working in these regions. This was particularly prominent in Scotland, where two main figures, Dugald Baird and Ian Donald, held hugely different views on abortion. This section will consider each of their viewpoints in turn, with a particular focus on Donald as he was based in Glasgow. It will also

[80] Brooke, 'Abortion Law Reform 1929-68', p. 18.
[81] Ibid., p. 19.
[82] Ibid.
[83] James Owen Drife, 'Historical Perspective on Induced Abortion Through the Ages and its Links with Maternal Mortality', *Best Practice & Research Clinical Obstetrics and Gynaecology*, 24:4 (2010), p. 439.

analyse how these views impacted on the services which were available in their respective regions, Aberdeen and Glasgow, building on concepts discussed in Davis and Davidson's article ''Big White Chief', 'Pontius Pilate', and the 'Plumber': The Impact of the 1967 Abortion Act on the Scottish Medical Community, c.1967-1980'. As was discussed in the literature review, Davis and Davidson are two of the leading commentators on the views of Baird and Donald. The following sections of this chapter will therefore consider their work in detail, but will explore further evidence regarding Donald in his relations with Ferguson-Smith. This will include primary source material from the Ian Donald and Malcolm Ferguson-Smith archives, in addition to oral history testimony by a clinician, Bill Hannay, who worked under the leadership of Ian Donald.

As described by Davis and Davidson, Sir Dugald Baird was a key medical proponent for the liberalisation of abortion provision. Baird was a registrar in gynaecology in Glasgow before becoming Regius Chair of Midwifery at the University of Aberdeen in 1936.[84] Born in Greenock in 1899, it was the time Baird spent working in Glasgow which helped to shape his strong views on abortion. As Davis describes, he began to 'recognise the various influences that social and economic factors could have upon maternal health and female physiology'.[85] Many women in Glasgow had large families, and Baird found that in the early 1930s, 'one third of all maternal deaths in the Glasgow Royal Maternity Hospital were in women who had six or more children'.[86] In addition, two women were dying each week in the Maternity Hospital from complications of childbirth.[87] Despite this, Baird noted, no contraceptive advice was given to these women, and it was 'scarcely surprising therefore that one third of all maternal deaths in Scotland at that time were due to septic abortion'.[88] Davis has outlined how Baird came to move from Glasgow to Aberdeen, and the impact this had on his clinical practice. She highlights that working with the women described above led Baird to develop a

[84] Davis and Davidson, '"A Fifth Freedom"', p. 33.
[85] Gayle Davis, 'The Great Divide: The Policy and Practice of Abortion in 1960s Scotland', online publication, *Royal College of Physicians of Edinburgh*, (2005) <https://www.rcpe.ac.uk/heritage/great-divide-policy-and-practice-abortion-1960s-scotland> [accessed 9th August 2018].
[86] Dugald Baird, 'Induced Abortion: Epidemiological Aspects', *Journal of Medical Ethics*, 1:3 (1975), pp. 122-123.
[87] James Willocks and Wallace Barr, *Ian Donald: A Memoir*, (London: Royal College of Obstetricians and Gynaecologists Press, 2004), p. 108.
[88] Baird, 'Induced Abortion', p. 123.

permissive view towards abortion, and he decided to make his views public around 1936, after a conflict with a Roman Catholic priest.[89] Davis describes how Baird found that his liberal leanings would not be supported in Glasgow, which had a large Roman Catholic population, and this was one of the factors which influenced his decision to move to Aberdeen, where the influence of the Catholic Church was much less.[90] Indeed, the varying rates of Roman Catholicism are still evident between Aberdeen and Glasgow today; the 2011 census showed that 27.3% of the population in Glasgow classed themselves as Roman Catholic, compared to only 8.9% in Aberdeen. The overall percentage of people identifying as Roman Catholic in Scotland was 15.9%, indicating that Glasgow has a higher than average number of Roman Catholic residents, whilst Aberdeen has a lower than average number.[91] The views of the Roman Catholic population in the city of Glasgow and surrounding areas will be a key focus of chapter six, where their outspoken views against abortion will be considered in detail.

By way of contrast to Glasgow, Davis outlines, the community of Aberdeen was receptive to Baird's views, and the city became one of the few places in Britain where terminations were carried out in significant numbers prior to the Abortion Act 1967. Baird had consulted the Professor of Law at the University of Aberdeen for clarification on abortion legislation in the late 1930s, and he was informed that it was unlikely prosecutions would be brought against him, unless it could be proven that there was criminal intent.[92] Baird utilised this flexibility in the law to extend abortion provision, with two out of every hundred pregnancies being terminated in Aberdeen under his leadership. As a result, Baird argued that fewer women died in childbirth in Aberdeen, and that fewer women accessed unqualified abortionists, as these women knew their 'difficulties [would] receive sympathetic and unprejudiced consideration from the medical profession in Aberdeen'.[93] Baird remained an ardent supporter of abortion provision and wider family planning. In 1965 he published one of his most famous

[89] Davis, 'The Great Divide', p. 2.
[90] Ibid.
[91] 'Scottish City Comparison – Religious Orientation in Scottish Cities', *Understanding Glasgow* <http://www.understandingglasgow.com/indicators/mindset/religion/scottish_city_comparison> [accessed 8th August 2018].
[92] Davis, 'The Great Divide', p. 2.
[93] Ibid., p. 3.

articles on the subject, entitled 'A Fifth Freedom?'. Baird added one freedom of his own to the four proposed by Franklin Roosevelt:

> You will recollect that Franklin Roosevelt in a speech on 6 January 1941 said: "In the future days, which we seek to make secure, we look forward to a world founded upon four essential freedoms." The first is freedom of speech and expression. The second is freedom of every person to worship God in his own way. The third is freedom from want. The fourth is freedom from fear." And I would suggest that it is time to consider a fifth freedom – freedom from the tyranny of excessive fertility.[94]

That women and men should be able to control their family size was of central importance to Baird, and whilst he believed that abortion should not be used as a method of contraception, he did believe it 'should be available in the last resort'.[95] Viewing obstetrics as social medicine, he advocated sterilisation if a woman had completed her family. Whilst Baird was confident in his own views, he was one of a small minority in the medical profession who were willing to carry out abortions in anything approaching substantial numbers prior to the Abortion Act 1967. The attitudes of others in the medical profession had not followed the same path as Baird, and Davis and Davidson have suggested that by 1966 Baird felt a 'sense of frustration that the law had to be changed at all, and that his fellow doctors were not following his lead'.[96] Despite this frustration, Baird was a supporter of the Abortion Act 1967, and campaigned strongly in its favour. He spoke of his own experience of carrying out terminations for social reasons which had 'striking benefit to the health of the mother and to the whole family'.[97] Baird was one of twelve signatories to a statement on Steel's Bill which expressed their unequivocal support for a Bill which they believed would give doctors 'the freedom to make the best choice for the mother, her established family, and the embryo within her'.[98] Baird maintained this view after the legislation was passed, and in 1975 when commenting on the Act he called it 'one of the most

[94] Dugald Baird, 'A Fifth Freedom?', *British Medical Journal*, 2:5471 (1965), p. 1141.
[95] Baird, 'Induced Abortion', p. 122.
[96] Davis and Davidson, '"A Fifth Freedom"', p. 35.
[97] Author Unknown, 'Annotations – Abortion in Britain', *The Lancet*, 287:7444 (1966), p. 970.
[98] Author Unknown, 'Medical Termination of Pregnancy', *The Lancet*, 289:7481 (1967), p. 101.

important and beneficial pieces of social legislation enacted in Britain in the last 100 years'.[99]

Baird's liberal views on abortion were not unchallenged, and many within the medical community in Scotland were strongly opposed to the idea of termination of pregnancy. One such opposing figure was Ian Donald, the pioneer of ultrasound. Donald was born in Cornwall in 1910 and studied at Saint Thomas's in London; he then undertook a number of medical roles before becoming Regius Professor of Midwifery at the University of Glasgow in 1954.[100] This section will examine Donald's views in detail, as he was a figure of central importance in Glasgow. Donald was a deeply religious man and an active member of the Scottish Episcopal Church, and as Nicolson describes, 'He was fairly High Church and while, as far as I am aware, he never actually described himself as Anglo-Catholic, that was broadly his doctrinal position.'[101] Donald was morally opposed to terminations in the vast majority of circumstances, and was particularly opposed to abortions for social reasons.[102] As vocal as Baird was in favour of abortion, Donald was equally outspoken in his opposition to it, and he claimed that only one pregnancy in 3750 was terminated in Glasgow, a sharp contrast to Aberdeen.[103]

Donald argued specifically against Baird's view of the 'tyranny' concept of excessive fertility and motherhood, which he believed 'contrasts sharply with the mother-and-child concept which has been glorified by the art of centuries'.[104] He strongly disagreed with Baird's views that ending a pregnancy for social reasons could improve the overall health and well-being of the pregnant woman, and wrote to the *British Medical Journal* protesting against the ideas put forward by Baird in his article 'A Fifth Freedom?'. The letter was written by Donald, and after some amendments his colleagues John McBride,

[99] Baird, 'Induced Abortion', p. 122.
[100] Malcolm Nicolson, 'Ian Donald – Diagnostician and Moralist', online publication, *Royal College of Physicians of Edinburgh*, (2000) <https://www.rcpe.ac.uk/heritage/ian-donald-diagnostician-and-moralist> [accessed 9th August 2018].
[101] Ibid.
[102] Malcolm Nicolson and John E.E. Fleming, *Imaging and Imagining the Fetus: The Development of Obstetric Ultrasound*, (Baltimore: The Johns Hopkins University Press, 2013), pp. 238-239.
[103] Davis, 'The Great Divide', p. 4.
[104] Ian Donald, 'Abortion and the Obstetrician', *The Lancet*, 297:7711 (1971), p. 1233.

Wallace Barr and James Willocks also agreed to sign it. Their letter was rejected for publication, but its text has been reproduced in the book *Ian Donald: A Memoir* by Willocks and Barr.[105] Donald and his colleagues began by acknowledging Baird's 'great authority and unquestioned sincerity', but argued that despite Baird's arguments being 'well-intentioned', they were also 'dangerous'.[106] They argued that there was a major difference between pregnancies which if continued would directly threaten the life of the woman (such as a patient with cervical cancer during pregnancy), and situations where the baby is 'unwanted because of inconvenience, expense or nuisance value'.[107] It was emphasised that there were other ways to help women involved in this situation, including using social services to help women in poverty.[108] Whilst this was advocated as a possible solution, those writing the letter did not expand on the situation which would face women if they did continue with a pregnancy in the hope of gaining social support, only for this to not be provided.

Whilst Donald was strongly against abortion for social reasons, he did carry out a small number of terminations for reasons of fetal anomaly, which was important for the medical genetics field in Glasgow. Donald himself spoke of his cut off point being 'when it was scientifically certain that the baby would be incapable of mental and spiritual development'.[109] Anencephaly was an example of such a medical circumstance. Donald's views have been investigated by other authors, including Davis and Davidson, and Nicolson and Fleming, but what has not been covered in the published literature is the possibility that the development of medical genetics in Glasgow, led by Ferguson-Smith, had an influence on his position. Despite their work potentially placing them in conflict, Ferguson-Smith described Donald as a 'neighbour and a friend', who he had worked with for many years, and spoke highly of him during his interview for this project.[110] Ferguson-Smith mentioned how he might have had an influence on Donald with regards to terminations for fetal anomaly, after getting him to speak to one of his patients who was undergoing prenatal diagnosis. The woman had

[105] Willocks and Barr, *Ian Donald: A Memoir*, p. 108.
[106] Ibid., p. 109.
[107] Ibid., p. 110.
[108] Ibid.
[109] Ian Donald Archive, Mitchell Library Glasgow, HB110/4/24, Letter to Tony, p. 2 (letter dated 26th May 1978).
[110] MAFS interview, DS300130, p. 1.

one living child who was affected by a metabolic disease, and had had a second pregnancy terminated because of the same condition. She then had another termination as during her third pregnancy she was found to be carrying an anencephalic fetus, and her fourth pregnancy which was being tested by amniocentesis was also found to have a fetus which had the same metabolic disease.[111] Ferguson-Smith recalled how the woman was articulate and was able to tell Donald how she felt. Donald 'was of course extraordinarily sympathetic and kind, and realised what a burden this had been for her. And he appreciated how impossible it was for this woman, without any kind of health service support, to look after these children and how difficult it would be for her to have another one.'[112] Whilst Donald did not have to terminate that woman's pregnancy, he did in the future go on to terminate the pregnancies of two women who had undergone prenatal testing in Ferguson-Smith's department in the early 1970's. The paper describing the cases was published in 1973 in *The Lancet* with Donald's name on it, which was an important step in linking Donald to terminations carried out for reasons of fetal anomaly.[113] Ferguson-Smith was aware of the significance of this decision, as when writing to a colleague in Manchester about one such case, he emphasised that this was the first termination to take place in the Queen Mother's Hospital in ten years.[114] This is of key importance when considering Donald's views towards termination of pregnancy. In some of the published literature Donald is portrayed as wholly opposing termination, and even amongst those who do highlight that he would terminate in cases of fetal anomaly, no mention is made of Ferguson-Smith.

When Donald was asked by the newly formed Society for the Protection of Unborn Children (SPUC) group at the University of Glasgow to take part in a debate on 'Congenital defects and abortion', he was entirely unimpressed with the idea, despite being a member of SPUC. He wrote back to the organiser stating that he thought the

[111] Ibid., p. 2.
[112] Ibid.
[113] The paper was Lindsey D. Allan, M.A. Ferguson-Smith, Ian Donald, Elizabeth M. Sweet and A.A.M. Gibson, 'Amniotic-fluid Alpha-fetoprotein in the Antenatal Diagnosis of Spina Bifida', *The Lancet*, 302:7828 (1973), pp. 522-525.
[114] University of Glasgow Archives, Papers of Malcolm Andrew Ferguson-Smith, UGC 188/3/3/8/6, Ferguson-Smith Correspondence with Rodney Harris, p. 13 (letter dated 17th May 1973).

subject was 'tasteless' as a 'debating stunt',[115] and that the matter of the debate was 'distressingly serious and not one for frivolity'.[116] Donald also stated that he would 'support the proposed motion in favour of aborting a malformed child since this is my current practice',[117] and highlighted his connection with Ferguson-Smith by stating that he had been working with him 'for some time and it is only fair to let you know that in the face of incontrovertible scientific evidence of gross fetal handicap I have no hesitation in terminating pregnancy. These are rare occasions, nevertheless important.'[118] This quote illustrates the direct working relationship between Ferguson-Smith and Donald, and emphasises Donald's willingness to terminate a pregnancy in the rare circumstances he approved of doing so. That Donald was in discordance with SPUC on this issue is not well-known. Donald is usually presented in the literature as a founding member of SPUC with sustained and vigorous opposition to abortion, with no discussion of his willingness to terminate a pregnancy in certain cases of severe fetal anomaly.[119]

Donald did indeed see these as rare cases, but he argued in favour of having the resources available to make these diagnoses. Whilst giving a lecture in Dublin, Donald argued that Irish obstetricians should be performing more terminations as a result of fetal anomaly diagnosis, emphasising that 'One cannot have at one's disposal highly accurate scientific information as is now available by modern techniques of prenatal diagnosis of fetal abnormality and not take the responsibility of making intelligent use of it.'[120] However, Donald maintained concerns about the numbers of terminations which were happening for fetal anomaly which did not sit well with his own moral code. Despite advocating for selective terminations to be allowed for fetal anomaly, he was keen to emphasise that by maintaining a strict selection criteria he was able to

[115] UGC 188/3/4/52/1, Ferguson-Smith Correspondence with P McCarthy, p. 14 (letter dated 6th September 1976).
[116] Ibid., p. 11 (letter dated 21st September 1976).
[117] Ibid., p. 14 (letter dated 6th September 1976).
[118] Ibid., p. 17 (letter dated 31st August 1976).
[119] Indeed, SPUC's website describes Donald as a 'Distinguished Founder', with no mention that his anti-abortion stance was not absolute. See 'On This Day 52 Years Ago SPUC was Founded', *Society for the Protection of Unborn Children* <https://www.spuc.org.uk/on-this-day-52-years-agoa-spuc-was-founded> [accessed 13th October 2019].
[120] Nicolson and Fleming, *Imaging and Imagining*, p. 240.

'count on his fingers and toes the number of abortions he had done'.[121] He also spoke in 1975 about how the whole subject of prenatal testing followed by termination of the pregnancy was becoming 'an increasing feature of obstetric practice in our country',[122] and that he often felt it was a 'joyless and morbid subject'.[123]

Donald had concerns that his own ultrasound technology was being used for such purposes, as it was a central feature both in increasing the safety of amniocentesis, and also in the direct diagnosis of structural anomalies during fetal development. As discussed in previous chapters, ultrasound was also involved in dating gestational age, which was essential for correct estimations of alpha-fetoprotein in neural tube defect screening programmes. Donald was a keen advocate of furthering research into the causes of the conditions which were being terminated, and stated in a letter to a Mrs Barnes in 1981 that he shared her 'view that research should be directed towards preventing fetal handicap, by mitigating its consequences when it occurs and by avoiding the present practice of liquidating the victims by a policy of indiscriminate abortion'.[124] Hoping that 'I myself would not like to feel that I had contributed to a Huxleyian Brave New World Society',[125] in a letter written in September 1977 Donald commented that with his involvement he 'may in the end have been contributing to therapeutic nihilism', a statement which was much to the dismay of the Ferguson-Smiths, who were attending the same meeting where he made the comment.[126] This section of this thesis shows the complex circumstances which surrounded Donald's views towards termination of pregnancy for fetal anomaly. Whilst for some, no mention is made of this perspective at all when discussing his views, others do note that he was willing to terminate pregnancies as a result of fetal anomaly under limited circumstances. What this presentation of the working relationship between Donald and Ferguson-Smith reveals is that the two men influenced each other's clinical practice. This link has not been described elsewhere in the published literature.

[121] David Nowlan, Medical Correspondent, 'Selective Abortions Urged in Cases of Foetal Damage', *The Irish Times*, 6th September 1978, p. 6.
[122] Ian Donald Archive, HB110/2/5, Speech on Unsuccessful Recurrent Pregnancy, p. 13 (dated 1975).
[123] Ibid., p. 15.
[124] Ian Donald Archive, HB110/5/7, Letter to Mrs Barnes (letter dated 24th April 1981).
[125] Ian Donald Archive, HB 110/4/35, Harding Award Speech 1979, p. 25.
[126] Ian Donald Archive, HB110/6/5, Letter to David Charles, p. 1 (letter dated 12th September 1977).

However, it should be noted that Donald, whilst willing to consider terminations under limited circumstances for fetal anomaly, was a strong anti-abortion advocate more broadly. Donald had concerns that ultrasound was assisting with terminations following prenatal testing, and he utilised the technology to strengthen his arguments against abortion on many occasions. Nicolson has described how Donald would show ultrasound images of the fetus to a woman who was seeking an abortion in the hopes of changing her mind.[127] Donald believed that ultrasound 'killed that dirty lie that the foetus is just a nondescript meaningless jelly, disposable at will, something to be got rid of',[128] and often showed ultrasound footage at public meetings and discussions to strengthen his anti-abortion message. He made a six minute film of a 12 week old fetus in the womb 'jumping around like a youngster on a trampoline', where it could be seen 'kicking, moving its arms, even moving its hands to its face from time to time'.[129] Pope John Paul II heard about the film and was so enthralled by it that he arranged a meeting with Donald at the Vatican. After the Pope had watched the film it was shown to around 20 million Italians on their main TV news bulletin, and Donald commented that he wanted the Italian public 'to judge for themselves whether this early scrap of humanity was a meaningless jelly or real life'.[130] His description of abortion as ''legalised murder' performed on 'flimsy reasons'' and his declaration that he would 'never, never destroy a healthy baby unless there are very serious reasons to do so' emphasise quite how strong his views were on this subject.[131]

VI. The Impact of Baird and Donald's Views on Abortion Service Provision

Throughout the years after the Abortion Act 1967 both Baird and Donald remained vocal on their views regarding abortion. Whilst Donald lamented the 'disheartening paradox' of improvements in fetal medicine coinciding with a 'rising tide of deliberate

[127] Nicolson, 'Ian Donald', p. 8.
[128] Ibid.
[129] Ian Donald Archive, HB110/4/20, Newspaper article in the *Sunday Mail* titled 'Pope Thrilled by Baby Film' written by Alex Scotland (published 22nd April 1979).
[130] Ibid.
[131] Gayle Davis and Roger Davidson, ''Big White Chief', 'Pontius Pilate', and the 'Plumber': The Impact of the 1967 Abortion Act on the Scottish Medical Community, c.1967-1980', *Social History of Medicine*, 18:2 (2005), p. 293.

wastage of healthy unborn life',[132] Baird had moved even further in his liberal leanings, from the belief that abortion should be freely available but its suitability for individual women decided by the medical profession, to 'come round to the view that abortion on request is the most realistic attitude to adopt in the present state of society'.[133] As has been discussed within the literature review, Davis and Davidson are two key scholars who have written about Donald and Baird. This section of the thesis will consider some of their work on how Baird and Donald impacted the availability of abortion within their regions, and will provide oral history testimony from a clinician who was interviewed for this thesis, Bill Hannay, to further examine how Donald's views influenced clinical practice in Glasgow. It is important to examine Davis and Davidson's work here, as it provides an overview of how inequalities developed throughout Scotland with regards to access to abortion services. These inequalities would greatly impact hospital services, which was a key focus for the Lane Committee, whose report will be examined in detail in the next section of this chapter. This section therefore provides an overview of how abortion service provision would develop, of which it is essential to have an understanding in order to place the responses to the Lane Committee report in Scotland in context.

Utilising Ingram's article in *The Lancet* on 'Abortion Games: An Inquiry into the Working of the Act', Davis and Davidson have discussed how the views of Donald and Baird affected access to abortion services in their regions after 1967. Ingram's article is based around the book *Games People Play* by Berne, which used a 'game model to analyse interpersonal manoeuvres or transactions which have both an apparent, manifest motive and a concealed one, which is hidden even from those involved'.[134] One category of medical professionals Ingram looked at was general practitioners (GPs), who, he believed, had many options available to them regarding abortion. One was to refer patients to a specialist who agreed with their belief system. If a GP did not agree with abortion then they could refer their patient to a consultant they knew held similar views, knowing a termination would be refused; Ingram classed this as a 'bounced

[132] Donald, 'Abortion and the Obstetrician', p. 1233.
[133] Baird, 'Induced Abortion', p. 125.
[134] I. M. Ingram, 'Abortion Games: An Inquiry into the Working of the Act', *The Lancet*, 298:7731 (1971), p. 969.

cheque'.[135] As Davis and Davidson have discussed, in Glasgow this would involve referral to Donald, who felt that the abortion requests he received were from doctors who were looking for a termination to be refused.[136] Donald himself confirmed this to be the case, in a publication in 1974 titled 'Life – Death – And Modern Medicine':

> Because of the strict line which my own unit has taken, many of our requests come from doctors who are really seeking support in their view that the request for termination of pregnancy should be refused. The number of our requests has not risen at all over the years since the Act was passed, and has remained fairly static at approximately one a week. You may attribute our attitude as you like – moral rectitude or sheer bloody-mindedness – we are nevertheless unrepentant.[137]

Ingram discussed the impact that specialist gynaecologists who were advanced in their field could have, for example by imposing on their staff a certain policy on termination. This 'Big White Chief', as classified by Ingram, would have a great deal of power, and their opinions would usually tend to spread 'from patients, staff, and hospital to whole cities and regions', which Davis and Davidson argued happened in Scotland.[138] Thus these specialists, such as Donald and Baird, would over time have become known for their stance on abortion, and it is likely that they would have hired staff with similar views to their own. Staff and hospitals would therefore have been linked with liberal or restrictive abortion policies, enabling GPs to identify the specialists whose views were closest to their own. Thus, as noted above, the number of termination requests that Donald's unit received, did not greatly increase in the years following the 1967 Act.

The hugely different belief systems of Baird and Donald clearly had a major impact on women living in the regions they were responsible for providing clinical care to. For Baird and Donald, the Abortion Act 1967 had little impact on their clinical practice, with both continuing to treat abortion in the same manner as they did before the legislation was passed. In the case of Baird, that meant offering abortions to women

[135] Ibid.
[136] Davis and Davidson, ''Big White Chief'', p. 301.
[137] Ian Donald, 'Life – Death – And Modern Medicine', in *Social Responsibility Series*, (London: Order of Christian Unity, 1974), p. 18.
[138] Davis and Davidson, ''Big White Chief'', p. 302.

who he deemed as in need of the service, whilst for Donald this meant refusing to provide abortions, except in a very limited number of cases, including where the fetus had no chance of spiritual development. Thus, each region became involved in a self-perpetuating cycle, whereby the numbers of abortion referrals and procedures were directly linked to the belief systems of the clinicians running the areas.

The cases of Baird and Donald highlight the control the medical profession had over the provision of abortion services; for them it was about their individual beliefs, but behind every abortion request was a woman who felt she could not cope with the continuation of her pregnancy. These belief systems are clearly reflected in the abortion rates for the different regions. In 1969 the abortion rate for the North-eastern Region of Scotland (comprising Aberdeenshire) was 3.9 per thousand women, compared to 1.6 per thousand women for the Western Hospital Board Region (comprising Glasgow).[139] The figure for the city of Aberdeen was 6.2 per thousand; no comparable figure exists for the city of Glasgow alone at this time, but it is reasonable to conclude that abortion rates in Aberdeen were almost four times as high as in the Western region of Scotland.[140] Hugh McLaren, an obstetrician and an opponent of permissive abortion legislation, commented on the differing rates. He remarked on how 'two cities, each offering a high standard of medical ethics and obstetrical care, may differ widely. For example, Aberdeen carries out abortion or abdominal hysterotomy in one in 50 pregnancies. In Glasgow the rate is one in 3,750, and without doubt social and economic pressures in the slum areas of Glasgow overshadow Aberdeen.'[141]

Baird argued that the social and economic pressures facing Glasgow were being exacerbated by the high birth and low abortion rates in the city. He attributed the lower abortion rate in Scotland when compared to England and Wales to the fact that '58 per cent of all births in Scotland take place in the Western Region'. He went on to single out Glasgow as the source for many of these figures:

[139] Ian MacGillivray, 'Letters – Therapeutic Abortion in Scotland', *British Medical Journal*, 3:5665 (1969), p. 298.
[140] Ibid.
[141] H.C. McLaren, 'Letters – Ethics and Abortion', *British Medical Journal*, 2:5605 (1968), p. 622. Note the discrepancy in the figures presented by McLaren, with those given by MacGillivray above.

> In Glasgow, the centre of the Western Region, the birth rate (per 1000 women aged 15-44) is 20 per cent above that of the combined rate for the other three Scottish cities and the illegitimacy rate per 1000 unmarried women is twice as high. The perinatal mortality rate in Glasgow is 20 per cent higher than the rate in other cities. These very high rates, especially the high illegitimacy rate, are important contributory factors to the notoriously high incidence of disease, delinquency and crime in Glasgow.[142]

That the birth rate was so much higher in Glasgow than in other Scottish cities led Baird to conclude that 'in four of the five Scottish regions there seems to be close agreement on the need for a liberal abortion policy amongst the leading obstetricians and gynaecologists and the family doctors with whom they work', but that the situation in Glasgow 'is due partly to the existence of a large Roman Catholic minority but basically to the anti-abortion views of several of the leading obstetricians in the region'.[143] It is not difficult to imagine that Donald, with his strongly outspoken and uncompromising views on abortions, was one of those Baird had in mind with this statement. For Baird and Donald, the situation may have involved their own moral decisions, but for the women living in these regions it resulted in a postcode lottery, where the decision to allow them to undergo a termination of pregnancy may not have been based on the merits of their case. As more hospitals restricted terminations to those who lived within their catchment areas, the impact of the 'Big White Chief' would be felt more keenly by those women attempting to access abortion services. Although areas such as Aberdeen were seen to have a more liberal abortion policy, they would only accept women who lived within their area, meaning women from Glasgow were unable to go there to have an abortion. To obtain a termination which was unavailable to them on the NHS, many women from Glasgow resorted to travelling to England to pay for an abortion privately. This was a common enough occurrence that the Glasgow to Liverpool train was nicknamed 'the Abortion Express'.[144]

[142] Baird, 'Induced Abortion', p 124.
[143] Ibid.
[144] Davis and Davidson, '"A Fifth Freedom"', p. 45.

These inequalities in access to abortion services did not exist solely between Glasgow and Aberdeen, but were also evident within the city of Glasgow itself. This is exemplified when comparing the experiences of Donald, with those of his more liberal colleague across the city, Professor Malcolm MacNaughton, who Donald was known to refer to as 'the abortionist in the East'.[145] MacNaughton had been a lecturer in Dugald Baird's department between 1957 and 1961, which is likely to have impacted his liberal views on abortion.[146] When working in Glasgow, MacNaughton was under rising pressure to perform more abortions, and as demand increased, he had to turn down the abortion requests of women who did not live within the catchment area of the hospital.[147] Even though MacNaughton was willing to assist the women that Donald would have refused to terminate, he was restricted in doing so due to time and resource constraints.

Evidence from an oral history interview carried out for this thesis has shown that these generalisations about Donald's stance were consistent with the realities of working with him. A clinician, Bill Hannay, who worked with Donald, confirmed that this divide in hospital abortion policy occurred not just in theory but also in practice in Glasgow, when recalling the case of a woman who had somehow been referred to the Queen Mother's Hospital for a termination of pregnancy, stating 'how she got to our clinic I don't know because it was well known that it wasn't done, it all went to the other side of town'.[148] He went on to describe how Rottenrow,[149] the maternity hospital located on

[145] Nicolson and Fleming, *Imaging and Imagining*, p. 239.
[146] 'Obituary: Malcolm Campbell MacNaughton', *Royal College of Obstetricians and Gynaecologists* <https://www.rcog.org.uk/en/news/membership-news/obituaries/obituary-campbell-macnaughton/> [accessed 18th May 2018].
[147] Nicolson and Fleming, *Imaging and Imagining*, p. 302.
[148] BH Interview, DS300155, p. 4. Interview with Bill Hannay, 14th April 2016. Bill Hannay qualified in medicine in 1966, and began working in gynaecology shortly after. He was working in obstetrics and gynaecology at a Scottish hospital when the Abortion Act 1967 came into effect, and moved to work at the Queen Mother's Hospital in Glasgow in the early 1970s.
[149] "The Rottenrow" was the nickname given to a maternity hospital, situated in the East End of Glasgow. The hospital began as the Glasgow Lying-In Hospital and Dispensary in 1834, and was re-named as the Glasgow Royal Maternity and Women's Hospital in 1914, which was shortened to the Glasgow Royal Maternity Hospital in 1960. The hospital gained its nickname when it moved in 1860 to Rottenrow Street in the city. In 1880/81 new buildings were constructed at the site, with various other building work to follow over the years, such as a clinical laboratory in 1926, and a new out-patient's department in 1955. Attempts were made to upgrade facilities and equipment at the site in the 1960s, but by 1966 the decision had been made that the hospital required replacement, and in 2001, Glasgow Royal Maternity moved to the Glasgow Royal Infirmary. See 'Records of Glasgow Royal Maternity

the other side of Glasgow, had MacNaughton as a staff member, and 'they had more liberal views on termination on that side of the city and GPs knew this and abortions went, termination requests went there. It's not that we didn't deal with spontaneous abortion of course we did you know, but the team on the other side they did all the terminations.'[150] As MacNaughton was working at Rottenrow, his clinical premises were physically distinct from those of Donald, as shown in Figure 5.1, giving him freedom to exercise these more liberal views.

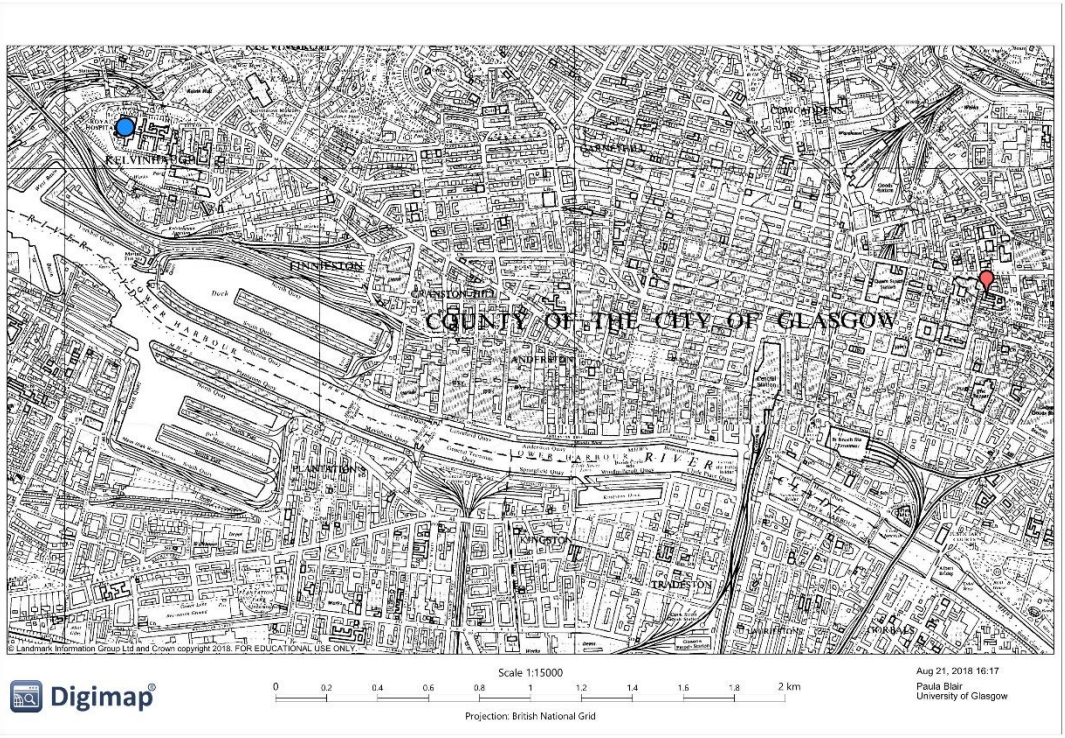

Figure 5.1 – Showing the physically distinct location of the Queen Mother's Hospital, where Ian Donald was based, and the Glasgow Royal Maternity Hospital, where Malcolm MacNaughton worked. The Queen Mother's Hospital is marked by the blue circle, and the Glasgow Royal Maternity Hospital by the red pin.[151]

Hospital, Glasgow, Scotland', *Archives Hub* <https://archiveshub.jisc.ac.uk/search/archives/c4f3c6b4-2941-3644-915c-4b980cc7e127> [accessed 25th May 2018].

[150] BH Interview, DS300155, pp. 4-5. Spontaneous abortion was the term used by the interviewee.

[151] "Glasgow - 1960s. National Grid Tile NS56NE" [JPG map], Scale 1:15000, Ordnance Survey National Grid 1:10560, 1st Imperial Edition 1948-1977 [TIFF geospatial data], Published: Year 1968, Landmark

Whilst it is possible that a particular stance towards abortion would become synonymous with a hospital, as shown in the examples of Donald and MacNaughton above, there would, of course, have been members of staff who worked with them who did not totally align themselves with their views. One such individual is the consultant quoted above, Bill Hannay. Hannay had worked under Ian Donald as a senior registrar in 1975, and managed to convince him that a woman who presented at the hospital had a worthy case for a termination. Donald eventually agreed that the termination could take place, and Hannay commented that this showed that Donald 'wasn't totally intransigent in that way'.[152] However, Hannay clearly had to convince Donald of the need for the abortion, and Donald came to watch the termination and take photographs, although Hannay never found out what these photographs were to be used for.[153] That Hannay could still recall the event more than forty years after it had taken place suggests this was a rare occurrence which stood out in his memory. This example emphasises the impact that personal relationships can have on decision making, and the importance of considering these relationships where possible.

VII. The Lane Committee Report – Responses in Scotland

The above discussion on the disparities which emerged within and between regions for abortion services highlights the volume of terminations which were being requested. This high demand for abortion services did not go unnoticed by those who had raised concerns about the possible impact of more permissive abortion legislation. Calls for an investigation into the working of the Act began almost as soon as it came into force, with medical professionals and religious groups at the forefront of the disquiet. However, since its implementation in 1968 there has only been one large scale review of the Act carried out, that of the Lane Committee, published in 1974.[154] The Lane Committee sought the views of a variety of groups and individuals regarding the

Information Group, Using: EDINA Historic Digimap Service, <http://digimap.edina.ac.uk/>, Created: August 2018.

[152] BH Interview, DS300155, p. 4.

[153] Ibid.

[154] One of the key figures involved in the lobbying for an enquiry into the Abortion Act was the M.P. Norman St. John-Stevas, who had campaigned for this for several years. See Hindell and Simms, *Abortion Law Reformed*, p. 221.

working of the Abortion Act, but crucially, their terms of reference did not entail an examination of the underlying principles of the abortion legislation. The Lane Committee were commissioned rather to investigate the working of the Abortion Act 1967 in practice, and the impacts it was having.

Much to the surprise of many people, the Committee voiced its full support for the working of the legislation, raising only a few concerns.[155] The Report of the Committee stated that they were 'unanimous in supporting the Act and its provisions' and had 'no doubt that the gains facilitated by the Act have much outweighed any disadvantages for which it has been criticised'.[156] However, they did highlight issues with the strain the new Act had put on medical staff who had little time to adapt, the inequality which existed in accessing abortion services on the NHS throughout the United Kingdom, and the 'instances of gross irresponsibility' amongst some doctors working in private practice, who were using the Act to terminate pregnancies on 'comparatively trivial grounds' in order to make money.[157] It is interesting to note that the main concerns which the Lane Committee raised do not seem to relate to termination for reasons of fetal anomaly. Perhaps this could be related to the distinct way in which abortion for these reasons was viewed, both by the wider public and by those who had played a role in moving abortion legislation through the legal system. That terminations for fetal anomaly did not seem to be a cause for concern could also be related to the small number of which were carried out each year in comparison to abortions for other reasons – the figure given for Scotland was only 1.6% for the year 1970 for fetal anomaly, compared to 89.6% on the grounds of 'Risk of injury' to the 'physical or mental health' of the woman'.[158]

In a number of publications, Davis and Davidson have considered the working of the Abortion Act in Scotland, including the specific role of Scottish clinicians and religious

[155] Ashley Wivel, 'Abortion Policy and Politics on the Lane Committee of Enquiry, 1971-1974', *Social History of Medicine*, 11:1 (1998), p. 110.
[156] The Hon. Mrs. Justice Lane, D.B.E., *Report of the Committee on the Working of the Abortion Act – Volume I Report*, (London: Her Majesty's Stationery Office, 1974), p. 184.
[157] Ibid., pp. 183-184.
[158] National Records of Scotland, HH61/1258, Document providing statistical information on pregnancy terminations in Scotland, p. 42.

groups with regards to the Lane Committee recommendations. These areas of study of concern in Scotland by Davis and Davidson will be considered here, alongside an examination of primary source material in the National Records of Scotland.

For the most part, the response to the Lane Committee Report was positive, with many key medical groups voicing their support for it. Two of the groups who gave their general support for the recommendations within the Lane Committee were the BMA and the RCOG. The BMA 'congratulated the Committee on "the publication of such an exhaustive and informative report which is yet so lucidly and pleasantly written" and go on to state that "the Council would not, in general, defer with the recommendations of the report"'.[159] The RCOG made similar comments about agreeing with the general themes of the Report, stating 'that "the majority of members of the Council welcome the recommendations of the report as a whole"', as did The Royal College of Psychiatrists.[160] It is interesting that the BMA, RCOG and Royal College of Psychiatrists all found themselves able to broadly support the conclusions of the Lane Committee Report, as when the changing abortion legislation was being debated, such parity between the BMA and RCOG with the Royal College of Psychiatrists was not in place. The Scottish Division of the Royal College of Psychiatrists 'made no substantial criticisms or comments on the report except to praise it for its comprehensiveness'. However, they did highlight that 'psychiatrists are less and less frequently involved in recommendation for termination as family doctors have now identified those gynaecologists who are willing to carry out the operation'.[161] This was certainly the case in Glasgow, where, as discussed earlier in this chapter, doctors could choose to send a woman to a liberal or restrictive professional in the city, with MacNaughton and Donald filling these respective roles. This unity within professional groups was not universal however, with specific comments from the Scottish Executive Committee of the RCOG highlighting the difference in opinion which still existed amongst its own members. Whilst accepting and having 'no comments on the statistical data in the

[159] National Records of Scotland, HH102/1232, Report titled 'The Committee on the Working of the Abortion Act (the Lane Committee)', p. 1 (introductory letter to the report written by M E G Fogden, dated 6th November 1974).
[160] Ibid.
[161] National Records of Scotland, HH102/1232, Letter from the Scottish Division of The Royal College of Psychiatrists to the Scottish Home and Health Department (letter dated 20th November 1974).

report', they also stated that 'The majority of members of Council welcome the recommendations of the Report as a whole, but a minority of members who are opposed to terminations of pregnancy on socio-economic grounds regret that the terms of reference of the Committee excluded consideration of subsections 1 to 4 of Section 1 of the Act.'[162]

Other medical groups also broadly came out in support of the Lane Committee Report and its recommendations, with the University of Edinburgh Medical School expressing 'its approval of the report and the conclusions and recommendations it had come to', and the Royal College of Physicians of Edinburgh holding the report as 'very satisfactory' and in line with their own views.[163] The views amongst two midwifery groups were also broadly supportive of the Lane Report, with the Central Midwives Board for Scotland wanting to 'convey their congratulations to the Committee on the production of an excellent Report on an obviously emotive subject', and the Scottish Board of the Royal College of Midwives approving of its main recommendations, and complimenting the Lane Committee 'for producing such a comprehensive and humane report'.[164] The Scottish Board of the Royal College of Midwives did, however, express the wish to limit the upper time restriction for abortion to 20 weeks, but perhaps in contrast with this, recommended 'that facilities for genetic study of cells, particularly for women over 40, should be extended so that any woman who desires it may have this investigation performed'.[165] Thus, while they wished to extend prenatal testing for women over the age of 40, a 20 week upper time limit could be restrictive, as women often would not find out the results of prenatal tests until around this time period. A 20 week time limit was also supported by the Scottish District Nursing Association, but in

[162] National Records of Scotland, HH102/1232, Letter from the Scottish Executive Committee of the Royal College of Obstetricians & Gynaecologists to the Scottish Home and Health Department, p. 1 (letter dated 29th July 1974).
[163] National Records of Scotland, HH102/1232, Letter from the University of Edinburgh Medical School to the Scottish Home and Health Department (letter dated 9th September 1974).
National Records of Scotland, HH102/1232, Letter from the Royal College of Physicians of Edinburgh to the Scottish Home and Health Department (letter dated 22nd August 1974).
[164] National Records of Scotland, HH102/1232, Letter from the Central Midwives Board for Scotland to the Scottish Home and Health Department (letter dated 19th July 1974).
National Records of Scotland, HH102/1232, Royal College of Midwives Scottish Board 'Comments on Report of the Committee on the Working of the Abortion Act', pp. 1-2 (dated 30th July 1974).
[165] National Records of Scotland, HH102/1232, Royal College of Midwives Scottish Board 'Comments on Report of the Committee on the Working of the Abortion Act', p. 1 (dated 30th July 1974).

contrast to the midwifery groups discussed above, they were not as complimentary of the Lane Report, describing the 'Committee's deliberations' as 'somewhat superficial'.[166] They did, however, support the recommendations in general. The Lane Committee looked at lowering the time limit at which abortions could be carried out, and recommended an upper time limit of 24 weeks gestation. It has been argued that their reasoning for choosing this limit was 'based mainly on the wish not to prejudice the use of diagnostic amniocentesis … as in some circumstances the final outcome of this procedure may not be available until about the 22nd week of gestational age'.[167] This would suggest that the Lane Committee were deliberately providing support for terminations to be available on the grounds of fetal anomaly.

Whilst there seemed to be broad support within the medical profession for the Lane Committee Report, some of the concerns which had been raised by the Committee were reflective of the criticisms of the Abortion Act in general. Within England some of the key issues were 'the role of the private sector, access by foreign women to British abortion services, and the advertising of British abortion services abroad'.[168] As Davidson and Davis highlight, these issues were not seen as being particularly important within the Scottish medical profession. However, other concerns were shared across the border, including 'the pressure on gynaecological services imposed by abortion work, the impact on staff resourcing of the conscience clause and of professional differences over the appropriateness of abortion procedures within normal maternity care, geographical variations in the interpretation of the act, and issues surrounding the statutory time limit for terminations.'[169]

As can be seen in the above quote, pressure on gynaecological services was raised as a key area of concern by medical professionals, when considering the impact of the Abortion Act 1967. It was clear that after the implementation of the new legislation,

[166] National Records of Scotland, HH102/1232, Letter from the Scottish District Nursing Association to the Scottish Home and Health Department, p. 1 (letter dated 14th August 1974).
[167] National Records of Scotland, HH60/665, Report titled 'Report of the Committee on the Working of the Abortion Act (The Lane Committee)', p. 3 (report written by RP Fraser, dated 28th December 1973).
[168] Davis and Davidson, '"A Fifth Freedom"', p. 44.
[169] Ibid.

many more women became aware that they could seek a termination of pregnancy, and numbers subsequently increased. Whilst David Steel welcomed these increasing numbers as a reflection that fewer women would be accessing back-street abortion services, Davis and Davidson have presented specific examples of medical professionals who showed their displeasure at the impact these increasing numbers of terminations had on their gynaecological services.[170] One such group was Lothian and Peebles Executive Council, who, Davis has highlighted, 'lamented, due to the limited number of consultants and because terminations required to be carried out as early as possible, many other gynaecological cases had to be deferred for unreasonable periods'.[171] This unhappiness at the impact on other services was articulated more fiercely by the Matron of Bellshill Maternity Hospital, who expressed unhappiness as the maternity hospital's 'commitments to our ordinary patients are barely met, standards of nursing care are falling, and yet we have to spread our professional skills still further to cope with this additional category of patient'.[172]

The Matron defines women seeking abortions as an 'additional category', suggesting that she views these cases as distinctively different from other gynaecological patients. This was true of many in the medical profession, and Davis and Davidson have presented evidence of nurses and midwives in particular feeling uncomfortable with being involved in abortion procedures. For instance, the Principal Nursing Officer for the Aberdeen Special Hospitals, commented that, in the opinion of many nurses, maternity hospitals were not, in general, the best place for abortions to be carried out.[173] The conscience clause was in place to ensure that those who were not comfortable being involved in terminations could opt out from doing so, but the situation was more complex than this. As Davis and Davidson have highlighted, utilising the conscience clause could cause distress for the individuals involved, particularly nursing staff. By 'having to refuse support to doctors for whom they had affection and respect, many nurses were said to be caused distress', and they were all too aware that by refusing to

[170] Davis and Davidson, ''Big White Chief'', p. 286.
[171] Gayle Davis, 'The Medical Community and Abortion Law Reform: Scotland in National Context, c1960–1980', in *Lawyers' Medicine: The Legislature, the Courts and Medical Practice, 1760–2000*, ed. by Imogen Goold and Catherine Kelly (Oxford: Hart Publishing, 2009), p. 154.
[172] Davis and Davidson, '"A Fifth Freedom"', p. 44.
[173] Ibid.

participate in abortion work, they were ‘placing the burden of the patient’s care on to one of their nursing colleagues’.[174]

In reality, what the utilisation of the conscience clause did was to lead to vast regional differences developing, or in some cases continuing, much the way they had prior to the implementation of the Abortion Act 1967. This regional variation was discussed repeatedly by the Lane Committee, who stated their unhappiness with the situation. Suggestions following the Lane Committee Report were for staff appointments to be made which would enable abortions to be carried out in all regions; this will be specifically discussed for Glasgow below. Many of those who provided evidence to the Lane Committee emphasised the impact these regional variations were having on their own medical practices, with the Board of Management for Glasgow Royal Infirmary ‘where an unusually liberal ideology prevailed’ presenting their evidence to the Lane Committee that it was the need for women to try and source an abortion by ‘‘shopping around’ that was responsible for their gynaecological waiting list having doubled in just one year’.[175]

Particularly relevant to this thesis is the response of the Faculty of Medicine at the University of Glasgow to the Lane Committee Report. Professor McGirr, the Muirhead Chair of Medicine, composed the reply to the Scottish Home and Health Department (SHHD) who were seeking responses to the Report. McGirr consulted the Regius Professor of Midwifery (Ian Donald) and the Muirhead Professor of Obstetrics and Gynaecology (Malcolm MacNaughton) for their views. As discussed above, the views of Donald and MacNaughton towards abortion varied drastically, which could perhaps have led to difficulties in forming a unified response. Indeed, McGirr himself highlights in his letter to the SHHD that it was ‘virtually impossible to present a Faculty view’ on the subject, and comments that on the subject of abortion there are wide-ranging views, which vary ‘from the view that the implied assumption of the utter disposability of life must entitle the Report to the distinction of being one of the most pagan in British

[174] Davis and Davidson, ‘‘Big White Chief’’, pp. 287-288.
[175] Ibid., p. 289.

parliamentary history to full agreement with the views expressed by the Committee'.[176] McGirr went on to discuss matters such as the importance of contraception education, and concluded that 'From the statistics given, it is evident that the services are inadequate in fact in the Western Region of Scotland.'[177] A few possible solutions to the development of more adequate provision are suggested, including enlargements of departments with the addition of more staff members, or that 'when university representatives are taking part in selection of gynaecologists to work in this area that they should be aware of this deficiency so that appropriate staff can be appointed'.[178] Appropriate staff, in this context, mean those who would be willing to carry out terminations. As has been shown within this chapter, however, those in a position of authority within the clinical sphere, such as Ian Donald, tended to surround themselves with individuals who shared their views on abortion. It is difficult to imagine this practice changing, and someone such as Donald, with his particularly stringent views on abortion, hiring a new member of staff with outspoken pro-abortion views.

A number of religious and lay organisations were also consulted for their views on the Lane Report. Whilst chapter six will focus on the views of the Catholic Church and the Church of Scotland to abortion more generally, the responses of a few religious and related groups to the Lane Committee will be outlined here, due to the relevance in this section. The Society for the Protection of Unborn Children, SPUC, who will be discussed throughout chapter six, held strong anti-abortion views, and were vocal about their desire to tighten up abortion legislation. Their response to the Lane Committee included a line-by-line critique of the Report, detailing their unhappiness. SPUC questioned what the Lane Committee's proposals were to deal with the 'abuse of the law' surrounding terminations of pregnancy in the private sector. They also maintained that the Lane Committee's comments that abortion must remain an individual decision 'can only be interpreted as a recommendation to permit, in practice, abortion on request'.[179] SPUC felt that the composition of the Lane Committee was not

[176] National Records of Scotland, HH102/1232, Letter from E.M. McGirr to Miss M.K. Macdonald of the Scottish Home and Health Department, pp. 1-2 (letter dated 30th July 1974).
[177] Ibid., p. 3.
[178] Ibid.
[179] National Records of Scotland, HH102/1232, The Society for the Protection of Unborn Children, 'The Lane Committee on the Working of the Abortion Act', p. 9 (dated June 1974).

representative of wider society, due to the Committee's comments that they unanimously supported the Abortion Act, with SPUC highlighting that the Committee members 'cannot have been representative of the views of the population as a whole, since a large majority of electors are opposed to abortion on request'.[180]

Another group who responded critically to the Report was the Society of the Innocents, a Glasgow-based organisation, set up in 1977 by a priest based in Lanarkshire. The society aimed to provide a 'caring alternative to abortion', in line with their belief that 'all human life is precious from the moments of conception and that abortion is the taking of a human life'.[181] As might be expected, they were not in favour of the findings of the Lane Report. They queried the statistical data presented, particularly relating to illegal abortions, and opposed the Lane Committee's advocacy of contraception, which the Society believed did not decrease abortion numbers.[182] In addition to the Report itself, the Society of the Innocents were strongly critical of the composition of the Lane Committee, stating that 'Surely it is not the norm to have Government Committees so badly balanced in opinion'.[183] This view was also held by the Catholic Child Care Office, who also commented that 'The fact that there were no anti-abortionist members meant that no balanced or worthwhile report would be forthcoming since there was no possibility of a minority viewpoint which might have contributed to a fuller understanding of the problem.'[184]

Groups associated with the Catholic faith were not, however, the only religious organisations putting forward criticism of the Lane Committee findings. The Free Church of Scotland were unhappy with the numbers of abortions taking place, and

[180] National Records of Scotland, HH102/1232, The Society for the Protection of Unborn Children comments on the Lane Report, p. 1 (undated, but document states 'Not for publication before Monday, January 27th, 1975').
[181] 'Innocents Society – How We Can Help', *Innocents Society* <http://www.innocentssociety.org.uk/service.html> [accessed 22nd September 2019].
[182] National Records of Scotland, HH102/1232, Society of the Innocents, 'The Lane Report', pp. 1-2, (letter accompanying the report dated 28th July 1974).
[183] Ibid. p. 1.
[184] National Records of Scotland, HH102/1232, Catholic Child Care Office, 'The Lane Committee Report Regarding the Conclusions', p.1 (letter accompanying the report dated 18th July 1974).

especially those which were occurring for social reasons.[185] This is a key point to consider; the Lane Committee was not looking at the terms of the Act, but this did not stop several commentators explicitly mentioning the category of terminations for social reasons. Davis and Davidson have highlighted that particularly strong resistance to abortions for social reasons came from obstetricians, nurses and midwives, with the Scottish Council of the Royal College of Midwives stating in their submission to the Lane Committee that abortion seemed to be 'to many nurses 'the antithesis of Midwifery''.[186]

The Church of Scotland were a key group who also provided comments on the Report. They led the opening of their own submission to the Scottish Home and Health Department with the words 'The findings of the Lane Committee must cause concern', and emphasised that 'the principles on which the Committee base their judgment are not necessarily those on which the Act is based'.[187] One of the key areas which the Church of Scotland disagreed with the Lane Committee on was their perception that the Lane Committee based its findings 'on the Principle of the "Quality of Life", usually that of the mother … a whole report written with this as the criterion is bound to reach very different findings on particular aspects of the working of the Act from those which the Church proposed'.[188] The Church of Scotland raised points in their report about the need for all women to receive counselling prior to an abortion taking place, and voiced their support for an upper time limit for abortion of 20 weeks. They expressed particular anxiety around the Committee's findings that abortion services would need to be expanded, and found the discussion by the Committee around staff appointments 'disturbing', as they believed it could undermine the conscience clause within the Act, if it was made an essential requirement that prospective recruits to obstetric departments would have to be willing to carry out terminations.[189] As can be seen in the discussion

[185] Roger Davidson and Gayle Davis, *The Sexual State*, (Edinburgh: Edinburgh University Press, 2012), p. 115.
[186] Ibid., p. 292.
[187] National Records of Scotland, HH102/1232, The Church of Scotland Moral Welfare Committee, 'The Working of the Abortion Act', p. 1 (dated November 1974).
[188] Ibid.
[189] Ibid., p. 3.

from the University of Glasgow above, such a policy was considered necessary to ensure adequate provision of services in any region.

From the evidence presented, it seems that there was not unanimous support for the findings of the Lane Committee, with several medical groups generally accepting the contents of the Report, whilst many religious organisations felt strongly that it was not representative of the general public's views on abortion. Despite raising these concerns, there have been no further in-depth analyses of how the Act is working since the publication of the Lane Committee's findings. There has been one major change to the legislation since its inception, which is the lowering of the legal time limit for abortion from 28 to 24 weeks. However, there are exceptions to this time limit when the immediate life of the mother is at risk, or if the baby is likely to be born with severe disabilities.[190] There continue to be a number of different pro- and anti-abortion perspectives, with people on both sides of the debate continuing to campaign for changes to the legislation. Whilst some individuals believe that the legislation is too restrictive, removing the choice of terminating a pregnancy away from women and into the hands of the medical profession, others feel that it is too lenient, allowing women access to abortion services when the rights of the fetus should be protected.

VIII. Conclusion

With the implementation of the Abortion Act 1967, terminations can be carried out under defined circumstances, enabling many women to access medically safe abortions. This legislation greatly influenced the field of prenatal testing, making it possible for women to terminate pregnancies suspected to be affected by fetal anomaly, if they chose to do so. However, the development and implementation of the Abortion Act 1967 was a source of great debate for society in general, and the medical profession in particular. This chapter has highlighted some of the campaigning which occurred by groups such as the ALRA to push for more permissive legislation, and has emphasised the importance of fetal anomaly for their cause. Many of those involved in the fight to

[190] 'Human Fertilisation and Embryology Act 1990', *legislation.gov.uk* <http://www.legislation.gov.uk/ukpga/1990/37/section/37> [accessed 21st April 2016] (para. 1, section 1A).

have abortion legislation implemented described how their views on fetal anomaly influenced their stance on abortion more generally, and surveys showed that many members of the public were in favour of termination for fetal anomaly, even if they disagreed with abortion for other reasons. It can also be seen that the fetal anomaly clause was generally accepted by those who were debating abortion legislation more broadly, with few challenges to alter or remove the clause from Steel's Bill. Indeed, even amongst those who were fighting against more permissive abortion legislation, there were some who agreed with the fetal anomaly clause.

Whilst the ALRA and other campaigners were working to have more liberal abortion legislation passed, one of the key groups involved in discussions on the subject were the professional medical bodies. As was highlighted in this chapter, it can be seen that each of these were responding in a way that would ensure their professional autonomy would be maintained. Whilst the RMPA were in favour of more progressive legislation, the RCOG and BMA were arguing strongly against some of the clauses in Steel's Bill, and they were keen for abortion to remain under the control of the medical sphere. As was seen in the discussions of Dugald Baird and Ian Donald, this control could have a major impact on the women living in the regions served by individual consultants, with the ease and difficulty of accessing abortion services greatly influenced by where the women lived, and which medical professional the women were referred to for an appointment. The case of Donald and Baird highlights how a number of factors such as moral, ethical and religious beliefs can all impact decision making surrounding termination of pregnancy. Personal relationships also play a key role, as highlighted in the interactions of Ferguson-Smith and Donald, who were able to work together and maintain respect for each other, despite holding different views on a number of areas surrounding termination of pregnancy. Archival and oral history testimony presented within this chapter has also shown that Donald was not inflexible on his views towards abortion, being willing to carry out terminations in limited circumstances, including in certain cases of fetal anomaly.

These inequalities in abortion provision, and the impact the legislation had on hospital services, were two of the key themes which emerged in the Report produced by the

Lane Committee which examined the working of the Act. Within this chapter the response of various medical and religious groups to the Lane Report is considered, which emphasises the differences in opinion which existed several years after the legislation was in place. It was noted within this section, that terminations for fetal anomaly were not an area of key concern for the Lane Committee. It is thought that they supported abortions in these cases, due to recommending an upper time limit of 24 weeks gestation for terminations. This time scale would enable women to undergo prenatal testing followed by an abortion if requested.

It was not only those within the medical profession who worked to gain control over abortion legislation, and some of the key figures involved in discussions on the subject were from religious organisations. The work presented in this chapter provides an overview of much of the changing landscape on abortion legislation, against which the responses of religious groups to these changes can be set. The next chapter will therefore consider the views of two of the main religious groups in Scotland – the Roman Catholic Church and the Church of Scotland – to abortion legislation, including their attempts to influence legislation prior to and after the implementation of the Abortion Act 1967.

Chapter Six – The Views of Religious Organisations on Abortion, Focusing on the Roman Catholic Church and the Church of Scotland

I. Introduction

The previous chapter considered the development of legislation which became the Abortion Act 1967, and emphasised the importance that the belief systems of local clinicians could have on availability of abortion services. However, there were other groups with strong feelings on the subject of abortion, with religious organisations particularly keen to voice their opinions. The main perspectives which will be considered in this chapter are those of the Roman Catholic Church and the Church of Scotland, who held different views on abortion. Two of the key sources which were used to gather information have been the *Scottish Catholic Observer* (*SCO*), a Scottish Catholic weekly newspaper, and *Life and Work*, a monthly Church of Scotland magazine publication.[1] However, the lack of direct discussion on prenatal diagnosis in either publication is noteworthy. Whilst letters and articles on abortion fill pages of both the *SCO* and *Life and Work*, there are few direct references to prenatal testing. The only real exception to this is a flurry of articles and letters in the *SCO* in 1981, which is probably linked specifically to this year, having been designated the International Year of the Disabled by the United Nations. The lack of discussion is unexpected, as the only available 'treatment' for a diagnosis made by prenatal testing during the time period of this research was a termination of pregnancy, which would be presumed to conflict with certain religious teachings on both abortion and disability.[2]

The time period of this study was one characterised by many social changes, including the passing and implementation of the Abortion Act 1967. As discussed in the previous chapter, this drastically changed the accessibility of abortions, and resulted in many women seeking to terminate their pregnancies legally under the clauses of the Act. For

[1] *The British Weekly*, a Protestant weekly newspaper was also consulted. However, it focused more on developments occurring in England, and in time was incorporated into the Church of England newspaper. *The Tablet*, a national Catholic newspaper, was also consulted, but as this thesis is examining the Scottish religious perspective, the decision was made to concentrate on the material gathered from the *Scottish Catholic Observer (SCO)* and *Life and Work*, from the years 1966 to 1987.
[2] The idea of abortion as a 'treatment' for a condition is a very subjective one.

both the Church of Scotland and the Roman Catholic Church, the Abortion Act 1967 resulted in a number of moral and theological questions which had to be dealt with over the years which followed. Within the Roman Catholic Church abortion was a highly emotive subject which was frequently discussed. Termination of pregnancy was strictly prohibited, and this viewpoint has remained until the present day. Within the Church of Scotland, abortion was a more nuanced matter, with Kirk discussions on the subject changing a great deal between the mid-1960s and late-1980s. At certain times abortion was seen as acceptable to the Kirk in a limited set of circumstances, whilst at other points it was condemned unequivocally, except to save the life of the pregnant woman. Thus, a complex situation was emerging for both the Church of Scotland and the Roman Catholic Church, where many members of society were in favour of legalised abortion, but religious organisations were grappling with their own views on the subject, which often did not align with those of wider society.

The *SCO* and *Life and Work* will be used as sources to gain an insight into how strongly each organisation fought in favour of or against abortion legislation, with fetal anomaly specifically mentioned when relevant. This chapter will begin by providing a broad overview of the perspective of the Roman Catholic Church to abortion, and will also examine the Church of England and Church of Scotland perspectives. It will argue that the Church of England's publication, *Abortion An Ethical Discussion*, was of central importance in influencing the Church of Scotland's perspective on the subject, and also played a key role in the development of attitudes to abortion more broadly.[3] The roles that the Catholic Church and Church of Scotland played in trying to influence legislative change will be considered, with the strategies and discussions taking place within both organisations analysed in detail. The formation of the Society for the Protection of Unborn Children (SPUC) and its impact on Steel's Bill will also be examined.

The Church of Scotland response to the abortion legislation will be considered, alongside the discussions which continued to take place for two decades after Steel's

[3] Church Assembly Board for Social Responsibility, *Abortion An Ethical Discussion*, 3rd Edition, (London: Church Information Office, 1973)

Bill was passed, both at the General Assembly and in *Life and Work*. With regards to the Catholic Church, the various ways in which their opposition was voiced will be discussed. Finally, this chapter will investigate if there was a link between religion and prenatal decision making, by examining publications which look at prenatal testing choices and the link with religious identity and observation. It will argue that the process of decision making surrounding prenatal testing is a complex one, which takes into account more than just religious beliefs. The experiences of individuals working in Glasgow will also be considered in this section, including clinicians and a midwife, with their oral testimonies further highlighting the complex nature of the interaction between prenatal testing and religion.

II. Broad Overview of Religious Perspectives

Within most of Christianity abortion has been viewed as a grave moral sin, even when society permitted termination of pregnancies.[4] Christian teaching argued that it was wrong to take an innocent life, and the current Catholic and Protestant perspectives on abortion reflect this belief. Catholic teaching emphasised that each child was a gift from God – thus to terminate a pregnancy was to 'destroy' such a gift, and to 'reject the honour and dignity of motherhood'.[5] The Catholic Church taught that direct abortion under any circumstances was morally wrong. There were no exceptions to this rule – a pregnancy should not be terminated if it occurred as a result of rape, or if an abortion was to save the life of the pregnant woman.[6] The only circumstances under which a termination of pregnancy would be carried out would be if the death of the fetus was an 'indirect' consequence of a medical intervention intended to prevent the death of the pregnant woman. There are very few examples given in Catholic Church teaching of relevant medical situations which would fit this category, but one such case would be if the pregnant woman was found to have cancer of the womb and a hysterectomy was

[4] Reginald F. R. Gardner, *Abortion: The Personal Dilemma; A Christian Gynaecologist Examines the Medical, Social and Spiritual Issues*, (Exeter: Paternoster Press, 1972), p. 98 and Gilbert Meilaender, *Bioethics A Primer for Christians*, 3rd edition, (Cambridge: William B. Eerdmans Publishing Company, 2013), pp. 26-27.
[5] Catholic Bishops' Joint Committee on Bioethical Issus, *Antenatal Tests: What You Should Know*, (London: Catholic Truth Society, 1989), p. 4.
[6] Catholic Archbishops of Great Britain, 'Abortion and the Right to Life', *The Tablet*, 234 (1980), p. 93.

urgently required. Catholicism would have permitted the hysterectomy to take place, the loss of the fetus being considered a foreseen but unintended consequence of this act.[7]

The situation in the Protestant churches was slightly different, as there was no one doctrinal position on the subject. As discussed by Callum Brown, the views on abortion of both the Church of England and the Church of Scotland changed a great deal in the 1960s. He outlines how in 1964 'none of the main churches had a policy in place of positive support for terminations and most had standing policies of opposition'.[8] Despite this, several Anglican clergy wrote to the Abortion Law Reform Association (ALRA) throughout 1964 and 1967 asking for information on abortion, many of whom were supportive of abortion reform. [9] The ALRA were also approached by the Church of England in 1965 to provide them with information on abortion, for a report which was being written by the Church of England Assembly Board for Social Responsibility. The ALRA provided written material, and arranged for representatives to discuss the subject with the Board.[10] The report was published in 1965, under the title *Abortion An Ethical Discussion*, and was broadly in favour of abortion reform, under limited circumstances. The Church of Scotland produced a similar document in 1966, which Brown considers was 'strongly influenced by that of the Anglican Church'.[11]

In *Abortion An Ethical Discussion*, the Church of England Assembly Board for Social Responsibility concluded that the fetus should be viewed as having a 'significance which must not be overlooked, minimized or denied' as it was 'potentially a human life'. However, they stated that under limited circumstances abortions could be acceptable.[12] The Church of Scotland expressed similar sentiments, such as 'that the inviolability of the fetus is one of the fundamentals and its right to life must be strongly safeguarded'. However, they also recognised that 'this general right is, in certain

[7] Helen Watt, 'A Catholic Perspective', in 'Religious Perspectives on Abortion and a Secular Response', ed. by Moira Stephens, Christopher Jordens, Ian Kerridge and Rachel Ankeny, *Journal of Religion and Health*, 49:4 (2010), pp. 515-516.
[8] Callum G Brown, *The Battle for Christian Britain: Sex, Secularism and Morality 1945-1980*, forthcoming Cambridge University Press, Chapter 9, p. 10.
[9] Ibid., Chapter 9, pp. 10-11.
[10] Ibid., Chapter 9, pp. 11-12.
[11] Ibid., Chapter 9, p. 12.
[12] Church Assembly Board for Social Responsibility, *Abortion An Ethical Discussion*, p. 61.

circumstances, in conflict with other rights', including those of the pregnant woman.[13] As a result of this conflict of interests the view has been formed over time by the Church of England and the Church of Scotland that whilst abortion is morally wrong, there are limited circumstances under which the termination of pregnancy is acceptable, to preserve the life, health, or well-being of the pregnant woman.[14] These views have led to the two churches being seen by some as readier than the Catholic Church 'to support abortion when the pregnancy has resulted from a clear act of injustice (*eg* rape, criminal assault, incest), when it gravely threatens the physical or mental health of the mother, or when the fetus is seriously abnormal'.[15] Brown argues that through their publications 'these key Protestant churches provided important general support' to the Abortion Act.[16] Both of these churches had no policy in favour of abortion in 1964, but only a few years later gave qualified support for reform. However, it would be wrong to assume that all members of the Church of Scotland were in favour of these changing views towards abortion. Indeed, as Brown has emphasised, 'because their churches were so divided on the issue, neither their members nor their churches as a whole were voluble campaigners for the Bill'.[17] This illustrates the more complex situation of varying opinions within the Church of England and the Church of Scotland, as a result of there being no consensus as to an appropriate doctrinal position.

III. Church of Scotland Response to Proposed Legislative Changes

The positions of the Church of Scotland and the Roman Catholic Church to abortion prior to the 1967 Act will now be discussed in detail. As highlighted above, the Church of Scotland published a key document in 1966 which gave an insight into their views on abortion. This was published after their 1966 General Assembly, and strongly supported the views put forward in *Abortion An Ethical Discussion*.[18] Although *Abortion An Ethical Discussion* had, as its authors emphasised, 'no authority beyond that of the

[13] Gardner, *Abortion: The Personal Dilemma*, p. 100.
[14] Church Assembly Board for Social Responsibility, *Abortion An Ethical Discussion*, p. 34 and p.61.
[15] Ian C.M. Fairweather, 'Abortion: Christian Traditions Not Unanimous', in *Abortion in Debate*, ed. by Church of Scotland's Board of Social Responsibility, (Edinburgh: Quorum Press, 1987), p. 82.
[16] Brown, *The Battle for Christian Britain*, Chapter 9, p. 12.
[17] Ibid.
[18] Church of Scotland General Assembly 1966, Social and Moral Welfare Board, 'Supplementary Report of the Social and Moral Welfare Board', May 1966, p. 476.

group which has created it',[19] it was designed to encourage Christians to think about abortion on a deeper level. This was the main text containing an Anglican view on the subject of abortion, and the information contained within it is frequently cited. Indeed David Steel, in his foreword for Hindell and Simms book *Abortion Law Reformed*, cited the publication as 'the best summary of the ethics of abortion yet published'.[20] As the Church of Scotland was heavily influenced by the report, it is important to consider the views presented within it in more detail.

For the Assembly Board for Social Responsibility of the Church of England who compiled the report, the crux of the abortion matter was summarised as 'the problem of weighing the claims of the mother against the claims of the foetus and *vice versa*, when they conflict'.[21] The Board came to the conclusion that:

> After surveying the matter afresh in the light both of traditional discussions and of present proposals, our broad conclusion is that in certain circumstances abortion can be justified. This would be when, at the request of the mother and after the kind of consultation which we have envisaged in this report, it could be reasonably established that there was a threat to the mother's life or well-being, and hence inescapably to her health, if she were obliged to carry the child to term and give it birth.[22]

With regards more specifically to fetal anomaly, they highlighted the anxieties which might be experienced by a pregnant woman when a diagnosis of fetal anomaly is made, including that the woman may be so worried about giving birth to a 'defective child' that her health may suffer, and/or that she and her partner may be so affected by raising such a child that it might impact adversely upon their current children if they have any, or stop them having any more in the future.[23] They also considered whether it is right to allow a baby who has a very high chance of having a 'deformity' to be born.

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[19] Church Assembly Board for Social Responsibility, *Abortion An Ethical Discussion*, Foreword.
[20] David Steel, 'Foreword' in *Abortion Law Reformed* by Keith Hindell and Madeleine Simms, (London: Peter Owen Ltd., 1971).
[21] Church Assembly Board for Social Responsibility, *Abortion An Ethical Discussion*, p. 61.
[22] Ibid.
[23] Ibid., p. 8.

The Assembly Board came to the conclusion that in certain instances there could be justification for a woman to have an abortion as a result of fetal anomaly. In this case the group concluded that these circumstances include an 'assessable risk of a defective or deformed child'.[24] Although this view is more liberal than the Catholic standpoint, the Board were adamant that abortion should not be available on demand, and that the decision to terminate a pregnancy could only be made when there was a real threat to the woman's health or well-being. The decision would have to be the result of a consultation with a licensed medical practitioner who viewed this as essential, and could not be made solely by the woman herself. Termination of pregnancy would not be permitted on the basis of fetal anomaly alone, and the decision would have to be based firmly on the prognosis of the pregnant woman and her specific circumstances.[25]

The Church of Scotland was involved in monitoring and participating in abortion discussions throughout the course of 1966 and 1967, and engaged with David Steel about the clauses within his Bill. In September 1966 an article was published in *Life and Work* in which the author, having met Steel, described his decision to proceed with the Medical Termination of Pregnancy Bill as a 'courageous choice'.[26] However, by January 1967 concerns were being raised by the Rev. L. David Levison that Steel's Bill was going 'much further' than their report had, and that within the Bill there were clauses that the Church could not validate.[27] Levison expressed the Church's 'sincere hope that when Mr Steel's Bill reappears from Committee that it will have been considerably amended, as he himself anticipates, and will in the end approach the Church's own considered view, which it certainly does not at the moment'.[28] It seems that in many ways this hope was met, as after the 1967 General Assembly the Social and Moral Welfare Board published further thoughts on the Bill, including that Steel 'had made much reference to our report and used a theological reference from it for the

[24] Ibid., pp. 61-62.
[25] Ibid., p. 62.
[26] Betty Sinclair, 'Profile of a Liberal David Steel M.P.', *Life and Work*, September 1966, pp. 34-35.
[27] L. David Levison, 'Termination of Pregnancy Bill', *Life and Work*, January 1967, p. 17.
The Reverend L David Levison was born in Edinburgh in 1917, and in 1967 was working in the central parish in Glenrothes. He would go on to become convener of the Ethical and Moral Welfare Committee of the General Assembly in 1970. See 'Obituary: Reverend L David Levison, 95', *The Scotsman* <https://www.scotsman.com/news/obituaries/obituary-rev-l-david-levison-minister-1-2255530> [accessed 14th May 2018].
[28] Ibid.

lines of his speech in presenting the Bill'.[29] The Working Group convened by the Church of Scotland on the matter of abortion was pleased to see that amongst the proposed amendments to Steel's Bill were 'proposals to drop clause (c) the controversial "social clause" and clause (d) the clause specifying several categories such as the deficiency of the mother, cases of rape and of the mother being under the age of sixteen, the categories that the Assembly had already found unacceptable'.[30] The Working Group felt that the Church should be 'grateful' that the proposed amendments brought the Bill more in line with their own report, and that people should 'pray that this will be the final outcome'.[31] The Church of Scotland played an active role in trying to ensure the legislation agreed with the views they held, by meeting with Steel to discuss the subject, and by publishing various documents on the matter. Overall, the Church of Scotland was in favour of abortion reform, but only to allow abortions to take place under rare circumstances, with the worth of the fetus still being carefully considered.

IV. The Catholic Fight Against Steel's Bill, and the Formation of the Society for the Protection of Unborn Children

By way of contrast, in the decades prior to the implementation of the Abortion Act 1967, the Catholic Church was already speaking out against abortion. In the encyclical *Casti Connubii*, issued in 1930 by Pope Pius XI, the 'grave sin' of abortion was discussed, in which it was stated that 'however much we may pity the mother whose health and even life is gravely imperilled in the performance of the duty allotted to her by nature, nevertheless what could ever be a sufficient reason for excusing in any way the direct murder of the innocent? This is precisely what we are dealing with here.'[32] More specifically on the subject of fetal anomaly, Pope Pius XII in a similar manner stated in 1951 that 'there is no man, no human authority, no science, no medical,

[29] Church of Scotland General Assembly 1967, Social and Moral Welfare Board, 'Medical Termination of Pregnancy Bill', May 1967, p. 510.
[30] Ibid., p. 511.
[31] Ibid.
[32] Agneta Sutton, *Prenatal Diagnosis: Confronting the Ethical Issues*, (London: Linacre Centre for the Study of the Ethics of Health Care, 1990), pp. 95-96.

eugenic, social, economic or moral "indication" which can establish or grant a valid juridical ground for a direct deliberate disposition of an innocent human life'.[33]

However, when it came to campaigning against Steel's Bill, the impression gathered from studying the *Scottish Catholic Observer* is that the Catholic Church were unexpectedly quiet on the subject, with only twenty-three articles/letters on the subject printed for 1966 and 1967, several of which criticised the lack of response to the Bill. In 1966 one of the first articles to address the issue of abortion was by Cardinal Heenan, who commented that 'Until recently the accepted view of Christians and, so far as I know, of all believers, has been that direct killing of the child-to-be is immoral. It is only because of what is called the liberalising of the law against abortion that the Catholic attitude has begun to appear eccentric'.[34]

Another article in the *Observer* condemned abortion unequivocally as 'plain murder'.[35] Nevertheless, when the House of Commons voted on the first reading of the Bill, only 14 of 32 Catholic M.P.s turned up, and it passed by, what Norman St. John-Stevas described as, a 'grotesquely large majority of 194 votes'.[36] One of the most outspoken voices in the fight against the Bill, St. John-Stevas condemned the absence of Catholic M.P.s from the vote as 'shockingly bad'. He was concerned that the longer-term effects of this lack of support would be 'all the more serious as the very small vote against the Bill will make it much more difficult to amend at the committee stage and get some of its worst features removed'.[37]

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[33] John T. Noonan Jr., 'Abortion and the Catholic Church: A Summary History', *Natural Law Forum*, 12 (1967), p. 120.
[34] Cardinal Heenan, 'Abortion – A Catholic view of a topical issue', *Scottish Catholic Observer*, 11th February 1966, p. 4. Cardinal Heenan was born in 1905, and progressed from being a parish priest in 1932, to Bishop of Leeds in 1951, Archbishop of Liverpool in 1957, Archbishop of Westminster in 1963, and Cardinal in 1965. He was an outspoken opponent against abortion, amongst other moral issues. See 'Cardinal John Carmel Heenan', *Diocese of Westminster* <http://www.rcdow.org.uk/cardinal/default.asp?library_ref=1&content_ref=14> [accessed 14th May 2018].
[35] Ask for an Answer, Father Frank's Column, 'Plain Murder – This sums up our view on abortion', *Scottish Catholic Observer*, 4th March 1966, p. 8.
[36] Norman St. John-Stevas, 'What happened to all the Catholic M.P's?', *Scottish Catholic Observer*, 5th August 1966, p. 2.
[37] Ibid.

These figures suggest that the Catholic Church was not as prominent as would have been expected in the fight which was mounting against Steel's Bill. In general it seems that the Catholic Church was caught off guard. As Francome has argued, the Catholic Church 'was not ready for this particular battle', and he has spoken of how Lord Craigmyle, the leader of the Catholic Union, said that the vote 'was a shock to us' and talked of the 'appalling weight of the abortion lobby'.[38] In the years after the Abortion Act had come into force, many Catholics echoed such sentiments. Kathleen Morton, the president of the pro-life group Cell, commented that there was 'no doubt we were caught napping in 1967 with the Abortion Act',[39] whilst another reader of the *Scottish Catholic Observer* stated 'Virtually nothing was said or done when the Abortion Bill was being debated and when it finally became law we held up our hands in horror and wondered why this "licence to kill" ever reached the Statute Book, as if it had crept up on us un-noticed.'[40]

Indeed it seemed that if anyone was leading the fight against Steel's Bill it was the lay people of the Catholic Church, a move which was viewed with 'satisfaction and approval' by some members of the clergy.[41] Lay involvement in Scotland included the printing of twenty thousand copies of a pamphlet against abortion, designed by the Catholic Young Men's Society and the Knights of Saint Columba. Within this pamphlet strong religious language was used to stir up the fight against Steel's Bill, with the pamphlet claiming that 'If the Abortion Bill goes through Herod will laugh in Hell. There will be perpetrated in one name a Massacre of the Innocents more dreadful in its scope than any Herod could have imagined.'[42] Use of phrases such as 'massacre' and 'innocents', and the direct mention of Hell, makes it clear that there was a strong revulsion felt about the Abortion Bill. Nevertheless, the advice it gave was somewhat

[38] Colin Francome, *Abortion Freedom: A Worldwide Movement*, (London: George Allen & Unwin, 1984), p. 91.
[39] Author Unknown, 'Hectic Time for A Pro-Life Cell', *Scottish Catholic Observer*, 16th November 1984, p. 10.
[40] Joseph McKenna, 'Postbag – Silent Onlookers', *Scottish Catholic Observer*, 16th June 1972, p. 12.
[41] Author Unknown, 'Now the doctors have THEIR say on the 'Baby Bill'', *Scottish Catholic Observer*, 25th November 1966, p. 3.
[42] Author Unknown, 'That Bill – the big campaign grows', *Scottish Catholic Observer*, 4th November 1966, p. 3.

mild, with readers urged to write to their M.P. to let them know their views, and to sign petitions.[43]

Petitions and rallies formed a central part of the Catholic fight against Steel's Bill, with a petition of 4000 signatures handed to Tom Fraser, the M.P. for Hamilton in Scotland. After a long discussion with a 'deputation' led by a local priest, Fraser assured the group that 'if the Bill were returned to Parliament unchanged he would have no hesitation in voting against it'.[44] A meeting in Greenock town hall in the West of Scotland attracted 'more than 1200 Catholics and non-Catholics' who came to listen to the views of three doctors about abortion. One of those speaking, Dr O'Reilly, a senior obstetrician at St Francis Maternity Home in Glasgow, stated his belief that 'there was no such thing as a therapeutic abortion' and that 'no woman's health has ever been improved by a direct attack on her unborn child'.[45] Such a statement is clearly in direct opposition to the beliefs of those campaigning for abortion reform, who felt very strongly that a woman's life could benefit from a termination of pregnancy under certain circumstances.

Whilst petitions and rallies were happening towards the end of 1966, no formal group against abortion was formed until the Society for the Protection of Unborn Children (SPUC) was launched at a 'well-publicised press conference at the House of Commons' in January 1967.[46] Given that the Abortion Act received the Royal Assent in October 1967, it is clear that the formation of SPUC happened very late in the abortion campaign. Members of the committee included Hugh McLaren, Professor of Obstetrics and Gynaecology at the University of Birmingham. McLaren said he was 'shocked into action … when the Bill was given the go ahead by an overwhelming vote in Parliament'.[47] As previously highlighted, other committee members included Ian

[43] Ibid.
[44] Author Unknown, 'M.P.'s Promise on "Baby" Bill', *Scottish Catholic Observer*, 11th November 1966, p. 1.
[45] Author Unknown, 'Now the doctors have THEIR say on the 'Baby Bill'', *Scottish Catholic Observer*, 25th November 1966, p. 1.
[46] Mary Pipes, *Understanding Abortion*, (London: The Women's Press Ltd., 1986), p. 152.
[47] Author Unknown, 'Scots Presbyterian speaks out for unborn child', *Scottish Catholic Observer*, 3nd February 1967, p. 2.

Donald. Interestingly, although this group was non-denominational, Catholic members had been specifically excluded from joining the council of the organisation. According to Hindell and Simms, this exclusion 'was repeatedly stressed at every press conference and public meeting, although as an Irish paper remarked, this was "more a tactical move than anything else", to prevent SPUC being identified as merely a vehicle of the Catholic Church. There was, however, no bar against Catholics joining the rank and file of the organization'.[48] Francome argues that pressure coming from the Catholic Church was easier to dismiss than pressure from other sources. He considers that the Catholic Church 'was not particularly astute in putting forward its views' and that, due to their opposition to contraception, they lacked 'credibility'.[49] While contraception was gaining more acceptability with the general public, the official Catholic Church statements were unflinching in their condemnation of any artificial methods of preventing pregnancy, leaving many churchgoers feeling isolated from the official Catholic Church standpoint.[50] Brown has argued that due to their views on contraception and abortion, the Catholic Church was 'at odds with British government policy and the general acquiescence in that policy that had evolved during the sixties amongst the main Protestant churches in Britain', leading to 'the isolation of the Catholic Church from an increasingly-liberal swerve of mainstream Christianity in Britain'.[51] Thus, the Catholic view on abortion could also be seen as inapplicable to the real lived experience of many individuals requesting abortions, and easier to dismiss as a lack of compassionate understanding by those in favour of reforming the abortion laws.

Despite the lack of Catholic members on the official committee, Lovenduski has commented that SPUC was 'unable, despite a large membership, to overcome its image

[48] Hindell and Simms, *Abortion Law Reformed*, p. 95.
[49] Francome, *Abortion Freedom*, pp. 91-93.
[50] Pope Pius XII in 1951 berated 'so-called "birth control"' for not being 'compatible with the law of God' and stated that any 'deliberate intention and positive action taken by any means to deprive sexual union of its procreative potentiality' was a sin, and therefore should be condemned. See Roger Davidson and Gayle Davis, *The Sexual State*, (Edinburgh: Edinburgh University Press, 2012), p. 134.
With the development of the contraceptive pill in 1961, it was hoped that this would be seen as an acceptable form of birth control to the Catholic Church. However, Pope Paul VI published his *Humanae Vitae* encyclical in 1968 which directly addressed the contraceptive pill, and concluded that 'Whoever deliberately renders coitus sterile attacks its meaning as an expression of mutual self-giving', and made clear the prohibition of chemical and physical barriers to conception. This decision was a surprise to many Catholics, who had expected use of the contraceptive pill to be sanctioned. See Lara V. Marks, *Sexual Chemistry: A History of the Contraceptive Pill*, (London: Yale University Press, 2001), p. 222.
[51] Brown, *The Battle for Christian Britain*, Chapter 10, p. 13.

of a narrowly-based, Catholic-inspired group and proved ill-equipped to prevent passage of the Act'.[52] The reason it could not shake this perception was that many of its most outspoken members were Catholic. One of SPUC's first acts was to petition the Prime Minister to set up a Royal Commission to investigate all the facts relating to abortion before any legislative changes were made. The two members of SPUC responsible for establishing the petition were both Catholic M.P.s – Norman St. John-Stevas and James Dunn.[53] They had hoped to gain one million signatures on the petition, but in the end gathered 530,000. Hindell and Simms have commented that 'With no Church structure to call on, it is doubtful whether the reformers could have collected so many in the same time', highlighting both the impression that SPUC was seen as a largely Christian organisation, and the potential it had to become a formidable opponent of abortion law reform.[54] Despite the large number of signatures on the petition, what was notable were the signatures which were missing, namely a great many Anglican vicars. The petition was distributed to 10,000 of them, but it seemed that 'most were not sympathetic', and when the British Council of Churches met in April 1967 they concluded that regarding abortion, 'Christian compassion in the face of human suffering did require a measure of reform.'[55] Thus while SPUC might have kept Catholic members off their committee, they could not prevent Catholic attitudes to abortion becoming the prevailing source of their fight.

Although they managed to secure over half a million signatures on their petition, Hugh McLaren, speaking in February 1967, emphasised that the protest should have come earlier.[56] Paula Davies, writing in the *Scottish Catholic Observer*, also in February, described SPUC as 'hastily formed' and was not optimistic about their chances of defeating the Bill.[57] However, the campaign against abortion continued to be waged, with Norman St. John-Stevas publishing an article in the *Scottish Catholic Observer* on

[52] Joni Lovenduski, 'Parliament, Pressure Groups, Networks and the Women's Movement; The Politics of Abortion Law Reform in Britain (1967-83)', in *The New Politics of Abortion*, ed. by Joni Lovenduski and Joyce Outshoorn, (London: Sage Publications, 1986), p. 52.
[53] Francome, *Abortion Freedom*, p. 93.
[54] Hindell and Simms, *Abortion Law Reformed*, p. 97.
[55] Ibid., p. 100.
[56] Author Unknown, 'Scots Presbyterian speaks out for unborn child', *Scottish Catholic Observer*, 3rd February 1967, p. 2.
[57] Paula Davies, 'Don't babies have a viewpoint?', *Scottish Catholic Observer*, 10th February 1967, p. 15.

the 24th February calling for 'the cooperation of all men of goodwill who see the dangers of the Bill'. He also called upon the hierarchy and the 'leaders of lay Catholic opinion' to 'take the initiative at once' as 'There are times to keep silent, but this is not one of them.'[58] Readers wrote letters to the *Scottish Catholic Observer* urging others to sign the petition by SPUC, and criticised the lack of opposition to the Bill as 'too feeble', querying why if there were '7 million Catholics in this country … only 300,000 names have been collected against the Bill'.[59] In the end, despite the petitions and rallies, Steel's Bill was passed, changing the availability of abortion services in an unprecedented manner. For those who had opposed the Bill, this decision in no way led to acceptance of the outcome. In March of 1968 Norman St. John-Stevas published another article in the *Scottish Catholic Observer*, this time titled 'Abortion – the struggle is just beginning' and for many individuals this was exactly the case.[60] The next section will focus on the aftermath of the Abortion Act, and the reaction to the new abortion legislation by religious organisations.

V. The Church of Scotland Perspective on Abortion from 1967 to 1987

After taking an active role in trying to influence abortion legislation, the Church of Scotland went quiet on the subject once the Abortion Act 1967 was in place. In 1968 and 1969 there were no relevant articles on abortion published in *Life and Work*, and in 1970 the only contribution of note on the subject was a letter from a reader who was pregnant with her fifth child and who refused to have an abortion as she believed God wanted her to have the baby.[61] The subject of abortion did not feature prominently in discussions occurring at the General Assembly either, with very few mentions of it by the Social and Moral Welfare Board. In 1968 their only comment was to remind readers that although the recent legislation on abortion had been 'in the direction of showing greater humanity and compassion', there were still those who 'consider such changes to

[58] Norman St. John-Stevas, 'Is this really abortion on demand?', *Scottish Catholic Observer*, 24th February 1967, p. 6.
[59] Margaret O'Rourke, 'Letter – Abortion Bill – Act Now', encouraging people to sign petitions, and Diana Reeves, 'Letters – Opposition too feeble', both *Scottish Catholic Observer*, 26th May 1967, p. 4.
[60] Norman St. John-Stevas, 'Abortion – the struggle is just beginning', *Scottish Catholic Observer*, 29th March 1968, p. 15.
[61] Author Unknown, 'Letter – No – not abortion!', *Life and Work*, February 1970, p. 16.

be but a half-way house to unbridled "freedom"'.[62] It would seem that, in the immediate years following the Abortion Act, the Church of Scotland did not have strong opinions on the functioning of the Act. However, by 1971 concerns were beginning to emerge, with a report by the Committee on Moral Welfare stating that 'the Act must have the Church's continued scrutiny while awaiting further evidence regarding its working'. Although it provided no evidence to back up the claims, the report concluded that it was 'doubtful' if the Act had done anything to stop 'back-street' abortions in any significant way, and that there was 'unease among many doctors, nurses and psychiatrists over the interpretation and operation of the Act'.[63] In the 1972 General Assembly the subject of abortion featured prominently in the Committee on Moral Welfare report, with five pages dedicated to the Abortion Act. The committee felt that the high numbers of abortions being carried out should give 'cause for concern', and that as 'Christians, we must reassert the sanctity of human life as the gift of God, which cannot be taken away lightly'.[64]

Interestingly, the report seemed to suggest that abortions carried out for reasons of fetal anomaly were to be viewed separately – they put forward the figures that in 1970 only 0.1% of terminations were carried out to save the mother's life, in addition to 1.6% of terminations 'because there may have been the risk of abnormal or mentally defective babies'. They concluded that 'These figures betray a disturbing attitude to human life, as the operation in 98% of cases involves the destruction of a potentially normal child.'[65] This viewpoint would seems to be representative of Church of Scotland members, as a Gallup poll carried out in 1966 found that only 26% of Church members opposed abortion being legalised in cases where the 'child may be born deformed'.[66] Whilst giving their support for terminations in these circumstances, the Committee spoke out strongly against 'the "social grounds" for abortion', stating that 'The only possible grounds acceptable to the Committee for the termination of a pregnancy are

[62] Church of Scotland General Assembly 1968, Social and Moral Welfare Board, 'Report of the Committee on Moral Welfare', May 1968, pp. 476-477.
[63] Church of Scotland General Assembly 1971, Report of the Committee on Moral Welfare, 'The Working of the Abortion Act (1967) in Scotland', May 1971, pp. 401-402.
[64] Church of Scotland General Assembly 1972, Report of the Committee on Moral Welfare, 'Ethical Issues – Abortion Act', May 1972, p. 455.
[65] Ibid.
[66] Ben Clements, *Religion and Public Opinion in Britain*, (London: Palgrave Macmillan, 2015), p. 130.

that there is a real conflict of interest between the health of the mother and the life of the child'.[67] They also raised concerns about the suitability of the conscience clause for providing the required protection to staff wishing to refrain from being involved in terminations, and suggested that the time limit for abortions should be lowered to 20 weeks gestation.[68]

The 1973 and 1974 General Assembly reports only briefly mentioned abortion, stating that the Church were still waiting on the findings of the Lane Committee, and were continuing to monitor the situation. As described in the previous chapter, the Lane Committee had been set up in 1971 to report on the working of the Abortion Act, under the leadership of Mrs Justice Lane. The committee was prohibited from examining the moral and ethical dimensions of abortion, and was instead to focus on how the Act was working in practice. However, within *Life and Work* correspondence on abortion began to increase from 1972 onwards, with many readers writing to express their unease about the current situation in the United Kingdom. Several correspondents emphasised their unhappiness at the number of abortions being carried out in Scotland, which they felt were too high. Geoffrey Allan was convinced that the medical profession was 'damned' if they could not hold 'strongly to the belief in the preservation of human life',[69] and Stewart MacPherson cited the number of abortions as one of the reasons he believed society was 'sick'.[70] Following on from these letters were several from Dr Jane Darroch, encouraging anyone who had concerns about the working of the Abortion Act to join SPUC.[71] She claimed that the majority of the abortions being carried out were 'because the shady end of the medical profession is willing to sacrifice human lives in order to gratify selfish women', and that nurses were particularly distressed at having to inspect 'the mangled pieces of a baby aborted by suction' and watch 'a breathing, crying baby die in a dish'.[72] This emotive language was typical of that used by SPUC, with the description of women who had undergone an abortion as 'selfish' being

[67] Church of Scotland General Assembly 1972, Report of the Committee on Moral Welfare, 'Ethical Issues – Abortion Act', May 1972, p. 456.
[68] Ibid., pp. 457-459.
[69] Geoffrey W. Allan, 'Letters – Wrong Solution', *Life and Work*, April 1972, p. 32.
[70] Stewart M. MacPherson, 'Have we lost it? The ability to be shocked', *Life and Work*, May 1972, p. 12.
[71] Jane Darroch, 'Letters – The Unborn', *Life and Work*, May 1972, p. 38 and Jane Darroch, 'Letters – The Unborn', *Life and Work*, September 1972, p. 33.
[72] Jane Darroch, 'Letters – The Unborn', *Life and Work*, September 1972, p. 33.

reflective of their attitudes. The somewhat gruesome images conjured up by their description of 'mangled' babies dying 'in a dish' was also a common shock tactic used, with the aim of spurring individuals to join the organisation.

However, this approach used by SPUC did not seem to be particularly successful in recruiting members from the Church of Scotland. In December 1973 Dr Jane Darroch was once again writing in to *Life and Work*, this time to lament the lack of support from their members. She queried why if the Church of Scotland has a million members only 8 of them are members of SPUC, questioning 'Where are the 999,992?'.[73] Several of those 999,992 members replied explaining why they were not part of SPUC, including the Rev. E.J. Brain, who had been a member of the group along with his wife. They subsequently quit the organisation because of its 'absolute and uncompromising nature' and 'because nowhere in their reasoning is there a place for compassion for the potential mother'.[74] Ann Gregory found it 'totally wrong' of Jane Darroch 'to assume that others should support her particular attitude either as Christians or as members of the Church of Scotland', stating that she found it 'utterly repugnant that this kind of appeal for mass support can be made on any basis for such a complex and sensitive issue'.[75] Gregory argued that she felt her own convictions to be 'equally Christian' when advocating for abortion services to be made easier to access for women living in poverty who were 'downtrodden and hopelessly exploited … crammed into our cities' housing schemes'.[76] Margaret MacKay wrote in to highlight that unless someone has experience with an unwanted pregnancy they cannot appreciate the situation, likening the 'horror' to 'being caught like a rat in a trap'.[77] These contrasting views highlight the complexities of the Church of Scotland position on abortion. As the Church did not have a doctrinal view on the subject matter (in contrast to the Catholic Church) then members were freer to follow their individual Christian conscience in matters, leading to debates on these differing viewpoints. The interactions happening in the correspondence columns of *Life*

[73] Jane Darroch, 'Letters – Doctor's concern about abortion', *Life and Work*, December 1973, p. 37.
[74] E.J. Brain, 'Letters – Abortion', *Life and Work*, February 1974, p. 38.
The Rev. Brain was born in 1908, and at the time of writing this letter to *Life and Work* was based at Saint Andrew's Church of Scotland in Liverpool. See 'Rev Ermest Brain', *The Guardian* <http://www.heraldscotland.com/news/12382251.Rev_Ermest_Brain/> [accessed 10th May 2018].
[75] Ann Gregory, 'Letters – Abortion', *Life and Work*, February 1974, p. 38.
[76] Ibid.
[77] Margaret MacKay, 'Letters – Abortion' *Life and Work*, February 1974, p. 38.

and Work also seemed to support the evidence put forward earlier that SPUC struggled to lose its Catholic 'label', and that many Church of Scotland members found it too strong a position for them to support.

The subject of abortion was discussed very infrequently over the next decade at the General Assembly, and no major changes were made to policy until 1985. At this General Assembly it was agreed, much to the surprise of many Church of Scotland members, that abortion could only be carried out 'in the case of risk to maternal life and after the exhaustion of all alternatives'.[78] In a controversial move, this ruled out abortion in cases of rape and fetal anomaly. When the specific subject of abortion in cases of rape was discussed, it was concluded that the 'unborn child' was 'an innocent party, and its destruction cannot undo the evil which has already been done'.[79] For fetal anomaly, the new stance was that 'abortion does not prevent handicap, it merely destroys those who are already its victims'.[80] The Church also committed itself to securing a review of the 1967 Abortion Act.[81]

Given that the Church of Scotland had traditionally taken a wider view on the circumstances in which abortion was acceptable, the response from those in the Church community was one mainly of disbelief. The pages of *Life and Work* were filled with readers writing in on the subject, mainly to voice their shock at the General Assembly decision. For many, it was the rejection of allowing abortions in cases of rape that caused the most anger. Even the Editor of *Life and Work* stated that it was 'very unfortunate' that the Church of Scotland had gone on record 'as rejecting the option of abortion in rape cases' and that 'many good Christians disagree with the Social Responsibility study group on the point'.[82] Comments from readers were also strongly-worded in their condemnation of the General Assembly decision. One reader commented that they were 'saddened, disgusted and appalled' by the decision which

[78] Church of Scotland General Assembly 1985, Board of Social Responsibility, 'Study Group on Abortion', May 1985, p. 287.
[79] Ibid., p. 284.
[80] Ibid., p. 285.
[81] Ibid., p. 287.
[82] Author Unknown, 'Editorial – Assembly Aftermath – 1', *Life and Work*, July 1985, p. 5.

they felt 'shows a crass insensitivity towards the tragic plight of any woman who finds herself pregnant after rape'.[83] Another commented that 'To condemn a victim of such a horrific experience to relive that experience every hour of every day is cruelty of the worst kind.'[84] The main themes of women's suffering being perpetuated were repeated several times over the following months, with many readers clearly identifying terminations in cases of rape or for fetal anomaly as beneficial for a woman's mental health. These comments suggest that the majority of Church of Scotland members were uncomfortable with a hard-line stance being taken on abortion, with one reader even suggesting that the decision was influenced by the Catholic Church.[85] Whilst there were some readers who were in favour of the decision, including one who stated that she was 'delighted' and believed that the Church was 'going back to biblical teaching on the sanctity of life',[86] their comments were in the minority of those writing in to *Life and Work*.

The realisation that the Church had taken a new view on abortion seemed to propel those who disagreed into action to change the 1985 General Assembly ruling. In February 1986 it was reported in an editorial in *Life and Work* that parishes were working to influence the Presbytery of Edinburgh, amongst other Presbyteries, to 'ask the General Assembly to instruct the Board of Social Responsibility to reconsider and revise their policy with fuller research and wider consultation with a view to meeting the needs of the Church's pastoral care'.[87] The anger felt at the 1985 ruling seemed to have the desired effect, as at the 1986 General Assembly it was agreed to remove the criteria from the previous year, and instead 'reaffirm the position held since 1966, that the criteria for abortion should be that the continuance of the pregnancy would involve serious risk to the life or grave injury to the health whether physical or mental, of the

[83] Brian Brown, 'First Post – Readers' anger at assembly abortion and rape decision', *Life and Work*, July 1985, p. 6.
[84] D. L. L. Ramage, 'First Post – Readers' anger at assembly abortion and rape decision', *Life and Work*, July 1985, p. 6.
[85] Peter Brown, 'First Post – Compassion, rape, abortion … and that assembly vote', *Life and Work*, August 1985, p. 4.
[86] Annette Shaw, 'First Post – Compassion, rape, abortion … and that assembly vote', *Life and Work*, August 1985, p. 4.
[87] Author Unknown, 'Editorial – Bid to renew abortion debate', *Life and Work*, February 1986, p. 12.

pregnant woman'.[88] The 1985 decision was described by Rev. Ogston as a 'mistake which was made with the best possible motives', but which had left a lot of people feeling that 'common sense had departed the Church and that compassion had disappeared'. He warned against the Church entering an 'ice age' where decisions forgot emotional factors, and 'pleaded with the Assembly to blot out the unfortunate impression given last year that "we care neither for women who have been assaulted nor for women told they might be pregnant with a handicapped child"'.[89]

As with the 1985 ruling, this change in stance caused a great deal of communication in *Life and Work*, with debate once again occurring. It was noted by the editor that the 1986 outcome was 'much more popular with media and public opinion outside the Church' but that a deep division remained within the Church itself, and that reversing the previous year's decision may turn out to be a mistake if it did not allow for 'seeking a major revision of the present law'.[90] Some readers strongly disagreed with the decision, which they felt was only done to please the public. The Rev. George Fiddes argued that the Church was 'starting from the wrong place if it is seeking to make policy in deference to the popular opinion of the people, rather than starting from a sound biblical and theological position',[91] and L.E. Bell disliked that 'biblical considerations' were being 'set aside in favour of popular will'.[92] For many others however the decision was a positive one, including a Christian staff nurse who believed that it was not enough to 'quote Scripture passages to a rape victim', and who herself assisted at terminations where it would benefit the woman's wellbeing.[93] The Rev. Graham Monteith, who was disabled, spoke at the Assembly advocating that 'parents

[88] Church of Scotland General Assembly 1986, Board of Social Responsibility, 'Deliverance of the General Assembly of the Church of Scotland on the Report of the Board of Social Responsibility', May 1986, p. 17.
[89] Muriel Armstrong, 'Change of Assembly's Line on Abortion', *Life and Work*, July 1986, p. 9.
The Rev. Ogston referred to in the article is possibly the Reverend David Ogston, born in 1945. From 1980 onwards he was based at St John's Kirk in Perth, and seems to have been popular with the parishioners, and was described as 'much loved and admired' by them. See 'Rev David Ogston – Minister at St John the Baptist Kirk, Perth', *The Scotsman* <https://www.scotsman.com/news/obituaries/rev-david-ogston-minister-at-st-john-the-baptist-kirk-perth-1-1135174> [accessed 14th May 2018].
[90] Author Unknown, 'Editorial – Mistake after mistake?, *Life and Work*, July 1986, p. 5.
[91] George R. Fiddes, 'First Post', *Life and Work*, July 1986, p. 6.
The Rev. George Fiddes quoted here is likely to be the Rev. Fiddes who is currently based at St. Nicholas Parish Church, Prestwick.
[92] L.E. Bell, 'First Post – Abortion', *Life and Work*, October 1986, p. 7.
[93] Jess S. Archibald, 'First Post – Abortion', *Life and Work*, October 1986, pp. 6-7.

should be allowed freedom of choice which comes from God in coming to a decision about an abortion when a woman is told she is expecting a handicapped child'.[94]

The debates surrounding the response of the Church of Scotland to the subject of abortion were clearly multi-faceted, with ordinary Church members voicing their opinions in the hope of changing official viewpoints on the matter. The Church was aware of the lack of uniformity on the subject matter, and in 1987 published the book *Abortion in Debate* on behalf of the Church of Scotland's Board of Social Responsibility. As previously described, this book enabled several different contributors to put forward their views on various aspects of the abortion debate, with two contrasting viewpoints presented in each chapter. Authors with opposing views were then able to reply to the work written by each other to further advance the debating process. In the foreword for the book it was outlined that 'No issue has been discussed by the Church in recent years with more vigour and strength of feeling than that of abortion', highlighting the awareness the Church had of the divisions running through it on the subject.[95]

VI. The Catholic Church Continues the Abortion Fight, After the Implementation of the Abortion Act 1967

By way of contrast, the next section will examine the response of the Catholic Church, who continued to maintain their view that abortion was not permissible under any circumstances. As mentioned earlier, over the decades that followed the passing of the Abortion Act, the Catholic Church stuck steadily to this belief, and this is still their teaching up to the present day. As this viewpoint has not changed, this section will focus on highlighting some of the events protesting against abortion that were being led by the Catholic Church in Glasgow and the West of Scotland, which were reported in the *Scottish Catholic Observer*. It will also examine the Catholic viewpoint surrounding termination of pregnancy for fetal anomaly, as this started to be discussed in more detail

[94] Muriel Armstrong, 'Change of Assembly's Line on Abortion', *Life and Work*, July 1986, p. 9. Efforts have been made to find out more information about the Rev. Graham Monteith, but these have not been successful.
[95] Church of Scotland's Board of Social Responsibility, *Abortion in Debate*, (Edinburgh: Saint Andrew's Press, 1987), p. 6.

in the *Observer* in 1981, which was the United Nations International Year of the Disabled. It will then go on to consider whether religion impacted decision making in the prenatal testing setting, examining both oral testimonies and published papers on the subject.

As previously discussed, petitions and rallies formed some of the main forms of protest against abortion led by those of a Catholic faith, and this was also true of specific events occurring in Glasgow after abortion legislation had been passed. One of the first events which displays the strength of interest surrounding the issue in the region was the '1000 strong audience' at a public debate, organised by the Scottish Catholic Renewal Movement in 1970.[96] On the political side Norman St. John-Stevas and David Steel were two of the speakers, and from the medical profession both Ian Donald and Dugald Baird participated in the event. As would be expected, St. John-Stevas and Donald both spoke out against the Abortion Act, and Steel and Baird were arguing in favour of it. The number of attendees indicates the strength of feeling in Glasgow on the subject, three years after the passing of the Act. The issues which arose in the debate included the high numbers of terminations being carried out (the figures being perceived as high by those against abortion), and the profiteering which was occurring in some areas, where gynaecologists were able to make large sums of money for carrying out abortions privately.[97]

In addition to meetings and debates, public protests formed a large part of the Catholic campaign, and some of these managed to attract high numbers of participants, with attendance at a rally in Glasgow numbering 12,000 in April 1974. The rally began with speeches in Glasgow Green, followed by a march to Glasgow Cathedral, where seven white wreaths were laid at the baptismal font, one for every 1000 abortions which had been carried out in Scotland in the previous year.[98] A key speaker was Thomas Winning, then Auxiliary Bishop of Glasgow, and a prominent spokesperson for the anti-

[96] Anne McGhee, 'Nurses are revolted by abortion duties', *Scottish Catholic Observer*, 13th March 1970, p. 2.
[97] Ibid.
[98] William Sutherland, 'End this Slaughter', *Scottish Catholic Observer*, 3rd May 1974, pp. 10-11.

abortion point of view.[99] He spoke out frequently against abortion, including at an event organised by the Glasgow Catholic Nurses' Guild, where he 'launched a strong attack' on what he described as the 'destroyers of life', concluding that nothing 'can justify the killing or maiming of innocent people'.[100]

There is also evidence in the *Scottish Catholic Observer* that Catholic schools in the West of Scotland played a role in these protests. As reported in January 1971, a group of pupils from St. Aloysius in Glasgow spent a day carrying a crib around five churches in the city, praying before it in each.[101] A large march was also organised in April of the same year, when 500 school pupils from Coatbridge went on a march against abortion, carried banners and handed out leaflets. The leaflets included pictures 'showing an aborted baby lying in a stainless steel bucket', and the banners displayed messages such as '"Abortion – Legalised Murder" and "Respect Life – Kill Abortion"'.[102] Around sixty teachers joined the students on the march. Canon Duddy, a parish priest, helped to lead the walk, which ended with a church service, during which he denounced the Act as 'obnoxious, evil and unjust' and said the purpose of the walk was to 'express our abhorrence against the Abortion Act and those women who want abortion on demand'.[103] That teenagers were being exposed to images of fetuses lying in steel trays highlights the shock tactics that were used by some Catholic members to try and get the message across that abortion was wrong.

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[99] Winning would go on to become Archbishop in 1974, a patron of SPUC in 1975, and Cardinal in 1994. He founded the Cardinal Winning Pro-Life Initiative in Glasgow in 1997, which aimed to provide practical, emotional, financial and spiritual support to women who were facing a crisis pregnancy. This work is continued on in the present day in Glasgow by the Sisters of the Gospel of Life. For information on Winning becoming Archbishop see Author Unknown, 'Glasgow Gets New Archbishop', *Scottish Catholic Observer*, 17th May 1974, p. 1, on him becoming a patron of SPUC see Author Unknown, 'Archbishop Winning is SPUC's New Patron', *Scottish Catholic Observer*, 4th April 1975, p. 7. Information on Winning becoming a Cardinal can be found at 'Obituaries Cardinal Thomas Winning', *The Telegraph* <https://www.telegraph.co.uk/news/obituaries/1312145/Cardinal-Thomas-Winning.html> [accessed 21st May 2018].

[100] Author Unknown, 'Archbishop Defends the Sanctity of Life', *Scottish Catholic Observer*, 29th November 1974, p. 7.

[101] Kay Gilmour, 'Thousands in abortion protest', *Scottish Catholic Observer*, 1st January 1971, p. 3.

[102] Author Unknown, 'Abortion Protest', *Scottish Catholic Observer*, 2nd April 1971, p. 1.

[103] Ibid.

Canon Duddy was based at various parishes throughout Lanarkshire, including St Margaret's in Airdrie, and St Monica's in Coatbridge. See 'History – the Age of Change', *St. Margaret's Catholic Church Airdrie* <https://www.stmargaretsairdrie.org.uk/ageofchange> [accessed 14th May 2018].

In addition to organising rallies and petitions, many members of the Catholic faith supported attempts to alter the abortion legislation, or remove it altogether. One of the campaigns they supported most strongly was that of James White, M.P. for Glasgow Pollok, who proposed a Bill which would tighten abortion legislation. Despite not being Catholic himself, White faced pressure from his Catholic constituents to make abortion the subject of his Private Member's Bill, and was inundated with letters to this effect. Catholics 'in many parishes in Glasgow were encouraged to write to Mr White to persuade him to make reform of the 1967 Act the subject of his Private Member's Bill'. It seemed this encouragement certainly worked.[104] By January 1975 it was reported that he had received over 8000 letters in support of his proposed Abortion Amendment Bill,[105] and at an event in Glasgow to discuss the proposed changes to the legislation, Archbishop Winning was one of the marchers in the crowd.[106] Some of the main clauses of White's Bill were that it would prohibit abortions on social grounds, reduce the upper time limit for abortions from 28 weeks to 20 weeks, and would prohibit experiments on live fetuses.[107] 8000 people attended an anti-abortion rally in Glasgow in September 1975, where support for White's Bill was voiced,[108] and in January 1976 White was presented with a petition signed by 30,000 women in Glasgow in support of his Bill. He stated that the petition 'overwhelmingly showed that Glasgow women had rejected the abortion promoting attempts of "trendy social engineers and manipulators"'.[109] White's Bill was withdrawn as the Government decided to establish a Select Committee to look into the subject of abortion. However, when the recommendations of the Select Committee were not put in place, other abortion amendment bills were devised. These included the Benyon Bill, which again had many Catholic supporters as it proposed restrictions to abortion legislation, and the Corrie Bill, which aimed to severely restrict abortion services. The Corrie Bill was proposed in 1979, and the terms included

[104] Author Unknown, 'New Move Against Abortion – Private Members' Bill Intended', *Scottish Catholic Observer*, 22nd November 1974, p. 1.
[105] Author Unknown, 'Support for Mr White', *Scottish Catholic Observer*, 17th January 1975, p. 1.
[106] Author Unknown, 'Amend the Abortion Act', *Scottish Catholic Observer*, 3rd January 1975, p. 2.
[107] Author Unknown, 'New Move Against Abortion – Private Members' Bill Intended', *Scottish Catholic Observer*, 22nd November 1974, p. 1.
[108] Author Unknown, 'The Battle Against Abortion – 8000 in Glasgow Rally', *Scottish Catholic Observer*, 26th September 1975, p. 8.
[109] Author Unknown, ''Parliament Will Back Our Fight'', *Scottish Catholic Observer*, 2nd January 1976, p. 1.

decreasing the gestational age at which terminations could take place to 20 weeks, making abortion permissible in only very limited circumstances, ensuring doctors did not receive financial gain from carrying out terminations, and strengthening the conscience clause.[110] The Bill received a great deal of support from Catholics in Scotland, and a debate on the Bill held at Glasgow University Union in October 1979 'produced an overwhelming vote in favour of the Bill'.[111]

While the above examples highlight some of the ways in which members of the Catholic Church in Scotland were involved in campaigning against abortion, many of those writing in to the *Scottish Catholic Observer* were unhappy with what they perceived as apathy on the subject from others. Writing in to the newspaper, one reader commented on how 'In recent years Catholics have stood as silent onlookers and watched the moral code of this country being torn asunder' and had 'made only the merest whisper in protest'. A mass held in Saint Mary's Cathedral in Edinburgh to pray for the success in lobbying M.P.s to repeal the Abortion Act 1967 was poorly attended, with the ceremony taking place in a 'near-empty' cathedral.[112] A motorcade event planned for Edinburgh also had to be cancelled on the day, when only five cars and fifteen pedestrians showed up to it, with the event being labelled a 'disaster' by one of the organisers.[113] The lack of enthusiasm for the anti-abortion events led one reader of the *Scottish Catholic Observer* to conclude that many members of the Church had 'contributed by the sin of omission, to the 170,000 innocents' deaths by abortion carried out in our hospitals in the past year'. This particular reader was unhappy that a great many Catholics were not members of SPUC, that few Catholic nurses had opted to use the conscience clause, and that around 9.9% of women having terminations identified as Catholic.[114]

[110] Pat Bolan, 'Mr. Corrie Spells Out His Bill's Proposals', *Scottish Catholic Observer*, 29th June 1979, p. 1.
[111] Author Unknown, 'Pro-Life Win Student Vote', *Scottish Catholic Observer*, 12th October 1979, p. 9.
[112] Author Unknown, '500 Scots March Against Abortion', *Scottish Catholic Observer*, 23rd November 1973, p. 1.
[113] Author Unknown, 'A Proposed Rally That Fell Flat', *Scottish Catholic Observer*, 27th June 1980, p. 2.
[114] J.R. Futers, 'Postbag – Do Catholics Favour Abortion?', *Scottish Catholic Observer*, 18th January 1974, p. 8.

There was also little discussion on the subject of prenatal testing, with few communications detailing the concerns which could arise between the testing and links with abortion. The issue of abortion for fetal anomaly was, however, raised in a letter to the *Scottish Catholic Observer* in December 1977. The reader, Denis Ferguson, was the father of a disabled child, and he described how Malcolm Ferguson-Smith and Ian Donald were 'equally eminent colleagues in Glasgow … who are opposed to the abortion of healthy unborn children but advocate the abortion of unborn children who suffer from congenital malformation'. He argued that Ferguson-Smith and Donald believed that 'in the case of the handicapped, death is the lesser of two evils'. However, Ferguson disagreed with this position, highlighting that the quality of life for children such as his had improved greatly over the last ten years.[115] There was, evidently, some wider awareness of the work being carried out in the prenatal field in Glasgow, and not everyone was in agreement with it. There is no published reply to this letter from either Ferguson-Smith or Donald, and it is not known if they were aware of it. Ferguson-Smith did, however, receive private correspondence expressing disapproval of his work. A letter written to him in 1978 maintained that he and his team must be 'very satisfied with your work considering your success rate in the murder of innocent babies'. The same author expressed their wishes that Ferguson-Smith would 'put the intelligence that God gave you to the fight to preserve life and not destroy it' as 'If God had meant these babies not to be born, then he could have ended their lives.' They concluded 'Do not fall into the false impression that you can play God. Remember, "What you do unto the least of my brethren, you do unto me."'[116] This quote places emphasis on the idea that how society treats those who are seen as more vulnerable is a reflection of society overall, and links to the idea put forward by Meilaender that an important aspect of Christianity is to 'value and protect – for Christians, to see Christ in – those who are "least" among us'.[117]

Whilst these communications are strong in their disapproval of Ferguson-Smith's work, their number were few, and there did not seem to be a great deal of discussion

[115] Denis Ferguson, 'Postbag – Our Son Was Left to Die', *Scottish Catholic Observer*, 2nd December 1977, p. 9.
[116] University of Glasgow Archives, Papers of Malcolm Andrew Ferguson-Smith, UGC 188/3/4/27/2, Ferguson-Smith Correspondence F, p. 13 (letter dated 11th January 1978).
[117] Meilaender, *Bioethics A Primer for Christians*, p. 33.

surrounding prenatal testing and abortion until 1981. 1981 was classified as the International Year of the Disabled by the United Nations, and it would seem that this prompted an awakening of the collective Catholic conscience to begin speaking out against termination for fetal anomaly. People with disabilities expressed similar sentiments to the parent, Denis Ferguson, quoted above. Peter McCann, a former Lord Provost of Glasgow who was himself disabled, queried 'How dare anyone tell any disabled person that their life is not a full life.'[118] Mrs Marilyn Gillies Carr, who was born without any arms, questioned if the doctors who promoted the testing stopped to consider how their comments would make people with disabilities feel. She highlighted that many people with disabilities found the current situation 'frightening', and described the BMA as being 'more fitting to a British Master-race Association than to a British Medical Association'.[119] Other voices were also beginning to speak out against prenatal testing, linking it to eugenics, including Archbishop Winning, who expressed his unhappiness about the developments which were occurring. In 1978 he likened prenatal screening to the efforts by the Nazis to sterilise 'those who were not able to contribute to pure healthy Aryan stock', questioning 'Is the screening of the unborn to detect deformity and eliminate it merely a more refined more euphemistic way of achieving the same end?'[120] Marilyn Gillies Carr also commented on 'the treatment meted out to the handicapped – which all too often seems more in accordance with the philosophy prevalent in Hitler's Germany that only what is useful is good, than the standards one would expect in a civilised society'.[121] Malcolm Ferguson-Smith himself has also recounted the story of being called a Nazi by an Archbishop in Glasgow, a claim that Marie Ferguson-Smith strongly objected to, as she had spent time in a Nazi concentration camp during the Second World War.[122]

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[118] Author Unknown, 'Paisley March for Life Calls for New Laws', *Scottish Catholic Observer*, 4th September 1981, p. 7.
[119] Author Unknown, 'Yes, The Disabled Are People Too', *Scottish Catholic Observer*, 10th July 1981, p. 4.
[120] Author Unknown, 'We Are A Nation At War', *Scottish Catholic Observer*, 17th March 1978, p. 4.
[121] Author Unknown, 'Pro-Life Candidate Without Arms Defends Mongol Babies', *Scottish Catholic Observer*, 14th August 1981, p. 7.
[122] History of Modern Biomedicine Research Group (Interview Questions by Ms Emma M. Jones, transcribed by Mrs Debra Gee, and edited by Professor Tilli Tansey and Mr Alan Yabsley), 'Ferguson Smith, Malcolm 06 Scotland, Genetic Counselling, Religious Objections', *YouTube* <https://www.youtube.com/watch?v=DzH-Mrh9Lrw> [accessed 20th July 2018]. 3 minutes 17 seconds to 4 minutes 44 seconds.

A key message which began to emerge from these communications was that people with disabilities should be treated as individuals, and that their worth should not be defined by what they could and could not do. Bishop Mario Conti of Aberdeen commented that there was a 'mentality that reduces situations and individuals to an assessment based on spurious categories of usefulness, of economic worth, of a so-called 'quality of life' which has more to do with physical integrity than with personal growth and spiritual fulfilment', but that this was unacceptable, as the 'real test of a caring society is the value it places on the individual'.[123] Bishop Conti maintained that 'Catholics stood beside the disabled and counted it a privilege to serve them' and emphasised that they would 'defend their right to be born … and to be protected from every misguided busybody who thinks they would be better dead'.[124]

VII. The Impact of Religion on Prenatal Testing Decisions

It therefore seems that a conflict should exist between Catholicism and prenatal testing, as the testing would lead to a termination of pregnancy in the majority of confirmed cases, which was strictly prohibited by the Catholic Church. This sequence of diagnosis followed by termination led Anthony Fisher, in *Catholic Bioethics for a New Millennium*, to describe prenatal tests as 'heat-seeking missiles to ensure that those babies who have certain genetic disorders never see the light of day'.[125] However, an interesting point raised in an interview with a clinician who had worked in the genetics clinics in Glasgow since 1982, was that religion of attendees at the clinic was initially recorded, but that this was stopped when it was found it did not have a direct association with decision making.[126] In a similar manner, the statistics reported by the Lane Committee found a lack of correlation between religion and abortion decisions, with the data suggesting that 'Catholics are probably not much (if at all) less likely than other

[123] Author Unknown, 'Todays Problems The Christian Response', *Scottish Catholic Observer*, 6th March 1981, p. 3.
Mario Conti was born in 1934, and ordained as a priest in Aberdeen in 1958. He went on to be ordained Bishop of Aberdeen in 1977, where he remained until he was appointed Archbishop of Glasgow in 2002.
[124] Author Unknown, 'We Support the Handicapped – Bishop', *Scottish Catholic Observer*, 25th September 1981, p. 5.
[125] Anthony Fisher, *Catholic Bioethics for a New Millennium*, (Cambridge: Cambridge University Press, 2012), p. 164.
[126] The time period when this process was stopped was not discussed by the interviewee.
MC Interview, DS300143, p. 14.

women to opt for an abortion.'[127] Rayna Rapp, in *Testing Women, Testing the Fetus*, also notes that the genetic counsellors she interviewed stated that Catholic women opt for amniocentesis as frequently as non-Catholic women.[128] This raises the question of whether or not the conflict between religion and prenatal testing existed in practice, or mainly in theory.

Interviews with researchers and clinicians who worked in areas associated with prenatal testing can provide an insight into whether or not conflict occurred which affected the work going on in the field. When one obstetrician was asked if there were many members of staff working in obstetrics who objected to terminations, he commented:

> There weren't a lot actually, there obviously were and I mean I've worked with Roman Catholic doctors who really, they didn't voice their objections, they just didn't get involved you know. On the whole I found that the people I was working with didn't make a song or dance about it if they didn't like to do it they just kept quiet. There must have been some around the place who created a fuss I suppose. There was you know occasionally there would be a nurse maybe, and senior nurses would identify that and just say you're not involved in this case. These were generally on religious grounds.[129]

Another clinician commented that it was a 'very difficult time in the early days of prenatal diagnosis. Although the majority of obstetricians were happy to refer their patients to clinical genetics, a small number would not.'[130] When asked why this was the case, he replied:

> That was to do with termination of pregnancy and that was particularly noticeable in some areas of Glasgow and Lanarkshire. And of course that's very bad for the families who lived there, who may have had different views to their doctors. In those days it was seen as a Roman Catholic issue but we found people's views on abortion depended on a whole lot of factors and religion was only one of them and probably not even the main

[127] The Hon. Mrs. Justice Lane, D.B.E., *Report of the Committee on the Working of the Abortion Act – Volume II Statistical Volume*, (London: Her Majesty's Stationery Office, 1974), p. 61.
[128] Rayna Rapp, *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America*, (New York: Routledge, 2000), p. 157.
[129] BH Interview, DS300155, p. 7.
[130] DW Interview, DS300142, p. 18.

> one. However, often the GP would refer at risk, expecting families for genetic advice, even if their obstetrician did not.[131]

Both of these interviewees were of the opinion that it was a small minority who had concerns about termination of pregnancy, and both mention the Roman Catholic faith as being a potential factor. Their recollections of how much religion impacted the profession are slightly different, with one feeling that the small numbers who did not want to be involved did not affect clinical arrangements greatly, whilst the other felt it made for a 'very difficult time' initially.

In discussions with the second clinician quoted here the question was raised of why some women might have chosen not to undergo prenatal testing when it became available, and religion was mentioned as a factor:

> There were some people who said that they wouldn't consider it for religious reasons, yes, but they were actually very few and not limited to Roman Catholics. In all the years that I did genetics I can think of probably fewer than 5 people who said they didn't want to have a termination for religious reasons. But you know other people may have felt that but just been embarrassed to say that.[132]

A conflict between religion and prenatal testing may have been less apparent, if women were uncomfortable expressing their religion as a reason for not being willing to undergo the testing. However, a qualified midwife working in the department has commented from her perspective on religion being quite an important factor:

> Religion was a big thing and there were many parents who would not proceed with prenatal diagnosis because their religious beliefs were such that that was not right for them to do. I met a reasonable amount of parents who found themselves in the situation of being told that the baby had an abnormality and they made the decision to end their pregnancy but really struggled with it because of their religious beliefs.[133]

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[131] Ibid.
[132] Ibid., p. 19.
[133] KM Interview, Transcript 1, p. 8.

She went on to explain that:

> So parents would sometimes find themselves in the situation of being given the information that their baby had an abnormality, making the decision to terminate the pregnancy because that was right for them, but had strong religious beliefs and the guilt associated with that was huge. The guilt associated with terminating a pregnancy for fetal abnormality is huge for any parent that has to make that decision, I think religion has an impact on that as many other factors do but if their religious or cultural beliefs were against termination of pregnancy then they struggled more with that decision.[134]

Even among those working in the field there were different perspectives about the role that religion played. Perhaps this could be due to the strength of religious beliefs amongst the specific patients they were encountering, but the relationship dynamic between patient and midwife versus patient and clinician could also play a role. In some situations, a female patient may feel more comfortable disclosing such information to a female midwife. However, the male clinician quoted here had built up very close relationships with the families he was working with over many years, so perhaps this would not have been a concern for his patients. What starts to emerge is a picture that is far more complex than would perhaps be expected from traditional religious teachings on the subject. For some women their religion was such a strong influence in their life that they refused prenatal testing, but for others, although their religious identity was strong, they still decided upon having the tests.

Examples of both of these situations can be found in the wider literature. Bennett found that 25 of 49 women who turned down prenatal screening did so for religious reasons.[135] Of the 44 women in Bundey's study who refused amniocentesis, the majority were actively practising Christians (66%).[136] Interviews carried out by Rapp for *Testing*

[134] KM Interview, Transcript 2 and 3, p. 1.
[135] M.J. Bennett, Gillian S. Gau and D.W. Gau, 'Women's Attitudes to Screening for Neural Tube Defects', *British Journal of Obstetrics and Gynaecology*, 87:5 (1980), p. 371.
[136] Sarah Bundey, 'Attitudes of 40-year-old College Graduates Towards Amniocentesis', *British Medical Journal*, 2:6150 (1978), p. 1476.

Women, Testing the Fetus also show this on a more personal level, with one woman refusing a termination after a diagnosis of anencephaly. This woman was devoutly religious, and she wanted to 'carry the fetus to term and accept God's mercy in taking the baby quickly to Him'; additionally, she 'saw her own suffering and the suffering of the baby as a test of God's mysteries'.[137] In *The Tentative Pregnancy*, Rothman quotes a letter received from a woman who strongly links her pro-life views to her religious beliefs, stating that 'I am a Christian. Every person has the right to live – no one has the right to decide for someone else that their life is not worth living.'[138]

From the descriptions above it seems that in some cases there is a link between religious identity and prenatal decision making. However, what becomes apparent when looking further into the literature, is that it is often not merely religious identification, but religious adherence which impacts decision making. Berne-Fromell and colleagues found a link between 'active participation in the life of various religious congregations' and refusal of prenatal testing,[139] and Cao and colleagues reported 'strict adherence to the Catholic religion' as a reason for women in their study turning down testing.[140] In addition, Tymstra and colleagues noted that fewer women would make use of a variety of prenatal tests if they were members of a church (36% of church members, compared to 46% of non-church members).[141] Singer and colleagues found a direct correlation between religious attendance and abortion attitudes, when considering the percentage of women who would 'want abortion in case of serious defect'. 56.3% of women who never went to church would want an abortion, compared to 45.9% who went several times a year, 42.4% who went monthly to almost weekly, and 25.5% who went weekly or more.[142] Beth and Donald Granberg reported similar findings amongst Protestants and Catholics, whereby 'approval of abortion decreases as religiousness increases' and

[137] Rapp, *Testing Women, Testing the Fetus*, p. 186.
[138] Barbara Katz Rothman, *The Tentative Pregnancy: Amniocentesis and the Sexual Politics of Motherhood*, 2nd Edition, (London: Pandora, 1994), p. 66.
[139] Kerstin Berne-Fromell, Gunilla Josefson and Berndt Kjessler, 'Who Declines from Antenatal Serum α-fetoprotein Screening – And Why?', *Acta Obstetricia et Gynecologica Scandinavica*, 63:8 (1984), p. 690.
[140] A. Cao, P. Cossu, G. Monni and M.C. Rosatelli, 'Chorionic Villus Sampling and Acceptance Rate of Prenatal Diagnosis', *Prenatal Diagnosis*, 7:7 (1987), p. 532.
[141] TJ. Tymstra, C. Bajema, J.R. Beekhuis and A. Mantingh, 'Women's Opinions on the Offer and Use of Prenatal Diagnosis', *Prenatal Diagnosis*, 11:12 (1991), p. 897.
[142] Eleanor Singer, Amy D. Corning and Toni Antonucci, 'Attitudes Toward Genetic Testing and Fetal Diagnosis, 1990—1996', *Journal of Health and Social Behaviour*, 40:4 (1999), p. 437.

this is particularly strong in the Catholic population, as 'it is Catholics who attend church once a week or more who are distinctly low in their level of approval'.[143]

The testimony from the midwife, however, highlights that even though having a termination of pregnancy went against their religious beliefs and resulted in guilt for the women involved, some still chose to proceed with the termination. It could be that for those of a strong religious faith, some women find that their concerns about being able to raise a child with a disability outweigh their religious beliefs and they decide to terminate. Pressure by society, family members and friends, and perhaps even the medical profession, combined with factors such as financial constraints, may of course all influence such a decision. McCoyd undertook a qualitative study of thirty women who chose to terminate their pregnancies after receiving a diagnosis of fetal anomaly. Many of these women gave similar reasons for choosing termination. One was thankful for the technology which she believed 'saved my life' as she felt that had she given birth 'life as I know it would be over. There would have been no more children, possibly a break up of my relationship, no financial security of a job, no quality of life for my son.'[144] For another woman the choice she made was not just for herself – she felt that whilst she 'did it for me' she also 'did it for my marriage. I did it for my other child. I did it for my home and job and way of life.'[145] For these women, although their decisions were multi-faceted, they felt that terminating the pregnancy would be the best thing to do in their individual circumstances at that time.

Despite many women feeling that they had made the correct decision, guilt associated with religious beliefs is also a pervasive theme in the testimonies in *Testing Women, Testing the Fetus*. Rapp's impression from the genetic counsellors that she interviewed was that whilst Catholic women use amniocentesis as frequently as non-Catholic women, they are 'more troubled' by it than Protestant women, who see 'reproductive

[143] The Protestant groups studied were Baptists, Methodists, Lutherans, Presbyterians, and Episcopalians. Donald Granberg and Beth Wellman Granberg, 'Abortion Attitudes, 1965-1980: Trends and Determinants', *Family Planning Perspectives*, 12:5 (1980), p. 257.
[144] Judith L.M. McCoyd, 'Authoritative Knowledge, the Technological Imperative and Women's Responses to Prenatal Diagnostic Technologies', *Culture, Medicine and Psychiatry*, 34:4 (2010), p. 598.
[145] Judith L.M. McCoyd, '"I'm not a saint": Burden Assessment as an Unrecognized Factor in Prenatal Decision Making', *Qualitative Health Research*, 18:11 (2008), p. 1494.

technology as occupying a space apart from their spiritual practices, for they saw both faith and reproductive medicine as private matters'.[146] Several of the counsellors 'were explicit in their statements concerning Catholic women's guilt and the need to provide sympathetic clerical references', and felt that the Catholic women 'seemed to carry an additional burden of guilt'.[147] One of her patient interviewees, Nivia, was described as 'guilt-wracked by having chosen abortion after the prenatal diagnosis of Turner's syndrome. Nonetheless, she believed that she had made the right decision.'[148] Another interviewee decided to terminate her pregnancy, but as it was Easter she decided to wait, stating that she just '"couldn't do it; I just couldn't do it until after His suffering was ended. Then my child could cease to suffer as well"'.[149] Of thirteen women who were Catholic and who had chosen termination after a diagnosis of fetal anomaly, ten 'believed that their Catholic backgrounds had made it harder to recover from abortion than they imagined to be the case for non-Catholic women'.[150]

If Rapp's study is representative of wider decision making, then those who categorise themselves as belonging to a religion, but who choose to terminate, could lead to a skewing of the data surrounding religion and prenatal decision making. A woman may record herself as belonging to a religious organisation, but still decide to terminate even though it goes against religious teachings, and is left dealing with the guilt associated with this decision after the procedure. More examples of the tension between religious identification and prenatal decision making can be found in the wider literature. Green, Snowdon and Statham found that '47% of women 'completely' influenced by their religion and 82% of those influenced 'quite a lot' indicated at least one situation in which they themselves might consider abortion'.[151] The same study concluded that 'many women who terminate for fetal abnormality may be acting against their own moral convictions. This may, for some, still be the less undesirable of two undesirable options.'[152] Robinson and colleagues interviewed 22 women who had undergone

[146] Rapp, *Testing Women, Testing the Fetus*, p. 157.
[147] Ibid., p. 253.
[148] Ibid., p. 252.
[149] Ibid., p. 143.
[150] Ibid., p. 253.
[151] Josephine M. Green, Claire Snowdon and Helen Statham, 'Pregnant Women's Attitudes to Abortion and Prenatal Screening', *Journal of Reproductive and Infant Psychology*, 11:1 (1993), p. 35.
[152] Ibid., p. 38.

amniocentesis and then continued with their pregnancies, carrying out the interviews when the children were a year old. They found that 'Many of the mothers had religious backgrounds consonant with the general antiabortion attitudes which they expressed. Fifteen women expressed a general opposition to abortion and 7 were generally in favour of it. Despite the disapproval of abortion and despite how badly they wanted their babies, most women were prepared to go ahead with abortion in the event of positive findings. Seventeen had no doubt that they would do so although some of these imagined that it would be difficult or that they would feel some remorse.'[153] The reason behind the decision for some of those interviewed was that 'they could not accept such a burden'.[154] Whilst viewing themselves as religious, and holding religious beliefs which are against abortion, most women in this study were willing to set aside religious teaching on the subject when it directly impacted them.

Another possible reason for the discrepancies between the expected conflicts could be that for many people religion is a fluid concept, and people do not always fit into a neat box of belonging to a religion and following every aspect of it. Voas has argued that whilst a number of people will identify as being either religious or non-religious, there will be a large population of people somewhere in the middle. These people, described by Voas as the 'fuzzy group' are neither regular churchgoers, nor are they against religion – they may retain some loyalties to traditional religious beliefs, but this is usually in an uncommitted way.[155] The 'fuzzy group' have been analysed by Storm, and split into four groups – those of moderate religious beliefs, those of passive religious beliefs, those who belong without believing, and those who believe without belonging.[156] Whilst these four groupings are useful, some people may fall into different categories at different times. The group that belong without believing could be particularly important in impacting statistics, as their religious label may not correlate

[153] Jean Robinson, Katherine Tennes and Arthur Robinson, 'Amniocentesis: Its Impact on Mothers and Infants. A 1-Year Follow-Up Study', *Clinical Genetics*, 8:2 (1975), p. 103.
[154] Ibid.
[155] David Voas and Abby Day, 'Recognizing Secular Christians: Toward an Unexcluded Middle in the Study of Religion', *Association of Religion Data Archives*, (2010), p. 3.
[156] Ingrid Storm, 'Halfway to Heaven: Four Types of Fuzzy Fidelity in Europe', *Journal for the Scientific Study of Religion*, 48:4 (2009), pp. 707-708.

with their own belief systems. Thus, they may choose to make decisions which seem to conflict with the beliefs of their religious label.

This is reflected in a study by Davies and Doran, who analysed the decision making of women of advanced maternal age, of whether to undergo or decline amniocentesis. 36 women in their study were Catholic and/or had a Catholic spouse, but only 11 of these women said that their religion had impacted their decision making. They found that 'One third of the Catholic families were not practicing their religion and two-thirds did not agree with the church's teaching on abortion.'[157] Thus, whilst still identifying as Catholic, these families were not likely to follow church teaching on the subject. A number of other studies have also shown that those who identify as Catholic agree with abortion for fetal anomaly. Green, Snowdon and Statham reported that 75% of Catholics thought that abortion should be available if there was a strong chance of fetal handicap,[158] and Kyle and colleagues found that 74% of Catholic women in their study definitely intended to undergo prenatal screening for neural tube defects.[159] In addition, Breslau reported that 55% of Catholics agreed with termination where 'There is strong chance of serious deformity in the baby.'[160]

Another factor which could have impacted decision making is that despite the Catholic Church being strongly opposed to abortion, no official statement was made by a Pope on prenatal diagnosis until the late 1980s. *Donum Vitae*, published by Pope John Paul II in 1987, outlined more specifically the position of the Church on the matter of prenatal diagnosis. He stated that prenatal testing could be 'morally licit' when it was used to protect the life and health of the fetus, for example by enabling the diagnosis of a medical condition which could be treated in the fetus prior to or just after birth. Thus the vast majority of prenatal testing, which is carried out with the potential of choosing to

[157] Barbara L. Davies and Terence A. Doran, 'Factors in a Woman's Decision to Undergo Genetic Amniocentesis for Advanced Maternal Age', *Nursing Research*, 31:1 (1982), p. 58.
[158] Green, Snowdon and Statham, 'Pregnant Women's Attitudes to Abortion and Prenatal Screening', pp. 34-35.
[159] Dorothy Kyle, Carole Cummins and Stuart Evans, 'Factors Affecting the Uptake of Screening for Neural Tube Defect', *British Journal of Obstetrics and Gynaecology*, 95:6 (1988), p. 561.
[160] Naomi Breslau, 'Abortion of Defective Fetuses: Attitudes of Mothers of Congenitally Impaired Children', *Journal of Marriage and the Family*, 49:4 (1987), p. 842.

have an abortion based on the results, is 'gravely opposed to the moral law' of the Catholic Church.[161] The women who would ask for prenatal testing on the basis of terminating the pregnancy if an anomaly was found would therefore be acting in a strictly discordant way with official teaching; Pope John Paul II stated that not only would she be committing a 'gravely illicit act', but that her spouse and relatives would also be doing so, along with the specialists who recommended the testing.[162] However, as this statement was not released until 1987 it is possible that many women had already entered into prenatal screening and testing programmes, and were using their own conscience to guide them on these matters. Rapp has characterised this situation as 'a precipitate of liberal, individualistic Catholicism separating out of official doctrine', whereby the women involved 'uphold a general ethical worldview which is deeply Catholic, and personally accept its emotional consequences. Nonetheless, they reserve the right (and accord it to others) to choose abortion under certain circumstances.'[163]

Thus, a situation seems to be occurring where decision making and beliefs vary amongst those who identify as belonging to a religious faith. Whilst the Church of Scotland sanctioned terminations for fetal anomaly in certain circumstances, the Kirk was divided on the subject of abortion more generally. As shown from the discussion of the Kirk's views towards abortion throughout this chapter, several years went by with no mention of the subject at all, and it is possible that women were not fully aware of what the Kirk's views were. In addition, the changing attitudes at the 1985 and 1986 General Assembly could have caused confusion for women who were looking to the Church of Scotland for guidance, and could have led to them relying more on their own moral beliefs for decision making. By way of contrast, it is unlikely that Catholic women would be unaware of the position of the Catholic Church on abortion, as it was such an important topic. The Catholic Church spoke out strongly against termination of pregnancy, and several Papal declarations made it clear that to have an abortion for any reason was sinful. However, the situation is far more complex than linking religion directly to prenatal testing, as several other factors are clearly influencing women's

[161] Congregation for the Doctrine of the Faith, *Instruction on Respect for Human Life in its Origin and on the Dignity of Procreation Replies to Certain Questions of the Day*, 1987.
[162] Ibid.
[163] Rapp, *Testing Women, Testing the Fetus*, p. 253.

decision making. From the data above it seems that it is a personal choice for each woman, who will take into account religious, moral and personal beliefs and situations before deciding on the best course of action for herself and her family. This is summarised well by Rapp, who as a result of her research concluded that:

> Religion provides one resource in the complex and often contradictory repertoire of possible identities a pregnant woman brings to her decision to use or reject amniocentesis. There is no definitive "Catholic," "Jewish," or "Protestant" position on reproductive technology, when viewed from the pregnant woman's point of view. Rather, each concrete, embedded pregnancy is assessed in light of the competing claims on maternity the individual acknowledges and to which she responds.[164]

It is certainly the case that, in the genetics clinics run by Ferguson-Smith, decision making did not correlate strongly with religion. Despite Glasgow being known for its religious population, prenatal screening services were highly utilised, and few women seemed to explicitly state their religion as a reason for turning down such services. However, as can be seen throughout this chapter, those who strongly supported the anti-abortion cause seemed unwavering in their views, and it is possible that they would not attend for any prenatal testing, causing their data to go unrecorded. It would therefore be very difficult to trace these women to find out more about their decisions, as they would be unlikely to have come into contact with genetic services. Whilst their reasons for turning down testing would possibly be recorded by midwives at their antenatal appointments, it seems unlikely that their details would be made easily available to researchers in the subject area due to patient confidentiality issues.

VIII. Conclusion

What can be determined from the data presented in this chapter is that abortion is a highly emotive and subjective topic, with wide-ranging views held by a variety of individuals. Religious organisations have played a key role in attempting to influence abortion legislation since the development of Steel's Bill, whether arguing in favour of or against the Bill. For the Church of Scotland, the subject of abortion has been a well-

[164] Ibid., p. 159.

debated but also divisive matter. Initially supporting Steel's Bill and aligning themselves with the Anglican publication *Abortion An Ethical Discussion*, they were seen to hold less restrictive views on abortion than the Catholic Church. However, within the Church of Scotland there were many who did not agree with this stance, and this can clearly be seen in the 1985 General Assembly, which voted that abortion would only be permitted to save the life of the pregnant woman. This decision caused backlash, and was subsequently reversed at the 1986 General Assembly.

The situation within the Catholic Church has remained steadier over time, as they have continued to stick to the viewpoint that they have held for centuries which is that abortion is morally wrong. The Catholic Church was surprisingly quiet in leading the fight against Steel's Bill, however since the passing of the Abortion Act 1967 they have been among its most vocal opponents. With such staunch views on abortion, it would be expected that there would have been a strong opposition from the Catholic Church to prenatal testing, as the outcome of a diagnosis of fetal anomaly tended to be termination of the pregnancy. However, this opposition seems to be surprisingly missing, with no official statement made on prenatal testing by a Pope until 1987.

Whatever the reasoning behind this lack of discussion, it is unclear whether the pronouncements of the Catholic Church would have had a direct impact on many women who were undergoing prenatal testing, as highlighted by the discussions of the complex nature of the influence of religion on prenatal decision making. Whilst there were some women who were unwilling to take part in prenatal testing, or act upon its results, due to their religious beliefs, for many their religion was only one part of a complex web of ethical and moral beliefs which impacted their decision making. It is hoped that this chapter has highlighted the key role played by the Church of Scotland and the Catholic Church in the abortion debate, particularly as it relates to the issue of fetal anomaly, and has shown the complex nature of interactions which exist between religion and prenatal testing that can impact decision making.

Conclusion

I. Introduction

This thesis set out to examine the development of prenatal diagnosis between 1950 and 1990, using the West of Scotland as a case study. As was highlighted in the introduction, this is an important original contribution as little scholarly attention has been paid to the history of prenatal testing in Scotland. Focusing analysis on the city of Glasgow was particularly significant, given the interesting circumstances under which prenatal testing was devised and applied. There are many benefits to using a local study to gain an insight into the medical innovations and social implications of the field of prenatal testing. Under the leadership of Malcolm Ferguson-Smith, Glasgow was at the forefront of the implementation of many of the prenatal testing and screening programmes. Concurrently, anti-abortion attitudes were held by many religious figures in the region. Glasgow therefore provided a unique opportunity to explore how scientific and social factors combined to impact the development of prenatal testing.

It has been shown that the role of certain individuals can greatly impact service expansion and availability in a region, as highlighted through the work of Malcolm Ferguson-Smith and his colleagues. Throughout this thesis it can be seen that the scientists and clinicians who worked in the prenatal testing field were driven to make these services available to the public. By analysing the role that Malcolm Ferguson-Smith and his colleagues played in bringing prenatal testing to Glasgow and the surrounding areas, a detailed picture emerges of the relevant scientific innovations which occurred in this region. It was possible to analyse the specific details of testing and screening programmes, particularly for chromosome anomalies and neural tube defects, and the administrative hurdles faced when creating a new specialty could also be revealed. It was, however, also essential to place these developments in a national context, which was achieved through the analysis of medical and scientific journals, newspapers and magazines.

Whilst the scientific and technical developments which were occurring in prenatal testing were a key focus of this thesis, these did not evolve in isolation from the social time period in which they occurred. As was highlighted throughout the introduction, the importance of considering the social context was paramount to gaining a fuller understanding of the development of the prenatal testing field, which was particularly important for Glasgow. Thus, an analysis of the role of abortion legislation in the form of the Abortion Act 1967 was undertaken, with a focus on the impact that the ability to diagnose fetal anomaly had on altering views surrounding termination of pregnancy. This analysis helps to show that the majority of the public supported abortion being available for reasons of fetal anomaly.

As the legislation kept abortion strictly under the control of the medical profession, their views were important for gaining an insight into how this affected access to abortion services, with the role of two influential clinicians in Scotland, Dugald Baird and Ian Donald, considered in detail. The examination of the views of Ian Donald provided a further insight into the effect that an individual could play on the availability of prenatal services. Despite holding strong anti-abortion views in the majority of circumstances, Donald was willing to carry out a termination of pregnancy if the fetus had, in his view, no chance of spiritual development, due to severe fetal anomaly. This thesis examines Donald's friendship with Ferguson-Smith, highlighting the importance of personal connections in influencing decision making. The importance of individuals is brought to the forefront, and the complex nature of decision making in prenatal testing highlighted.

As the West of Scotland had a highly religious population the views of two of the main Christian denominations, the Church of Scotland and the Catholic Church, towards abortion were considered. This work is particularly significant, as little attention has previously been given to the attitude of the churches towards abortion for fetal anomaly. Throughout this thesis it becomes apparent that Glasgow was a highly religious city, where the Catholic Church frequently promoted anti-abortion messages. Large protests, marches, and rallies were well attended by local people, and this general atmosphere could have caused difficulties for those involved in prenatal testing. However, such conflicts did not materialise between the groups involved, at least not on the scale that

might have been predicted. There were only a few direct attacks on prenatal testing by religious organisations, and equally few official proclamations on its moral acceptability. This lack of conflict is also apparent when decision making following prenatal testing is considered.

Thus, by using a local case study, what emerges are the stories of several individuals and groups, who all played a role in impacting the field of prenatal testing. Through the investigation of scientific technologies and laboratory tests, the campaign for more permissive abortion legislation, and the strongly held views regarding the rightfulness of prenatal testing, this thesis has drawn out the stories of the people involved. Linking these stories into a narrative emphasises the importance of treating both the technical and social aspects with equal importance, as outlined in the introduction of this thesis. This work makes an important contribution to the current literature on the development of prenatal testing, by detailing how the scientific and medical discoveries evolved over time, and how they were received by society. Specifically, for Glasgow, it becomes clear that prenatal testing became a routine aspect of antenatal care, despite broader opposition to abortion by certain groups within the city.

The work which was undertaken in Glasgow also contributed to the overall expansion of the field of prenatal testing in a national and international context. For example, work confirming the link, first shown by Brock and Sutcliffe, between alpha-fetoprotein and neural tube defects, and the ability to screen pregnant women for these conditions using maternal serum, would change the field of prenatal diagnosis entirely. In addition, by contributing a number of patients to research studies such as that examining the link between folic acid and neural tube defects, the medical genetics department in Glasgow directly contributed to the revision of international protocols of pregnancy management. Debates between Ferguson-Smith and Ernest Hook on the specifics of the maternal age effect on chromosome disorders exemplifies the international span of the community of clinicians and scientists who were investigating various aspects of the prenatal diagnosis field, as did Ferguson-Smith and Yates' work on the significance of maternal age. For Ferguson-Smith specifically, his role as the first Editor of the journal *Prenatal Diagnosis* increased his international profile. Ferguson-Smith also communicated with

researchers and clinicians from around the world about prenatal diagnosis projects, including obtaining reagents from Nishi in Japan to assist with the maternal serum alpha-fetoprotein screening programme.[1]

One of the most important international links that Ferguson-Smith maintained throughout his career was with the department of medical genetics at Johns Hopkins University in Baltimore, led by Victor McKusick. McKusick played a central role in the development of the field of medical genetics. He was responsible for establishing the first medical genetics clinic at Johns Hopkins in 1957, and was centrally involved in many key research projects throughout his career, including the Human Genome Project. McKusick also created *Mendelian Inheritance in Man*, a catalogue of human phenotypes which is updated on an annual basis (initially published as a text, and now available online).[2]

Ferguson-Smith contributed a chapter to a book written about Victor McKusick and the history of medical genetics, within which he described McKusick as having earned 'the title of "founding father" of medical genetics'.[3] Ferguson-Smith speaks of McKusick in an almost biblical sense in this chapter, describing the trainees that McKusick had 'gathered around him' at the Moore Clinic, as his 'disciples', many of whom would go on to 'spread the word and create clinical genetics centers around the world'.[4] Ferguson-Smith remained in correspondence with McKusick throughout his career, and McKusick was invited to open the Duncan Guthrie Institute when it was established.[5] This highlights the continued impact that training in McKusick's department had on Malcolm Ferguson-Smith, and the high regard in which he held McKusick. Through his connection with McKusick and the department in Johns Hopkins, Ferguson-Smith had

[1] Details on this provided in chapter four of this thesis.
[2] 'The Victor A. McKusick Papers', *NIH U.S. Library of Medicine* <https://profiles.nlm.nih.gov/JQ/> [accessed 5th September 2019].
[3] Malcolm A. Ferguson-Smith, 'Cytogenetics and Early Days at the Moore Clinic with Victor McKusick', in *Victor McKusick and the History of Medical Genetics*, ed. by Krishna Dronamraju and Clair Francomano (New York: Springer, 2012), p. 53.
[4] Ibid.
[5] Ibid., p. 62.

strong international links in the medical genetics community in North America and beyond.

This reputation of medical genetics in Glasgow can be seen in the number of students who would travel from abroad to learn from those working in the department. One of the key ways in which Glasgow contributed to the expansion of medical genetics internationally, was through the MSc course which was set up under the leadership of Malcolm Ferguson-Smith, and expanded by Douglas Wilcox. This course has been described as disseminating widely the basic principles of genetics. At a more advanced level, researchers and clinicians came to study and learn the techniques at the Duncan Guthrie Institute, before taking up key positions in genetics departments elsewhere. One example is Maria Guida Boavida, who came from Portugal to gain experience in Glasgow. [6] As described in chapter two, one interviewee commented that there couldn't have been many places in the United Kingdom that didn't have a staff member who had spent time at the Duncan Guthrie institute.[7] Many of the staff of the Glasgow Institute had also spent time studying elsewhere, including Elizabeth Boyd, who worked in a laboratory in Paris, David Aitken, who spent time in Holland, and Mike Connor, who worked with McKusick at Johns Hopkins University.[8]

II. Chapter Findings

The main focus of chapter one was to detail the technical developments which made prenatal diagnosis feasible. These technologies formed the central component of testing and screening programmes, both in the West of Scotland, and throughout the rest of Europe and North America. A key feature of this chapter was the description of the elucidation of the correct chromosome number in humans. It is argued that this discovery was the foundation upon which much of prenatal diagnosis was based, enabling it to become feasible and clinically relevant. By establishing the human

[6] EB Interview, DS300139, p. 4.
[7] JL Interview, DS300179, p. 9.
[8] For information on each of these, see the relevant pages of their interview transcripts:
EB Interview, DS300135, p. 3.
DA and JC Interview, DS300190, p. 1.
MC Interview, DS300143, pp. 1-2.

chromosome count as 46, it became possible to identify chromosome conditions which differed from this number, thus enabling the detection of chromosome anomalies.

This information became particularly relevant to prenatal testing when combined with amniocentesis. The development of this procedure in the 1950s, which entailed the extraction of amniotic fluid for analysis, was complimented by the discovery that cells obtained from amniotic fluid could be cultured in the laboratory. In 1966 Steele and Breg showed that the chromosome constitution of the cells found in amniotic fluid could be determined. This was a fundamental turning point for prenatal testing. Amniocentesis went on to become an integral part of antenatal care, despite being associated with an increased miscarriage risk. Amniocentesis was also used to analyse the biochemical properties of the amniotic fluid, particularly with regards to alpha-fetoprotein, which was found to be a useful diagnostic marker for neural tube defects and Down's syndrome. The discovery that alpha-fetoprotein could cross the placental barrier, and be detected in the maternal serum, transformed prenatal testing. Increased levels of alpha-fetoprotein in the serum were linked with neural tube defects, whilst decreased levels were associated with Down's syndrome. It thus became possible to take a simple blood sample from a pregnant woman, identify the likelihood of her fetus having these conditions, and if necessary, refer her on for further diagnostic testing. This innovation, it has been argued, opened up the prenatal field to all pregnant women, resulting in prenatal screening becoming a routine aspect of antenatal care.

Despite these developments, throughout the 1960s and 1970s, a number of medical professionals were concerned that the testing could only take place in the second trimester of pregnancy. This would result in terminations of pregnancy usually taking place after 20 weeks gestation, which was more medically challenging and thought to be more emotionally upsetting for the women who faced this situation. Several attempts were therefore made to develop methods which would enable a diagnosis to be made in the first trimester of pregnancy. This was realised with the development of chorionic villus sampling (CVS). However, despite the high hopes that many had for CVS, the test did not prove to be as popular as expected. The procedure was associated with a

higher miscarriage rate than amniocentesis, and women who were not identified as being at increased chance of anomaly generally opted for amniocentesis.

As women were becoming more aware of the increased miscarriage risks associated with invasive procedures, ultrasound was beginning to play a role in the direct diagnosis of structural anomalies of the fetus. Pioneered in the 1950s by Ian Donald and his colleagues, ultrasound made the fetus visible, and was not associated with any increased risk of miscarriage, as it was an entirely non-invasive technique. Ultrasound was able to visualise conditions such as anencephaly, and was also centrally involved in improving the safety of invasive prenatal testing methods, such as amniocentesis. Thus, a combination of invasive and non-invasive prenatal testing techniques became available, which made it possible to detect an increased number of fetal anomalies.

However, in order for these technologies to be clinically significant, they had to be developed for use in a clinical setting, and then accepted by pregnant women. The clinical and advisory services of the Glasgow Department of Medical Genetics facilitated this transition. As outlined in the introduction, this thesis aimed to use the case study of Ferguson-Smith to examine the development of prenatal testing in detail, and Ferguson-Smith's career was therefore the focus of chapter two. Ferguson-Smith's education and early job roles were examined. During his school and university studies, he already had an interest in the subject of genetics. His movement into the field of chromosome studies occurred as a result of a chance meeting with the pathologist Bernard Lennox, who was looking for someone to assist him with a nuclear sexing project. This study, examining males with Klinefelter's syndrome, piqued Ferguson-Smith's interest, and convinced him of the importance of studying human chromosomes in more detail. This interest was, however, not shared by others working in Glasgow at this time, and Ferguson-Smith moved to Johns Hopkins University in Baltimore, to further his skills.

The time Ferguson-Smith spent at Johns Hopkins structured his future career, and he returned a few years later as the first Lecturer in Medical Genetics at the University of

Glasgow. He then spent a number of years setting up a chromosome diagnostic service within the West of Scotland region. As chromosome studies advanced and amniocentesis became feasible, he then turned to establishing a range of prenatal testing services. As was highlighted in chapter two, the work using amniocentesis in prenatal testing in Glasgow was first begun with the aim of enabling women to continue on with pregnancies, which would otherwise have been terminated on the basis of possible fetal anomaly. From Ferguson-Smith's perspective, the development of prenatal testing in Glasgow was carried out with the aim of enabling women to consider further pregnancies, who had previously been impacted by fetal anomaly during a previous pregnancy. This is important to note, as questions are often raised in the literature about the link between prenatal testing and eugenics. This was seen in the discussion in chapter six, when figures such as Archbishop Winning and Marilyn Gillies Carr publicly condemned what they saw as the link between prenatal testing and eugenics.

The department became exceptionally busy with the advent of prenatal testing, and initially did not even advertise their services, as they had a great deal of work from patients who were already known to the medical genetics department, or whose clinicians had connections to Ferguson-Smith. As prenatal testing continued to expand, and it became possible to detect both chromosome anomalies and neural tube defects, the workload grew exponentially, with several thousand maternal serum samples needing processed each year. This increased caseload required more staff, and with more staff came the need for larger premises.

Despite financial difficulties, expansion of facilities was eventually achieved with the building of the Duncan Guthrie Institute of Medical Genetics. As outlined in chapter two, the Institute was one of the first of its kind in the United Kingdom, and was responsible for bringing together a number of individuals working on various aspects of prenatal testing, including clinicians, scientists and technicians. The founding of the Duncan Guthrie Institute and an analysis of its services again illustrates the importance of local case studies; it was possible to examine working relationships between staff, weekly routines, and specific details of testing programmes to gain a detailed insight into how the creation of such a facility impacted service availability. Although

Ferguson-Smith moved to Cambridge in 1987, the Duncan Guthrie Institute continued to provide prenatal services for several decades after this relocation, highlighting the demand for the services that were being provided.

The detection of chromosome anomalies formed a central part of the department's workload, and as highlighted in chapter one, was the cornerstone on which prenatal diagnosis was founded. Chapter three therefore focused on the development, implementation and uptake of testing for chromosome anomalies, both within the West of Scotland and further afield. Prior to the discoveries which enabled the analysis of the fetal karyotype, chromosome studies focused on patterns of heredity. It was hoped that it would be possible to predict the likelihood of a future pregnancy being affected by the condition being studied, but there was little thought towards preventing the birth of these future children through termination of affected pregnancies. It is argued in chapter three that the combination of the ability to culture and karyotype cells from the amniotic fluid, alongside the passing of more permissive abortion legislation in the form of the Abortion Act 1967, paved the way for the development of testing for chromosome anomalies.

Beginning with amniotic fluid samples gathered from Rhesus-incompatibility pregnancies, the Glasgow group gained experience in developing these cell cultures, and a short time later were able to offer amniocentesis for the purposes of prenatal diagnosis. Other groups throughout the United Kingdom and further afield were also carrying out such work, and publications appeared in several prominent medical journals detailing their experiences. Although prenatal testing for chromosome conditions was shown to be relatively accurate, the testing faced a number of technical difficulties such as mosaicism, where a mixed chromosome constitution was discovered. As is argued in chapter three, these findings not only presented a challenge to the medical profession, but also to the pregnant women, who faced a choice of whether or not to terminate their pregnancies based on an uncertain prognosis. With problems surrounding the test results, and the link between amniocentesis and an increased miscarriage rate, it is perhaps unsurprising that many clinicians were wary of offering amniocentesis to all pregnant women. Instead, the association between

increased rates of chromosome anomalies and increasing maternal age was used to limit the testing to women who were seen to be at a higher chance of having a fetus with an anomaly. A great deal of debate existed within the scientific and medical community around what age should be used as a threshold for an offer of amniocentesis. Ferguson-Smith was centrally involved in these debates, and advocated for an age of 35, which was a lower age than many of his colleagues and contemporaries opted for.

Whilst debates were ongoing surrounding maternal age, it became apparent that uptake rates of prenatal testing programmes were lower than anticipated, with fewer women willing to undergo amniocentesis than expected. The number of fetuses with chromosome anomalies being detected was therefore small, which was deemed to be disappointing by some within the medical community. However, the advent of prenatal screening programmes extended the possibility of detecting fetal anomalies to the entire pregnant population. As decreased levels of alpha-fetoprotein in the maternal serum were associated with an increased likelihood of Down's syndrome in the fetus, the possibility opened of detecting the condition in women who would not have typically been offered an amniocentesis, for example, if under the age of 35.

As noted above, in the detection of neural tube defects, alpha-fetoprotein was also key, with elevated levels of the protein being associated with an increased likelihood of anencephaly or spina bifida. The rate of neural tube defects was particularly high in the West of Scotland, and was of significant medical concern. They therefore formed a major research focus for the group led by Ferguson-Smith. The development of testing and screening for neural tube conditions was described in chapter four. The screening programmes for Down's syndrome and neural tube defects proved to be popular, with large numbers of women taking part. They have been developed over time, and are still in use today.

There existed huge variations in the rates of neural tube defects amongst different geographical regions, and the detection rates using screening programmes varied greatly as a result. It was often found that screening programmes only played a useful role in

detection in areas where high rates of neural tube defects were prevalent. Indeed, one region cancelled their screening programme entirely, as they viewed their results as unsuccessful. What emerged was a situation in which access to such programmes was based on geographical location, a situation many were unhappy with. It did, however, become possible to circumvent these differences, when it was found that folic acid played a key role in preventing the formation of neural tube defects. Taking folic acid supplements decreased the recurrence rates of neural tube defects in future pregnancies of women who had previously had an affected child, therefore reducing the numbers of children born with these conditions. Despite the controversy surrounding the ethics of the clinical trials of folic acid, it was decided over time to recommend supplementation for all pregnant women. Thus, for the first time, it became possible to prevent the formation of a fetal condition, as opposed to terminating an affected pregnancy. This would be a far more acceptable outcome for many prospective parents.

Whilst the first four chapters of this thesis examined the development of many of the technical and clinical aspects of the prenatal diagnosis field, these developments were happening amongst the changing social context of the decades in which they were situated. One of the key changes which occurred in the 1960s, was the passing of the Abortion Act 1967, which made access to abortion legal throughout Scotland, England, and Wales, with fetal anomaly forming a specific category within the legislation. The focus of chapter five was therefore the development of the Abortion Act 1967, and the various factors which influenced this, and the aftermath of the implementation of the legislation.

Throughout this thesis it was argued that the passing of more liberal abortion legislation was essential for the prenatal field to expand in the manner in which it did. Without legal abortion, prenatal testing could have been used for information only. However, when confronted with a diagnosis of fetal anomaly, most women would choose to terminate their pregnancies. It is therefore unlikely that prenatal testing and screening programmes would have become such an established feature of antenatal care if providing information about the fetus without the option to terminate an affected pregnancy was its only use. One of the key arguments throughout chapter five is that

fetal anomaly played an important role in changing attitudes towards termination of pregnancy, with public opinion being broadly sympathetic towards women who wanted to abort their pregnancy for this reason. The importance of fetal anomaly for impacting abortion legislation was described in detail, and it was highlighted that many people viewed abortion after a diagnosis of a fetal condition as being 'different' to terminations for social reasons. It has been put forward by a number of commentators that the particular crises brought about by Thalidomide, and the rubella epidemic, in the 1960s, were influential in changing attitudes. This thesis presents evidence which supports these claims.

An analysis was undertaken of the ways in which fetal anomaly was discussed within the abortion debates, with a key theme of uncertainty emerging. Concerns surrounded how sure a clinician could be in predicting a diagnosis, which was difficult prior to the advent of prenatal testing. Although there were worries over the termination of unaffected fetuses, many were still in favour of a fetal anomaly clause despite this uncertainty, including Steel himself. Attempts were made to alter the language within the fetal anomaly clause. However, these were defeated. By the time of Steel's Bill, it was clear that there was widespread support for a fetal anomaly clause, although there were still some individuals who wanted the clause removed. It has been argued that those who opposed the fetal anomaly clause were those who were against abortion more broadly.

Whilst fetal anomaly may have played a key role in changing views surrounding termination of pregnancy, it was relevant in only a small number of cases put forward for abortion requests, which could perhaps explain why it was viewed as different to some of the more controversial clauses. As was highlighted in the earlier discussion of chapter two, figures such as Ferguson-Smith also hoped that the advent of prenatal testing would actually lead to continuation of pregnancies which would have otherwise been terminated due to suspected fetal anomaly, without a confirmed diagnosis. By way of contrast, far more concern surrounded the idea of abortions taking place for 'social' reasons, under the provisions of the Abortion Act 1967. As the medical profession were going to be responsible for carrying out abortions, it is unsurprising that many of them

entered into debates surrounding the ethics of termination of pregnancy. The views of key medical professional bodies were considered in chapter five, with a key theme emerging that each of these organisations was acting in its own interests. As a whole, the medical profession was keen for clinicians to retain autonomy over the abortion decision making process, controlling access to abortion services. The specific views of two clinicians based in Scotland, Dugald Baird and Ian Donald, were examined in detail. As was emphasised throughout this section, these clinicians had a major impact on availability of, and access to, abortion services throughout their region. As Ian Donald was based in Glasgow, his story was of particular importance. As already noted, Donald's view was that termination of pregnancy should be carried out only if the fetus had little prospect of spiritual development. Donald did carry out terminations of pregnancy on Ferguson-Smith's patients whom he felt fitted into this category. This aspect of Donald's views is not widely known, and a link with Ferguson-Smith has not been raised in the published literature. Donald's refusal to carry out abortions for other reasons resulted in a problem with access to abortion services in Glasgow, illustrating the control that such senior medical figures exercised. The interesting case of Donald again emphasises the benefits of using a local area as a case study, in order to analyse these nuances in detail.

Geographical inequality of access to abortion services, such as that which existed in Glasgow, became apparent in the years following the implementation of the Abortion Act. In response to this and other areas of concern, calls were made for an inquiry into how the legislation was working in practice. The Lane Committee was set up, and, in 1974, published a detailed report of its findings. Although the Lane Report highlighted areas of concern, overall it unanimously supported the working of the Abortion Act. This chapter examines the Scottish response to the Report, from the perspective both of the medical profession and several religious organisations. Generally, the response of the medical profession was positive. One of the key areas of discussion, however, was the upper time limit at which abortions could take place, with many of the nursing and midwifery groups supporting a limit lower than the 24 weeks which the Lane Committee supported. The alternative of a 20-week limit was often suggested. However, an upper limit of 20 weeks could prove restrictive given the time necessary to

undergo prenatal testing, receive a diagnosis, and proceed with a termination of pregnancy.

In addition to considering the medical profession's views towards the Lane Committee report, several religious organisations were also considered. However, it became clear in the evidence presented within chapter five, that there was not such widespread support for the Lane Report amongst these groups, as there was by the medical groups. Several areas of concern were raised by religious organisations, including feeling that anti-abortion views were not represented within the composition of the Lane Committee. Whilst this section of chapter five briefly examined the opinions of several religious organisations, the views on abortion of two of the main religious denominations in the West of Scotland, the Church of Scotland and the Roman Catholic Church, were the focus of chapter six. Interestingly, it had been envisaged that the views of the Church of Scotland and the Roman Catholic Church to prenatal testing would be considered in detail for this thesis, but there was only sparse material available on the subject. Instead, the majority of the primary sources discussed attitudes towards abortion more generally. As the only options available after prenatal testing during the time of the study were either continuation or termination of the pregnancy, the views of both the Church of Scotland and the Catholic Church to abortion more generally were considered.

It was shown throughout chapter six that the views of the Church of Scotland members to abortion were fluid, and changed a great deal over time. The Church of Scotland worked to influence the provisions of the Abortion Act 1967, and for almost two decades after the Act was passed, remained generally in favour of abortion being permissible in limited circumstances. However, the official views of the Church did change, albeit only temporarily, in the mid-eighties. By way of contrast, the views of the Catholic Church have remained fixed over time on the subject of abortion. They have declared that direct abortion is not permissible under any circumstances. Despite their stance, it is argued throughout chapter six that the Catholic Church did surprisingly little to prevent the development and implementation of the Abortion Act 1967. Very few campaigns took place, and it appears that the legislation took them by surprise.

However, the Catholic Church became one of the most vocal groups in the fight against abortion throughout the 1970s and 1980s. They were responsible for organising huge rallies, petitions, and sponsoring Bills in an attempt to restrict the circumstances under which abortion was available. Despite all of their efforts, the Abortion Act 1967 remains in place, with many women making use of the legislation to legally end their pregnancies.

It might therefore be expected that a conflict would exist between the Catholic Church and prenatal testing, due to the main clinical intervention following testing being a termination of pregnancy. However, interviews with medical professionals who worked in the West of Scotland reveal a much more complex story, whereby decision making did not seem to be directly linked to religious identification. Throughout the wider literature, it is apparent that women who identified as religious could still choose to undergo prenatal testing. It seemed to be religious adherence, as opposed to religious identification, which impacted such choices. Women who frequently attended religious services and who viewed their religion as being of central importance in their life, were found to be the least likely to undergo prenatal testing. For many others, whilst they identified as belonging to a religious group, their desire not to have a child affected by the conditions which could be tested for was more important than their religious faith. Thus, a complex system seemed to emerge, whereby prenatal decision making was determined by a number of factors, with religion one component which formed part of their consideration.

III. Contribution to the Literature

As was highlighted in the introduction of this thesis, there is a lack of published literature on the development of the prenatal testing field in the West of Scotland, and particularly the contributions made by Ferguson-Smith and the department he led. The few papers which do exist on Ferguson-Smith's contribution have been celebratory in nature, or written by Ferguson-Smith himself. This lack of publications has led to a dearth of critical analysis. The detailed study of this particular region has enabled a comprehensive picture to be built up of the scientific and clinical research which was undertaken, and the impacts it had on service provision in the West of Scotland. By

utilising a wide range of sources throughout this project, a narrative has emerged which takes into account many regional differences, rather than considering the United Kingdom as a whole, in contrast to many previous studies. In their article examining the development of medical genetics as a specialty area in Manchester, Coventry and Pickstone highlighted the need for 'comparative studies of other regional and national centres' which they felt was 'particularly true with regard to Scotland'.[9] Whilst this thesis focuses on the West of Scotland, and not the country as a whole, it has highlighted some of the specific nuances of the developments which occurred in that region, which would differ from experiences elsewhere.

Peter Harper, in his book *A Short History of Medical Genetics*, expressed the hope that professional historians of science and medicine would 'open their eyes to the importance of the field as part of science and of medicine, and in particular to the richness of the material available to be analysed from a historical perspective, most of which has been barely used until now'.[10] This thesis confirms Harper's assertion that there is a 'richness' of research material available. If comparable studies were carried out in geographical regions throughout the United Kingdom, then a more comprehensive picture could be built up of the particular trajectories that prenatal testing went through as it became established as a discipline.

From the literature review in the introduction of this thesis, it can be seen that there are several different texts available which cover various aspects of the development of the field of prenatal testing, and in some cases medical genetics more broadly. However, whilst all of these contain useful information, none focus specifically on the West of Scotland context, or on Ferguson-Smith's contributions. There are texts which do have similarities, including Ilana Löwy's *Imperfect Pregnancies: A History of Birth Defects and Prenatal Diagnosis*, and Malcolm Nicolson and John Fleming's book *Imaging and Imagining the Fetus: The Development of Obstetric Ultrasound*. Both of these focus on the scientific and clinical developments which were occurring in prenatal testing and

[9] Peter A. Coventry and John V. Pickstone, 'From What and Why Did Genetics Emerge as a Medical Specialism in the 1970s in the UK? A Case-history of Research, Policy and Services in the Manchester Region of the NHS', *Social Science and Medicine*, 49:9 (1999), p. 1236.
[10] Peter S. Harper, *A Short History of Medical Genetics*, (Oxford: Oxford University Press, 2008), p. 3.

ultrasound, respectively, and also look at the social context in which these were taking place. Löwy charts in detail the development of the field of prenatal testing as a whole, with only a brief mention of Glasgow or Ferguson-Smith. By way of contrast *Imaging and Imagining* is focused heavily on developments which happened in the Glasgow region. However, it deals specifically with the development of the ultrasound scanner. Therefore, the prenatal testing elements discussed are those which involved the direct application of ultrasound technology e.g. dating pregnancies and visualising physical anomalies. Thus, this thesis expands the scope of Löwy, and Nicolson and Fleming's work into a different context, looking specifically at the wider developments occurring in the field of prenatal testing, but within a specific Glasgow context.

Other texts discussed in the literature review which examined the social aspects of prenatal testing are *The Captured Womb: A History of the Medical Care of Pregnant Women* by Ann Oakley, *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America* by Rayna Rapp, *The Tentative Pregnancy: Amniocentesis and the Sexual Politics of Motherhood* by Barbara Katz Rothman, and *Heredity and Hope: The Case for Genetic Screening*, by Ruth Schwartz Cowan. Whilst these texts are essential for gaining an understanding of the social context of the development of prenatal testing, and also consider some of the key scientific and clinical advances enabling these developments, none specifically consider the developments which took place in Scotland. As already argued, what this thesis adds is a more nuanced story of developments within a particular geographical region. This thesis is able to discuss, for example, specific cases where an incorrect diagnosis was made, and can also look at a broad variety of identified individuals who worked in prenatal testing. In addition, whilst some of the texts named above take a stance on whether prenatal testing is inherently right or wrong, this thesis does not take such an approach. The scientific and clinical developments are considered, alongside the social context in which they were occurring, from a neutral perspective.

Within the literature review, the importance of Witness Seminars was also considered, with several of these being recognised as relevant to the development of the field of medical genetics more broadly, and in specific instances to prenatal testing too. Whilst

the advantages of these Witness Seminars were highlighted in the literature review, this thesis contributes to the literature in a different way. One of the key differences is that the oral history interviews carried out for this thesis took place individually in the homes or places chosen by the interviewees. Within such a setting, the interviewer has a greater freedom to lead and extend discussion on particular topics that may be of interest. The dynamic is also different within an individual interview, to that of a group discussion. Additionally, the selection of interviewees for this research was wider, involving many local technicians and other staff, thus representing a diverse group involved in prenatal testing in Glasgow.

From the above discussion it can be seen that there are several texts available which consider a variety of aspects of the development of prenatal screening. However, none of these consider the issues from the same perspective as this thesis. Whilst some consider developments which were occurring in Scotland, others consider the scientific and clinical perspective from a larger geographical perspective, and others still are more focused on the social climate and connotations of the implementation of prenatal screening. What this thesis adds to the literature, therefore, is a nuanced, specific and technically informed discussion of the contribution of Ferguson-Smith and his colleagues. This can be placed against the wider developments which were occurring in the prenatal testing field, and the specific social climate of the West of Scotland can be examined.

Whilst the above considers the contributions this thesis makes to the broader literature of prenatal testing, this thesis also examined the subject of abortion, due to its inextricable links to prenatal diagnosis. The importance of fetal anomaly in shaping abortion debates is considered by several scholars, but the work by Gleeson is perhaps the most in-depth. This thesis adds to the published literature on how fetal anomaly issues influenced legislative change. The ways in which fetal anomaly was discussed within abortion bills is examined, as is the role it played as an impetus of change. This thesis develops the idea of fetal anomaly being viewed as a separate category with regards to abortion, when considered alongside areas such as terminations for ‘social’ reasons. The original research carried out for this thesis highlights that much of the

concern initially surrounding a fetal anomaly clause was to do with the uncertainty of diagnosis. Interestingly, although for the most part prenatal testing had not become widely accessible prior to Steel's Bill being presented, the fetal anomaly clause was subject to less debate than other clauses within the Bill.

Within the literature review of this thesis it becomes clear that two of the most important scholars for consideration when examining Scotland are Gayle Davis and Roger Davidson. Davis and Davidson have written a great deal about the changing abortion legislation from a Scottish perspective, and their work is of key importance for chapter five. As Davis herself has commented, and as was previously highlighted, the lack of discussion focussing on Scotland in the published literature on abortion 'is a particular shortcoming'.[11] This thesis addresses this shortcoming, by considering many aspects of the abortion discussions from a Scottish perspective.

As can be seen within this thesis, a key topic within Davis and Davidson's work is the roles that Dugald Baird and Ian Donald played in impacting both abortion legislation, and the availability of abortion services within Scotland. This thesis pays particular attention to the case of Ian Donald, due to him being based in the Glasgow region. It examines the ideas put forward by Davis and Davidson that Donald was able to restrict access to abortion services, and provides a more nuanced analysis of Donald's practice, by utilising primary sources such as archive material and oral history testimony to consider in more detail the situation which was occurring in the West of Scotland. Specifically, this thesis looks at the views of Donald towards termination of pregnancy for fetal anomaly, and links this to his working relationship with Ferguson-Smith. This builds on the work which was been carried out both by Davis and Davidson, and also by Nicolson and Fleming, on the importance of Ian Donald as a figure within the region, but goes further by considering the ways in which relationships within the region could also have impacted clinical practice. As has been emphasised, this link between Donald and Ferguson-Smith is not well known, and therefore by bringing this material forward

[11] Gayle Davis, 'The Medical Community and Abortion Law Reform: Scotland in National Context, c1960–1980', in *Lawyers' Medicine: The Legislature, the Courts and Medical Practice, 1760–2000*, ed. by Imogen Goold and Catherine Kelly (Oxford: Hart Publishing, 2009), p. 144.

within this thesis, a new contribution to the literature surrounding Donald's views on abortion is made.

Davis and Davidson also examine key themes such as the role that medical professionals played in influencing abortion debates, and look at the ways in which the Lane Committee Report into the working of the Abortion Act 1967 was composed and received. Within this thesis, the Lane Committee Report is considered within chapter five, with an examination of the response to it from groups including those who were specifically based in Scotland. Where possible, the response to the Lane Report from groups who were based in the Glasgow region was considered, adding further contributions to the published literature on the responses of Scottish groups and organisations. It is hoped that such work helps to contribute to the work done by Davis and Davidson to highlight the specific situations and responses which were occurring in Scotland, which were often different from those which were happening in England. By examining Scottish responses, this thesis helps to add to the current literature on Scotland, which is important as the published literature which is available at present, aside from the work done by Davis and Davidson, often does not consider the nuances which existed in Scotland.

In addition to contributing to the current literature available on the subject of abortion, another key area of consideration for this thesis are the views of religious organisations to prenatal testing, particularly the Roman Catholic Church and the Church of Scotland. One of the most substantial contributions of this thesis to the wider literature, is in the examination of the views of the Church of Scotland, both towards abortion more generally, and prenatal testing specifically. As is shown in the literature review of this thesis, very few texts exist which examine the viewpoint of the Church of Scotland to abortion, and there are no texts specifically considering their views on abortion as a result of prenatal testing. This is a significant gap in the literature, and the material presented within this thesis can act to fill this gap, due to the detailed analysis that was undertaken of the changing views of the Church of Scotland. Aside from published books such as *Abortion An Ethical Discussion* and *Abortion in Debate*, there is not a great wealth of information on the viewpoints of the Protestant faith to abortion. As is

seen in this thesis, this is of central importance, as the Church of Scotland viewpoint did not remain static on abortion issues, and was influenced by the views of its members.

A similar statement could be made for the literature which exists on the Catholic Church viewpoint towards abortion. Whilst it was shown in the literature review that there are publications which discuss this viewpoint, most do not look specifically at prenatal testing. Indeed, even within the primary sources consulted for the research for this thesis, this material was difficult to locate. By instead examining the Catholic viewpoint to abortion more generally in the West of Scotland, this thesis contributes to the regional literature on the effect of Catholicism in the Glasgow area. This is of importance, as it provides a more detailed insight into the regional circumstances which existed within an area. For Glasgow, an area with a high population of Catholics, this is reflected in this thesis by highlighting that a great deal of work was going on to campaign against abortion legislation, which may not have been evident in other regions with a lower population of Catholics.

IV. Reflection and Recommendations for Future Research

This thesis set out to examine the history of prenatal diagnostic testing, utilising the case study of the West of Scotland. Specifically, key research questions included an analysis of the development of invasive and non-invasive prenatal technologies, and the role that Ferguson-Smith and his colleagues played in these developments, particularly for chromosome disorders and neural tube defects. It was argued in the introduction that the technical developments which occurred in the prenatal field were not stand-alone events, and were influenced and impacted by the social climate in which they were developing. By considering both the technical and social perspectives in detail, in a specific geographical region, the development of prenatal testing in Scotland can be placed amongst the broader history of prenatal diagnosis. This adds an important new perspective to the existing literature on the history of this antenatal development.

To undertake this project, a variety of source materials were used, including the Malcolm Ferguson-Smith archive, oral history interviews, and published scientific and

clinical papers. In addition, to analyse the social context around which the prenatal testing field was developing, newspapers and magazines were also consulted. It is useful to reflect on the nature of these sources, particularly the Ferguson-Smith archive and the oral history interviews, to gain an insight into their overall contribution to this thesis.

As mentioned previously, the Ferguson-Smith archive has been digitised as part of the Codebreakers: Makers of Modern Genetics programme, funded by the Wellcome Trust. This has resulted in the vast majority of the archive being available to access digitally, in PDF format. These documents were particularly useful to consult when constructing chapter two, as they gave a more personal insight into the developments which were occurring in the West of Scotland region than published scientific papers could. This was particularly true for the large correspondence section which contained communications to and from Ferguson-Smith spanning several decades. These letters helped to provide an insight into Ferguson-Smith's personality, and his changing status within the medical genetics community as his career developed. It was possible to get a sense of the emotions Ferguson-Smith felt at various points in his career, including excitement when new developments were progressing, and disappointment when issues such as lack of funding had to be faced.

However, as with all personal archives, there are limitations associated with using these sources. The documents housed in the archive are unlikely to be the full complement of all the written material that Ferguson-Smith gathered throughout his working career. It is likely that documents will have been discarded over time. Items that could be useful to a researcher may not have been deemed as of importance at the time they were created. It is also possible with any personal archive that decisions have been made not to include specific material, which the individual may not wish to have available to view by researchers or the wider public. This leads to the researcher not having access to documents which could provide a deeper insight into sensitive topics. It is also possible that the institution receiving the archived materials could make decisions as to which items were appropriate for inclusion in their holdings. This can also be reflected

in the way items are catalogued, which could result in items not being viewed in the same manner as when they were originally created.

As with many personal archives, the Ferguson-Smith collection is made up mainly of written material, which can result in certain information being missed from the archival record. In the case of the Ferguson-Smith archive, this was particularly clear for his colleagues. As discussed in the introduction of this thesis, that this group are largely missing from the archival record is unsurprising – it is far more likely that colleagues would have been communicating in person, rather than writing letters to one another. That Ferguson-Smith's colleagues were not represented in the written archival documents led to the decision to carry out oral history interviews, to try and gain a further insight into the inner workings of the department. Initial interviews were carried out with Malcolm and Marie Ferguson-Smith, and during these discussions the names of others who had worked in the department were given. Several colleagues who worked during the time period that this thesis is focusing on were traced and invited to interview, whilst others contacted me directly having heard details of this research project, and as discussed in the methodology section of the introduction, unstructured interviews were carried out with all of these individuals. By speaking to a variety of individuals who had held different roles within the department, it was possible to build up a more complex picture of how the department functioned, both in terms of scientific research and clinical practice, and also with regards to working relationships within the team. These oral history interviews gave many individuals who had been involved in the prenatal testing field in Glasgow an opportunity to tell their story, which for many was the first chance they had been given to do so. By hearing about some of the key work which had taken place, it gave the project a sense of direction in which to focus my research attentions, particularly for published scientific and clinical papers.

Oral history interviews also have potential drawbacks. In the specific case of this research project, Malcolm Ferguson-Smith's knowledge of and support for the project could have impacted the research material which was generated. He had the ability to choose what information was given during the interview process; his awareness of the potential legacy that this interview could leave behind could have impacted the stories

that he chose to share. As mentioned in the methodology section of the introduction, having previously taken part in other oral history interviews, it is also possible that Ferguson-Smith had already created a narrative of his career history, which would be more difficult to deviate from. That Ferguson-Smith gave his support for the project could have also impacted both the pool of interviewees who agreed to take part in the research process, and also the stories they might have shared. It would perhaps have been more difficult for interviewees to speak negatively about their time in the department, knowing that their past colleagues would have the opportunity to read their testimonies when they were deposited in the Ferguson-Smith archive. It is also potentially less likely that employees who did not enjoy working in the prenatal field, or perhaps did not enjoy working specifically in the department in Glasgow, would have become central figures within the team. If this was the case, then it is unlikely that these individuals would have been invited to interview, or would have approached myself directly having heard of the research project. However, not all interviewees were directly suggested by Ferguson-Smith, so it is hoped that a broader picture has been created. Despite this, the majority of interviewees had at some point worked with Ferguson-Smith, and this potential lack of diversity in the interviewee group could have impacted the material that the interviews generated.

To triangulate these oral history testimonies, it could be useful in the future to hold a witness seminar to bring together former members of the department. Due to time and resource constraints this would not have been possible within the scope of this research project, but it could have played a useful role in helping to advance further the history of the medical genetics department. As can be seen in the Wellcome Trust Witness Seminars, having an open forum where individuals can recall their memories collectively plays an important role in untangling the unreliability of memory. If such a witness seminar was opened up to a broader constituency than just the medical genetics staff who worked under the leadership of Ferguson-Smith, perhaps to also include other research and clinical staff, it could perhaps go some way towards ensuring that the discussion of the development of the prenatal testing field in the West of Scotland was as balanced as possible.

In addition to widening the research focus within the West of Scotland, a particularly illuminating study which could be carried out in the future would be a comparison between the developments which occurred in the Glasgow and Edinburgh regions. This would help to further contribute to Coventry and Pickstone's wish for more comparative studies, and could perhaps provide information on their theory that 'The rapid institutionalisation of medical genetics in Edinburgh and Glasgow may well have stemmed from the historically closer ties between teaching hospitals and regional services in Scotland.'[12]

Even using substantial archives in combination with extensive oral history interviews cannot provide a complete characterisation and contextualisation of the history of prenatal testing. However, in order to ensure that the developments which were occurring in Glasgow were being placed in a national and international framework, a wide range of published sources were also examined for this thesis. Examination of a variety of academic journals helped to develop a more detailed understanding of how the work of the Glasgow group fitted in amongst all of the other scientific and clinical work in the prenatal testing field. Published papers also often provided a high level of detail of the tests which were being carried out, and the laboratory procedures involved. What is missing from published papers is the story behind the work. However, it is hoped that the combination of the use of archive material alongside oral history interviews, in addition to published papers, provides a widely rounded view of the developments which were occurring in the prenatal field in Glasgow. This is also the case with placing this work in the relevant social context of the time period in which it was occurring – archive sources, interview material and published sources such as magazines and newspapers, all combined to provide this rounded view, with all of these sources subject to limitations similar to those already alluded to.

A vast array of materials have been studied for the research for this thesis, but the voices of a few key groups are missing, namely, the women who underwent prenatal testing, and the religious figures who were active during the time period of the study.

[12] Coventry and Pickstone, 'From What and Why Did Genetics Emerge as a Medical Specialism in the 1970s in the UK?', p. 1236.

The tracking down of women who had underwent early prenatal diagnostic testing would be difficult, both in terms of access to the population, and also from an ethical standpoint. As was seen in discussions within this thesis, many women who underwent a termination after having a positive prenatal diagnosis struggled with this emotionally. Finding and approaching these women would therefore have to be done in a sensitive manner. This, however, should not preclude research taking place with the stories of these women as a central focus. Whilst the project was successful in locating a number of the scientists and clinicians who were active during the 1950s to late 1980s and beyond, it was not possible to find Catholic priests or Church of Scotland ministers who also fitted into this category. Interviews were carried out with two serving priests, and a midwife who strongly identifies as Catholic, but these individuals could not comment directly on many of the issues raised in the study. Of particular interest would be evidence relating to religious leaders who took an interest in the implications of prenatal testing.

Moreover, this study does not contain the voices of those who live with the conditions for which the testing has been designed. Individuals with Down's syndrome, for instance, could provide an important insight into how they feel the testing has impacted their lives. This would be particularly important and timely, given the discussions which currently surround the implementation of non-invasive prenatal testing (NIPT). As described in chapter three, NIPT involves analysing cell-free fetal DNA to determine the chromosome constitution of the fetus. The test is over 98% accurate in calculating the chance that the fetus has Down's syndrome.[13] NIPT is currently available from private providers at a cost of several hundred pounds. Talks are also underway to discuss its implementation by NHS Scotland. Concerns have already been raised that this programme will increase the numbers of terminations for Down's syndrome. Groups such as the Don't Screen Us Out campaign have been formed to protest against the implementation of the NIPT screening programmes.[14]

[13] 'NIPT for Down Syndrome A Guide For Patients and Healthcare Professionals', *The NHS Rapid Project* <http://www.rapid.nhs.uk/guides-to-nipd-nipt/nipt-for-down-syndrome/> [accessed 24th July 2018].
[14] 'Don't Screen Us Out', *Don't Screen Us Out* <http://dontscreenusout.org/> [accessed 26th July 2018].

Löwy has argued that prenatal diagnosis 'did not acquire the fame of other medical feats of that period', and that there was a lack of media discussion on the subject.[15] She has remarked that 'Recent developments in prenatal diagnosis seem to follow the trajectory of earlier innovations in this domain: a (mostly) incremental and (mainly) unexamined transformation of a new diagnostic method into a routine medical technology.'[16] The implementation of NIPT programmes would therefore benefit from a closer scrutiny as they are implemented, and future research could focus on analysing these developments as they occur. Similar sources to those used throughout this thesis, such as monitoring the medical journals, alongside analysing the media response, would provide an important insight into current perspectives on such issues. Discussions with figures such as the medical professionals involved in the testing, alongside religious organisations, women taking part in such programmes, and the communities of individuals that the testing would greatly impact, such as individuals with Down's syndrome and their families, would hopefully inform public discussion surrounding these issues. Whilst this thesis has analysed the historical development of prenatal testing, there is therefore a great deal of potential for the approaches used here to be implemented to analyse further developments.

[15] Ilana Löwy, *Imperfect Pregnancies: A History of Birth Defects and Prenatal Diagnosis*, (Baltimore: Johns Hopkins University Press, 2017), p. 3.
[16] Ilana Löwy, 'Prenatal Diagnosis: The Irresistible Rise of the 'visible fetus'', *Studies in History and Philosophy of Biological and Biomedical Sciences*, 47 (2014), p. 291.p. 296.

Appendix 1: Participant Information Sheet Given to all Interviewees

University of Glasgow

College of Social Sciences

Participant Information Sheet

School of Social and Political Sciences

The Genetics of Prenatal Diagnosis and Its Social Impact, c1950-c1990: the case of Malcolm Ferguson-Smith

Researcher – Paula Blair, PhD student in History of Medicine

Supervisors – Professor Malcolm Nicolson, Professor Kevin O'Dell and Professor Callum Brown

You are being invited to take part in an interview for a research project. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study?

This study examines the development of genetics in the twentieth century, with a focus on the advances in prenatal diagnostics in the West of Scotland during this time. It will also consider the social impact of these advances, with a particular focus on the interaction between those working in the field and religious groups, who often had strong views about the testing for moral and ethical reasons.

Why have I been chosen?

You have been chosen due to the unique perspective you can provide on one or more of the following areas: the social, scientific and/or medical developments which occurred in prenatal testing during this time period.

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen to me if I take part?

Taking part will involve participating in one or more face to face interviews, and should not take more than a few hours of your time in total. The interviews will be audio recorded and transcribed.

Will my taking part in this study be kept confidential?

Due to the nature of the research project it will not be possible to keep your identity confidential. However you will have the opportunity to read the transcript before it is used for the research, and will be given a copy of the transcript to keep.

Please note that assurances on confidentiality will be strictly adhered to unless evidence of wrongdoing or potential harm is uncovered. In such cases the University may be obliged to contact relevant statutory bodies/agencies.

What will happen to the results of the research study?

The results of the research study will be incorporated into a PhD which will be submitted in 2018. With your permission the transcript of this interview will be retained and housed in the Malcolm Ferguson-Smith archive at the University of Glasgow.

Who is organising and funding the research?

The research is through the University of Glasgow, but has been funded by the Economic and Social Research Council.

Who has reviewed the study?

The study has been reviewed by a number of Professors at the University of Glasgow, including Professor Malcolm Nicolson. It has also been reviewed by the College of Social Sciences Research Ethics Committee.

Contact for Further Information

If you have any questions regarding the study please contact me at p.blair.1@research.gla.ac.uk, or Professor Nicolson at Malcolm.Nicolson@gla.ac.uk

If you have any concerns regarding the conduct of this research project, you can contact the College of Social Sciences Ethics Officer Dr Muir Houston, email: Muir.Houston@glasgow.ac.uk

Appendix 2: Consent Form Given to all Interviewees

University of Glasgow

College of Social Sciences

Consent Form

Title of Project: The Genetics of Prenatal Diagnosis and Its Social Impact, c1950-c1990: the case of Malcolm Ferguson-Smith

Name of Researcher: Paula Blair

1. I confirm that I have read and understand the Plain Language Statement 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.

3. I consent to interviews being audio-taped and transcribed by the researcher.

4. I acknowledge that due to the small sample size anonymity will not be possible with this project, but that I will be given a copy of the transcript for verification.

5. I agree to the transcript of this interview being retained and housed in the Malcolm Ferguson-Smith archive at the University of Glasgow.

5. I agree / do not agree (delete as applicable) to take part in the above study.

Name of Participant	Date	Signature
Researcher	Date	Signature

Appendix 3: Details of Interviewees

David Aitken and Jenny Crossley:

David Aitken graduated with a BSc degree, and his initial role in the Department of Medical Genetics at the University of Glasgow was in the area of cytogenetics. He began studying for his PhD whilst based in the department, which involved examining the biochemical aspects of gene mapping. He spent time during his research working in Holland, learning about biochemical genetics, and would go on to lead the biochemical genetics team within the Duncan Guthrie Institute. He worked as a Consultant Clinical Scientist and spent time working on screening programmes for conditions such as neural tube defects and Down's syndrome, and was centrally involved in the research aspect of the department.

Jenny Crossley graduated with a degree in biochemistry from the University of Strathclyde. She initially worked in the Beatson hospital in Glasgow after graduating, and then took a career break. Upon returning to work, she took up a role in medical genetics in the Duncan Guthrie Institute in 1983, initially in the area of cytogenetics, before moving over to biochemistry in 1985. She worked as a Consultant Clinical Scientist, spending time on a variety of screening programmes and research projects throughout her time in the department.

Both David and Jenny retired in 2011.

Elizabeth Boyd and Anne Boyd:

Elizabeth Boyd studied for a BSc degree at the University of Glasgow, which she graduated with in 1956. She then went on to study for her honour's qualification in Botany, receiving this in 1958. This was followed by studying for a PhD in cytogenetics, under the supervision of Bernard Lennox. She moved over from working with Bernard Lennox to work with Malcolm Ferguson-Smith when he returned from the United States in 1961, and remained in the medical genetics department in Glasgow for the rest of her career. Worked in the diagnostics side of the department, working on blood and bone marrow samples.

Anne Boyd did not work in medical genetics in any capacity, and was present at the interview only to support her sister.

Mike Connor:

Graduated with his medical degree from the University of Liverpool in 1975. Spent time working in Liverpool after qualifying, before moving to take up a post to work at Johns Hopkins University in Baltimore, in the department led by Victor McKusick. Returned to the UK and spent time working on an MD in Liverpool on a genetic-based project, before returning to Johns Hopkins once again. Moved to Glasgow in 1982, when he was appointed a consultant in medical genetics on an NHS post. Moved over to a senior lectureship post at the University of Glasgow in 1984. Was the first NHS consultant in Scotland in genetics. Succeeded Malcolm Ferguson-Smith as the Chair of Medical Genetics in 1987, when Ferguson-Smith moved to the University of

Cambridge. Acted as the Professor in Medical Genetics, and the Director of the West of Scotland Regional Genetics Service; was involved in both the clinical and research aspects of medical genetics in Glasgow.

Alexander (Sandy) Cooke:

Completed an undergraduate degree in molecular biology at the University of Glasgow, before going on to undertake a PhD at the University of Dundee, and a post-doctoral research post at the University of Aberdeen. He began working in the Department of Medical Genetics in Glasgow in December 1980, initially in cytogenetics, before moving over to biochemical genetics. Spent time working in flow cytometry in the department, and also carrying out some molecular genetics research. Retired in 2013.

Malcolm Ferguson-Smith:

Graduated with his medical degree from the University of Glasgow in 1955, and after completing his residencies, began a job in the pathology department of Western Infirmary in Glasgow in 1956. Remained in this role until he moved to Johns Hopkins University in Baltimore in early 1959, to begin working as a Research Fellow in the medical genetics laboratory which was being set up by Victor McKusick. Remained at Johns Hopkins until late 1961, when he returned to the University of Glasgow as the first Lecturer in Medical Genetics at the institution. He was promoted to the post of Senior Lecturer in 1965, and Reader in 1971, before going on to become a Professor in 1973, the same year in which he was named the Burton Chair of Medical Genetics. He was responsible for the formation of the Duncan Guthrie Institute in Glasgow and remained working in the city as the key figure in medical genetics until 1987. He was involved in all aspects of medical genetics, including developing and implementing prenatal testing and screening programmes. He moved to take up the post of Professor of Pathology at the University of Cambridge in 1987 and went on to run their regional genetics service in East Anglia. He retired from his post in pathology in 1998 and went on to form the Cambridge Resource Centre for Comparative Genomics.

Marie Ferguson-Smith:

Began studying for a degree in history and economics in 1956, before becoming involved in genetics in 1958 through a part-time job working for Victor McKusick at Johns Hopkins University in Baltimore. She worked in medical genetics in Glasgow from its inception, initially working for the University of Glasgow, before moving over to an NHS contract in 1966/1967, where she would go on to lead the cytogenetics division of the prenatal testing section. She remained in Glasgow until she moved to Cambridge in 1987 with Malcolm Ferguson-Smith. Continued to work in medical genetics in Cambridge until her retirement from this field in 1993.

Fr. Fitzpatrick:

Qualified as a medical doctor in 1990. Worked in medicine until 1995, before entering the seminary to study to become a Roman Catholic priest. Has an interest in medical ethics, and is still active as a Roman Catholic priest at the time of interview.

Gordon Graham:

Obtained his biology degree in 1979, and upon graduating began working in the biochemistry department in Gartnavel General Hospital in Glasgow for 18 months. Moved to the Department of Medical Genetics in Glasgow in 1981, to take up a post as a Medical Laboratory Scientific Officer. He remained in the department throughout the rest of his career, working in a variety of roles such as screening for neural tube defects, and also completed a PhD in the early 1990s, part of which involved looking at folate metabolism. Retired in 2016.

Bill Hannay:

Qualified as a medical doctor in 1966, began working in obstetrics and gynaecology in 1967. Moved to Glasgow and started working with Ian Donald in 1974. Promoted to Senior Registrar in 1975, and Consultant in 1976, which resulted in a career move to work in the Lanarkshire hospitals. Retired in 2000.

Stuart Imrie:

Graduated with a degree in genetics in 1983, and began working as a Clinical Scientist in the medical genetics department in Glasgow the same year. Worked in various areas of the department initially including postnatal blood studies, before moving over to the prenatal section in 1985. Still working in the department at the time of interview.

Jennifer Lambert:

Graduated in 1976 with a degree in biochemistry. Worked in various research roles before moving to work as a Research Associate at the Duncan Guthrie Institute in 1984. Remained in medical genetics at Glasgow for the rest of her career, working in a variety of roles including a short period of time in the cytogenetics section, before moving over to the molecular genetics section. Retired in 2013.

Catherine McConnell:

Began working in the department of medical genetics in Glasgow in 1972, as a Junior Medical Laboratory Scientific Officer, based on her school qualifications. Studied various qualifications throughout her degree, and progressed on to become a Clinical Scientist. Spent time working in various areas of the department, including cytogenetics, assisting on a CSV research project, and working in molecular genetics. Retired in 2015.

Karen McIntosh:

Trained as a nurse in 1978, before going on to study for her midwifery qualifications in 1981. Began working in the medical genetics department in 1984, when they were looking for a midwife to be attached to the department. Heavily involved in direct patient care throughout her time in the department, and also worked on research projects. Remained in the department until she retired in 2014. Took up a role working with the charity Antenatal Results and Choices in the same year, as their Scottish Co-Ordinator.

Fr. Maguiness:

Began studying to become a Roman Catholic priest in the 1980s. Has a special interest in moral theology, and wrote a PhD thesis on that subject. Still active as a Roman Catholic priest at the time of interview.

Catholic Midwife:

Began studying to become a nurse in 1975, and followed her nursing training with also gaining her midwifery qualifications. Worked abroad for many years, before returning to Scotland in 1987, and resuming work as a midwife in a Glasgow hospital in 1988. Remained working as a midwife in this Glasgow hospital until 2015.

Sandy and Arlene Raeburn:

Alexander (Sandy) Raeburn qualified with his degree in medicine from the University of Edinburgh in 1964. He worked in clinical roles in Edinburgh, before moving to take up a post as a lecturer in the Netherlands in the early 1970s. He remained in this post as a lecturer whilst also studying for his PhD, and continued this research when he moved back to Edinburgh in 1973 to take up a post as a senior lecturer in medical genetics. He remained in this role until 1990, when he moved to take up the role of Chair of Clinical Genetics at the University of Nottingham. During his employment in Edinburgh, he spent time on secondment to the Duncan Guthrie Institute in Glasgow. Throughout his career he specialised in the study of cystic fibrosis and Down's syndrome, and after retiring in 2003 he was appointed a professor of genetics at the University of Oman, where he worked until 2008. He passed away in 2018.

Arlene Raeburn qualified as a primary school teacher, and after a career break became involved in the Scottish playgroup association. She set up a playgroup for babies and children with Down's syndrome in Edinburgh, which Sandy was also involved in. She returned to teaching full-time, and worked with children with a variety of disabilities in the school and college sectors, also in Edinburgh. She went on to pursue a qualification in counselling, and moved to Nottingham alongside Sandy, where she went on to take up a role as a counsellor at an IVF research unit.

Mary Shade:

Graduated in 1972 with a degree in bacteriology and genetics. Began working in the Galton Laboratory at University College London after graduation, and spent four years there working in cytogenetics. Moved to Edinburgh from London, and took up a job working with the Medical Research Council, where she remained for four years. Moved over to a prenatal cytogenetics role at the Royal Hospital for Sick Children in Edinburgh in 1979, and aside from a three-month period, remained there for the rest of her career, until retiring in 2011.

Margaretha van Mourik:

Qualified as a nurse in the Netherlands, and also completed qualifications in midwifery. Worked in these areas and the public health field, before starting work at the Duncan Guthrie Institute in 1982, as a research assistant on the folic acid/neural tube defect link project. Remained in medical genetics in Glasgow for the rest of her career, spending time as a nursing officer in genetics, before going on to become qualified as a consultant genetic counsellor. Still working in the department at the time of interview.

Douglas Wilcox:

Graduated with his intercalated medical and science degree from the University of Glasgow in 1979. After two years of rotations in the medical wards, began working in the Department of Medical Genetics in 1982. He became an Honorary Consultant in the department, and was heavily involved in the teaching and organising of the medical genetics course at the University of Glasgow. He spent his entire career in the department and focused a great deal on muscular dystrophy throughout his working life. Retired in 2011.

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