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**GENETIC INFORMATION, LIFE ASSURANCE, AND THE UK  
POLICY AND REGULATORY FRAMEWORK**

**By**

**JAMES MITTRA**

A thesis submitted in partial fulfilment of the requirements for the degree  
of Doctor of Philosophy in Sociology

University of Warwick, Department of Sociology

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### List of Abbreviations

<b>ABI</b>	-	Association of British Insurers
<b>ACGT</b>	-	Advisory Committee on Genetic Testing
<b>BSHG</b>	-	British Society for Human Genetics
<b>CEST</b>	-	Centre for the Exploitation of Science and Technology
<b>COE</b>	-	Council of Europe
<b>ESHG</b>	-	European Society for Human Genetics
<b>GAIC</b>	-	Genetics and Insurance Committee
<b>GIG</b>	-	Genetic Interest Group
<b>HGAC</b>	-	Human Genetics Advisory Committee
<b>HGC</b>	-	Human Genetics Commission
<b>HUGO</b>	-	Human Genome Organisation
<b>IPPR</b>	-	Institute for Public Policy Research
<b>MORI</b>	-	Market and Opinion Research International
<b>NHGRI</b>	-	National Human Genome Research Institute
<b>OST</b>	-	Office of Science and Technology
<b>UKFGI</b>	-	UK Forum for Genetics and Insurance
<b>UNESCO</b>	-	United Nations Educational, Scientific and Cultural Organisation
<b>WIHSC</b>	-	Welsh Institute for Health and Social Care
<b>WHO</b>	-	World Health Organisation



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**Declaration**

I confirm that this thesis is entirely my own work and has not been submitted for a degree at any other university. The thesis has been prepared in accordance with the university of Warwick's guidelines on the presentation of a research thesis.

## **Abstract**

This thesis provides the first extensive sociological analysis of the genetics and life assurance debate in the UK. It uses data from original qualitative interviews, as well as various policy documents and reports, to investigate the likely implications of genetic information for life assurance provision, reveal the narrative strategies used by key stakeholders as they account for their concerns on the issue, and evaluate the efficacy of the policy and regulatory framework. It also attempts to evaluate the suitability of the citizens' jury model as an alternative to existing decision-making procedures. The thesis begins by revealing the most likely social, commercial, legal, and ethical implications of allowing insurers to access new kinds of genetic information. A history of insurance, risk and probability is used as a starting point to challenge many of the pervasive fears and anxieties. This part of the thesis critically analyses the social and philosophical basis of such contested notions as 'discrimination', 'social exclusion', 'genetic information', and 'social justice', and begins to reveal some of the key strategies of stakeholders in the debate. The thesis then analyses stakeholder accounts of their concerns, and begins to reveal the ways in which they draw on a broad narrative repertoire to give their beliefs a degree of moral legitimacy/coherency. The impact this may have on the quality of debate is also investigated. Following from the analysis of stakeholder accounts, the thesis proceeds to investigate the nature of the policymaking and regulatory framework. Through a sociological analysis of the work of various advisory committees, which led to the implementation of a moratorium on insurers' use of genetic information, the thesis investigates how fair and equitable the overall political process has been, particularly in terms of the treatment of stakeholder evidence. It also assesses the role of the public and media in shaping the political response to this issue. The thesis concludes by assessing the citizens' jury as suitable procedures for resolving the conflicts around genetic information and life assurance. Both the potential advantages and persistent problems with the model are critically evaluated.

## CHAPTER 1

### INTRODUCTION: DEFINING THE RESEARCH PROBLEM AND ESTABLISHING THE METHODOLOGICAL FRAMEWORK

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#### 1. INTRODUCTION

The social, political, and epistemological imbroglio that has enveloped contemporary debates on the implications of the 'new genetics' is complex and multifaceted. A burgeoning volume of social research is investigating various aspects of this emerging technology. The purpose of this thesis will be to assess the impact new kinds of genetic information might have on access to private life assurance in the UK and critically evaluate the policy and regulatory framework. It will investigate the extent to which key stakeholders mobilise around a contentious policy issue, and use political rhetoric to shape the policymaking process. This introductory chapter will explain the underlying theoretical rationale of the thesis, highlight the ways in which it builds on previous work within the broader area of the sociology of science, and illustrate the specific aims and objectives of the research.

A full description of the methodology used will also be provided. The introduction will conclude by providing a brief synopsis of each chapter.

## **2. SOCIAL SCIENCE AND THE 'NEW GENETICS'**

Social scientists' interest in the implications of the new genetics has grown significantly in recent years. Sociologists, in particular, have begun to apply their theories and methods to this intellectually fertile field of enquiry. Levitt (1999) argues that sociology is a discipline well suited for exploring substantive empirical issues constitutive of the new genetics, as well as its related ethical dilemmas. She writes:

'The area of genetics seems particularly apt for a study of the broader sociological effects as well as individual psychological effects because genes are shared and the diagnosis of genetic disorders has implications for other family members.' (Levitt, 1999, 157)

Sociology can provide theoretically sophisticated and empirically diverse analyses of this new technology, which is not always possible through philosophical discussion alone. Levitt proceeds to argue that:

'While it may be suggested by medical professionals that genetic screening techniques could remove some of the inequalities given by nature, a social perspective would lead to the (testable) expectation that the effects of screening procedures on individuals will mirror the inequalities in society; socio-economic class and racial inequalities as well as those of gender.' (Ibid, 161)

Levitt argues that as genomic knowledge continues to advance, the social implications will become more palpable and relevant. A sociological approach may

enable us to question received wisdom and begin to explain what is happening from the standpoint of the diverse groups affected by particular applications of the technology. Levitt argues: 'Sociological perspectives look critically at the new technology and ask how it will be used, whom it will benefit and what the wider social consequences will be.' (Ibid, 164)

It is important to recognise the impact historical trends in sociology have had on contemporary social science approaches to the new genetics. Work in the sociology of science and technology, coupled with the recent emergence of a 'risk society' perspective, has had a strong influence on contemporary social research.

The first academic accounts of the nature of scientific knowledge and technology were rooted primarily within philosophical epistemology. This approach attempted to reveal and explicate the internal logic of a 'scientific method' abstracted from its social context. Luminaries such as Popper (1959) sought to protect a notion of 'scientific truth', through a theory of 'falsification', in order to demarcate authentic scientific hypotheses from their pseudo-scientific aberrations. Lakatos (1984) also provided a rationalist account of science, but instead of focusing narrowly on scientific hypotheses, his work was concerned with the broader concept of a 'scientific research programme'. According to Lakatos, a research programme could be either 'progressive' or 'degenerative' depending on the extent to which it could predict new facts (increase empirical content as it develops), explain the success of predecessors, and be legitimated through independent corroboration. Even those philosophers who were critical of the orthodox belief in a 'rational' and 'value free' science, such as Feyerabend (1975), focused on the notion of method when challenging the dominant paradigm. It was not until Merton's (1973) account

of the crucial role social factors play in determining the reward distributions bestowed by the scientific community, that a sociological account of the institutionalisation of science began to take shape. This work, coupled with Kuhn's (1970) groundbreaking ideas on the paradigmatic nature of science<sup>1</sup>, would lay the foundations for the Sociology of Scientific Knowledge (SSK), which came to dominate the 1970s sociology of science literature.

Bloor (1976) was one of the pioneers of the SSK approach. Although Merton had revealed the ways in which social factors could shape the career trajectories of scientists and destabilise particular scientific fields, as a 'functionalist' sociologist, he clung to the idea that there was a 'value-free' scientific method. However, Bloor wanted to demonstrate that scientific knowledge was not a pure and abstract mirror on nature, but was itself socially constructed. Work in the sociology of knowledge had already revealed that all forms of human knowledge were socially constituted. SSK adherents simply applied this logic to scientific knowledge and argued that science, as a social institution, did not deserve its exalted status as a form of disinterested inquiry.

Supporters of the SSK approach began to analyse a variety of ostensibly 'hard' sciences and reveal the social and political interests shaping the very production of scientific knowledge. Eventually, SSK came under criticism for its relativistic implications. It was also challenged for failing to respond adequately to the associated problem of 'reflexivity', which was illuminated by social theorists such as

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<sup>1</sup> See Fuller, 2000a for an extensive critique of the philosophy of science offered by Kuhn. He argues that the inherent conservative slant of Kuhn has largely been ignored by the many 'radicals' who have discerned from his work profound political messages that he never really intended and often sought to distance himself from.

See also Fuller, 2003 for an erudite reconstruction of the Kuhn/Popper debate

Woolgar (1988a, 1988b). While the philosophers of science had focused too heavily on the science pole of a manufactured science/society dichotomy, SSK supporters of Bloor's 'Strong Programme' appeared to grant social explanations privileged status by anchoring all scientific knowledge to the context-dependent social relations of a particular society or culture. Although they operated with a nominalist conception of science, they hypocritically embraced an essentialist view of social science. Furthermore, because they treated scientific knowledge as a macro phenomenon, they appeared to ignore scientific praxis at the micro level. Subsequently, they failed to recognise and understand the complex and nuanced internal power dynamics that often shape scientific knowledge and technological progress.

At the end of the 1970s, and throughout the 1980s, a number of scholars began to recognise the limitations of the SSK approach and sought to develop 'post-relativist' theories. Latour and Woolgar (1979) began this trend with their groundbreaking anthropological study of laboratory life. Taking on the role of 'anthropological outsider', Latour and Woolgar tried to demonstrate that sociologists use of 'science/society', 'inside/outside', and 'nature/culture' dichotomies to describe the production of scientific knowledge could stymie our understanding of how science 'really' functions within society. According to the authors, sociologists attracted to such binary oppositions ultimately allow science to immunise itself from sociological investigation. Latour and Woolgar claimed that there were four inherent problems with prioritising the 'social' in studies of scientific practice. Firstly, the range of phenomena open to sociological investigation becomes limited, as only those sciences clearly influenced by external social agencies can form a legitimate object of study. Secondly, a critical gaze can be



cast only on 'bad' science, which contravenes Bloor's appeal to treat 'bad' and 'good' symmetrically. Thirdly, there is an inevitable tendency to provide a sociology of scientists rather than a sociology of the actual knowledge they produce. Finally, one can become drawn into questioning scientists' statements to outsiders rather than critically appraising the technical aspects of the science itself. This was a particular flaw in Mertonian sociology.

Knorr-Cetina (1983) argued that the micro approach adopted by Latour and Woolgar opened the door for scholars to '... consider the objects of knowledge as the outcomes of processes which invariably involve more than one individual, and which normally involve individuals at variance with one another.' (Knorr-Cetina, 1983, 117) Such an approach was presented as being neither subjectivist nor relativist, because it conceptualised scientific practice as a complex and intricate process encapsulating a variety of nuanced elements, not all of which could be defined crudely as 'social'. Because of this work, a completely new approach to investigating science and technology was born. Scholars began to apply the micro-oriented 'science as practice' method to a diverse range of scientific disciplines. Furthermore, they moved beyond crude descriptive accounts of how science *is* and began to question how it *ought* to be. Nelson (1993) describes her work on 'epistemological communities', for example, as one based on the idea that:

'... reconstructions appeal to and are recognised as interdependent with a larger body of experience and knowledge (also historically relative and dynamic) rather than any alleged ahistoric or extra theoretical foundations or standards.' (Nelson, 1993, 126)

For Nelson, 'evidence' is a communal activity that can be labelled reasonable only if it is coherent with a particular community's experiential knowledge. However, in order to avoid the relativist trap of claiming all theories are equally valid, she argues that some theories will always have a more tenuous relationship to experienced reality than others.

Post-SSK sociology of science allowed for more diverse and extensive analyses of knowledge production as it was constructed by, and impacted upon, particular groups in society. Now it was possible to think in terms of a 'feminist' or 'disability' discourse (Harding, 1991; Smith, 1987), which permitted the situated epistemological views of traditionally 'outside' groups to demand recognition and legitimacy. Science was recognised as a social construction, but now it was necessary to explore ways in which it could be reconfigured to empower social actors and work to the advantage of society as a whole. Fuller's (2002a) *Social Epistemology* was firmly rooted in the idea that knowledge systems have a strong normative dimension. His work supported the practical ideal of reconstituting the science policy process so that it could begin to judge specific applications of science and technology by reference to their socially ameliorating potential. Fuller argued that a policymaker influenced by social epistemology would begin to consider explicitly the ways in which scientific knowledge *ought* to be distributed.

This concise, and admittedly oversimplified, account of the changing theoretical orientation of science studies reveals how a gate was eventually opened for a more nuanced critical evaluation of the social consequences of the new genetics. By moving beyond an abstract and descriptive account of scientific knowledge, and instead providing a normative analysis focused on the very subjects of knowledge

production, a diverse range of issues associated with, and constitutive of, the new genetics could now be explored in more detail. However, one further theoretical development appealed to a number of scholars interested in the sociology of genetics. This was the emergence of Ulrich Beck's (1992, 1999) 'risk society' theory. Beck's central argument was that modernisation had induced acute feelings of insecurity amongst citizens, largely because of the ubiquitous 'hazards' that unconstrained scientific and industrial progress had precipitated. Consequently, people had begun to engage with science and technology by reference to its potentially adverse and unintended consequences rather than its social benefits.

Beck (1999) posited a supposedly unique relationship between a 'first' and 'second' modernity. First modernity characterised the traditional nation state, in which social relations were understood in territorial terms. Five unique processes constitutive of a second modernity undermined the patterns of social life constitutive of this first modernity, which included full employment, social progress, and exploitation of nature. These five processes were 'globalisation', 'individualisation', 'gender revolution', 'underemployment', and 'global risk'. (Beck, 1999, 2) Beck writes: 'The real theoretical and political challenge of the second modernity is the fact that society must respond to all these challenges *simultaneously*.' (Ibid, 2)

Giddens (2002) has also written extensively about risk. He contrasts two particular types of risk, which he argues are historically dependent. The first kind he refers to as 'external' risks, which emerge from the fixities of tradition or nature and characterised the pre-modern world. A second kind of risk, which he labels 'manufactured', emerges from the impact of our developing knowledge upon the

world. (Giddens, 2002, 26) This latter type of risk, analogous to Beck's conception of global risk in advanced modernity, refers to situations we have supposedly no historical experience of confronting. Neither Beck nor Giddens suggest that there was no risk before modernity, although both imply that modern conceptions of risk are unique. Instead, they argue that individuals' perception of risk fundamentally changed. Beck, for instance, argues that contemporary 'techno-scientific' risks are qualitatively different from those in the past, because they are global and imperceptible. Douglas (1994) argues that there has been a distinct conceptual change in language from 'danger' to 'risk', and a new kind of blaming system, now applied to institutions, has slowly replaced the traditional moral condemnation that was often directed towards individuals for their personal culpability in failing to avert a particular danger. (Douglas, 1994, 16) She proceeds to claim that modern conceptions of risk are generally used to refer to negative outcomes, while 'good' things are couched politically in other terms. Douglas writes: 'The language of risk is reserved as a specialized lexical register for political talk about the undesirable outcomes. Risk is invoked for a modern-style riposte against abuse of power.' (Ibid, 24) However, Beck employs the concept of 'reflexive modernisation' to illustrate an immanent feature of second modernity. People came to recognise that they are not only negatively affected by social, political, and technological change, but simultaneously have the power to respond to them as independent and active citizens.

Both Beck and Giddens' work on risk theory is now firmly entrenched in the sociological canon. However, one might legitimately criticise their theories on the grounds of over-generalisation and inconsistency with the empirical evidence. In particular, the argument that modern conceptions of risk are fundamentally different

from those in the past is questionable. Beck's uncritical and ambiguous use of the term 'advanced' or 'late' modernity is deeply problematic when one begins to look at the empirical evidence. Dingwall (1999), in an extensive critique of Beck's work, questions the central notion that contemporary risks are imperceptible. He argues that '... neither the nature of risk nor its association with the distribution of wealth is particularly new.' (Dingwall, 1999, 481) Dingwall argues that the contemporary rich can often buy insulation from risk; a crucial point that explicitly challenges Beck's argument that in late modernity risk is imperceptible and largely unavoidable. We will return to this issue in chapter 2, where an historical analysis of the birth of the life assurance industry and the probabilistic revolution will be provided. This chapter will reveal that the ubiquity of risk-averse individuals, particularly amongst the middle classes, is anything but a unique modern day phenomenon, and that the generalised risk theory perspective provides an inadequate theoretical tool for making sense of the genetics and insurance problem.

These developments in the sociology of science, as well as the pervasive influence of a 'risk society' literature, have enabled social scientists to engage critically with the nature of policymaking processes around controversial science and technologies. The notion of risk is central to genetics-based technologies and particularly pertinent to this research on genetics and insurance. However, while the sociology and philosophy of science has undergone profound change in recent years, and the emergence of the 'risk society theory' has clearly influenced many social scientists, it would be counterproductive to apply one of the existing theoretical frameworks to the present research problem. The sheer complexity and multifaceted nature of the genetics and insurance issue can be more clearly illuminated by engaging with the existing literature more critically. This research will

draw upon a number of sociological theories, as well as disciplinary fields, in order to provide an integrative analysis of the research problem that is not constrained by any attachment to a single theoretical framework.

### **3. GENETIC INFORMATION, LIFE ASSURANCE, AND THE DEMOCRATISATION OF POLICYMAKING: RESEARCH AIMS AND OBJECTIVES**

The genetic information and life assurance problem provides an opportunity to explore a number of interrelated social, political, commercial, and scientific issues that have emerged contemporaneously with genetic progress. When contemplating the issue of commercial access to genetic information, it is important to recognise that we are dealing with a highly emotive public policy issue that has attracted the attention of a variety of interest groups. The principal objectives of this research will be to investigate the most likely implications of genetic information for life assurance provision, reveal the rhetorical complexity of 'stakeholder' accounts, and evaluate the efficacy of the policy/regulatory process.

The basic research questions may be stated as follows:

1. What are the most likely social, commercial, legal, and ethical implications of life assurance companies using genetic information for underwriting purposes, and might recognition of the history of insurance, risk, and probability enable us to better understand this contemporary problem? Furthermore, does the rhetoric expressed by key stakeholders advance or problematise our understanding of the theoretical complexity underlying the

issue? The substantive issues to be investigated include the nature and role of modern commercial insurance, the business of discrimination, equity and social exclusion, and the ownership and management of genetic data. One preliminary hypothesis might be that the emergence of new kinds of genetic information does not fundamentally affect the nature of private life assurance provision, but that relevant stakeholders and academics have antagonised the debate through their strategic use of rhetoric.

2. Do relevant 'stakeholders' operationalise a variety of definitional frameworks around 'genetic information', and might such definitions reveal underlying social, political, or professional agendas? More precisely, do particular stakeholders and interest groups, through their interview talk, render new kinds of genetic information 'special', even if they do not believe in a fundamental technical difference between it and other forms of medical information. One hypothesis might be that stakeholders will constantly shift the definitional framework of the issue in order to defend a sectional interest.
  
3. What are the specific concerns of relevant stakeholders with regard to the use of genetic information by life assurance companies, and do they account for such concerns, judge the nature of the policy process, and articulate potential candidate solutions by reference to a broader set of social, clinical, or commercial values? One might expect to observe acute differences of opinion between insurers, clinicians, and patient or consumer support groups, each of whom may have an interest in framing the issue in a particular way, in certain social contexts. The extent to which interest

groups draw upon a broad narrative repertoire (social, commercial, ethical and clinical), and use a variety of rhetorical strategies to express morally adequate accounts of their beliefs, will be investigated through semi-structured interviews.

4. How has policy developed on this issue, and how equitable has it proven? How effective have the various advisory/regulatory committees been in deliberating the broader nuances of the issue, and have stakeholder accounts been fairly evaluated by political decision-makers? One might expect political institutions to grant differential levels of legitimacy to the evidence provided by various stakeholders, depending on what they consider politically expedient. An extensive analysis of the policy debate will reveal the extent to which this is a valid statement.
  
5. In what ways has 'perceived public opinion' affected both the strategies of stakeholders and the more general political framework of policymaking? In particular, has 'uninformed' public opinion polluted the policy and regulatory process and led to inequitable decision-making?
  
6. Considering the diversity of views, and the seemingly intractable nature of this politically sensitive problem, might a 'citizens' jury' provide a more suitable means for arbitrating the competing interests? If so, how may we ensure that this new public-centred mechanism both significantly improves the quality of decision-making and enjoys greater democratic legitimacy?



In contemplating these broad questions, this research will critically engage with a diverse range of substantive issues, which include 'definitions of genetic information', 'genetic risk and privacy', 'the public understanding of science', 'social discrimination and exclusion', 'commercial rights, ethics and regulation', 'sociology of science, technology and expertise', and 'the democratisation of science policy'. This thesis therefore establishes theoretical connections between a number of substantive issues that have so far only been analysed by sociologists in isolation. The paucity of any substantial sociological work on genetic information and the insurance industry is in many ways surprising. It appears to provide an excellent case study for exploring a number of interrelated social, political, commercial, and ethical exigencies. This thesis therefore provides the first extensive sociological investigation of an increasingly controversial and complex science and society issue. The research has both a theory and policy oriented slant. It draws upon a diverse range of academic and policy literature in order to make an original contribution to the sociological study of the new genetics.

### **3. METHODOLOGY**

This research uses qualitative methods to investigate the stated research questions. A great deal of social research on the new genetics has used quantitative methods to unpack some of the diverse social issues surrounding this growing technology. Such work has proven invaluable in advancing our understanding of such things as the class, race, and gender variables that often determine attitudes towards specific areas of genetic progress and has revealed growing public fears around the commercial exploitation of genetic information. Such studies will be referred to throughout the thesis. However, in order to

investigate the decision-making processes around the issue of genetics and insurance, a qualitative approach provides the most appropriate methodological strategy.

#### **4.1. Research Strategy**

There has been a lack of extensive sociological research into the nature of policymaking around the issue of genetics and insurance in the UK. In fact, throughout the 1990s there was not only a paucity of sociological literature on the potential social implications of allowing life assurance companies access to new kinds of genetic information<sup>2</sup>, but there was also a lack of political motivation to initiate a proper and informed policymaking and regulatory process. More recently, a number of governmental and non-governmental committees have been established to investigate this issue. Growing public and interest group concern provided much of the impetus for political action. This research is therefore timely, in that it provides a comprehensive analysis of an important social policy concern in which both technological progress and a politically contentious decision-making process are developing apace. This creates certain methodological difficulties, as the theoretical and empirical approach of the research must be flexible enough to react to changing social, political, and scientific circumstances. However, there are also advantages in that the research does not have to rely on retrospective

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<sup>2</sup> Although sociologists may have been slow to recognise the importance of the genetics and insurance issue, and recognise it as an area worthy of sociological attention, other social science disciplines have been engaged with some of the substantive issues. Economists, in particular, have looked extensively at some of the financial implications of denying or permitting insurance companies access to new kinds of genetic information. The Centre for Risk and Insurance Studies at the Nottingham University Business School, as well as the Genetics and Insurance Research Centre at Heriot-Watt University, have both researched these issues for a number of years now. But there is a need for a sociological investigation of the nature of the policymaking process and the political strategies of key stakeholders who have contributed to it.

analysis but can, instead, provide an account of an active process as it is flourishing.

Scientific knowledge and technological innovation do not emerge and evolve within a social vacuum; rather both are constructed within a complex, multifaceted, and ever-changing social dynamic. Moreover, technology is not only constructed by society but may also fundamentally change its constitution. The use of genetic information in life assurance underwriting conforms to this conceptual understanding. This research used qualitative methods to describe and explain this fluctuating process. In particular, the thesis uses data from interviews with key stakeholders, as well as a number of public policy documents published in the past five years, in order to investigate the stated research questions and test the validity of preliminary hypotheses. These methods will now be described in detail.

#### **4.2. Qualitative Interviews**

Qualitative methods in social research are often portrayed as less 'scientific' than quantitative methods, because the data cannot easily be generalised. Qualitative data are in many ways open to subjective interpretation, so the method is usually practical only when applied to small samples. However, such methods do have a distinct advantage over their quantitative counterparts in that they enable the researcher to explore a particular topic in depth, and tease out the nuanced beliefs and attitudes that research subjects encapsulate. Qualitative interviewing, in particular, strives to uncover the *reasons* why individuals express certain beliefs, which is a goal that often remains elusive to adherents of quantitative methods. Silverman (1993) argues that a putative aim of qualitative interviewing is to gather

an 'authentic' understanding of individuals' subjective experiences, and that the relationship between interviewer and subject is, in contrast to that found in quantitative studies, politically rather than scientifically grounded. However, authenticity is a problematic concept in the context of social research, as Silverman acknowledges, and this will be discussed in more detail later.

In conducting any kind of social research, it is essential to consider the methodological implications of the research strategy. As Mason (1996) argues:

'This means being clear about how and why a particular method and data source are going to help you to address your research questions rather than assuming that, for example, a series of unstructured interviews, or some documentary analysis, will obviously and unproblematically tell you what you want to know.' (Mason, 1996, 19)

This research used semi-structured interviews with a small sample of individuals, and analyses a diverse range of policy documents, in order to reveal the range of perspectives on the genetics and insurance issue, and test/develop the theory that key stakeholders will use a variety of rhetorical strategies when giving account of their beliefs, perhaps in order to further their broader interests or values.

#### **4.2.1 Sampling**

The original aim was to interview between ten and fourteen individuals, representing a variety of stakeholder/interest groups. Interview subjects were selected from three broad professional groups: insurance industry representatives, clinical geneticists/counsellors, and consumer/patient-support groups.

Initially, letters were sent to various individuals and organisations falling under the broad categories defined above. Ten were addressed to insurance companies, twenty-two to patient/consumer support groups, thirteen to clinical genetics departments, and four to major research genetics units. Specific groups and individuals were randomly selected from lists provided on various internet websites, or cited in official policy documents. The letters described the central objectives of the research, accentuated the importance of gaining input from organisations that may be affected by policy in this area, and gave a brief description of how the interviews would be structured. When the letters were addressed to companies or organisations, rather than named individuals, it was requested they be forwarded to appropriate individuals who might be interested in participating in the research.

It is often difficult, particularly when establishing contact with insurance companies, to gain access to specific individuals in a position to make a positive contribution to the research. When the letters were addressed to the headquarters of insurance companies, there was either no reply or the responses were ambivalent. Overall, the general response rate was relatively low. There was no positive feedback from the insurance industry or organisations involved in genetics research, five responses from patient/consumer support groups, and four from clinical genetics units, which included a consultant clinical geneticist, two genetic counsellors, and a professor of clinical genetics. At this stage, it became clear that the recruitment of research geneticists into the project was going to prove difficult, so it was decided that only those working in a clinical setting would be interviewed. Furthermore, because the replies from clinical genetics units included both clinicians and counsellors, it was decided that this data would be categorised simply as 'clinical perspectives.' However, it was still necessary to include

insurance industry perspectives, so twelve letters were then sent to individual underwriters and directors within specific companies. The names of these individuals were drawn randomly from the Association of British Insurers (ABI) website, as well as from various official documents dealing with the genetics and insurance issue. There were seven positive replies, and four individuals working in the commercial insurance sector were interviewed.

The recruitment process for these interviews was always going to generate a relatively skewed sample. Most of the individuals recruited were either directly involved in debates around genetics and insurance or had, by the nature of their professional work, an interest in the outcome of the policy process. The most positive responses came from insurance representatives who had worked with the ABI on policy formation or who had an important role disseminating their company's position on the issue. Similarly, some of the respondents from the patient-support groups and clinical departments had an intimate knowledge of the policy process, by virtue of their role in articulating their organisation's concerns in discussion forums, media outlets, and journals. However, the aim was not to create a totally representative sample, so it was essential for the research to interview people who were 'engaged' with the issue. In one sense, the recruitment method could be regarded as a form of 'theoretical sampling'. Arber (1993) provides a succinct description of this method when she writes:

'This approach eschews attempting to obtain a representative sample, arguing that sampling should be entirely governed by the selection of those respondents who will maximise theoretical development. The sampling should aim to locate strategic data which may refute emerging hypotheses. Sampling stops when "theoretical saturation" is reached, that is, when no new analytical insights are forthcoming from a given situation.' (Arber, 1993, 74)

By selecting to interview individuals working within clinical, insurance, and interest group sectors, the research aimed to access a range of perspectives, and use the data pragmatically, in conjunction with an analysis of official policy documents, to answer the research questions and test/develop the preliminary theories and hypotheses. Although it may have proven instructive to interview a greater number of individuals with little knowledge of the underlying issue, and therefore no prior ideological attachment to any given solution, practical considerations dictated it would be better to interview the smaller number of 'knowledgeable' research subjects, who generally demonstrated a greater willingness to participate. As it happened, one respondent from a patient-support group, and two genetic counsellors, had little knowledge of the legislative process. They therefore provided a counterbalance to the greater number of 'informed' and 'engaged' respondents. The analysis of various policy documents and public debates, as well as the use of secondary data sources, would complement the research by providing a more diverse range of data from which to investigate the research questions.

Some might ask why 'victims' of insurance practices were not interviewed. Why exclude from the sample individuals who have suffered 'unfair' discrimination at the hands of commercial insurers? The reason for this exclusion was that the evidence base for practices of unfair discrimination is extremely weak. Most studies have had to rely on individuals' subjective reports of their treatment by insurers. However, there is no way of knowing ultimately whether such individuals were actually the victims of unfair discrimination. Applicants for insurance are rarely told the reasons why they have been denied a policy, or been charged a loaded

premium. In chapter 4, interview and questionnaire based studies claiming to have uncovered practices of unfair genetic discrimination are critically evaluated.

The table below displays the names of the final eleven interviewees (three requested anonymity), and provides brief details of their professional position, organisation in which they were employed at the time, and the date the interview took place.

<b>NAME</b>	<b>POSITION</b>	<b>ORGANISATION</b>	<b>DATE OF INTERVIEW</b>
Keith Bedell-Pearce	Executive Director	The Prudential Plc.	18/07/01
Graham Austin	Director	Munich RE. Life Branch	19/07/01
Tony O'Leary	Deputy Managing Director	ERC Frankona RE.	21/05/01
Anonymous	Chief Underwriter	Insurance company	12/06/01
Dr. Quarrel	Consultant Geneticist	North Trent Clinical Genetics Service	25/05/01
Anonymous 1	Genetic Nurse Counsellor	An NHS clinical genetics service	25/07/01
Anonymous 2	Genetic Counsellor	An NHS clinical genetics service	25/07/01
Prof. Sandy Raeburn	Professor of Clinical Genetics and ABI Genetics advisor	University of Nottingham Clinical Genetics Service	05/06/01
Alistair Kent	Director	Genetic Interest Group (GIG)	04/04/01
Dr. Katherine Darton	Policy Officer	MIND	08/06/01
Dr. Julia Cream	Policy Officer	Alzheimer's Society	19/06/01

Dr. Darton was the respondent who did not have any significant prior knowledge of the genetics and insurance decision-making process, while the others had varying



degrees of knowledge. Furthermore, because almost all of the respondents held relatively high positions within their organisations, this may have affected the data. In addition, it is important to note that specific organisations employ a variety of discrete professional groups. For example, the sample included one chief underwriter and three directors of insurance companies under the insurance industry category. It must be recognised that different types of professionals within the same organisation may have varying beliefs and attitudes to the issue because of their divergent professional roles, status, and experience.

It must also be recognised that the majority of employees in patient-support groups do not suffer the medical conditions that their organisations represent, so one should be careful not to uncritically accept their discourses as 'authentic' accounts of the concerns and experiences of the medically afflicted. This is a recurrent problem faced by social researchers aiming to tap into the subjective beliefs and experiences of 'vulnerable' groups. Often, access is granted only to 'representatives' or 'advocates', who act paternalistically as gatekeepers to such knowledge. Of all the support groups contacted, only the larger organisations, which were politically and publicly engaged with the issue, replied positively. Many of the smaller groups have extremely limited resources, because they are often established by families of affected individuals and employ only a small number of part time volunteers. Such groups do not often have the time or inclination to participate in social research projects. Indeed, many question researchers' stated intentions.

Overall, the final sample did include a broad range of individuals with divergent opinions on the issue under investigation. The sample would contribute significantly

to the intended research outputs. It is now necessary to explain the structure of the actual interviews in some detail, and clarify the status of the data generated.

#### *4.2.2. Interview Structure*

Semi-structured interviews were used for this research. Gilbert (1996) differentiates between three general types of interview, which he defines respectively as 'standardised or structured', 'semi-standardised', and 'non-standardised or unstructured'. (Gilbert, 1996, 135,136) The choice of interview structure will always determine the type and quality of data generated. For example, standardised interviews provide data that can easily be coded and cross-referenced to provide a relatively 'objective' measure of variations in peoples' attitude toward specific social phenomenon. However, because the questions are pre-defined, and the interview process is relatively inflexible, this method is unsuitable for research projects that aspire to understand more deeply the subjective opinions of individuals, and reveal the rhetorical strategies they use when accounting for their beliefs. On the other hand, an entirely unstructured interview can be time consuming and pose significant analytical difficulties. Here, the researcher has a far less active role in directing the interview process, so it becomes far more difficult to ensure the data remains pertinent to the specific research problem. May (2001) argues that:

'In moving from the structured to the unstructured interview, researchers shift from a situation in which they attempt to control the interview through predetermining questions and thus "teach" the respondent to reply in accordance with the interview schedule (standardization), to one in which the respondent is encouraged to answer a question in their own terms.' (May, 2001, 121)

According to May, in the semi-structured interview: 'Questions are normally specified, but the interviewer is freer to probe beyond the answers in a manner which would appear prejudicial to the aims of standardization and comparability.' (Ibid, 123) The use of probing has a positive and edifying function. Rather than asking specifically what the respondent thinks about X, the interviewer can flexibly deploy specific arguments or hypothetical case studies as a heuristic device to aid the process of mining respondents' subjective opinions. May writes:

'... a change in the emphasis of a question, or a similar question posed in a different way, not only can provoke further thought on the subject, but also offers a catalyst enabling the interviewee to make links to other answers already given.' (Ibid, 129)

However, at this point it is necessary to clarify the status of the interview data and the use that is made of it in this research. One significant problem that can arise with qualitative interviewing is that the researcher can take for granted the validity of interview responses. There is significant debate in the field of qualitative research about the extent to which the interview process generates 'accounts' of respondents' beliefs/attitudes rather than literal reports of them. Ethnomethodologists have long maintained that interview data can only make legitimate claims about what occurs in the interview itself, but has no referential legitimacy to a world 'out there'. This point is particularly significant in the context of the present research, because many of the interview subjects were part of a policy process in which they had to express different kinds of rhetoric in different contexts. For example, insurers often tell different 'stories', and may operationalise a complex variety of narrative strategies, depending on their audience (politicians,

the public, shareholders, policy applicants etc). Similarly, clinicians and patient-support groups may have specific agendas that are best served by expressing their concerns in different ways depending on the particular social context they find themselves in. The way in which individuals or groups communicate their interests in one context provides no guarantee that they will do so the same way in a different context. The search for an individual's 'true' belief/attitude, through their interview talk, will always remain an elusive ideal.

Silverman (1993) asks, 'Must we choose between seeing interviews *either* as potentially "true" reports or as situated narratives?' (Silverman, 1993, 108) One approach, according to Silverman, is to follow the work of Gilbert and Mulkay and treat interviews as giving us access to the 'repertoire of narratives' that are used in producing accounts. Here, it is recognised that what respondents do through their interview talk is not generate a single, coherent narrative that reflects a 'true' underlying belief or interest, but that a whole range of narrative strategies are both consciously and unconsciously deployed in order to express one or a number of 'stories'. Silverman's 'twin track' approach recognises that how respondents interpret their actions is as important as what they literally report. Redley (2003) used this approach in a recent sociological study of deliberate self-harm. He writes:

'Rather than only trading on what respondents have to say about self-harm and life in an area of multiple deprivation, an exclusively externalist position towards interview data, the analysis presented here initially takes a constructivist position focusing on *how* the respondents, in conjunction with the interviewer, produce accounts of their lives. Then and only then does the analysis turn to *what* is reported.' (Redley, 2003, 351)

Miller and Glassner (1997) try to establish a position outside what they refer to as the objectivist-constructivist continuum; yet still take seriously the critiques of researchers at both these poles. They argue that: '... information about social worlds is achievable through in-depth interviewing.' (Miller & Glassner, 1997, 99)

The authors go on to explain:

'... interviewers need not resort to romanticism, or to identifying experience with authenticity, in order to call upon interviewees' experiences and produce authentic accounts of social worlds ... All we sociologists have are stories. Some come from other people, some from us, some from out interactions with others. What matters is to understand how and where the stories are produced, which sort of stories they are, and how we can put them to honest and intelligent use in theorizing about social life.'

This research recognises the problem of trying to uncover 'real' and 'authentic' attitudes or beliefs. It therefore uses the interview data to reveal the various forms of rhetoric and narrative repertoires drawn upon by socially situated actors, as they attempt to further specific interests or give a morally adequate account of their beliefs. By critically analysing the interview transcripts, in conjunction with official policy documents and debates, this part of the research aims to improve our sociological understanding of the different ways in which stakeholders situate their accounts of the genetics and insurance issue, and perhaps prioritise or marginalise particular substantive issues, in order to further broader political or professional interests.

It was desirable that the actual interviews be based on a 'reflexive' and 'dialogical' approach, in which the progress of the interview would be determined largely by the flow of communication between interviewer and respondent.

However, before conducting each interview a basic schedule was drawn up, in order to ensure that all the relevant issues were discussed. Each interview covered two broad substantive areas. The first part focused on how the respondent conceptualised the general problem of genetics and insurance; that is what particular concerns did they express, and what kinds of solutions did they consider appropriate. This part of the interview was concerned with the underlying technical and theoretical issues, such as the definition of 'genetic information' and the likely social and ethical implications of insurance companies using that data. The second part of the interview was centred on the decision-making process. The respondents were asked how engaged they were with the policy process, how effective they considered the regulatory approach to be, and what kinds of political intervention they considered appropriate or necessary. Their views on the role 'public opinion' has had on this process were also requested. Furthermore, at the end of the interview, respondents were asked briefly their opinion on the role of citizen participation.

The framing of the questions varied depending on the particular individuals being interviewed. Thus, interviews with insurance representatives covered technical commercial issues and concerns, while interest groups and clinicians were asked questions relevant to their own particular spheres of interest and expertise. Therefore, although all respondents were asked a broad range of questions around the basic themes of 'genetic information', 'discrimination', 'commercial and individual rights', 'policymaking', and 'social exclusion', the interview was flexible enough so that respondents were free to express, in their own terms and from their particular professional vantage point, some of the broader social, political, and technical issues. The interviews lasted, on average, one hour, and all were

conducted at the respondent's place of work. All interviews were tape recorded and later transcribed.

In conceptualising my role in the interview process, I attempted to maintain as impartial a stance as possible. I did not offer the interviewees my own personal opinions on the specific issue, even when asked on occasion to do so. Instead, I often played the role of devil's advocate in order to draw out the variety of respondents' opinions and beliefs. For example, if a member of an interest group expressed ambivalence about the insurance industry's probity when articulating their commercial rights, I would explain the industry's fear of 'adverse selection' and request a response. Similarly, when insurance representatives talked about the commercial problems of prohibiting access to all pertinent medical data, I would raise the public concerns of social exclusion and 'unfair discrimination'. This approach of fostering two-way dialogue proved constructive. I was able to gain unexpected information and technical insights that I had not previously considered, and often the respondents claimed that the interview process had enabled them to contemplate issues they had previously not thought about in any great depth.

By not explicitly displaying a partisan attachment to any one belief or opinion, and therefore remaining relatively open-minded, an environment conducive to the free expression of ideas was created. Many researchers believe that an impartial approach to certain kinds of qualitative interviewing is impossible, and perhaps even undesirable. Finch (1986) notes some problems with adopting an impartial approach to research on policy issues. She writes:

'... policy-oriented research of a qualitative kind can realistically be carried out only on the understanding that the knowledge created cannot be "objective" in the sense of being neutral in relation to the political process of policy-making.' (Finch, 1986, 209)

This statement suggests that the researcher is deeply embedded in a political process, particularly when the research has clear implications for public policy. She goes on to claim that:

'... there is a strong likelihood that the political stance adopted will be oppositional, perhaps subversive, in respect of the status quo, since the methods used get close up to the people studied, and are very likely to challenge the "official version" of their situation.' (Ibid, 210)

Disability researchers also suggest that the researcher ought not to conceal their personal political beliefs when researching 'vulnerable' groups. Oliver (1992), for example, claims that such research ought to be 'emancipatory' and explicitly confront pervasive 'social oppression'. (Oliver, 1992, 110) The problem of course is that if one automatically assumes that a particular policy is indeed oppressive to a certain group, then one has already limited the scope of the research and prejudged the nature of a process that is yet to be elucidated. The researcher ought to be open-minded, and allow for the possibility that the data may necessitate a fundamental rethinking of the underlying theory.

Although the partisan approach may appear, in some cases, appropriate and justified, for this research political neutrality brought clear advantages. Although neutrality may ultimately be only an expedient façade, it is a role that ought to be adopted during the actual process of interviewing. For example, representatives of



the insurance industry are more likely to feel comfortable articulating their commercial concerns if they do not feel the researcher is an advocate for the 'socially excluded'. Similarly, when interviewing interest groups, the dialogue is likely to be more open and constructive if the respondents do not feel the researcher is ideologically attached to a particular solution, particularly if it is one that legitimises commercial interests and values. Even if true objectivity can never be fully realised, it is still an ideal worth striving for.

#### **4.2.3 Data Analysis**

The process of data transcription and analysis began immediately after the first interview was conducted, rather than waiting until the entire fieldwork had been completed. Miles and Huberman (1994) recommend such early analysis because:

'It helps the field-worker cycle back and forth between thinking about the existing data and generating strategies for collecting new, and often better, data ... It makes analysis an ongoing, lively enterprise that contributes to the energizing process of fieldwork.' (Miles and Huberman, 1994, 50)

Each tape was listened to a number of times before transcription, and 'relevant' points then highlighted. Information emerging from each interview was then used to inform the structure of subsequent interviews. However, with semi-structured interviewing, a great deal of 'irrelevant' data is often generated. Therefore, it is important that the researcher select only those strands of narrative pertinent to the research questions. However, such a selective process is liable to suffer from researcher bias, as there is a natural tendency to transcribe only data that validates the underlying and prejudicial intuitions of the research. One therefore had to be

constantly aware of this problem when analysing the tapes, and endeavour to be as impartial as possible when both transcribing and analysing the data. Furthermore, it was important not to become closed-minded to any emerging data that challenged some of the basic hypotheses. In fact, new and unpredictable insights that emerged through the interview process often led to a reconfiguration of the very framework of the research. Any possible bias was also mitigated by the fact that the interview data was being used in conjunction with an analysis of official policy documents and public debates. Empirical validation did not rest solely on the quality of this relatively small sample of interviews.

#### **4.3. Document Analysis**

Documents are an invaluable resource tool for most kinds of social research. This research required an extensive analysis of a variety of governmental and non-governmental policy documents, political debates, and secondary research data. Throughout this research, a variety of publicly available documents circulated by genetic interest groups, medical organisations, insurance companies, and government committees were collated and analysed.

Analyses of policy documents and transcripts of public debates engender the same kind of methodological problems as the interpretation of data derived from qualitative interviews. One must be constantly attentive to the political context of such documents, and recognise that the rhetoric encapsulated within them may not provide an authentic guide as to how particular groups 'really' perceive an issue. This problem is particularly relevant to the interpretation of government reports, but also manifests itself in the narrative analysis of policy documents circulated by

commercial organisations and interest groups. However, because the issue of genetics and insurance is so emotive and politically embedded, such documents provide an opportunity to study the various ways in which stakeholders may manipulate the political process in order to have their beliefs and concerns publicly recognised and legitimated. By utilising documentary evidence, in conjunction with the interview data, this research contributes to a more profound and nuanced sociological understanding of the ways in which interest groups mobilise around a contentious political issue in order to ensure their broader interests are realised.

Over the past five-years, there has been a proliferation in the number of reports and documents specifically concerned with the issue of genetics and insurance. As each new official report has been published, a number of organisations with vested interests have formally responded. Many have also disseminated their concerns through consultation mechanisms promoted by both the Government and the insurance industry. This research has attempted to use as much of this data as possible, but again a certain degree of selection has been required. Within this thesis, only the most important documents have been analysed extensively. The principal focus has been on governmental reports published in the UK, and a small selection of interest group and industry responses. Most of the insurance industry perspectives have been investigated by analysing documents released by the Association of British Insurers (ABI), which is the official representative of the industry in the UK. In providing an analysis of interest group concerns, the focus has mainly been on comparing the different approaches of the Alzheimer's Society and the Genetic Interest Group (GIG), which have been arguably the two patient organisations most engaged with this issue. A variety of other organisations are referred to, as well as media responses and social surveys, but those documents

that have had the most profound and direct impact on shaping policy deserved greater attention.

#### **4.5. Ethical Considerations**

Because issues around the social implications of genetic knowledge and technology are highly emotive, it is important to recognise some of the ethical problems associated with research in this area. By interviewing insurance representatives, and members of patient-support groups, this research became situated in a politically sensitive area of public policy. There was therefore an ethical duty to document and interpret the data fairly, and provide confidentiality to any respondents who requested it. In this research, three respondents asked that they not be named in any written material. However, even those who displayed little objection to being named deserved an assurance that their views would not be misquoted or misrepresented. All researchers have an ethical obligation not only to their research subjects, but also to future social researchers who may be denied access to respondents who have had negative experiences participating in social research. All the people interviewed during this research were asked if they would like copies of the interview transcripts, and were told they could offer any further comments, not provided in the initial interview, at a later date if they so wished.

The ethical dimensions of social research may appear most acute when the research subject can be defined as a member of a 'vulnerable' group, historically excluded from the processes of decision-making. However, all the respondents who participated in this research held relatively high positions within their organisations, so could not be labelled 'vulnerable' in this limited sense. Often, they

were representatives or advocates of traditionally excluded groups, but it was still important to be sensitive to the ways in which they perceived the equity of the research process. The interviews were conducted fairly and ethically, as was the analysis and interpretation of interview data. Some of the personal accounts expressed by the interview subjects do come under criticism at various points throughout this thesis. Nevertheless, the available evidence corroborated any criticism made.

## **5. BRIEF OVERVIEW OF THESIS CHAPTERS**

The rest of this thesis is split into four main chapters. A brief précis of each chapter will now be provided to conclude this general introduction.

Chapter 2 provides a background to the substantive issue of genetic information and its possible implications for access to life assurance in the UK. The theoretical complexity inherent to the controversy is elucidated, and a critique of abstract, and frequently taken-for-granted, concepts such as 'ownership', 'privacy', 'discrimination', 'fairness', and 'social exclusion' is provided. The chapter provides a social history of insurance, risk, and probability, explains the principles underlying modern insurance practices, and investigates the social, legal, commercial, and ethical implications new genetic information may have for commercial underwriting. Drawing upon a wide range of scholarly literature, as well as interviews with key stakeholders, this chapter provides an essential background to some of the substantive issues. It also begins to assess the role of stakeholder rhetoric in shaping the parameters of the debate, particularly with regard to definitions of genetic information and the social role of private insurance. The primary argument

advanced is that the ethical boundaries imposed on commercial insurance practices ought to be dependent on the type of 'social good' individual insurance products are considered to exemplify, and that genetic information may in fact have only a marginal impact on the life assurance business as it currently exists. This chapter details the complex social, commercial, and philosophical issues underlining the problem of genetics and insurance, which should be used to inform any policymaking process that endeavours to provide pragmatic and fair resolve. This long chapter will provide answers to research questions one and two.

Chapters 3 and 4 are concerned with the formal decision-making process on genetics and insurance, as well as stakeholder contributions to it. Chapter 3 provides an extensive sociological analysis of the accounts given by relevant stakeholders, as they have tried to provide a morally justified framework for their policy positions. The focus will be on the ways in which stakeholders draw on a broad narrative repertoire, and marginalise or prioritise certain substantive issues, in order to give a morally adequate account of their opinions and beliefs. Chapter 4 will, through an analysis of interview data and official governmental and non-governmental policy documents and debates, investigate the political nature of a process that has appeared to prioritise 'public opinion' as the guiding principle for action, and perhaps undermined reasoned, balanced, and unequivocal policymaking. The chapter will build on the one preceding it by investigating the treatment of stakeholder accounts by members of advisory committees, and the differential legitimacy interest groups appear to give to relevant regulatory and policy bodies. It will assess the extent to which they differentially situate their understandings of the issue, and judge the efficacy of the policy process, within a broader social, political, and scientific context. The focus of these chapters will be

on the ideological and political beliefs that resonate within government advisory committees, genetic interest and patient-support groups, as well as commercial organisations. All these bodies, it will be demonstrated, have tended to react simply and uncritically to perceived public fears of a possible 'genetic underclass'. The argument is made that a more rational and pragmatic decision-making process may be required; one that can balance the competing views more equitably, and not simply acquiesce to the emotive and uninformed views of both a credulous public, and interest groups with a clear stake in a particular policy outcome.

By analysing the formal policy process, and investigating the diverse range of opinion on the issue, these chapters evaluate the equity of the current policy process, the differential status granted to particular kinds of scientific evidence by interest groups and political institutions, and consider the extent to which perceived public opinion has shaped the strategies of principal stakeholders. By the end of these central chapters, research questions three, four and five will have been answered.

Chapter 5 assesses the suitability of the 'citizens' jury' approach to policymaking as a potential alternative to the current decision-making framework. First, a critique of representative institutions is given. Next, the deliberative turn in democratic theory is discussed, and the possible virtues of public deliberation debated. The chapter then moves on to discuss the citizens' jury as a practical application of abstract deliberative theory, and considers whether a particular formulation of this model might overcome some of the inherent flaws of policymaking revealed in previous chapters. Both the advantages and disadvantages of the model are presented so that a fair evaluation of its suitability

can be made. This chapter is concerned primarily with providing an answer to the sixth research question.

The concluding chapter rehearses the research questions in light of the data provided within the thesis. It reviews the extent to which the thesis has succeeded in answering them and identifies appropriate directions for future work.



## CHAPTER 2

### GENETIC INFORMATION AND THE PRIVATE LIFE ASSURANCE BUSINESS IN THE UK: SOCIAL, COMMERCIAL, LEGAL AND ETHICAL IMPLICATIONS

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#### 1. INTRODUCTION

The controversy over commercial insurers' access to the genetic test information of applicants proposing for life assurance is complex and

multifaceted. The question cannot be one simply of whether or not to allow commercial underwriters to consider new kinds of genetic test information when calculating premiums, because the underlying theoretical contingencies are far too complex for such a one-dimensional approach to be appropriate. This issue engenders broader philosophical, social, political, and ethical problems, which are best revealed by critically analysing the nature and role of private commercial insurance in the UK. The aim of this chapter will be to assess the most likely social, commercial, legal and ethical implications of introducing new kinds of scientific/technical knowledge to the domain of traditional insurance underwriting. This will require a critical assessment of the intellectual foundations of abstract concepts such as 'corporate responsibility', 'genetic information', 'ownership', 'privacy', 'discrimination', 'fairness', and 'social exclusion', as they have been used by academics and stakeholders concerned about the impact genetic information may have on access to private life assurance.

The opening section of this chapter will briefly discuss the possible influence that the history of genetic testing, and its eugenic foundations, may be exerting on contemporary debates about third-party use of genetic information. Although there is little empirical evidence to suggest that individuals' views on the genetics and insurance issue have been directly influenced by the historic abuse of biological science, many of the contemporary terms and definitions used by both geneticists and insurers do carry significant historical baggage. Because genetics is not an abstract science insulated from the social world, it is important to acknowledge the possibility that history may be having an impact on the way people engage with these current controversies.

Section 3 will provide a history of life assurance in the UK. It will situate the birth of this new form of prudent financial planning within the social and historical context of a time when developments in statistics, probability, and risk were beginning to subjugate the old, unpredictable world of divine providence. This section will illustrate the ways in which insurance evolved from relatively unsophisticated beginnings to the complex financial and socially embedded institution it is today, yet continued to retain many of its basic foundational principles. This history of probability, risk, and insurance will be presented as a sociological phenomenon. The analysis will pay particular attention to the class bias in insurance provision, which is a crucial issue that may undermine the 'social exclusion' argument. The relationship between the growth of insurance and the development of modern capitalism will also be discussed through the work of Foucault and Weber. This analysis will also challenge some of the intuitive beliefs of contemporary sociologists of risk. The historical data will be crucial for understanding the birth of insurance and its accepted role within society.

Next, the underlying principles of contemporary insurance will be described and analysed. Data from interviews with insurance representatives will be used to assess the social legitimacy of the modern life business. The section will begin by contrasting the dual concepts of 'solidarity' and 'mutuality', as they pertain respectively to social and private forms of insurance. The question of whether or not private life assurance ought to be considered a 'primary social good' will be considered, and the perennial problem insurers face in trying to balance commercial and social interests will be evaluated. Interview data will be used to reveal the various ways in which representatives of the insurance industry manipulate the relationship between market and social values when giving account of the normative framework of commercial insurance provision.

The section will then critically assess the 'business of discrimination' that results from a risk pooling process and problematise the abstract philosophical concepts of 'fair' and 'unfair' forms of discrimination. The contested notion of actuarial and statistical relevance will also be introduced within this context. By the end of this section, the role of insurance and its basic commercial principles will have been critically evaluated, and a foundation will have been built for assessing the most likely social, commercial, legal, and ethical implications of modern life assurance companies using genetic information to rate policyholders. The analysis of insurance representatives' accounts of their social function will also begin to reveal the role stakeholders may have in shaping the framework of the debate. This section will contribute to answering the first research question.

The fifth section will focus on the issue of genetic information and its potential impact on both existing underwriting processes and access to specific insurance products. It will begin by looking critically at the way genetic information is often defined in the scholarly literature, as well as by relevant stakeholders in the debate, and illustrate the problems that can emerge when we attribute such an ambiguous concept privileged status in the context of private insurance contracts. This will provide a response to the second research question by increasing our understanding of the ways in which stakeholders and interest groups may erect particular definitional frameworks, and use various narrative strategies, to express value judgements on this controversial issue. The extent to which the social, ethical, and commercial implications may be dependent on the type of 'social good' various insurance products are considered to exemplify, will also be discussed.

Section 6 will look at the issue as it may affect general medical ethics. The ways in which the legal and ethical norms defining the doctor/patient relationship may be being reconfigured because of new developments in genetic testing will be highlighted and discussed. Various philosophical and legal issues regarding the ownership of medical information will also be critically evaluated.

The final section will look at various candidate solutions to the problem, in light of the theoretical issues discussed. In particular, it will assess whether the flexibility of a commercial market, and the creative capacity of the insurance industry to introduce novel products in response to changing market structures, might mitigate any negative social consequences engendered by the 'new genetics'. This section will also flag one of the critical issues of genetic information; that is the implications it may have for the privatisation of welfare.

This chapter will provide a necessary theoretical background to the general problem of genetics and insurance, and provide an answer to the first research question by identifying the most likely social, commercial, legal, and ethical implications of permitting life insurers unconstrained access to new kinds of genetic test information. It will also make a contribution to the second research question by revealing the ways in which 'stakeholders' may manipulate the boundaries of the issue by operationalising particular definitional frameworks.

## **2. THE SPECTRE OF EUGENICS AND ITS POSSIBLE IMPACT ON CONTEMPORARY GENETICS DEBATES**

Before assessing the substantive issue of genetics and insurance, it is necessary to consider briefly the influence 'eugenic anxiety' may be exerting on peoples' engagement with contemporary genetics-related controversies. It may be that such anxiety pre-configures their understanding of the likely social implications. When contemplating the diverse issues surrounding the 'new genetics', we cannot entirely abstract contemporary debates from the history of the eugenic past. Public consternation over controversial issues such as human cloning, genetic testing, screening programmes, and third-party access to genetic information, may in part be the result of eugenic anxiety, aroused by an increasingly vocal opposition to genetic progress by groups such as the radical section of the disability movement.

It is almost impossible to engage with contemporary debates on the 'new genetics' without encountering the two extreme views of 'scepticism' and uncritical acceptance'. These crude and opposing positions frequently find representation in what may be termed respectively the 'disability' and 'geneticist' discourses. The disability discourse often portrays current progress in genetics as an extension of the illiberal eugenic ideologies of the past. In contrast, the geneticist discourse tries to impose a line of demarcation between the historical abuse of biological science for ideological ends, and the ostensibly value-neutral genetic science that now promises to revolutionise medicine for the social good.

One problem with contemporary references to the past is that the antagonists tend to manipulate the historical framework so that it supports their own ideology. For example, if one takes Nazi eugenics as one's point of reference, as do various disability activists, then one has a very different conception of contemporary genetic science than if the point of reference taken is post-war

American geneticists trying to eradicate disease. Both the radical disability activists and those who uncritically embrace genetic progress often antagonise debates on the specific use of genetic technologies. Consequently, they may limit the potential for informed and balanced decision-making. The popularity of the determinist myth in many contemporary discourses on genetics, particularly in the fields of evolutionary psychology and sociobiology, may further threaten informed public debate on the increasingly complex issues facing modern society.

The topic of this thesis is the issue of genetics and insurance. It may appear odd to suggest that the history of eugenics could have any bearing on a debate about how much of an individual's medical information a commercial company should have access to. It would seem logical to consider eugenics only in terms of contemporary debates about pre-implantation genetic screening or genetic counselling. However, the term 'genetics' elicits strong emotive responses, because it carries such a great deal of historical baggage. This may pre-configure peoples' beliefs on the normative issues associated with various aspects of genetic science and its social utility. If we consider the lexicon of insurance, the prevalence of such terms as 'impaired lives' and 'preferred lives' should alert us to the ways in which what appear initially to be value-neutral concepts have a particularly chequered history. Life assurance companies essentially place a value on peoples' lives, and new developments in genetic testing might enable them to do this with far greater precision. The possibility of an emerging 'genetic underclass' resulting from the misuse of genetic information cannot be ignored. Overcoming a sense of historical myopia may be a prerequisite for fully understanding the social implications of contemporary genetic testing and screening.

The genetics and insurance issue has become very public and controversial, as will be illuminated throughout this thesis. It is difficult to believe that the debate would have been so heated had genetics not been the focus of the issue. Indeed, the debate over HIV testing and insurance did not engender the same level of public or political opprobrium. We should not ignore the possibility that public understanding of the eugenic past, coupled with the recent popularity of determinist theories of social behaviour, has influenced all social policy debates centred on genetic science and its social applications. It is therefore necessary to be aware of the historical record, and individuals' differential understanding of it, as foreshadowing the present dilemma over the use of genetic information in life assurance underwriting.

### **3. PROBABILITY, RISK, AND THE BIRTH OF UK LIFE ASSURANCE**

#### **3.1 The Early Beginnings of Life Assurance**

The birth of life assurance in the UK can be traced to the late sixteenth century, when the earliest registered contract was written in 1558 at the Chamber of Commerce on behalf of a William Gibbons, whose life was insured for £382 6s. 8d for a one-year period. (Cockerell and Green, 1976, 34, 35) However, life assurance had existed much earlier in the Mediterranean countries, where its practice can be charted as far back as 1400. Clark (1999) argues that in the early period, life assurance was often part of marine insurance policies rather than a discrete entity in its own right. For example, the insuring of slave cargoes was routine practice in the fifteenth century and, according to Clark, was '... indistinguishable from marine insurance since it simply indemnified slave-owners for the market price of their chattels lost at



sea.' (Ibid, 14) <sup>1</sup> Individuals travelling overseas could also enjoy some form of life cover as part of a broader marine policy, but these early contracts were often limited in scope and only covered the proposer for a single journey.

For those life assurance contracts that were not simply a constitutive part of marine insurance, the only condition of acceptance was that '... the insured was in good health and was not travelling outside England within the term of the insurance.' (Cockerell & Green, op cit, 35) Of course, in the late sixteenth century, the very concept of 'good health' was rather ambiguous. Its definitional boundaries were determined both by the vagaries of a theocentric medicine and a public with little alternative than to place its faith in the transcendental world of religious mysticism. Nevertheless, this period would represent the prelude to a Copernican turn in history, when a new science of probability and risk would eventually seek to replace the chaotic and unpredictable world of chance that had for so long inhibited social progress. It would be within this new world of supposedly inexorable 'natural laws' and the predictable regularity couched within them, where life assurance would become socially embedded.

### **3.2 From Divine Providence to Probable Futures**

Bernstein (1998) argues that new advances in mathematics, particularly calculus and algebra, provided the foundation for what would become the social application of probability. The initial stage in the advance towards a world of risk

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<sup>1</sup> Clark points out that the terms of these policies usually only covered incidents of capture or shipwreck, and explicitly precluded disease and suicide. Clark recounts the disturbing case of Luke Collingwood, the captain of the Zong, who, in 1781, ordered 122 diseased slaves to be thrown overboard so that his company could maximise its claim against the insurers. Clark argues that this action implied '... a thorough familiarity and long experience with the technicalities of marine insurance law.' (Clark, 1999, 17)

and probability was the establishment of scientific measurement, which began to take shape in the early seventeenth century and would later enable scientists to predict the order and regulatory of nature. (Bernstein, 1998, 55) Until this period, people had a relatively naive conception of natural order and regularity. When cataclysmic events occurred, people attributed their cause to the will of God, who was conceived as the ultimate, but largely unpredictable, harbinger of both life and death. Furthermore, medicine was inextricably linked to theology in this early period.<sup>2</sup> It would have been impossible to develop life assurance, as it now exists, in such a world of perceived chaos and arbitrary death. Small-scale and short-term insurance products for seafarers could operate under these ostensibly chaotic conditions, but the statistical and probabilistic revolution was required before a broader conception of life assurance could become realised as an expedient and profitable social institution.

Bernstein acknowledges the work of Fermat and Pascal in laying the foundations for this probabilistic revolution. They began corresponding in 1654, and developed the first method for predicting the likelihood of future events when multiple possibilities existed. This method became known as 'Pascal's Triangle'. (Bernstein, op cit, 63) Bernstein writes: 'The inescapable uncertainty of the future will always prevent us from completely banishing the fates from our hopes and fears, but after 1654 mumbo jumbo would no longer be the forecasting method of choice.' (Ibid, 72)

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<sup>2</sup> Female lay healers were at this time practicing a more evidence-based and empirical medicine in their communities, but they soon became marginalised as medicine began to acquire professional status through the establishment of formal training and accreditation. This new institutionalised medicine was essentially a male preserve. The universities that provided the training were still theological in their approach, and this was reflected in the formal text based medicine they taught. See Oakley, 1976 for a discussion of this male takeover as it applied to childbirth, and Witz, 1992 for a slightly different analysis of gender and the professionalisation of medicine. For an excellent general history of medicine, which includes an erudite analysis of these and many other important social issues related to medical practices, see Porter, 1999

The next significant development emerged with John Graunt's publication entitled '*Natural and Political Observations made upon the Bills of Mortality.*' In this seminal text, Graunt compiled data on the births and deaths that occurred in London between 1604 and 1661. Bernstein describes this work as a breakthrough in the cultivation of sampling methods, which would become crucial for the calculation of probability. Furthermore, because many Dutch towns and principalities were financing themselves through the sale of annuities, an abundance of mortality data was also being collected and analysed there. However, some credit must be given to the English astronomer Edmund Halley (1656-1742), who in 1693 made the most significant theoretical advance towards the potential realisation of a marketable assurance industry. He developed the first life tables, based on population data gathered in the Prussian town of Breslau, which '... could be used to reckon the price of insuring lives at different ages.' (Ibid, 87) Abraham de Moivre (1667-1754) later perfected Halley's methods and used them in his study of annuities.

The end of the seventeenth century was a period in which significant advances in knowledge and understanding of statistics and probability slowly began to change humanity's conception of itself and its place in the universe. The collection and dissemination of population mortality data provided an essential empirical foundation necessary for the creation of new and ameliorating social welfare institutions and a commercially expansive life assurance market.

### **3.3. Risk, Insurance, and the Growth of Capitalism**

These developments in probability and statistics facilitated not only the growth of the insurance industry but also contributed to the evolution of capitalism itself.

In fact, one might even argue that the growth of insurance played an important role in the organic growth of capitalism. It would be useful to explore the deeper sociological insights that emerge from Bernstein's historical data. It may be particularly instructive to look at the broader social and economic context in which this mass of new and revolutionary data was being generated. As Hacking (1990) notes, the original impetus for collecting population data was for military purposes. Such data was an invaluable tool for the State, as it provided logistical information on such things as the number of able-bodied men available to fight in times of war. This data, which essentially allowed the State to measure its true power and strength, remained relatively clandestine because of its military implications. It was only when the amateurs began collating and analysing their own data that a broader probabilistic revolution ensued. Once this data entered the public realm, the very structure of society could potentially undergo profound social, political, and economic change.

However, not all of the changes engendered by the probabilistic revolution had an ameliorating impact. In particular, statistics became an enabling tool for the many enthusiasts of eugenic policies. Members of society did not enjoy the positive social impacts of applied probability theory equally. Foucault (1994a), for example, argues that the increasing obsession with the strength of populations, particularly in France, England, and Austria, was a precursor to the birth of social medicine and the dominance of a new 'medical gaze'. Individual bodies slowly became an object of state control and intervention. Foucault's (1979) *Discipline and Punish*, provides an erudite analysis of the process by which the individual body eventually became a site for the exercise of discipline, through new technologies, which contrasted with the antecedent focus on punishment. At first, France, England, Austria, and Germany used the new science of statistics merely to record population strength. They had no explicit

commitment to the improvement of public health. However, Germany eventually developed a new medical science focused on public health, and the other countries soon followed suit. The new obsession with public health, and an increasing desire to place the 'contagious' under surveillance, perhaps inevitably resulted in the poorest and most vulnerable sections of society becoming the primary targets of state power.

In his essay, *Governmentality*, Foucault (1994b) cites again the importance of the statistical revolution. However, this time he looks at it more positively in the context of the emergence of modern political economy. He writes:

'... in the late sixteenth century and early seventeenth century, the art of government finds its first form of crystallization, organized around the theme of reason of state, understood not in the negative and pejorative sense we give it today (as that which infringes on the principles of law, equity, and humanity in the sole interests of the state) but in a full and positive sense: the state is governed according to rational principles that are intrinsic to it and cannot be derived solely from natural or divine laws or the principles of wisdom and prudence.' (Foucault, 1994b, 212,213)

For Foucault, the new science of political economy emerges from the '... perception of new networks of continuous and multiple relations between population, territory, and wealth; and this is accompanied by the formation of a type of intervention characteristic of government, namely, intervention in the field of economy and population.' (Ibid, 217) Governmentality, for Foucault, means among other things the

'... ensemble formed by the institutions, procedures, analyses, and reflections, the calculations and tactics that allow the exercise of this very specific albeit complex form of power, which has as its target population, as its principal form of knowledge political economy, and as its essential technical means apparatuses of security.' (Ibid., 219,220)

Foucault reveals the impact that the statistical and probabilistic revolution had on both the development of political economy and the micro power relations between individuals and the State. Apparatuses of security were only possible in a rational state with access to the tools of statistical and probabilistic reasoning. As Bernstein remarks: 'The capacity to manage risk, and with it the appetite to take risk and make forward-looking choices, are key elements of the energy that drives the economic system forward.' (Bernstein, *op cit.*, 3) Without risk, and the means to tame it, there could be no profit and therefore no capitalism. Without the tool of probability theory, society could never have become 'future-oriented'. Foucault's most important theoretical contribution was his recognition that the fundamental social changes engendered by the new techno-rational approach to political economy had both positive and negative impacts. Rational probabilistic reasoning could enable society to manage risk, and therefore contributed to capitalist growth and the improvement of public health; yet simultaneously, state science could lead to new forms of subjugation and disempowerment.

Bernstein's rather sanguine celebration of the way society learned to master risk stands in contrast to Foucault's more nuanced and critical perspective. However, a more acute contrast is revealed if we compare the work of Bernstein and Foucault with Beck's seemingly dystopian vision of uncontrollable risk. Bernstein's data, and the general analysis so far provided, appears to challenge the basis of Beck's pessimism. The risks circulating in modern society are arguably no more incorrigible than those in the past. Indeed, one could argue that they are now far better understood and manageable than ever before. Furthermore, as will be explained in more detail later, the wealthier sections of society can, just as they did in the past, buy a certain degree of immunity from the risks that routinely affect the poor. The rational state, and the

various risks it has strived to master, has had differential impacts on individuals and groups. Foucault perhaps captures this more than most authors. Although the rational capitalist state may use science and technology to achieve greater control over its population, the emergence of free floating and discursive discourses, as well as more nuanced micro power relations between subjugated groups and the state, could also prove empowering. Bernstein's optimistic vision perhaps fails to capture some of the negative consequences of this scientific revolution, while Beck's pessimism fails to recognise that many modern risks are manageable and may enable certain groups to avoid their devastating impact.

Weber (1927) also talks about the influence that rational, future-oriented statistical and probabilistic reasoning had on the development of capitalism and its underlying social relations. Both Foucault and Weber regard modern society as driven by rationalisation and discipline, which engenders norms of purposeful rational action in various aspects of social life and activity. Weber describes the rational capitalistic enterprise as one that employs, among other things, rational capital accounting according to the methods of modern double-entry bookkeeping, rational technology to permit calculability, and calculable law. All these necessary elements of the capitalist enterprise were made possible by the probabilistic revolution. Indeed, Weber argues that modern capitalism can *only* survive in the modern rational state. (Weber, 1927, 276)

Although both Foucault and Weber do not talk about insurance as a rational mechanism for the protection of financial wealth, their arguments are still useful for understanding the fundamental changes that had a lasting impact on the structure and development of modern society. Their insights can build on Bernstein's data and provide a more general and critical social analysis of the

influence these revolutionary ideas had on broader social and economic progress. From this kind of analysis, one can begin to assess the work of contemporary sociologists of risk far more critically and provide a more comprehensive analysis of the historical role of insurance.

Although it is not possible to explore these issues in more detail, they are nevertheless crucial to our understanding of both the significance of insurance as a revolutionary mechanism for taming risk and its role in the evolution of modern capitalism. More precisely, the work of Foucault and Weber allows us to explore not only the positive impacts probability theory had on the growth of the rational capitalist state, but also the negative consequences that specific applications of statistical reasoning engendered for certain groups. For example, commercial insurance was an application of probability theory that was of direct benefit only to the few. Those able to use the new science to make investment decisions and protect their financial wealth were predominantly the middle classes. Although their actions enabled capitalist society to flourish, we cannot ignore the fact that there were also many losers. Even rationalised medicine through public health initiatives, made possible by the probabilistic revolution, was often perceived as a direct threat to the liberty of the poor and vulnerable.

However, it is important to realise that despite the abundance of mortality data at the end of the seventeenth century, the life assurance industry did not use them extensively for the underwriting of policies until much later. Cockerell and Green argue that the market in the early eighteenth century was relatively small. The Royal Exchange Assurance and London Assurance offered the only realistic alternatives to the mutual societies, who themselves only began underwriting life policies in 1721. At this time, the authors argue: 'Assurance



was provided for a maximum of one year, and the two companies refused sick or elderly lives and victims of smallpox.' (Cockerell and Green, op cit, 35) Because no use was made of scientifically based underwriting, the market remained relatively bounded and marginal. This was to remain the case until 1756, when James Dodson (1710-1757), a pupil of de Moivre, proposed that a life assurance society be established on the equitable principle: "that the price of insurance on lives might be regulated by the age of the persons on whose life the insurance is made." (Quoted in Supple, 1970, 55) <sup>3</sup> This society was inaugurated in 1762, and became known as the Society for Equitable Assurances on Lives and Survivorships. Following this fundamental change in approach to insurance provision, numerous life assurance companies were born, and underwriting based on actuarially significant data soon became standard practice. As new policies were introduced, and underwriters became more adept at predicting mortality, the assurance companies began to obsessively demand increasing amounts of personal medical information. Cockerell and Green write:

'... from the 1830s onwards, offices recorded details of each proposer's family, and the incidence of gout, asthma, consumption and brain disease ... Extra premiums for life assurance were also charged for corpulence, intemperance, and other health-affecting habits ... Suicide and duelling were exceptional risks ... Unusual personal habits such as opium-eating also affected the practice of the life assurance offices. After a test case involving a Scottish nobleman in the 1830s and the subsequent investigations of the Edinburgh societies, life offices refused to insure proven addicts.' (Cockerell & Green, op cit, 44,45)

Although the life assurance industry did eventually accept the commercial advantages of an underwritten insurance market, it is surprising that they

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<sup>3</sup> Dodson was enraged when he was denied a life assurance contract by the Amicable because of his age, believing he would have been eligible for a policy if underwriting based on sound actuarial data had been employed. He was rejected purely because the life business operated within such narrow margins.

procrastinated for so long. This is perhaps illustrative of the time lag that often exists between an emerging science and its practical application. However, it must also be noted that some of the early statistical information was erroneous, largely because of inherent methodological flaws in the data collection process. The mortality data John Graunt collected in London was flawed, because he failed to factor into his calculations the highly mobile and fluid nature of the population within the capital. The data was incomplete, and could have had serious financial implications if used to underwrite life policies. However, the insurance industry was still being economically irrational in failing to adopt some of the more obvious and rudimentary principles of mortality. They preferred to rely instead, as Clark notes, on their parochial and imperfect 'rules of thumb'. (Clark, op cit, 117)

The historical data presented here suggests that in the embryonic stage of capitalism, insurance could only have had a marginal impact on its development, because the market remained relatively small and bounded. However, for late-stage capitalism, insurance would become crucial as a means of financial security for the middle classes and would make a greater contribution towards capitalist growth. It is now necessary to look at the social context of insurance in more detail, as this will become important when looking at the contemporary issue of genetics, insurance, and social exclusion.

### **3.4 The Social Context of Insurance**

Clark provides one of the most erudite social histories of insurance from its inception in the seventeenth century to the late eighteenth century. He makes the interesting point that in the early seventeenth century, England was one of

the few countries in Europe to permit the assurance of lives. Those countries under the influence of the papacy, in contrast, eschewed life assurance for its impiety and imposed draconian restrictions on commercial practices. There was an unwavering belief that it was somehow immoral to estimate the value of a human life in monetary terms, because this was considered an ultimate transgression of the sacred boundary between God and his mortal subjects. However, in England there was little public objection, and the treasury remained quiescent because of the extra tax revenue it derived from insurance transactions. (Clark, op cit, 22) Furthermore, according to Clark, the Anglican Church was reluctant to denounce life assurance on theological grounds, because they recognised the sublime virtue of financial prudence constitutive of the life business.

However, regulation became an issue in England when the insurance market digressed from its putatively virtuous function as a means of prudential financial planning and oriented itself towards the promotion of risky speculative investments. The 1774 Gambling Act '... introduced the first appreciable regulation of life insurance by barring any insurance on a life or event except insofar as the policyholder had a financial interest (a so-called "insurable interest") in that life or event.' (Ibid, 22) It had reached the point where people were speculating on lives they had no legitimate interest in. Clark cites two macabre examples that occurred in 1765 and 1757. The first concerned the fate of eight hundred German refugees stranded for three days without food on London's eastern outskirts. Before charitable groups could be mobilised, '... speculators and underwriters at Lloyd's had already begun placing bets on the number of Germans still alive by a given future date.' (Ibid, 50) The second case occurred in 1757 and concerned an Admiral Byng, who was standing trial for dereliction of duty because of his abject failure to defend Minorca from the

Spanish. Clark writes: '... premiums on his life varied with the strength of the latest testimony offered against him in court.' (Ibid, 50)

These examples reveal the insurance industry's dual nature. That is, insurance provides an avenue for exploring the theoretically nuanced domains of risk and security, which are essentially flip sides of the same coin that the probabilistic revolution allowed both insurers and consumers to balance more precisely. Insurance therefore encapsulates both a gambling and a prudential aspect. Both were necessary for the development of modern capitalism. Although there were many attempts to tame the excesses of the life business through regulation, the speculative aspect of life assurance has always been part of its nature.

It was not until the nineteenth century that the insurance industry grew, and life assurance products began to catch the public imagination. However, insurance continued to be a middle class preserve, because members of the industrial classes were unable to afford the premiums. Supple draws attention to this class bias in the insurance market when he claims that:

'As early as the 1820s Charles Babbage made the significant point that the assured population had a lower than average mortality precisely because they were "selected from the middle and higher ranks of society, and are consequently exempt from many sources of unhealthiness to which the poor are liable.' (Supple, op cit, 113)

In the Victorian period, life assurance became recognised as conducive to, and indeed constitutive of, the general drive towards social progress. The new and revolutionary knowledge of statistics and probability provided the means for social amelioration through insurance, just as it offered the possibility of

improving the body politic through eugenics-based social policy and increased medical surveillance. Supple describes insurance as:

'... a product which both reflected the importance of individualism and independence, and buttressed the institution of the family and the habit of prudence ... life insurance was bound to benefit from and exemplify the extension and strengthening of middle-class virtues in Victorian Britain.'  
(Ibid, 116)

The insurance industry was keen to accentuate the social virtue role that that it was perceived to embody and sold itself as an institution compatible with the philanthropic ideals of the Victorian middle classes. The promotion of financial prudence that characterised the life assurance business also flattered the Victorians' Calvinistic pretensions. This certainly contributed to the unprecedented growth of the life business throughout the nineteenth century. Weber's, *The Protestant Ethic and the Spirit of Capitalism*, captured the relationship, or what he referred to as 'elective affinity', between the religious virtues of Protestantism, such as prudence and worldly asceticism, and the progress of modern Western capitalism. Again, a rational future-oriented outlook was a prerequisite for capitalist growth, and the emergence of insurance products undoubtedly aided the Protestants in their quest for prudential living.

Weber does not refer to the role of products such as life assurance as a specific strategy of financial prudence and security at this time, yet its importance for the middle classes should not be underestimated. Insurance was a product that gave them a degree of security in a risky world. The inability of the aspirant working classes to access such products meant that their security from risk was far more limited. Therefore, although private insurance was an enabling product for the wealthy, and undoubtedly made a contribution to the growth of capitalism, its role as a socially ameliorating institution for wider

society was at first limited. Of course, eventually social insurance systems would be established, and indeed many of the social engineering programmes aimed at helping the 'deserving' poor were dependent on the same kinds of scientific principles underlying private insurance. Nevertheless, life assurance itself only benefited a sub-section of the general population.

It is important to recognise that this social history of insurance, risk, and probability calls into question some of the basic assumptions made by risk society theorists such as Beck and Giddens. Beck, for instance, makes the claim that in modern society risk is pervasive and imperceptible by all. This is an extremely general and uncritical statement. In particular, it fails to recognise distributive issues around risk, which have remained relatively unchanged for centuries. Risks do not affect 'society as a whole', implied by Beck's 'world risk society' theory. To aggregate risks, as both Beck and Giddens do, is to lose sight of the fact that the wealthy can avoid most of the risks that routinely affect the poor. Financial risks can be averted by purchasing life assurance, and health risks can be avoided by consuming the right products, purchasing health insurance, or living in areas with clean air and good medical services. Choices about consumption habits, social relations, and lifestyle significantly affect risk status, and the wealthy generally have far greater choice than the poor. This is as true today as it was in the past.

As was argued in the previous chapter, both Beck and Giddens have a tendency to generalise various issues around risk. They frequently overlook empirical evidence that appears to contradict their intuitive beliefs on the changing nature of risk and its social impacts. The authors often move uncritically from the particular to the general, with the result that many of their theories can easily be challenged by the historical evidence. The risk society

theory provides an inadequate tool for understanding the genetics and insurance problem, precisely because it does not adequately deal with the differential distribution of both risk and security in the modern world.

The following important insights emerge from the analysis provided in this section:

- 1) The birth of UK life assurance, and indeed the emergence of capitalism, was largely dependent on the statistical and probabilistic revolution. The ability to tame risk and promote financial prudence through insurance aided the capitalist enterprise.
- 2) However, the statistical revolution did not bring benefits to all in equal measure. The rational state's obsession with the control of populations affected groups in a variety of different ways. Life assurance only really benefited the wealthy middle classes, because they were the only social group with the financial resources to be prudent and future-oriented. Foucault and Weber's writings are useful in that they alert us to the broader and more nuanced social context in which the statistical revolution was evolving, and reveal the differential impacts this revolution engendered.
- 3) Although life assurance contributed to the growth of late-stage capitalism, its role in the embryonic stage was probably limited. This was because the market remained relatively small and bounded, and the use of statistical data was not initially used in actuarial decision-making.
- 4) The history of risk, insurance, and modern capitalism challenges the generalised risk society theory of Beck and Giddens, because it demonstrates that, a) modern conceptions of risk are not qualitatively

different from those in the past, and b) risk and security are not distributed equally amongst all groups in society.

The convergent histories of probability theory and life assurance represent both the triumph of science over superstition, and financial security and prudence over uncontrollable destiny. The insurance business, and the new science underpinning it, provided some individuals with a greater degree of control over their futures. The promise of security in an ostensibly risky world was always going to resonate within the Victorian middle class mindset, and this promise still holds indelible appeal to the contemporary insurance buying public. Insurance undoubtedly performed an important social function, and continues to do so, but the birth of actuarially determined underwriting also provided a means for discrimination and exclusion. This has become an important issue in the context of contemporary insurance provision. This chapter will now move on to discuss the principles of the modern life assurance business and the statistical discrimination on which it is based. The issues discussed in this section, particularly the class bias in insurance provision, will become of fundamental importance when exploring the contemporary problem of access to life assurance in the age of genetics.

#### **4. THE UNDERLYING FINANCIAL AND ETHICAL PRINCIPLES OF MODERN PRIVATE AND SOCIAL INSURANCE: RISK ANALYSIS, RISK POOLING, AND THE BUSINESS OF DISCRIMINATION**

In the UK, commercial life assurance exists within a complex system of state funded welfare. Both social and private forms of insurance have an intricate and interdependent relationship, despite being underpinned by two contrasting



guiding principles. The level of state sponsored social insurance provision can have a direct impact on the commercial limits of the private sector. It may also shape society's perception of the type of 'social good' particular private insurance products are considered to exemplify. Private insurance often fills the residual spaces left by state funded welfare providers but may also replace social provision in part or in whole.<sup>4</sup>

Although this chapter is concerned with the principles and ethics of private life assurance, it is important to understand the ways in which these two complementary forms of indemnity interact, and appreciate that the level of provision available within the social realm can affect the financial and ethical framework of any private system incorporated into the social fabric. It is important to recognise this point, and look at it in the context of the historical issues so far discussed, if we are to make some progress on research question one, which is concerned with the likely social, legal, commercial, and ethical implications genetic information may have for life assurance provision.

#### **4.1 'Solidarity' and 'Mutuality' in Social and Private insurance**

'Solidarity' and 'Mutuality' are the two fundamental principles that guide social and private insurance respectively. Solidarity is constitutive of social forms of insurance in which coverage is universal and not dependent on the risk-status

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<sup>4</sup> See Erskine, 1997 and his argument that social insurance is an anachronistic institution designed for a post-war era demographically very different from contemporary British society. He recognises a greater political momentum towards the private supply of insurance and countenances the argument that the private sector's interest in opening up new markets is influenced by the vacuum left after state cover has been exhausted. (Erskine, 1997, 143,144).

of users.<sup>5</sup> The finance required for this form of provision comes from general taxation and access is based purely on need. Mutuality, on the other hand, characterises those forms of private insurance where coverage is voluntary, and the financial contribution of the applicant is dependent on the risk he/she brings to the insurance pool. This is commonly referred to as the 'equity principle', which underlies all risk-based private insurance models. In the absence of actuarial underwriting, and the equitable pooling of risks, commercial insurance is not a particularly profitable enterprise.

A solidarity based social insurance system is relatively straightforward to implement. It requires only the willingness of government to set aside a percentage of tax revenue for the supply of what is widely recognised as an indispensable 'social good', and an amenable public willing to support such a mechanism of provision. The rest is simply a matter of financial planning. However, a number of *a priori* conditions must be satisfied if a private system of insurance is to be socially and commercially viable. Nicholas Barr (1993), in his classic text, *The Economics of the Welfare State*, proposes five crucial probability conditions that must be met if an efficient private insurance system is to be implemented. Firstly, the probability of an insurable event occurring for one individual must be independent from the probability of it occurring to another individual. Secondly, the probability must be less than one. If the probability were one, there would be no *risk* for the commercial insurer to pool. This is an important point when we consider the genetics issue. It is because genetic information is not absolutely deterministic that such knowledge

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<sup>5</sup> A narrow definition of solidarity has been proposed here mainly for pragmatic reasons, but it must be recognised that there are many varieties of solidarity. Husted, 1999 contrasts 'constitutive'/alliance' solidarity with 'communal' solidarity. The latter represents people with 'common interests' and is exemplified in social insurance systems oriented towards the protection of weak members of a group. The former, on the other hand, characterises people with an 'interest in common' but acting essentially for self-interested reasons. This is exemplified in most private insurance contracts. (Husted, 1999, 3)

becomes a valuable commodity in the hands of the insurance underwriter. Thirdly, the probability of the event must be known or estimable; otherwise, insurers cannot calculate with any precision the risk-based premiums fundamental to a private insurance market. Fourthly, there must be no 'adverse selection'. This will be discussed in more detail later. Finally, there must be no 'moral hazard'. Moral hazard can occur, according to Barr, in one of two ways. The customer can either manipulate the probability of the event occurring or influence the size of the loss incurred. The latter, often referred to as the 'third party payment problem', does not make the practice of commercial insurance impossible, but it does precipitate inefficiency by tolerating over-consumption. Moral hazard is a problem commonly experienced by private healthcare providers. Barr writes:

'If an individual's insurance pays all medical costs, then health care is "free" to the patient. Similarly, on the supply side, the doctor knows that the insurance company will pay his charges; he is therefore not constrained by the patient's ability to pay. As a result, both doctor and patient can act as though the cost of health care were zero. This is inefficient: it causes over-consumption and creates upward pressure on insurance companies.' (Barr, 1993, 130)

In addition to these technical requirements, there must also be a positive demand for insurance (which requires plenty of risk-averse individuals), the administrative infrastructure to deliver insurance, and the ability to supply insurance products at a price that individuals are willing to pay. (Ibid, 123) These commercial necessities distinguish the private market from state funded provision. However, as has been mentioned, the two systems do mutually interact, as one constantly defines and configures the parameters of the other. This point becomes clearer when we consider the 'social good' aspect of private life assurance. However, it must be recognised that European systems of social

insurance are often based on compulsory participation in schemes managed by private or mutual providers. Therefore, the polarisation of tax-funded and private provision may appear to be an artificial construct. Nevertheless, in the UK, private and social systems of insurance are institutionally autonomous, for the most part. In order to understand the 'social good' aspect of insurance, it is sometimes instructive to operate with 'ideal types'. Wiesing (1999c) provides an analysis of European styles of insurance provision and highlights the different ways that mixed systems may affect access to various kinds of insurance products. However, when looking at life assurance in the UK, it is legitimate to make a distinction between tax-funded and commercial insurance.

#### **4.2 Life Assurance and the 'Social Good' Argument**

When considering the ethical boundaries that envelop the commercial supply of any given insurance product, one is naturally drawn into considering the product's 'social good' status. Sandberg (1995) posits the existence of three distinct types of social good. Firstly, there are 'primary social goods'. These are goods that everybody has a 'right' to access, because they provide the minimum standards of welfare deemed necessary for the enjoyment of a 'decent' life.<sup>6</sup> Most people would consider the British National Health Service a primary social good on this definition. Secondly, there are 'commodities'. These are goods or services sold in an open market in which there is no moral imperative to distribute them according to egalitarian principles. They are, in this sense, non-essential luxuries. Thirdly, there are 'non-primary social goods'.

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<sup>6</sup> Of course people will always disagree on what constitutes a 'decent life', so the very concept is in this sense relative, and may vary significantly between different kinds of society. However, within any single society, there will always be some objective criteria for measuring the general standards of living, and although the methods may be imperfect and disputable, they are still useful for providing a general baseline of what may be considered universal social essentials.

These goods lie conceptually in-between the other two. Sandberg regards European life assurance as a 'non primary social good'. He writes: 'It is an instrument for rational agents to secure a certain economic standard of living, above the publicly guaranteed minimum floor, for their dependants in the event they die.' (Sandberg, 1995, 1554) However, it cannot justifiably be regarded as a primary social good, because dependants of those who cannot afford life assurance policies still have the social security system as a financial safety net. Nevertheless, it ought to be regarded as more than a mere commodity, according to Sandberg, because it does still distribute various social benefits.

The upshot of this conception of life assurance as a non-primary social good is that commercial providers have a legitimate right to employ risk-assessment as an underwriting tool. However, the social and ethical impact of a commercial market can be mitigated or intensified by the level of state provision. The commercial and ethical parameters of private life assurance should not be regarded as static and immutable, but as constantly fluctuating in response to changes in the level of social welfare. In the United States, life assurance could be defined as a primary social good, because the general level of state funded welfare is woefully inadequate by European standards. But even in the UK, where the provision of welfare is relatively comprehensive, life assurance may be shifting conceptually in the same direction. As a greater number of people begin to purchase their own homes, for example, society's conception of the minimum economic standards of living may be modified. Since life assurance is often a prerequisite for obtaining a mortgage, its conception as a primary social good becomes more greatly justified. However, one must make a distinction between an endowment-linked mortgage and a simple repayment mortgage. It would be far more difficult to justify a fundamental right to the former.

Nevertheless, if home ownership is considered a primary social good, basic insurance products necessary to access this good ought to be open to all.

The question that arises is: how can economic rationality, and the requirement to equitably distribute social goods, be squared within a private insurance market whose *raison d'être* is the search for ever-increasing profit.

#### **4.3. Balancing Commercial and Social Interests: The Insurance Industry's Double Truth Doctrine**

Private insurance is guided by the principle of economic rationality, yet it is simultaneously expected to fulfil certain social responsibilities and obligations. It is interesting to analyse the various ways in which representatives of insurance companies juxtapose market and social values in their interview accounts. On the one hand, insurers often accentuate the social benefits of a private insurance market. However, they are also quick to point out that insurance is a 'business like any other'. The use of both a 'rhetoric of social altruism' and a 'rhetoric of market freedom' was a central feature in the interview accounts of insurance representatives. There was a sense that in order to defend commercial freedom, a narrative repertoire that included a strong social value dimension had to be expressed. One could refer to this strategy as an attempt to create a 'morally adequate' account of commercial norms and values.

Three of the insurance representatives made explicit reference to the idea of social values and responsibility. Keith Bedell-Pearce, a director at the Prudential, claimed when interviewed:

... I feel quite strongly that the insurance industry as a whole ... has this franchise to operate as commercial concerns in aggregate, through permissions granted by society, and therefore there has to be some reciprocal arrangement in terms of the way in which we behave. (Keith Bedell-Pearce, Director at Prudential Plc., interviewed by James Mittra, 18 July 2001)

Later in the interview, when asked specifically about the moral dimension of corporate decision-making, he recapitulated by arguing:

With the growing emphasis on corporate social responsibility, which is very important and again sort of in the wider extension of the concept that you only engage in commercial activities with the consent of society; therefore there is some need to reciprocate that by exercising a degree of corporate social responsibility. Within that corporate social responsibility ... is the need to look at the implications of the decisions we make, and if we can mitigate that in human terms, then I think it's the job of insurance companies to do that .

Within the insurance industry, there is a prevalent belief that the social implications of commercial practices matter. This is often expressed through the rather equivocal concept of 'corporate responsibility'. It is necessary, however, to examine the way in which respondents articulate and use this rather vague concept. If one were to interpret the above extract as a literal and authentic statement, one would have to believe that insurance companies have a deep concern for the insurance needs of citizens. The above extract states that mitigating the negative consequences for individuals should, if possible, be a 'job of insurance companies'. However, the phrase 'if we can' might be read as 'if commercially sound'. Although a social value narrative is revealed in the extract, a narrative of economic rationality appears to envelop it.

The anonymous insurance underwriter, lamenting the fact that the media only ever report negative stories about the industry, stated:

There are positive stories coming out ... the monies paid out on death claims runs into hundreds of millions every year. But nobody looks at that. Nobody talks to these people and says well what did [a well known insurance company] do for you? (Anonymous underwriter, Interviewed by James Mittra, 12 June 2001)

Insurance companies undoubtedly distribute various social benefits. This particular insurance representative expresses clear concern that the benefits are often ignored. However, the following extract, from the same respondent, signals one of the reasons why insurers may have an interest in advertising the fact that they distribute social goods and are socially responsible agents.

We want to pay claims, we want to pay genuine claims because that's good news. It ups the standing of the company, it ups the standing of the industry. The client's family doesn't benefit if they're expecting x tens of thousands of pounds and get nothing. (Ibid.)

This extract reveals how insurance companies see the distribution of insurance products primarily within a business framework, even though they may reference the benefits reaped by the family. It is interesting that the benefits to the family (a social value) are only expressed after the benefits to the industry (a market value) have been articulated. However, one may not wish to read too much into this, as lists are not necessarily indicative of respondents' priorities. Nevertheless, this extract illustrates the dual use that is often made of a market and social value narrative. Of course, in this case what benefits the client simultaneously benefits the industry. This same insurer accentuated this point when he stated:

'At the end of the day the insurance companies are there to make a profit, but also to provide a service. But through that service they make a profit for their shareholders and for policyholders in mutual companies. So they are there for the greater benefit.'



What is most striking in this extract is that the concept 'greater benefit' does not refer to 'protection of the vulnerable', but to the creation of a vibrant economy in which shareholders and policyholders can enjoy financial gains. Therefore, although insurers may invoke a social value narrative to legitimate their commercial interests, 'greater social benefit' acquires a definition most people outside the industry would reject. However, whether or not the social value concept is used in an extended or restricted sense, it still appears to be used strategically to express a particular economic narrative.

However, what may be termed the 'double truth doctrine' ('concern for access to insurance products' and 'concern for profit') may sometimes run into contradiction. At some point, there must be a trade-off, and in such cases, it is the concern for wider social values that is often relegated in priority. The above extract, which stated that 'at the end of the day insurance companies are there to make a profit', is telling in this regard. Other insurers expressed similar statements. Keith Bedell-Pearce, after extolling the virtues of a socially responsible insurance market that distributes various social benefits, made the following statement when asked his opinion on those individuals who may have no access to life assurance because of a positive genetic test.

... there is no inalienable right to have insurance ... No one is forcing anyone to take out life or health insurance. Equally, **no commercial organisation should be forced to provide insurance if it doesn't want to do so.** It's not as straightforward as that because there's things like reputation, position, and the social responsibility aspect, but I don't think life assurance is a special case.

Although insurers express the need to be socially responsible, by enabling more people to enjoy access to various insurance products, in the final analysis it appears to be the economic 'bottom line' that takes priority. The rhetoric of

social value is fine only if it is advantageous to the company. However, when social values may challenge commercial rights, the rhetoric of commercial freedom is used strategically to defend discriminatory practices. Insurers therefore appear to draw upon both an 'altruistic' and 'market freedom' value narrative, often blurring the boundaries between the two, in order to defend a particular business framework. Social values are referred to when they can be used to promote the normative framework of existing commercial practices. However, the focus quickly shifts to market values when pressure is exerted to provide products to all applicants regardless of their risk-status. When the two values appear to contradict each other, the commercial ones appear to take precedence. Tony O'Leary revealed this in the following statement:

There are issues where the insurance industry has to be moral but obviously you've got to look at it as a business. (Tony O'Leary, interviewed by James Mittra, 21 May 2001)

This respondent states that there are shades of grey concerning the social and moral issues, and the industry has a responsibility to be practical and sensible. Nevertheless, he appears adamant that this responsibility does not extend to accepting the whole cost on behalf of society. Interestingly, the respondent also uses a social/moral value framework to *defend* the discriminatory nature of insurance. After citing a public document that had accused the insurance industry of being more concerned about its right to underwrite than the social implications of differentiating applicants, Tony O'Leary claimed:

To a degree that is an element. But I would find it very hard to stand up in front of the Diabetic Association and say "you guys are paying an extra premium whereas these guys aren't." Because I don't think that's fair.

Again, the distinction between market and social values is made to look ambiguous. When representatives of the insurance industry are accused of being immoral, they may often draw upon an alternative narrative repertoire, where a different spin on social and moral values can be used to defend commercial freedom. Actions that others characterise as immoral are now inverted, through a rhetorical sleight of hand, and shown to be the most fair and equitable. The above extract is a perfect example of the way individuals strive to create a 'morally adequate account' of their actions. This insurer does not feel comfortable defending commercial interests purely on the basis of economic rationality, so instead he articulates the moral problem of breaking commercial norms in order to enable a sub-set of policy applicants to acquire insurance cover.

It is impossible to know for sure what the 'true' motivations of the insurance industry are. However, these extracts reveal that insurers may tell different stories, and draw upon a broad narrative repertoire, in order to defend existing commercial norms and provide a morally adequate account of their beliefs. Two principal strategies for operationalising particular social and commercial value narratives are revealed in the preceding extracts. One strategy is to accentuate the fact that what benefits society also benefits the industry. Paying out on premiums increases the reputation of the company and helps generate new business. Distributing social benefits, and being socially responsible, simply makes economic sense. Here, the social and market value appears synonymous, so a rhetoric that draws on both can be used to provide a morally adequate account of commercial freedom. A second strategy is to argue that because insurance is a business like any other, it should not be expected to take responsibility for the whole costs of society. In this case, a market value overrides any social values. However, the market value is presented as being

the best way to promote equity in the distribution of social benefits. Tony O'Leary used this strategy when he argued that it would be immoral to subsidise genetically at-risk applicants.

It appears unlikely that corporations honour their social and ethical obligations out of altruism and an authentic concern for wider societal values. Rather, the motive for their behaviour is more likely to be the desire for profit. Indeed, authentic altruistic behaviour, implicitly suggested in the concept of 'corporate responsibility', is usually considered anathema to this fundamentally economic aspiration. However, we must concede that private insurance does perform an important social function by distributing social goods amongst policyholders. Of course, because life assurance only really benefited the wealthy, as revealed by the historical evidence, one must be cautious about talking in terms of general social benefits. Nevertheless, the socially desirable benefits of commercial insurance provision are likely to emanate from an economic rationalisation guided by corporate self-interest, rather than from the virtue of altruism and the social values assumed to be encapsulated within it. Although we may never be able to truly 'get behind' insurers' accounts and discover their 'real' motivations, the analysis of their accounts suggests the existence of an underlying economic story.

Insurers are able to blur the distinction between market and social values, because the social benefits are not *just* a by-product of economically rational decisions but are simultaneously constitutive of that very same commercial process. Without the social benefits there could be no private insurance market, because individuals would not pay premiums for a product they did not believe would rescue them in time of financial need. Nevertheless, these social goods,

from a corporate perspective, are best recognised as the consequence of rationalised economic decisions.

Insurers claim to be concerned about those individuals who find themselves 'socially excluded', and often declare that there is an affinity between their commercial practices and wider social and moral values. They may do this in order to express a morally adequate account of their commercial beliefs. Although many of their actions may be justified, one should not ignore the economic rationality that appears to envelop their seemingly altruistic behaviour. Such rationality is not necessarily a bad thing. Just because insurance companies make vast profits does not mean that wider social benefits do not exist. Furthermore, as Wiesing (1999a) points out, when insurers act on economically rational criteria, they should not be held responsible for the consequences of their actions. In addition, he argues that any external interference with such a rational process might undermine the very foundations of the commercial market. A frequent mistake made by many interest groups is to treat market and social values as mutually exclusive. Of course, such groups may have an incentive to tell this particular story in order to defend an anti-commercial position. However, once we recognise that insurers, like all stakeholders, will express a variety of stories, and draw upon different kinds of values in order to defend existing practices, then we are in a better position to understand the role of rhetoric in the evolution of policy debates around genetics and insurance. Only then, can we stand back and look critically at the moral dimensions of the debate and the likely outcomes of particular policy decisions.

Society may desire selfless corporations that act against their economic nature, but should not perhaps *expect* it. This might be regarded the first

principle of private insurance. It is why the concept of 'social good' may become so instrumental to how society sets the social, economic, and ethical boundaries. If an insurance product is defined as a 'non-primary social good', society might find it difficult to justify legislative restrictions on commercial activities. If, however, the insurance product is defined as a 'primary social good', society may be justified in restricting commercial freedom by prescribing certain ethical boundaries. However, one must be aware that this may undermine the principle of equity that is fundamental to all private risk-based insurance. This will be discussed in more detail shortly, when the issue of genetic information is introduced. Now it is necessary to discuss in more detail the 'business of discrimination' and the process of risk pooling that underlies the economically rational private insurance system.

#### **4.4 Risk Analysis and Risk Pooling: The 'Business of Discrimination'**

The primary maxim underlying all private insurance contracts is *uberrima fides* (utmost good faith). *Uberrima fides* imposes a duty on the proposer for life assurance to disclose all relevant information necessary for accurate risk analysis and pooling, which leads inevitably to what is commonly referred to as 'discrimination'. Discrimination characterises the very business of private insurance, and is what distinguishes it most from social insurance systems. The following statement from Keith Bedell-Pearce is instructive in this regard:

The whole of insurance, whether it is life assurance, or property and casualty insurance, is based upon discrimination. That is the art of the underwriter, and it is art and science for the underwriter, but a lot of it is art ... In some types of insurance an underwriter for one company will, because its an art and not a science, take a different view as to the discrimination that is applied, than another insurance company ... And that's what makes a market

This portrayal of underwriting as both art and science is important in the context of risk pooling and discrimination. As well as providing the background conditions conducive to the practice of 'unfair' discrimination, it also creates the necessary commercial environment for underwriters to offer a diverse range of prices on risk. People do not have to be denied access to insurance, or pay exorbitant premiums, as long as they can find an underwriter willing to take a greater risk than his/her competitor at the same or lower price. Underwriting, in this context, is just as much art as science. However, in reality the market is not so fluid that there are rogue underwriters audaciously undercutting the premiums offered by competitors. Although it is possible to acquire better rates by 'shopping around', the market remains relatively bounded. Underwriter freedom is generally restricted to the margins of risk. Nevertheless, the larger the market becomes, the greater the freedom individual underwriters enjoy in pricing risk. This results in a far more flexible market, which is obviously advantageous to the consumer. However, the industry as a whole may have an interest in sustaining a relatively bounded market through regulation, if this will allow them to limit the potential for rogue actions. Through mutual agreement, companies may submit themselves to internal or external regulators so that a viable market can remain both relatively stable and commercially reputable.

Couched within the rubric of the principle *uberrima fides* is essentially the 'freedom to underwrite'. This is the freedom to classify risk and differentially categorise those individuals who embody it. In theory, this right ought to remain sacrosanct if the founding principles of private insurance are to be adhered to. Leigh (1998), an often outspoken defender of the traditional maxims underlying commercial insurance, exclaims: '... only a fool or a rogue would disagree with this principle.' (Leigh, 1998, 11)

#### 4.4.1 Adverse/Anti Selection

One of the main functions of the principle *uberrima fides* is to prevent what in insurance terms is referred to as 'adverse selection' or 'anti-selection'. The commercial fear is that in the absence of symmetry between applicant and insurer, regarding knowledge of the applicant's risk-status, high-risk individuals will purchase excessive amounts of insurance at standard rates. This would lead to the insurer having to bear the added cost of the uncalculated risk. The insurance industry therefore demands equal access to all available and pertinent information regarding an applicant's current state of health and susceptibility to future illness.

A related issue to adverse selection is 'moral hazard', which was mentioned briefly when describing Barr's prerequisites for a viable commercial insurance market. Moral hazard refers to situations in which the policyholder manipulates the size of the risk by virtue of having insurance cover. People with home contents insurance who neglect to secure their property, because they know they are covered in case of loss, provides a classic example of 'moral hazard'. In this case, the existence of coverage appears to reduce incentives to minimise the risk. In the 1980s, the emergence of HIV and Aids sensitised health insurance providers to the problem of moral hazard. However, because moral hazard is not a significant problem for life assurance providers, the current focus will be on adverse selection.

The cause of adverse selection is not always fraudulent non-disclosure on the part of the policy applicant. It can also emerge because of underwriter error or basic flaws in the design of application forms. A prime example of the latter



occurred in the early 1980s. Because of the unprecedented housing boom, life offices recognised that there would be an increased demand for mortgage-related life assurance. Since the excessive medical and lifestyle questions on existing proposal forms posed an administrative and financial burden, companies decided to minimise the underwriting process for mortgage-related life assurance. They did this by reducing the number of questions within the medical section of the application form.<sup>7</sup> The industry figured that adverse selection would not pose a significant threat, because homebuyers were not presumed to be high-risk applicants. The industry assumed that the applicant's primary motivation for accessing the product was the desire to purchase a home, rather than acquire a life assurance policy. Although the industry did impose age restrictions, all applicants effectively needed to obtain the life assurance as an offer of a mortgage. However, what the industry failed to realise was that the thousands of people who had been denied mortgage-related life assurance in the past, now found they were eligible and were taking advantage of the offer. To compound the problem, insurance agents working on commission were actively approaching those individuals they knew had been denied cover in the past, because they realised there were no longer any barriers. Many applicants purchased a mortgage just so that they could acquire the life assurance. Graham Austin, a chief underwriter, made the following comment during interview:

People on their deathbed were taking them. [The policies] Companies lost hundreds of millions of pounds. And people said we won't be selected against. As soon as somebody realises they can get something that they couldn't get before without having to lie ... they will do it. (Graham Austin, Director at Munich RE. Life Branch., Interviewed by James Mittra, 19 July 2001)

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<sup>7</sup> From the 1980s, there has been a general trend towards reducing the number of questions on proposal forms. As life assurance has become more popular, the 'transactional costs' of excessive underwriting has become regarded as surplus to requirements.

This statement offers an excellent insight into the way the insurance industry understands the internal psychology of its policy applicants. The prevailing wisdom appears to be that individuals will invariably take advantage of any loophole in the insurance contract, especially if doing so does not require them to break the law. It is interesting that this insurer makes a point of stating 'people said we won't be selected against'. Insurers frequently use this riposte against those who belittle their commercial fears.

This example of adverse selection is a 'legal' form resulting from commercial mismanagement. However, we should not ignore those applicants who do seek to defraud insurance companies. The salutary lesson for the insurance industry is that it must be sensitive to the psychology of policy applicants and be diligent when formulating proposal forms. Although one may want to make a 'moral' distinction between fraudulent and non-fraudulent non-disclosure, the consequences for the industry may be just as severe in both cases. Insurers therefore appear to create a decision-making framework guided by the principal 'assume the worst of individuals' in order to protect their commercial interests.

The insurance industry does find itself placed in a difficult position. It must protect itself against adverse selection, yet at the same time increase the pool of policy applicants in a socially responsible way. The various rhetorical strategies that representatives of the insurance industry use, and the diverse narrative repertoires they draw upon in order to express a morally adequate account of their actions, might in part be a consequence of having to respond to a number of different external pressures. This is a crucial point that will be made clearer in the following chapters.

If we consider the implications of 'genetic testing' for adverse selection, a number of diverse opinions emerge. Macdonald (1997) argues that genetic information might be more relevant than other criteria, such as gender, because a positive test creates an incentive to purchase insurance. Le Grys (1997) also raises the possibility of adverse selection resulting from genetic testing but argues that judgements can only be speculative at present, because there is a paucity of scientific evidence to validate any one argument. He does not believe that a positive test would cause somebody to buy life assurance, although he concedes that it may subconsciously influence their decision. Harper (1997a), a clinical geneticist, is more explicit when he argues that the new genetic tests are unlikely to have a significant impact on existing insurance industry norms. Harper provides an extensive analysis of the most common genetic disorders, and the current scientific wisdom on predictive testing, and claims that almost all have no discernible relevance to insurance underwriting. Of those that may be relevant, he predicts that their impact will be relatively innocuous.

Adverse selection is certainly a controversial issue, with many scholars and stakeholders seriously questioning its true significance for the insurance industry. However, documented cases do exist, so we should not discount it entirely as a legitimate commercial concern. Nevertheless, we must also recognise that the potential for adverse selection is often dependent on the particular insurance product being provided. For example, it is far more likely to occur in health, critical illness, and long-term care insurance, where there is a direct connection between the onset of illness and the salutary benefit of possessing the relevant insurance cover. However, in the case of a product like life assurance, it is not necessarily an individual's primary concern, after discovering they are susceptible to some deleterious medical condition, to suddenly seek life cover. Of course, they may try to acquire as much health

insurance as possible. In contemplating the complex issue of genetics, insurance, and adverse selection, it is important to recognise the differential consequences that particular insurance products may engender. Therefore, the level of freedom granted to underwriters ought, perhaps, to be dependent on these observable variations in impact.

#### 4.4.2 The *Equity Principle and 'Discrimination'*

Underlying the freedom to underwrite is the principle of 'equity', which dictates that individuals pay a 'fair premium' commensurate with the risk they bring to the insurance pool. Individuals who bring a greater risk to the insurance pool pay higher insurance premiums than those who bring a lower risk. The risk status of some individuals is so high that they become in effect uninsurable. This notion of risk pooling, based on individual risk-status, is often defended on the grounds of 'actuarial fairness', which is a concept analogous to 'fair discrimination'. The underlying philosophy is that if an individual embodies an actuarially or statistically significant risk, it is 'fair' to charge them a higher premium or deny them an insurance contract. As Brokett and Tankersley (1997) write:

'Insurers generally hold that *statistical* justification is a sufficient defence for a classification scheme. That is, the use of a particular variable in a rate structure does not constitute "unfair" discrimination if individuals with differing levels of the variable have statistically and significantly different projected loss costs.' (Brokett and Tankersley, 1997, 1664)

The principle of actuarial fairness is not to the exclusive advantage of the insurer. It also benefits low-risk policyholders in the insurance pool. If commercial insurers lost the right to use a differential rate structure for high-risk

and low-risk applicants, commercial norms would demand that the latter cross-subsidise the former by paying premiums incommensurate with the low-risk they bring to the insurance pool. For a social insurance system based on communal solidarity, this kind of redistribution may be both pragmatic and virtuous. However, such redistributive norms are anathema to a mutuality-based commercial system that embraces the principle of equity.

So long as the insurer is using actuarially relevant information to differentiate applicants, it is considered fair and amoral. Wilkie (1997) points out that even the Disability Discrimination Act contains a clause that permits insurance companies to use discriminatory risk-assessment against the disabled, if the disability has actuarial relevance to the particular insurance product. Wilkie sees nothing iniquitous in the use of this principle. If *everybody* is categorised on the basis of scientifically valid and relevant information, it is claimed that there is no moral ambiguity. Launis (1999) defines this kind of discrimination as 'value-neutral', 'non-arbitrary', and 'indirect'. In contrast, 'arbitrary discrimination', in which irrelevant, non-present, or statistically spurious characteristics are used as a basis for discriminatory practices, is generally considered unfair. O'Neill (1997b) posits an additional third category, which she refers to as 'legally forbidden' discrimination. (O'Neill, 1997b, 9) For example, it is illegal to discriminate on the basis of racial characteristics even if doing so could be justified on the grounds of actuarial and statistical relevance. However, insurers are permitted to use gender as a discriminatory tool, which is why women generally pay less for life assurance than men. Nevertheless, it must be recognised that the proscription against insurers differentiating policy applicants on the grounds of ethnicity does contradict the principle of equity. This illustrates the fact that in practice actuarially fair information is not always treated as an amoral concept. In reality, ethical boundaries that undermine the

equity principle are sometimes imposed on commercial insurers. However, at present we are focusing primarily on the 'ideal' and 'pure' principles of private insurance. The practical realities, and deviations from the ideal, will be discussed later.

There is another important dimension to this issue of discrimination. Many hold the intuitive belief that it is somehow more justifiable to discriminate on the basis of characteristics or traits that the applicant has control over, such as smoking or obesity, than on what are often referred to as 'no fault' conditions; a term that encompasses most genetic disorders. People generally believe that those who find themselves in the latter category are morally entitled to special dispensation. However, within a private insurance system, the apportioning of blame is considered superfluous. Insurers care less about the cause of an applicant's risk than they do the actuarial and statistical consequences of it. As Leigh states:

'If a proposer is more likely than the average person of the same sex and the same age to die prematurely, the premium should be higher: It is the increased probability of death that is important to the life office and not how it has arisen.' (Leigh, op cit, 24)

The insurance business is concerned ultimately with outcomes rather than causes. Abstract, normative arguments about the ethics of discrimination are sociologically and philosophically interesting, but one must question where they lead in practice. Although certain forms of discrimination are perhaps more morally suspect and unjustifiable than others, in the case of insurance it ought to be the outcome for the individual that we prioritise rather than the philosophical route by which that individual was excluded. Whether or not someone was discriminated in a 'fair' or 'unfair' way is immaterial when one

begins to assess the impact on the individual who is denied access to an insurance product. There is, perhaps, a need to embrace this kind of consequentialist ethical framework when contemplating the issue of discrimination. Such a framework should be linked to a social good criterion. When imposing ethical boundaries on the provision of private life assurance, we should perhaps do so based on the kind of social good it is perceived to be and experienced as. Sorell (1998) is one author who accepts that underwriting takes place within limits, but claims that the particular insurance product should determine where the parameters are fixed.<sup>8</sup> He writes: 'How free insurers are to underwrite depends mainly on how morally bad it is for people to be denied the relevant form of insurance.' (Sorell, 1998, 69)

If it is morally and ethically right that individuals should have access to a particular form of insurance, and if a significant number of people would be socially disadvantaged if denied such a product, then there may be justification for providing systems of protection. However, such protection must apply to everybody regardless of whether they were being denied insurance in a predefined fair or unfair way. Furthermore, one must realise, in these specific cases, that one is compromising the fundamental tenets of equity based private insurance. In fact, if one truly desires universal access to a particular insurance product, which has become defined as a 'primary social good', then the system of provision itself should, in theory, be modified. Within a private life assurance contract, to be unfair in one's discrimination is to either categorise individuals based on imperfect data, or allow value judgements to influence actuarial

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<sup>8</sup> Sorell provides an antithesis to Leigh's, 1998 contention that the freedom to underwrite should in principle be 'absolute'. Leigh decries the case of HIV and AIDS, which he believes set in motion the tide that would slowly attenuate this freedom. He goes as far as to argue that if such freedom is eroded any further, many life offices will be forced to withdraw from the market, as it will become commercially unviable to operate within its continually circumscribed boundaries.

decision-making. All other discrimination is fair within this context and deserves a certain level of legitimacy.

This section has provided a lengthy analysis of the principles underlying private insurance provision and revealed the general ethical framework surrounding all private insurance contracts. A number of important insights relevant to the first research question emerge from the preceding analysis.

- 1) The relationship between solidarity and mutuality based insurance is symbiotic. The ethical parameters of the latter depend in part on the level of support provided by the former.
- 2) The concept of 'social good' (non-primary or primary) can be used fairly and effectively to determine whether a given insurance product ought to be provided through a mutuality or solidarity based system.
- 3) If the product is considered a 'non-primary social good', then the historical normative framework of commercial insurance provision (discrimination and risk pooling) perhaps ought to be respected. Fair discrimination is justified because in its absence, commercial insurance is unviable and insurers face the risk of adverse selection.
- 4) Commercial insurers may render the distinction between social and market values ambiguous. Through their interview talk, they may strategically draw upon both narratives in order to defend their commercial interests. This is interesting sociologically, and accentuates the point that commercial insurers exist ultimately to make a profit. Again, if they are offering a non-primary social good, there is no iniquity in this approach. However, the upshot of this is that society cannot *expect* insurers to prioritise social values/benefits.



- 5) The preceding arguments are of fundamental importance to any fair assessment of the likely social, ethical, and commercial implications genetic information may have for the provision of private life assurance.

All of the issues so far discussed in this chapter become increasingly important when we begin to consider the likely impact of new kinds of genetic information on traditional life assurance underwriting. In order to make further progress on the first two research questions, it is necessary, in light of the ideas so far raised, to look at how genetic information may change the traditional practice of life assurance provision. In order to provide a response to the second research question, it will also be necessary to assess whether stakeholders' differential definitions of genetic information may play an important role in shaping the ethical parameters of the debate.

#### **5. GENETIC INFORMATION AND LIFE ASSURANCE UNDERWRITING: LIKELY SOCIAL, LEGAL, COMMERCIAL, AND ETHICAL IMPLICATIONS**

Because of the unprecedented progress made in predictive genetic testing, people have become increasingly concerned about the commercial practices of the insurance industry and its possible interest in using new kinds of genetic information to underwrite policies. Ewald (1999) argues that both genetics and insurance are epistemologically similar, as both evolved from the probabilistic revolution. Therefore, insurers might have a clear financial interest in harnessing the power of these emerging genetic technologies. (Ewald, 1999, 27)

There is a now prevalent belief that the new information emerging from DNA and chromosome testing represents something qualitatively different from

existing forms of medical information. The possibility of widespread 'genetic discrimination', and the fear that a 'genetic underclass' will emerge in society, has led various individuals and organisations to call for a legislative response. The regulatory framework, and the specific concerns expressed by stakeholders, will be explored in more detail in the following two chapters. This section will begin by critically evaluating academic and stakeholder accounts of the status of genetic information. Such accounts will reveal the extent to which individuals operationalise particular definitional frameworks around specific technical issues in a way that supports their broader social, political, or professional values. As before, emphasis will be placed on the forms of rhetoric and narrative repertoires identified in the interview transcripts. This section will provide answers to the second research question.

### **5.1 The 'Special' Nature of Genetic Information**

Those who believe there to be a qualitative difference between 'genetic information' and other traditional forms of medical information tend to raise two particular arguments in support of their position. Firstly, they claim that the consequences of genetic knowledge are never restricted to individuals but have probabilistic implications for their entire biological kin. O'Neill (1997a) is sympathetic to this particular argument. A second argument emphasises the fact that individuals often acquire knowledge of their genetic abnormalities when they are pre-symptomatic, and at a time when there is little hope of cure or treatment. This, the argument goes, renders such knowledge ostensibly more serious and problematic than that derived from the more traditional methods of medical diagnosis. Carter (1995) points to the implications this new information may have for our notions of health and illness. He argues that: 'The application of expert probabilistic reasoning manages to make the categories of health and

illness ambiguous.' (Carter, 1995, 140)<sup>9</sup> The new genetic data, according to the sceptics, serves only to intensify this ambiguity.

These arguments give credibility to the idea that genetic information poses a significant and special social problem.<sup>10</sup> Many claim that it is the greater predictive capacity that the new genetic tests promise to offer that has concretised social fears of discrimination. However, we must recognise the breadth and scope of the very term 'genetic information', and recognise that a simple analysis of family history can provide useful and accurate predictive medical information. From this perspective, genetic information derived from DNA testing or chromosome analysis may not be fundamentally different in its social and commercial impact.

McLean (1998) argues that the social implications of genetic diagnoses perhaps appear more acute because they are less well understood and '... more intimate to how we perceive ourselves.' (McLean, 1998, 93) The logical corollary of this argument is that we ought as a society to mitigate the negative social consequences experienced by individuals with 'faulty' genes. Burley (1999) goes as far as to claim that society has a moral responsibility to share the costs of those who fare badly in the genetic lottery. She argues that society should act as a 'People's Republic of Underwriters' and compel the genetically advantaged to subsidise the disadvantaged. (Burley, 1999, 55) This argument is credible, so long as we do not expect private insurers to bear the ultimate responsibility for redistributing such benefits and losses. The principle of

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<sup>9</sup> Carter provides a general analysis of 'health risk appraisal', where both lifestyle traits and biological characteristics become factors in a danger/safety dualism. Again, the argument is that new genetic information has a profound impact on these kinds of measurements.

<sup>10</sup> See Murray, 1997 for a critique of what he refers to as 'Genetic Exceptionalism'. He writes: 'Genetic information is special because we are inclined to treat it as mysterious, as having exceptional potency or significance, not because it differs in some fundamental way from all other sorts of information about us.' (Murray, 1997, 71)

redistributive justice that perhaps ought to underlie the political actions of 'society at large' is qualitatively different from redistribution within a private insurance market. Burley appears to concede this point when she argues for some form of mandatory state insurance scheme. Nevertheless, she does still exhibit 'genetic disadvantage' as a discrete moral and social category.

Juengst (1996) is one dissenter who does not consider the social and ethical implications of genetic information to be conceptually distinct from other forms of medical data. In fact, he claims that as predictive testing advances, and begins to understand the pathology of multi-factorial based conditions, to differentiate between genetic and non-genetic components of disease will become indefensible. (Juengst, 1996, 71)

## **5.2. Interview Responses to the Status of Genetic Information. Equivalency and Non-Equivalency Arguments**

The interview data reflected the difficulty of establishing a fixed definitional framework around genetic information. However, it is important to look critically at the various contexts in which stakeholder representatives express their views on this particular issue. The following statement from Graham Austin, an insurance representative, nicely captured the commercial angle.

As far as we are concerned it's not special ... it's another piece of medical information. If we said to somebody who's a diabetic you need not disclose you're a diabetic, people would probably find that odd. If we said to people you need not disclose information about genetic tests, they would think that's tremendous. Neither of them is anyone's fault.

In this statement, the respondent does not use scientific arguments to defend an 'equivalency argument'. Instead, his response is framed by commercial

norms and social values. The respondent invites us to consider the logic of disclosure and then tries to demonstrate that if genetic information were treated as a 'special case', this would appear odd in the context of existing commercial practices. Furthermore, it would prove inequitable for other high-risk policyholders. The final statement, which accentuates the fact that neither forms of diagnosis are anybody's fault, again reveals the strategic use of a social value narrative. The attempt to render genetic and non-genetic conditions equivalent, by claiming neither are anybody's fault, may be an insurance industry strategy to demonstrate that their approach is consistent. Their goal may be to protect their right to use both kinds of information in underwriting. Tony O'Leary used a similar strategy, which was revealed earlier, when he expressed the moral case for commercial underwriting.

Graham Austin also appeared to look at the issue from a business angle. The following statement is particularly interesting.

The business angle to me is quite clear-cut. If the boot were on the other foot would anyone say we were justified in withholding information? But because it's always the big insurer against the poor individual then people think there is an issue.

This statement reflects the tenuous position in which insurers often find themselves placed. Society appears to demand that they fulfil certain moral obligations, but often overlooks the responsibility of policy applicants. The final statement in this account, which refers to peoples' perception of the big insurance company constantly working against the poor individual, is also interesting in light of the historical data provided at the beginning of this chapter. Life assurance is a means for the wealthy to protect themselves against

financial risk. It is not, and never has been, about the poor and downtrodden. This issue will be raised again in the following chapter.

Insurers prefer to conceptualise new kinds of genetic information as commercially no different from existing medical information. They do this in order to protect their historical right to access all the medical data of an applicant. Occasionally, however, insurers do make statements that suggest they would like to treat the new kinds of genetic information differently. When it was put to Graham Austin that if existing family history data were treated as equivalent to the new genetic test information, a coherent argument could be made for prohibiting insurers from using both as an underwriting tool, he responded: 'Not asking for genetic tests is one issue, but not asking for family history is another issue.' Insurers argue that the two kinds of information are conceptually analogous if it serves their commercial interests (allows them to use both to rate applicants). However, when the equivalency argument may challenge the legitimacy of the business narrative (by denying them the right to use traditional kinds of medical information), there is then a tendency to argue the opposite; to imply that the commercial implications of treating them as equivalent would be disastrous. The 'double truth doctrine' reveals itself once again.

Other insurers were also keen to stress that from a business/scientific perspective the argument of non-equivalency does not stand. The anonymous insurance underwriter claimed, when asked if there were a difference between genetic information and other forms of medical information: 'Well my personal view is no, from a risk-assessment perspective.' Tony O'Leary elaborated by stating: 'The answer is fundamentally no, but the perception is yes.' The latter account really takes us to the crux of the issue. From a business and scientific

perspective, there is no technical difference. However, the public believes new kinds of genetic tests to be 'special'. The rhetorical forms insurers' accounts often take seem to be influenced by the existence of this public attitude. This became evident when insurance representatives talked about the industry's position on requesting policy applicants to take a medical test, as opposed to just divulging information from tests already taken. Insurers do not currently ask people to take a genetic test as a prerequisite for acquiring a policy, and claim that they have no intention to do so in the future. However, the following dialogue from the interview with Tony O'Leary revealed an inherent contradiction in the industry's approach. In particular, the following account of Tony O'Leary explicitly contradicts his previous argument of equivalency:

**J.M:** Do you ever ask policy applicants to take non-genetic medical tests?

**T.O:** Yes

**J.M:** Isn't that actually treating genetic tests as something very different then?

**T.O:** Absolutely

In this case, it appears that public perception has forced the industry to compromise on its traditional practices. Tony O'Leary conceded this point when he stated:

I think in practice what the insurance industry has done is said that genetic information is slightly different in the way we treat it, because of the public perception and concerns, and what we felt was morally right. Technically speaking we should really send you for a battery of tests.

Whether or not what is 'morally right' factors heavily in the minds of insurers is debateable. However, to imply that it was considered morally wrong to request people take a genetic test before being given insurance cover, when companies routinely ask applicants to undergo other forms of medical testing, does appear

inconsistent. The anonymous insurance underwriter tried to justify this special dispensation on the grounds that genetic tests are emotive, and that in many cases the individual has no control over the outcome. He also stated: 'I know we do ask for HIV and AIDS tests, but we do pre and post test counselling for those.' He also revealed that applicants who have recently visited certain high-risk countries are often told they must take a Hepatitis B test. The above extract reveals a common strategy of insurers to try to justify actuarial decisions; to in a sense create a morally adequate account of their actions. One could argue, however, that knowledge of HIV infection is no less traumatic than knowledge of a genetic condition. Why pretend that there is a moral difference? In fact, since insurers claim that they only require the results of medical tests in order to protect themselves from adverse selection, one might rightly ask, what is the commercial justification for asking people to take HIV or Hepatitis tests before being granted a life assurance policy? If the individual is unaware of their medical status, there is no asymmetry in knowledge between insurer and applicant. Therefore, adverse selection should not be a concern.

The data from insurance representatives reveals a fundamental inconsistency in the treatment of new kinds of genetic test information. Insurers want to claim that there is no scientific/commercial justification for treating it as 'special', most likely because they want the freedom to use it as an underwriting tool. Yet, in practice, they do treat the information differently, perhaps in order to placate wider social pressures. By drawing on a broad narrative repertoire, and constantly shifting the definitional framework of the problem, the practices of insurers actually begin to look questionable. Their arguments begin to contradict one another, and it becomes clear that commercial expediency takes precedence over any social values. Now it would be instructive to look at how those working in a clinical setting expressed their views on the status of genetic



information. One needs to assess the extent to which their accounts are linked to wider social, political, or professional values, as appeared to be the case with the insurers.

Those working in a clinical setting differed slightly in the way they expressed their views on the technical status of genetic information. Dr. Quarrel, a clinical geneticist, made the following statement:

Genetic testing is not unique. If you have information which is derived from family history it might not be as accurate as a genetic test, but if you have somebody with say a father with Familial Adenomatosis Polyposis then they are at 50% risk ... Now your DNA test might move them to 100% or 0% but family history itself is a genetic test. If you come on to another issue, if you measure somebody's cholesterol levels then that can give you a handle on the fact that somebody's got familial Hypercholesterolaemia. Similarly, if you take adult polycystic kidney disease and you do an ultrasound scan, if the person has lots of cysts at a young age, then you've got a diagnosis of APKD; You do not need a DNA test. (Dr. Quarrel, Consultant clinical geneticist, interviewed by James Mitra, 25 May 2001)

From this account, one may discern that the only real technical difference between the new kinds of genetic tests and traditional family history/medical tests is their predictive potential. In all other regards, an argument of equivalency may be justified. However, Sandy Raeburn, a professor of clinical genetics, countenanced the argument that genetic tests may have to be conceptualised differently from most other kinds of medical tests. He stated:

A genetic test is unlike some medical tests in that it is not telling about the here and now ... One difference would be that most medical tests are measuring abnormal X-Rays or abnormal proteins, or abnormal substances in the blood which are actually quite a long way along the line towards disease. A genetic test is showing susceptibility to future problems. (Sandy Raeburn, Professor of clinical genetics, interviewed by James Mitra, 5<sup>th</sup> June 2001)

He continued to state:

If you ask in insurance terms is there a difference? Then I would say actually there isn't. It is a bit unfortunate that people see genetics as so very different from other tests.

This respondent does believe that there is a slight technical difference between genetic tests and some other medical tests. The former can predict susceptibility to future disease, while the latter generally detect current disease states. Of course, family history may also predict susceptibility to future disease, so the argument that it is concerned only with the 'here and now' may be flawed. The equivalency of family history information and genetic test data can still be justified on scientific grounds. In the context of insurance, Sandy Raeburn changes tactic and begins to defend the argument of equivalency. He states that for underwriting purposes, genetic and non-genetic tests should not be differentiated. It is important to note that Sandy Raeburn is an advisor to the insurance industry on the issue of genetic testing, so we should perhaps not be too surprised at this last statement. His strategy appears similar to those of the insurance representatives.

The above extracts suggest that we need to differentiate between 'genetic tests', 'other non-genetic tests', and 'family history'. The argument of equivalency is appropriate with regard to genetic tests and family history, although the former is more predictive, but the argument of non-equivalency may be valid when comparing genetic tests and certain other non-genetic tests (although as Dr. Quarrel pointed out, a blood test that reveals high cholesterol might indicate an hereditary condition). For the purposes of this section, however, we are concerned mainly with comparing family history and genetic

test data and assessing the extent to which relevant stakeholders conceptualise genetic information in a restricted or extended sense.

One of the anonymous genetic counsellors did believe that there was a difference between family history information and new genetic test information. However, she expressed the difference by reference to how the information might be interpreted, rather than by reference to the scientific/technical status of the information. She made the following comment during interview:

Well one of the things about the new genetic tests is the fact that they're not all definitive. There's a lot of interpretation in there and we don't fully understand all the factors that come into play. My worry is the insurance industry won't understand that either, and will discriminate when it's perhaps not appropriate to do so. (Anonymous 1, interviewed by James Mitra, 25 July 2001)

This statement reveals a common fear amongst many clinicians that insurance companies may not have the scientific expertise to interpret the information correctly. Although this counsellor did concede that family history data is a form of genetic information, she claimed that because many new genetic tests are not well understood, it is perhaps best to treat the information differently.

So far, if we compare the clinical perspectives with the insurance perspectives, it is difficult to detect any fundamental professional disagreement with regards to the status of genetic information. Each representative had their own personal take on the issue, although two of those working in a clinical setting did, perhaps unsurprisingly, prioritise the scientific arguments. Insurers, like the clinicians, operationalised an extended definition of genetic information, but only in certain contexts. For actuarial decision-making, genetic test information was presented as simply an extension of traditional family history.

However, in practice, insurers were willing to operationalise a restricted sense of genetic information by singling out particular tests for special attention. There is an underlying logic to this strategy. Restricting the definition of 'genetic information' to particular kinds of genetic tests not only allows insurers to portray themselves as socially responsible but also narrows the framework of the issue, which in certain circumstances may be advantageous. If public pressure eventually leads to regulatory restrictions on commercial practices, it would be better for the industry to lose only their right of access to specific pre-defined genetic tests, rather than traditional family history information and non-genetic test results as well.

Certain members of patient-support groups also expressed the argument of equivalency regarding the status of genetic test information and family history. However, in the context of insurance, they too began to shift the definitional framework by articulating a non-equivalency argument. Extracts from the interview with Julia Cream, policy officer at the Alzheimer's Society, provided useful data in this regard. In particular, her account illustrated the extent to which interest groups with particular agendas may re-configure the definitional framework, in specific contexts, in order to justify a broader political goal. In this regard, her strategy was analogous to that of the insurers. The following extract is her account of the non-equivalency argument.

**J.M:** Do you think there is a difference between genetic information derived from particular genetic tests and other forms of medical information, such as family history?

**J.C:** Yes. I think that actually what this debate has done in the last couple of years has really heightened that debate and we argue that genetic information should be treated differently at the moment because people understand it to be special; they treat it differently. And it also reveals information about people that might need to be treated differently. (Julia Cream, Alzheimer's Society, interviewed by James Mittra, 19 June, 2001)

This account is analogous to the insurers' argument that genetic information is treated differently, because the public perceive it to be different. Of course, insurers do not regard this as a good thing. Julia Cream argues that there are some technical differences with regard to the social context of testing. Nevertheless, her stated belief that genetic information should be treated differently because people perceive it to be special suggests that she cannot think of any specific scientific argument to support a non-equivalency view. However, later in the interview, she offered a very different account. In the context of insurance, she began to imply the need for equivalency. That is, she argued that in certain circumstances new genetic test information *should not* be treated as a 'special' case. This alternative account was revealed after Julia Cream was asked to respond to the insurance industry's argument that if they make a special case for genetic test information, this would prove inequitable to people denied insurance on non-genetic based information. Her response was:

Well hopefully, I think it should open up the debate on family and medical history. We've got to a position where we're now looking to insurers to re-examine how they use family history.

Before, Julia Cream operationalised a restricted definition of genetic test information in order to justify denying insurers access to it. However, now she broadens the definitional framework in order to challenge the insurance industry's existing use of family history. This was a concern of the insurance industry representatives who, in their interview accounts, sought to operationalise a restricted definition of genetic information to defend their historic right to access family history data. These extracts from Julia Cream, as well as those from insurers and clinicians, illustrate the ways that stakeholders

may reconfigure the definitional framework in order to push a particular social, political, or professional agenda.

However, not all members of interest groups were content with the special status accorded to new kinds of genetic test information. Alistair Kent, director of the Genetic Interest Group (GIG), called for scientific reality in the debate. He stated:

I think one of the important things that have been missing from the debate is scientific reality. If you listen to the conversations ... yes it would be terrible if we did those things [discriminated on the basis of genetic tests] based on the assumptions you're making about the predictive power of genetic information. But everything we know about genetic information tells us that it ain't likely to be so. (Alistair Kent, GIG, interviewed by James Mitra, 4 April, 2001)

Alistair Kent challenges the idea that the new genetic tests will be highly predictive and have a significant affect on the existing framework of insurance provision. Just as was revealed in the clinicians' accounts, he expresses the view that there are many ways to acquire predictive diagnostic information. He stated:

What is the quality of the evidence that you have for somebody going to become ill in the future, or going to die prematurely? There are a number of different types of evidence that you can have. You can have the results of a DNA test, you have family history, you can make a biochemical diagnosis, you can diagnose on the basis of observed symptoms or clinical symptoms. You can make a predictive diagnosis based on thinks like ultrasound or MRI scanners under certain circumstances for different types of disease ... So our emphasis has been you look at the those who are pre-symptomatic, but predictably going to have a problem in the future, and ask what is the quality of the evidence, not what is the route by which you arrive at that evidence.

This extract represents a defence of the equivalency argument. New kinds of genetic tests are different only at an instrumental level; that is at the level of initial methods of diagnosis. However, the information itself has substantial equivalence to various other medical tests, some of which have been used by insurance companies for centuries. Katherine Darton, a representative from the charity MIND, made a similar point when she said:

I personally come from a very cardiovascular family, so if somebody did a genetic test on me and said yes you've got genes for high blood pressure and heart attacks I'd say that's exactly what I'd expect to have, tell me something I couldn't have guessed. Just looking at a family tree has got just as much information in it. (Katherine Darton, MIND, interviewed by James Mittra 8 June, 2001)

Both these respondents could not see any technical justification for singling out particular genetic tests and defending a non-equivalency argument. However, respondents like Alistair Kent draw from this observation the logic that insurance companies should not be expected to provide special protection for those individuals denied insurance on the grounds of a positive genetic test. However, others, such as Katherine Darton and Julia Cream, take an opposite view, as will be explored in the next chapter.

Any single definitional framework may be used to justify a variety of normative arguments on the issue of genetics and insurance. Analysis of these interview accounts reveals that respondents will shift the definitional boundaries, in specific contexts, in order to justify normative beliefs about how insurers ought to treat the information. However, the data also revealed that we should not assume all interest groups, particularly patient-support groups, have a shared agenda. Once this is recognised, it is no surprise that Alistair Kent's account of

the scientific status of the issue is used to justify a very different approach to Julia Cream.

From a scientific and philosophical perspective, no clear and legitimate demarcation lines ought to be drawn between the new kinds of genetic test information and various other forms of medical data, but the perception continues to persist that new genetic tests are 'special'.<sup>11</sup> In practice, all that the new DNA derived information is likely to deliver is a higher predictive value, yet the precise implications for insurance are unlikely to be significantly more serious. However, as revealed in the interview data, individuals may operationalise a restricted or expanded definitional framework in order to advance a personal agenda.

### **5.3 'Genetic Discrimination' and Insurance**

Although there appears to be no scientific justification for treating new kinds of genetic test information differently from various other forms of medical data, as most stakeholders concede, some people continue to regard 'genetic discrimination' as a real danger and have petitioned for legislative redress to protect those they have come to label the 'genetically disadvantaged'. This section will critically analyse this specific issue, and argue that the debate might need to be hinged at a very different level; one that recognises and respects the foundational principles of private insurance and the limits to its social largesse. However, it would be instructive to first consider the historical case of HIV

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<sup>11</sup> Biesbecker, 1997 supports this view when she points to the fact that genetic counsellors often report that 'persons in families affected by genetic conditions perceive genetic information as more personal, revealing and stigmatising than other medical information.' (Biesbecker, 1997, 109)



discrimination within insurance, as this has had a profound influence on subsequent debates about genetic information and life assurance.

### **5.3.1 *The Case of HIV and Aids Discrimination in Private Insurance***

As was argued earlier in this chapter, 'discrimination' is fundamental to all equity-based private insurance models, and before public controversy over the use of genetic information began to emerge, most people were willing to accept, albeit reluctantly, the general legitimacy of this principle. It is worth recounting the case of HIV and AIDS as an exemplar of a significant social problem that had clear implications for insurance provision but did not engender the same level of public and political indignation, as does the current prospect of insurers accessing applicants' genetic information.

As Draper (1998) notes, the ABI and the House of Commons have recently recognised the need to protect the personal genetic information of those applicants seeking mortgage-related life assurance. However, similar protection was never considered a matter of social and political urgency in the 1980s, when many HIV positive people found it difficult to acquire insurance. (Draper, 1998, 105) In the absence of any legislative or regulatory constraints, insurers were permitted for years to transgress the ethical boundary by normalising 'unfair discrimination'. They often used information in a way that was actuarially unjustified, or allowed pervasive social prejudice to influence decision-making .

Schatz (1987) recounts a number of examples of unjustified commercial practices that occurred in the United States. One insurance company required its agents to segregate applications from single men with no dependants, and

employed in non-physically exerting professions, in order to isolate those who were presumed to be 'high risk' homosexuals. Lifestyle information was used as a proxy to detect ostensibly related risk factors. When commercial organisations are prohibited from accessing information directly, they will often attempt to derive this information by more indirect and surreptitious means. Another company in the United States, required its agents to scrutinise applicants who were not married and named someone other than a spouse or child as the beneficiary of a life assurance policy or who exhibited traits that implied a 'promiscuous lifestyle'. (Schatz, 1987,1787)

Roth (1995) claims that in the UK, insurers often requested that high-risk applicants seeking substantial life cover take an HIV antibody test. It is interesting to recount again the interview data, in which some insurers stated that they would never compel an individual to take a genetic test as a prerequisite for obtaining cover. It is generally accepted that such a practice is morally inappropriate because individuals are entitled to a 'right of ignorance'. However, the insurance industry did not extend this right to those at-risk of HIV. If there is a fundamental 'right of ignorance' regarding one's health, it appears iniquitous to proclaim the existence of this right, and indeed positively embrace it, but apply it differentially depending on the nature of the medical condition and the amount of insurance cover being sought.

Legislation to minimise practices of unfair discrimination was eventually implemented in both the United States and the UK, but it is necessary to accentuate the point that it was considered more acceptable to discriminate

against HIV positive applicants than those with genetic conditions.<sup>12</sup> The 'no fault' condition status often assigned to diseases with a genetic origin<sup>13</sup>, coupled with a pervasive social prejudice against homosexuality, may partly explain the two very different responses. However, as McGleenan (1999) points out, both categories of medical information have many analogous features. Just like genetic tests: 'HIV testing is predictive, it has a variable, but often lengthy, latency period, there is currently no available effective cure and in many instances the disease is fatal.' (McGleenan, 1999, 60) This illustrates, once again, how a restricted definition of genetic information may fail to capture the similarities between genetic test information and various other forms of medical data. Reasons for restricting the definition may be associated with broader social, political, or economic interests/values.

It is important to recognise at this point that one of the reasons why the insurance industry might have become so concerned about the emergence of HIV was the potential problem of 'moral hazard', which was briefly referred to earlier. The fear was that by virtue of having health insurance cover, individuals at-risk of HIV infection might engage in risky sexual practices, safe in the knowledge that their medical expenses would be covered. Moral hazard is a significant concern for providers of health insurance, critical illness cover, and long-term care insurance. However, the problem is more difficult to extract in the case of life assurance, as there is no evidence to support the claim that individuals will change their behaviour by virtue of having a life assurance policy. Therefore, the differential treatment of HIV testing by life assurance companies was still largely unjustified.

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<sup>12</sup> Some people did, however, believe that AIDS was unjustifiably being granted special status through the prohibitory legislation in the United States. See Clifford and Luculano, 1987 for a critique of Schatz' view that legal protection was essential.

<sup>13</sup> Frank, 1999 invokes this 'no fault' clause when he claims that differentiation based on genetics is a different form of discrimination because it is something the individual has no control over and cannot always change.

### 5.3.2 Genetic Discrimination and Social Exclusion

When it comes to the potential discrimination that may transpire from the commercial use of genetic data, there is a prevalent belief amongst many scientists, policymakers, and the public that insurers, on principle, ought to treat such information differently. The reasoning used is that to use such knowledge in a way that denies people access to private life assurance falls unquestionably within the bounds of 'unfair discrimination'. Many people accept the philosophical argument that there is a categorical difference between 'fair' and 'unfair' forms of discrimination. Furthermore, they have argued that this conceptual distinction should serve as the lynchpin for judging the legitimacy of corporate practices. In the context of genetics, insurers might engender unfair forms of discrimination by misinterpreting the genetic data or using the information duplicitously for financial gain. In both these cases, the use of such emotive terminology as 'unfair discrimination' might be justified. Both these practices are indeed iniquitous and run counter to the principle of *uberrima fides*. However, this relatively objective line of demarcation between 'fair' and 'unfair' discrimination is often contested. What one person considers 'fair' may be considered 'unfair' by another.

A growing body of anecdotal evidence suggests that insurance companies have unfairly discriminated against genetically at-risk policy applicants by simply misinterpreting the data. It has been alleged that certain companies have translated an increased risk into certainty or conflated recessive traits with actual presence of disease. Hudson et al (1995) describe the perverse case of insurers who misinterpreted sickle-cell trait throughout the 1970s, which

resulted in many carriers of the disease being unfairly discriminated against.<sup>14</sup> Without any scientific evidence to back their case, insurance companies operated on the assumption that carriers of sickle-cell trait embodied the same level of risk as those actually afflicted with the sickle-cell disease.

Low et al (1998) used a postal questionnaire to investigate possible 'genetic discrimination' by insurance companies in the UK. 7000 respondents from various genetic support groups were asked to comment on how they had been treated by insurance companies. 33.4% claimed to have encountered various problems. The authors write: 'thirteen per cent of study respondents ... who represented no adverse actuarial risk on genetic grounds reported that their treatment by insurers seemed to represent unjustified discrimination.' (Low et al, 1998, 1632) Another study by Lapham et al (1996) investigated the same issue in the United States. From a sample of 332 members of genetic support groups, they discovered that 25% believed they had been denied life assurance, and 22% health insurance, on the grounds of their genetic susceptibility. (Lapham et al, 1996, 621) Many of the respondents who were denied health insurance recalled being asked specific questions about their genetic status.<sup>15</sup> The Council for Responsible Genetics (2001), a national bioethics advocacy organisation based in the United States, also claim that a number of 'healthy' individuals have suffered genetics-based discrimination at the hands of various kinds of insurance providers.

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<sup>14</sup> See Macintyre, 1997, a sociologist who believes the case of sickle-cell should serve as a cautionary tale to those optimists who see in genetic screening only the great promise of an ultimate panacea for disease. (Macintyre, 1997, 1097)

<sup>15</sup> See also Phillips et al, 2000, whose questionnaire-based study of 134 Jewish women in a research testing programme for Ashkenazi Jews, found that the main factors of concern regarding perceived risks: 'related to insurance discrimination, confidentiality, accuracy, and interpretability of results ...' (Phillips et al, 2000, 376)

It is important to recognise that many of these studies investigated only the subjective perceptions of individuals at-risk. Therefore, they do not provide us with an objective measure of the true extent of any actual discrimination that may have taken place. Such studies should be treated with a high degree of caution.

Many authors have challenged studies claiming to have revealed practices of unfair discrimination. Reilly (1999) argues that studies based on flawed methodologies have led to a great deal of spurious data. One consequence of this, according to Reilly, has been that people have become overly sensitive to perceived fears of mass discrimination. In reality, such discrimination is unlikely to become prevalent. Reilly writes: 'Hundreds of popular articles warning of genetic discrimination rely at best on flimsy evidence.' (Reilly, 1999, 127)

Bonn (2000) also believes the fears to be unfounded. She argues that genetic discrimination '... is unlikely to become the social evil of the new millennium.' (Bonn, 2000, 1526) Any 'unfair discrimination' will likely be limited and be the result of either commercial ignorance of genetic science or erroneous administrative practices. The most obvious solutions would be to improve managerial acumen, expand the provision of education and training for underwriters on the limits of genetic prediction, and take greater punitive action against insurers who continue to make fallacious actuarial decisions. As Ross (1997) argues: 'In my view it is not wise to restrict access to information just because people may misuse or misunderstand it. It is better to educate people in the proper use of the information.' (Ross, 1997, 1106) <sup>16</sup>

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<sup>16</sup> There are certain cases of insurance companies breaking the law, or ignoring their own codes of practice. A report in the *British Medical Journal*, 2000 referred to a study in the Netherlands that found insurance companies circumventing the Dutch ban on genetics-based discrimination. Therefore, Ross' call for greater education may prove more salutary than continued legislation.

Once again, it is important to stress that discrimination in life assurance, be it fair or unfair, is most unlikely to lead to the widespread social exclusion of vulnerable members of society. As the historical evidence presented at the beginning of this chapter demonstrated, life assurance has generally provided a means for the wealthy to protect their financial interests. Genetic discrimination would therefore only remove from the market a sub-section of the wealthy population. It is difficult to think of such people as part of a growing vulnerable underclass. Of course, social exclusion might be a problem for those genetically at-risk applicants who want to purchase life assurance attached to a mortgage. It is important to specify the context so that we do not make spurious generalisations. However, the claim that if insurance companies are permitted to use new kinds of genetic test information to rate policyholders large sections of the population might become socially excluded and form a growing 'genetic underclass' appears to be deeply flawed.

It is also important to point out that UK life assurance companies do not like to deny policies to too many individuals. Insurance companies are commercial entities with reputations to maintain, and rejecting too many applicants may have negative repercussions for their business interests.<sup>17</sup> Furthermore, as life assurance companies increase their portfolios, their profits become far more stable. Common sense dictates that a large market is economically less risky than a restricted one. For this reason, there is considerably less rating involved in the provision of life assurance, as opposed to say long-term care insurance. With this knowledge in mind, companies do have an incentive to manage new

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<sup>17</sup> It must be noted that things are very different in the United States health insurance system, where there is an identifiable 'insurance underclass' that can only increase as genetic testing becomes more widely available. See Peters, 1998 for an ethical analysis of the underclass scenario as it applies to the United States.

kinds of genetic information correctly, thus limiting the potential for unfair discrimination and widespread social exclusion.

In the case of life assurance provision in the UK, 95% of applicants pay standard rates, 4% pay a loaded premium, and only 1% are rejected outright. Furthermore, this latter group of 'uninsurables' are only denied access to a particular type of life assurance policy. They may be offered alternative forms of cover specifically designed for their high-risk status. It is important to accentuate this point in order to keep the issue in perspective. Genetic information is unlikely to have a considerable impact on these existing figures. In fact, most insurers in the UK have no intention of using the new genetic tests as a discriminatory tool. They claim only a right to defend themselves against adverse selection. Whether or not adverse selection is a justifiable concern may be debatable, but it is the primary reason used to justify commercial underwriting.

Bodmer (1997) dismisses the fear that as a greater number of multifactorial diseases become linked to specific gene sequences, insurers will demand to use them for underwriting purposes. He writes:

'Since the insurance industry is often quoted as saying that even a two-fold increased risk is not enough for them to adjust their life insurance premiums, any genetically identified component of multifactorial disease susceptibility should, especially if targeted with prevention, be of no interest for life insurance.' (Bodmer, 1997, 1050)

When contemplating the possibility of genetic discrimination, it is important to recognise that only a small number of applicants are likely to be affected. Most of these individuals already have problems acquiring insurance, in the absence of new genetic tests. Indeed, some of these individuals may actually benefit



from insurance companies' using new kinds of genetic test information. Somebody with a family history of Huntington's disease, for example, would in the past have been denied life assurance, or been charged a premium so high it would essentially be rendered unaffordable. However, if they now take a genetic test, and it proves negative, they can conceivably re-enter the market at a standard rate. From this perspective, we might look at the use of genetic test information as ruling people into the insurance market, rather than ruling them out of it.

This issue is extremely complex, and should not perhaps be framed simply in terms of people being illegitimately denied insurance. Of course, we must recognise the diverse ways in which particular types of insurance products are affected by the issue of genetic information. The commercial and ethical boundaries of the insurance business should not be thought of as static. At present, long-term care insurance is generally considered a non-primary social good, but if the parameters of the welfare state continue to recede, it could in the future become a necessity for the majority of the population. O'Neill (1997a) supports the contention that legislation may be required if significant changes are made to the social landscape within which private insurance exists. However, at the present time, the problem does not appear so acute.

If we now return to 'fair discrimination', the argument goes that individuals pay a premium for life assurance that is commensurate with the risk they bring to the insurance pool. If an individual embodies a gene that predisposes them to a particular disease, then the principle of equity dictates that they pay a higher price for insurance. Those who wish to privilege such individuals, and bestow upon them special legislative protection, may actually engender new forms of inequity. The logic of their argument leads to the rather dubious claim that those

people whose condition is diagnosed through a specific and pre-defined genetic test are more worthy of protection, and have a greater moral claim to access a particular insurance product, than those who are denied insurance as a result of a positive non-genetic based test. This is a paradox caused by a restricted definition of genetic information, a desire to single it out for regulatory attention, and a growing belief that discrimination is fundamentally more insidious when it is of the genetic variety. Hamilton et al (1995) countenance this point when they write: 'The ability to obtain insurance should not depend merely on the mechanism of a diagnostic test.' (Hamilton et al, 1995), 1164)

It must be conceded, however, that there are some important issues raised by genetic testing and the information it generates, but the evidence seems to imply that it is only a matter of scale. The preceding theoretical arguments, as well as the critical sociological analysis of the interview data, suggest that genetic information is likely, at most, to simply refine existing underwriting risk-analysis. In the future, genetic tests may facilitate more precise predictive diagnoses, but access to life assurance is unlikely to be significantly affected. There are no fundamentally new social and ethical perplexities. Rather, historic problems and anxieties continue to persist, although they may have the potential to affect a slightly greater number of people. Many people believe that this issue of scale is sufficient to warrant extra legislative protection. For example, after admitting that there are only relative differences between genetic information and other forms of medical data, Gevers (1993) would still like to conceptually isolate and protect genetic information, because he believes '... the insurer's or employer's interest in requesting cooperation in a medical examination will be sooner disproportional to a person's privacy interests than in

the other cases.' (Gevers, 1993, 128)<sup>18</sup> Gevers wrongly assumes that medical examinations are routinely used to underwrite basic life assurance policies. However, even if it were true, one should perhaps still use a consequentialist ethical framework, and argue that the crucial issue is the impact on the individual who is denied a primary social good. Singling out the 'genetically disadvantaged' may be socially inequitable, as well as commercially illogical, for non-primary social goods such as UK life assurance.

One could make the argument that all insurance products offered by the private sector should be recognised as non-primary social goods. The logic being that primary social goods ought to be distributed through non-risk based insurance systems. Subsequently, companies offering such non-primary social goods must be allowed to pool risks using actuarial underwriting methods, as this is the only way to guarantee that the principle of equity is sustained. The situation becomes a little more complicated when a non-primary social good slowly becomes a primary social good. When it has moved significantly enough in this direction, any individual previously denied a policy, regardless of whether their discrimination was labelled 'fair' or 'unfair', may have a moral claim to some form of redress. One may ask if there are any historical examples of a private good slowly transforming into a public good. One may be healthcare in the UK. Before the creation of the welfare state, and nationalised healthcare, access to medical treatment was based on an ability to pay rather than need. Eventually, healthcare became recognised as a primary social good and the National Health Service was born. Other, perhaps more trivial, examples might be goods such as refrigerators, telephones, and electricity/gas supplies. Over time, these products have shifted from being regarded as mere commodities, to

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<sup>18</sup> Gevers, 1992 admits that asking for other medical tests is also an infringement on privacy but still seems to think that there is greater at stake with regard to genetic tests, and this alone justifies more extensive legal protection.

non-primary social goods, and finally to primary social goods. The fact that individuals receiving state welfare benefits may receive extra money to buy such goods as refrigerators, or still be permitted to access gas and electricity if they fail to pay their bills, signals that society no longer considers these products mere luxuries or non-primary social goods.

This talk of social goods brings us back to the issue of balancing commercial and social interests, which was discussed earlier in the chapter. In a country like the United States, where health insurance is entirely private, this is a far more pertinent issue. As Rizzo (1999) argues, the ethical minefield of the United States healthcare system will only be exacerbated by the genetics issue. He asks whether the insurance providers can 'be convinced that it is in their best interest, as well as in the interest of the public, to sacrifice economic prospects for the sake of preventing grave harm to individuals.' (Rizzo, 1999, 127) Rizzo believes that because insurance companies enjoy advantages such as government tax breaks, they should as a matter of principle act with a social conscience. However, one should not expect the system to have a social conscience. Although the situation in the United States may be lamentable, it ought to be resolved through a fundamental change in the provision of healthcare, not through a false expectation that corporate entities should, or even could, have a social conscience. Either one changes the underlying structure of the system of provision, or one makes it profitable for corporate entities to act in a socially responsible manner. Morgan (1996) supports this view, in part, by arguing that: 'Widespread genetic discrimination in the private insurance market would furnish a compelling argument for instituting a public insurance programme or instituting across the board regulation of the private insurance market' (Morgan, 1996, 194)

Peters (1998) conceptualises the conflict between insurers' right to genetic information, and society's interest in providing healthcare to all, as one between 'libertarian' and 'egalitarian' values. Constitutive of private insurers' appeal to libertarian values in risk-classification is an individual's right to benefit from 'good' genes, and thus in a private insurance market to pay lower premiums. Risk-classification is underpinned by libertarian ideals, which conflict with the social equality values of egalitarianism. The libertarian considers genes 'natural property', and the advantages they bestow on the individual who 'owns' them ought to be protected on the grounds of individual liberty. However, Peters claims that one cannot appeal to personal liberty when proclaiming a right to benefit from 'good' genes, but must seek justification through other moral considerations. (Peters, 1998, 210) In considering the United States healthcare system, Peters writes:

*'Egalitarianism thrusts on libertarian-orientated commercial insurers a burden of proof to morally justify risk classification and the prorating of health insurance premiums to risk status – if these risks are arguably not brought about by an individual's voluntary action.'* (Ibid, 213)

There is an instructive lesson here for the UK. If we move towards a private form of healthcare provision, it perhaps ought to be made compulsory for everybody, remain free at the point of entry, and be based upon a hybrid system of social and private finance, rather than simply private provision alone. This contrast between libertarian and egalitarian values is also relevant to the life assurance context. Currently, because life assurance is generally regarded as a non-primary social good, the libertarian values of policyholders override egalitarian principles. Only when a product is conceptualised as a primary social good may egalitarian values subsume libertarian ones.

This section has provided a largely theoretical account of the reasons why the use of genetic information is unlikely to have a significant social impact on access to life assurance. The social exclusion argument has been shown to be deeply flawed for two main reasons. Firstly, the 'vulnerable' individuals who are likely to be ruled out of life assurance because of a positive genetic test constitute only a sub-section of the wealthy middle class, rather than the reputedly 'poor and downtrodden'. Secondly, very few people are denied life assurance to begin with, and it is unlikely that predictive genetic testing will have a serious impact on existing figures. Furthermore, as will be described in the final section, the insurance industry has a history of creating innovative new products to help those who represent too high a risk to be eligible for existing products.

Issues such as the social good aspect of insurance, fair and unfair discrimination, adverse selection, and the equity principle of private insurance, have been shown to be deeply complex, and often misunderstood by scholars. However, it has also been shown that we can understand the problem in terms of existing norms and principles. Genetic information does not have to be a problematic concept in the context of insurance, despite interview accounts to the contrary. Genetic information may simply lead to a refinement of existing underwriting practices, and will unlikely engender significant social, commercial, or ethical problems.

It is now possible to make a preliminary conclusion regarding research question one, and claim that the social, ethical, and commercial implications of

using genetic information in life assurance underwriting are unlikely to be as significant as many scholars, and some stakeholders, have suggested. Many appear to have neglected the theoretical roots of the problem, as well as the practical realities of the contemporary insurance market, which suggest that genetic information is not really that 'special' and is unlikely to fundamentally change the prevailing systems of insurance provision. Genetic information appears to be no different from existing forms of medical data, particularly family history. However, an argument could be made for restricting insurers' access to these various other forms of medical information. Nevertheless, this would perhaps only be legitimate if the insurance product were considered a primary social good.

The interview data illuminated the various ways in which stakeholders and academics erect particular definitional frameworks around genetic information. The transcripts revealed how the use of both restricted and expanded definitions could affect the validity of claims about the impact of genetic testing on access to life assurance. In their interview talk, stakeholders frequently alternated particular definitional frameworks, which appeared in some cases to represent a rhetorical strategy for legitimating their broader social, political, ethical, or moral values. Such strategies may problematise the issue, and lead to confusion as to how the potential impacts ought to be conceptualised. One consequence of stakeholders operationalising various narrative strategies is that attention may be diverted from the underlying theoretical roots of the problem. The issue becomes conceptualised as both significant and in need of urgent attention, when the reality might be that the issue is far simpler and easily resolved. With regard to the second research question, we may now conclude that stakeholders do strategically manipulate the definitional

framework around genetic information in order to express value judgements on how the issue ought to be conceptualised. Their broader political goals and ideologies might also play a role in determining how their accounts are framed. This question will be explored further in the following chapter.

Although it has been argued that genetic information will unlikely have a significant impact on future access to life assurance, and will not fundamentally change the way insurers currently rate policy applicants, there is one area where genetic information may have an impact. This is in the context of the doctor/patient relationship, which raises questions about the way the genetic information and insurance debate may draw greater attention to issues around the ownership and control of medical data.

## **6. THE MEDICAL CONTEXT: PRIVACY AND OWNERSHIP**

### **6.1 The Medical Profession and Confidentiality**

Clinicians enjoy a rather precarious position in the genetics and insurance dilemma. They often find themselves as reluctant intermediaries who must carefully balance a moral duty to protect the interests of patients with a legal duty to provide clinical information to insurance companies.

Pergament (1997) raises the important question: what should a doctor do when presented with a patient who has a genetic disorder, but request that this information remain confidential so he/she can obtain life assurance? Should the



clinician comply with the patient's wish and become an accomplice to a fraudulent claim? Pergament believes that progress in genetic testing will increase the frequency of these ethical dilemmas.

When an individual applies for life assurance in the UK, they must sign a consent form granting access to their full medical history, as contained within the notes of their general practitioner. However, since large numbers of genetic tests are conducted within private clinics, the results can remain relatively clandestine. In fact, even if one consults a clinical geneticist as an NHS patient, one is entitled to request that the general practitioner not be informed of the result. Dr. Quarrel gave an account of this practice during interview.

... if somebody wants a predictive test and absolutely forbids me to write a letter to their GP, then I will report that in the notes and write them a letter saying these are the results, you have not asked me to disclose the same to your GP ... It's an NHS service, but I suppose it's the equivalent of being in private practice ... I should emphasise, and perhaps we ought to record in the transcript, that in the case of insurance ... I routinely explain to patients that there is an issue and I advise them that they must answer questions honestly. So even if they said they didn't want their GP informed I would still give the advice that if they are filling out a new form it is a legal contract, and they must take it out in good faith and answer questions honestly ... that is so much a routine part of my practice.

One of the anonymous genetic counsellors confirmed this statement in her interview. She gave the following account when asked if the insurance problem was often raised in counselling sessions:

... what I tend to say to people is we're still a little bit unclear of where this is going to go, we would suggest if you are thinking of genetic testing conditions which could be significant in this way then look at your cover before going ahead.

It is clear that those working within a clinical setting are primarily concerned with patient health and well-being. They clearly recognise the implications genetic testing may have for their patients' future access to insurance. Clinicians routinely explain to patients that they are duty bound to inform insurance companies of their medical status. It is then left to the patient to decide whether to be truthful on the application form and enter the contract in good faith. However, the fact that this is becoming a frequent issue in genetic counselling sessions should sensitise us to the potential scale of the problem. Consequently, we should consider more carefully the whole issue of ownership, privacy, and consent regarding personal medical information.

Orentlicher (1997) believes that patients should have far greater control over their medical records, particularly those aspects relating to genetic information. He states: 'Although insurers and employers may want genetic information, physicians need not and should not participate in efforts by insurers or employers to obtain genetic information.' (Orentlicher, 1997, 88) It is important to recognise that granting consent is not a form of empowerment, and does not represent greater individual control over medical information, if to refuse access results in being denied an insurance policy. However, the social good aspect of insurance is crucial in this regard. Insurance companies providing non-primary social goods have a legitimate right to access applicants' medical history. The problem lies in squaring this commercial right with an individual's right to privacy.

## **6.2 'Privacy' and 'Ownership' of Genetic Information**

The very term 'genetic privacy' encompasses a number of discrete concepts. Allen (1997), for instance, regards it as encapsulating concerns about access to information, physical privacy of personal space, third-party interests in individual choices, and propriety concerns and interests in human personality. (Allen, 1997, 33) However, she argues that it tends to be the informational aspect that creates the greatest concern. Nevertheless, the concept of privacy is multidimensional, and a number of issues are at stake. For example, one may seek to protect an individual's right to keep their medical information private, but there may be circumstances in which it is considered, in Kantian terms, a categorical moral imperative to reveal such information. This point is particularly pertinent to specific genetics-based information that reveals the risk status of not only a specific individual, but also his or her entire biological family.<sup>19</sup> Sandor (1999) recognises this point when he claims that data protection:

... does not provide sufficient guarantees for the protection of genetic data, since once genetic data has been obtained, the notification about the potential danger for children and relatives or disclosure for the partner is often regarded as a moral duty.' (Sandor, 1999, 189)

However, this is not a problem exclusive to genetic information, but can apply to a diverse range of medical and personal data. In the opening section of this chapter, reference was made to Foucault's theory of the medical gaze and his account of the various ways in which the rational state began to blur the public/private divide in order to protect public health. The duty to disclose medical information for the benefit of others is not a unique modern day

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<sup>19</sup> Clarke, 1997a also raises the special issue of genetically testing children who, since they cannot give formal consent and make informed decisions as adults can, may suffer greater psychological and social disadvantage.

The Human Genome Organisation (HUGO), 1998 also recognises a difference between the moral obligations to disclose information to biological kin, and the requirement to grant access to institutional third parties such as insurance companies.

phenomenon. The only difference here is that the duty is imposed not to benefit wider society, but to protect members of immediate family or the interests of private commercial enterprises. Many would perhaps consider the former a noble duty, but be far more critical about imposing a duty of disclosure to protect commercial interests.

It is also important to stress that the right to privacy is linked to the issue of discrimination because, as Rothenberg (1999) recognises:

'... an individual who believes he has been discriminated against has the difficult task of proving it; a person might not even know that his information was actually used ... it becomes important to protect access to the information, not just erect safeguards against discrimination.' (Rothenberg, 1999, 86)

Nevertheless, a single privacy policy would likely prove inadequate. As Powers (1997) argues:

'... the kinds of information that ought to be protected from access, the degree and nature of the protection needed, and the institutional arrangements that determine the contingent importance of privacy will vary, depending on the kinds of harms threatened by a loss of privacy and the vulnerabilities of persons under any given set of economic and social arrangements.' (Powers, 1997, 362)

This argument supports the central claim of this chapter; that the moral and ethical boundaries are relative to the social context within which private insurance exists. The upshot of Powers approach is that if an individual's interest is threatened by another person gaining access to their genetic information, then the policymaker must either restrict access to the information

or modify the institutional arrangement within which that information exists. (Ibid, 363) In the case of insurance, one can either deny access to the genetic data or change the institutional arrangement of insurance provision so access is no longer required.

Lebacqz (1998) believes that protection of privacy rights will not in the end be of immediate benefit to the most vulnerable members of society, because such rights construct problems as personal rather than societal. (Lebacqz, 1998, 248) Social consequences come second to individual interests when we seek to protect privacy on the grounds of individual liberty. In the case of healthcare, she claims that privatising decision-making does not challenge the underlying values of health provision in the United States, which by its very nature discriminates against the poor. Lebacqz argues that the protection of privacy will not fundamentally change this institutionalised framework of discrimination.

However, legislation to protect particular privacy rights might in certain circumstances be essential. A moral case could be made for changing the present system of consent, in which people are forced to concede access to the totality of their medical record. Mandl et al (2001) argue that patients should be able to grant differential levels of access to various parts of their medical record, with each section requiring independent authorisation. (Mandl et al, 2001, 284) This would give patients far greater control over their personal medical data, and could reduce the potential for improper use of that information. However, within the insurance context, people may still be required to grant certain, albeit more limited and specific, access as a precondition of receiving insurance

cover.<sup>20</sup> Again, the moral and ethical status of this kind of request depends largely on the type of insurance product being provided.

There is a legitimate right to privacy, as well as a right to control sensitive personal information. As Moore (2000) points out in his Lockean analysis of intangible property rights, such control over personal data protects autonomy and can serve as a defence against possible totalitarian forms of government intervention. (Moore, 2000, 104) However, such rights are clearly not absolute. Others also have legitimate claims on certain rights, and their rights can sometimes impinge on others. Even private insurance companies have certain rights, but only if they are offering non-primary social goods.<sup>21</sup>

As far as genetic information is concerned, it is difficult to justify the creation of special systems of protection. The ethical dilemmas that the genetics and insurance debate have illuminated, and brought to society's immediate attention, should perhaps be used to question the entire system of access to the medical information of individuals.<sup>22</sup>

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<sup>20</sup> Laurie, 2000 points out that within The Data Protection Act 1998 personal health information, which includes genetic data, qualifies as "sensitive personal data" and is afforded greater protection in that it can only be processed under limited circumstances and with explicit consent. However, what good is consent if to deny access leads to ineligibility for an insurance contract? Laurie approaches this issue from a legal perspective, but questions whether legal redress always offers the best solution. He concedes that a more universal approach is required, one that does not single out genetic information for special protection, and he regards the data protection laws as a positive step forward in this direction, precisely because it refers to health information as a universal and inclusive category.

<sup>21</sup> I do want to note that corporations should not be granted the *same* rights as individuals, because in a trade-off between the individual and the corporation the individual's rights ought to be stronger. Many global corporations have tried to use individual rights based legislation to grant themselves the most dubious property rights, which can be damaging to many developing countries, and I argue fervently against this particular trend.

<sup>22</sup> The National Genome Research Institute (NHGRI), 1993 believe genetic privacy requires protection but concedes this important notion that various types of health related information are equally sensitive. They argue that such information should never be used to deny health care. However, this task force has a vested interest in framing the issue beyond merely 'genetic information' since they operate as part of the Human Genome Project, which is clearly interested in promoting genetic research.

This section has illustrated the ways in which genetic information may affect the relationship between doctors, patients, and insurance companies, and perhaps render issues around consent, privacy, and control of medical information far more complex. The increasing knowledge of genetics, and advances made in screening technologies, will most likely heighten public sensitivity to these complex issues. However, such dilemmas are not new, but the risk is that genetic information once again is granted special status in this context. These issues certainly need to be resolved, but the debate should perhaps be extended to all medical information, not just the genetic aspects. Access to family history information is crucial in this regard. It is important to note that some European countries, such as Norway, have used formal legislation to prohibit insurers from requesting family history information. As such, they have at least demonstrated a consistent approach to the issue by not ring fencing new kinds of genetic test information for special attention. Whether or not this restriction on commercial freedom succeeds in the long-term remains to be seen, but there are some lessons for the UK. The logic of this debate does lead naturally to a more critical consideration of the use of all medical information by third parties.

Having looked in some detail at the various theoretical roots of the problem of genetics and life assurance, and certain groups' accounts of the definitional framework, it is now necessary to look at some of the practical realities of the insurance business. So far, it has been demonstrated that the likely social, legal, ethical, and commercial implications of genetic information for access to life assurance are not as great as perhaps the level of concern has implied. Of course, there will certainly be some social and commercial impact, but it seems wrong to single out new kinds of genetic test data for special regulatory

attention. Even if new kinds of genetic test information were likely to prove significant in the context of access to private life assurance, the everyday practical realities of the life business would most likely mitigate any negative social consequences. These practical realities, combined with the creative capacity of the insurance industry to create novel products, will now be shown to offer possible candidate solutions to the problem of genetics and insurance.

## **7. COMMERCIAL REALITIES OF THE LIFE ASSURANCE INDUSTRY**

Throughout this chapter, the issue of genetic information and its implications for life assurance provision has been presented mostly in abstract theoretical terms. Thus, the nature and role of actuarial underwriting was presented as an 'ideal'. However, practical reality often deviates from pure theory, so it is incumbent upon policymakers to recognise the commercial realities of the life assurance industry when evaluating candidate solutions to the problem.

### **7.1 The Flexibility of a Commercial Market**

In the UK, life assurance companies do not conform rigidly to the theoretical principles of underwriting presented earlier in the chapter. They may often provide insurance with minimal underwriting, treat specific genetic test information as a special category, and accept restrictions on rating policies because of formal legislation (for example the Race Relations Act). Furthermore, they can often make allowances for individual policyholders because the market is so flexible. A good example of this is the case of risk re-classification. This particular issue emerged during the interview with Tony



O'Leary. He was asked whether it was possible for individuals to be re-underwritten if their risk-status improved, and therefore pay a reduced premium.

He responded:

The theory is no --- an insurance company offering life assurance is different from house insurance and car insurance where you renew it every year and if something changes the rates change. Life assurance is forever, for the term of the policy ... from a theoretical point of view I shouldn't change the terms [because only those whose risk-status improved would ask to be re-classified. Those whose risk status did not improve would not ask to be rated higher.

This account expresses the pure theory that re-classification of risk is economically unsound. Graham Austin confirmed this theory in his interview. However, because the insurance market is so competitive, there is always the possibility that an individual will cancel their existing contract and take out a new policy with a competitor company in order to get better rates. This is known in the industry as 'lapse and re-entry'. When Graham Austin was asked if this commercial reality might sometimes make re-classification necessary, he responded:

**If your good lives walk away and your bad lives stay, and then the ones that you did charge an extra premium for you allow to come back and have ordinary rates, in actuarial terms you have a skewed group of people. But I accept that we do it sometimes.**

The competitive nature of the insurance industry suggests that most people could find affordable insurance if they were both willing to take action to reduce their risk status and understood the commercial realities of the market. Even the genetically at-risk might be able to access affordable insurance this way. Of course, for many monogenetic conditions it is impossible to reduce risk-status through lifestyle changes. However, most people seem to be worried about a

future in which genetic testing becomes routine for multi-factorial conditions. In these cases, some prophylactic action is likely to mitigate the severity of the condition, so the competitive nature of the market might advantage these at-risk individuals.

However, most evidence suggests that individuals are usually bad at modifying their lifestyle in order to reduce risk of illness. Clarke (1997c), commenting on the financial costs incurred by health promotion programmes, argues that lay understandings of risk often conflict with the scientific reality. Some people become fatalistic when they discover they are highly susceptible to some illness, while others who are told they have a low susceptibility begin to assess the extent to which they can abuse their bodies. Both reactions can have a negative impact on future health. This view is shared by Marteau and Lerman (2001), who claim that current evidence suggests that providing people with DNA related information does not increase their motivation to change behaviour any more than it does for non-genetic information. (Marteau & Lerman, 2001, 1058) Evans et al (2001) point additionally to the lack of any straightforward and effective measures to reduce the risk of many cancer predispositions, even if individuals are willing to comply with a strict medical regime, and Davison et al (1992) note the consistent failure of the general public to embrace medical lifestyle advice and acquiesce to received medical wisdom. Internal irrationality may be one of the reasons why people are largely unsuccessful at reducing their risk-status. We will return to this issue in the final chapter, as it has significant implications for the public understanding of science.

The fact that insurers are willing to compromise on their standard norms and practices, because the market is so fluid and competitive, demonstrates that

bad genetic luck does not have to seriously affect access to insurance products. Of course, as Nikerson (1996) points out, most of the benefits of genetic testing will be monopolised by those individuals with negative results who will ultimately pay less for life assurance. Those with positive test results will generally pay more. The insurance industry is usually no better or worse off as a result. (Nikerson, 1996, 386)<sup>23</sup> Nevertheless, insurers have demonstrated a willingness to provide alternative arrangements for high-risk individuals. For example, because onset of illness almost invariably starts in middle age, individuals with the gene for Huntington's disease can often acquire term life assurance because insurers recognise that the applicant will have a number of years where their risk-status is 'normal'.

## **7.2. The Creative Capacity of the Insurance Industry to Create Novel Products**

Even if the nature of the life assurance market renders certain individuals ineligible for an insurance policy, there are insurance products available that are tailored to the specific needs of high-risk applicants. What is often neglected in debates about genetics and insurance is the 'creative capacity' of the industry to respond to 'deviant' cases in the market. This capacity to design novel products for individuals who cannot access existing ones is reflected in the growth of the annuities market. The emergence of such policies as 'impaired life annuities', or 'smokers' annuities', demonstrate that the industry can respond to a variety of emerging consumer needs.

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<sup>23</sup> It must be noted that offering lower premiums to the genetically 'fit', or what are known in the trade as 'preferred lives', is considered unethical and all insurance companies have promised they will not 'cherrypick' low risk applicants. However, they do cherrypick for other risks, so again a false demarcation line is often drawn between genetic and non-genetic factors.

Annuities are extremely important to how we conceptualise the genetics and insurance debate, because they essentially represent an inversion of the life assurance dilemma. With life assurance, high-risk applicants pay greater premiums than low-risk ones. However, with 'impaired life annuities', high-risk policyholders pay the lowest premiums. The basic principle of an 'impaired life' annuity is that the applicant pays a one off premium, and the provider subsequently guarantees the policyholder a regular income until death. Therefore, from the insurers' rational economic perspective the hope is that the applicant dies sooner rather than later. However, such a product also provides the opportunity for those high-risk individuals to gamble with the insurer on their own mortality. Many companies offer smokers annuities, and it is not inconceivable that a similar market could grow as genetic testing becomes more prevalent. This could offer some form of financial security to the so called 'genetically disadvantaged'.<sup>24</sup> One of the advantages of this approach is that it avoids having to provide special protection to a sub-set of high-risk policy applicants in an equity based insurance pool. This would prove unfair to both low-risk policyholders who would be forced to pay higher premiums, as well as other high-risk policy applicants who might be charged a loaded premium because they suffer from conditions not pre-defined as deserving special protection.

It is surprising that various protagonists in the genetics and insurance debate have neglected the case of annuities as a potentially straightforward solution to the genetics and insurance dilemma. Instead, many scholars and interest groups have advocated legislative restrictions on the life assurance market. Baroness Warnock (1993) argues we should average out the increased costs

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<sup>24</sup> This does raise the interesting scenario of a new form of anti-selection whereby those people with low risks pretend to lead unhealthy lifestyles in order to get favourable annuity premiums.

amongst all policyholders, in order to protect the 'genetically disadvantaged'. She wrongly believes that this provides the most equitable solution. The insurance company would not suffer financially, but those people in the insurance pool only just able to afford their premiums could be disadvantaged and may even fall out of the market altogether. McGleenan and Wiesing (1999) offer another solution. They propose that we make it a pre-condition of taking a genetic test that the individual prove he or she has already taken out a life assurance policy. This would prevent anti-selection, so the insurance industry would be content, but there is a liberty issue here; should one be forced to obtain insurance, especially if it is not considered a primary social good?

There are other possible piecemeal solutions that do not necessarily challenge the principle of equity. One could be to offer people with genetic disorders the kind of state subsidisation that military personnel enjoy when they propose for life assurance policies. Basically, they apply for an insurance product and the government pays the loaded part of the premium. This does not challenge the principle of equity, because within the specific insurance pool, people are still paying premiums commensurate with their risk. However, some members are being state subsidised. This is something society may wish to implement, although it could prove unfair to those who are not eligible for the state subsidy but are still excluded from accessing life cover, or are forced to pay excessive premiums. Maybe this principle of state subsidisation could be extended to all those who are denied insurance? Whether people would be willing to support those whose risk is self-inflicted is another matter, but worth discussion.

Warren (2001) proposes another possible solution. Talking about long-term care insurance, she argues that the Government could give tax relief on

premiums so companies could offer standard rates to all those wanting moderate cover, yet grant such companies the right to access all information for those seeking substantial amounts of cover. (Warren, 2001, 1060)

All these solutions provide some form of protection without undermining the principle of equity. However, each of them does require singling out particular groups of policy applicants for special legislative protection. The creation of novel products appears to be the fairest, and perhaps simplest, way to provide protection in the unlikely case that new kinds of genetic information leads to widespread social exclusion.

### **7.3. Implications of Genetic Information for the Privatisation of Welfare**

Although the creation of novel products might prove useful in providing alternative coverage for high-risk applicants, for those products that are considered primary social goods, such an approach is likely to be inappropriate. The logic of insurance discrimination is that for certain products, such as healthcare, long-term care, and perhaps in the future life assurance attached to a mortgage, it is simply inappropriate to provide such products through a mutuality based model. The genetics issue has perhaps sensitised people to the mechanisms by which 'social goods' are distributed. The Government's increasing obsession with privatised welfare may therefore have to be reconsidered in light of this evidence

Solutions may be needed that go further than the creation of novel insurance products or state subsidies, and lead essentially to the re-evaluation of the institutional structures of private and social insurance more generally. Something like European models of public finance and private provision could

be implemented, at least for healthcare. The genetics issue, if anything, should perhaps lead to a major rethink of the fundamental place of insurance in modern society. At this moment in time, it would probably be unwise to significantly modify the institutional framework of private life assurance, as piecemeal solutions are likely to prove sufficient at present. However, a strong argument could be made for applying these solutions to the entire 1% of people who are denied access to such products, not just the genetically disadvantaged. However, if greater numbers of people do end up falling into this unfortunate category of 'uninsurable', then the equity principle may have to be challenged and some form of social insurance or solidarity based private insurance introduced.

A major problem for the policymaker is how to judge when a non-primary social good has shifted significantly enough towards conception as a primary social good to warrant a fundamental change in the institutional provision of insurance. It may be an incremental process, with even minor changes in the level of welfare payments shifting life assurance closer to consideration as a primary social good. It is really all a matter of degree. The solution required is dependent on where along a linear continuum an insurance product is considered to lie at any given time. The closer an insurance product moves towards conception as a primary social good, the greater the need to transfer provision from the private to the state sector; from risk-based mutuality to non-risk based communal solidarity.

## **8. CONCLUSION**

The aim of this chapter was to provide some answers to research questions one and two. Research question one asked: what are the most likely social,

legal, commercial, and ethical implications of life assurance companies using genetic information to rate policyholders, and might the history of insurance, risk and probability enable us to better understand this contemporary problem. It also asked whether the political rhetoric of stakeholders advances or problematises our evaluations. In order to investigate this issue, the chapter began by looking at the history of probability, risk, and insurance. The first section discussed briefly the impact eugenic anxieties might be exerting on peoples' perception of the genetics and insurance issue; perhaps by sensitising them to the potential abuse of genetic science. Although there was no clear evidence to support the view that people were being directly influenced by the eugenic past, it was claimed that the historic abuse of genetics might need to be seen as foreshadowing contemporary debates.

The first main section of the chapter provided a short historical account of the issue at hand. The birth of life assurance was shown to be linked to the development of a new science of probability, both of which also had an impact on the growth of late-stage capitalism. This section challenged some of the basic assumptions held by contemporary sociologists of risk, particularly the idea that modern risks are qualitatively different from those in the past. Although the 'risk society' theory presented by writers such as Beck and Giddens may have served an important purpose in sensitising sociologists and the public to issues around risk, their theories were shown to be inadequate for understanding the genetics and insurance issue. Analysis of the social context of insurance revealed the distributive issues around risk that have often been neglected by risk society theorists. Because insurance has always existed primarily as a means for the wealthy to protect their financial interests, talk of widespread social exclusion appears flawed. The statistical revolution and the birth of insurance did not benefit all equally.



The next section proceeded to analyse the foundational principles of the modern insurance system, both social and private, and argued that the ethical boundaries of the private market should be dependent on the type of social good particular products are perceived to exemplify. The logic of this section dictated that any insurance product that falls within the private sphere should be considered a non-primary social good, and in such cases, insurers ought to be able to use risk-assessment as a discriminatory tool. Fair and unfair forms of discrimination were also contrasted. However, the argument was made that it is the impact on the individual denied insurance that is most important to consider, rather than the route by which that individual is excluded. Nevertheless, for private insurers distributing non-primary social goods, the distinction was shown to be valid. The main conclusion of this section was that private insurers were above all else a business. Although many may talk of social values/benefits, as revealed in the interview transcripts, there always appears to be a commercial narrative enveloping the social narrative. Insurers often render ambiguous the social/commercial value distinction, in particular contexts, in order to provide a morally adequate account of their commercial norms and practices.

The next section looked specifically at genetic information in the context of insurance. In light of the previous arguments, it was shown that genetic information was unlikely to have a significant social, commercial, ethical or legal impact. Regarding social implications, the fear that widespread social exclusion would be engendered if commercial insurers were allowed to use new kinds of genetic information, was challenged. This riposte was based on the historical data that revealed the class bias in insurance provision. Furthermore, the commercial realities of the insurance business, discussed in the final section, demonstrated that the likelihood of an uninsured genetic underclass emerging

was low. It was also pointed out that genetic information might rule people into insurance, as well as out of it, so talk of unfair discrimination leading to social exclusion appears deeply flawed. On the commercial implications, the potential impacts were also shown to be minor. The argument was made that genetic information is likely to simply refine existing underwriting practices. On the ethical side, it was argued that genetic information does not really engender new ethical complexities, but may compel us to reconsider the use of all medical information in private insurance underwriting, and indeed the very role of the private insurance sector. Any ethical boundaries imposed on commercial underwriters, it was argued, should be dependent on the type of social good the insurance product exemplifies.

The genetic information section also sought to provide an answer to the second research question. A great deal of the controversy over genetics and insurance was shown to be dependent on the definitional framework. Interview data from relevant stakeholders highlighted the ways in which people operationalise various definitional frameworks around the issue of genetic information, which may then be used to justify particular positions on the issue. Although there were no acute differences between the various representative groups, individual members did appear to alternate definitional frameworks, through their interview talk, which might have been influenced by their broader social, political, or professional values. One consequence of imposing different definitional frameworks may be that the issue appears more complex than they really are, and that some of the underlying roots of the problem may be neglected.

Section 6 looked at the legal implications, in terms of the doctor/patient relationship. It was shown that genetic information does illuminate certain

ethical issues around ownership and control of medical data. However, again it was shown that many of the problems seemed to apply to various kinds of medical information, not just genetic ones. Therefore, the argument was made that the genetics and insurance controversy perhaps ought to be used to question insurance companies' access to all kinds of medical information.

The final section looked at the practical realities of the life assurance industry, and again demonstrated that the putative impacts of genetic information were likely to be innocuous. However, even if genetic information were special, and likely to engender a number of social and ethical problems, it was shown that the industry has a long history of creating novel insurance products. Indeed, it was argued that the growth of the annuities market might obviate the need for any serious debate over, or legislation on, genetics and life assurance. This section also raised the issue of the implications genetics might have for the privatisation for welfare. The logic of insurance discrimination is that primary social goods, such as healthcare and long-term care insurance, should only be provided through a solidarity based social insurance system.

Overall, this chapter has provided a comprehensive overview of the life business, and the likely impacts genetic information may have on traditional underwriting processes. It has tried to capture the complexity of the issue, and demonstrate the ways in which various individuals may bound the issue through their interview talk. The following chapters will critically analyse the formal policy process in the UK, and stakeholders' engagement with it, in light of the insights that have emerged in this chapter.

## CHAPTER 3

### STAKEHOLDER ACCOUNTS OF THEIR CONCERNS OVER GENETIC INFORMATION AND LIFE ASSURANCE IN THE UK

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#### 1. INTRODUCTION

The previous chapter investigated the likely social, legal, commercial, and ethical implications of permitting life assurance companies access to new kinds of genetic information. It also began to reveal some of the narrative strategies used by stakeholders to establish certain definitional parameters to the issue. The analysis provided answers to the first and second research questions. This chapter will try to provide answers to the third research question by analysing stakeholder accounts of their concerns about genetics and insurance. If the evidence suggests that the likely implications of genetic information for life assurance are relatively innocuous, then one has to begin to look at stakeholder rhetoric as one possible explanation as to why the debate has become so controversial.

This chapter will use data derived from the interviews, as well as a number of publicly available policy documents, to investigate the differential ways in which stakeholders and interest groups express concern about the use of genetic information by life assurance companies. In particular, it will look closely at the broad narrative repertoire drawn upon by insurers, clinicians, and patient-support groups, as they have given account of their beliefs on some of the substantive issues underlying the debate. It will assess whether the way stakeholders articulate and frame their beliefs is influenced by a broader set of social, political, or professional values/interests. The policy positions of various professional bodies will also be analysed, in conjunction with the interview data, to provide a broader sociological account.

One aim of this chapter will be to examine the extent to which individuals and groups engaged with the genetics and insurance problem marginalise or prioritise certain substantive issues in order to provide a coherent, and perhaps morally adequate, account of their beliefs. In the previous chapter, the use of both a 'social' and 'commercial' value narrative was revealed in the accounts of insurance industry representatives. This chapter will build on this analysis and reveal further evidence that stakeholders will use a variety of rhetorical strategies to legitimise their ideologically dissonant positions. This chapter will build a solid foundation for an assessment of the formal policy process, which will be presented in the following chapter.

## **2. INTEREST GROUPS AND THEIR IDEOLOGICAL COMMITMENTS**

A variety of stakeholders have made significant contributions to the genetics and life assurance debate in the UK. Indeed, one could argue that the political rhetoric of key stakeholders has played a fundamental role in shaping the policy process. The primary objective of the following sections will be to reveal, and critically analyse, the range of narrative repertoires drawn upon by specific stakeholders and interest groups, as they have attempted to provide coherent accounts of their beliefs and concerns. It will be argued that the various rhetorical strategies used by key stakeholders may have antagonised the debate, and negatively affected the quality of the policy process, by granting exclusivity to the perceived ideological beliefs and concerns of those individuals they claim to represent.

It may be of little surprise to discover that representatives of specific organisations are inclined to frame social problems, and offer candidate solutions to them, in a way that reinforces confidence amongst the sectional interests they represent. In one sense, this tendency ensures that all opinions in this complex debate can enjoy some form of public expression. However, it is necessary to analyse the strategies of such groups, and subject their statements to critical sociological analysis, precisely because they may have such a strong influence on the policymaking and regulatory process.

### **3. CLINICAL/SCIENTIFIC INTEREST GROUPS**

Professionals involved in the scientific/clinical aspects of the new genetic technologies have raised a number of concerns regarding the use of genetic information by third parties such as insurers. The previous chapter discussed the ethical boundaries of the doctor/patient relationship, and revealed growing concern

amongst clinical geneticists and counsellors that patient health might suffer if insurers are permitted unconstrained access to the genetic information of their policy applicants. One principal concern was that insurers might overestimate the predictive power of genetics and rate policy applicants on fallacious scientific evidence. Another interesting issue revealed in the clinicians' interview accounts was the fact that the insurance problem was becoming a central feature of genetic counselling sessions. This section will build on the findings presented in the previous chapter and provide a broader sociological analysis of the clinicians' interview accounts. The policy positions of various professional bodies representing the clinical community will also be critically evaluated.

### **3.1. Interview Accounts of the Genetics and Life Assurance Problem**

The clinicians appeared to draw upon a broad narrative repertoire when articulating their concerns about the commercial use of genetic information. One could identify in their accounts a subtle interplay between social, clinical, and commercial values. However, the respondents frequently prioritised the clinical aspects of the issue. Dr. Quarrel, for instance, gave the following account when asked to articulate his primary concerns:

Well I suppose the principal concern I have is that, because of the issue of insurance, people will not access genetic tests which may be of benefit to them, not because they don't want them or because they feel it's inappropriate for them, but because they will be financially disadvantaged. I suppose the other concern has to be that if the welfare state is rolled back and more of social provision has to be provided by the insurance industry ... then that will become more of an issue.

The respondent's account incorporates a number of underlying values. However, some appear to be marginalised while others are prioritised. There is a central clinical value, expressed as a concern that patients' health might be compromised if there is continued uncertainty about access to insurance products. There is an implicit assumption that a patient's propensity to undergo a medical examination is directly influenced by the status of the genetics and insurance problem. From this premise, the respondent infers that our priority must be given to the clinical interests of the patient rather than the commercial needs of the private sector. The respondent also draws upon a broader 'social value' narrative when he expresses the concern that continued recession of state-funded welfare may exacerbate the clinical impacts and disadvantage certain social groups. This is an example of the classic 'social exclusion' argument, which attempts to judge the moral legitimacy of commercial insurance by reference to its accessibility. Dr. Quarrel also intimates that particular types of insurance ought to be considered 'social goods', which should be made available to all individuals regardless of their risk-status. Again, his fear is that in a risk-based insurance system, patients may not come forward for treatment if they believe they will be denied insurance.



It is difficult to decouple clinical and social values in Dr. Quarrel's account, as he often appears to conflate the two. For example, the statement that patients are concerned that they will be financially disadvantaged if they seek medical care (a social value) also engenders the concern that patients will subsequently reject genetic testing (a clinical value). Because the clinical community has an interest in improving patient health through medical screening, they may draw on both a social and clinical value narrative to give their clinical concerns additional rhetorical power.

Anonymous genetic counsellor 2 expressed a similar clinical concern, but also brought into play the notion of unfair discrimination. She stated:

I think, myself, I would be concerned. Part of me is concerned because I always perceive insurance as spreading risk, and I can see potential there for people who are at genetic risk through no fault of their own being unfairly discriminated against and not being able to get cover which actually for them could be more important to have ... I also worry about the potential for insurance companies requiring people to have genetic tests. We spend a lot of time talking about the pros and cons of, you know, "is this the right thing for you" ... The last thing we want is for someone to feel pressurised to have a test which might not be the best thing for them.

Again, one can identify in this account a broad narrative repertoire that incorporates clinical, social, and commercial values. It contains a personal opinion on the commercial norms of insurance, a social concern that individuals may be 'unfairly discriminated' against, and a clinical concern that patients may be forced to undergo medical procedures that ultimately disadvantage them. The respondent also refers to the 'no-fault' clause in order to try to realign the commercial norm of risk spreading with a putative right of at-risk patients to receive adequate cover.

The concern that patients may be compelled to take a genetic test by insurance companies is a central feature in the respondent's account. Whereas Dr. Quarrel expressed concern that people may refuse to take clinically necessary genetic tests because of fears about social exclusion, this respondent expresses the parallel concern that patients may be *forced* to take clinical tests that have no clinical value. When asked to respond to the insurance industry's claim that it will not ask people to undergo genetic testing as a prerequisite for receiving insurance cover, genetic counsellor 2 responded by stating:

'I know that is what they say, but I tend to say to people that we are still a little bit unclear of where this is going to go, and we would suggest that if you are thinking of taking a test which could be significant then look at your cover before going ahead.'

It is clear that clinicians take a very patient-centred approach to this issue, which may explain their ambivalence towards the insurance industry's promise that it will not ask people to take genetic tests. The interview accounts also reveal the frequent priority given to clinical and social values over commercial ones.

The scientific/clinical value narrative became more conspicuous in the interview accounts, when the competency of the insurance industry to use new kinds of genetic test information fairly and accurately came under question. Genetic counsellor 2 recounted the following case from personal experience:

We have had the odd situation where somebody has had the test, and tested negative, but has still had trouble getting the insurance company to take that on board, and it has required a letter from one of the consultants to say look they have been tested for the gene area which has caused this family history and they have not got it ... Obviously, whoever's dealing with it hasn't

completely taken on board the facts. Patients I have seen have become quite wary. We always ask if it is ok to write to their doctors, but some of them ask us not to or think twice because they're worried about things getting into their medical records.

There is growing concern amongst clinicians that the insurance industry is incapable of using new kinds of genetic information fairly and accurately. The personal accounts of clinicians reveal that patients often have to deal with personnel in the commercial sector who are ignorant of the scientific facts. Genetic counsellor 2 argued that as genetic testing becomes more common, the insurance industry would find it increasingly difficult to make both scientifically informed and socially equitable decisions. When asked if the insurance industry would be more likely to misuse genetic information for multifactorial conditions, the respondent stated:

Yes, absolutely, because those are the conditions which are less straightforward. They're not like Huntington's with the 50-50 almost complete penetrance. And the worry would be that people could start feeling obliged to have tests for predispositions when it's not completely clear what that means.

Again, a great deal of emphasis is placed on the scientific complexity of genetics, and there is an explicit assumption that insurance companies are likely to misuse the data. The insurance industry is portrayed as an institution that problematises both the 'scientific value' of genetic testing and the 'social value' of economic inclusion. However, both genetic nurse counsellor 1 and Dr. Quarrel did concede that some insurance companies had made a tentative effort to become 'more informed' by engaging in dialogue with members of the clinical community. When asked whether the insurance industry was competent enough to use genetic information fairly and legitimately, genetic nurse counsellor 1 stated:

It used to be that I would have said no, but I think they are asking more questions and there are a number of leading consultants on some of the insurance boards and they are getting direct information, so I think that their knowledge is getting better, particularly when they are consulting with us. It's whether they use it correctly.

Similarly, Dr. Quarrel stated:

Well it's becoming competent isn't it? I mean the difficulty is, well I can't speak for individual companies, but the members of the insurance industry with whom I have had dealings are the ones that attend seminars and link with the genetics community and so they are very well informed. So the insurance industry has the ability, if it wants to, to become well informed.

Both these accounts attribute the primary cause of the insurance industry's misuse of genetic information to a knowledge deficit, which may require the commercial sector engaging more widely with the professional genetics community and recognising its specific expertise in this area. However, both respondents implicitly assume that geneticists are a homogenous professional group with a shared belief in the status of the science, and are in a position to educate the 'ignorant' insurers. The statement: 'I think that their knowledge is getting better, particularly when they are consulting with us' reveals the extent to which clinicians believe themselves to have an educative role to play.

The following account by Dr. Quarrel captured the tense relationship that often exists between the genetics and insurance communities. He stated:

It [the insurance industry] seems to me to be far too defensive about the good principles it has, and says look this is the way it is, "I'm sorry genetics community, you are seriously misguided, you don't really know insurance.

We'll talk to you but in order to facilitate discussion you have to understand our principles". We now have the two groups understanding their professional language as it were, but they're still in parallel. You've got to have that understanding of the two group's professional jargon, but then you've got to have some sort of meeting of minds. We haven't achieved that.

This account signals the respondent's concern that although the insurance industry could, in principle, become competent enough to use the new kinds of genetic test information fairly and accurately, the reality is that they continue to be defensive about their actuarial principles, seem unwilling to concede ground, and appear to regard geneticists as ignorant of the underlying principles of insurance. Although the genetics community portrays insurers as ignorant of genetic science, they also assume that insurers consider the genetics community to be ignorant of actuarial expertise. This professional dissonance is crucial to understanding policy debates on genetics and insurance, as it may engender a great deal of conflict and confusion. Both professional communities concede that there is a great deal of professional discord, which may necessitate greater and equal professional engagement. This, it would seem, requires not only the insurance industry conceding ground to the geneticists, but also the geneticists recognising some of the concerns of the commercial sector.

The interview accounts appear to support Kerr et al's (1997) research on professionals' discursive boundaries. Both clinicians and insurers appear to be erecting such boundaries, through their interview talk, in order to protect their professional status and autonomy. While Kerr et al's analysis revealed the ways in which clinical geneticists use rhetoric in order to create a boundary between themselves and their patients; here they seem to be using a similar strategy to

protect their expert status in the face of intrusion by another professional body, with its own interests, values, and professional agenda.

So far, the interview transcripts have revealed that clinicians tend to account for their beliefs on the genetics and insurance issue by drawing predominantly from their professional experience and expertise. Consequently, a clinical value narrative, which is sometimes conflated with a social value narrative, often appears to be prioritised in the interview talk. The clinicians appear to marginalise the potential impact of genetic information on existing insurance industry norms and commercial values. This was revealed further when the respondents were asked to express their opinions on how the problem might best be resolved. The social/clinical values dimension became even more conspicuous.

All but one of the four respondents expressed the belief that some form of legislative response was perhaps necessary to protect patients from unfair discrimination, and ensure that they take genetic tests that might be of clinical benefit to them (again, the social value is linked directly to the clinical value). However, there was a clear sense of unease when the respondents began to consider this issue. On the topic of legislation, the dialogue with genetic nurse counsellor 1 proceeded as follows:

**JM:** Do you think there needs to be some form of legislation (The current status of the moratorium is explained)? Do you think this moratorium is sufficient, or would you prefer some other form of regulation or legislation?

**Respondent:** I would have thought that we are moving to a time when there would need to be some legislation ... yeah I think there needs to be.

**JM:** What kind of legislation would you prefer?

**Respondent:** Well, by definition, because of my professional role I have to think of the confidentiality of the client. If somebody turned around to me and said that I had to release information against a client's wishes I wouldn't want to do that.

**JM:** Would you prefer an outright blanket ban on insurers asking for new kinds of genetic information so that clients wouldn't even have to think about the implications for their insurance needs?

**Respondent:** Well in an ideal world that would be great, but I think I'm realistic enough to know that that isn't going to happen and there's going to be an increasing number of tests available and that means insurance companies are going to be increasingly interested in them. So that's why I say there needs to be a balance, some legislation from people who aren't involved in the insurance companies.

This respondent's account appears to be clouded by how she finds herself professionally situated. She expresses a story based on her everyday experience of working with genetically at-risk patients who, she tells us, worry a great deal about the confidentiality of their medical records. She also responds positively to the idea of an outright legislative ban, and implies that the protection of patients' interests should be our primary concern in an ideal world, even if this undermines commercial freedom. The clinical/social values are again given priority over commercial ones. The account also acquires a certain degree of moral adequacy by anchoring itself to a putative need to protect the medical interests of the at-risk client. However, the respondent also acknowledges that reality is far more complex, when she concedes that such ideal legislation is unlikely to be implemented. Subsequently, she calls for 'balanced' legislation. However, 'balance' for this respondent appears to entail taking insurance representatives out of the decision-making process and involving only those with no commercial stake in the outcome. The respondent does not appear to recognise representatives of the insurance industry as legitimate actors who might perform an important role in establishing fair and balanced legislation. Their professional and commercial

interests are once again marginalised, while additional power is given to the rhetoric of other interest groups and stakeholders.

Genetic counsellor 2 shared the opinion that there had to be balanced and well-informed legislation, but admitted that this could be difficult as genetics is such a fast moving field. She also gave an account based on her experience working with at-risk clients, but did try to recognise the insurance industry's position. The following statement was particularly interesting:

I'm not unsympathetic to the cause of the insurance industry. I've got relatives who work in the insurance industry and I can understand their concerns about people potentially abusing the system by having tests and taking out policies. And I know they have to be stringent because I know people try and defraud them so I'm not unsympathetic ... but at the same time, because of the nature of my job, I'm sort of very conscious of the issue as it might affect my clients. I can understand the concerns of the insurance industry, but I think you know from the family and patient point of view, I'm just aware that people who are in a difficult situation anyway might have things complicated for them.

This respondent tries to conceptualise the issue from both the perspective of a citizen who knows people in the insurance industry, and is therefore sympathetic to their concerns, but also as a concerned clinician who must consider the problem in terms of how it may affect her clients. There appears to be an internal conflict, and perhaps even contradiction, between her conceptualisation of the issue as an 'ordinary' citizen and as a situated professional in the genetics field. The difficulty she experiences in trying to resolve this conflict leads her to call for a balanced response from others. Although she appears to recognise that the issue is multifaceted, and that the account she is expressing from a clinical perspective is only one amongst many, it is implied that for the purpose of the interview, the clinical position will be expressed most strongly.



Dr. Quarrel's opinion on the matter of legislation was that the insurance industry had to be willing to concede ground on its long established principles, and that in the absence of primary legislation there had to be at least enforceable regulation.

He stated:

The insurance industry quote all sorts of principles ... I think we can move away from that by saying that we as a society recognise that there's going to be a small group of people who are going to be at a substantial disadvantage when it comes to obtaining insurance and, in a large insurance market like life assurance, it may be that the excess cost of that, which has to be borne by somebody, can be accommodated by the insurance industry itself. You can regulate the market such that the degree of adverse selection is limited and that's society making a stand and saying yes we know all those principles, we accept all those principles, but there's a problem that this group are excluded, we don't want that exclusion therefore we are regulating your market. I think what we need to do is come up with a regulation, an enforceable regulation on the insurance industry that enshrines these concessions.

This account opens with recognition that the insurance industry has established a number of principles that it considers crucial in order to remain commercially viable. For the first time, the respondent appears to understand the underlying logic of commercial values. However, once again a social value narrative framework appears to subsume and trivialise the commercial values. Dr. Quarrel now talks of 'we as a society' recognising that some people may be significantly disadvantaged because of prevailing commercial norms and values. In previous accounts, the clinical values appeared to be given priority, but now it is a far broader set of social values that have become central to the account. The respondent recognises that somebody must bear the cost of protecting the 'disadvantaged', but argues that because the life assurance market is so large, it could be forced to bear this burden without its profit margins being affected. This is then described as 'society taking a stand', as if the social values of wider society ought to take priority over any

commercial concerns, which are themselves treated as being relatively trivial and marginal.

All three clinical accounts share a number of analogous features. All give account of specific clinical and social values, which are used to marginalise commercial interests and values. However, tensions persist as respondents try to give a morally adequate/coherent account of why they believe stronger regulation, or primary legislation, may be necessary to protect patients' interests, while at the same time having to recognise that this is a complex policy area where commercial interests must also be considered. A broad narrative repertoire is therefore drawn upon in order to try and make sense of the complexity, and give account of professional concerns in a way that appears fair, coherent, and morally justified.

However, one of the clinicians interviewed expressed very different views on this issue. He was Prof. Sandy Raeburn, a clinical geneticist who is also an advisor to the ABI. He did not believe that the principles of insurance should be entirely ignored, and that genetically at-risk individuals should be given special legislative or regulatory protection. However, he still used a similar strategy to the other clinicians by drawing upon a strong clinical and social value narrative, in order to give his alternative account a degree of moral adequacy. His defence of commercial freedom was not framed by a desire to support the narrow commercial interests/values of the insurance sector, but was rooted in a belief that a flexible and viable commercial market would bring the most salutary benefits to both patients and society as a whole.

The following account from Sandy Raeburn captured his very different approach to the issue.

If you can identify the people who are having difficulties with insurance, rather than just let all the insurance premiums go up and everybody as it were paying the extra risk in a small group, why not look at that small group and find out what they really need, and see if you can actually design insurance policies which are going to be better for them. Now I've got strong suspicions that on the whole it would be cheaper to do that.

This statement reflects the respondent's more nuanced understanding of the genetics and insurance problem. He appears to recognise that providing protection to a specific sub-class of at-risk policy applicants is inequitable to other high-risk policyholders not given special dispensation, and that this is perhaps not the best way to protect the 'genetically disadvantaged'. When asked whether actuarially relevant data should always be used by life assurance underwriters (a commercial value) the respondent continued by stating:

Well I think so. I'd like to think that we are a civilised society; if a test is actuarially relevant, and if that means a proportion of people are at such a high risk they can't easily get insurance of the type you or I could get, I think we should provide a way of handling their needs in a different way ... I think that if it is relevant it should be used in commercial insurance, and if you want to have this civilised socialistic bit that I like, then you would have some sort of tax advantage, or one of another models of provision.

As somebody who advises the ABI on genetics-related issues, and is therefore aware of the commercial perspective, this respondent appears far less critical of the 'business of discrimination' narrative. However, his account also contains a strong social value dimension, expressed in terms of 'civilised' society and the need for 'socialistic' principles to have their place. Nevertheless, commercial

norms, values, and interests are not considered by the respondent to lie in contradiction to a social value narrative framework. Although he implies that at-risk patients should not be placed in a position in which they essentially become uninsurable (an argument against social exclusion), he also recognises that the commercial practice of risk-classification ought to be respected (an argument promoting the continued viability of the life business). In his account, commercial and social values are presented as being mutually reinforcing. Individuals who are genetically disadvantaged may not be able to access a particular form of life assurance, but the flexible nature of a competitive industry means that special products can be designed specifically for the unique needs of at-risk applicants.

Sandy Raeburn clearly has an interest in promoting genetic science, and he appears to be intimately concerned about the insurance needs of patients. However, unlike the other clinicians interviewed, he expresses the belief that we should look to the commercial sector itself as the primary mechanism through which to provide financial protection to at-risk individuals. Both a social and commercial value narrative repertoire is drawn upon, but they are not portrayed as mutually exclusive. The underlying logic appears to be that clinical and social interests and values cannot be decoupled from commercial ones if we truly wish to reach an equitable solution to the problem of social exclusion in insurance.

### **3.2. Clinical Organisations and Policy**

Organisations representing the clinical community have also focused their attention on the scientific/clinical aspects of the genetics and insurance problem, such as medical confidentiality and the validity of genetic tests. The World Health

Organisation (WHO) gave a great deal of rhetorical space to the confidentiality issue when they published proposed ethical guidelines for medical genetics. (WHO, 1997) They proposed that genetic data ought to be used only if it empowers individuals or families, has positive effects on their health, and should only be divulged to third parties with explicit and informed consent. (Ibid.) Earlier, in 1992, the WHO had raised concerns about genetic discrimination, and argued that it should be considered as morally equivalent to racial discrimination. (WHO, 1992) Just as was revealed in the interview accounts, this statement appears to attach clinical concerns to specific kinds of social values, such as 'discrimination' and 'social exclusion'. Commercial values appear to be marginalised by the emphasis placed on individual patient rights. However, both statements expressed by the WHO appear to have been made without due consideration of the complex, and often paradoxical, problems that often emerge when dealing with such deeply contested social and philosophical concepts as discrimination and genetic information.

The British Society for Human Genetics (BSHG) also released a statement on genetics and life assurance in 1998. They argued that it would be inappropriate to compel applicants to grant insurers access to all their genetic test information. Instead, they argued that insurance companies should only be permitted access to those specific test results that they could prove are actuarially relevant. (BSHG, 1998, Section 4) This statement assumed that insurance companies purposely use data that is scientifically unsound; a concern also expressed by most of the clinicians interviewed. The problem is framed not in terms of the existing structures and principles of the modern life business, but by reference to a belief that

commercial organisations simply cannot be trusted to use new kinds of scientific/technological data appropriately.

Both the BSHG and WHO clearly wish to promote the new genetic technologies and patient-screening programmes as a progressive development in medical care. They therefore have a stake in promoting public confidence in genomics related research. In their statement on insurance, BSHG expressed concern that perceived fears of 'unfair discrimination' might be affecting testing patterns by reducing individuals' willingness to participate in genetic research programmes. The Royal College of Pathologists, in their memorandum to a House of Commons Select Committee, countenanced this fear when they claimed: 'We feel very strongly that publicity surrounding use of genetic test results by insurers is likely to make some patients reluctant to participate in research, thus slowing down progress.' (House of Commons, 2001, appendix 17) Here, one can observe the centrality of a clinical/scientific value (patients may be reluctant to participate in important research), which is then shown to be compromised by increasing publicity on the potential negative social consequences of commercial norms and values. The result, from a clinical perspective, is that the very progress of the science may be stalled. Although this fear may have some validity, neither the BSHG nor the Royal College of Pathologists provide any reliable evidence to support their belief that people actually have been reluctant to participate in research for these stated reasons. Nevertheless, in order to defend the clinical narrative, such fears are expressed as though they are based on compelling evidence.

Although the BSHG, and various other clinical organisations, are right to raise their particular concerns<sup>1</sup>, problems may occur when they proceed to make broad political claims, such as that the insurance industry ought to bear the burden of responsibility for countering public fears by: '... acknowledging that those facing genetic risks need special consideration (and probably small concessions) that would prove of great emotional and practical help to the families and yet pose little if any threat to the life insurance industry.' (BSHG, op cit., Section 6) This broad statement is expressed without any explanation of *why* special consideration is justified for this one group of patients and not others, and in the absence of reliable accompanying evidence to support the belief that the consequences for the insurance industry would prove so innocuous. Furthermore, compelling the insurance industry to allay public fears of discrimination by providing protection to policy applicants who test positive within a genetic research environment, is qualitatively different in its commercial implications to obliging insurers to treat genetic information derived from a clinical examination as protected and privileged knowledge. Nevertheless, various clinical organisations and representatives of the medical profession often conflate the two contexts, believing that protection ought to apply equally in both cases. This is an example of a particular science-based interest group raising a legitimate clinical concern, but then overextending their logic by making general propositions based upon particular interpretations of specific social and commercial values. Such organisations appear to draw selectively from social, clinical, and commercial values, and often marginalise or

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<sup>1</sup> A joint statement by BSHG, UKFGI and the ABI on genetic research and insurance was announced at the Royal Society on 24 April 2001, and the ABI accentuated the point that insurers are only interested in genetic test results validated by the GAIC and that individuals receive as part of a clinical diagnostic process. They proceed to claim that research subjects rarely fall into this category and so will be protected in the context of insurance, thus rendering the clinical concerns mute.

prioritise one or more value frameworks, in order to render their position the most coherent and justifiable.

For the clinician attempting to allay the fears of his/her patients, or the research geneticist trying to recruit viable research volunteers, the commercial norms and interests of private life insurers tend to be trivialised as a value worthy of consideration. Often, scientific organisations that seek to promote public confidence simply misrepresent the practical realities of the commercial insurance market. The Centre for the Exploitation of Science and Technology (CEST), for example, argued in a policy document that since the new genetic tests are not highly deterministic, they can have only marginal utility in the context of insurance. (CEST, 2001) The organisation simply failed to realise that it is precisely because genetic diseases involve complex interactions between the gene and its environment, and are therefore not highly deterministic in the biological sense, that insurance underwriters have an interest in them. The insurance industry does not want absolute biological certainty; rather it needs the element of risk constituted within uncertain futures, which an interactionist approach to genetics provides. This is another example of the disparity in knowledge that exists between genetics experts and insurance professionals, each of whom appear incapable of comprehending the other's standard theories and practices.

This section has revealed that clinicians and scientific organisations, like the various other interest groups contributing to this debate, have expressed their concerns, and offered potential candidate solutions, based largely on their professional clinical interests and values. The priority given to particular value narratives, combined with the tendency to marginalise or prioritise certain



substantive issues, illustrates that specific stakeholders may manipulate, through their interview talk, the social, moral, and political boundaries of the debate in order to render their account the most coherent and morally adequate. The following section will try to discover if similar strategies are revealed in the accounts of patient-support group representatives.

#### **4. PATIENT-SUPPORT GROUPS**

##### **4.1. Interview Accounts of Patient-Support Group Concerns**

Three representatives from different patient-support groups were interviewed as part of this research. Interest groups working on behalf of those most likely to be affected by policies around genetic information and life assurance have, for the most part, been the most vociferous critics of the 'business of discrimination' narrative that has come to define the role of the modern life assurance industry. Instead, they have anchored their accounts to a 'politics of inclusion' narrative framework, in which commercial norms and interests are often marginalised. However, the interview data challenged the theory that interest groups are homogenous entities with shared agendas. Interview accounts of key representatives, and documentary evidence from policy papers, revealed acute differences in approach to the problem. Differences in the accounts given by representatives of the Alzheimer's Society and the Genetic Interest Group were particularly striking. However, despite believing in different policy approaches, both respondents did appear to share a belief in the normative social framework that envelops the issue of genetics and insurance. Also, both were keen to accentuate

the importance of a social value narrative as a means to protect the 'vulnerable'. This section will concentrate predominantly on these two accounts. A third representative, from the charity MIND, had a far more limited knowledge of the underlying issues and had not developed any fixed ideological position. Her account therefore provides a counterbalance to the more strongly opinionated and 'informed' accounts provided by representatives of the Alzheimer's Society and the Genetic Interest Group.

The most conspicuous feature of the accounts given by both Julia Cream (Alzheimer's Society) and Alistair Kent (Genetic Interest Group) was the extent to which they drew on a strong social value narrative to defend very different opinions on the genetics and insurance issue. Both respondents opened their accounts by explaining their role as advocates for individuals and families affected by genetic conditions and Alzheimer's disease. Both were attempting to express a concern for the needs of the 'vulnerable'. They were, in a sense, couching their principal role within a putative social value framework. Both stated explicitly their campaigning remit, which signalled again that they saw themselves as primarily representative organisations working on behalf of the interests of patients and their families. However, when it came to the substantive issues around genetics and insurance, the respondents diverged in what they considered appropriate solutions. The following dialogue from the interview with Julia Cream reveals a clear attempt to prioritise certain social values and marginalise commercial ones.

**JM:** The insurance industry claims it needs to know all the information the applicant has to prevent adverse selection. Do you think that this is a valid defence? Is it legitimate?

**JC:** I think it could be a legitimate argument, but for life assurance and genetic information I don't think that they have any defence. They've failed to provide any evidence that it represents any risk at all, the numbers are absolutely tiny. Several companies have emphasised the fact that they're willing and able to take anyone with a positive genetic test and withstand that risk. So if one company can do it the whole industry can.

**JM:** Do you believe the ethical issues change when we consider different forms of insurance? Some people suggest that access to life assurance is not a fundamental right and that the debate should be around other forms of insurance such as health and critical illness insurance.

**JC:** I think that most people probably accept that life assurance and long-term care insurance is something that people need to be able to access. I don't think insurers have a legitimate argument at the moment.

The first statement explicitly challenges the insurance industry's claim that access to genetic test information provides a necessary safeguard against adverse selection. The respondent draws on her knowledge of commercial norms and practices to challenge the 'business of discrimination' narrative and marginalise the primary values and concerns of the industry. By representing the issue as it is today (few available genetic tests with any commercial value to current life assurance companies), the respondent claims that the argument of a 'right to underwrite' is in this case spurious. So far, the respondent has appeared to use a particular interpretation of commercial norms in order to marginalise and undermine the commercial narrative underpinning it. However, her second statement, which represents life assurance as a product people ought to have access to, is very much rooted in a social value narrative framework. Now it is implied that life assurance is a 'primary social good' that individuals should not be denied on the grounds of commercial freedom. 'Social exclusion' is flagged as a particular concern that ought to be prevented on principle. This statement acquires a degree

of moral adequacy/coherency because it is preceded by an argument claiming that commercial values will not be compromised if at-risk individuals are permitted to acquire standard life assurance policies.

Julia Cream appeared to express thinly veiled contempt for the insurance industry's position when giving account of her concerns. She accused the industry of failing to understand the implications of genetics and establish transparent decision-making procedures. 'Informed consent' was a prominent issue in the interview. Julia Cream stated:

We have serious concerns about the level of informed consent an applicant gives about medical records. They just sign it without thinking because they feel they have no choice but to sign ... it's not informed consent if you don't know what you are signing, if you don't know what your GP will be asked, and we know GPs give too much information to insurance companies, which may lead to unfair discrimination.

In this account, the respondent appears to recognise the complexity of informed consent, but intimates that ambiguity and lack of transparency in the process may be leading to iniquitous practices by the commercial sector. However, it is difficult to know ultimately whether 'unfair discrimination' engendered by this lack of transparency is the result of duplicity or simple incompetence. The respondent leaves this question open, perhaps implying that the underlying cause is irrelevant. The social consequences for vulnerable applicants is given priority over the exact cause of their exclusion. The account also implicitly suggests that applicants' ignorance of how insurance works, and what exactly it is that they are signing as part of a contract, represents failure on the part of the insurance industry. Again,

the onus is placed on the commercial sector to protect policyholders. Insurers are expected to both establish equitable policies *and* make such policies transparent and easy to understand. There is no suggestion that policy applicants perhaps ought to take some responsibility by making sure they are 'informed' before they sign a policy contract.

Julia Cream's lack of sympathy for commercial concerns, her constant prioritisation of particular social/clinical values over commercial ones, and her lack of confidence in the probity of the commercial insurance sector in general, leads to a perhaps unsurprising policy position. The following extract highlights the respondent's position and perhaps reveals an underlying political agenda.

**JM:** How do you feel about the role of government in all this? Do they need to do more?

**JC:** It has to introduce legislation.

**JM:** So you would prefer this to the moratorium?

**JC:** Yes, the moratorium hasn't worked.

**JM:** So you would simply ban access to genetic information, as have a number of other European countries?

**JC:** Unless it is in the applicant's favour.

This extract reveals the respondent's desire for a legislative response to the issue. Julia Cream expresses the belief that the political response of a moratorium has proved inadequate, and that legislative action is urgently required. If we look at this account in light of Julia Cream's other statements, the implicit assumption appears to be that the insurance industry's concerns over adverse selection are unfounded, and that the equity principle, which defines private insurance contracts, is illegitimate on the grounds that it economically excludes vulnerable groups. Of

course, we must note again the conclusions of the previous chapter. The practical realities of the UK life assurance market suggest that vulnerable groups are unlikely to be affected by the genetics and insurance issue, and that the fear of widespread genetic discrimination is largely unfounded. However, the most striking statement in the above extract is the final comment that genetic information *ought to be used* if it is in the applicant's favour. This reveals the extent to which some patient-support groups consider the needs of applicants to outweigh the needs of the commercial sector. As was explained in the previous chapter, the principle of *uberimma fides* dictates that there should be symmetry between insurer and applicant regarding knowledge of the risk. If insurers are only permitted to use genetic information that benefits the client, and not information that may disadvantage him/her, then this principle is being undermined by loading the dice in the applicant's favour. If it is wrong for insurers to use genetic information to protect their own financial interests, then it is perhaps similarly iniquitous for applicants to profit from negative genetic tests. Asymmetry between insurer and policy applicant regarding knowledge of risk information is perhaps no more justifiable if it is loaded in the applicant's favour.

Julia Cream was also asked about the possible consequences of a legislative ban. The following dialogue reveals once again the priority given to a social value narrative framework.

**JM:** If a legislative ban was implemented, would you be satisfied with the insurance industry raising everybody's premium to cover the loss?

**JC:** I think the increases, from what I understand, would be negligible and that the public would be prepared to pay the tiny increase in cost. I kind of think

people are willing to pay for that. There is evidence from social surveys to suggest the public would do this.

The respondent again assumes that the financial implications of limiting insurers' access to genetic information would be marginal. She therefore challenges the legitimacy of the commercial value narrative that insists the equity principle is crucial for sustaining a private insurance market.

However, the respondent also assumes that a particular social value is widely accepted. Julia Cream expresses the belief that the public are essentially altruistic and would be willing to subsidise the vulnerable, even in a commercial insurance pool. She cites evidence from social surveys to support her claim. However, one must recognise that what people say they are prepared to do when asked by survey researchers is not necessarily a good indicator of how they will subsequently behave in a particular situation. It is not at all surprising that members of the public claim that they would be willing pay higher premiums for life assurance to enable more people to access the product. Social scientists have long recognised that individuals like to present themselves to others as caring and altruistic, even if they are motivated essentially by economic self-interest. However, purchasing patterns almost always reveal that individuals ultimately purchase the cheapest products available. The cheapest insurance products usually attract the highest number of applicants. Those companies that offer the most expensive products generally remain uncompetitive. However, it could well be that if an insurance company advertised more expensive products with the promise that they would commit to providing cover to all, regardless of risk-status, a market could emerge. Providers of free trade products, for example, have often discovered markets for 'ethical products'. Nevertheless, such markets are rarely as large as

those for standard products, and there is no evidence that ethical insurance products would attract the same interest. Julia Cream's statement simply assumes that the insurance buying public are essentially altruistic and will sacrifice economic self-interest for a greater good.

If we now compare Julia Cream's interview transcript with that of Alistair Kent, a number of interesting contrasts are revealed. Alistair Kent's account opened with the same expressed commitment to the needs of the genetically disadvantaged, thus emphasising the importance of a social value framework. He stated:

We try to promote the climate such that changes in scientific understanding spin through quite quickly into things that benefit patients. But we also try to resist the inappropriate uses of genetic technology.

From this initial statement, it appears that the respondent conceives his role to be similar to representatives of various other clinical and patient-support groups. He wants his members to enjoy the medical benefits of the genetic revolution (clinical value) but also recognises that all technologies engender positive and negative consequences, hence the stated commitment to preventing the misuse of biology (social value).

However, when asked what concerns him most about the genetics and insurance problem, Alistair Kent did not, as Julia Cream did, express an explicit anti-insurance stance and demand proscriptive forms of legislation. Rather, he stated:

The thing that concerns us most about this whole issue is the need to contextualise it. There are a number of important questions that have not been



addressed. What do we mean by genetic information? Are we talking about diagnostic information, in which case you have somebody who is currently sick or has a chronic health problem, the nature of which may be confirmed by a genetic diagnosis, but the implications for that individual are already extant. Now the question is, if that is a rare event, we're talking about a rare single gene disorder, how good is the insurance industry at dealing with things that are rare and what is the issue for them? Is there any incentive for them to look seriously at this particular situation or is the economics of it simply that it's easier to take a fairly broad brush and paint a fairly high risk scenario and judge accordingly? You get a lot of people who are saying "I've got a genetic condition and I can't get insurance, therefore it is genetic discrimination". It may be discrimination, it may be unfair, but it is not genetic discrimination. It is discrimination against you because you have an extant medical condition that the industry hasn't evaluated properly.

This account appears to recognise the ambiguity surrounding issues such as genetic information and discrimination. It appears to be critical of the simplistic stance taken by many interest groups, that genetic discrimination in life assurance is widespread. Rather than adopt the same logic, this respondent draws from a commercial narrative framework, and asks whether the existing norms and practices of commercial insurance might give us a handle on how good private insurers generally are at dealing with rare events. The primary concern expressed by the respondent is the need to contextualise the debate, and base decision-making on sound and realistic scientific evidence. Interestingly, for a representative of a patient-support group, he also appears to marginalise the social exclusion argument, as the following account reveals:

People do not seem to separate out the large number of people who are currently symptomatic and might want insurance but will probably have problems, and those people who are currently pre-symptomatic but who can reliably be predicted as going to be sick at some point in the future. Now the number of people who fall into that second category is very small, for two reasons. One, most of us are not riddled with highly penetrant genes in the absence of family history. Two, because those genes which are highly penetrant are so rare. Also, most penetrant genes manifest themselves in the individual prior to them reaching an age when insurance purchase is an issue'

In this account, 'scientific reality' is used to undermine the social exclusion argument, which claims new kinds of genetic test information will most likely rule out a large number of people from the insurance market and lead to them being socially and economically excluded. Rather than argue for the protection of at-risk patients through incumbent forms of commercial regulation, the respondent appears to believe that the social value of inclusion is best protected through good science. The following dialogue is particularly revealing.

**AK:** If the discussion was about the ability of the insurance industry to appreciate, to interpret, to use predictive medical information fairly, then we'd be having a very different debate now. The current emphasis on DNA analysis and whether the insurance industry should be allowed to have access to DNA test results, seems to us to be a distortion of the real issue.

**J.M:** So your argument would be that there is no problem with them accessing this information as long as they interpret it correctly?

**A.K:** And fairly, and appropriately. I mean if they have the DNA test result and say we are going to use this simply as a way of saying under no circumstances will we insure you for anything, then that is clearly inappropriate. But that's not the case. If you have an insurance industry selling products through a system of mutuality, then it is up to the industry to make a case for doing that, to show they are using the information in a logical and equitable way.

The respondent appears to draw from his knowledge of the insurance industry to demonstrate that the commercial practice of risk-assessment, if scientifically sound, negates the possibility of widespread genetic discrimination. The commercial value narrative is presented as justifiable if it is coherent. This represents the most crucial difference between the policy positions of GIG and the Alzheimer's Society. The latter has no faith in the existing norms of insurance provision, and believes that the inevitable result will be further unfair discrimination against the vulnerable and

excluded. GIG, on the other hand, recognise that if the industry abides by its own actuarial principles, then such a dystopian future will unlikely materialise.

However, the respondent shares with other pressure groups a commitment to the social value narrative. He does not appear to be defending insurance practices in order to promote the commercial sector. Rather, he appears to recognise the social value of a competitive insurance industry and regards this as the most appropriate means by which to help those with genetic disorders. In fact, he proceeds to argue that those who lobby for restrictions on commercial practices (by allowing insurers access only to genetic test results favourable to the applicant) may in effect engender economic exclusion.

If you have got a risk pool that is based on family history and you can declare that you're not going to get something, then you are out of that risk pool and into the population risk pool. This automatically increases the risk of the people remaining in the pool, and the assumption by the industry will be that those people who haven't come forward with tests favourable to them must have something wrong because if they didn't they would try to get cheaper rates. The question is over what population is the increased risk going to be shared. If it is only shared over remaining members of that pool then the price of the premiums will be disproportionately increased and you'll get economic exclusion; people kept out of insurance because they are poor rather than because they are genetically vulnerable. And given that caring for people with chronic health problems has a major impact on families' economies, that's likely to have a disproportionate affect on those people with genetic diseases. It's not at all simple, and it's bad to take a knee-jerk response and ban insurers accessing the information. You have to remember that insurance companies are private sector organisations with a profit-making motive, and whatever else happens they will guard that. If they don't they're out of business

This account is firmly rooted in a social value narrative framework, in which the needs of the genetically disadvantaged play a central role. However, unlike Julia Cream, the respondent sees economic exclusion as a possible consequence of over-regulating the insurance industry. The respondent also pays heed to the

commercial value narrative by recognising that private insurers are for-profit organisations that have an interest in protecting their freedom to underwrite. Whether or not commercial norms are morally right is beside the point; it is the consequences for individuals that are presented as being of primary importance. The respondent is convinced that a robust commercial sector that abides by its principles will ultimately provide protection to policy applicants, including the genetically disadvantaged. If there comes a point when the private sector cannot offer such protection, the respondent claims a public debate may be needed to decide how best to provide for their needs. By narrowing the debate to specific genetic tests, and arguing over whether to limit insurers' access to certain medical information, the respondent claims we 'might be eliminating one form of inequity but replace it with a much greater problem for a lot more people.'

The respondent favoured balanced regulation, as opposed to restrictive legislation. The following account was interesting.

You can see that legislation ends up creating a nightmare that is more likely to end up with insurance companies saying we won't sell the product because it is unprofitable. What happened in the States when there was a ban on medical insurers having genetic information was they withdrew from the market. Well, who benefits from that? You're dealing with powerful private sector organisations whose primary motivation is to make a profit

Blanket legislation is presented as being counter-productive. Again, revealed in the account is recognition that the insurance industry's *raison d'être* is the search for profit. There is an implicit message, however, that we do not have to regard insurers as philanthropic in order to recognise that their commercial values may also be advantageous to policyholders.

The accounts of Julia Cream and Alistair Kent appear at first highly polarised. However, what is perhaps more sociologically interesting is that there are many similarities in the way both respondents account for their beliefs. Both appear to prioritise a social value narrative framework, expressed as a commitment to protecting the needs and interests of the disadvantaged. The rhetoric in both accounts makes constant reference to those who may fare badly in the genetic lottery, and both representatives appear to value social and economic inclusion. Both also represent the insurance industry as motivated primarily by profit. However, one regards commercial values as anathema to the interests of those who are socially, economically, or medically at-risk, while the other regards commercial and social values as mutually reinforcing. Although both start with a similar commitment to social inclusion, each appears to frame the problem slightly differently. Subsequently, their strategies for resolution lie in discord.

Alistair Kent's account is similar to that of Sandy Raeburn, the clinical geneticist. It is perhaps no surprise that both respondents have engaged extensively with the insurance industry. Both appear to value the needs of the medically afflicted, but both also have a degree of respect for the underlying principles of insurance. Those interest groups that have been most vociferous in their critiques of insurance practices have often tried to avoid dialogue with the commercial sector.

While the comparative analysis of Julia Cream's and Alistair Kent's interview accounts illustrate how very different policy strategies could emerge from two informed and politically engaged patient-support groups that share a strong belief in a social value narrative framework, the interview with Dr. Darton from the charity

MIND gave us access to the views of a relatively uninformed and disengaged representative of an interest-based group. While organisations such as the Alzheimer's Society and GIG have spent a great deal of time and resources debating the issue and disseminating their policy positions, many smaller organisations do not have any official policy. The interview with Dr. Darton, policy officer with the charity MIND, appeared to mirror the public's ambivalence towards insurance companies.

Like the other patient-support group representatives, Dr. Darton began by explaining MIND's public role. She stated:

Well national MIND is I suppose as much as anything a pressure group and the main things people here actually do in the organisation is campaigning, raising issues, and trying to get things better for people with mental health problems.

This statement reflects, perhaps unsurprisingly, the respondent's commitment to representing the interests of those with mental health problems. Her partiality is therefore apparent from the outset. However, unlike the previous respondents, Dr. Darton admitted to knowing little about the genetics and insurance issue. Despite this, she expressed her views strongly. The marginalisation of commercial concerns, and the priority given to social/clinical ones, was again quite apparent in her narrative. Early in the interview, Darton expressed ambivalence about the power of genomics. She challenged genetic determinism, and criticised those who expound it. The respondent displayed some expert knowledge of the science of genetics, but her comments on the insurance industry were based on lay understandings, as the following dialogue revealed.

K.D: Regarding mental health, there isn't anything for the insurance industry to get a hold of. It's kind of theoretical. Supposing anything is found; you know I'm actually sceptical about whether they'll pin down genes, certainly in the near future.

J.M: Some worry that some time in the future, if there is reliable evidence to suggest a link between genes and mental health, that the industry will take an interest.

K.D: But if they're only linked, that's not good enough is it? I mean with Huntington's it's not a predisposition, it's a dead certainty. But if you've just got something that is just linked with manic depression, where does that leave you?

The respondent tries to demonstrate that commercial interest in genetic links to depression simply reflects a lack of genetic knowledge. She does not recognise that a genetic link is potentially more useful to an insurance underwriter than absolute certainty. Commercial concerns are therefore marginalised by being associated with supposed genetic ignorance. Later in the interview, the respondent linked the commercial ignorance of science to the practice of unfair discrimination. Drawing on a social value narrative, she objected to insurance discrimination because it economically excludes certain vulnerable groups. However, rather than present genetic discrimination as a potential future concern, she claimed that insurance discrimination was a current reality.

The insurance industry already discriminates horribly against people with mental health problems. People get discriminated against if they've had an episode of depression and they write it down in their insurance form, just for going abroad on holiday. It happens such a lot. I mean there is already huge discrimination. I think the insurance industry really have to demonstrate an important need to know in order to have this genetic information.

In this extract, the respondent conflates a number of issues. She begins by representing insurance as inherently discriminatory, implying again that they often

assess risk on the basis of fallacious science. People suffering from mental illness are presented as being particularly vulnerable. However, the respondent talks specifically about travel insurance, as if the type of insurance product under consideration is a trivial issue. Rather like the uninformed public, the respondent wants to express an opinion about unfair genetic discrimination in life assurance, but talks about a more general form of discrimination in the context of travel insurance. She proceeded to state:

And they are already prejudiced against people with mental health problems. They already expect to pay high premiums, unreasonably. You know, we get loads of people ringing up about it.

In this statement, the commercial practice of risk-classification is translated by the respondent into endemic prejudice against the mentally ill. 'Prejudice' is a highly emotive term, and the respondent appears to suggest that the insurance industry makes normative, rather than science-based, judgements when calculating premiums. Their standard practice of charging high-risk applicants loaded premiums is assumed unreasonable because it unfairly discriminates. The respondent proceeds to claim that insurers need to be 'educated' about mental health so that they may stop 'stigmatising patients'. Again, the commercial norms and practices of insurers are presented as being based on ignorance and prejudice. The respondent appears to be drawing from her experience working with those who have been the victims of social discrimination to make value judgements about the commercial norms of insurance. Because she starts from this social value framework, it is unsurprising that she expresses a negative view of the commercial value narrative.



The respondent's anti-commercial rhetoric became more conspicuous when she was asked her opinion on regulation.

**JM:** Do you think this is an issue that requires legislation?

**KD:** I think it probably needs legislating ... because there are always unscrupulous people ...

**JM:** Do you trust the insurance people? Are they competent enough to use the information correctly?

**KD:** uhm, no I don't think I do actually. I suspect that they're as likely to be as misinformed by the media as the rest of the population and be prejudiced. Because I do think it does engender a lot of prejudice because people think genetics is so deterministic. I think it's quite likely that a substantial proportion of the insurance industry have those sorts of prejudices as everybody else.

**JM:** Do you think their being a profit-making organisation influences this?

**KD:** Yes, Yes, I mean some of them are going to think there is money to be made out of this aren't they, and manipulate it for those reasons.

The respondent argues for legislation, because she assumes that insurers are unscrupulous and cannot be trusted to use new kinds of genetic information competently and fairly. She also assumes that insurers want to make a profit out of such information. There is currently no evidence to suggest that the insurance industry is consciously seeking to discriminate on the basis of new kinds of genetic information simply to augment its profit margins. Rather, it claims a right of access only so that it defend itself from adverse selection. Darton's antagonistic rhetoric appears to be symptomatic of broader media and interest group scaremongering, which feeds on extant public fear and scepticism.

It appears, from the interview data, that it is not only by virtue of being a member of a particular interest group that determines precisely how attitudes to this issue

are shaped and presented. Dr. Darton's account demonstrates that the level and quality of knowledge that particular individuals can draw upon in formulating their beliefs is of fundamental importance. Of course, once one has procured a certain amount of knowledge, one may use it strategically for particular social, political, or ideological ends, as appeared to be the case in Julia Cream and Alistair Kent's accounts. But within the interview accounts, it was the observable disparities in how 'informed' particular respondents were, and the extent to which they had engaged with the theoretical and social exigencies of the problem at some substantial meta-level, which was more defining of how they viewed both the substantive issues and the decision-making framework around its possible resolution. However, despite the various respondents having slightly different opinions on how policy should develop, all shared a commitment to the needs of the at-risk and couched their rhetoric within a strong social value narrative framework.

#### **4.2. Patient-Support Groups and the Policy Process**

The Alzheimer's Society has been the patient-support group most critical of the insurance industry. They have argued for legislation to abrogate insurers' right to genetic information. However, GIG has been far more pragmatic in developing their policy position. The policy statements disseminated by these organisations, and other consumer and patient-support groups, reveal the ways in which pressure groups with a particular social or political agenda can shape the policy framework.

The Alzheimer's Society released its first official policy statement in January 1999. This was in response to the Government's decision to allow the insurance industry to regulate itself rather than be subject to official legislation. The Society argued that this decision was iniquitous because it essentially legitimised discrimination. Furthermore, they protested that the inclusion of Alzheimer's disease on the ABI list of genetic diseases insurance companies have an interest in validating: '... reveals how flawed the thinking is around genetic disease.' (Alzheimer's Disease Society, 1999, 1.4) In particular, the Society claimed that this inclusion was misleading because it did not distinguish between the common form of late-onset Alzheimer's and the rarer gene-based familial form of early onset Alzheimer's. (Ibid, 1.6) According the Alzheimer's Society, this oversight aroused a great deal of unnecessary fear and anxiety. However, it could be argued that the ABI had no duplicitous intent. They were not suggesting the existence of a genetic link to the more common late-onset form of the disease. However, they perhaps ought to have made this more explicit within their document. Nevertheless, the Alzheimer's Society appeared to translate a simple oversight into endemic incompetence, or perhaps even duplicity.

The Alzheimer's Society also highlighted the 'public fear' issue by claiming commercial incompetence and lack of transparency might adversely affect peoples' willingness to participate in research trials. Here, their strategy mirrors that of those clinicians who sought to restrict commercial practices on the grounds that it may threaten genetic research. Both therefore appear to use a social and clinical value narrative to undermine a commercial one. The Alzheimer's Society argued that the voluntary nature of the ABI code of practice was simply 'insufficient to protect

consumers.' (Ibid, 3.1) Their rhetoric implied that industry self-regulation could not work because of insurers' inherent ignorance and incompetence.

The Society's own research discovered what it believed to be serious breaches of the ABI code of practice by member companies. (Cream, 2001, 7) Ideally, the organisation desired effective and formal legislation to prohibit insurance companies accessing the genetic test results of proposers for life assurance, ostensibly to protect the 'poor and vulnerable'. Over the years, they have attempted to counter all the arguments that the insurance industry has expressed in its defence of the right to use actuarially relevant medical data. In their defence, however, the Alzheimer's Society appears to have been rather more consistent in its approach than many of the official advisory committees. For example, they have conceded that genetic test information is not qualitatively different from other forms of medical data, and have therefore extended their criticisms to the general use of family history in insurance underwriting. By seeking to restrict insurers' access to all forms of genetic information, regardless of the specific method of diagnosis, the Society has at least recognised that there is 'substantial equivalence' between the various forms of diagnostic data. However, the interview data analysed in the previous chapter did reveal the ways in which particular interest groups may sometimes shift the definitional boundaries of the issue in order to render their position most coherent; the Alzheimer's society being no exception.

The principal flaw in the Society's approach does not appear to stem so much from the quality of the specific arguments they have put forward. Indeed, many have been quite valid, and the organisation has served an important role by

uncovering breaches of the code of practice. Rather, it is the apparent political and ideological intransigence of their approach, where disparities between companies in how they have interpreted a code of practice have translated into endemic incompetence or duplicity, which perhaps ought to be called into question. It appears from the Society's literature that they have set themselves up as the radical opponent of the insurance industry; an ideological position that seems to have influenced their entire approach over the past few years. Unlike many other interest groups, they have made a conscious decision not to enter into discourse with the insurance industry at any substantial level. The following dialogue from the interview with Julia Cream is interesting in this regard, as it appears to reveal the underlying logic of this approach.

**JM:** Does your society have much contact with the insurance industry?

**JC:** We have had numerous communications with the ABI and tend not to get a very satisfactory response.

**JM:** It seems that a lot of committees use GIG as the standard representative of the patient perspective, and there seems to be far less input from other organisations such as yourself.

**JC:** I guess we're involved differently. I mean the GIG is represented on the ABI genetics committee, and I guess even if we were asked we probably wouldn't accept an invitation to sit on that committee.

**JM:** Why not?

**JC:** I don't know why, I think we probably wouldn't (Laughter). I think we've been extremely effective being outside, being able to criticise the committee.

**JM:** Do you feel organisations such as GIG, by being involved in actual decision-making and talking with industry representatives, are basically allying themselves ideologically with the commercial sector?

**JC:** They've taken a much less critical line

It appears that the Society regards active dialogue with the insurance industry as counterproductive, and has instead chosen the strategy of political lobbying, which has been achieved largely through extensive dialogue with the HGC. On 23 October 2001, the Society released a rather sanguine response to the five-year moratorium negotiated by the Government and the ABI. They welcomed many of the Select Committee's recommendations, which are discussed in the next chapter. Again, the Society argued that the voluntary code of practice was insufficient to protect consumers and claimed that there was no reliable scientific evidence to justify using genetic test results for risk-classification. (Alzheimer's Disease Society, 2001) Their response also stated that the moratorium should not extend to the use of negative test results, which implies that the Society regards asymmetry between insurer and insured as more palatable if it is to the advantage of the latter. Again, the concerns of insurers appear to be marginalised while those of the applicant are given priority.

The organisation GeneWatch UK, an interest group claiming to be concerned with the social, environmental, and welfare aspects of decision-making around genetics, were far more sceptical of the moratorium decision, and characterised it in a policy statement as 'hopelessly inadequate'. (GeneWatch UK, 2001a) They argued that this system of regulation '... amounted to a step-by-step approach by the insurance industry to expanding its use of genetic tests in spite of public opposition.' (Ibid) Again, public opinion was cited as a justifiable and reliable guiding principle for policymaking. Dr. Helen Wallace, deputy director of GeneWatch UK, was quoted as saying 'This temporary agreement is a slippery

slope to creating a genetic underclass'. (Ibid.) In a previous policy statement on the issue of genetics, GeneWatch had attempted, like the Alzheimer's Society, to discredit the primary arguments articulated by the insurance industry. However, they too provided counter arguments in the absence of debate, evidence, and consideration of the broader issues at stake. (GeneWatch, 2001b) For them, anything short of a permanent legislative ban was simply unacceptable. The use of the term 'genetic underclass' is also interesting in that it highlights once again the ways in which pejorative language, with no factual basis in reality, may often be used by pressure groups to render their policy position not only logical, but also perhaps morally imperative. As has been demonstrated throughout this thesis, the possibility of a genetic underclass arising from unfair discriminatory practices in life assurance provision is minimal. The explicit suggestion that the insurance industry is consciously and pro-actively attempting to create such an underclass is perhaps illustrative of the emotive rhetoric that is often used strategically by interest groups to scare the public into accepting their own policy recommendations.

Both the Alzheimer's Society and GeneWatch, as well as various other interest groups concerned with the ostensible prevalence of 'unfair discrimination', tend to cite various international rights-based legislation as a guiding principle for how we ought to treat the genetics and insurance issue. UNESCO's *Universal Declaration on the Human Genome and Human Rights* Article 6 (1997) is often quoted in defence of stringent legislation. The Article states that: 'No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity.' (UNESCO, 1997, Article 6) Similarly, Article 11 of the Council of Europe (COE)

*Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine* states that: 'Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited.' (COE, 1992, Article 11) The fundamental problem with these kinds of formal declarations is that they are often so all-encompassing that they inevitably conflict with practical realities. The COE Convention Article 26 does recognise this, to an extent, when it states that restrictions on this right may be permitted in the interests of public safety, prevention of crime, protection of public health, or for the protection of the rights and freedoms of others. This essentially creates a reservoir of rhetorical space for legalistic interpretation, and one can conceivably envisage it being used to articulate justification for all kinds of discrimination. This essentially renders Article 11 rather impotent as a vehicle for both social and individual justice. Such conventions tend to reduce solutions to complex and intricate problems to a series of simple legalistic propositions, which then masquerade as practical ethics. Interest groups concerned with preventing unfair discrimination might do better by engaging with the social, political, and philosophical foundations of such emotive and equivocal concepts as 'discrimination' and 'social exclusion', rather than simply accept global conventions that appear to lose all power and meaning when they encounter the contradictions and nuances constitutive of social, political, and economic reality.

In contrast to both the Alzheimer's Society and GeneWatch UK, GIG has been far less adversarial in their approach to the genetics and insurance problem, and has tried to rationally debate the genuine relevance of genetic information for commercial insurance provision. Furthermore, GIG has both engaged the



insurance industry in active dialogue and participated in various committees and policy forums. Consequently, they have tended to reject proposals for an all-encompassing restriction on insurers' access to genetic information. Instead, they have sought to negotiate practical solutions that protect the genetically disadvantaged from 'unfair' treatment, but also sustain the commercial vibrancy of a private insurance market, which is recognised as an essential social institution that dispenses various social benefits.

Policy documents released by GIG have consistently expressed concerns about genetics and insurance, but the organisation has tried to avoid being ideological obstinate. For example, in their response to the GAIC consultation document, GIG concurred with the need for insurers to demonstrate actuarial relevance before requesting genetic test data from applicants. However, it also raised a variety of concerns about the technical aspects of the proposals without overtly demonising the commercial sector. For example, GIG was one of the first groups to criticise the lack of peer review in actuarial research, arguing that this was unacceptable if the validation system was to be both fair and transparent. (GIG, 2000) One reason why GIG has operationalised a very different policy approach to other interest-based groups is, perhaps, because they have actively engaged with the commercial sector and come to recognise the practical realities of insurance provision.

## **5. INSURANCE PERSPECTIVES**

The previous chapter revealed that representatives of the insurance industry may often draw from a broad narrative repertoire in order to provide moral justification for their commercial practices. They appeared to draw from a complex rhetoric around commercial, social, and clinical values, often blurring the boundaries between them, in order to give a morally adequate account of their belief in commercial freedom. The accounts of clinical and patient-support group representatives, analysed in this chapter, have revealed the ways in which other stakeholders may also use rhetoric strategically in order to render their policy position the most coherent, acceptable, and indeed logical. This section will continue to investigate the third research question, by critically analysing the complex ways in which insurers account for their concerns on the genetics and insurance issue. This will be accomplished through a focused sociological analysis of the interview data. Documentary and policy data from insurance industry interest groups will not be assessed in this section, as the work of the ABI, which is the principal representative body of insurers in the UK, will be analysed in detail in the following chapter.

### **5.1. Interview Accounts of Industry Concerns**

The principal theme revealed in the interview accounts of insurance industry representatives was the concerted attempt by respondents to morally justify the underwriting process and present themselves as competent actors able to deal with the introduction of new kinds of genetic test information. This strategy of 'presenting an image of competency', and accentuating the social value of private insurance, appeared to stem from the need to defend the commercial freedom of

underwriting. Commercial freedom had to be protected in order to defend commercial providers of insurance products from potential adverse selection. The principal concern of insurers was that the restriction of commercial freedom, through incumbent forms of legislation, might precipitate adverse selection.

Tony O'Leary's account began by establishing and defending the fundamental principles of commercial insurance. He began by distinguishing 'population mortality data' and 'insured lives mortality data'. The following account was particularly interesting.

Insured lives mortality is quite different from population mortality because a) people applying for insurance are creating a subset of the population anyway and b) people have different reasons why they apply; they could be in different groups, they could be people who are working and got money to spend on insurance, so if they are working they could be healthier because they are in jobs. There are a number of factors that come into account. Insured lives mortality is different and also better. It's better because there is an underwriting process. Why is there an underwriting process? Well, because what we have to do is take into account the reasons people might apply for insurance ... The role of the underwriter is two-fold. One is to protect against anti-selection. The other is to say if we do identify an extra risk in you then we charge you a premium that is fair. That premium has got to be fair to you, but also to other policyholders in the fund. If we don't charge you enough then your fellow policyholders end up paying more because you are getting a payout sooner than you should.

By citing the differences between insured lives and population mortality data, the respondent, perhaps unconsciously, negates the social exclusion argument. By demonstrating that the insured lives pool contains individuals who are generally wealthier and in better health than the general population, he is in effect saying that it is predominantly the middle classes who purchase life assurance. This statement supports the claim by Charles Babbage, referred to in the previous chapter, that class bias in insurance provision fundamentally affects the risk pool. To rehearse

the argument, insurance is more an institutional mechanism through which the wealthy can protect their financial interests than a means of providing social welfare to the poor and vulnerable. The use of insured lives mortality data is 'better', according to the respondent, because it offers a more precise guide for underwriting. Of course, it is worth mentioning that it is only 'better' for the commercial provider and that small subsection of the population who can afford insurance. It is of no benefit to the aspirant poor who may also desire a degree of financial security.

In stating the role of the underwriter, the respondent talked of a need to defend against adverse selection and create an equitable insurance pool in which policyholders are charged a 'fair' premium. Revealed in this account is a central 'commercial value' that only through the principal of actuarial fairness can insurance equitably distribute social goods. The implicit message is that there is moral justification in using commercial risk-assessment, because those individuals who are denied insurance are done so on the grounds of equity.

All the insurance representatives cited adverse selection as their primary concern, and each used the commercial principle of 'equity' to frame the problem.

Keith Bedell-Peace stated:

If society is going to say you mustn't use any underwriting in life assurance, you mustn't have genetic testing or any medical history, then that is fine. It just changes the rules of the game and the cost of covering everyone will simply increase.

In this account, the underwriting process is justified on the grounds that without it, there will be negative financial consequences for policyholders. The commercial freedom to underwrite, and therefore make a profit, is presented as 'good' (equitable) for the average policy applicant with no extant medical condition or at-risk of some future malady. However, the respondent also tries to defend the freedom to underwrite on the grounds of 'societal good', as the following account reveals:

If you're providing motor insurance and you're not allowed to ask medical questions, are you going to put society at risk by providing insurance for someone who has got a newly developed syndrome of epilepsy? There are no black and white answers.

Here, risk-assessment is presented as a moral imperative. Within this narrative framework, underwriting serves to protect society from individuals with dangerous medical conditions. Again, a social value narrative is presented in such a way as to defend the existence of particular commercial values. The respondent continued to talk about how the industry looks at the issue of genetic information from a technical angle. The following account reveals that insurers initially regarded the use of genetic test information as not only appropriate but indeed practical. Bedell-Pearce stated:

I think actuaries and underwriters thought, actually this is a more precise tool than just going through the family history, and therefore it's a good thing. They had no difficulty convincing themselves that given a negative genetic test leads to a better underwriting decision than in the absence of one, by and large they were improving the lot of society rather than diminishing it.

This statement offers an interesting insight into the actuarial profession. For them, the issue is conceived as purely technical. Genetic tests improve underwriting, thus life assurance provision inevitably becomes more equitable. The consequence is that genetic test information is inherently a 'good thing' for the industry, and subsequently for society as a whole, because it improves actuarial decision-making and renders the process of distributing social goods more efficient. Of course, it must again be recognised that because wealthy, low risk individuals are likely to benefit most, talk of 'good for society' is perhaps a little sanctimonious.

Having presented the principal concerns of the industry, and defended existing commercial norms, the insurance representatives then attempted to project an 'image of competency'. Because a number of interest groups have accused the industry of being incapable of using the new information fairly and accurately, the industry has tried to counteract these accusations and present at least a veneer of competency. Tony O'Leary stated that the insurance industry has always had to adapt as new scientific and technological developments emerge. He said:

If you look back twenty or thirty years ago, if you'd had a kidney transplant it was difficult to get insurance cover because the risk was unknown. But the insurance industry followed the developments in medical science and now it is easy to get cover ... So the natural way the industry has gone is that if something new comes along initially it is difficult to provide cover, but as medical science learns and mortality improves, the insurance industry watches that and then say look we have come up with some terms for short-term policies and then gradually long-term policies. And I think the 5% figure of people who pay an extra premium and the 1% who can't get cover is a fair testament to this working. With genetic information we have to think about how we will handle it, and we apply the same principles.

In this account, the respondent concedes that it can take time for insurers to respond to new scientific and technological developments, because at first there is

a great deal of unknown risk. However, it is also stated that the industry is highly adaptive, and its standard norms and practices allow for technological progress. The sub-text appears very much to be 'there is no problem with new kinds of genetic test information' and 'the industry's competence should be in no doubt'. In order to qualify this opinion, the respondent refers to the case of Huntington's disease. He uses this case as an exemplar of how the industry has learned to deal competently with novel genetic testing. It is perhaps convenient for members of the insurance industry to cite the case of Huntington's, because it is relatively simplistic in science and insurance terms. It also has the additional benefit of being a genetic test that can rule people into insurance as well as out of it. It is an example often referred to by insurers when they are trying to defend prevailing commercial values, as it can quite easily be used to marginalise fears of social and economic exclusion and give extra strength to the commercial value narrative framework.

All the insurance representatives shared a belief in the legitimacy of insurance underwriting. All similarly protested against what they considered the widespread ignorance of actuarial science and the norms of insurance provision. The anonymous insurance underwriter stated:

People talk about insurance too generally, and don't distinguish between term assurance or whole life, or any of the other disability or illness related products set up beneath that banner. Life assurance is simplistic, it's easy to underwrite and the whole thing is simple. It's the next layer down that contains all the complexity.

This respondent appears to try and marginalise the fear that social and economic exclusion will inevitably occur if genetic test information is used to underwrite

insurance policies. The subtext of this account is that the focus of interest groups, the media, and politicians on the *problem* of life assurance and genetic information, reflects only their ignorance of commercial norms. Just as the clinicians sought to protect their autonomy and expert status by labelling insurers scientifically ignorant, the insurers similarly imply that those outside the industry are ignorant of actuarial science and the norms of the insurance business. Perhaps they too are trying to create a discursive boundary between themselves and those who want to abrogate their commercial freedom.

The anonymous insurer continued on the theme of public ignorance when he sought to challenge the legitimacy of public fears. He claimed that people generally have false expectations of what insurance companies can provide for them. He cited an example of a butcher who had a critical-illness policy. The man cut his finger, claimed under total and permanent disability, and expected to receive from the insurer about thirty thousand pounds because he had to take four weeks off work for a lacerated finger. The respondent stated:

If I was a man on the street, would I think that the insurance company would pay me thirty thousand pounds because I cut my finger? If that situation exists then it's a real perception that the insurance industry has to address. And its got to look at its product design and say God this is too complicated; how can the average person on the street understand that. Because there is emotion involved in giving insurance, but it's ten times worse when you claim and have the claim turned down.

The respondent expresses the belief that public ignorance is creating false expectations. There is also the implicit assumption that growing concerns over the commercial practices of insurers may be being fuelled by these false expectations. His candidate solution is to 'educate the public' and simplify insurance policies so



that people may develop a more balanced and informed view of the insurance industry. Tony O'Leary countenanced this view when he argued that the industry needs to 'get its message across to the public' and explain to people the basic underwriting process. However, he also stated that the social and moral issues should not ultimately be the responsibility of the insurance industry, as the following account made clear.

What about the moral and social issues? What are the concerns for people with regard to healthcare and long-term care? I think these are tremendously important issues that should be addressed but they are not insurance issues. The political parties should put into their manifestos that we can't keep the health service going as it is, we can't cover everybody for long-term care and protect everybody's financial security, this is how we will deal with it. Now they say we either do it through taxation or some other means, but that is a public sector debate. At the moment the debates over here in the private sector and people are saying we're scared about the future; we have a right to insurance. But insurance is not set up on that basis, it is set up as a commercial situation. There's no compulsion for people to take out insurance. If there is compulsion it changes the game completely. But when there is no compulsion the private sector cannot be expected to carry the extra costs of protecting everybody.

This account is very much rooted in the idea that insurance companies ultimately exist to make a profit, and therefore they should not have the responsibility for mitigating social and economic exclusion. The respondent appears to be trying to avoid responsibility when he claims the Government should be open and transparent about its long-term plans. A commercial value narrative framework is again central to the account. The complex and messy world of social values, ethics, and moral responsibility is presented as a problem for others to resolve.

The respondents' accounts of how best to tackle the issue of genetics and insurance again appeared to reflect their professional situatedness. All resisted the suggestion of a legislative response, claiming that fears of a genetic underclass

emerging were unfounded, and that the principle of a 'right to underwrite' should not be undermined. Bedell-Pearce claimed:

The thing that worries me most is that statutory interventions is that those that are made in haste in developing scientific and technological areas are very difficult to overturn and may actually work against the interests of society.

This account rejects legislation as a candidate solution, but rather than couch the argument within a commercial value framework, the respondent talks about a broader threat to society and its underling values of economic inclusion and access to social goods

Overall, the insurance industry representatives used similar strategies to other interest groups and stakeholders when accounting for their concerns. They prioritised one or another value narrative (predominantly a commercial one), and constantly tried to undermine the beliefs and opinions of other groups and professional bodies. However, just as was revealed in the previous chapter, they also drew on a broad narrative repertoire; shifting the boundaries and conceptual understandings of social, clinical, and market values. Various configurations of these values could be used strategically to marginalise the legitimacy of an anti-commercial rhetoric and trivialise public fears of social and economic exclusion. In so doing, the interests of the commercial insurance industry could be implicitly prioritised and presented as socially, morally, and commercially legitimate.

## **6. CONCLUSION**

This chapter has, through an extensive sociological analysis of the interview data and policy positions of specific stakeholders, sought to provide some answers to the third research question. It has been revealed that relevant stakeholders in the genetics and insurance debate employ a variety of rhetorical strategies, and draw on a broad narrative repertoire, when giving account of their beliefs and opinions on the genetics and insurance issue. The prioritisation or marginalisation of particular substantive issues or values also appeared to be dependent on respondents' broader political or professional values. It appears that key stakeholders have attempted to frame the issue, and disseminate their opinions on how best to resolve it, in a way consistent with where they find themselves professionally or ideologically situated. Clinicians tended to be ideologically wedded to the clinical value narrative; prioritising the needs of patients and marginalising the rhetoric of commercial freedom. Patient-support groups used a similar strategy by prioritising the social needs of the vulnerable and economically excluded. Insurers generally used a rhetoric of commercial freedom, although they did envelop this within a social value narrative framework in order to give their account a degree of moral legitimacy. Nevertheless, all respondents, regardless of where they were ideologically situated, at times drew on all three value narratives in order to justify their particular position. Clinicians and patient-support groups often conflated social and clinical values, while insurers frequently advocated commercial values on the grounds that they supported particular social and clinical ones.

It must be recognised, however, that not all representatives of the same professional constituencies expressed shared ideological beliefs and concerns.

Neither did they use exactly the same narrative strategies to legitimise their candidate solutions. The contrasts between the GIG and the Alzheimer's Society were revealing in this regard. However, even in this case, both respondents appeared to prioritise the social value dimension by revealing their deep commitment to the interests of the at-risk. The contrast between Sandy Raeburn's account, and other representatives of the clinical community, also revealed alternative strategies for resolving the genetics and life assurance dilemma. Raeburn appeared to recognise that the best way to protect patients was to sustain a competitive, evidence-based system of underwriting. The other clinicians intimated that it might be necessary to impose restrictions on the 'business of discrimination' narrative in order to ensure at-risk patients could enjoy the clinical benefits of the genomics revolution.

It appears, despite some anomalies in the accounts, that relevant stakeholders and professional groups have a relatively fixed idea of how the issue should be conceptualised and resolved. They then appear to use rhetoric strategically in order to make their position appear the more logical, balanced, and equitable. In so doing, the relevant protagonists may become more ideologically and professionally dissonant. One consequence of this may be that it becomes increasingly difficult for politicians, and the broader public, to fully understand the complex exigencies of the problem and reach fair, evidence-based policy solutions. If narrow interests and values constantly impinge on the policy process, it becomes far less likely that informed and pragmatic decision-making will materialise. The fact that certain interest groups appear to marginalise or prioritise certain substantive issues, and reduce a complex problem to interest-based conflict, may problematise attempts to

establish equitable and rational policy on this issue. By revealing some of the ways in which stakeholders and interest groups have tried to narrow the conceptual framework of the debate, and expressed a variety of stories based on their professional situatedness, this chapter has laid the groundwork for a critical assessment of the formal policy and regulatory process. This chapter has focused on the third research question. The following chapter will build on the analysis presented here and investigate the political process that has enveloped the genetics and insurance debate. It will provide answers to the fourth and fifth research questions.

## CHAPTER 4

### GENETIC INFORMATION AND LIFE ASSURANCE IN THE UK: A CRITIQUE OF THE FORMAL POLICY AND REGULATORY PROCESS

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#### 1. INTRODUCTION

The previous chapter critically analysed the accounts of key stakeholders as they expressed their concerns about the genetics and insurance issue. The various 'stories' they told revealed a deep sociological complexity. The data appeared to confirm the hypothesis that interest groups will draw on a broad narrative repertoire, when accounting for their beliefs, in order to render their particular position morally adequate and consistent. This chapter will build on the previous analysis and evaluate the formal policy/regulatory process. It will provide answers

to the fourth research question by assessing how equitable the policy process has been in the UK. This chapter will also provide a response to the fifth research question by assessing the impact public opinion, and media representation of the issue, may have had on the strategies of key stakeholders and the decision-making bodies.

Section 2 will offer an in-depth sociological analysis of the formal policy process. A critical examination of the work of various advisory and regulatory bodies, which culminated in the Government endorsing a five-year moratorium on the use of genetic tests by insurance companies, will reveal the extent to which the decision-making process has privileged political expediency over rational, fair, and evidence-based policymaking. A brief history of the policy process will be provided, followed by an extensive critical examination of the central regulatory bodies. The focus will be on how robust and equitable this process has been. A lengthy analysis of the House of Commons Science and Technology Committee Report, for instance, will enable us to assess the extent to which political representatives differentially judge the legitimacy of stakeholder evidence. Might the politicisation of genetic technology and its social applications undermine effective deliberation on this issue? This section will provide answers pertinent to the fourth research question.

Section 3 will investigate how relevant stakeholders have judged the equity of the policy process. Interview accounts will reveal whether stakeholders confer greater legitimacy to those organisations that they perceive to support their ideological/political beliefs. Are stakeholders selective in which advisory committees and policy reports they are willing to endorse, and have insurers been

forced to 'play the game of politics' in order to ensure that their interests are recognised by the political community?

Section 4 will assess the influence public opinion and the media have had on the nature of the policy process and the strategies of key stakeholders. The various surveys and polls that have sought to reveal the 'public attitude' will be challenged for their failure to recognise the crucial difference between an 'informed' and 'uninformed' public. This point, it will be argued, may have serious implications for the equity of policymaking on this controversial issue. This section will provide an answer to the fifth research question.

The final section will consider the efficacy of the five-year moratorium decision, in light of the data provided. Does the moratorium provide the best opportunity to resolve this issue equitably, or might it have undermined the possibility of lasting consensus by failing to recognise the deeper underlying issues of the controversy?

## **2. POLITICS WITHOUT REASON? A CRITICAL ANALYSIS OF THE FORMAL POLICY PROCESS**

### **2.1. A Short History of Regulation**

The present status of the genetics and life assurance issue in the UK is that a five-year moratorium is in place, which restricts commercial insurers' access to the genetic information of individuals applying for policies under £500,000. This moratorium is due to end in October 2006. The moratorium decision was reached



after eight years of governmental and non-governmental advisory committee investigations and industry self-regulation. The 1995 House of Commons Science and Technology Select Committee report, entitled *Human Genetics: The Science and its Consequences*, was the first official governmental report to highlight the potential significance of genetics for access to insurance. The report criticised the insurance industry for having failed to recognise the problem and develop an adequate policy position.<sup>1</sup> It recommended that the insurance industry be given one year to propose an equitable solution. The report also suggested that a statutory Human Genetics Commission be established, with a dual remit to monitor developments in genetics and advise the Government on how it should deal with the emerging issues.

The Association of British Insurers (ABI), an umbrella organisation representing the majority of UK insurance companies, responded to the report by drafting a code of practice. The ABI instructed its members not to compel applicants to take a genetic test as a prerequisite for obtaining insurance. Members were also informed that they could use the results of genetic tests applicants had already taken, only if the newly appointed ABI genetics advisor had validated such tests as actuarially and scientifically relevant and if the applicant were seeking a policy over £100,000 that was not attached to a mortgage. (ABI, 1997a) This code of practice was essentially a self-imposed moratorium on the use of genetic test results. The code

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<sup>1</sup> In 1993, the Nuffield Council on Bioethics released a report entitled 'Genetic Screening: Ethical Issues'. Part of this report raised the issue of genetics and insurance. However, the report stated that because genetic testing was still in its infancy, it was unlikely to pose a significant and immediate problem in the context of insurance. It recommended that the insurance industry continue with their policy of not requesting people to take a genetic test as a prerequisite for acquiring life assurance, and hoped the commercial sector would maintain general standards of 'good practice'. The report did raise the possibility of future ethical dilemmas but was not too concerned with the insurance industry's policy position at that time. The insurance industry itself did not believe the issue required immediate attention, because they were not using new kinds of genetic tests at the time, and realised that greater scientific understanding was required before they could even consider it.

was updated in 1999 (ABI, 1999), when another two-year non-statutory moratorium was put into effect.

The Government's response to the Select Committee report was to establish the Advisory Committee on Genetic Testing (ACGT) and the Human Genetics Advisory Committee (HGAC). Although the ACGT was inaugurated as a non-statutory body, its initial remit was to investigate a broad range of issues related to genetic testing and establish 'good practice' guidelines for providers of genetic testing services. The two official documents it released were only marginally relevant to the insurance issue. The first document was a code of practice for organisations that deliver genetic testing services direct to the public. The code dealt with issues such as confidentiality, informed consent, and genetic counselling (ACGT, 1997). The second document was a report on the use of genetic testing for late-onset disorders. This report discussed a variety of pertinent social, scientific, and ethical issues. (ACGT, 1998)

The HGAC also published two reports; one in 1997 on the implications of genetic testing for insurance (HGAC, 1997), and a second in 1999 on the potential implications for employment. (HGAC, 1999) The report on insurance recommended a two-year moratorium on the use of genetic information by life assurance companies until specific genetic tests could be validated. The HGAC developed a criterion for validation that included demonstration of actuarial relevance. Although the HGAC welcomed many of the ABI initiatives, they argued that the ABI's general policy position was insufficient to meet the wider concerns in the area. Although the HGAC did not consider it appropriate to entirely ban insurers from using new kinds

of genetic information, they did not believe insurers should have unlimited and unquestioned access. The HGAC also recommended that an independent mechanism for genetic test validation should be negotiated between the Government, the insurance industry, and the HGAC.

In November 1998, the Government responded to the HGAC report (Office of Science and Technology, 1998). However, they did not accept the recommendation of a moratorium, because they believed the ABI code of practice at that time provided sufficient protection for consumers. Moreover, the Government felt that the insurance industry had made significant progress, through consultation with the genetics community, developing a robust validation system, which was overseen by Professor Sandy Raeburn. However, it did accept the need for an independent validation process, so the Genetics and Insurance Committee (GAIC) was established. In October 2000, the GAIC validated the Huntington's disease test, which heightened public fears and amplified the concerns of many interest groups. The Human Genetics Commission (HGC) was also established in May 1999, and the work of the ACGT and HGAC was transferred to this new advisory body. It is important to recognise the lack of continuity, both in organisational structure and membership, within many of these formal committees. Subsequently, there is always the possibility that such committees will establish a narrow and myopic decision-making framework and focus only on short-term goals. The following section will assess whether this was the case here.

The HGC released its interim recommendations in May 2001 (HGC, 2001a), based largely on data that emerged from its public consultation exercise. (HGC,

2000) It recommended a three-year moratorium on the use of genetic tests for policies under £500,000. It argued that the current system was ineffective, drew attention to the public fear issue, and concluded that it was important to establish a 'clear' and 'defensible' regulatory system that can both balance the interests of stakeholders and promote public confidence. A House of Commons Science and Technology Select Committee fifth report (2001) also accused a number of insurance companies of breaking the ABI code of practice. Subsequently, it questioned the legitimacy of industry self-regulation and recommended a two-year moratorium on the use of genetic tests. The Select Committee threatened that if the insurance industry did not implement this new moratorium then Government intervention would be forthcoming. The ABI confirmed on 1<sup>st</sup> May 2001 that it would extend the moratorium for a further two years and would not request test results from applicants seeking policies up to a value of £300,000. (ABI, 2001a) In October 2001, the Government responded to the various reports (Department of Health, 2001a) and negotiated with the ABI a new moratorium that would last five years and provide protection for those seeking life assurance policies up to a value of £500,000. Furthermore, applicants for a variety of other insurance products, such as critical-illness, income-protection, and long-term care insurance, would be protected when applying for policies under £300,000.

This complex and multifaceted issue, as the number of official bodies considered necessary for overseeing its regulation testifies, appears to be both politically and ideologically embedded. One might ask if the political arena exists principally as a site for ideological and political conflict, where stakeholders and interest groups can frame the issue in their own terms and use ideological rhetoric to shape the policy

process. Broader concerns and fears invoked by genetic technology's unrelenting growth perhaps attune us to the capricious nature of the formal policy/regulatory framework, which often reveals itself more as a site for the expression of ideological rhetoric than a mechanism for fostering rational deliberation and consensus. The following section will now provide a more in-depth analysis of these relatively autonomous policy and regulatory authorities, so that we can begin to assess how progressive and equitable the general process has been.

## **2.2. The Central Regulatory Bodies**

In their ideal formulation, the various advisory committees and regulatory bodies are supposed to impartially investigate the full complexities and subtleties of the issue, and impartially consider the diversity of conflicting perspectives expressed by key stakeholders. This section will provide a sociological analysis of the formal regulatory and policymaking bodies so that we can evaluate their effectiveness and provide some answers to the fourth research question.

### **2.2.1. Association of British Insurers (ABI)**

The ABI is the only non-governmental organisation with direct regulatory authority over the insurance industry. It is also the primary representative of the insurance industry and its commercial interests. The organisation's general approach to the genetics and insurance issue appears in many ways to have been reactive. It appears to have been placed in the unenviable position of having to constantly re-negotiate its policy position as unrepentant criticism from outside

authorities and interest groups has been directed against it. Analysis of key ABI policy documents reveals the organisation's use of two very different strategic responses. One response has been to prioritise a commercial value narrative framework in order to defend insurers' 'freedom to underwrite'. A second response has been to acquiesce to the stringent demands of critics by recognising the importance of both social and economic inclusion, and public confidence. This strategy appeared to be the one most frequently deployed.

The publication of the ABI's first code of practice<sup>2</sup> was a strategic response to the severe criticisms that the insurance industry received from the 1995 House of Commons Science and Technology Committee. This code established minimum standards of 'good practice' for insurers dealing with new kinds of genetic information. The most important directives within the code were as follows:

1) Applicants must not be required to take a genetic test as a prerequisite for obtaining life assurance. (ABI, 1997a, Paragraph 2)

2) Until the GAIC is established, members may only factor in those tests already taken by an applicant if they have been deemed actuarially and scientifically relevant by Prof. Sandy Raeburn, the ABI genetics advisor. (Ibid, paragraph 4)

Prof. Raeburn formulated the ABI's criteria for genetic testing, which would later be used as the conceptual framework for genetic test applications to the GAIC. The ABI also established the Genetics and Insurance Forum as an online public

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<sup>2</sup> A revised code of practice was published in 1999, which took into account the transference of the role for evaluating genetic tests from the ABI genetics advisor to the GAIC. The confidentiality guidelines were also re-written to take into account the Data Protection Act 1998. (ABI, 1999)

resource providing important information on the industry's position. The testing criteria were published on this site. (Genetics and Insurance Forum, 1999)

3) Insurers must not offer lower than standard premiums to those applicants with negative genetic test results. (Ibid, Paragraph 38) The inclusion of this directive was rather surprising, since insurers have always sold 'preferred lives' policies. Nevertheless, the ABI might have considered this a pragmatic and commercially acceptable compromise. The lack of any reliable genetic tests would have made 'cherry picking', as it is known in the industry, at that time impractical. The ABI conceded that the philosophy underpinning this proscription deviated from standard commercial practice. However, they argued that 'insurers consider it necessary to allay public concern that an uninsurable underclass may develop.' (Ibid)

4) No medical information may be obtained from an individual's medical practitioner 'without the applicant's prior, explicit, informed consent.' (Ibid, Paragraph 14) This part of the code was rather ambiguous, because it did not specify whether consent would permit insurers access to the entire medical record or only certain sections of it. Furthermore, the power of informed consent may be rendered impotent if refusal of disclosure results in the applicant being denied insurance.

5) The code states that: 'Existing Genetic Test Results need not be disclosed in applications for life assurance up to a total of £100,000, which are directly linked to a new mortgage for the purchase of a house to be occupied by the applicant ... if an applicant chooses to disclose the result, it must be ignored unless it is in the applicant's favour.' (Ibid, Paragraph 31) This restriction would protect the majority

of applicants who require life cover in order to purchase a mortgage. By imposing this restriction, the ABI implicitly recognised mortgage-related insurance products as important social goods. The directive to use genetic test results only if it is to the applicant's advantage appeared to be another compromise on standard commercial practice. This perhaps illustrates the industry's desire to present itself as socially responsible.

A number of interesting sociological insights emerge from the ABI code of practice document. The careful use of rhetoric suggests that the organisation was attempting to strike a balance between social and commercial values. In particular, the ABI appeared to recognise the need to create a code conducive to both social prosperity and commercial expediency. The most striking feature of the code was the extent to which the ABI seemed willing to compromise on the existing norms and standards of insurance provision. Why would an organisation that represents the interests of the insurance industry willingly undermine commercial values? The interview data presented in chapter 2 suggested that insurers ultimately prioritise a commercial value narrative framework. One needs to ask whether the ABI's motive for promoting a 'rhetoric of social inclusion' was also perhaps economic in nature. The ABI knew that the science of genetic testing was still in its infancy and was therefore of little use to life assurance underwriters. Therefore, they could compromise on commercial norms and values without suffering financially. Indeed, by stating publicly that they would not use such tests as an underwriting tool, they may have been trying to reduce public fears and placate the sceptics who were questioning their ability to establish a fair and pragmatic process of self-regulation.



A conspicuous feature of the code of practice was the absence of rhetorical space dedicated to promoting the insurance industry's 'right to underwrite'. There was also no defence of the argument that 'genetic information' is substantially equivalent to other forms of medical data, and therefore may not deserve 'special' attention. Even in paragraph 24, where the code states that private insurance cannot meet the needs of everybody and some individuals will always find themselves uninsurable, this is qualified by the statement: 'The industry is willing to discuss with interested parties the public-private interface and the potential for extending cover in a way which is consistent with sound commercial practice.' (Ibid, Part 6, Paragraph 24) This statement attempts to square the commercial norms of risk-assessment (discrimination and exclusion) with the social value of economic inclusion. Although commercial values are promoted, they appear to co-exist with an explicit social value narrative.

However, in a policy statement also published in 1997, the ABI did express concern over the possibility of adverse selection. It stated: 'In the absence of full and accurate disclosure of information, proper evaluation of risk cannot take place. Insurance companies could be "selected against".' (ABI, 1997b, 1) In this document, the ABI appeared to draw on a commercial value narrative framework in order to defend existing insurance practices. Nevertheless, the ABI were keen to point out that they did not wish scientific progress to be undermined by public fears that commercial insurers would misuse genetic information. They appeared to recognise the concerns of scientists and clinicians but claimed that because genetic testing is not yet prevalent, it is impossible to predict the precise impact of genetic information on the future provision of insurance. The ABI promised to

collect data on the genetic tests received from applicants (but not use them as an underwriting tool) and therefore accumulate some evidence-based knowledge to inform future policy and debate. They also provided assurance that such data would remain confidential. (Ibid, 2)

Until 2001, when a variety of advisory committees and interest groups began to question the system of industry self-regulation, this code of practice, and its self-imposed moratorium, provided the only effective control over the use of genetic information by private insurers. However, in response to criticisms made by the House of Commons Select Committee, the ABI Director General, Mary Francis, claimed:

'The insurance industry will consider the Select Committee's report very carefully. We recognise how much public concern there is about the way genetic information is used – whether by government, the police, employers, insurers or others.' (ABI, 2001a)

Despite insisting that genetic information cannot simply be ignored by underwriters, the ABI did express the need to consider the status of the self-imposed moratorium, which was about to end. They intimated that conciliatory talks with the HGC, consumer groups, patient-support groups, and medical experts would be essential if any constructive progress were to be made. However, the ABI also accentuated the advantages a flexible, self-regulatory framework had over the permanence of formal political legislation. This latter point is perhaps fundamental to our understanding of the ABI's general approach of compromise. The fear of government intervention may have compelled the ABI to act in a socially

responsible way. By negating certain commercial values in the short-term, they may have been attempting to pre-empt future legislation. If the ABI appeared intransigent to certain regulatory restrictions, the Government might have considered it necessary to intervene with formal prohibitory legislation. From this perspective, it was perhaps in the industry's interest to appear quiescent.

In May 2001, the ABI confirmed that the moratorium would be extended for a further two years. (ABI, 2001a) Again, Mary Francis accentuated the public concern issue and called for calm and rational discussion. She hoped that the moratorium would 'provide a period of stability while new and more permanent arrangements can be put into place.' (Ibid) In October 2001, the Government published their response to the issue and a new 5-year moratorium was negotiated with the ABI. This moratorium did not significantly improve on the one preceding it, would in reality provide little extra protection to the 'genetically disadvantaged', and little closure had been made in trying to resolve the underlying issues. Nevertheless, there was optimism that lasting consensus could be achieved during the new moratorium.

A compliance report published by the ABI on 23 October 2001 reveals how insignificant genetic test information is likely to be in the context of insurance. This report listed all genetic test results received by insurance companies bound by the ABI code of practice. In 1999, the total number of tests disclosed to insurance companies was 239. In 2000 this rose to 328. Furthermore, 106 of those tests in 1999, and 135 in 2000, were already prohibited by the ABI. Of those tests that insurers were entitled to use, few led to an adverse underwriting decision. The

report concluded by affirming that all member companies were adhering to the code of practice, and that some were implementing policies that transcended the minimum requirements set by the ABI. (ABI, 2001d) This report provides further evidence that the social and commercial implications of genetics for life assurance are likely to be minimal, which supports the conclusions of chapter 2.

Despite the fact that life assurance companies currently receive few genetic tests with applications, in January 2001 the ABI commissioned Dr. Tony McGleenan, a member of the Law school at Queens University in Belfast, to assess the general impact of genetic information on the insurance industry. In the subsequent report, the public concern issue was a central theme. After insisting that no valid conceptual distinction could be made between genetic information and other forms of medical data, the report stated:

'...the popular and political perception appears to be that there is an important difference. In the absence of change in these perceptions insurers ought to make plans to deal with public policy interventions based on the argument that molecular genetic information is categorically different.' (ABI, 2001e, 5.1.2)

Despite recognising that there was no scientific justification for asymmetrical treatment of various categories of medical data, the ABI decided to act *as if* certain kinds of genetic information were qualitatively different in order to inspire public confidence and escape criticism.

Part of the report did defend the industry against accusations of practising 'unfair discrimination' and endorsed the idea of a 'right to underwrite' as a defensive shield

against adverse selection. The report also advanced the rather spurious argument that a policy aimed at prohibiting actuarially relevant genetic test information, on discriminatory grounds, might end up encouraging the use of indirect rating by proxies. It stated:

'Studies suggest that if restrictions on underwriting are introduced in an effort to prevent discrimination then the competitive pressures of the market may lead to the use of proxies which actually increase inequality through inaccurate classification.' (Ibid, 4.1.3)

This was a rather erroneous defence of the right to use genetic information, and one that could only have a negative impact on the socially responsible image that the industry has strived to foster. This statement mirrors the themes and strategies revealed in the interview accounts. The narrative framework is shifted in order to provide justification for protecting particular commercial values. The ABI, like the interview respondents, use a variety of rhetorical strategies, and draw upon a broad narrative repertoire, in order to provide moral justification for their commercial position.

The work and progress of the ABI appears to have been defined by political expediency; that is the need to balance commercial values with the putative economic needs of society. They were essentially forced to accept a regulatory system by increasing public fears of a genetic underclass. Although they have attempted to counter many of these fears, and justify commercial insurance on the grounds of the social benefits it distributes, they have also striven to be sensitive to public concerns. The ABI's strategic approach reflects the fact that policymaking

processes around controversial science and society issues tend to compel stakeholders to 'play the game of politics' in order to have their interests recognised. Insurers, like all stakeholders, must shift the definitional and conceptual boundaries of the issue, in specific social contexts, in order to express a morally adequate account of their position. In doing so, the deeper and more nuanced roots of the problem may be neglected or marginalised, and policymaking might become defined not by the quality of evidence but by the persuasive force of rhetoric. The evidence so far seems to support this hypothesis.

Although the ABI may have been forced to marginalise their commercial interests on the grounds of political sensitivity, there have been other organisations and debate forums where the industry has been permitted to defend its commercial rights more openly. One such organisation has been the UK Forum for Genetics and Insurance (UKFGI). The organisation was established in 1999 to encourage discussion amongst various stakeholders (physicians, geneticists, social scientists, actuaries, underwriters, and insurers). In formulating a response to an HGC consultation document, UKFGI criticised the way genetic information had been so narrowly defined and requested clarification on the nature of 'unfair discrimination' and its conceptual boundaries. It also questioned the distinction made between genetic test information and other forms of medical data. (UKFGI, 2001a) The actuarial profession also critiqued the HGC's consultation document for its parochial approach. In their response to the HGC, the profession called for a broader debate on the 'social good' aspect of insurance and defended the process of risk-classification. (Faculty and Institute of Actuaries, 2001) A one-day conference held at the Royal Society in 1999, organised by UKFGI, provided an

opportunity for the actuarial and insurance profession to disseminate their concerns and offer their professional insights openly and constructively. (UKFGI, 1999)

Nevertheless, despite the existence of various committees and forums that have allowed insurers to express their concerns and defend their interests, the ABI has clearly had to play a political game in order to represent itself as socially and morally responsible, fair, and equitable in its commercial activities. It may have been rendered impotent as a forceful lobbying group by a policy/regulatory framework that has coerced it into defending specific kinds of social values, and forced it to establish policy positions that serve only to inspire public confidence. If the process had been truly open and equitable, perhaps the ABI would not have felt it so necessary to marginalise its concerns in public documents.

### **2.2.2 *The Genetics and Insurance Committee (GAIC)***

The primary role of the GAIC was to validate specific genetic tests for insurance purposes; thereby introducing a degree of 'scientific reality' to the regulatory process. Because the ABI had a stake in the outcome of any validation process, policymakers decided to transfer responsibility from the ABI to an autonomous GAIC. There was an implicit assumption that insurers could not be trusted to make sound and equitable decisions, and that the maintenance of public trust ought to take precedence over the interests of industry.

The GAIC tried to introduce a mechanism of validation based on sound scientific and actuarial evidence. It proposed that insurance industry applications to use specific genetic tests satisfy minimal requirements in three substantive areas. The first area concerned 'clinical impacts'. GAIC demanded that: 'A reasonable body of current medical literature should support the extent and variability of the clinical impact.' (GAIC, 2000a, Note 1, 10) Furthermore, the GAIC stated that applications must demonstrate understanding of the natural history of the condition for which the genetic test relates, such as. age-of-onset and variability of clinical effects, and provide any evidence of medical interventions that may mitigate the clinical effects, expected morbidity, and survival probabilities. (Ibid, Note 3, 12)

The second area referred to 'scientific and technical test standards'. GAIC demanded all applications include any evidence relating to the types of identifiable mutations associated with the test and their proportions in affected individuals. Furthermore, any technical flaws found to be associated with the genetic test had to be referenced.

The final area was concerned with the 'actuarial relevance' of the genetic test. The insurance industry had to demonstrate the actuarial relevance for *each* insurance product that they wanted to apply the information to. The notes stated:

'Evidence to support a case for actuarial relevance should normally take the form of an actuarial investigation of the additional mortality and/or morbidity risk (as appropriate) associated with the relevant genetic test results or combination of genetic test results with other factors.' (Note 8, 17)



It is important to note that although the insurance industry was not required to provide peer-reviewed evidence in support of their case for actuarial relevance, this was a strict requirement for the clinical impact and scientific test standards criteria. One reason for this asymmetry in the requirements may have been that very little actuarial data is peer-reviewed. However, if the intention was to have a fair and equitable validation process, the same procedural standards perhaps ought to have applied equally to each of the three requirements.

The above criticism notwithstanding, the GAIC had at least tried to implement a comprehensive set of evidence-based procedures to reduce the possibility of insurance companies misusing genetic information and engendering 'unfair' forms of discrimination. However, the GAIC defined genetic information narrowly and equivocally as 'a test to detect the presence of or absence of, or change in, a particular gene or chromosome.' (Ibid, Annex B, 1.1, 25) Although they did not, like the various stakeholders and interest groups, shift between an extended and restricted definitional framework, the GAIC did appear to exclude from their remit various other forms of clinical diagnosis and testing. A number of other tests do exist that could equally disadvantage proposers for life assurance. Furthermore, because the remit of the GAIC was limited to the 'scientific' aspects of genetic testing, the complex social implications were largely ignored. Although one might argue that it is essential to develop some kind of evidence-based process for certifying genetic tests as scientifically and actuarially valid, disassociating this entirely from the social and ethical issues may be problematic. Because the two issues of 'scientific validity' and 'social legitimacy' are in many respects linked, it

might have been more appropriate to use a synergetic approach and unify the validation process with an assessment of the wider social and ethical impacts.

There were a number of problems with the GAIC's scientific approach. Since its inception, the GAIC has validated only the Huntington's disease genetic test; an extremely rare single gene disorder that can already be predicted relatively accurately through family history analysis. (GAIC, 2000b) It would be extremely difficult, at present, to satisfy the GAIC requirements for more complex but common multifactorial conditions. This raises questions over the present need for such an extraneous process.

Another problem with the GAIC's technical criteria has been revealed by Prof. Martin Bobrow, a clinical geneticist. He argues that the evidence base for determining population risk in clinical studies poses problems when applied uncritically to the context of insurance. In a paper delivered to a UKFGI (2001b) consultation meeting, he referred to certain biases within clinical studies that could have crucial implications for the use of such data in underwriting. Firstly, bias can occur when geneticists try to ascertain a gene's penetrance. Clinical researchers tend to recruit research subjects from families with a large number of affected individuals in order to improve their chance of discovering a correlation. Consequently, the correlation may end up being over-exaggerated, while alternative non-gene specific factors that could be relevant, since they too will be over-represented in the sample, may be conflated with the genetic cause. Secondly, severity of the disease may be over-exaggerated, because clinical researchers tend to recruit only those individuals with acute manifestations of the

disease. They do this in order to prevent contamination of the sample. Thirdly, the efficacy of treatment may take decades to establish, because early treatments generally prove less salutary than later ones. According to Bobrow, 'treatment effects' are often underestimated. The crucial point in all this is that insurers who use clinical data uncritically may overestimate the clinical implications of particular genes and underestimate the efficacy of particular treatments. Bobrow's account raises serious questions about how effective a scientifically grounded process of validation can be when dealing with complex genetic information. It does not appear that the GAIC have considered the deeper implications of translating clinical data into actuarial data. If Bobrow is correct, the clinical and actuarial relevance criteria may be insufficient for validating genetic tests for insurance purposes.

In general, the GAIC might consider itself successful in terms of the limited remit it was given. It has also tried to be open and transparent in its decision-making. In its first annual report (GAIC, 2000c), GAIC proclaimed that it had drawn together in a single committee a broad range of expertise. It stated its intent to promote public confidence by establishing a rigorous complaints procedure, and provided an assurance that ABI compliance with its decisions would be carefully monitored. The GAIC openly invited interest groups to review its process and stated: 'GAIC sees it as an important safeguard for the views of those who may be affected by any decisions to have an input in the deciding process.' (GAIC, 2000c, Para 5.5) It is interesting that a committee very much focused on the scientific evidence base of the genetics and insurance issue would make such a strong statement about public confidence. This perhaps illustrates further the political nature of the policy framework. Although the GAIC tried to disassociate the scientific principles from the

social ones, this proved impossible in the context of a controversial public issue. The rationale for the validation process had to be linked to a putative concern for the public. Although the establishment of an organisation committed to the scientific and actuarial principles underlying the debate was perhaps pragmatic, to initially disassociate these issues from the social and commercial ones was perhaps flawed. It essentially permitted subjective public concerns to enter 'through the back door'. If the GAIC had sought from the beginning to investigate the clinical, commercial, and social impacts, political rhetoric about the need to raise public confidence and calm their fears of social and economic exclusion may have perhaps been unnecessary.

This analysis of the GAIC's work has revealed that even when official advisory/regulatory committees try to be rational, fair, and equitable, they often revert to political rhetoric and allow value judgements to pollute their work. With such a complex issue as genetics and insurance, it is very difficult for a validation process to be entirely objective and scientifically sound.

### **2.2.3. *The HGAC and HGC***

The HGAC, and its successor the HGC, have been the two most influential government advisory committees on the 'new genetics'. Both were given an extensive remit to assess the broader social and ethical issues relating to genetic science. In trying to fulfil their role, both introduced a novel system of public consultation into their decision-making framework. The results of their consultation with various stakeholders were used to construct pragmatic policy

recommendations for the Government. However, it is important to investigate how these important advisory committees have framed the issue of genetics and insurance, and critically analyse the process of public deliberation they have striven to initiate. It will then be possible to further assess the efficacy and equity of the general policy/regulatory framework and make some progress on the fourth research question.

The HGAC released their first report in December 1997, entitled *The Implications of Genetic Testing for Insurance*. (HGAC, 1997) Although this report supported many of the ABI initiatives, it claimed that the industry's general approach was insufficient to meet the wider concerns in the area. (HGAC, 1997, Paragraph 1.5) Although the HGAC acknowledged that the hereditary implications of new kinds of genetic tests might appear significant, they conceded that similar medical conclusions could be reasonably drawn from family history data. Here, we can observe once again the rhetoric of clinical equivalency. However, the HGAC also expressed concern that the insurance industry had not designed special insurance products tailored to the needs of the 'genetically disadvantaged'. These two statements appear to contradict one another. The HGAC appear to marginalise the issue of genetics by expressing a substantial equivalence argument, yet simultaneously criticise the insurance industry for failing to treat new kinds of genetic information as special. This criticism was unfair to the commercial sector. If the information emerging from new kinds of genetic tests was not radically different from existing family history information, and if the actuarial relevance of most genetic tests was unlikely to be known any time soon, as the report concedes in Paragraph 2.12, then the question arises; why should the industry have a duty to

design theoretically novel and population-specific insurance products? The implicit assumption underlying the rhetoric of the HGAC was that insurers should be obliged to accept primary responsibility for protecting an imagined 'genetic underclass'. The onus was placed on insurers to prioritise specific social values and marginalise existing commercial ones. It appears evident from the HGAC's inconsistent rhetoric that a fundamental social value rationale has enveloped their supposedly objective remit.

The report proceeded to claim that the industry could withstand limited levels of adverse selection, hence their recommendation of a moratorium. This recommendation appeared to be influenced by their finding that:

'... there was a strong and persistent sense of unease among those who had provided genetic test results to insurers about the way this had been interpreted. Despite inadequate quantitative evidence, we therefore could not set aside perceptions of unacceptable discrimination as groundless.' (Ibid, Para 3.14)

This statement is particularly interesting, because it is expressed by a governmental committee with a central role in directing policy on this emotive issue. Despite acknowledging that there is no empirical evidence to confirm whether an individual who perceives him/her self to have been discriminated against actually has been the victim of discrimination, the HGAC suggest that mere public perceptions provide sufficient grounds for strict regulation. Not only is the very nature of discrimination, as a complex and ambiguous philosophical concept, not considered in any detail, but neither are a whole range of other social and ethical contingencies of the genetics and insurance dilemma. The central policy and

regulatory authorities appear, just like the interview respondents, to marginalise or prioritise certain substantive issues. In this case, the social value of preventing 'unfair' discrimination appears to be a central feature in the account, yet there is no supporting evidence to suggest that discrimination, or the perception of it, really exists or is prevalent. This statement suggests that inspiring public confidence, through a 'politics of inclusion' rhetoric, is more important than supporting commercial interests and values.

Soon after this report was published, the HGAC was disbanded and its work transferred to the HGC. The HGC initiated a broad public consultation exercise to tap into the diverse views of stakeholders and the public. The data from this exercise would be used by the HGC to inform their recommendations to Government. In 2000, they released a document entitled *Whose Hands on Your Genes?* Within this document, the HGC set out what they considered the most important issues regarding the new genetics and requested responses from interest groups and the public.

The *Whose hands on your genes?* document expressed a number of important concerns about the issue of genetics and insurance. The HGC deserves recognition for being one of the few advisory committees to seriously investigate some of the 'big questions' germane to this issue. In many respects, their work has proven both bold and salutary. For example, the HGC did not fudge the issue of what exactly constitutes 'genetic information' and questioned whether it deserved 'special' status. They appeared to recognise that personal genetic data is conceptually complex and equivocal. However, the HGC then argued that for the

purposes of the document, the definition of genetic information would be restricted to information derived from DNA or associated biochemical tests. They claimed that:

'... it is these new sources of genetic information based on DNA technology that provide new possibilities and challenges. There is public concern about the extent to which existing safeguards and regulation of information may be effective in the face of what can be done with the new technologies.' (HGC, 2000, Para 2.4, 3-4)

The principal problem with this statement was its presentation as fact. The HGC presented as incontrovertible what was in reality a deeply nuanced and contested issue. They appeared to recognise the equivalency argument as valid, but proceeded to adopt a narrow definitional framework of non-equivalency, implied by their vague reference to 'new possibilities and challenges'.

The document then stated a number of reasons why new kinds of genetic information may require special legislative attention. The HGC argued that such information could identify unique individuals from small amounts of their biological material, predict late-onset disorders, and be of commercial interest to third parties. (Ibid, Para 3.2, 7) Again, the pre-framing of the issues in such a way meant that the lay public were asked to consider the validity of a number of normative arguments, in the absence of an adequate explanatory/interpretive framework to render the underlying philosophy intelligible. The public were simply instructed to register either their agreement or disagreement with the HGC's interpretation of the problem, without being offered a range of competing knowledge claims to draw upon before formulating their responses. For example, the HGC did state the



insurance industry's argument that genetic test information is no different from other forms of medical data and should therefore be divulged to them. However, three arguments were then presented for why access may need to be restricted. Stakeholders and the public were asked if they believed this to be a fair representation of the issue. They were also asked if it was important to distinguish different types of insurance products, medical conditions, and value of policies. Again, an 'intelligent' and 'informed' response was expected, even though respondents were given little background on the social, ethical, and commercial complexities.

Some of the questions posed by the HGC were valid, and perhaps useful for initiating public debate. Nevertheless, a number of methodological flaws would mean that the public responses would have to be treated with caution. The HGC's goal of mining public attitudes and establishing rational, pragmatic, and evidence-based recommendations was compromised because they, like the various stakeholders and interest groups, drew selectively from a broad narrative repertoire so that certain substantive social, clinical, and commercial values appeared to be prioritised while others were marginalised.

The consultation period ended on 23 March 2001, and the data was collated and analysed. Overall, there were 250 responses. 181 were tick box, 32 included additional comments, and 87 provided detailed written commentary. (64 of these came from named organisations and 23 from members of the public). The number of responses was considerably low considering the amount of time dedicated to the consultation exercise. However, this may not be too surprising. One must question

how many 'ordinary' members of the public would be prepared to read a fifty-page document and present extensive written responses to it. Further methodological flaws of this exercise will be explored in more detail later.

Although the HGC's initial goal was to initiate public debate and set out some of the basic issues of principle, it would have perhaps been more constructive to have discussed the intellectual basis of these various principles at the beginning of the exercise. If they had illuminated the social, ethical, and scientific complexities, without appearing to prioritise one value narrative framework over another, the HGC may have been more successful at building a strong and critically-adept foundation to the policy debate. This would not necessarily have required that the consultation document be profoundly esoteric. An intellectually fertile range of perspectives could have been presented to the lay public without the document becoming inaccessible to the non-expert.

The recommendations the HGC presented in May 2001 reflected the flaws in their decision-making process. Although they had consulted extensively with stakeholders and the public, and tried to initiate open and transparent public debates, the final recommendations appeared biased. . The HGC concluded that it was '... important to establish a clear and defensible regulatory system which not only balances the interests of insurers, insured persons, and the broader community but also enjoys the confidence of the public.' (HGC, 2001b, 1) The HGC recommended a 3-year moratorium on the use of genetic tests by insurers, except in cases where applicants were applying for policies over £500,000, during which time a full review of the regulatory process should take place. Furthermore, they

recommended that insurers should only be permitted to use genetic tests that have been approved by the GAIC. However, the HGC also argued that the current system of self-regulation was inherently flawed and suggested that an independent body enforce the moratorium. This recommendation was influenced by the rather austere comments of the Select Committee report.

The HGC also argued that a moratorium was necessary to prevent 'social exclusion.' They seemed to ignore the fact that few genetic tests are currently used by insurance underwriters. This is a crucial point that undermines the 'social exclusion' argument. The HGC also cited the clinical concern that individuals might be reluctant to use genetic testing services or participate in research if they believe they will be discriminated against. Of course, no empirical evidence was cited in support of this concern. Again, the HGC appeared to prioritise certain social and clinical value narratives and marginalise commercial ones.

The HGC did appear more rational and less myopic on some of the substantive issues. For example, they argued that family history should be looked at more critically in the context of insurance. They recognised that there was a degree of parity between the social implications of new genetic tests and more traditional clinical tests. Furthermore, the HGC stated that in future it would try to identify means of access to insurance for the genetically disadvantaged, consider various regulatory systems, investigate the role insurance might play in a reformed welfare state, and discuss how a private insurance system might best provide social goods. These are certainly fundamental issues that any policy process must recognise, but they appeared to have been neglected in the initial consultation and advisory

framework. The HGC, as well as the other advisory/regulatory organisations, appeared to be neither equitable in the way it treated alternative value frameworks, nor effective in deliberating the broader nuances of the issue. The HGC's moratorium recommendation, for example, was justified on the weak basis that procedural inadequacies had been identified in the system of self-regulation, the technology was still in its infancy so could be misinterpreted, and the public feared social and economic exclusion would be engendered by prevailing commercial values. It certainly appeared that the public concern issue was privileged in the decision-making framework, especially when one considers the following comment by Baroness Helena Kennedy, Chair of the Human Genetics Commission:

*"Our consultations have shown very real public concern on the issue of genetics and insurance. On the basis of the evidence we have received, we have profound misgivings about the industry's handling of this information and its ability to keep its own house in order. I hope that these proposals go some way to reassure the public. They will also give the Commission the opportunity to consult further and devise an enforceable system which can enjoy the confidence of everyone."* (HGC, 2001c, my italics)

This is an extremely critical statement about the insurance industry's competence. Insurers are portrayed as having neither the ability nor motivation to protect the public from the unrelenting power of its commercial values and interests.<sup>3</sup> This statement, perhaps more than others, undermines the HGC's initial commitment to assess the broader issues of genetics and insurance rationally and equitably. The future effectiveness of the organisation may depend on its ability to engage with the underlying issues and stakeholder concerns far more impartially.

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<sup>3</sup> Recently (May 2002) the HGC published their final report *Inside Information: Balancing Interests in the Use of Personal Genetic Data* (HGC, 2002) In this document, the HGC reassert the recommendations they made previously, provide a detailed account of their decision-making process (including evidence received from interest groups), and establish their objectives for future research.

*2.2.4 House of Commons Science and Technology Committee Fifth Report.  
Politicians' Differential Treatment of Stakeholder Evidence*

A number of sociological insights into the process of evidence evaluation in formal political settings emerge from an analysis of the House of Commons Science and Technology Committee Fifth Report. This was a crucial document in the genetics and life assurance policy/regulatory framework, as it had a strong influence on Government decision-making. By assessing in some detail the committee process, we will be able to provide further answers to the fourth research question, particularly the issue of political institutions treatment of stakeholder accounts.

The principal aim of the Select Committee was to collate and interpret evidence from the various advisory committees, regulatory authorities, and various stakeholders. It would investigate the issue of genetics and insurance in some detail and provide further recommendations to government ministers. The process included two oral evidence sessions; one with Prof. Martin Bobrow (head of the department of medical genetics at Cambridge University) and another with representatives of the Cooperative Insurance Society, Norwich Union, and Prudential. The committee also received 37 written memoranda from a variety of organisations including insurance companies, patient-support groups, and genetic research institutes.

Ideally, this inquiry should have served as an impartial mechanism for filtering the diverse concerns of stakeholders. It should then have constructed pragmatic recommendations based on an extensive and impartial analysis of all the relevant issues. However, a critical analysis of the witness examination transcripts, and the listed recommendations, will reveal that the virtue of impartiality was seriously compromised, and that the general approach to the underlying theoretical issues was both narrow and superficial. One can observe the politicisation of the genetics and insurance issue most acutely within the deliberative process of this Select Committee investigation. 'Politics without reason' may be an appropriate description of the nature of this decision-making process.

The most conspicuous feature of this Select Committee process, and the issue that our attention will be focused on, was the differential treatment dispensed to the various experts who appeared as witnesses at the evidence sessions. Most strikingly, the questioning of the medical geneticist appeared noticeably less confrontational and invective than the cross-examination of the insurance representatives. It appeared that the political members of the committee held preconceived ideas about the quality and legitimacy of the witness statements they were to hear. For example, the opening statements offered by Prof. Bobrow were generally accepted as fact, while those given by the insurance representatives were often met with incredulity.

Prof. Bobrow opened his account by stating his career history and arguing that significant scientific progress will be required before we can predict with any accuracy the complex effects of gene/environment interactions, and therefore the

penetrance of specific genes in affected individuals. His career history clearly impressed the committee members who responded: 'That is very impressive, and thank you very much. It gets us off to a good start.' (House of Commons (HOC), 2001, Minutes of Evidence, Question 2) After Bobrow challenged the widely held assumption that the 'new genetics' will soon prove highly predictive, the following dialogue took place:

7. (Dr. Williams) Can I come in with just a brief one? You are speaking with great restraint and accuracy in what you tell us, but are there other clinical geneticists out there that believe that the blueprint will be more predictive than that, or in certain instances, like in Huntington's or some of the genetic defects, where maybe in five or ten year's time ... we will be able to say a good deal more, or are there some enthusiasts in the field that think there is more information here than you are telling us?

(Professor Bobrow) Of course, there is always a spectrum of opinion. I think, if we take the specific question you asked me, which is whether there are people who believe we will have tests that will predict time of onset and rate of progression of Huntington's disease, I do not know any such people, nor do I know of any scientific work that leads us to believe that we are seriously going to crack that problem. Every scientist believes that every problem will be solved, so I'm not going to say never, but there is nothing on the horizon, at this stage, in my view.

8. (Dr. Gibson) And you would not really think that the insurance companies can predict epistatic effects between genes, we are a long, long way from understanding that, we have never really understood the phenomenon, although it has been around for years, the interaction of genes and different chromosomes, for example? So they are nowhere near that, they are millions of years from it, would you say?

(Professor Bobrow) Millions of years is not the kind of thing that falls naturally from my lips; it is not easy to see it happening ... I do not think there can be any doubt that the horizon between now and the time one could have a validated, verified test that predicted the sort of thing we are discussing must be certainly decades away.

(Chairman) ... You did say, very early on, that, even if there is a gene that is likely to lead to some disease, you cannot be sure whether the person will get that disease in their childhood, in their middle life, or indeed not at all. To what extent then is it valid ... for insurance companies to use genetic information at all in setting premiums, if scientists have no idea at all when this gene is going

to kick in with its trouble. How can insurance companies say that someone should have a loaded premium, just because they have particular gene?

*(Professor Bobrow)* Can I go back and clarify something, because I have clearly left somewhat of an overstatement in the air. Some genetic conditions clearly manifest in childhood, pretty well always, and if I gave the impression that there was no idea of when things would start to have effects. That was not quite accurate. For those that start in adulthood, there is, in general, a relatively wide range of onset. The particular example that I was discussing of Huntington's ... can have onset very early and very late ... but, in general, it is a disease with onset about 40, plus or minus 15 years.

*(Ibid., Questions 7 & 8)*

This strand of dialogue illustrates the problem of moving uncritically from the clinical to the actuarial realm. Bobrow gives account of what he believes to be the current status of genetic testing. In doing so, he essentially marginalises the arguments of those who claim that genetic testing is highly predictable. He tries to demonstrate that genetic science is highly complex and that predicting factors such as age-of-onset and penetrance is not yet possible, even for single-gene disorders such as Huntington's. However, the interesting part of the dialogue occurs when the Committee members try to shift focus onto the insurance problem and ask Bobrow for his opinion on this. Revealed is an unsubtle attempt by the committee to coerce the witness into validating an anti-insurance argument on the foundation of clinical reality. The committee begin by trying to render Bobrow's 'genetic complexity' rhetoric more powerful and compelling. They do this by translating his rather balanced and diplomatic words into an argument that the insurance industry is 'millions of miles away' from gaining any utility out new kinds of genetic tests. The Committee appeared to be trying to steer the respondent into criticising the commercial use of genetic information, based on *their* interpretation of the scientific status of the issue. In his defence, Bobrow did claim that he may have been falsely interpreted as overstating the case. His initial claim that genetic testing cannot yet



predict how a disease will manifest itself was later restated less strongly as an argument that genetic information may only give us an age-range of about 15 years for when the gene may express itself. The Committee's assertion, which they appeared to want Bobrow to verify, that insurers have no use for genetic information because it has little predictive value, was now being undermined. However, this assertion was deeply flawed. The insurance industry does not need, nor desire, absolute certainty. A broad spectrum for age-of-onset can be factored into their calculations. Therefore, limited genetic information is still commercially useful, despite the Committee members' comments.

The argument that there is no justification for loading a premium on the basis of an applicant having a faulty gene, which is not fully understood and cannot with any accuracy be predicted to express itself on a specific date, demonstrated the actuarial ignorance of the Committee members. It was one thing to place absolute trust in the scientific/clinical expertise of a witness, but to shift the focus onto the complex issues of insurance and assume the respondent's competence extended to this area was, perhaps, disingenuous. It appears from the transcript evidence that the Committee members began as committed sceptics of insurance industry competence and probity. It appeared that they were merely trying to validate their prejudices with the veneer of a supposedly objective science. The transcript revealed the problems that can be engendered when one attempts to assess evidence from two very different knowledge domains.

It is important to emphasise that not all clinical geneticists support Prof. Bobrow's account of the predictive potential of genetics. For example, Bobrow

argues that insurers over-interpret the predictive potential of genetic tests in a way that is inconsistent with the scientific evidence. This view is not shared by other 'experts', such as Prof. Sandy Raeburn, the ABI genetics advisor. Because the science is still in its infancy, there is still no established consensus, or indubitable evidence-based facts, on the predictive power and value of genetic testing. However, the Select Committee appeared quite willing to display a degree of deference to the opinions of Prof. Bobrow, and uncritically accept his account, despite the fact that he was quite willing to concede that there is a degree of professional disagreement amongst clinicians on the predictive capacity of the new genetic technologies.

Prof. Bobrow was also asked his opinion on the policy aspect of this issue. Bobrow expressed doubts about the viability of an outright legislative ban but wanted to see a stronger moratorium put in place. He expressed concern that the industry had been slow to respond to the issue and questioned the appropriateness of self-regulation. Interestingly, he also signalled a desire to extend the debate to the use of all genetic information, including family history. The following account was particularly interesting.

... insurers at the moment do have access, without contest, to very strong genetic information by asking about family history; how that is interpreted in detail, I honestly do not know, but they do have access to that, every time you go for a life examination, you are asked about your family history. As I understand it, the reality for these diseases and others is that if you do not declare a family history of Huntington's, or whatever it is, you have not declared a germane item of information and your insurance will be null and void; if you do declare that family history, they have you, they know you are at a very high risk, and they do not actually need to do genetic tests to validate that. Therefore, if one is going to try to impose a real ban on the use of genetic information, as opposed to just tinkering with laboratory tests, I think one needs to grapple with the use of family histories ... So I see it as a bit of a sham, to be honest, because I think it does not address the real issue, which is

the information, it addresses the trivial issue, which is the test.' (Ibid., Question 29)

This account represents an attempt to challenge the 'business of discrimination' value narrative, by extending the arguments against the use of new kinds of genetic test information to family history. However, while the objection to insurers using genetic tests was based on a narrative of clinical validity, in this account the objection appears rooted in a social value of economic inclusion. Insurers' access to family history has never really been challenged on the grounds that it is an imperfect scientific/technical tool, but always on the basis of the wider social and economic consequences for the at-risk. The account also demonstrates, once again, an ignorance of the commercial realities of insurance. The statement about the consequences of revealing a family history of Huntington's disease implies that insurance companies would deny somebody a policy on these grounds. However, as revealed in chapter 2, the insurance industry often underwrites applicants with such a family history. Sometimes they might offer a term policy instead of a whole life policy, or they may simply load the premium to take account of the increased risk.

The Committee asked Bobrow if he believed the fear of a genetic underclass was valid. He responded:

'I think there is an extremely serious risk of creating a group of people who see themselves as a genetic underclass, which may be almost as damaging, because they will avoid some forms of medical care, and so forth, or research participation, because of this concern.' (Ibid', question 31)

The principal theme in this account is that a perception of social exclusion is as morally insidious as actual exclusion, particularly if it has a negative impact on clinical values. Again, as revealed in the interview accounts, the clinical and social value framework is conflated, while the commercial concerns are marginalised. The Committee then asked: 'But careless use, or poor use, of genetic information by insurance companies is going to exacerbate whatever the problem may be?' Bobrow responded: 'I think it is a public issue, clearly, or you would not be having this hearing.' (Ibid.) The Committee's questions appeared value-laden. Even when Bobrow tried to remain circumspect, the Committee appeared to want him to provide evidence in support of the belief that there would be substantial and negative consequences if insurance companies were permitted access to the information. They accepted a great deal of the evidence presented by this one clinical representative, and encouraged him to speak on various issues that deviated from his specific area of expertise. They uncritically accepted both the clinical narrative he offered, as well as the complex social and commercial narratives that he was encouraged to express.

If we now contrast this evidence session with that of the insurance representatives, we can observe a very different process at work; one that was palpably more confrontational and lacked the same level of deference to expertise. When it came to questioning representatives of the insurance industry, the Committee members used the account given by Prof. Bobrow as a foundation for their cross-examination. After the Prudential witness, Keith Bedell-Pearce, talked about the Huntington's gene test, and stated that it was relatively accurate in determining the disease's age-of-onset, the Committee chair Dr. Gibson replied:

"Bobrow went further when he gave evidence. I am sure you have read it. He does not have the same confidence that Sandy Raeburn has in being able to predict. He said that he is not sure if you have the gene that you can predict "when the disease will start, how rapidly it will progress and thus when death will occur." ... It is a mess, is it not? You cannot really predict and yet with these uncertainties you feel confident to talk about increasing or decreasing premiums. It is an uncertain science.' (House of Commons (HOC), 2001, Minutes of Evidence, Question 79)

In response to this accusation of applying scientifically spurious data, Bedell-Pearce exclaimed:

'... I do not want to stand in the middle of an argument about the efficacy or otherwise of genetic testing between two academics. The evidence that the insurance industry advisor has provided us with and indeed the GAIC also has confirmed is that there is a degree of predictive certainty so far as the Huntington's chorea is concerned ... there is a considerable body of scientific evidence and practical experience of the emergence of Huntington's chorea to indicate that with certainty, where the nucleotide repetition is more than 39 times, the disease will emerge.' (Ibid)

The science appeared now to be in question, and the principal antagonists in this exchange were simply countenancing the disparate accounts of two academic geneticists to support their particular case. One was an insurer hoping to use scientifically valid genetic information as an underwriting tool, and the other was a politically motivated Select Committee member trying to undermine the insurance industry's veracity in interpreting and utilising complex genetic data. The very style and conceptual framework of the questioning appeared far more invective and critical. The implicit assumption was that the testimony of the insurance representative could not be taken at face value.

In question 81, the belligerent approach continued when the Committee asked Mr. Urmston, an insurer representing the Cooperative: 'Have not the insurance companies a better chance of predicting by looking back at what your great granny or your grandfather and your mother and father died from?' (Ibid, 81) Urmston replied:

'That was what I was trying to refute earlier [Urmston had argued that genetic tests provide a greater predictive power, even by discovering the absence of the gene in those individuals with a family history] If you remember the figures I quoted, I was trying to say we have gone back and said that, if we had used the family history methods, what we have been able to demonstrate ... is that the practices that we use [current genetic test results] are more accurate and are giving better information' (Ibid)

The committee retorted: 'How do you know that? You are being conned by the scientists.' (Ibid, question 82) Urmston came back by arguing:

'With respect, if your father or mother have had this disease, there is a 50 per cent chance that you may have it. If we rate on the basis of that, all the people who have parents with Huntington's chorea we will end up rating in line with that sort of probability. The genetic test means that at least half of them we will not rate at all. [Because they will be discovered to be free of the gene].' (Ibid)

Interestingly, when the respondent cites scientific evidence that supports the commercial use of genetic information, the clinical narrative then appears to be questioned by the Committee. Those clinicians who give a different account from Bobrow are represented as 'conning the insurance industry'. It appears that only scientific evidence that validates a critical assessment of the insurance industry is shown respect and deference. In reply, the Committee member stated: 'I say you

can only say they have the gene, period. You cannot say more than that.' (Ibid, question 82) Clearly, the Committee failed to comprehend the basic concept that absence of a gene can have as much predictive power as discovery. This simple misunderstanding appeared to result in the insurance industry being castigated for what could only be imagined duplicity and incompetence.

Later in the inquiry, it was discovered that some insurers, such as Norwich Union, were using genetic tests on the ABI list that had not yet been approved by the GAIC, albeit with the promise that policies underwritten on the basis of those tests would be retrospectively reassessed if the GAIC subsequently refused to validate them. The view of many insurers was that this would prompt the GAIC to initiate the validation process immediately, and treat it with a greater sense of urgency. This practice of using genetic tests not yet validated by GAIC was not explicitly prohibited by the ABI. However, the Committee decided to characterise both the ABI, and the companies it represents, as acting: '... in a free market, picking up tests that have channelled through this one academic from Nottingham. He may well believe strongly but nevertheless it is one person's advice, not government body advice.' (Ibid, question 110) This statement implicitly assumes that government advice, by its very nature, is somehow more reasonable and deserving of public legitimacy. This is a rather spurious authoritarian view of 'government knows best' that many may justifiably reject. There was also a degree of hypocrisy in accusing the insurance industry of relying on the evidence of one academic, when the Committee itself also appeared to be prioritising the account of a single clinician.

The appropriateness of this practice was posed to Bedell-Pearce, and he rebuked the negative implication by asserting the view that Prof. Raeburn was an eminent geneticist who: '... has been retained for some time by the ABI not because I believe the ABI went expert shopping, but simply because of his eminence and his ability to give a disinterested professional opinion.' (Ibid) The Committee then argued again that the industry should follow government advice and proclaimed: '... you have jumped the gun and you have applied this knowledge, funnelled through this academic, not funnelled through the arm of government.' (Ibid, question 113)

There is a degree of truth to the claim that insurers varied in how they interpreted the ABI code. Some applied it far more liberally than others. However, the ABI only ever proposed minimum standards. Just because a few individual companies decided to go beyond the minimum requirements does not justify characterising those who did not as duplicitous, incompetent, inconsistent, or a threat to public confidence, as the Committee both implicitly and explicitly suggested. It must be noted that concern was also expressed over Prof. Raeburn sitting as both the ABI advisor and a member of the GAIC body responsible for validating genetic test applications, which could be seen as a conflict of interest. This was certainly a legitimate concern that the Committee was correct to identify, but it was not necessarily a blatant or conscious deception.

Overall, the actions of the insurance industry did not seem to warrant the opprobrious level of criticism directed at them by the Select Committee members. Dr. Ian Gibson even accused Norwich Union of trying to set up a 'genetic ghetto'.



He claimed: "self-regulation is clearly not working. These companies are attempting to identify a genetic underclass which can only lead to them profiting from individuals being discriminated against." (Quoted in The Times, Thursday February 8<sup>th</sup>, 2001) The evidence does not support this kind of politically charged conspiracy theory, so the moral condemnation again appears largely unjustified.

The question that needs to be asked is why a supposedly impartial Select Committee differentially judged the veracity of stakeholder evidence. It is clear that there is a broad range of opinion on the issue of genetics and life assurance, and various stakeholders have perhaps complicated the issue by drawing on a variety of value narratives to defend particular sectional interests. However, the Select Committee report appeared to further politicise and ideologically polarise the relevant constituencies, rather than establish a consensus-based position after diligent deliberation of all the complex issues.

The Committee focused predominantly on procedural inadequacies of the ABI code of practice and the insurance industry's failure to promote public confidence. Broader theoretical issues such as the nature of discrimination, the definitional boundaries of genetic information, and the role of commercial insurance in contemporary society were not deliberated in any great detail. The social good aspect of insurance appeared to be a crucial omission. Furthermore, the limited number of witnesses that contributed to the evidence sessions suggests that this political inquiry was inadequate. Although supplementary memoranda were provided by a number of organisations, it was predominantly the witness testimony that informed the final recommendations.

The Committee made a number of recommendations. They suggested that organisations such as the GAIC and HGC be given greater resources, after it was discovered that their current budget was woefully inadequate. On the issue of genetic test validation, the Committee felt that the scientific evidence was inadequate (they based this on Bobrow's testimony) and recommended that the GAIC re-examine their decision to approve the Huntington's test and demand the insurance industry provide peer-reviewed data to support their case for actuarial relevance. Although the call for peer-reviewed evidence may be valid, it seemed an extreme response to have the GAIC re-examine the validity of this test. It not only cast doubt on the integrity of the GAIC, but also illustrated the Committee's lack of knowledge about Huntington's chorea and its implications for life assurance provision. This genetic test can indeed benefit the applicant who has a family history of the disease but tests negative for the actual gene. Furthermore, individuals found to have the gene would have already had problems acquiring insurance based on family history, so they would not suffer any additional discrimination if insurers were permitted to use positive genetic tests.

The Committee also questioned the industry's competence to regulate itself. They recommended that an independent monitoring system be established. Furthermore, they proposed a voluntary moratorium for at least two years, while more research is conducted on the actuarial relevance of specific tests and their implications for access to insurance. The Committee stated: 'If the insurers are unable, or unwilling, to regulate themselves and enforce this moratorium, we recommend that Government enforce its will by legislation.' (HOC, *op cit.*,

Paragraph 71) The industry was therefore being coerced into accepting a new moratorium. The commercial sector would certainly find this more desirable than legislation, but again the severity of the Committee's criticisms seemed incommensurate with the real shortcomings of the ABI's policy position. Although the idea of a moratorium may seem reasonable in principle, the process used to reach this decision appears deeply flawed.

The Select Committee report reveals a number of interesting sociological insights into the political nature of decision-making on controversial science and society issues. It is interesting to observe the various ways in which stakeholder evidence is differentially judged by politicians in order to give their particular value position a veneer of legitimacy. Once an issue enters the realm of representative political institutions, political expediency appears to become a central feature. Instead of reaching fair and equitable decisions, the process appears to simply polarise and antagonise political/ideological sensitivities further. This particular Committee report appeared to be more concerned with responding to perceived public fears of a genetic underclass, excluded from financial security, and an unrelenting science with the power to do much harm as well as good. Perhaps this was the principal reason why insurance industry accounts were treated with so much hostility, while evidence from the clinical community was so much revered.

### ***2.2.5 The Government's Response***

The Government responded to the various advisory committees in October 2001, and entered into conciliatory talks with the ABI. A new five-year moratorium was

negotiated. In their response, the Government claimed to recognise both the 'understandable' public fear of discrimination as well as the industry's concern about adverse selection. The Government appeared to frame the issue superficially as a simple discordance between public and commercial values and interests. This is hardly surprising, as the advisory committees responsible for investigating the wider concerns in the area had already reduced the debate to the level of a simple dichotomous conflict. The Government recognised this to an extent, as they argued that the moratorium was unlikely to provide a lasting solution. (Department of Health, 2001a, 4)

The Government report did take into account the procedural shortcomings of industry self-regulation that were identified by the Select Committee. Their recognition of the need to independently monitor ABI compliance was perhaps a pragmatic response. Their decision to raise the financial ceiling under which applicants need not divulge genetic information would also offer individuals the opportunity to purchase a substantial, and arguably adequate, amount of insurance cover without fear of being unfairly discriminated against. Of course, there are many other methods of discriminatory risk-assessment not prohibited by the moratorium. Despite recognising this point, by noting that the Secretary of State for Health would consult with the insurance industry and genetic-support groups on how to make access to insurance easier for those currently excluded because of their family history, the Government was still relatively unsuccessful in establishing any fixed boundaries to this expansive problem.

What further complicated matters was that the Government, just like the various advisory committees, appeared to prioritise the public fear issue. It is important to remember that in 1998, after the publication of the HGAC report, the Government decided that self-regulation was sufficient and lauded the actions of the ABI. However, in 2001 the Government fundamentally changed its position and argued that self-regulation was not working. One might assume that it was the recognition that the public was becoming increasingly concerned about the issue that caused the Government to change its approach.<sup>4</sup>

This section has revealed a number of flaws in the formal policy/regulatory process around the issue of genetics and insurance. With regard to the fourth research question, the evidence suggests that the policy framework has served merely to simplify the underlying issues, and polarise stakeholder accounts, rather than reach rational and equitable solutions acceptable to all stakeholders. The process has appeared to prioritise certain substantive issues, and marginalise others, and has failed to equitably balance stakeholder interests. The analysis has also revealed the power that perceived public opinion has had on this process. Every committee and regulatory body has made explicit reference to the need for public confidence to be inspired. Even committees focused on the clinical and scientific issues have enveloped their rhetoric with concerns for public interests and values. This issue of public opinion will be investigated in more detail later. Now it

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<sup>4</sup> The Secretary of State for Health Alan Milburn, in his speech given at the International Centre of Life in Newcastle in April 2001, had also highlighted the concerns of the public, and raised the dire prospect of a "genetic underclass" resulting from discriminatory practices. He stated "Without appropriate regulation, lack of public confidence will remain a significant barrier to fully harnessing the health benefits genetics developments represent." (Department of Health 2001b) The ABI responded by claiming it was willing to work closely with the government to ensure a fair resolution to the problem. (ABI, 2001c)

is necessary to assess stakeholder accounts of the policy process, and assess whether the data corroborates the preceding interpretation.

### **3. STAKEHOLDER ACCOUNTS OF THE POLICY PROCESS**

The previous chapter revealed the complex ways in which key stakeholders in the genetics and life assurance debate accounted for their concerns, and suggested candidate solutions, by drawing selectively from a broad narrative repertoire. This analysis contributed to answering part of the third research question. This section will complete the investigation of the third research question by assessing the extent to which stakeholders have differentially judged the efficacy and legitimacy of the policymaking and regulatory bodies. This section will also further reveal the flaws of the currency policy process.

Almost all of the stakeholders interviewed expressed concern about the veracity of the current decision-making and regulatory process. However, the transcripts also revealed considerable variation in both the strength and focus of stakeholder accounts. It became evident that some respondents were judging the process by reference to how it satisfied their own ideological goals and interests. For example, Julia Cream of the Alzheimer's society responded as follows when asked her opinion on the general advisory committee system:

**JC:** I guess I've been encouraged more recently because I think the recommendations that everyone has been coming out with have been very similar ... we've been very critical about the GAIC since they were set up ... and have said publicly that we have little faith in that process.

**JM:** You don't think that a validation system is necessary?

**JC:** We're not even getting into that. We don't have faith in the process that has been set up.

When asked whether she believed the various committees had sufficiently deliberated the broader underlying issues of the problem, and established pragmatic conceptual boundaries, Julia Cream was once again selective in which specific committees she had faith in. She stated:

'... in some ways, I've been really impressed by some of the work. I think the Select Committee did a good report really quickly ... I think the HGC is very interesting. I think the way they hold their meetings in public are fascinating and very brave, and you actually see them debating the issues and saying, I think, quite controversial things. It's very honest and very transparent ... GAIC has not been so good ... their meetings aren't in public, they've had one meeting where pressure groups were invited but I don't think adequately answered our questions, or been able to justify why they have made certain decisions ... There are quite a lot of bodies now where things get debated, like the UKFGI, which is very heavily dominated by insurance groups ... I think what surprises me is that all the committees say the same thing, have the same criticisms, and the Government doesn't act. And to me it reflects just how powerful a lobby the ABI is. Because the public aren't in favour of what the ABI is doing ...'

This interview took place before the implementation of the five-year moratorium. Nevertheless, Julia Cream reveals her incredulity towards the UKFGI and the ABI, because she perceives them to be producing proposals that the insurance industry finds palatable. She then translates this into the organisation being 'dominated' by the lobbying activities of the commercial sector. However, this criticism could also be applied to the HGC and the Select Committee, who have perhaps allowed certain stakeholders and the 'uninformed' public, who are generally critical of industry practices, to influence their decision-making. It is also interesting that Julia Cream makes explicit reference to the 'public' and accuses the Government of failing to respond to their legitimate concerns about the regulatory process. The

respondent assumes that the public hold strong and negative views about the ABI's self-regulatory process, and that by failing to enact legislation, the Government is failing in its duty to represent the interests of the electorate. This strategy of deferring to a perceived 'public mood' is one frequently employed by interest-based groups who believe the formal political process is ignoring their interests. The bold statement that 'the public aren't in favour of what the ABI is doing' remains unsubstantiated. However, by linking her political rhetoric to claims about what the public truly needs and wants, the respondent may be trying to acquire further legitimacy for her narrow interest-based objectives.

It is interesting to contrast Julia Cream's account with that of Alistair Kent. As revealed in the previous chapter, Alistair Kent was far less critical of the insurance industry's position, and argued that the best way to protect the genetically at-risk was to sustain a competitive insurance market. In stating an opinion on the policy process, the focus of his attention was once again on the scientific uncertainty underlying the issue. He stated:

I think one of the important things that has been missing from the debate is scientific reality. If you listen to the conversations, if you read the House of Commons report, yes it would be terrible if ... we did those things based on the assumptions you're making about the predictive power of genetic information, but everything we know about genetic information tells us that it ain't likely to be so ... You know people have not in a sense stopped to define the size of the event that needs to happen in order for it to appear on the actuaries' radar ... if you have a population risk of a certain thing happening of ... 1 in a thousand, at what point, you know what's the bandwidth for that normality. If you have an event that happens 1 in 750 as opposed to 1 in 1000 is that still within the normal bandwidth? ... There comes a point at which the likelihood of something happening becomes significant and what I think, the insurance industry, geneticists, actuaries, underwriters, need to do is sit down and say that's the size of the blip, we can see a blip of that size, anything smaller than that is white noise. ... On the one hand if you can define the size of the event that must happen for it to appear on the radar then you can look at the science and ask well actually what is genetic information going to tell us that is of that order of magnitude or greater? And what I am absolutely convinced of is that in



the vast majority of cases the answer will be nothing. For a few cases it will be something. And for even fewer cases it will be something so big that we can't actually ignore it ... But the idea that we are going to end up with a large uninsurable underclass is media scare mongering.

In this account, the respondent reveals his, deeper, and perhaps more informed, understanding of the likely implications of genetics for life assurance provision than those interest groups that have chosen to defer uncritically to perceived public opinion. Alistair Kent tries to conceptualise the problem in terms of what is already known about the practical realities of the insurance industry and the power of genetic information. Of course, his desire to see the relevant professional bodies communicate and create a pragmatic definitional framework around the problem is perhaps too optimistic in light of the evidence provided.

In commenting on the House of Commons report, and the advisory committee system in general, Alistair Kent stated:

I think it's very clear from the House of Commons report that there is a great danger of bandwaggoning here. That report is very clearly saying "something must be done and quickly" and the danger is that you take a knee-jerk reaction ... So I think the danger is that you take this kind of bandwaggoning that something must be done so you do something. You say right we'll ban genetic information. So you say well actually are you talking about DNA testing? ... Is that positive test results and negative test results? Or just positive test results or just negative or whatever?

Again, the respondent expresses concern that in the absence of balanced, evidence-based decision-making, policies around genetic information and life assurance may begin to reflect the narrow and unsophisticated views of an uninformed public. When asked about the role he believed his organisation should play, Alistair Kent stated, rather interestingly:

The role that we have been trying to play is to try and get people to focus on what the real issues are rather than what the public are led to believe the real issues are. If you simply go by what the public wants we'd be hanging sheep stealers ... we'd have the death penalty back tomorrow, but we don't because people with the power to change that feel that this is an inappropriate use of their power.

There is a clear perception within GIG that equitable policies can only be achieved through a process of informed decision-making. However, this statement is perhaps just as uncritical as those expressed by Julia Cream. Alistair Kent appears to believe that the process of revealing, deliberating, and resolving the 'real' issues is relatively simple. He presents the ideal process as one requiring greater education, dialogue, and conciliation. However, this thesis has revealed how complex and multifaceted the problem of genetics and insurance is. The 'real' issues may simply be those that particular constituencies have perceived to be the most important, and congruent with their social and political ideologies. It certainly appears to be the case that a number of competing, underlying narratives have structured the general debate. However, to claim that 'scientific reality' will automatically reveal what the 'real' issues are, and allow us to resolve them, is perhaps too neat and simplistic. Although informed debate and a truly conciliatory process may be constructive, it should not be taken-for-granted. There are a number of issues that may challenge the efficacy of such a process, which will be discussed in the following chapter. Although GIG have tried to engage with the more subtle complexities of this issue, we should not be too uncritical of their position. Like all interest groups, they have tried to express a particular story, and drawn upon a broad narrative repertoire, in order to create a consistent and perhaps morally adequate account of their particular policy position.

The clinicians were equally concerned about the nature of the policymaking process. However, both the anonymous genetic counsellors were uninformed about the nature of the policymaking framework and were at first tentative about stating any opinion on this matter. However, after having the policy and regulatory process explained to them, both expressed the desire that clinical/scientific perspectives be represented in the decision-making framework. Dr. Quarrel was one clinician who was relatively informed about both the underlying issues and the regulatory framework. His account was critical of the policy process and the insurance industry's position within it. He stated:

... there have been various government, non-governmental and quasi-governmental organisations, looking at the issue and writing reports. I think that it would be better if the insurance industry could come forward with a set of proposals, to either the HGC or the GAIC, for primary legislation that would allow us to move forward, but they seem to be most reluctant on doing that. Ultimately if it gets to MP's then there's going to be a tremendous ground swell of opinion that we cannot have a genetic underclass, which is a bit of a pejorative term, but if they are not careful then primary legislation will be written, because it is going to be popular with the public.

This account reveals a thinly veiled contempt for the efficacy of various governmental and non-governmental committees. The respondent argues that the onus should be placed on the insurance industry to take a stance and establish a fair and equitable process for resolving the issue. The respondent appears to recognise the political implications of the process, when he predicts that primary legislation, which could undermine commercial freedom, may be inevitable if the insurance industry continues to procrastinate, and public opinion swings further against standard business norms.

One problem with the advisory committee system is that it can become increasingly difficult to track the flow of decision-making and assess the suitability of candidate solutions. This point was illustrated by Sandy Raeburn when he talked about the problems the ABI and GAIC had in simply defining genetic information:

I can recall at least 2 meetings of the ABI genetics committee about 4 years ago when we were trying to define genetic tests ... in the end we came to the definition of a genetic test which is in the ABI code of practice. Of course, about a year or two later in the GAIC, we had at least one meeting where we debated the same thing. I think these committees have debated the issue and I'm aware that on both occasions there was a feeling by most members of both committees that we had to move on ... but I think ... we didn't actually resolve it just by getting a semi-agreed definition. We didn't resolve the issue in a way which the public would find reassuring or robust ...

Two committees deliberated the same issue but ended up with only a 'semi-agreed' definition. If it is so difficult for the committees to complete basic boundary work, it is likely to prove almost impossible for them to resolve the trickier social, political, and economic issues. Such committees are also likely to be as politically and ideologically charged as stakeholder groups, since they too constitute professionally dissonant members. Raeburn's account perhaps suggests that the idea that the formal political process can easily resolve interest-based conflict is naïve.

The respondents most critical of the decision-making process tended to be the insurance representatives, which was revealed in their interview accounts. In commenting on the Select Committee report, Tony O'Leary stated:

... I think there is a political agenda there where its, you know, if I was an MP I'm far better standing up here shouting "protect the poor and downtrodden", than "protect the massive great capitalist insurance companies" ... so I think there's all those elements in there ... My personal view is that you go in front of a Select Committee and they have some preconceived ideas or views of the people they are seeing. So if they are seeing a Professor in Genetics, here's a good guy who's looking after the people ... and up there to tell the truth, and the whole truth, and even when the Professor in Genetics said "its not really my area of expertise but I think...", then that's a definite down there. Now when you get the big bad insurance company up there, just trying to wriggle out of what they haven't been doing, it gets a little more like an inquisition, you treat everything with suspicion ...

This account supports the findings from our investigation of the differential treatment of stakeholder evidence by the Select Committee. The respondent questions the legitimacy of juxtaposing the eminent clinician, who is portrayed as someone out only to protect the interests of the poor, with the untrustworthy insurer, who is portrayed as someone seeking to exclude the poor and vulnerable. The policy community, just like the clinicians and patient-support groups, appeared to draw predominantly from a social/clinical value narrative in order to advance a 'politics of inclusion' rhetoric. This narrative was then used to present the commercial sector as a threat to social and economic inclusion. This strategy is sociologically interesting. A politics of inclusion narrative appears to be used as a rhetorical weapon against commercial interests and values. It acquires legitimacy by claiming to engender trust within a community of citizens ostensibly motivated by egalitarian values. The irony is, of course, that life assurance never provided a means for the poor and vulnerable to protect their financial interests. It was, and still is, primarily an institution that protects those wealthy enough to pay the premiums. Nevertheless, the politics of inclusion narrative was convenient in that it helped critics challenge the norms and values of big business and render their own

position socially and morally adequate. Such a narrative has appeared to define the policy framework of the genetics and life assurance debate.

Although Tony O'Leary appeared uncomfortable with the overtly political nature of the policy process, Keith Bedell-Pearce was more circumspect when commenting on the work of the Select Committee. He argued that the parliamentary democratic process does have some advantages. However, he qualified this by stating:

Select committees are playing to a number of agendas, including local interest, lobby groups and the need to make a bit of a splash on whatever. This is well understood and part of the deal ... There are always political agendas because these are political people sitting on it and they're going to pursue those political agendas.

The anonymous insurance underwriter countenanced this view when he stated that:

Unfortunately, I think the genetics debate is driven by one or two individuals who have particular views which we may never change. And I think we are losing out to that thought process. And I would like to know that these people fully understood the totality of the way the insurance industry works.

Again, these accounts raise questions over the suitability of the advisory committee process. Although the ABI has publicly supported the moratorium decision, the pervasive scepticism expressed by many insurance representatives should sensitise us to the possible flaws in the decision-making process. Bedell-Pearce's

comment that political agendas are well understood and 'part of the deal' should not lead us to simply tolerate the political hubris of individuals who sit on governmental committees. If the system reveals itself to be manifestly prejudiced, then it is perhaps necessary to change it and not simply demand stakeholders 'play the game' of politics.

The anonymous insurance representative raised another problem with the decision-making framework. He claimed:

Ok I'm pretty well informed of the sort of total picture of the insurance industry and genetics, I was one of the 4 people drawing up the final code of practice. I asked them to do me a cascade chart from the government perspective of whose making the decisions, because I've lost track of it. And if I don't know hardly anybody's going to know. So I'm just waiting from the ABI to say right this comes from the Department of Health ... I'm losing track of whose making the decisions, who's reporting to who?

This statement raises a serious problem. With so many committees and policy forums each taking responsibility for different facets of the issue, it is difficult to keep track of where real progress is being made. Furthermore, it makes it far more unlikely that all the information will be deliberated fairly. There is perhaps a need for a more focused approach where fewer institutions could enjoy a wider remit and free themselves from the vagaries of the political arena. However, the anonymous underwriter also talked about the political motivations of certain insurance people. He stated:

I personally believe that there are some within the insurance industry who are taking the genetics debate, and seeing it as a marketing opportunity, I think it's important that the insurance industry maintains its solidarity here.

When he was asked to elaborate he replied:

Its not what they do its what they say ... they're always seen in the financial and national press, and read very carefully what they're saying because it doesn't mean necessarily what they're going to do ... and you can always stand up and say pleasing words which everybody wants to hear ... but the proof comes in what they actually do.

This is certainly a disturbing comment, which if true could jeopardise the openness and transparency the industry has sought to promote and foster. It also illustrates that not all members of the insurance industry share the same agenda. Just like various other stakeholder groups, insurers do not constitute an homogeneous group. There are a number of individuals with vested interests in the outcome of the policy process. The stories they tell, and the strategies they employ, are complex and multifaceted. Although there may be certain similarities in the ways that representatives from particular profession constituencies account for their interests, within all stakeholder groups there is a broad spectrum of opinion that may represent individual rather than group interests.

This section appears to provide further support to the argument that the genetics and life assurance debate in the UK is driven more by political strategising than rational evidence-based deliberation. Just as the formal political process appeared to grant differential legitimacy to stakeholder accounts, here it has been shown that relevant stakeholders judge the equity and efficiency of the political process by reference to how it may serve their broader social, political, or ideological interests. Some may even defer to perceived public attitudes when it is advantageous for them to do so. This section has contributed further to our understanding of the third research question. It has also provided evidence to corroborate earlier conclusions about the nature of the policy and regulatory process. This now concludes our



investigation of the third and fourth research questions. It is now necessary to look more closely at the way a very particular kind of public opinion has influenced the strategies of various political groups and institutions, and perhaps further threatened fair and effective policymaking. This analysis will provide an answer to the fifth research question.

#### **4. THE ROLE OF PUBLIC OPINION AND THE MEDIA IN SHAPING THE POLICY PROCESS**

Throughout this chapter, 'perceived public opinion' has revealed itself to have had a central role in the genetics and insurance controversy. One explanation for why governments now appear so sensitive to public attitudes may be the negative experiences they have had in the past when dealing with complex science and society issues. In the past, public fear and scepticism often emerged as a threat to government policy. The crisis of public confidence over the issue of BSE, for example, might be characterised as symptomatic of an institutionalised political arrogance that privileged those scientific accounts that were politically expedient, and subjugated the legitimate fears of a public who did not trust the information they were being fed. With controversy now enveloping genetics based technologies, the Government has recognised the need to be open and transparent in its decision-making, but has now privileged public opinion as the *primum mobile* of policy.

Every advisory committee and interest group has referenced data on public attitudes when formulating and disseminating their policy recommendations. However, most of the research on public attitudes has failed to distinguish the

'informed' from the 'uninformed' public. This methodological oversight may have serious implications for policymaking. In order to provide some answers to the fifth research question, this section will investigate the role of public opinion and the media in shaping the policy framework around genetic information and life assurance.

#### **4.1. The Problem of an Uninformed Public**

Although there has been a great deal of research on public attitudes toward the 'new genetics' in general, few have specifically investigated the genetics and insurance issue. This section will critically review a couple of these studies and reveal their methodological flaws. Various 'public attitude' surveys will be shown to have produced largely uncritical and superficial findings, which may undermine their utility for policymakers.

The largest quantitative survey of public attitudes toward genetic information was conducted by MORI in 2000. The research was based on 1,038 interviews with members of the People's Panel, conducted between 6 October and 17 December 2000. On the use of genetic information by insurance companies, the survey discovered that: '... two thirds are aware that human genetic information can be used for setting insurance premium levels, but only eight per cent back its use for this purpose.' (MORI, 2000b) Greater awareness was evident in those respondents with 'high genetic knowledge', who also tended to be more sceptical of the commercial use of such information. However, the criterion used to determine those with high genetic knowledge' was rather simplistic. It was based solely on the

ability of respondents to recognise three diseases as having an hereditary origin. Furthermore, one must question the underlying rationale of distinguishing respondents on the basis of their knowledge or ignorance of the *science* of genetics. A high knowledge of genetic science does not necessarily make one more proficient in assessing social policy issues around the use of genetic information. It would have been more appropriate, perhaps, to stratify respondents on the basis of their knowledge or ignorance of the more nuanced social and philosophical issues that underpin the issue; knowledge that may be more useful for assessing the validity of competing knowledge claims.

The primary finding of the MORI report was that the majority of respondents (78%) considered it inappropriate for insurance companies to use genetic test information for setting premium levels. 57% disagreed strongly with the statement that insurance companies should be permitted access, while 62% believed that although there was no *technical* reason why insurance companies could not use the information for this purpose, they *ought to be prevented* from doing so on. The survey also discovered that in terms of third-party access to genetic databases, insurance companies were least trusted to be responsible users. Four in five respondents stated that insurers should be prevented from accessing such information. The 1999 *British Social Attitudes Survey* found that 75% of the public did not believe insurance companies should be able to rate policy applicants based on genetic test information, which is consistent with the more current MORI data. There appears to have been no improvement in public confidence. Opinions were also found to vary considerably with age. 25% of those aged over 65 thought insurance companies should have access but only 5% of those under the age of 25

considered access appropriate. Those with low levels of genetic knowledge were also more likely to support commercial use of genetic information. This data corroborates other studies, referred to in the following chapter, which reveal that publics that are more knowledgeable tend to be more critical of the social applications of science and technology.

One interesting finding of this research was that respondents thought it more appropriate for insurance companies to access genetic information for health-related insurance products than products such as travel and home insurance. For life assurance, 30% of respondents thought it appropriate for companies to use genetic information. The results for other products were; home contents (6%), travel (18%) and pensions (19%). 35% of respondents thought health insurers should be permitted access. These are interesting results. On the one hand, they appear to reveal respondents' awareness that the commercial need for accurate predictive data is more acute for health-related insurance products. However, it also demonstrates, rather surprisingly, that the public does not believe that there is a greater moral imperative to provide health-related products to everybody regardless of their risk status. Much is made by various interest groups of the public's desire to promote a 'politics of inclusion' and provide health-related insurance products to all. However, this data suggests that people are not as critical of life assurance providers as they are of travel and motor insurance providers.

Overall, the findings of the MORI poll were fairly mixed. There was certainly evidence to suggest the public are cynical of the insurance industry in general. However, many of the findings were not particularly surprising. We know that in

general insurance companies do not enjoy a great deal of public support or confidence. Most people asked to comment on the insurance industry tend to draw upon anecdotal evidence of insurance companies acting duplicitously. Furthermore, individuals' personal experiences of the seemingly arbitrary and unregulated practices of car and travel insurance providers might shape their frame of reference when responding to these very specific issues. Again, it is interesting that there were very different responses when respondents were asked to comment on the use of genetic information for specific insurance products. Although a majority believed that insurance companies should not have access to the genetic test data, this majority was greatly reduced when the question specified particular insurance products. Yet, many interest groups continue to claim that a significant majority of the public do not condone the use of genetic information by commercial organisations. Such groups do not appear to have looked at the data critically.

The MORI survey also distinguished 'knowledgeable' and 'ignorant' respondents rather too simplistically. Therefore, there was no accurate data on how public beliefs are modified. There is a need to understand the ways in which people modify their beliefs once they become 'informed' of the underlying theoretical complexities of the issue. When there is both an ignorance of the scientific basis of genetics, and an intuitive distrust of the private insurance sector, it is no surprise that most people randomly surveyed express a desire to prohibit insurance providers accessing their genetic medical records. Such quantitative data can provide us with little more than a superficial veneer of what the public thinks about these issues.

The 101 public responses to Section 1 of the HGC *Whose Hands on Your Genes* document produce the same kinds of results as the MORI survey, because once again there was little attempt to tap into the views of the 'informed public'. In this study, it was discovered that 59% of respondents did not believe insurance companies should be permitted to use the results of an individual's genetic test to calculate their premium.<sup>5</sup> (HGC, 2001d, HGC01/P9, Annex A) 49% of respondents thought that genetic information needed to be protected in a different way to other forms of medical information. The respondents believed that genetic information raises new social and ethical problems, ought to be singled out for special legislative attention, and that genetic privacy should to be protected in the context of insurance contracts. This particular survey should be treated with even more caution than the MORI research, because the number of responses to the HGC consultation document was so low. Furthermore, there is no way of knowing what background knowledge the respondents were drawing upon when expressing their opinions. Also, the question asked by the HGC was simply whether insurance companies should have access or not. There was no opportunity for the public to respond to the issue within a contextual framework, where specific commercial or social circumstances might challenge their opinions and lead to a re-evaluation of initial beliefs. For example, if one responds that no company should be permitted to factor in genetic test information when underwriting policies, the question arises

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<sup>5</sup> Voss, 2000 reported to the HGC on public attitudes towards the use of genetic information through a literature review on work conducted over the previous 10 years on the issue. She discovered only five reports, which generally revealed a strong public scepticism of the insurance industry's use of genetic information. She referred to Radar's, 1999 work, which found that there was stronger opposition only to employer's use of genetic information. (Voss, 2000)

See also Singer et al, 1998 who reviewed trends in public attitudes to genetic testing, therapy, and engineering, based on Gallup questions, Roper Centre for Public Opinion Research, and polls in the Public Opinion Quarterly between 1937 and 1998. Although their focus was on the United States, the results were analogous to similar studies conducted in the UK. There has been a general upward trend of public scepticism regarding privacy, and increased public perceptions of adverse risk. (Singer et al, 1998, 635-637)

as to whether this would apply both to positive tests and negative tests. These two very different contexts require clarification. Such narrowly focused and superficial surveys may prove dangerous if they are used uncritically to buttress particular social goals or political ideals.

Public surveys might prove useful for discovering how general public attitudes perhaps vary by age, class, and gender. The Office of Science and Technology (OST), with the aid of the Wellcome Trust, conducted this kind of survey on public attitudes to science in 2000. They categorised respondents as 'confident believers', 'technophiles', 'supporters', 'concerned', 'not sure' or 'not for me', based on the kinds of answers given to a series of questions on controversial science issues. (Office of Science and Technology & Wellcome Trust, 2000) Each category tended to be monopolised by certain social groups. This was not a survey on a single issue, which often requires respondents to be given some background knowledge if it is to be useful. However, studies may contribute towards our understanding of the disparities that exist between different social groups' engagement with science. This could provide a basis for future qualitative research on more specific concerns. Nevertheless, such surveys should not, on their own, be granted a legitimacy they do not deserve, and certainly should not be considered a suitable basis from which to shape formal policy.

#### **4.2. The Role of the Media**

The media have had a central role in shaping public attitudes towards both genetic science and the specific issue of genetics and insurance. The tendency of

the media to over-hype genetic science may have been crucial to the way negative public beliefs and attitudes have been formed. It is evident that the media has been keen to accentuate the determinacy of genes. The potential interest of the commercial sector in using such genetic information serves only to increase the rhetorical power of their headlines. For example, a story appearing in the Financial Times in February 1997 was headlined 'Losers in the lottery of life'. The article contemplated the 'brave new world' of genetic testing and expressed fears that:

'... affordable life and medical insurance could eventually become the preserve of a select, healthy minority with people who are too ill, too old or simply have the wrong genetic make-up being charged prohibitively expensive premiums –or even refused cover all together.' (The Financial Times, 22 February 1997, page 3)

Despite adding the caveat that we are still in the realm of speculation, the article still attempted to portray a potentially dystopian future in which insurance companies perniciously discriminate against at-risk policy applicants who then form a 'genetic underclass'. Another article on 7 November 1998 was headlined: 'A premium issue: The cost of life insurance could one day depend on your genetic code.' (The Financial Times, 7 November 1998, p 9) Yet another from August 1999 read: 'Your life in their hands – like it or not: do you fancy the idea of insurance companies probing your genes for potential diseases before providing you with cover?' (The Financial Times, 14 August 1999, p 1) More recently, an article in the *Guardian* Newspaper, 'Cancer Gene Tests 'will destroy private health'', reported the views of Sir Paul Nurse, a Nobel prize winning scientist and head of the charity Cancer Research UK. He claimed that advances in genetic testing would eventually collapse the private insurance market altogether, and that in the next



few decades socially-based insurance systems would have to come to replace all forms of private provision. ( Guardian Unlimited, August 5<sup>th</sup>, 2002)

It must be recognised that the media, just like all other social institutions, is not composed of homogenous actors with shared goals and ideologies. The media is a complex and heterogeneous medium for knowledge dissemination, with varying degrees of quality and objectivity. However, although there is a great deal of constructive and responsible reporting, the liberal use of extremely emotive language, even in the broadsheet media, and a tendency to grant greater legitimacy to those who are radically opposed to insurance companies using genetic information, may have only a negative impact on both public attitudes and the political system that chooses to react to them. Many of the interview respondents had serious reservations about the role of the media, particularly the insurance representatives. Graham Austin replied to the question on media influence by exclaiming:

It's a good media story. I mean to run the story that X, Y, Z, has got a family history of this, has got BRCA 1 [Breast cancer gene] and was turned down for life assurance makes a great story. Whereas someone with a positive Huntington's test gets life assurance. Where is the story in that.

Clinicians tended to point to the negative impact media reporting on genetics may have on peoples' expectations of what current genetics services can offer them. Some also pointed out that their patients are more likely to raise the concern over insurance when there is a particular flurry of media attention around it. Patient-

support groups claimed to have experienced the same problem. Julia Cream expressed ambivalent views about the media. She stated:

It's often in our favour, so while it might not always be correct or may be sensationalist it's usually helped get our message across and keep it alive. But the downside of that is that when there is a mixed message, so when they talk about Alzheimer's rather than identify it as familial early onset Alzheimer's, its our staff on the helpline that have to deal with all the extremely anxious members of the public'

Just as she was selective in which advisory committees she chose to place her faith in, Julia Cream again makes no apology for supporting media coverage that gets the Alzheimer's Society message across, even if the stories are inaccurate or sensationalist. This statement illustrates the way stakeholder and interest groups may, through their support of particular media sources, obfuscate truth in order to have a broader set of social, political, and ideological goals realised. Alistair Kent of GIG was more critical of the media. He claimed that their frequent demonisation of the insurance industry does nothing to enhance the quality of debate. He stated:

Oh this is a great story. Everybody thinks that the insurance companies are out to screw them ... It's a great story and I certainly wouldn't claim that the insurance companies are philanthropists, but ... Individuals within the companies are ... like you and me ... they're sort of mere mortals and fallible, but you know most of them are not ... overtly getting up in the morning thinking "how many claims can I reject today, what excuses can I find to screw the customers?" They are trying to do a decent job against the standards that are set for them. Again, it's about our own expectations.

Again, we must consider the differential treatment of evidence. Earlier, it was revealed that political institutions had granted differential levels of legitimacy to particular stakeholder accounts. Here, stakeholders appear to be differentially treating the quality of media reporting by reference to how well it represents and

supports their particular interests. For some, the media exists as a necessary evil to be tolerated if it largely supports their political cause. However, if we do not have balanced reporting by the media, then members of the public are always going to have a skewed perception of the broader nuances of any controversial policy issue. If one subsequently situates 'uninformed' public opinion at the centre of policymaking, one *is de facto* basing important policy decisions on the reports circulated by a sensationalist media. This is both undemocratic and may lead to iniquitous policymaking based on the lowest common denominator.

This section has illustrated the problematic nature of public opinion, and its influence on the strategies of policymakers and interest groups. Members of the policy community constantly refer to the public mood, or the public attitude, claiming that their decisions must be based on what the public needs and desires. However, this section has demonstrated that few have drawn a line of demarcation between the informed and uninformed public. Even fewer have considered the role of the media in arousing public fear and scepticism. One might ask if the social position of media representatives affects their coverage of the genetics and insurance issue. Personal insurance products are important to self-employed people such as journalists, so they have a stake in the outcome of this issue. The genetics and life assurance problem is certainly one that has been given a great deal of attention within both the policy community and the media. Why a problem that currently affects such a small section of society, and is unlikely to be significant in the near future, garners so much focus and attention certainly requires further analysis.

At the beginning of this section, it was argued that the Government is now far more attentive to the perceived concerns of the public, partly because of the social and political crisis that enveloped the BSE controversy. However, one must question how far, and for how long, the Government will be willing to prioritise what it perceives to be the 'public mood'. At the moment, the Government has nothing to lose by imposing moratoriums and reprimanding the industry for its commercial excesses. The reality is that in the short-term, the commercial sector will not suffer adversely from a moratorium. The Government's decision poses little threat to their traditional interests and freedoms. Furthermore, the moratorium ensures that the Government need not begin contemplating subsidisation of the genetically disadvantaged through public taxation. The question becomes: if at some point in the future a real threat to commercial insurance emerges, will the Government shift their position and begin to represent the sectional interests of the corporate sector? Appeasing public attitudes is all well and good if there are no economic burdens to deal with.

The Government's recent crisis over MMR vaccination serves to illustrate the point that political institutions are quite willing to turn against the public if it is politically advantageous. The Government's policy position on MMR can be contrasted with their policy approach to genetics and insurance. In the former case, Government endorsed 'experts' shaped the policy framework. However, in the latter case, it has been largely the 'uninformed public' who have driven policy. Nevertheless, a politicised decision-making framework has been the guiding principle in both cases. Representative institutions often fall into one of two extremes. Either they attempt to represent the ambiguous and highly problematic 'Public', or alternatively represent particular sectional interests; usually powerful

commercial lobby groups. Both responses denigrate the power of reasoned argument and equitable decision-making.

In considering the fifth research question, the evidence suggests that perceived public opinion has had a palpable influence on the strategies of key stakeholders and the evolution of the policy process. The media has also been shown to have aroused public fear and scepticism. However, it has also been demonstrated that representative institutions, and stakeholder groups, have failed to recognise the crucial distinction between an informed and uninformed public. The consequence has been that the decision-making framework has proved inadequate as a means of establishing some rational, evidence-based boundaries to this complex and expansive social and technological problem. When one draws too heavily on a perception of what the public thinks, wants, or needs, then policy is likely to be based on the lowest common denominator of decision-making. It is likely to reflect the narrow prejudices of an ambiguously defined public. Stakeholders may then strategically use this ambiguity in order to envelop their ideological beliefs with a veneer of legitimacy. In the following chapter, the problems that can arise when one seeks to uncritically represent the public will be investigated further. The final section of this chapter will look critically at the moratorium decision, in the context of the insights gained through the preceding analysis of the policy process, and assess its suitability as the best means to reach equitable decisions on this issue.

## **5. REFLECTIONS ON THE CURRENT MORATORIUM**

Because of the highly political nature of the genetics and life assurance debate in the UK, and the apparent failure of the policymaking organisations to initiate a broadly based, informed, and impartial consensus-building approach, many people have argued for a more comprehensive strategy.

### 5.1. *Towards More Effective Debate*

Harper (1997a) believes that there has been a serious lack of constructive dialogue between the insurance industry and clinical geneticists on the scientific and social aspects of the genetics and life assurance problem. In 1993, Harper argued that many genetics professionals had already foreseen the potential implications, but they had been largely ignored by the insurance industry. (Harper, 1993) One of the crucial observations to emerge from the analysis of the policy process was the extent to which the issue had been defined by the mobilisation of a variety of distinct 'experts', from a number of disparate professional fields, who had failed to communicate with each other effectively. Harper had stressed in 1993 the vital importance of extensive discussion between a *variety* of stakeholders. He wrote: 'To allow an issue of such practical and ethical importance to drift into unconsidered and piecemeal applications is unacceptable.' (Harper, 1993, 227) Konotey-Ahula (1993), in response to Harper, argued that no one group should be permitted to dominate such a dialogical process. Although Harper has generally been critical of the insurance industry's interest in new kinds of genetic information, his appeal for broader deliberation was noble and constructive. Other scientists, such as Dykes (1996), concurred with Harper's call for rational dialogue. He wrote: 'Open and informed debate including scientific, medical, commercial, lay, ethical

and legislative representation is urgently required to ensure that safeguards agreed to be necessary are put in place.' (Dykes, 1996, 694) The most salient word in this quote is 'informed'. One cannot deny that the formal decision-making process has been 'open' and 'transparent', particularly since it has involved groups usually excluded from the decision-making process, but the evidence suggests that it has not been 'informed'.

Kaufert (2000) accentuates the politicised nature of the debate when she argues that:

'...the debate over insurance is interesting, not for the accuracy of the different predictions, but as a source of insight into the claims being made by different groups as they manoeuvre for a stronger position or struggle to defend their existing interests. It is also interesting because it is contentious and its conflicts best reveal the differences in perspective between key actors.' (Kaufert, 2000, 827)

The analysis of stakeholder accounts and their representation in the policy framework, provided in this and previous chapters, supports Kaufert's view that what is interesting in this debate is the ways in which various actors have sought to use the political process instrumentally in order to ensure their interests and values are both recognised and prioritised. Every stakeholder hopes that their definitional framework, moral position, and ideal means of resolution will be the one that wins through in the political process. This may be one reason why stakeholders appear to use rhetoric strategically, draw on a broad narrative repertoire, and shift between definitional frameworks in particular contexts. Kaufert is quite right to promote greater research into the political manoeuvring of certain interest groups, and the competing knowledge claims they articulate. When one is developing policy on

contentious science issues that have relatively unknown social consequences, political and ideological intransigence is more likely to impede constructive progress and undermine strategies for resolution. Kaufert herself describes the debate as a:

'literary construct, put together by lawyers, ethicists and journalists, based on their knowledge of how the existing insurance system works, and coupled with a series of assumptions about the new genetics ... there are too many unknowns, too little data and too few cases from which to generalize.' (Ibid, 827)

It is partly a consequence of the lack of reliable evidence, and thus the diminishing explanatory power of any single perspective, that ideologically-based political rhetoric tends to dominate proceedings. Commercial practicalities and professional rules of thumb may have directed the conjectures of 'experts', but when the debate entered the political realm, it appeared that a precautionary principle based on 'fear of an unknown future' existed as the guiding rationale. Although it is ultimately society as a whole that must set the ethical boundaries of genetic technology and its social applications, not just the appointed 'experts', (Kinderlerer et al, 1998), it is important to promote rational, evidence-based deliberation for evaluating competing knowledge claims.

## **5.2. Moratoriums, Regulation, and International Perspectives.**

It is interesting to note that the UK has been one of the few countries in the world to take the regulatory path, through the establishment of a series of moratoriums. Most countries have enacted legislation to prohibit insurers' use of specific genetic



test information. However, the initial policy of industry self-regulation in the UK lacked the confidence of both the public and various interest groups. Baldwin and Cave (1999) claim that such self-regulatory mechanisms often attract criticism because they are perceived to be unfair to those affected by the regulatory decisions. (Baldwin and Cave, 1999, 132) The authors write: 'Past experience suggests that self-regulators have a sporadic, unstructured, and patchy record of consulting those with interests in the workings of their systems.' (Ibid) This was somewhat true of the ABI system of self-regulation where, despite gaining feedback through a citizens' jury, the code of practice was established without significant consultation with both the wider genetics community and those vulnerable groups who may in the future be affected by the decisions.

The current regulatory framework, which contains greater checks and balances on industry practice, still falls short of any formal proscriptive legislation. Many believe that the legislative response of other countries should be applied to the UK. However, one must be careful in using cross-national comparisons as a basis for policymaking. The social framework within which various kinds of insurance products exist has significant implications for the kind of policy likely to prove appropriate and effective in the long-term. Firstly, many countries have been concerned solely with health insurance, particularly the United States. There is a much stronger argument for legislative redress in this area, since healthcare has a greater claim to being considered a primary social good than life assurance. Nevertheless, even in the United States, legislation has not been all encompassing. Federal protection of privacy only extends to those who acquire their cover through group insurance plans. Little protection is given to those who purchase individual

policies. Most European countries have also focused on healthcare, particularly those whose systems are managed by the private sector. Of those that have looked specifically at life assurance, the majority have implemented simplistic legislation prohibiting the use of genetic information in underwriting.<sup>6</sup>

It might have been pragmatic for the UK to avoid legislation and establish a flexible regulatory approach. However, the evidence presented in this chapter suggests we should question the ability of the moratorium to promote a dialogical process acceptable to all key stakeholders. However many committees are set up, and however many public consultation exercises are established, if stakeholders do not feel confident that their own interests will be assessed rationally and fairly, then the process itself can enjoy little legitimacy. Outcomes do not enjoy legitimacy simply because they satisfy the majority view. The process itself must be seen to be fair and acceptable, in principle, to all. Even if the decision made through a conciliatory and equitable process leads ultimately to a less ideal outcome than one achieved through political bargaining, it may still enjoy greater legitimacy in principle. If one proceeds indefinitely with a politically entrenched process in which some views are given greater priority than others, simply because it is politically expedient to do so, eventually a decision will be made that unjustifiably subjugates the rights and interests of a particular group. So far, there has been little attempt to reach consensus on some of the substantive issues underlying the debate. Since the implementation of the five-year moratorium, many of the official regulatory and

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<sup>6</sup> See Reilly, 1997 and Chin-Hul Lai and Kleiner, 1999 for a comprehensive analysis of State and Federal legislation on genetic information and insurance. Frankel, 1999 also provides an excellent analysis of the political interests in the US shaping congressional decision-making. He points to the coalitions that have been established, under the banner of genetic privacy rights, which have had a significant impact on the way Government has framed the agenda. Rather like in the UK, it has mainly been those people against insurer's access to genetic test information whose voice has resonated loudest in the political process.

policy bodies have produced very little in the way of new strategies for resolution. One exception has been the HGC and GAIC. Recently (24 September 2003) they set up a joint public meeting to discuss genetics, insurance, and fairness. Three substantive issues discussed were insurance products and the relevance of genetics, the use of family history by insurers and geneticists, and individual protection against risk. (HGC, 2003, page 1) The rationale for the meeting was to allow various stakeholders to discuss some of the broader issues pertinent to the problem. These kinds of meetings are certainly important, and likely to provide a means of reaching consensus, but their role has, historically, been relatively marginal. There have been far too few meetings like this over the past few years.

Cook (1999) argues that ethics and morality must be used to aid society in coming to terms with the genetics and insurance issue. He points to the danger of allowing geneticists and insurers to make decisions alone. Cook believes that legislation can be avoided if professional bodies can maintain general good practice and enjoy the support and confidence of the public. He writes: 'The retreat to legislation is a confession of failure in terms of our ability to relate to each other and to order our medical and insurance practices.' (Cook, 1999, 162) A decision-making structure that recognises political and ideological dissonance, but does not allow this to define a particular policy outcome, may provide the only means of avoiding the worst consequences of rash and emotive policymaking, and might truly enjoy both public and commercial confidence.

## 6. CONCLUSION

This chapter, and the one preceding it, has provided a comprehensive sociological analysis of stakeholder accounts of the genetics and insurance problem, and their representation in the formal policy and regulatory process. The first section of this chapter assessed in detail the work of the various advisory committees and regulatory processes that have been responsible for shaping policy over the last few years on the issue of genetics and insurance. This section was guided by the fourth research question. The formal policy process, it was argued, emerged in response to growing fears and concerns that a genetic underclass might emerge if insurers have unrestrained access to new kinds of medical information. This process was supposed to provide a balanced assessment of the likely social, commercial, and ethical implications, and offer the Government pragmatic, evidence-based policy recommendations. However, an analysis of how this process emerged and evolved, and a critical examination of the advisory committee system and those interest groups that have contributed to it, revealed inherent flaws that could undermine equitable policymaking. The various committees appeared too narrowly focused and often neglected the deeper social, ethical, and commercial complexities of the problem. They, like the relevant stakeholders, tended to operationalise particular narrative frameworks and marginalise or prioritise certain substantive issues. They also differentially judged the legitimacy of stakeholder evidence based on what was for them politically expedient. The frequent use of emotive language such as 'discrimination', 'social exclusion', and 'genetic underclass', without recognition that such concepts are

highly ambiguous and contested, served to underlie the extent to which the debate had become politically-charged and ideological.

The third section focused on stakeholder accounts of the policy process. This contributed further to answering the third research question. Even though most stakeholders could accept, in principle, the current moratorium, the lack of faith in the political process itself revealed the underlying flaws in using this kind of system for arbitrating competing interests. The fact that the various stakeholders had very different reasons for accepting the moratorium, differentially judged the nature of the political process and the legitimacy of those committees constituting it, and appeared divided as to what the eventual outcome of the compromise ought to be, demonstrated further the political conflicts that will likely persist throughout and beyond the moratorium.

The fourth section further revealed the politicisation of the genetics and insurance debate, through a critical analysis of the impact public opinion, and media representations, has had on the strategies of stakeholders and the policymaking/regulatory process. Perceived public opinion appeared to be driving not only the political response to the issue, but also the strategies of key stakeholders as they gave account of their beliefs. The media was also shown to have aroused public fear and scepticism with their emotive anti-insurance industry rhetoric. The frequent reference to 'the public', within policy documents and expressed by interview respondents, was shown to be based on an inaccurate perceived understanding of who the public are and what they really believe. The various polls and surveys carried out to reveal the true public mood were also

critiqued for failing to distinguish between an informed and uninformed public. Because survey data is often used strategically by various organisations and interest groups to legitimise their beliefs, and may directly influence the policy framework, the distinction becomes even more crucial. The failure to look more critically at public attitudes resulted in a policy process that responded to the perceptions of an uninformed and ambiguously defined public who, unsurprisingly, had little interest in commercial norms and values. This section provided interesting answers to the fifth research question.

The final section concluded the chapter by reflecting on the status of the current moratorium. It was argued that the debate may need to be broadened so that the deeper and more nuanced roots of the problem can be deliberated in a fair and equitable manner. The continued conflict between the basic interests and values of stakeholders has done little to help the policymaking process. If anything, it has rendered it evermore complex and capricious. The question is whether an alternative, citizen-centred process of decision-making might provide a better means of resolving this conflict. The final chapter will assess the suitability of the citizens' jury approach and provide answers to the final research question.

## CHAPTER 5

### TOWARDS PUBLIC CENTRED DECISION-MAKING: THE CITIZENS' JURY AND THE VIRTUES OF DELIBERATION

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#### 1. INTRODUCTION

The preceding chapters critically assessed a number of complex issues surrounding the use of genetic information by life assurance companies, and revealed a number of flaws in the policymaking and regulatory process. They

offered a critical sociological analysis of the substantive theoretical issues underlying the debate, and began to highlight the diverse ways in which key stakeholders can manipulate the social, political, and ethical boundaries of the problem by marginalising or prioritising particular value narratives. The purpose of this chapter will be to assess, in light of the issues so far discussed, the suitability of the citizens' jury as an alternative policymaking model. This chapter will provide answers to the sixth research question. The substantive theoretical issues underlying the citizens' jury method, as well as its practical exigencies, will be critically evaluated.

The opening section will look at the role of representative democratic institutions and reveal their inherent flaws. In practice, such institutions have a tendency to represent either what they perceive to be the ideological beliefs of the majority or the sectional interests of a minority. This section will discuss the political ideals of the early intellectuals who helped create the liberal tradition of representative government. However, it will situate their defence of liberal democracy within an historical context; one where the majority had no political voice and procedurally representative institutions emerged as the only conceivable alternative to minority privilege. This historical 'ideal' still resonates with contemporary democrats who often fail to recognise the limited quality, legitimacy, and fairness of the actual decision-making that takes place within representative institutions.

The next section will present the deliberative turn in political theory as foreshadowing contemporary experiments in citizen-centred decision-making. The case for basing policy decisions on the deliberative reasoning of citizens will be juxtaposed to the weaker proceduralist/constitutionalist conception of



representative democratic institutions. This section will lay the foundation for a critical assessment of the citizens' jury.

Section 3 will move beyond the abstract theories of deliberative democrats and provide a critical sociological analysis of the citizens' jury model in action. Although the benefits such a model might bring to democratic decision-making will be presented, various theoretical and practical problems associated with such a radical system will also be raised. Most contemporary experiments with the citizens' jury method will be criticised for having operationalised ill-conceived notions such as the 'common good', uncritically defended an ideal of representation, and failed to give participants any real decision-making power. Difficulties around the issue of facilitation and democratic legitimacy, as well as the more complex problem of how citizens' juries can supersede weak proceduralist representative institutions when they are bound by similar procedural rules, will also be addressed. Such problems may require the model being presented simply as an 'ideal' regulatory mechanism for resolving the genetics and insurance dilemma.

In the final section, further internal and external contingencies of the citizens' jury model will be contemplated. The issue of the public understanding of science and expertise is one particularly crucial issue, because the way in which we conceptualise the relationship between lay and expert opinion may have fundamental implications for the efficacy of any jury system.

By the end of this chapter, the citizens' jury model will have been critically assessed. The advantages and disadvantages of the approach will have been presented so that we can offer some answers to the final research question.

## **2. INTERESTS, IDEOLOGY, AND THE POVERTY OF REPRESENTATIVE DEMOCRACY**

Evolution of the idealised form of representative government that now dominates most Western societies was a slow and arduous process. It was dependent on the experiences of individuals who found themselves situated in a succession of tumultuous and ideologically unstable historical periods, which began to mould their conception of the constitutional boundaries of 'good government'. The Enlightenment, in particular, played a significant role in reconfiguring peoples' perception of their place in traditional social hierarchies. The emergence of liberalism, as a political movement based on the inviolable rights of individuals, both shaped and represented these changing constructions of the political order, and served to challenge the minority power and privilege that dominated the antecedent social and political landscape.

Once liberalism became the dominant ideology, representative government emerged as the archetypal democratic model for uniting both the liberties and obligations of citizens within a new framework of political equality. The early proponents of representative democracy focused predominantly on the design and formal implementation of procedural rules to guarantee all interests would be recognised within the social and political institutions of a government by and for the people. However, although the intentions of these early democrats were laudable, and perhaps imperative in the context of the great inequalities of their time, it would be inappropriate to take for granted the democratic procedures they considered so essential for effective government. In particular, one may need to question the premise that formal representation within the central political institutions, coupled with regular casting of votes within a party political system, by its very nature enhances the quality and legitimacy of decision-

making. However, the widespread acceptance of the contemporary representative democratic model, held by many to be the emblem of a free and open society, has perhaps undermined critical analyses of the quality of deliberation that takes place within its institutions.

### **2.1. Proceduralism Within Representative Institutions as a Means of Protection Against Tyranny**

John Stuart Mill's famous essay *Considerations on Representative Government*, offers one of the most salient defences of the representative system of government and the procedural rules necessary for sustaining it. However, despite being an advocate of the representative structures of government, Mill also recognised that political institutions are the conscious creation of human subjects. Therefore, the mere existence of the system does not by itself determine the quality of decision-making. Mill posited an important qualitative distinction between the machinery of government and those citizens who actively engage with it. Even if the quality of the formal political machinery is high, this can prove impotent as an equitable and legitimate vehicle for social and political change if participants lack certain fundamental qualities or virtues. Mill wrote:

'... if the checking functionaries are as corrupt or negligent as those whom they ought to check, and if the public, the mainspring of the whole checking machinery, are too ignorant, too passive, or too careless and inattentive, to do their part, little benefit will be derived from the best administrative apparatus.' (Mill, 1998, 228)

Mill wanted to promote the ideal of an active and educated citizenry, as he believed that those who wield political power should be drawn from the most

intelligent and virtuous members of the community. However, he also longed for the representation of *all* interests, not just those of a minority or majority. Mill was as much concerned by the possibility of 'tyranny by the majority' as he was of an 'elected dictatorship'. He wrote: '... no class, not even the most numerous, shall be able to reduce all but itself to political insignificance, and direct the course of legislation and administration by its exclusive class interest.' (Ibid, 326) Tocqueville, in his classic text *Democracy in America*, also feared that American democracy, despite its laudable attempt to harness a 'spirit of liberty' that resonates naturally within free, fair, and democratic institutions, might fall into the trap of acquiescing to the whims of a majority. He wrote: 'If it be admitted that a man possessing absolute power may misuse that power by wronging his adversaries, why should not a majority be liable to the same reproach?' (Tocqueville, 1994, Vol 1, 259) In his book, *The Road to Serfdom*, Hayek (1944) also argued that it would be a mistake to assume that as long as the majority will is the primary source of power then that power is non-arbitrary. He wrote:

'There is no justification for the belief that so long as power is conferred by democratic procedure, it cannot be arbitrary; the contrast suggested by this statement is altogether false: it is not the source but the limitation of power which prevents it from being arbitrary. Democratic control *may* prevent power from becoming arbitrary, but it does not do so by its mere existence.'  
(Hayek, 1944, 74)

The concerns and anxieties expressed by these early democrats are just as important today. However, despite recognising the possible aberrations of representative government, most early intellectuals believed that solutions lay within the framework of the representative system itself. They believed that tyranny by majorities or minorities could be tempered by simply reconstituting the rules and procedures of the political system. The intractable problem of how

best to balance the competing interests and ideologies of particular individuals and groups was not considered one germane to the system of representation itself, but merely to the way in which it was constituted and utilised by the people.

Today, the constitutionalist/proceduralist system of representative government is revered as the best and most practical model for contemporary liberal societies. Many believe that the virtue of a representative institution lies in its ability to aggregate individual preferences and prescribe inexorable rules and procedures for guaranteeing their expression. However, by idolising a particular form of representative government, they often ignore its inherent flaws as an equitable system of decision-making.

## **2.2. Ideology, Interests, and Politicisation: The Poverty of Representative Institutions**

Decision-making flaws within representative institutions have a number of root causes. These fall broadly under the categories of ideology, interests, and politicisation. Once representative democracy establishes itself as the dominant model of a nation's political order, every decision tends to be defined as a political action guided by political interests and expediency. In party political systems, individual rights, interests, and reasons for embracing certain political and social beliefs become subsumed under an imagined group ideology, which the respective political parties then attempt to represent, manipulate, or even create. This is perhaps inevitable, as no political institution or party can effectively represent the totality of diverse interests circulating within society. Therefore, they must aggregate the preferences of atomised individuals under

the rubric of a single coherent political philosophy. Touraine (1998) grasped this point most clearly when he wrote:

'If interests are multiple and diverse and if, ultimately, all voters have a series of particular demands ... it is impossible to define a policy that represents the interests of the majority or of a number of important and active minorities. If representativity is to exist, the demands that emanate from very different individuals and sectors of social life must be aggregated.' (Touraine, 1998, 51)

However, in trying to aggregate individual preferences, representative democracies tend to operationalise a 'universalist' approach to policymaking. When confronted with a particularly complex policy problem, such as the issue of genetics and insurance, representative institutions conceptualise solutions by reference to how they may satisfy the demands of various group interests. The inherent quality of the arguments becomes subordinate to an appreciation of both the real and imagined power of 'stakeholders' and the 'public'. The previous chapter revealed how the Government sought to placate an imagined public opinion when developing its policy on the genetics and insurance issue. They could have simply appeased the minority interests of the commercial sector, or those individual consumers who wished to profit from their 'healthy' genetic constitution, but this would still have been a political and ideologically based solution; one that would have simply prioritised either the rights of an open market or the right of individuals to acquire 'social justice'. Representative institutions often fail to equitably balance competing interests because they are driven by a political expediency that becomes practical only by viewing society as a number of stable ideological groups or interests that must be either appeased or antagonised.

What problematises this kind of decision-making process further is that it fails to recognise interests as fluid and unstable individual preferences, which may only emerge through a process of active dialogue. Through deliberation, individuals may modify their beliefs and come to realise that their underlying interests are different to how they imagined them to be prior to discursive engagement with fellow citizens. However, in pluralistic societies dominated by representative institutions, the scope for citizen participation in deliberative forums has become severely limited. Therefore, interests are aggregated and artificially fixed under totalising group ideologies. The political representatives then merely play the game of politics in order to increase their power and influence. Politics becomes, as Weber aptly described, a vocation whereby: 'He who is active in politics strives for power either as a means in serving other aims, ideal or egoistic, or as "power for power's sake," that is, in order to enjoy the prestige-feeling that power gives.' (Weber, 1946, 78)

For Weber, this competitive and elitist form of parliamentary government was inevitable in modern bureaucratic societies. As someone intuitively distrustful of the masses and their 'emotionality', and a vociferous critic of direct participation, he welcomed the emergence of the intellectual career politician as a constructive development in modern bureaucratic governance. He believed that the electorate should enjoy the minimalist role of periodically removing incompetent leaders. Schumpeter (1943) expressed a similar view with his theory of 'competitive leadership'. He argued:

'... the democratic method is that institutional arrangement for arriving at political decisions in which individuals [politicians] acquire the power to decide by means of a competitive struggle for the people's vote.'  
(Schumpeter, 1943, 269)

Weber's analysis of bureaucratic governance, and Schumpeter's writings on competitive leadership, aptly describe a contemporary political landscape, in which the power and influence of the citizen has become seriously corroded. However, while Weber and Schumpeter believed the attenuation of power invested in the citizen to be a panacea for democratic poverty in pluralistic societies, an argument could be made for weakening the stronghold of political elites in order to reinvigorate democratic citizenship.

It is not just the political parties and institutions that must politicise every policy issue, and think in terms of universal ideological categories, within the modern structures of representative government. Individual citizens, if they desire any form of real political power, must themselves subsume their individual preferences under the banner of a universal group identity. The political system is then used instrumentally to promote the supposedly shared ideology of the group. Interest groups become mere lobbyists who attempt to force government to accept their own conceptualisation and interpretation of the 'social good'. Touraine asks:

"How can democracy be preserved if African Americans, Native Americans, and women define themselves primarily in terms of their being and see institutions merely as instruments promoting the interests of an elite or, alternatively, their own interests?" (Touraine, op cit., 65)

Again, the preceding analysis of the genetics and insurance debate revealed the ways in which stakeholders ultimately use the political system to protect sectional interests. It is a consequence of stakeholders having to use representative institutions instrumentally, that individuals must imagine themselves as part of a broader political interest. Otherwise, they lose any



effective voice and have no guarantee that their disparate interests or desires will be satisfied.<sup>1</sup>

The argument put forward in this section has been that representative institutions provide an inadequate mechanism for resolving complex disagreements in policy areas requiring reasoned and impartial deliberation. Because those who defend the existing representative institutions have focused almost exclusively and uncritically on the procedural rules that guarantee all views and interests may be freely expressed, there has been little critical analysis of the actual forms of deliberation fostered within the representative structures themselves. The present system falls under the category of what Held (1996) refers to as 'protective democracy'. This position is predicated on the idea that, '... given the pursuit of self-interest and individually motivated choices in human affairs, the only way to prevent domination by others is through the creation of accountable institutions.' (Held, 1996, 75) In contrast, there is 'developmental democracy', which: '... avers that political participation is a desirable end in itself and is a (if not *the*) central mechanism for the development of an active, informed and involved citizenry.' (Ibid, 75) For developmental democrats, the casting of a single vote every few years does not provide a sufficiently strong basis for informed political participation.

It is clear that the ideal of democracy may often lie discordant with its lived and practical reality. A far stronger conception of democracy may be essential if

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<sup>1</sup> Sometimes groups seek to have their interests legally protected on the basis that their cultural identity is under threat. This often breaks with the equality principle of liberalism in not extending the new rights to those external to the culture. The political theory of "multiculturalism" tends to be supportive of such practices, and often tries to demonstrate that equality is not really being compromised when we allow specific cultures to retain all their identity-dependent practices and traditions. See Barry, 2001 for a comprehensive egalitarian liberalist critique of this strand of the multiculturalism agenda.

we wish to realign the 'ideal' and the 'real' of democratic citizenship. The deliberative turn in democratic theory tried to move us in this direction.

### **3. THE DELIBERATIVE TURN IN DEMOCRATIC THEORY**

#### **3.1 'Thin' and 'Strong' Democracy**

The deliberative turn in democratic thought began to highlight the poor quality of deliberation fostered within representative democracies and tried to create a more active role for citizens. The existing system was labelled 'thin' democracy, because citizens had such a limited role. In the 1980s, Barber (1984) provided a communitarian critique of 'thin' liberal democracy. He advocated an alternative 'strong' democratic model based on direct citizen participation. Barber argued that although the narrow proceduralism of thin democratic models was capable of protecting the individual from unjustifiable assault on his or her private interests and property, it could not promulgate a broader conception of civic virtue and participation. (Barber, 1984, 4) He wrote:

'... thin democratic politics is at best a politics of static interest, never a politics of transformation; a politics of bargaining and exchange, never a politics of invention and creation; and a politics that conceives of women and men at their worst (in order to protect them from themselves), never at their potential best (to help them become better than they are). (Ibid, 24,25)

With 'strong' democracy, Barber imagined the possibility of a community of citizens galvanised by civic purpose, rather than homogenous and stable ideological interests, who unite in search of a common purpose through participatory institutions. (Ibid, 117) Barber considered his conception to be not

only consonant with, but also dependent upon, the politics of conflict, the sociology of pluralism, and the separation of the public and private sphere. Furthermore, the sheer scale of modern bureaucratic and pluralistic societies did not, according to Barber, reduce the scope and efficacy of participatory politics. Therefore, the new model was: 'wedded neither to antiquarian republicanism nor to face-to-face parochialism.' (Ibid, 117) Barber defined 'strong democracy' formally as:

*'Politics in the participatory mode where conflict is resolved in the absence of an independent ground through a participatory process of ongoing, proximate self-legislation and the creation of a political community capable of transforming dependent, private individuals into free citizens and partial and private interests into public goods.'* (Barber, op cit, 132)

Barber believed that his participatory model challenged 'the politics of elites and masses that masquerades as democracy in the West.' (Ibid, 117)

Barber's work influenced a number of deliberative democrats throughout the 1990s. Their debates require some analysis, because they may be crucial to any fair assessment of the suitability of the citizens' jury.

### **3.2 The Nature of Deliberative Democracy**

Bohman (1996) provided one of the most expansive accounts of the nature and scope of public deliberation. Influenced by the work of Habermas, Bohman believed that the 'dialogical approach' to decision-making offered the best alternative to thin representative democracy. He argued that within a truly deliberative process, citizens justify their decisions through appeals to common interests. They are encouraged to base their arguments on reasons that all participants could accept in principle. There is therefore something in the nature

of deliberation, when organised effectively, which produces 'reasonable decisions' that are epistemically superior to those not 'publicly tested'. Deliberative democracy appears to both improve the quality of the reasons for decision-making and simultaneously promote egalitarian principles. (Bohman, 1996, pp 5,6)

Although procedures are a necessary element of any institutionalised form of decision-making, proceduralism itself cannot, according to Bohman, explain why deliberative participants find various arguments convincing. Proceduralism may tell us how to guarantee equality, but it does not: '... specify when a reason is publicly convincing.' (Ibid, 32) Bohman claims that only in a deliberative system can we achieve this publicity requirement. Although representative systems can satisfy two other requirements of any truly authentic democracy, that is non-tyranny and political equality; it rarely satisfies the third precondition.

Fishkin (1991) also supported these three essential conditions of democracy, but argued that most political models are forced to trade-off political equality and public deliberation. He argued that democrats such as J.S. Mill sacrificed political equality in order to achieve non-tyranny and some form of publicity, while most modern democratic theorists have tended to sacrifice deliberation. Fishkin writes: 'We seem to face a forced choice between equal but relatively incompetent masses and politically unequal but relatively more competent elites.' (Fishkin, 1991, 1,2) However, both Fishkin and Bohman believed that only through the deliberative model could all three requirements be met.

Deliberative democrats argue that rationality is an emergent property brought into existence only through co-operation and active dialogue amongst self-

reflexive participants. They recognise that minimal procedural constraints must be imposed on deliberation in order to mitigate the effects of selfishness, the tyranny of vested interests, and the problems associated with the size of deliberative groups. However, it is the primacy of dialogue that most clearly differentiates adherents of this approach from their constitutionalist detractors.

This tendency to construe rationality as an emergent property, realised only through active dialogue, is firmly rooted in the Habermasian idea of 'communicative action' and 'discourse ethics'. In communicative action:

'... actors are prepared to harmonize their plans of action through internal means, committing themselves to pursuing their goals only on the condition of an agreement – one that already exists or one to be negotiated – about definitions of the situation and prospective outcomes.' (Habermas, 1992, 134)

Habermas argued that only through active dialogue could universal norms emerge. His discourse ethics, guided by the principle of communicative action, challenged the contractualist liberalism advocated by Rawls in his seminal text *A Theory of Justice*. Rawls believed in the primacy of justice and exhibited rational deliberation as an ideal means for formulating its aims and objectives. In deliberation, the appeal would be made to public reasons, which in a recent article Rawls claims are characteristic of a democratic people and represent the reasons of citizens and thus the 'public good'. (Rawls, 1997, 93) However, in *A Theory of Justice*, Rawls constructed a hypothetical 'original position' in which deliberative participants are under a 'veil of ignorance' regarding their social position and individual desires and needs. The conception of 'justice as fairness' that he subsequently claimed any rational person in the hypothetical

position would choose for society,<sup>2</sup> rendered actual physical dialogue superfluous. Because the 'right' was considered independent of and prior to the 'good', and the original position was constructed in such a way that unanimity were possible, Rawls could subsequently argue that: 'the deliberations of any one person are typical of all.' (Rawls, 1999, 232) For Rawls, any solitary individual could imagine him or herself placed in the hypothetical original position and reason their way toward the rights that justice requires. However, Habermas argued that if agreement in moral argument was to be reached:

'... it is not enough for the individual to reflect on whether he can assent to a norm. It is not even enough for the individual to reflect in this way and then to register his vote. What is needed is a "real" process of argumentation in which the individuals concerned cooperate.' (Habermas, op cit, 67)

The deliberative process favoured by most supporters of citizen participation is rooted in the Habermasian, as opposed to the Rawlsian, formulation.

### 3.3. The Process of Deliberation: A Range of Approaches

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<sup>2</sup> See Sandel, 1998 for a general critique of Rawlsian liberalism and the primacy of justice it is based upon. Sandel argues that Rawls' attempt to detach the Kantian approach from its transcendental idealism fails because deontology with a Humean face (The Rawlsian approach which claims the self need not be transcendental) 'either fails as deontology or recreates in the original position the disembodied subject it resolves to avoid. Justice cannot be primary in the deontological sense, because we cannot coherently regard ourselves as the kind of beings the deontological ethic – whether Kantian or Rawlsian – requires us to be.' (Sandel, 1998, 14)

See also Gray, 1995 for a lucid account of the flaws in certain theoretical strands of political liberalism, in particular those that retain '... a deep attachment to liberal institutions in which their authority is not conditional on their contribution to the well being of those they serve.' (Gray, 1995, 88) Gray proposes a post liberal/pluralist view that is willing to discard liberal practices if well-being is subsequently improved. The task of post-liberal theory is to promote peaceful co-existence amongst different cultural groups without appealing to universal standards. (Ibid, 96) In his most recent work, *Two Faces of Liberalism*, Gray argues against the liberal search for rational consensus on the best way of life, and endorses liberalism's alternative philosophy, which avers liberal toleration as the search for peaceful co-existence amongst contradictory values and conceptions of the good life, and employs a notion of *modus vivendi* that recognises certain liberal principles may not be suitable for all groups and societies. (Gray, 2000)

When we come to consider the potential advantages of deliberative politics, a number of diverse issues arise. How we conceptualise deliberation as a discrete concept will ultimately determine the practical utility of those citizen centred decision-making structures that have sought to cultivate the deliberative virtues.

Pellizoni elucidates the strengths of the deliberative model by reference to three inherent virtues. Firstly, there is a 'civic virtue' in that discussion has an educative effect on the citizens who participate. Secondly, there is a 'governance virtue'. Decisions made after open discussion are more likely to be perceived by participants as legitimate. Thirdly, there is a 'cognitive virtue'. Pellizoni writes:

'If opinions and preferences are not fixed, open dialogue may give rise to new or more articulated points of view ... And since it is impossible to say *a priori* which are the most valid arguments, there are no grounds for restricting participation to a minority.' (Pellizoni, 2001, 66,67)

For Pellizoni, the deliberative virtues are all connected. However, many theoretical approaches concentrate too much on one virtue and ignore the others. Pellizoni is particularly critical of the Habermasian approach for prioritising the cognitive virtue of deliberation and imposing a 'unity of reason' framework on the deliberative process. This provides a weak foundation because, as Pellizoni writes:

'The force of the best argument seemingly dwindles as the dialogue becomes more problematic, as the conflict grows fiercer. Reason seemingly shatters into fragments impossible to reassemble, and communication seems entangled in the web of strategy, technocracy or rhetoric. In these situations the force of the best argument is only a myth.' (Ibid, 72)

Nevertheless, Pellizoni believes the ideal of deliberation can be rescued from the unity of reason if it is not compelled to rest on the internal force of argumentation. Instead, one must embrace the 'plurality of reason', and organise deliberation on the cooperative values that naturally emerge from it. (Ibid, 82)

Gutman and Thompson (1996) argued that the concept of 'reciprocity' offers the best guiding principle for the deliberative process. Reciprocity is a form of mutuality whereby:

'Citizens try to offer reasons that other similarly motivated citizens can accept even though they recognize that they share only some of the other's values. When our deliberations about moral disagreements in politics are guided by reciprocity, citizens recognize and respect one another as moral agents, not merely as abstract objects of others' moral reasoning.' (Gutman and Thompson, 1996, 14)

By conceptualising deliberation in a reciprocal sense, Gutman and Thompson argue: '... we do not face the stark choice that is often posed in contemporary political theory. We do not have to choose between modeling democracy on procedural principles or founding it on comprehensive conceptions of the good.' (Ibid, 92) Appeals to a 'common good' may have a pathological impact on the quality of deliberation. The 'common good' argument is a particular flaw in both contractualist liberal and communitarian approaches to democracy, because it assumes the existence of an *a priori* and independent 'social good' that any rational being ought to accept and be guided towards realising. Rousseau referred to this as the 'general will'. He wrote:



'So long as a number of men gathered together consider themselves as a single body, they have a single will also, which is directed to their common conservation and to the general welfare ... the common good is so obvious everywhere, and all that is required to perceive it is good sense.'  
(Rousseau, 1994, 134)

The totalitarian/tyrannical interpretation of this passage may apply equally to those theorists who believe such inexorable laws ought to guide deliberative participants. However, they provide no explanation of what such universal maxims constitute, how in practice they may be realised, or what impact they may have on the quality of outcomes.

Deliberation guided by the ideal of mutual reciprocity and not constrained by appeals to a 'common good', builds a foundation for a citizen centred model of decision-making. What lies at the heart of the deliberative process is the collective nature of decision-making. Dryzek (2000) uses the term 'discursive democracy' in order to accentuate this point. The point is that this new form of political democracy provides, according to its supporters, the best means of achieving rational, fair, and democratically legitimate decisions.

The theories of deliberative democracy presented in this section emerged as a direct response to what was considered a deliberative and democratic deficit within contemporary representative political institutions. In a sense, these ideas laid the groundwork for subsequent experiments in citizen-centred policymaking. However, many of the recent converts to this method have applied the new decision-making models without appreciating the theoretical complexity of the deliberative approach. If citizens' juries are to supplant the

existing policymaking frameworks, it is important to recognise both their advantages and disadvantages.

#### **4. THE CITIZENS' JURY AND POLICYMAKING: DELIBERATIVE DEMOCRACY IN ACTION**

As was illustrated in previous chapters, the emotive issue of genetics and insurance has been one of immense complexity, in which conflicting scientific, social, and political interests have vied for recognition and representation in the formal policy process. However, the lack of informed, balanced, and reasoned deliberation of the issue appeared to undermine the possibility of an equitable solution being found. The question is whether a well-structured and critically adept citizen-centred decision-making process might improve the quality of policymaking, and render deliberative theory more than simply an abstract ideal.

##### **4.1. The Basic Structure of the Citizens' Jury: A Critique of the ABI Jury**

Advocates of the citizens' jury have constructed a standard formulaic model for its implementation. A citizens' jury usually consists of 12-16 representatives of the lay public who are asked to deliberate a contentious policy issue and offer guidelines and recommendations for action. Usually a specific commissioning body, which is seeking public attitudes to, or justification for, a range of possible policy alternatives, requests an independent organisation to organise and manage the process. This independent body consults extensively with the commissioning organisation before framing the overall aims and objectives of the jury. The independent body also takes responsibility for selecting the

witnesses and facilitator, collating relevant materials, and assigning roles to the participants. The actual jury usually sits for up to 4 days, but the entire process may last many months. The pre-jury 'boundary work' does not often involve citizens.

The citizens' jury has two fundamental processes at its core. One process is 'witness testimony', in which pre-selected 'experts' deliver presentations, hand out reading materials, and subject themselves to cross-examination by jurors. A second process involves deliberation amongst the individual jurors, which is managed by a professional facilitator. Here, the jurors are required to discuss the witness testimony and collectively formulate fair and equitable solutions to the policy problem posed to them. The facilitator's role is to ensure that deliberation is managed effectively (i.e. jurors do not digress too far from their predefined objectives), and that the deliberative virtues of equality, non-tyranny, and reasonable/non-selfish discussion are sustained. In certain cases, the facilitator writes the final report on behalf of the jurors.

Many argue that this method provides the best (in terms of rational, fair, and democratic decision-making) approach to policymaking on issues defined by a number of complex and ideologically dissonant agendas. By reducing the power of political elites, and delegating greater responsibility to the lay citizen, it is argued that decision-making can become freed from the whims of political expediency, and lead to more focused, rational, and equitable policy. However, the uncritical application of the citizens' jury, in this minimalist procedural sense, may defile both the underlying ethos of the model and the supposedly sublime deliberative virtues at its core. If such a system is to be applied to the issue of

genetics and insurance, both the strengths and weaknesses of the model must be recognised.

The citizens' jury commissioned by the ABI in 1997, to gain public feedback on the first draft of its code of practice, illustrates how easily deliberative ideals can be compromised during practical experimentation in participatory politics. The Institute for Public Policy Research (IPPR) took responsibility for running the ABI Jury. (IPPR, 1997) After consulting with the ABI on the key questions they wanted addressed, and the general objectives they hoped the process would achieve, the IPPR spent three months constructing an agenda for a four-day jury. The agenda setting process consisted of advisory meetings, focus groups, and consultation with stakeholders. Draft agendas were formulated and sent to various interest groups for feedback.

It could be argued that because the general aims and objectives of the jury were framed by the ABI, who had a stake in the outcome of the process, the democratic legitimacy of the jury was compromised from its inception. Furthermore, because the IPPR selected the witnesses and drafted the agenda, without any significant input from those who would eventually be subject to its theoretical and practical constraints, the power of the jurors to effect any real change was always going to be limited. Stewart et al (1994) argue that the organisation of citizens' juries by independent bodies raises the same concerns about accountability as those juries managed by official organisations with vested interests. The fact that in this case the IPPR took responsibility for writing the final report, as well as disseminating the outcomes of jury deliberations, should alert us to the diverse ethical dilemmas engendered by all citizen-centred decision-making processes. However, although Stewart et al

defend the idea of a citizens' jury in principle, they do present it simply as a complement to the existing representative systems rather than an autonomous and independent process. They foresee the role of citizens as one limited to exploring issues and making recommendations.

Ortwin et al's (1993) 'three-step' model of participatory politics implicitly supports this minimalist conception. In the first step, concerns are identified and evaluative criteria established through consultation with stakeholders. In the second step, independent 'experts' establish a framework for identifying and measuring the impact of various decision options. In the final stage, randomly selected citizens aggregate and weigh the pre-defined options given to them and make 'informed' decisions. This model involves citizens in the most limited sense. Although the ideal of an informed citizenry who make value judgements in a non-selfish, informed, and politically-neutral way is still encouraged in the final stage of the process, the citizens' power and influence is limited because they have no role in establishing the evaluative criteria. This was also the case in the ABI citizens' jury. The jurors were not making binding decisions that the ABI had pre-committed to implement, and the ABI promised only to consider the jurors' recommendations and provide reasons for either accepting or rejecting them. In this sense, the jury was little better than a focus group; existing simply as one of a variety of methods to reveal public attitudes. Pickard (1998), in her critique of two juries run by a health authority, argues that without legislative authority the citizens' jury can in the end prove disempowering. (Pickard, 1998, 243)

With any model of public participation, the question of why the public ought to be involved requires a response. The way in which we conceptualise the role of the public, and the quality of the outcomes we expect from their deliberations, is dependent on the general structure of the model and the framing of its objectives. As Lenaghan (1999) writes in relation to public involvement in health care decisions:

*'... when ordinary people are given the time and opportunity, they can participate meaningfully in decisions about the allocation of finite resources for health care. However, this is not a given, but depends on the nature of the question that is put to the jury, the development of the agenda and the kind of information which they have access to.'* (Lenaghan, 1999, 53, my Italics)

In the case of the ABI jury, one could argue that meaningful participation was compromised precisely because the kind of information offered for juror deliberation, and the procedural methods used to frame the agenda, were democratic and comprehensive in the weakest possible sense. For example, the diversity of witness testimony was limited, and the jury had no option to request additional testimony if *they* believed this would enhance the quality of their decision-making. The hypothetical case studies that were deployed as a heuristic device to aid the jurors in their deliberations were also provided by the ABI. This perhaps ought to have been questioned on impartiality grounds. The ABI jury did deliberate the issue of whether insurance companies should be permitted access to genetic information, extensively discussed the code of practice, and considered important general questions such as who should have ultimate responsibility for the insurance needs of citizens. However, the final recommendations emerged from a crude method of aggregative voting on specific issues within the code of practice. In the end, the jury supported the ABI's general approach. The ABI (1997a) responded enthusiastically to the

recommendations, and considered what jurors perceived to be lacking in the code. These were relatively minor procedural details. One must ask how the ABI would have responded had the jurors been far more critical of their approach and demanded a fundamental shift in policy.

The ABI case study demonstrates that if citizens' juries are to become effective decision-making bodies, a number of procedural problems need to be resolved. One could argue that the role of citizens ought to extend beyond the deliberative process itself and include the actual framing of the agenda. Those with a stake in the outcome of the process should also have a far more limited role in any organisational design. Many of the problems associated with practical implementations of the citizens' jury are often a consequence of the process being non-institutionalised. Because juries are commissioned by specific organisations, who bear the financial burdens (around £16,000-£24,000 for a 4-day Jury), these organisations are likely to demand a certain level of control over the outcome. They can do this by ensuring that the process is organised in such a way that their pre-defined ideal position is more likely to find representation in the outcome. They then simply reap the reward of having their position enjoy a simulacrum of democratic legitimacy by having involved the public. Even Ortwin et al recognise this when they claim that stakeholders may challenge the legitimacy of the process if they begin to perceive themselves as having little real power. (Ortwin et al, op cit., 201) Irwin (2001), makes the important point that: 'Viewed critically, this 'pre-framing' of the agenda ... restricts the possibilities for public responses to operate within their own terms of reference and frameworks.' (Irwin, 2001, 9)

Slaton (2001) notes that while participatory models are useful at a time when the public has an intuitive distrust of government, people will not settle for such models if they do not lead to both an increased voice for the people and a real commitment that their decisions will be represented in formal policy. (Slaton, 2001, 360) Similarly, Fuller (2001) argues, in relation to consensus conferences on the disposal of industrial waste, that public confidence is unlikely to be inspired if: '... the public is not involved in constructing the knowledge base it needs for considering the disposal options.' (Fuller, 2001, 22) Citizens must be central to *all* parts of the jury process. It may not be possible for the specific citizens sitting on the final jury to perform the preliminary 'boundary' work, but it should be members of the lay public all the same.

So far, this section has outlined some necessary procedural conditions relating to the general framework of the citizens' jury, and its pre-jury planning, through a critique of a particular citizens' jury in action. However, the efficacy of the deliberative process ultimately stands or falls on the quality of the deliberation manifested within this basic structure. It is now necessary to look more closely at the role of jurors, witnesses, and facilitators. This will allow us to critically evaluate the potential of the process for resolving something like the genetics and insurance problem.

#### **4.2. Citizen's Juries and Deliberative Rationality**

The citizens' jury rests on the idea that ordinary members of the public can bring to the surface new perspectives on social and scientific issues and make a positive contribution to policymaking. Stewart et al point out that, 'theirs [citizens] are not the judgements of vested interests, but of ordinary citizens with



no particular axe to grind. They bring too experience and understanding which is not otherwise available to government "experts". (Stewart et al, op cit, 7)

The notion that citizens can improve the quality of decision-making because they are non-political, attached ideologically to no particular solution, and guided only by their duty as a citizen to seek 'reasonable' and 'fair' decisions, resonates deeply with advocates of the citizens' jury model, but it should not be regarded as a given. One cannot simply place citizens in the jury system, provide them with a series of 'expert' testimonies and the time and space for deliberation, and then simply assume that the decisions made will conform to an ideal of deliberative reasoning. One must look critically at the construction and management of the actual deliberative process.

#### **4.2.1. *Selection of Jurors and Witnesses, and the Roles they are Ascribed***

The potency of the citizens' jury rests in part on the methods used to select jurors and witnesses. Most supporters of the citizens' jury model argue that jurors ought to constitute a 'representative' sample. The central idea is that the model can only be democratically legitimate if participants in some way represent the various communities and interests that may be directly or indirectly affected by the particular policy decision. However, by prioritising representation in the citizens' jury, one may simply be recreating the problem of politicisation and ideological intransigence inherent to representative institutions. Fuller (2002b) makes the important point that:

'There is nothing intrinsically valuable about having citizens' juries constituted in certain proportions of the population. A "cross section of the public" is valuable only insofar as it results in a framework that adequately distinguishes between the personal interests of the jurors and the diverse interests of the larger society, with the understanding that the full range of

those interests can never be represented by a single jury.' (Fuller, 2002b, 215)

Smith and Wales (2000) argue that 'inclusivity' may be a more useful term in conceptualising the ideal make-up of the jury, because it avoids any essentialist connotation. (Smith and Wales, 2000, 56) If jurors are selected on the condition that they represent some essential social category, identity, or political position, then equitable decision-making may become impossible. Smith and Wales argue that: 'This emphasis on representation may undermine the democratic ideal of the inclusive jury.' (Ibid, 56)

The primary principle when selecting jurors is that the process is as inclusive as possible. The greatest variety of social actors should be afforded the opportunity to participate, but only on the basis that this may have a salutary impact on decision-making. However, it may sometimes be necessary to exclude certain individuals from the deliberative process. For example, individuals who are unwilling to be constrained by the procedural rules of the jury or who manifestly refuse to be receptive to alternative arguments, perhaps ought to be prohibited from participating. Similarly, individuals with a clear stake in the outcome of the issue being deliberated should not be considered as a lay member of the jury.

The goal of true inclusivity will likely be an elusive ideal never fully realised. Evidence from studies of legal juries illustrates that many people do not wish to participate, and those who do often find the process deeply unfulfilling. Some individuals therefore allow their personal prejudices, or antipathy towards the general legal process, to affect the quality of their deliberations. Page (1998) makes the important observation that social class differences in perceptions of

citizen participation may also affect the desire to participate. His research on the People's Panel discovered that:

'... many working class people remain suspicious of anything at all to do with "government" (any government) – or research activities that demand more than answering a questionnaire ... we found that mentioning the potential to be invited to a focus group or a citizens' jury was actually disturbing and alarming to a few people.' (Page, 1998, 6)

Because most advocates of the citizens' jury method believe passionately in the idea of representation, most have had to contemplate the controversial idea of compelling citizens to participate. However, to compel a recalcitrant citizen to engage at any substantial level with complex social policy issues, and deliberate effectively with fellow citizens, would defile the very virtues presented by deliberative democrats. Participants must essentially *want* to participate. This does of course raise the problem of how such a process achieves legitimacy if it is not at all representative. This crucial issue will be dealt with in more detail later.

Witness selection differs from juror selection in that a representative process must be incorporated. The witnesses that testify in citizens' juries are expected to represent the totality of interests and perspectives germane to the policy issue being deliberated. This is the only way to ensure that no particular scientific, social, or political frame of reference is excluded from the deliberative process. Because the witnesses are not expected to deliberate, reach agreement, and ultimately resolve the specific policy dilemma, the fact that their views may be partial does not challenge the deliberative ideal.

Although the witnesses are expected to deliver formal testimony, and may dispense to the jurors various written materials, the essential requirement is that the jurors are afforded an opportunity to engage the witnesses in active dialogue. Many experiments with the citizens' jury model have neglected this important aspect, usually because time constraints have rendered extensive two-way discussion impractical. However, in its ideal formulation, the citizens' jury cannot compromise on these matters. If there is no opportunity for the jurors to engage with witness testimony, there is little chance that the process will prove much more ameliorating than the existing policymaking processes.

This section has presented the basic framework of the citizens' jury, but challenged the emphasis many advocates have placed on representativeness. Now it is necessary to focus on the deliberative process itself, because this is where adherents of citizen-participation claim their model improves most on existing ones.

#### **4.2.2 *Facilitators and the Management of the Deliberative Process***

The primary role of the facilitator is to organise and manage the participants as they deliberate the evidence presented by witnesses. Before considering this aspect of the citizens' jury in detail, it is important to elucidate the general principles that must guide this process. Proponents of the citizens' jury often talk about such things as the 'social' or 'public' good, 'social justice', 'welfare maximisation', 'disinterested reasoning', and 'community interests', as the primary guiding principles for citizen deliberation. However, few have unpacked these deeply problematic philosophical and political concepts and considered what impact they may have on the quality of deliberation. One consequence of

adopting universal guiding principles is that a number of problems and contradictions begin to emerge. Price (2000) highlights a contradiction in the idea of a disinterested juror who is expected to simultaneously be interested in his/her own community. He writes:

\*A citizen is impartial, lacking a vested interest, or neutral, and yet also a taxpayer and member of the community, committed to family, friends, his or her city, or even the NHS. Citizens are at once disinterested and committed. They contemplate broader interests and yet are motivated by relatively narrow ones. They take the longer view and yet may also have to be educated into it.' (Price, 2000, 274)

The imposition of a particular framework of social justice on the deliberative process compounds these kinds of problems. Price is particularly critical of the 'welfare-maximising' criterion often favoured by deliberative theorists. He argues that in everyday practice, the individual beliefs people hold, and the way they express them, are often incompatible with such immutable ideals. Instead, individuals generally consider issues in personal terms. By forcing jurors to deliberate within the constraints of a particular pre-defined framework of social justice, one actively suppresses alternative frames of reference and political rhetoric. (Ibid, 274) For example, if one were to accept a Rawlsian framework of justice for guiding deliberation on the insurance and genetics problem, then one would have to direct the jurors to consider a solution that maximised the benefits for the most disadvantaged, such as those likely to be denied insurance. On the other hand, if one accepted a libertarian inspired entitlement framework, such as that proposed by Nozick (1974), then any solution must support the right of individuals to benefit from their 'good' genetic constitution and enter into fair contractual relations with an insurer. Although jurors should be encouraged to base their deliberations on fair, rational, and publicly defensible reasons, no prior concept of what the social good constitutes can be

imposed upon them. Although the most obvious solution may well be one that conforms to a welfare maximising or entitlement conception of justice, this cannot be determined *a priori*. It is something that should be recognised as emerging spontaneously as an individual's reasons are publicly tested.

Parker (2000) supports this view by arguing that we should support an idea of public reason and justification that embraces personal autonomy as a guiding principle for decision-making, especially on ethical issues surrounding genetics. He advocates a process that:

'... offers the possibility of a resolution of some of these questions [around genetics] without itself depending upon an extensive set of deeply shared values, or the imposition of individualistic or communitarian principles. While it does not itself depend upon a non-existent consensus, it offers the possibility of a developing, emerging consensus in a context of diversity.'  
(Parker, 2000, 165)

The main point deliberative democrats wish to accentuate is that all the good that comes from deliberation emerges from individuals' capacity to understand complex information and collectively make value judgements. If 'rationality' is an emergent property, any prior conceptual constraints to the deliberative process must be minimal. This idea has implications for the suitability of citizens' juries for the genetics and life assurance issue. In chapter 2, it was argued that certain forms of insurance might be defined as 'primary social goods'. However, one cannot begin the deliberative process by accepting this definition as given. It is up to the jurors, after contemplating the issue in some detail, to decide whether a particular insurance product can reasonably be defined as such a 'good' and if commercial constraints can justifiably be imposed in the name of 'justice'.

Most of the flaws that threaten practical experiments with the citizens' jury model, stem from problems in the management of deliberative participants. Most evaluations of citizens' juries point to the educative aspects of the general process, highlight the fact that jurors tend to reach enlightened decisions, and maintain that the transparency of the method improves the quality of decisions. This was the case in Pellizoni and Ungaro's (2001) analysis of three Italian case studies of participatory decision-making. Most participants stated that the defence of values, fostered in the participatory model, was more important than defending material interests. The authors write: 'Participation is seen as a citizenship right to co-operate, rather than as the possibility to protect one's own interests.' (Pellizoni & Ungaro, 2001, 278) Similarly, McIver (1998), in her evaluation of six pilot citizens' juries in health authority settings, found that most achieved their intended objectives in terms of enabling jurors to become informed, deliberate effectively, and make recommendations. However, research into the social psychological nature of deliberation serve to illustrate how the virtues of deliberation might ultimately depend on effective juror management.

The role of the facilitator is to ensure that all deliberative participants have an equal opportunity to speak and that any dominant personalities are prevented from 'taking over' discussions. These problems frequently arise in citizens' juries and are well documented. Barnes' (1999) evaluation of two citizens' juries revealed a number of problems. In the first jury conducted in Belfast on the issue of health service changes: 'It was evident both to facilitators and to the jurors themselves that there were some people who were playing very little part in the plenary discussion.' (Barnes, 1999, 26) Similarly, in a second jury conducted in Swansea, which discussed policy issues relevant to an aging population, Barnes observed that when deliberation occurred it was often

chaotic, with participants 'talking over' one another. Furthermore, jurors often drew on personal experiences but were non-specific when they did so, and they made little use of the witness evidence and other information sources they had access to. (Ibid, 37) It is imperative that the facilitator establishes and sustains a coherent internal dynamic within the deliberative process, makes sure that nobody is excluded, and ensures that all participants fulfil the important role given to them. A report on a jury commissioned by the Welsh Institute for Health and Social Care (1997) pointed out, in relation to facilitation, that:

'The moderator's role was to bring together a group of people from diverse backgrounds, build their confidence, manage proceedings and facilitate both large and small group discussions in such a way that everyone felt that they had a say throughout the entire process. Essentially his job was to ensure that the Jury addressed the question and performed their task of making recommendations effectively.' (WIHSC, 1997, Part 2)

This provides an excellent description of how the facilitator's role ideally ought to be conceptualised in any citizens' jury. However, the quality of deliberation will depend ultimately on how good the facilitator is at managing the emotional dynamics of group behaviour.

Thompson and Hoggett (2001) provide an account of those emotional dynamics that may undermine citizens' juries. However, rather than seek to expunge emotion from the process, the authors attempt to illustrate how its power can be harnessed for the good. They write:

'... since emotions are always a necessary and inevitable aspect of the life of all groups (including those that appear cool, calm and collected), the restrictions of deliberation to reasonable dialogue is simply not an option. The point is that wishing the emotions were not there will not make them go away.' (Thompson & Hoggett, 2001, 353)



The crucial point is that to expect a lay citizen to enter the deliberative forum stripped entirely of their emotional, ideological, and individual beliefs is dangerously naive. Emotions are a constitutive part of what it is to be a socially embedded human, so to pretend that individuals can simply switch off the subjective, partial, and irrational facets of their psychology is to underestimate the inevitable power that emotional rhetoric will bring to bear on any ostensibly reasonable discussion. The role of the facilitator should not be to artificially create the rational, de-situated citizen who will discover, through deliberation with other equally rational social agents, some pre-determined 'common good'. Rather, his/her role should be to effectively manage the inevitable emotional dynamics of collective decision-making and *guide* it towards the realisation of 'rational' and 'fair' outcomes, which are themselves recognised as emergent properties.

Thompson and Hoggett refer to research on the social psychology of group behaviour, particularly Wilfred Bion's groundbreaking work on Group Relations Theory, in order to discover a practical means of harnessing emotion within deliberative forums such as citizens' juries. The authors begin by noting the ways in which a particular emotional culture within the deliberating group can result in inequality of opportunities for discussion. They write: '... if a group is under the sway of a particular basic assumption, it will listen to certain speakers and certain acts of communication much more readily than it will to others.' (Ibid, 356) As an example, they cite the possibility of a 'dependent culture' that pays greater attention to those displaying calm authority and little doubt, and scant attention to those who challenge the dominant authority by questioning the intellectual foundations of its legitimacy. Thompson and Hoggett therefore

warn against selecting jurors who show too much deference to authority or seek to reduce the opportunity of other participants to have their views expressed. These patterns of inequality: '... may shift from moment to moment as the emotional culture of the group ebbs and flows.' (Ibid, 356) Certain dependent emotional forces, the authors argue, may destroy the group itself. They write:

'Group Relations theory describes cases in which a group finds or creates some sort of holy text, and then uses this text to discipline itself. In the most extreme case, if a dependent culture grips the group with sufficient force, then slavish obedience may be preferred to democratic debate ... In the case of citizens' juries, then, we should watch out for cases in which jurors are too attentive to the suggestions of the commissioning body ... or in which they heed too closely the words of its moderator or facilitator, or its expert witnesses.' (Ibid, 356,357)

The authors then outline various ways in which emotion may aid the process of deliberation. They begin by arguing that the closer a citizens' jury comes to resemble a 'work-group, the better it is equipped '... to contain and then to harness the affective power of the basic assumptions.' (Ibid, 357) Drawing on Bion's work, they postulate four necessary features of the deliberative group. Firstly, there must be a clear goal and purpose. The remit given to the jury is crucial here. If it is too vague or broad, no effective decision-making will be possible. However, if it is too narrow, aggregative voting may be a necessary outcome. An argument for permitting jurors to establish the agenda for deliberation may be fundamental here. For issues as complex and conflict-based as genetics and insurance, the efficacy of the approach may be contingent upon clearly defined and consensually accepted objectives.

Secondly, there must be no rigidly defined sub-groups. This may necessitate a maximum limit to the number of jurors. Group Relations theory demonstrates that above a certain number, internal factions may emerge and develop their own internal dynamic. This implies that splitting the jury into smaller groups or plenary sessions may prove unwise. However, the authors reject this argument by claiming such a practice is justified on the contrary finding that only small groups can immunise themselves against the emergence of factions. They write: '... the subdivision of juries is justified since only these subunits will not themselves have internal psychological divisions.' (Ibid, 358) However, the facilitator should rotate the groups so that all participants can enjoy face-to-face interaction.

Thirdly, all contributions by participants must be equally valued. The authors write: 'There is a certain cheery optimism in the literature of citizens' juries which holds that social barriers against participation are dissolved simply in the course of a jury's deliberations.' (Ibid, 359) However, the authors argue that practical ground rules for conduct might need to be established, and they suggest the jurors produce their own codes of conduct. Furthermore, the small group system may help make sure that all views are equally valued.

Finally, participants must have clear and accepted roles. (Ibid, 357) The authors cite two conceptions of the facilitation role. This first is a 'hands-off' approach. Here, the facilitator minimises his/her involvement in order to empower the jurors. This often proves counterproductive because it allows strongly opinionated participants to then hijack deliberations and dominate proceedings. Przeworski (1998) criticises deliberative democracy on the grounds that 'ideological domination' by certain participants is inevitable, as

'strong minds' will strive to transform the beliefs of others. Stokes (1998) also talks about the general social phenomenon of 'preference inducement', which may act on any social or political group. Deliberative forums, she argues, are particularly susceptible to the inducement of artificial or pseudo preferences by both fellow participants and broader societal norms and expectations. The point is that the facilitator has a crucial role in trying to minimise such pathologies of deliberation. A second 'hands-on' approach grants the facilitator a far more proactive role in maintaining order and reducing inequality. However, this may produce a dependent emotional culture. Thompson and Hoggett argue that one possible solution to the problem of defining and organising these two contradictory roles may be to appoint two facilitators, each with their own distinct responsibilities. The authors write:

'The first is a "jury facilitator" whose role is to organise the task of deliberation, and the second is a "process facilitator" who acts as a "jurors' friend". While the former is in charge of time keeping, note taking, ensuring the jury sticks to the agenda and so on, the latter's role is to support the ordinary jurors in whatever way necessary – for example, encouraging them to speak in their own voices, to express contrary thoughts, to be creative and so on.' (Ibid, 361)

In this section, the possible advantages of using a citizens' jury to help resolve the genetics and insurance dilemma have been presented. The process was juxtaposed to existing systems of representative decision-making, which were shown in previous chapters to have proved inadequate as an equitable means of balancing competing interests on this controversial issue. However, contemporary experiments in citizen participation have been shown to be deeply flawed, so an 'ideal' model has been suggested. This model substitutes the goal of 'inclusiveness' for the goal of 'representation' and seeks to give far

greater power and control to citizens. However, there are still a number of persistent problems with the method. In particular, difficulties concerning democratic legitimacy, the process of facilitation, and the procedural constraints imposed on jurors, might threaten the practical realisation of such an idealistic model. If we are to assess the suitability of the method, these difficulties require a response.

### **4.3. Flaws of the Citizens' Jury Process**

Despite the apparent attractiveness of a revised citizens' jury method of decision-making, a number of challenges still face the model. This section will reveal the arguments against the suitability of the model and assess whether or not they are pathological.

#### **4.3.1 *The problem of proceduralism***

The first problem with the account given above concerns the internal contradiction between the objection to representative democracy because of its proceduralism, and the specification of certain procedural preconditions for effective deliberation in the citizens' jury. The opening section of this chapter argued that representative institutions essentially fail because their elaboration of strict procedural rules to ensure the representation of all interests diverts attention from the quality of deliberation. However, even in the citizens' jury, it became necessary to establish certain procedures and rules to ensure good management of deliberating citizens. Johnson (1998) argues that advocates of deliberation, if they truly seek to foster democratic legitimacy and fairness, must apply the same critical standards to their own approach that they do to the

aggregate and social choice models. The imposition of certain rules of behaviour in the forum, and limitations on the range of views permitted, are considered by Johnson to be one area where deliberative democrats show themselves to be as constraining and superfluously proscriptive as their opponents. (Johnson, *op cit*, 164)

However, one could argue that opposition to representative institutions is based not so much on the mere existence of proceduralism within their formal constitutions, but on the basis that such institutions appear to take-for-granted that proceduralism on its own may guarantee fair representation and good quality outcomes. Although the citizens' jury still requires the adherence to certain rules and regulations, there is an additional commitment to the quality of deliberation, which may render the model more suitable as a means of achieving rational and equitable decisions.

Another way to avoid the apparent contradiction may be to consider the work of sociologist, J.M. Atkinson (1982). His paper on formality in institutional life sought to reveal the impact proceduralism may have on the way actions are identified as being 'formal' or 'informal'. The evidence suggested that a taken-for-granted model of conversational interaction is often used by lay and professional analysts to assess the formality or informality of particular social settings. Atkinson argued that such procedures result '...in evaluative interpretations which fail to address the question of how such interactions may be operating to produce orderliness in the settings where they are found.' (Atkinson, 1982, 86) Atkinson developed this theme in relation to the way recurrent features of multi-party interaction, such as those found in citizens' juries, may provide solutions to the practical problem of creating and sustaining

the attentiveness of participants. The central idea was that certain non-conversational rules (which help render the action formal rather than informal) may in fact be vital for the practical accomplishment of the setting's goals.

Atkinson rallied against those who believed it might be advantageous to render formal settings less formal. He wrote:

'... the distinction between 'formality' and 'informality' is used evaluatively, with 'formality' a source of nervousness and something to be avoided, and 'informality' being equated with a 'relaxed atmosphere' in which there need be few inhibitions about speaking.' (Ibid, 95)

Analysts have identified settings as formal or informal by reference to interactions noticeably different from those found in the production of other conversational encounters. As group size increases, the provisions for maintaining orderliness and participant's attentiveness are eroded to the extent that modifications to conversational practice may become relevant. Non-conversational procedures may therefore be necessary to ensure that order is maintained in multi-party settings. Atkinson writes:

'Attempts to make courts [or any multi-party setting] 'more informal' ... may call for the abolition of a whole range of evidential and procedural rules dealing with what might be talked about and who might speak when – in spite of the fact that it is not clear how the orderly conduct of proceedings within finite time limits could be assured in the absence of at least some non-conversational procedures.' (Ibid, 114)

In summary, both conversational and non-conversational procedures are a crucial element of any multi-party setting, because they ensure order is maintained and local objectives are accomplished. Procedures in the citizens' jury exist primarily to enhance the quality of communication between

participants. This is very different from the elaborate constitutional procedures that determine the formal structure and practices of representative institutions. So, although there may appear to be a contradiction in rejecting proceduralism as it applies to representative democracies, but an acceptance of it as it applies to deliberative institutions, once the subtle differences of what these procedures constitute are recognised, the contradiction appears less problematic. Atkinson's work provides an entry point for more subtle and nuanced considerations of proceduralism in multi-party settings. Such considerations may support the need for specified conversational and non-conversational rules within citizens' juries. Although such procedures may render the jury a more formal social setting, they may be essential if the jury is to locally accomplish its goals. Furthermore, such procedures appear qualitatively different from those used to constrain representative institutions, so the apparent contradiction need not prove pathological.

#### ***4.3.2. Difficulties Around Facilitation***

It has been argued that the advantages citizens' juries might bring to policymaking on the genetics and insurance issue are dependent on effective management and facilitation of the deliberative process. A number of crucial issues regarding facilitation were raised and an ideal formulation of the deliberative process was presented. However, it is necessary to look more critically at facilitation, through empirical work in cognate fields, in order to fully assess the suitability of the citizens' jury model. Might evidence from other social settings dependent on facilitation render the ideal model of the citizens' jury impractical?



Evidence from studies on mediation and counselling, as well as sociological work on group decision-making, reveals a number of difficulties with facilitation. The problem of group psychology has already been discussed through the work of Thompson and Hoggett. They tried to reveal the ways advocates of the citizens' jury could use social psychology to enhance the process. However, further investigation is required, because the facilitation process within citizens' juries is so susceptible to pathological social and psychological effects.

Greatbatch & Dingwall's (1999) work on divorce mediation highlights a common problem with the process of facilitation. Their research revealed the various ways in which participants in mediation sessions can, consciously or subconsciously, marginalise or prioritise certain issues to such an extent that the social dynamic of the encounter is fundamentally changed. The authors looked specifically at the marginalisation of domestic violence in divorce mediation encounters. They discovered that although mediators rarely questioned the validity of clients' accounts of domestic violence, they often sidelined them '... by proposing that they lay beyond the scope of the sessions and/or by shifting to different topics.' (Greatbatch & Dingwall, 1999, 177) The authors suggest two possible reasons why the counsellors might have marginalised the issue. Firstly, the mediators may not have considered the mediation session to be the most suitable venue for exploring domestic violence. Secondly, particular characteristics of the clients may have led the mediators to conclude that the issue was not particularly serious.

However, closer inspection of the transcripts revealed that the process of marginalisation did not always begin with mediator intervention. Instead,

... it began with the disputants' allegations which were produced in ways which could be heard either to minimise the severity and impact of the violence or to raise the possibility that they were not 'serious' accusations. Thus the allegations were open to interpretations which could justify and perhaps lead to their marginalization by the mediators.' (Ibid, 177)

The authors cite a number of examples where the issue of violence was marginalised through the social interaction of participants. They describe marginalisation as a general social phenomenon, which often arises only because the disputants formulate their accusations in such a way to permit marginalisation. The authors write: 'All the mediators subsequently undertake marginalizing actions, which include remaining silent, asking questions on different topics, treating the reported incidents as non-serious, and/or ruling the issue out of bounds.' (Ibid, 185)

This evidence has significant implications for the facilitation process of the citizens' jury. The marginalisation of certain issues, arising from the actions of either facilitators or participants, appears to be inevitable in any social setting defined by dynamic interactions. This has been a long recognised problem in genetic counselling sessions. Third-party mediators often find it incredibly difficult to ensure choices made by clients are both informed and made freely. Even if counsellors are noble in their intent, and try to remain impartial, conversational cues and implicit, rather than explicit, suggestions can affect the nature of decision-making. In the past, genetic counselling came under strong criticism as counsellors appeared to coerce clients into making particular reproductive decisions. Attempts have been made to render the process less judgemental, but problems do persist. Despite the medical profession's claim to stand morally neutral when consulting with patients, the reality often belies this. Steinberg's (1997) research on the practice of IVF (*In Vitro* Fertilization) treatment found that some medical practices: '... reflect, reproduce, and

perhaps most importantly, (re)normalise eugenic sensibilities.' (Steinberg, 1997, 76) In particular, she argues that IVF often normalises the heterosexual family, which is judged to be the *only* 'normal' family. Patient selection often reflects these eugenic sensibilities. Geneticists and counsellors may not even be aware that their value judgements are impacting on choice. In fact, Mahowald (1998) argues that non-directive counselling may not necessarily be a good thing. Some people welcome directness as they often crave professional advice and wish everything to be 'out in the open'.

A facilitator managing a citizens' jury is placed in a similar position to genetic counsellors and other kinds of mediators. They are expected to be impartial, and merely facilitate juror deliberations, yet the evidence suggests that this may ultimately be impossible. It may not even be desirable. They may, as the social dynamic evolves, contribute to the marginalisation, or indeed prioritisation, of particular issues, and therefore play an undue role in the outcome of the proceedings. This process of marginalisation may not even be conscious. It might simply be a 'normal' response to the rhetorical form of participant accounts. Furthermore, some jurors may expect cues from the 'expert', and positively embrace their contribution. This idea was touched upon when discussing the social psychology of deliberating groups. These issues are extremely difficult to resolve, and as such may necessitate the citizens' jury being regarded more as a regulatory ideal. There are some practical means by which the negative effects of facilitation may be reduced, but a deeper understanding of group psychology is still required.

At this point, it would be useful to consider the work of Simmel. Simmel was a conflict sociologist who was interested in the impact of group size on the nature of group interaction. His work is pertinent to these issues of facilitation. Simmel

recognised the problems that can emerge when one moves from a 'dyad' to a 'triad' form of interaction. The dyad is a relatively straightforward social encounter, in that each participant can present him/herself in such a way that their identity is preserved. Furthermore, each can end the encounter by simply withdrawing from it. However, in a triad there is a significant change in the form of interaction. Strategies emerge that may engender competition, alliances, and mediation. The consequence may be the emergence of a group structure independent of the individuals constituted within it. Individuals in the triad will more likely feel compelled to sublimate aspects of their individuality in order to participate. Simmel believed that the move from a two-person to three-person group was the single most important marginal change in group size; far more significant than moving from say fifty people to a thousand.

The problem of group psychology was discussed earlier. Simmel demonstrates how difficult the task of effectively managing the process may ultimately prove. One can never really know if the consequences of third-party involvement in the social encounter will be positive or negative. The third person could be a source of mediation and promote group unity. However, there is always the chance that he/she will be a source of conflict. The point is that facilitation in citizens' juries is subject to the same complex problems as mediation or counselling in other social settings. As we move from dyadic to triadic relationships, interaction is likely to become far less stable. However, it may also become far more effective. Because there are both positive and negative consequences associated with the facilitator's role, effective management of the process is crucial. The problem lies in understanding the true nature of group decision-making, and establishing a pragmatic role for the

facilitator. Until more work in this area has been completed, the facilitation process can be presented only as a regulatory ideal or aspiration.

#### **4.3.3. Difficulties Around Juror Deliberation**

In the previous section, the advantages of deliberation were presented. It was argued that deliberative models might widen the scope for rational and depoliticised engagement with contentious issues. However, again there may be problems with this optimistic view. Evidence from jury deliberations suggest that the ideal of equal citizens reaching fair and enlightened decisions is often a naïve ideal.

Sommer et al (2001) cite two experiments that examined group decision-making in legal juries and found that pre-established decision criteria often led to outcomes that violated distributive justice. The first experiment revealed that noncompliant jurors in a civil trial were biased when they awarded damages for negligence when the decision-criteria explicitly prohibited an award. They were more likely to absolve the plaintiff of negligence, if negligence on his or her part precluded an award for damages. The second experiment replicated the first at a group level and ‘... revealed that juries also biased their attributions of negligence to justify reducing damages when the decision-criteria required an excessive award.’ (Horowitz et al, 2001, 309) Jurors tended to absolve the defendant of negligence when such negligence required a high award for damages. This evidence suggests that juries may often fail to comply with the law. There is always a possibility that juries may recruit information to reach a desired rather than an objective result. Noncompliant jurors justified their decisions by recruiting and discussing information that supported their

decisions, but often ignored information that was contradictory (or favoured the opposing party).

Another study, by Winship (2000), discovered that jurors often sideline the evidence and draw on their own personal or group narratives. Group verdicts are often the product of '...preferences, expectations, inferences and stories that individual jurors brought to the deliberations.' (Winship, 2000, 552) There is always a risk that juries might act in a populist manner; basing decisions on what they think the majority desires rather than what is 'right' and 'equitable'. In this sense, their actions might be analogous to political representatives who always consider a broader 'public mood'. One must ask if this problem is likely to reveal itself in the citizens' jury. If so, the role of the facilitator, and the formulation of procedural rules, may become crucial. There is always a risk that jurors will act in a populist manner, or produce agreement, but on the wrong policies. The evidence from experiments with legal juries shows how participants may even ignore the procedural framework and reach decisions that undermine it. There is no way of knowing *a priori* how a particular jury will deliberate. They are liable to suffer the same problems faced by all decision-making bodies. However, as long as this is recognised, it may be possible to reduce the negative impact of individual non-compliance.

There are a number of problems with the deliberative aspect of citizens' juries. It is an open question as to whether basic ideological agreement is required before deliberation can begin, or if successful deliberation itself diminishes ideological divisions at a later date. Participants must certainly agree, prior to deliberation, to adhere to certain rules of deliberation. However, they do not have to be in ideological agreement on the specific issue being

deliberated. As was stated earlier, emotional commitment to a belief or attitude is something that ought to be part of the deliberative process. Through discursive discussion, participants are expected to subject their beliefs to critical public scrutiny. The hope is that good decisions/reasons will emerge collectively from this process. This may be an abstract ideal, but it could still bring many advantages to the policy process.

It is perhaps right to criticise the cheery optimism of many deliberative democrats, who often fail to recognise the limitations of their approach, but it would be wrong to reject the model outright because it may never fully live up to its lofty ideals. Citizens are not ideological robots who will be truly objective, rational, and de-situated. But neither should we assume they are totally irrational, emotional, and permanently driven by their social situatedness. There is likely to be a middle ground that the citizens' jury can attempt to tap into. Whether it succeeds will depend on the organisation and management of the jury, and the extent to which it recognises the limitations of group decision-making.

#### ***4.3.4 Citizens' Juries and Democratic Legitimacy***

One final difficulty with the method presented concerns the extent to which citizens' juries achieve democratic legitimacy if they are non-representative. Earlier, it was argued that the goal of the model should be to promote inclusiveness rather than representation. This indeed leads to the fundamental problem of how one ensures that decisions are based on merit rather than the ability of committed participants to negotiate amongst themselves. Even the

apathetic must be assured that decisions that may affect them are based on good evidence.

One could argue that this is not a problem exclusive to the citizens' jury. Representative institutions are constantly criticised for not being truly representative, and the apathetic constantly challenge the legitimacy of policymaking. The difference with the citizens' jury model is that it explicitly recognises the democratic deficit inherent to many liberal, representative institutions. Rather than strive for the same elusive goal of true representation, it promotes the alternative, and perhaps more realistic, goal of inclusivity. If it is successful in reaching that goal, it is likely that members of the jury will constitute a good cross-section of the general population; perhaps greater than is found in many representative institutions. However, this cannot be taken for granted as it is far from a trivial point. It is perhaps the greatest barrier to the institutionalisation of the method. More empirical work is required to investigate the extent to which decisions by citizens' juries adequately take account of the diverse interests and groups within society, and base decisions on the best available evidence. It is difficult to state exactly what a fair evaluation would constitute. How do we study the citizens' jury? It would most likely require in-depth analyses of juror deliberations and an assessment of how they interact when discussing witness testimony. A criteria for assessing the extent to which final verdicts correspond to the ideals of rational, equitable, and non-partisan decision-making would also need to be established. This may prove difficult, but it is not impossible.

This section has raised a number of difficulties associated with the citizens' jury method. Evidence from cognate fields has demonstrated that it is perhaps best to regard the citizens' jury at this point as a regulatory ideal, rather than an



established practical method for improving decision-making. However, it is likely that the problems identified with the process will not prove pathological. It is possible to resolve some of the issues, or at least mitigate their impact, by refining the way in which the process is organised and managed. Furthermore, many of the problems are not ones exclusive to the deliberative model, so there is a strong chance that the method may be suitable for use on the genetics and insurance problem. Such an issue may in fact be a good candidate for experimentation with the citizens' jury method.

Before concluding this chapter, one more issue needs to be looked at if we are to fully assess the viability of the citizens' jury. This is public understanding of science and expertise, which has crucial implications for the witness testimony aspect of the citizens' jury.

## **5. THE PUBLIC UNDERSTANDING OF SCIENCE AS CENTRAL TO CITIZEN PARTICIPATION AND THE DEMOCRATISATION OF DECISION-MAKING**

The suitability of the citizens' jury is in part dependent on recognition of lay citizens' competence to understand, disseminate, and perhaps challenge received scientific and expert opinion. Recent work in the public understanding of science literature may support the case for the citizens' jury.

### **5.1. The 'Public' and their Attitudes to Science**

Before considering the literature on the public understanding of science, it is important to unpack the very term 'Public'. It is necessary to appreciate that the juxtaposition of 'public' and 'expert', is an artificial construct. For example, the

identity of 'experts' in a particular scientific discipline is not defined exclusively by their specific expertise, technical competence, and beliefs within that body of knowledge. At the same time, such individuals are non-experts in those fields they have acquired no formal training in. However, Sclove (1995) argues that, 'Although experts are also citizens ... their views are structured by their expert status.' (Sclove, 1995, 52) When we talk about the public attitude to, or knowledge of, a specific scientific field of enquiry, we are referring to a set of assumptions, beliefs, and interests that exclude a particular institutionalised form of scientific expertise. This may seem a trivial point, but it is important to recognise that 'the public' is an artificial construct used to polarise the differential interests and understandings of 'experts' and 'non-experts'.

Various studies have revealed differences in attitude and understanding of science between 'experts' and 'non-experts', and 'informed' and 'uninformed' publics. Evans and Durant (1995) discovered that greater knowledge correlates strongly to positive attitudes towards 'useful' science, but negative attitudes towards morally contentious and 'non-useful' areas of research. (Evans & Durant, 1995, 70)<sup>3</sup> Furthermore, low scientific knowledge was discovered to have a strong correlation to more inconsistent and less discriminating attitudes to specific areas of research. The 'informed' public therefore appear less susceptible to context manipulation or preference inducement, particularly through such things as the wording of survey questions and general framing of science issues. The authors argue that because the more informed are generally more discriminating in their attitudes, and less likely to support areas of controversial science, policymakers and scientists

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<sup>3</sup> Mitchie et al, 1995 in their comparison of public and professional attitudes towards genetics, also discovered the public to be generally more sceptical than geneticists, ethicists, and obstetricians, but the differences were not as acute as many tend to imagine.

should not presume that a more informed public will inevitably embrace new science and technology. (Ibid, 70)

Social scientists have also revealed differences between lay and expert understandings of genetics. Parsons and Atkinson (1992), studied the construction of risk by female patients carrying the gene for Duchenne Muscular Dystrophy. They discovered that many women translate the mathematical figure of risk into a descriptive category and use this as a basis for determining reproductive behaviour. (Parsons & Atkinson, 1992, 441) The authors provide the following example: 'Mrs Powell and her two daughters all had carrier risks that were medically defined as less than 2 per cent. They had not translated them into certain carrier status but certain exemption. They said very clearly that none of them was a carrier.' (Ibid, 441) The authors claim that through the process of translation from ordinal to categorical measurements, a great deal of important information can be lost.

Many patients often display a poor understanding of basic Mendelian genetics. Richards (1996a) has documented the personal narratives of various individuals at-risk of genetic-based diseases. One patient stated:, 'I felt that I would get breast cancer as my body was similar to my mother's in many ways.' (cited in Richards, 1996a, 28) Lay members of the public may often associate physical similarities with shared genetic fates. This data suggests a need for greater public education on basic genetics. Richards (1996b) argues that: ' ... the starting point for genetic education should be existing lay knowledge and the social processes that support this.' (Richards, 1996b, 226) Pritchard (1993) suggests that the point of entry for genetics education ought to be the doctor-patient interface. Here, the non-expert patient could be treated less as a

passive recipient of information and become an equal and informed participant in the assessment of their risk. (Pritchard, 1993, 10)

These kinds of studies illuminate striking disparities in knowledge between experts and the public. Such research may be crucial to the efficacy of public-centred decision-making processes. However, it may be inappropriate to frame the issue in terms of the public's 'knowledge-deficit' or 'ignorance' of science. Although a certain level of education may be essential, there is far more to science policymaking than simply this. Although lay citizens may often engage with science differently than the 'experts', their alternative explanatory framework might be recognised as a legitimate input into the normative policy process.

## **5.2. Beyond a 'Knowledge Deficit' Model**

Until recently, the problem of public ambivalence towards science policy, and concerns that citizens were not positively engaging with technological progress, was regarded as a consequence of deficiencies in scientific literacy. This became known as the 'knowledge deficit' model, which was rooted in an Enlightenment view of scientific knowledge. Because, 'science' was considered a coherent and rational search for indubitable truth, based on universally applicable methods, engagement with science policy was seen to require a degree of technical competency. Many policymakers considered the increasing communication gap between science and the public to be an inevitable consequence of specialisation. They lobbied for improved public education on the fundamental principles of science in the hope that this would make it easier to proselytise sceptical publics into the scientific faith. A recent MORI (2000a) investigation revealed that many scientists consider 'knowledge deficit' to be the

greatest hurdle for a more 'informed' public understanding of science. More significantly, many scientists expressed the belief that they should retain primary responsibility for communicating the ethical and social implications of their work. (MORI, 2000a, 3)

Most scientists endeavour to protect their existing monopoly over scientific 'expertise' by erecting what Kerr et al (1997) refer to as 'discursive boundaries'. In their interviews with genetics professionals, the authors discovered that most respondents believed in an independent and objective science, established boundaries to demarcate 'good' and 'bad' science, and used a rhetoric of neutrality in order to protect themselves from blame for the social consequences of their work. (Kerr et al, 1997, 291) They also expressed a desire to educate the 'ignorant' public. (Ibid, 291) Similarly, Ettore (1999) has portrayed genetics experts as 'storytellers' and 'producers of genetic ideology' who:

'... construct complex genetic narratives accessible for popular consumption ... This is an important, if not the most important, part of "genetics work", establishing their scientific and cultural authority by the stories scientists tell, the metaphors they use ... and the global range of their influence.' (Ettore, 1999, 40)

Bensaude-Vincent (2001) argues that although the phenomenon of a knowledge and communication gap is not new, the emphasis on an ignorant public only really began in the mid-twentieth century. She argues that the advent of cold war physics, and the domination of the military-industrial complex, marginalised the role of public opinion. Before science became 'industrialised' and 'institutionalised', there was no suggestion that the public could not be active contributors to scientific progress. The eighteenth century

was very much defined by the popular science of amateurs, who conducted their experiments in public and appeared to embrace the contributions of lay citizens.

In the context of contemporary public engagement with science policy, it might be necessary to try and recapture the Enlightenment view of public opinion and reconceptualise the positivist view of science. The end of the cold war, and the current domination of the biological sciences (which do not fit so easily within a monolithic positivist view of science and expertise), may provide the necessary access point for re-configuring the historically subservient relationship between scientists and the public.

The old 'knowledge deficit' model appears to be untenable in the context of the biological sciences. The fragmentary nature of the biological sciences has created a multiplicity of experts with knowledge and technical proficiency within increasingly narrow sub-disciplines. The policy debate on genetics and insurance illustrates how difficult it is to find a single 'expert' with access to the 'whole picture'. Instead, there is a diverse range of knowledge domains (encompassing clinicians, molecular biologists, actuaries, insurers, social policy experts, interest group representatives, and economists) that are relatively independent from each other, and bring to the policy process only a partial perspective.

Zimmerman (1999) cites '... the lack of complete information, *even in the hands of experts*, with respect to the ultimate success or predictability of many of the new applications of science' (Zimmerman, 1999, 229, *my italics*) as contributing to public controversy and ambivalence. In fact, in the case of

genetic information and insurance, the 'knowledge deficit' model was used predominantly by insurers to label their critics 'ignorant' of insurance as a specific form of expertise. The clinical and scientific community have at least tried to engage with non-scientists without simply replicating the positivist view of science<sup>4</sup>. However, because insurers never contributed to the public understanding of science debates, they have remained largely wedded to the 'knowledge deficit' mindset.

Nevertheless, some have argued that we should not allow increased public involvement to denigrate the legitimacy of scientific expertise. Miller (2001) argues that even without the deficit model there will always be a knowledge deficit. He writes: "We do not want a public understanding of science political correctness in which the very idea that scientists are more knowledgeable than ordinary citizens is taboo." (Miller, 2001, 118) Although Miller welcomes public involvement, he argues that citizens must be able to recognise scientific controversy without rejecting science itself. Stern (1991) argues that citizens should be taught the meaning of scientific disagreement. If this educative process avoids portraying science as pure and incontrovertible, citizens might become less confused when confronted with the inevitable conflicts that define contemporary science. (Stern, 1991, 112)

This literature suggests that the scientists who appear as witnesses in citizens' juries might still have an educative role to play. As Garland (1999) rightly points out: 'Society needs geneticists to describe factually what is known about genetics and what can be done.' (Garland, 1999, 250) The crucial point,

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<sup>4</sup> Geneticists, more than most 'scientific experts', often speak of the need for more active dialogue with the public on the applications of genetic technology. This is certainly a positive development but should be observed with a critical eye. It may well be that geneticists simply wish to use public forums to defend their scientific practices and convince an increasingly sceptical public, rather than partake in an equal and politically neutral exchange of ideas.

however, is that the transference of knowledge and information from expert to non-expert should not be based on an assumption of knowledge-deficit. Instead, the critical skills, experiences, and 'expertise' of the citizens should be recognised as a legitimate input to the process. Knowledge of esoteric science is not necessarily essential for developing science policy. As Fuller (1997) argues, '... most of what non-scientists need to know in order to make informed public judgements about science fall under the rubric of history, philosophy, and sociology of science, rather than the technical content of scientific subjects.' (Fuller, 1997, 10)

Although it is necessary to recognise that citizens may competently judge the validity of competing knowledge claims, equally important are the socially embedded lay perceptions of science that professionals are often either ignorant of, or denigrate as irrational. Black (1998) argues that such lay perceptions: 'are not arbitrary or irrational but based on identifiable criteria, exhibit a systematic pattern, and are institutionally embedded. It is the acceptance of this proposition which has to underlie any system of regulation which seeks to facilitate full integration.' (Black, 1998, 63) Similarly, Condit (1999b) writes: 'The public is not ignorant and irrational, but portrayed so only because elites such as social critics and scientists perceive that the public disagrees with their own views.' (Condit, 1999, 177) Her research discovered that the public were not always passive recipients of genetic knowledge. They often read scientific and media accounts critically and intelligently.

However, the suggestion that citizens are competent enough to engage critically with science appears to contradict other evidence presented in this thesis. In chapter 2, data revealed that patients often reject medical advice or interpret risk in a way that contradicts received wisdom. Earlier in this chapter,



social science research revealed the apparent ignorance of many patients at risk of certain genetic disorders. If we want to reject the 'knowledge-deficit' model, these apparent contradictions require a response. One way to get around the contradictory evidence might be to argue that the apparent internal irrationality of individuals who reject medical advice that *directly affects them* may not necessarily indicate a more general phenomenon of scientific ignorance. It may not preclude the possibility that such individuals could rationally judge phenomena *relating to other people*. For example, smokers often reject medical advice and may even try to rationalise smoking in a way that runs counter to received medical wisdom. However, we should not assume they are inherently ignorant of the dangers of smoking and unable to make rational decisions on general smoking policy. The fact that many in the medical profession smoke indicates that an internal cognitive distinction should be made between assessments of individual and group risk. This argument may find support from 'attribution theory' in social psychology. Attribution theory states that people explain their own behaviour differently to how they explain the behaviour of others. For example, an individual who is successful may claim their success is a result of personal effort. However, when others are successful, they may attribute it to luck of the draw. Similarly, an individual who fails may attribute his/her failure to unforeseen external social circumstances. However, when others fail, they may attribute it to some behavioural defect in that individual's personal constitution.

The general point is that people tend to regard advice and principles as applying to 'people in general', but are willing to treat themselves as the exception. There is even a degree of rationality to this. Because most medical advice is based on statistics, so exceptions are indeed to be expected in the normal pattern of events, those who do not take the advice, or operationalise an

alternative rational framework, may simply be taking a calculated risk based on what they believe to be more in-depth knowledge of their own personal circumstances. Therefore, the documented 'irrationality' or 'ignorance' may not undermine the argument that lay citizens can, in principle, come to judge the validity of competing knowledge claims and make important science policy decisions.

### **5.3. A New Relationship Between Scientists and the Public**

Macintyre (1995) argues that the social context of the new genetics is crucial for policy decisions. She argues that 'sound policy' requires both a good public understanding of science and a scientific understanding of the public. She writes:

'... it is crucial that laboratory and clinical scientists, doctors, health-service administrators, and regulatory authorities are knowledgeable about those aspects of our culture and social institutions which are likely to influence the introduction of, and response to, the new genetics.' (Macintyre, 1995, 228)

The knowledge deficit model assumed that a continual one-way flow of information from scientists to the public was the only solution to public scepticism. The idea was that the public could be convinced to accept the legitimacy of any particular technological development if only they were 'informed' of the science. However, with genetics, it is increasingly difficult to separate the science from its social embeddedness. Durant et al (1996) argue that:

'The main consequence of embedding public understanding of the new genetics within a contextual rather than a deficit model of the public understanding of science is that it points to the need for a far more subtle and textured characterisation of the interrelation between speakers, media and audiences.' (Durant et al, 1996, 246)

Durant et al point out that DNA has become constitutive of a public discourse in which constant shifts in meaning, particularly the transformation from a conceptualisation as mere genetic material to a socially connotative part of mass culture, must be taken account of if a true public understanding of the new genetics is to be framed effectively. Such understandings are never:

... passive reflections of professional, scientific understandings; rather, they are active constructs, the products of multiply-mediated historical and cultural ... influences, which may be expected to diverge significantly from those professional understandings of science with which they coexist.' (Ibid, 236)

It appears to be imperative that scientists turn to the public and begin to draw upon their own unique insights as lay citizens. Locke (2001) believes that an SSK approach, which challenges the universalistic claims of Enlightenment science, offers the most promising avenue for understanding public ambivalence towards rationalised expertise. (Locke, 2001, 4) Eden (1996) also seeks to extend the notion of expertise in order to undermine the priority often granted to institutionalised scientific rationality. For Eden, true democratisation requires that counter-experts be granted the same legitimacy as mainstream experts. (Eden, 1996, 199) Irwin's (1995) case studies of lay citizens who used 'local knowledge' of the environmental impacts of technology to challenge the scientific orthodoxy, demonstrate how democratisation might work. Irwin argued that 'citizen-centred' science policy could reverse the flow of power in decision-

making by recognising the public's unique knowledge generating capacities.

Kerr et al (1998) extended this idea to the genetics debate by arguing that:

'Expertise is ... not solely the province of professionals, but lay people have valuable knowledge and understanding of the social world which equips them to discuss the new genetics in a sophisticated and reflexive manner ... technical details are but a small part of this "stock of knowledge" and are far from fundamental to lay people's sociological intellect and imagination.' (Kerr et al, 1998, 52)

Bucchi's (1996) analysis of the communication of scientific discourse recognises the reverse flow of information and understanding from the public to the scientists. He criticises the 'the canonical account' of public understanding, analogous to the deficit model, which assumes that that the public appears only at the end of a unilinear cognitive chain. The public only has a role after the science has been produced and validated by 'experts'. (Bucchi, 1996, 376) Bucchi writes: 'As a unidirectional linear communication transfer from one sender (the scientific community) to a completely passive receiver (the broad, uninformed public), the process should in no way affect the nature and content of original information.' (Ibid, 377)

Bucchi argues that a modification of the 'continuity model', which emerged from the sociology of science, might reveal the ways in which scientists turn to the public during 'marginal crisis situations'. When the science is new and contentious, scientists often need public support. Bucchi writes: '... public support is particularly necessary when what is at stake is not just the negotiation (however massive) of the boundaries but rather their constitution.' (Ibid, 382)

Bucchi claims that crude continuity models try to overcome the canonical view of science communication by bounding themselves to a rigid sociology of science perspective. They focus their attention on the scientists and take-for-granted the public realm. He argues that:

'... communication of science at the popular level may influence core scientific practice in many more different and subtle ways than simple support and reinforcement ... it can foster the inclusion or exclusion of actors or theories from the specialist's discourse, and it can make room for new interpretations or confer a different status on existing models by linking them to other public issues and themes.' (Ibid, 386)

This idea becomes increasingly pertinent when we consider the witness testimony aspect of citizens' juries. It recognises that deference to the authority of 'experts' may be counterproductive, and that scientists can learn as much from the public as the public learns from them.

#### **5.4 Citizen Jurors Cross-Examining 'Expert' Witnesses**

The public understanding of science literature has implications for the suitability of the citizens' jury. If the model is to be effective in establishing policy on the issue of genetics and insurance, the 'experts' who appear as witnesses must not assume a 'knowledge deficit' model. It is crucial that the dialogue flow both ways and jurors be allowed to challenge the testimony. Evidence from consensus conferences demonstrates how this can work in practice. A recent report on a GM crops conference in Japan revealed that citizens were quite willing and able to challenge 'expert opinion'. The report states:

'... lay citizens not only can sufficiently uptake complicated technical issues but also can make significant contributions to the development of scientific and technological discourse by raising some vital questions from their own standpoints as consumers, parents, students, or agricultural producers.' (Hirakawa, 2001, Para 2.4)

Both jurors and witnesses must be encouraged to regard the process as open and mutually beneficial. Experts should be encouraged to reject the 'deficit model' as they present their opinions, and jurors must not prejudge the legitimacy of expert testimony. The former is perhaps the most difficult goal to accomplish. Evidence suggests that experts, generally try to protect their cognitive authority on matters of science and expertise. They also appear bounded by an institutional framework that runs counter to democratic openness. The citizens' jury might offer the best opportunity to redress this problem. The process can only be effective if experts are not afraid to express their opinions. Fuller (2000b) argues that the political theory of science required for an open society, and thus for an effective model of scientific decision-making, is republicanism. He writes:

'The open society is possible only in a republican regime, where, unlike liberal or communitarian regimes, a clear distinction is drawn between staking an idea and staking a life ... This distinction underwrites the fundamental principle of the open society: the right to be wrong.' (Fuller, 2000b, 5)

If expert witnesses are unable to present their views without fear of having their careers or reputation damaged, then the knowledge available to jurors for deliberation will be inadequate, and may undermine fair, informed, and effective decision-making.

Because the genetics and insurance debate has been so controversial, the potential for closed-mindedness and ideological obstinacy is high. However, if

the various witnesses are given assurance that their testimonies will be deliberated rationally and equitably, there is no reason why they should consider the citizens' jury less legitimate as a decision-making body than the current system. However, we are still in the early stages of recognising the importance of the public in scientific policymaking. The knowledge-deficit model continues to persist in many professional circles. A number of anomalies could undermine the realisation of a true citizen-centred science. In particular, many still criticise citizen participation methods. Such challenges require a response.

#### **5.5. Criticism of Citizen Participation as Based on a Lack of Faith in Increased Democratisation of Policymaking**

The genetics and insurance problem has offered a perfect case study for assessing the suitability of the citizens' jury model. The final question that remains is whether criticism of citizen participation is based on a simple lack of faith in the further democratisation of policymaking.

Critics of citizen-centred decision-making often reveal their lack of faith in the competency of the public to understand technical details and reach informed decisions. Keith Bedell-Pearce reflected this view in his interview. He stated:

As undemocratic as it may seem I'd much rather rely on committees or forums of informed, objective individuals. Citizen's juries ... can be swayed by advocacy and it's not just the advocacy of people in front of you, but all of the stuff they pick up from television programmes through to Watchdog or Panorama or whatever. People take a large amount of baggage in with them ... I'm not sure that a randomly drawn jury would come to an appropriate solution taking on board all the interests involved.

This general scepticism was shared by most of the interview respondents, but insurers and geneticists were most likely to talk in terms of 'knowledge deficit'. In commenting on the ABI citizens' jury, the anonymous insurance underwriter explained:

'... there were people with all respect, who had absolutely no knowledge at all ... the majority of the time was taken trying to explain to them the difference in policies. We were talking about life and disability insurance but they wanted to talk about problems they had with travel insurance.'

Both these comments illustrate that peoples' attitude towards the citizens' jury may be shaped by their knowledge of particular examples. Flawed experimentation with citizens' juries may be worse than none at all, if they give people a false impression of the model's suitability.

Critics may also account for their lack of faith in the process by arguing that the method is only suitable for relatively homogenous societies with shared belief systems and underlying cultural assumptions. The fact that citizen's juries and consensus conferences tend to have been used most in the Scandinavian countries and Japan, appears to support the critics' argument. The efficacy of the model may depend on the social and political constitutions of the societies in which they are used. This point was revealed in Nelkin's (1977) comparative analysis of technological decision-making and participation in Sweden, The Netherlands, and Austria. Citizen participation was affected by the countries' very different assumptions about who should participate, which was often dependent on how they traditionally dealt with opposition and conflict. Sweden's homogeneity and historical tendency to foster participation of citizens lay at one extreme, while the historical religious and regional conflicts of the Netherlands lay at another. (Nelkin, 1977, 92) These national differences



affected the quality of citizen participation, and even its basic aims and objectives. However, these observations do not necessarily imply that the model cannot be transported internationally. Einsiedel et al (2001), drawing on case studies of consensus conferences in Denmark, Canada, and Australia, argue that:

'Our case study suggests that the consensus conference model is one that "travels well" and is easily adapted to contexts outside Europe. All three countries are, of course, similar as post-industrial liberal democracies with common Western cultural foundations. Having said this, it appears our observation still holds when one considers that the model has also been applied in Japan and South Korea.' (Einsiedel, 2001, 94)

Although national contexts may influence the quality of citizen models of participation, they do not negate its efficacy *a priori*. Any deviations from the ideal of deliberative reasoning may be resolved within any national context. The fact that the model seems to work well in a variety of countries serves to illustrate its potential malleability. Furthermore, one must be careful not to prejudge the effectiveness of participants based upon national historic traditions of behaviour. For instance, Japan has an historical tendency towards deference to authority, but in the consensus conferences used there, Japanese citizens appeared more than willing to challenge received scientific wisdom.

These criticisms of the citizens' jury method may appear at first to provide *prima facie* evidence that the model is simply inappropriate beyond a limited public consultation role. However, the basis of such criticisms appears to rest on an intuitive lack of faith in the reasoning capacities of citizens a scepticism of increased democratisation more generally, and a belief that the model is inappropriate for pluralistic societies. However, such criticisms do not

necessarily have to prove terminal; rather they may simply require us to make procedural changes to the constitution of the method and deploy greater social and political resources to encourage and accelerate its practical realisation.

## **6. CONCLUSION**

This chapter sought to assess the suitability of the citizens' jury model for determining policy on the genetics and insurance problem. The assessment began by juxtaposing the deliberative model with a weaker proceduralist/constitutionalist one. The latter was revealed to be inadequate as a rational mechanism for balancing competing interests through evidence-based evaluation. The citizens' jury, as it has been constructed by adherents of deliberative democracy, was then presented. However, such experiments in participatory politics were criticised for their obsession with representation, and their failure to grant citizens any real power. An alternative model was then presented; one which promoted the goal of inclusivity and placed citizens at the centre of all parts of the policymaking process. Various procedural issues were then raised, and the role of facilitators, citizens, and witnesses were documented. However, a number of persistent flaws in the process were also revealed, and attempts were made to evaluate their likely impact on the practical implementation of the model. In the final section, the issue of the public understanding of science and expertise was illustrated. It was argued that a far stronger recognition of the competence of lay actors to judge the validity of competing knowledge claims was required before citizens' juries could be contemplated as a legitimate and practical policymaking process.

Overall, one has to admit that the citizens' jury method has both advantages and disadvantages. It certainly appears to be a method well suited to an issue such as genetics and insurance, which engenders controversy and ideological/professional dissonance. The current policy mechanisms were shown in previous chapters to have foregone rational, evidence-based solutions in favour of political expediency; the result being a continuing moratorium in which little lasting progress has been made. The citizens' jury may well be one way of exploring the issue in greater depth and establishing policies that treat stakeholder accounts more equitably. However, persistent flaws in the model cannot be neglected.

There are a number of difficulties around such things as facilitation, group behaviour, and democratic legitimacy. One major problem is that the model has no formal recognition because it is not institutionalised. However, if it were institutionalised, various other problems might arise. For example, if citizens' juries were granted legislative power, then one would have to consider the impact of the UK's harmonisation with other EU and international treaties on its practicality and legitimacy. Should unelected citizens determine not only policy in the UK, but also other countries? This problem, as well as a number of others documented in this chapter, has no simple solution. Therefore, the citizens' jury may have to be presented as a regulatory ideal rather than a practical method ready for formal implementation.

It is likely that the method will bring many advantages to the policymaking framework, and perhaps lead to more enlightened decision-making on the issue at hand. However, far more empirical work will be required, and some compromise on the model's ideal constitution may be necessary, if it is to be

used as a pragmatic method of decision-making. Perhaps the current moratorium on the genetics and insurance issue would be an ideal time to start experimenting with the citizens' jury. At the very least, it may be an appropriate time to start thinking about how citizens' juries might be studied and provide a more extensive evaluation. Citizens' juries are becoming evermore popular in various countries around the world. There is therefore increasing amounts of data being generated, which might enable us to assess the suitability of the model more effectively. The answer to the sixth research question, however, is still left relatively open. The model does have many advantages over the present system and might improve decision-making on the genetics and insurance issue. However, further research is required so that the flaws may be ironed out.

## CHAPTER 6

### CONCLUSION: SUMMARY AND FURTHER ANALYSIS

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#### 1. INTRODUCTION

This thesis has provided the first extensive sociological analysis of the genetic information and life assurance debate in the UK. It has used both original data derived from interviews with key stakeholders, as well as secondary data from policy documents, reports, and debates, in order to provide a response to a number of crucial research questions around this increasingly controversial social issue. The genetics and insurance debate in the UK is a perfect case study for exploring the variety of ways in which social, political, commercial, and scientific values can envelop contemporary policy problems and play a critical role in shaping the policy framework. This concluding chapter will rehearse the research questions, and assess the extent to which the thesis has succeeded in providing an adequate response to them. The chapter will conclude by listing some of the limitations of the research and highlighting a number of issues that may require further investigation and analysis.

#### 2. SUMMARY AND FURTHER ANALYSIS

## **2.1. The Implications of Genetic Information for Life Assurance Provision**

The first research question asked what would be the most likely social, commercial, legal, and ethical implications if life assurance companies were permitted to use new genetic tests as an underwriting tool. It also asked if the rhetoric of key stakeholders serves to advance or problematise our understanding of the theoretical complexities underlying the issue. A second related research question asked if key stakeholders operationalise particular definitional frameworks around genetic information in order to legitimise particular social, political, or professional values. Chapter 2 attempted to provide a response to these first two critical research questions.

Chapter 2 began by providing an historical analysis of insurance, risk, and the impact of probabilistic reasoning on capitalist society. This revealed two important issues relevant to the stated research questions. Firstly, it demonstrated that the emergence of insurance from the probabilistic revolution concretised a number of commercial principles that have continued relatively unchanged to this day. Historically, the insurance industry has been compelled to deal with the introduction of novel technologies. Secondly, the historic role of insurance within society appeared to challenge the generalised 'risk society' theory of Beck and Giddens. The historical data revealed that insurance has always existed primarily as an institution to protect the middle classes from financial risk. Because both Beck and Giddens fail to recognise such distributive issues around risk, their theories were shown to be inadequate for enabling us to understand the complexity of the genetics and insurance problem. Although the 'risk society' theory may have served an important function by sensitising social scientists to the importance of risk as a social phenomenon, its practical

utility for understanding genetics and insurance was shown to be minimal. However, the work of Foucault and Weber did allow for a deeper understanding of the differential impacts the probabilistic revolution had on both society, and the various social groups constituted within it. The revelation of the historical class-bias in insurance provision also proved crucial to our understanding of the differential implications of genetic information for access to insurance. The fear that insurance companies' use of genetic information might engender widespread social and economic exclusion appears groundless when one recognises that the 'poor and vulnerable' have historically been excluded from the insurance market.

The second section of chapter 2 began to look at the underlying commercial principles of the modern life assurance business. These principles were contrasted with those of social insurance systems. It was revealed that the 'business of discrimination' narrative that underlies the commercial provision of insurance products was based on the historical principals of 'equity' and the 'freedom to underwrite'. A lengthy analysis of the standard norms of commercial insurance, and its putative social role, revealed a critical issue regarding the distribution of social goods through private insurance. If an insurance product is considered a 'non-primary social good', as opposed to a 'primary social good', then the principle of equity, and the associated process of discriminatory risk-assessment, is largely justified. The ethical boundaries of commercial insurance were presented as being dependent on the type of social good being distributed. If society defines a good as 'non-primary', then commercial providers have a right to use actuarial underwriting to rate applicants and place them in an appropriate 'risk pool'. However, if a good becomes recognised as something everybody should have a 'right' to access, then the restriction of

commercial freedom, or the substitution of a social insurance system for a private one, could be justified.

This analysis also discussed the important issue of 'fair' and 'unfair' discrimination; emotive terms that are often misused by both stakeholders and scholars. Fair discrimination is the natural consequence of commercial risk-classification. If such classification is based on sound actuarial evidence, many claim it is by definition fair. Unfair discrimination, in contrast, may occur if insurers rate applicants on imperfect data or allow normative judgements to pollute the actuarial decision-making process. The underlying logic is that if insurers simply abide by their own long-established principles, there will be no unfair discrimination. However, one might wish to argue that discrimination is unfair if an individual is denied access to an insurance product defined as a primary social good, even if the insurer uses standard actuarial methods. Again, it appears that the type of social good being provided is crucial to our understanding of what is fair or unfair. What is clear, however, is that both concepts are highly complex, and when misused by stakeholders, policymakers, or academics, may lead to unjustified demands being placed on the commercial sector.

However, insurers were also shown to have problematised this issue of fairness. Chapter 2 uncovered the complex rhetorical strategies used by representatives of the insurance industry to morally justify their commercial practices. The interview transcripts revealed the extent to which respondents envelop their 'business of discrimination' narrative within a social value narrative framework. They appeared to shift between commercial, social, and clinical values, in order to provide a morally adequate account of commercial freedom. Although they were perhaps justified in defending their business interests, by



presenting themselves as philanthropic distributors of social goods they may have problematised our understanding of the issues' ethical boundaries.

By presenting the commercial role of insurance and its underlying principles, and offering a critical analysis of such problematic concepts as fair and unfair discrimination, equity, and social exclusion, a solid foundation was built from which to explore the implications of genetic information for life assurance provision. The principal conclusion drawn was that genetic information is unlikely to have a significant impact on the provision of life assurance. The fear of widespread social and economic exclusion (a social implication) was rejected because of three revealed facts.

Firstly, the poor and excluded have never really had access to life assurance. Therefore, they would unlikely constitute a new 'genetic underclass' if insurers were permitted to use genetic information as an underwriting tool. Secondly, the flexibility of a commercial market, coupled with the ability of insurers to create novel products for at-risk individuals, would likely mitigate any significant social impacts. Finally, genetic information can often rule people into insurance as well as out of it. For example, if somebody with a family history of Huntington's disease takes a genetic test and it proves negative, they could acquire a standard life assurance policy when previously they would have been rejected. This chapter also discovered that the commercial implications were likely to be relatively minor. It was more likely that genetic information would simply lead to a refinement of existing underwriting practices. Although commercial fears of adverse selection were found to have some validity, they were not necessarily significant in the case of life assurance provision. Because the provision of life assurance requires minimal actuarial underwriting, the introduction of new kinds of genetic test information is unlikely to be of much use to a commercial

underwriter. With regard to potential ethical implications, it was again revealed that few new ethical dilemmas or perplexities arise. Furthermore, all potential social, commercial, and ethical implications might be rendered innocuous by the fact that the insurance industry has demonstrated its creative capacity to create novel products for at-risk applicants. The growth in the annuities market was signalled as one particularly crucial area; important to any considerations of the genetics and life assurance issue.

The emergence of new kinds of genetic information may simply have sensitised people to the commercial practices of insurers, and their historical use of actuarial data. In this sense, society might want to reconsider the role of private insurance and third-party use of clinical information more generally. The final section of chapter 2 raised a number of legal/clinical issues around the ownership and control of genetic information, as well as the 'trust relationship' between doctors and patients. It was argued that the use of genetic information by insurers does raise some important issues regarding ownership and consent, and may fundamentally affect the traditional relationship between clinicians and patients. However, the increasing tendency for people to conceptually isolate certain kinds of genetic information was also shown to be unjustified. The conclusion was drawn that the debate should now be centred on third-party access to all medical data, not just the genetic variety.

Once we recognise that new kinds of genetic information will have little impact on the existing system of life assurance provision, the question then becomes why genetic information has been singled out for special attention. Might stakeholders have played a crucial role in rendering genetic information special? The second research question sought to investigate the extent to which key stakeholders operationalise particular definitional frameworks around

genetic information to perhaps justify broader social, political, or professional agendas. Chapter 2 provided a response to this question. The interview accounts revealed that clinicians, patient-support group representatives, and insurers alternate particular definitional frameworks, in very specific contexts, in order to render their broader social, political, or professional values most coherent and logical. They may draw upon either a 'restricted' or an 'expanded' definition in order to legitimate a normative belief about how the information ought to be used. At times, respondents' accounts appeared to imply that genetic information is no different to family history data or various other kinds of medical information (the argument of 'substantial equivalence'); while at other times, respondents seemed to want to treat certain kinds of genetic information as special (the argument of non-equivalence). Often, the creation of a particular definitional framework appeared to be used to either legitimate or challenge the commercial value of the 'freedom to underwrite'.

However, the interview accounts also revealed that stakeholders representing a particular professional constituency do not always have shared opinions and values. Julia Cream and Alistair Kent, for example, disagreed on the issue of whether or not insurers should be able to access genetic information. They therefore used very different rhetorical strategies when constructing a definitional framework around genetic information. However, it was certainly the case that all respondents used a shifting definitional framework when expressing their accounts. This may be one reason why the genetics and insurance debate has become so controversial. Both stakeholders and academics may have problematised the issue by displaying an inconsistent approach to the very definitional boundaries of the debate. By drawing on a complex repertoire of social, commercial, and ethical values, insurance industry representatives, in particular, revealed themselves at times to be both

inconsistent and contradictory. For example, they claimed they would not request people to take a genetic test as a prerequisite for obtaining insurance cover, but then tried to defend the practice of requesting that certain individuals take an HIV antibody test. Other stakeholder accounts also appeared to engender certain inconsistencies and contradictions, partly because of their need to provide a morally adequate account of their beliefs by drawing on a broad narrative repertoire.

Overall, chapter 2 demonstrated that genetic information will unlikely have a significant impact on the existing provision of life assurance in the UK, although the controversy may have served an important purpose in sensitising people to the role and function of private insurance in society. The controversy may have emerged because of the iconic status genetics seems to enjoy in modern times. At the beginning of chapter 2, reference was made to the issue of eugenics. It was suggested that the past abuse of biological science for ideological means, might have sensitised people to the potential social implications of new genetic information. The fact that HIV testing did not raise the same level of concern as new kinds of genetic testing, serves to illustrate the special nature often ascribed to genetics-based information.

Although it was argued that genetics would have little impact on the life assurance industry, it could have an impact on other forms of insurance such as health and long-term care cover. Such products might be considered 'primary social goods'. Therefore, if society becomes increasingly dependent on private forms of insurance to meet these needs, the use of genetic information to rate policyholders may prove to be unjustified. A crucial point of this chapter was the need to consider the implications genetic information may have for the privatisation of welfare. Risk-assessment is morally justified only if the good

being distributed through a mutuality-based system of insurance is considered a non-primary social good.

## **2.2. Stakeholder Accounts of their Concerns about Genetic Information and Life Assurance.**

The third research question asked: what are the specific concerns of stakeholders regarding genetics and insurance, and do their accounts draw on a broad set of social, clinical, and commercial values? Chapter 3 focused on this research question and provided an extensive sociological analysis of stakeholders' interview accounts. Policy documents circulated by relevant professional interest groups were also analysed to substantiate the interview data.

Both the interview transcripts, and data from relevant professional organisations, revealed that stakeholders draw on a broad and complex narrative repertoire when giving account of their concerns on this issue. They appeared to draw selectively from a social, commercial, clinical, or ethical narrative value framework, and marginalise or prioritise certain substantive issues, in order to provide a morally adequate account of their beliefs.

Clinicians were found to draw predominantly from both a clinical and social value narrative framework, often conflating the two, in order to legitimise their belief that commercial freedom may need to be curtailed. Through their interview talk, they appeared to marginalise commercial concerns and prioritise clinical and social ones. Sometimes, they would appear to recognise the concerns of the insurance industry, but would then present a professionally

situated account and give ultimate priority to the needs of their patients. Their strategy was to argue that restrictions on the commercial 'right to underwrite' might be justified, because it might prevent social and economic exclusion, which would then ensure that all members of society benefit from the genomics revolution. Clinicians' primary concern was that fear of social exclusion might prevent people taking genetic tests. Therefore, in order to protect the clinical value of testing, clinicians often drew on a 'politics of inclusion' narrative.

Patient-support groups also appeared to marginalise commercial values by wrapping their rhetoric in a social value narrative framework. Julia Cream, from the Alzheimer's Society, was most critical of insurance industry practices and often drew on various configurations of social, commercial, and clinical values in order to undermine the 'business of discrimination' narrative. Insurance industry representatives used similar strategies. They frequently prioritised a commercial value narrative, but often enveloped this within a social or clinical value framework. Through their interview talk, they would shift the conceptual boundaries of clinical, social, and commercial values to both marginalise the significance of an anti-commercial rhetoric, and trivialise public fears about social and economic exclusion. Evidence from policy documents distributed by various professional bodies appeared to support the interview data analysis. Patient-support groups would often criticise insurance industry practices, because they exclude vulnerable groups, while clinical organisations would challenge the business of discrimination narrative, because subsequent fears of discrimination may reduce patients' willingness to undergo genetic testing.

However, this chapter also revealed a deeper complexity to the stakeholder accounts. One hypothesis of this research was that there would be acute

differences of opinion between insurers, clinicians, and patient-support groups. However, this chapter revealed that such broad professional constituencies were not homogeneous. Not all members of clinical or patient-support groups believed that incumbent forms of legislation were necessary to protect individuals from the discriminatory practices of insurers. The contrasts in the accounts of Alistair Kent and Julia Cream, and Sandy Raeburn and other clinicians, were striking in this regard. Kent and Raeburn accepted commercial insurers as important distributors of social goods, whereas Cream perceived them as a threat to social and economic inclusion. Therefore, one could observe the use of very different rhetorical strategies in their respective accounts. It appeared that membership of a particular professional constituency was not the principal determining factor of how beliefs are formed. Rather, it appeared that individuals' beliefs, and the rhetorical strategies they used to account for these beliefs, was determined more by their level of knowledge of the issues' underlying complexity, and the extent to which they had engaged constructively with other stakeholders. Nevertheless, some common strategies were revealed. For example, although Kent and Cream appeared to be in ideological disagreement as to how the issue should be legislated, both expressed an explicit commitment to the needs of the at-risk. Subsequently, both prioritised a social/clinical value framework when accounting for their beliefs. Similarly, Raeburn prioritised clinical values, just like his professional colleagues, when he sought to defend existing commercial practices.

In terms of the third research question, we can say that despite some anomalies in the accounts, key stakeholders do have a relatively fixed idea of how they would like to see the issue resolved. They then appear to use rhetoric strategically in order to render their position the most logical, coherent, and morally adequate. The kinds of value frameworks prioritised, and those

marginalised, appear partly determined by the professional situatedness of the respondents. One consequence of these strategies is that the protagonists appear more professionally and ideologically dissonant. The complex, and sometimes inconsistent, use of a variety of value frameworks serves only to polarise accounts and add another layer of complexity to the issue. The professional dissonance that emerges may serve only to antagonise public debates on this issue. If narrowly defined interests and values constantly impinge on the policy process, and if stakeholders problematise matters by operationalising complex narrative strategies when accounting for their concerns, it may become far more difficult to engender informed and equitable debate.

### **2.3. Genetic Information, Life Assurance, and the Policy Process**

Following from the assessment of stakeholder accounts, the thesis moved on to investigate the policy framework around genetic information and life assurance. Chapter 4 sought to provide answers to the fourth research question, which asked whether the advisory/regulatory system had produced an equitable process that could rationally judge competing narratives, or if political decision-makers had granted differential legitimacy to stakeholder evidence. It also tried to investigate the extent to which perceived public opinion had negatively influenced the strategies of key stakeholders and politicians. This would provide an answer to the fifth research question.

Through an extensive sociological analysis of the formal policy process around the genetics and life assurance debate, a number of important insights began to emerge. The impetus for a formal political process appeared to



emerge from growing public fears that the use of genetic information by life insurers might lead to widespread social and economic exclusion. The complex political rhetoric of key stakeholders, identified in chapter 3, may have played a crucial role in shaping the policy and regulatory framework. A critical analysis of the advisory committee system, and its inconsistent treatment of interest group accounts, revealed the inadequacies of such a deeply entrenched political process.

The various committees appeared too narrowly focused and appeared to neglect some of the more subtle and complex nuances of the problem. Just like the various stakeholders, committee representatives appeared to prioritise or marginalise certain substantive issues, draw selectively from a broad narrative repertoire, and differentially judge evidence based on what they considered politically expedient. The frequent and uncritical use of emotive concepts such as 'discrimination', 'social and economic exclusion', and 'commercial values', by various representatives of committees and advisory groups, appeared to underlie the extent to which the process was very much political in nature. A lengthy analysis of the House of Commons Select Committee report revealed an explicit attempt by politicians to undermine the validity of insurance industry accounts by prioritising clinical evidence. Within this report, insurers appeared to be portrayed as untrustworthy and motivated only by profit, while clinicians appeared to be portrayed as part of a noble profession concerned only with enabling society to benefit from the genomics revolution. The clinician's evidence was taken largely at face value, but the insurers were forced to defend their commercial practices and values. Analysis of the ABI's policy approach provided further evidence that the insurance industry are often compelled to marginalise their own concerns, and implicitly support a 'politics of inclusion' narrative, in order to demonstrate that they are socially responsible.

Although a variety of advisory committees were established to investigate the broader social, scientific, and ethical implications of genetics for life assurance provision, it appeared that most had taken a narrow and relatively unsophisticated approach to the problem. Genetic information had been narrowly defined, no attempt was made to distinguish insurance products and their unique implications, and the 'politics of inclusion' narrative was uncritically represented. It seemed that most of the institutions had pre-framed the issue as one of a need to 'protect consumers' and the 'genetically at-risk' from unfair discriminatory practices. Again, the analysis of the ABI's policy approach appeared to reflect the political strategising that was required if interest groups were to have their views recognised by representative political institutions.

Interview accounts of the policy process revealed a degree of disenchantment with the political nature of decision-making on this issue. Although most stakeholders accepted the moratorium decision in principle, their lack of faith in the process itself was palpable. Insurers believed that the process failed to recognise their interests and concerns as legitimate. Clinicians pointed to the lack of scientific evidence in the debate. Members of patient-support groups also appeared to be selective in which specific committees they approved of. Julia Cream, for example, rejected the ABI's system of self-regulation but praised both the work of the HGC and the House of Commons, because she perceived these institutions to be generally supportive of her ideological beliefs.

The question then became: why has this policy process become so ideologically and politically dissonant, and why have the representative institutions not taken a rational, evidence-based approach to the issue? The

impact of 'public opinion' and the 'media' appeared crucial in this regard. Public opinion revealed itself as a central feature in the accounts of stakeholders, the media, and members of advisory committees. Even the ABI frequently referred to 'the public', and expressed the need to earn their confidence. However, there appeared to be little discussion on what the public constituted and what their 'real' concerns were. Various surveys were criticised for their failure to distinguish the 'informed' from the 'uninformed' public, and media accounts were criticised for their sensationalism of the issue. It appeared that a potential, yet largely undefined, problem had emerged as genetic science had progressed. Media representations had then aroused public fears by portraying dystopian visions of our pre-determined genetic future. A policy framework was then established, but committee representatives, politicians, and stakeholder groups then appeared to react uncritically to a perceived view of an incredulous public concerned about a potentially large genetic underclass emerging in society. Representative institutions were then forced to use political expediency as a guide for action, and stakeholders were compelled to respond to the public fear issue by demonstrating that their values were consonant with a broader set of social values.

The evidence presented in this chapter appeared to support the contention that the political process was less rational, focused, and equitable than it would have been if pragmatic policymaking acceptable to all stakeholders were the primary goal. One might ask what made this issue so different from other controversial science/society issues such as ADHD, Gulf War syndrome, BSE, or MMR vaccination. All are, in a sense, complex and controversial science/society issues that have engendered political conflict, public concern, and professional dissonance. Perhaps it is because the term 'genetics' has become such a powerful iconic symbol, and arouses such strong feelings in

people, that the significance of genetic data for insurance became so inflated and conflictual.

The evidence from chapter 4 seemed to provide us with a solid foundation for responding to the fourth and fifth research questions. The regulatory/advisory system might be judged successful in the sense that no single stakeholder group had their values or interests completely undermined by formal legislation. However, a number of flaws inherent to this representative system of decision-making were revealed. The intrusion of 'uninformed' public opinion appears to underlie the extent to which the process deviated from rational and equitable decision-making. The moratorium decision may have been constructive in the sense that it avoided irreversible legislation, but this does not detract from the fact that the process provided an inadequate response to this complex issue. Since there has been little progress, since the establishment of the moratorium, in resolving the underlying conflict over social, commercial, and clinical values, there is reason to believe that the controversy will continue. For this reason, it was necessary to contemplate an alternative form of decision-making.

#### **2.4. Evaluating the Citizens' Jury Approach to Policymaking.**

The final research question asked whether the citizens' jury method was a suitable procedure that might improve policy on the genetics and insurance issue. Chapter 5 provided an evaluation of the citizens' jury by illustrating the flaws of representative institutions, describing the deliberative turn in democratic theory, and raising arguments for and against the use of citizens juries.

Representative institutions were accused of failing to balance competing interests equitably, because they are guided by a political expediency that is only practicable by construing society in terms of a number of relatively stable and homogenous ideological groups who make demands on government. The narrow and uncritical proceduralism of representative bodies, and their obsession with representation, was shown to problematise fair and rational decision-making on complex science/society issues such as genetics and insurance. The deliberative turn in democratic theory, which focuses explicitly on the quality of deliberation in modern democracies, was then shown to offer a potentially better alternative to the weak democratic systems that currently prevail. The citizens' jury model was then critically evaluated.

The limited number of experiments with citizens' juries were criticised for failing to give jurors any real decision-making power, and insisting that jurors constitute a representative sample of the population. They were also criticised for failing to take account of the underlying complexity of deliberative theory. An 'ideal' model of the citizens' jury was then described and explained. It was argued that the citizens' jury model could provide a suitable means through which to establish rational, fair, and pragmatic policies acceptable to all stakeholders in the genetics and insurance debate, if certain criteria were met. Firstly, jurors would have to be given real decision-making power, or at least be assured that their decisions would be taken seriously into account. Secondly, the process would have to be guided by the principal of 'inclusivity' rather than 'representation'. Finally, intelligent and pragmatic procedures would need to be established to guide jurors, facilitators, and witnesses, and ensure they fulfil their roles adequately. Issues such as the public understanding of science were shown to be crucial to the success of citizens' juries. It was argued that, in theory, citizens could make intelligent decisions that were not directly influenced

by ideology, interests, and political bargaining. The genetics and insurance problem provides a perfect case study for exploring the suitability of such a model, because it is an issue that illuminates so much the inadequacy of policymaking

However, a number of crucial issues that may challenge the suitability of the model were also presented. Firstly, the chapter highlighted the contradiction in trying to criticise representative institutions for their narrow proceduralism, but then elaborating a number of rules and procedures necessary for effective citizens' juries. However, by referring to Atkinson's seminal paper on formality in institutional life, it was argued that there might be a qualitative difference between the procedures used by representative institutions and those required in the citizens' jury. In particular, certain conversational and non-conversational procedural rules were shown to be vital for effective deliberation. Such rules often determine whether a social setting is formal or informal, and may be a necessary feature of any formal decision-making body. However, to avoid the contradiction, it was argued that the procedures constitutive of representative institutions are different, and perhaps more problematic, than those required for citizens' juries, because they are narrowly defined and apply mainly to structural aspects of a democracy rather than conversational/deliberative ones. This crucial distinction might render the apparent contradiction innocuous. However, the fact that it may still prove difficult to ensure deliberation is fair, rational, and based only on 'good reasons' may require the model being presented for the time being as a regulatory ideal.

Secondly, a number of problems regarding facilitation were revealed. Evidence from studies in genetic counselling and mediation revealed that third

parties involved in formal interactions might, through their presence, marginalise or prioritise certain issues, or unduly influence the process of deliberation. Reference was made to the inherent problems of group behaviour, revealed by sociologists such as Simmel, and social psychologists such as Thompson and Hoggett. Such work signalled a number of problems with the organisational aspects of deliberation. In particular, it might continue to prove difficult to ensure that 'dominant personalities', or 'emergent group cultures', do not destroy a preferred internal dynamic of group deliberation. This evidence suggested that certain rules and procedures might be necessary as a managerial tool. However, pathologies of deliberation do not necessarily have to be terminal. Problems of group decision-making occur in a variety of institutional settings. The fact that the citizens' jury model explicitly recognises such problems, and tries to resolve them, may render the method suitable as a decision-making process.

A final problem revealed was the lack of representation in the 'ideal' citizens' jury model. How can the process be democratically legitimate if it is not representative in some sense? Again, one could argue that this is not a problem exclusive to the citizens' jury. Representative institutions are almost never entirely representative, and are constantly criticised for not responding to the needs of the apathetic. The citizens' jury model accepts this problem, and argues that the goal of true representation will always remain elusive. Therefore, it replaces representation with inclusivity as its primary goal. This does not mean that the interests of the apathetic are automatically excluded, or that decision-making will be based simply on the bargaining abilities of committed citizens. If inclusivity is a realisable goal, it is likely that the juries will constitute a broad range of opinion and include a number of individuals from a variety of socio-economic groups. Of course, we cannot simply assume this.

Further research is necessary to assess if the citizens' jury can truly live up to its ideal.

To answer the final research question, we can say that the citizens' jury could, in principle, prove a legitimate alternative to the existing system of decision-making. Although the evaluation did raise a number of persistent problems and inconsistencies with the model, there is no compelling reason why they cannot in time be resolved. However, more work still needs to be done before we can fully evaluate the model. We may need to look more closely at the democratic legitimacy of the model, and assess how effective deliberation and facilitation can be in real case studies. A number of questions remain to be answered. How do we ensure juries do not act in a populist manner? Might jurors produce agreement but on the wrong policies? Does successful deliberation diminish ideological division at a later date? Might the UK's harmonisation with EU and international treaties affect the legitimacy of unelected citizens' juries? All these are important questions that require further analysis. Of course, one would need to establish evaluation criteria. Nobody has yet described adequately how a jury might be studied. Perhaps there is a need for the academic community to begin assessing more rigorously the suitability of alternative methods of decision-making. Most citizens' juries have been commissioned and managed by policy groups and think-tanks. Few sociologists have tried to study the intricacies of the method. The ESRC might be an appropriate body through which to lobby for more research in this area. However, there is no reason to believe that the model will prove an unsuitable mechanism through which to arbitrate conflicts over the genetics and insurance issue. The fact that citizen participation has proved relatively successful in a number of different countries, illustrates the malleability of the method.



Overall, this thesis has provided a number of answers to the important research questions it set out to assess. It has provided an extensive sociological analysis of a continuing controversy that is yet to be fully resolved, and furthered sociological research on the new genetics. The evidence largely supported the preliminary assumptions and hypotheses, although others were challenged by the data. However, there were limitations to the research, and there still are further issues that need to be investigated. To conclude the thesis, these will now be detailed.

### **3. LIMITATIONS OF THE RESEARCH AND ISSUES REQUIRING FURTHER INVESTIGATION**

The qualitative approach used to investigate the stated research questions could not provide an exhaustive assessment of the issue. The research could certainly have benefited from greater quantitative input. Although quantitative studies have been cited in order to substantiate some of the primary arguments, further research on how beliefs on this issue may be determined by such things as class, gender, age, and professional situatedness, could be useful. Furthermore, more focused quantitatively based narrative/discourse analysis of the various policy documents circulated by interest groups, as well as media accounts of the issue, might also improve on the research findings presented. In addition, further qualitative work on stakeholder beliefs might prove useful. This research focused only on three types of stakeholder groups. Interviews with politicians, members of regulatory authorities, and perhaps members of the public might have generated some more useful data. Practical considerations dictated that a more narrow and focused qualitative analysis was the most

appropriate methodological strategy. However, alternative methods must still be recognised as equally valid and potentially useful.

In terms of the broader issues associated with the genetics and insurance controversy, the following list details some of the issues neglected in this research, but perhaps in need of further investigation by sociologists.

- International comparisons on the issue of genetics and insurance (this research focused only on the UK genetics and life assurance debate).
- Further analysis on how genetic information may affect access to different insurance products. Also worth investigation is the implications of genetic testing for employment (this research focused only on life assurance.)
- Further research on the social impact of genetic databases.
- Continued research on progress made during the current moratorium. This research looked only at the debate up until the negotiation of the moratorium. Documents released since this date, as well as policy debates, may require analysis.
- A great deal more sociological work on the suitability of citizens' juries. This research presented some of the advantages and disadvantages of this approach, but further work will be required to validate the model.

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