MULTIPLE EXPERTS: SCIENTIFIC, MEDICAL, MEDIA AND LAY DISCOURSES ON 'NEW GENETICS'

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University of Plymouth

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MULTIPLE EXPERTS: SCIENTIFIC, MEDICAL, MEDIA AND LAY DISCOURSES ON 'NEW GENETICS'

By

CLARE ELIZABETH WILKINSON

A thesis submitted to the University of Plymouth in partial fulfilment for the degree of

DOCTOR OF PHILOSOPHY

School of Sociology, Politics and Law
Faculty of Social Science and Business

DECEMBER 2004
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ABSTRACT

MULTIPLE EXPERTS: SCIENTIFIC, MEDICAL, MEDIA AND LAY DISCOURSES ON ‘NEW GENETICS’ Clare Elizabeth Wilkinson

The significance of public relationships with scientific and medical expertise has increasingly been highlighted as an area of importance in governmental policy formulation and scientific activities. Central to this relationship has been the role of the media, frequently depicted as increasing the strained communications between science, medicine and the public in the present UK ‘crisis’ of expertise.

Sociological research has contributed to our understandings of science, medicine, the media and lay knowledge. The research presented in this thesis correlates these contributions. It focuses on ‘new genetics’ to elicit the views towards communication and understanding expressed by three groups; media professionals, members of the public and medical and scientific experts. Utilising a range of quantitative and qualitative methods, this research reflects on the relationships and identities created during interactions between these three groups, ignored by prior studies that have frequently focused on one or two participants in such relationships.

This thesis contributes to present debates surrounding the role of the media and public, concluding that the present climate for dialogue is a politically motivated, theoretical context, challenged by a lack of practical methods to confront long-held notions of understanding and communication between expertise and lay persons. This offers original insight into the identities members of the media, public and scientific and medical experts create, maintain and displace in their interactions. The ‘crisis’ in science and trust instead comes to represent a manufactured perception of the public and media, which continues to exclude the public from true dialogue with medical and scientific experts and maintains traditional notions of the media as incompetent.
## CONTENTS

### List of Tables

<table>
<thead>
<tr>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>iii</td>
</tr>
</tbody>
</table>

### List of Figures

<table>
<thead>
<tr>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>iv</td>
</tr>
</tbody>
</table>

### Acknowledgements

<table>
<thead>
<tr>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>vi</td>
</tr>
</tbody>
</table>

### Author's Declaration

<table>
<thead>
<tr>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>vii</td>
</tr>
</tbody>
</table>

### Chapter One: Introduction

<table>
<thead>
<tr>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
</tr>
</tbody>
</table>

- 'New Genetics'
- The Role of The Media
- Measuring Public Attitudes to Science, Medicine and Genetics
- Scientific and Medical Expertise; Interactions with the Public
- Communicating science with the public; discourse, dialogue or discord?

### Chapter Two: Literature Review

<table>
<thead>
<tr>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>14</td>
</tr>
</tbody>
</table>

- Classical Theories of Scientific Knowledge
- Critical Theories of Scientific Knowledge
- Traditional Public Understanding of Science
- The Media Role, Communicating Science and Genetics to the Public
- Public Views Regarding Science and Genetics
- The Third Wave of SSK: Where do we go from here?
- Summary

### Chapter Three: Methodology

<table>
<thead>
<tr>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>50</td>
</tr>
</tbody>
</table>

- Research Aims
- Research Strategy
- Sampling
- Research Design and Collection
- Data Management and Primary Analysis
- Ethical Issues
- Summary

### Chapter Four: Media Approaches to Science and the Public

<table>
<thead>
<tr>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>82</td>
</tr>
</tbody>
</table>

- Journal Content Analysis
- Journal and Newspaper Relationships
- Newspaper Content Analysis
- Journalists: A Questionnaire and Case Study
- Summary
## List of Tables

<table>
<thead>
<tr>
<th>Table</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Distribution of articles – All Journals</td>
<td>83</td>
</tr>
<tr>
<td>2</td>
<td>Location of Article By All Journals</td>
<td>84</td>
</tr>
<tr>
<td>3</td>
<td>Article Content by Specific Journals</td>
<td>91</td>
</tr>
<tr>
<td>4</td>
<td>Scientific Reference in headline by Individual Newspaper</td>
<td>98</td>
</tr>
<tr>
<td>5</td>
<td>Public Respondents Occupation</td>
<td>122</td>
</tr>
<tr>
<td>6</td>
<td>Question 14 Which newspapers do you read regularly?</td>
<td>124</td>
</tr>
<tr>
<td>7</td>
<td>Where do you conduct the majority of your work?</td>
<td>162</td>
</tr>
<tr>
<td>8</td>
<td>Question 23 How would you rate the general publics' understanding of the following areas?</td>
<td>165</td>
</tr>
<tr>
<td>9</td>
<td>Main Characteristics of Journalists, Scientific and Medical Expert Samples</td>
<td>238</td>
</tr>
<tr>
<td>10</td>
<td>Main Characteristics of Public Sample</td>
<td>239</td>
</tr>
<tr>
<td>11</td>
<td>Main Characteristics of Journal Sample</td>
<td>240</td>
</tr>
<tr>
<td>12</td>
<td>Main Characteristics of Newspaper Sample</td>
<td>241</td>
</tr>
<tr>
<td>13</td>
<td>Headlines by Newspaper</td>
<td>268</td>
</tr>
<tr>
<td>14</td>
<td>Public Interviews Thematic Links</td>
<td>270</td>
</tr>
<tr>
<td>15</td>
<td>Expert Interviews Thematic Links</td>
<td>273</td>
</tr>
</tbody>
</table>
### List of Figures

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Research Strategy</td>
<td>51</td>
</tr>
<tr>
<td>2</td>
<td>Frequency Articles Containing Keyword By Journal</td>
<td>82</td>
</tr>
<tr>
<td>3</td>
<td>Research Content by All Journals</td>
<td>85</td>
</tr>
<tr>
<td>4</td>
<td>Article Content by All Journals</td>
<td>89</td>
</tr>
<tr>
<td>5</td>
<td>Article Frequency by Newspaper</td>
<td>95</td>
</tr>
<tr>
<td>6</td>
<td>Article Frequency by Daily Newspaper and Date</td>
<td>96</td>
</tr>
<tr>
<td>7</td>
<td>Article Frequency by Sunday Newspaper and Date</td>
<td>97</td>
</tr>
<tr>
<td>8</td>
<td>Medical Research Articles by Overall Impression</td>
<td>100</td>
</tr>
<tr>
<td>9</td>
<td>All Newspaper Articles by Individual Sources</td>
<td>104</td>
</tr>
<tr>
<td>10</td>
<td>Question 23 From which sources have you gained information concerning genetics?</td>
<td>125</td>
</tr>
<tr>
<td>11</td>
<td>Question 26 Whom of the following would you trust if reading an article on genetics?</td>
<td>126</td>
</tr>
<tr>
<td>12</td>
<td>Question 28 In general do you think medicine, science, genetics is...</td>
<td>129</td>
</tr>
<tr>
<td>13</td>
<td>Question 19f ‘Human cloning might be acceptable in certain cases’</td>
<td>132</td>
</tr>
<tr>
<td>14</td>
<td>Question 19g ‘genetic researchers are intruding on areas of life, which should be left untouched’</td>
<td>133</td>
</tr>
<tr>
<td>15</td>
<td>Question 12 Of the time you spend working in genetics, what amount of time relates to...</td>
<td>162</td>
</tr>
<tr>
<td>16</td>
<td>Question 21 Do you think the media reporting of scientific and genetic issues is largely...</td>
<td>164</td>
</tr>
<tr>
<td>17</td>
<td>Question 28 Comparison of responses</td>
<td>211</td>
</tr>
<tr>
<td>18</td>
<td>Journal Coding Schedule</td>
<td>242</td>
</tr>
<tr>
<td>19</td>
<td>Newspaper Coding Schedule</td>
<td>243</td>
</tr>
<tr>
<td>20</td>
<td>Media Interview Aide Memoir</td>
<td>244</td>
</tr>
<tr>
<td>21</td>
<td>Public Interview Aide Memoir</td>
<td>245</td>
</tr>
<tr>
<td>22</td>
<td>Scientific and Medical Expert Interview Aide Memoir</td>
<td>246</td>
</tr>
</tbody>
</table>
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Authors Declaration

At no time during the registration for the degree of Doctor of Philosophy has the author been registered for any other University award without prior agreement of the Graduate Committee.

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Conferences Attended:

PFGS Annual Conference, University of Cambridge, September 2002.


BA Festival of Science, The University of Exeter, September 2004.


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Signed ________________________________

Date  11.04.05  

vii
Chapter One: Introduction

The focus of the Government's Science and Society public engagement activities has moved forward from simply promoting public understanding of science to the wider agenda of facilitating public engagement with science and its application. This has the aims of: government and scientists responding proactively to public priorities and concerns; people having greater confidence in the benefits offered by science; greater engagement with major issues facing society, such as climate change; and careers in science becoming more attractive to both adults and children (HMT/DfES/DTI 2004:103).

This statement appears in the Science and innovation investment framework published in July 2004 by HM Treasury, The Department for Education and Skills, and The Department for Trade and Industry. Like a number of recent policy recommendations the report advocates increased 'dialogue', 'engagement' and 'upstream communication' between members of the scientific community and the public. We are it seems faced with a sense of 'crisis' where members of the public and media are presented as a challenge and risk to the scientific and medical communities, and better communication strategies have increasingly been depicted as the key means to navigate this crisis (Hargreaves and Ferguson 2000, HMSO 2000a, HMSO 2002, POST 2002).

The BSE controversy, genetically modified foods, climate change, mobile phones, the Human Genome Project and new reproductive technologies are just some of the highlighted areas of concern amongst the public and media in the UK. Prior to these controversies there have been a number of significant crisis points in public support of science including apathy after the Second World War, concern regarding nuclear radiation, the use of chemicals and pesticides, and the health risks associated to asbestos or thalidomide (Wynne 1992, Irwin and Wynne 1996, Dickson 2000, Greenpeace 2002). What is unique about the present situation is not the prescribed or suggested public anxiety towards science, but the scale these public controversies have reached and their possible commercial implications in an era when we are more reliant on science and technology than ever before (Grove-White et al. 2000, Irwin 2001). Of greater interest for this research
is the culmination of this crisis with new attempts to understand how to communicate with
the public, and the opportunity to advance communication as new scientific innovations
and technologies appear on the horizon.

Developments like nanotechnologies and hydrogen energy are by definition unknown or
unfamiliar outside of a very small numbers of experts (Flynn 2004, The Royal Society and
Royal Academy of Engineering 2004). They are then optimum examples of science and
societies continual movement towards ‘unknown futures’ (Nowotny et al. 2001). Thus for
scientists, the media, communicators and medical experts these will be the sites, if science
fulfils its predictions, where the views of the public truly become upstream and dialogue
forming. In this research I will consider an area of recent public familiarity and uncertain
futures, the science, medical and technological innovations of ‘new genetics’, to examine
where communication is at present and how it may develop in the future.

1.1 ‘New Genetics’

Science and technology pervades every aspect of our day-to-day lives. Access points to
public viewpoints are then not difficult to identify and a number of sociological studies
have accessed public attitudes towards science and technology. New genetics provides the
focus for this research while concurrently allowing it to explore a number of aspects of
science, technology and society; funding and commercial interests, access and regulation,
healthcare and ethics, nature and nurture. While new genetics has been prominent in the
natural and social sciences for a number of years, the history of genetics spans only the last
century and has been marked by a number of significant milestones including Watson and
Crick’s double helix model and the announcements surrounding the ‘completion’ of the
Human Genome Project in June 2000 (Glasner and Rothman 2004a).
The term new genetics has become associated with a series of sciences and technologies existing at the theoretical, research and development stage. These presently include genetic sequencing, mapping, screening, diagnosis and therapies, as well as specific areas attracting public interest, media coverage and funding like pharmacogenetics, stem cell research and genetic modification (Marteau and Richards 1996, Conrad and Gabe 1999, Kerr and Shakespeare 2002, Pilnick 2002, Lewens 2004). Analysis of the potential ethical, legal and social implications (ELSI) of these developments have been prominent, due both to the historical context of eugenics and the considerable funding genetic research has received despite the argument that it raises no new ethical issues (Kelves and Hood 1992, Wilkie 1993, Paul 1994, Glasner 2002, Lewens 2004, Sharp et al. 2004).

Scientists have advertised the ethical issues that genetic research involves—and have thereby projected an image of sensitivity that can be used to sell the overall endeavour...they have compartmentalised the problems so that research can proceed without distraction (Cranor 1994:3).

Sociological studies have become well established and extensive, advancing in some cases the scientific and technological applications they originally sought to examine (Martin 2004). Expertise has been drawn from a range of disciplines, including the social sciences, bioethics and disability rights, challenging or complementing the expertise of clinicians and scientists in a manner which has rarely happened with past scientific projects (Cunningham-Burley and Kerr 1999). Following this trend set by new genetics, consideration of the social and ethical implications of research is now tending to occur in parallel to other scientific research and development (Flynn 2004, Wilsdon and Willis 2004).

While a number of these studies have occurred as the scientific and technical applications of new genetics emerge, the pervasion of genetics into medical practices is increasingly recognisable. To this end Brown and Webster (2004:17) describe new genetics as one of the ‘paradigmatic shifts in the form and content of medical science and practice’, adding to
the growing individualisation and commodification of medical interventions in health. As Glasner and Rothman (1998:1) state new genetics

...has become a focus for study by social as well as natural scientists because, unlike many of the other new technologies, genetics most directly affects all of us at a very personal level.

The potential applications of new genetics are therefore being felt in such areas as genetic testing and screening, while in others we are some years from the initial hype and still anticipating its promises (Jonsen 1996, Cunningham-Burley and Kerr 1999, Glasner 2002, Brown and Michael 2003). Genetic advances have captured the public and media attention, while remaining progressive and largely un-applied; this 'possibility' of genetic interventions encourages the association to risk but also demonstrates the relationship between public concern and imagined realities.

Before the new technology has materialised into new services and products, it first assumes a largely symbolic existence. Thus, its 'real' appearance is preceded by requests for venture capital, from the state, banks or stock market, and by attempts to persuade investors, producers and consumers to endorse the new technology in imagination (Bauer and Bonfadelli 2002:149).

New genetics, like other developing areas of science, represents an insight into how the public and media interpret unknown and unpredictable science and medicine. Further its connections to ideas about the body, relationships, and hereditary factors are personalised to the degree that they are areas members of the public relate to. How can their ideas be inaccurate if these largely remain imagined technologies and imagined futures? (Wynne 2003)

1.2 The Role of the Media

Amongst discussion of the 'crisis' in UK science has been considerable emphasis on the ineffectiveness of British media coverage. In particular the coverage of genetically modified crops and foods, has contributed to the critical discussion of the role of the media amongst the scientific and medical communities. The media are typified as both the victims of government propaganda, and as unreliable sources that distort truth and debate
(Hargreaves and Ferguson 2000). The Press Complaints Commission Code governing inaccurate, misleading or distorted material regulates scientific and medical coverage, but despite this, coverage is often inferred to neglect this code (Bateson and Cookson 2001).

The media stands accused of inaccuracy, poor quality, over-emphasising minority views, and of framing science both too negatively, informing the general lack of reverence towards expertise, and too positively, contributing to claims of sensationalism (Nelkin 1987, Friedman et al 1999, Kitzinger 1999, Allan 2002). At a practical level there are issues regarding the journalists' professional role, news environments and editorial constraints which also contribute to the difficulties in achieving good quality science coverage (Friedman et al. 1986, Nelkin 1987, Hansen 1994, Kitzinger and Reilly 1997).

Criticism of the media coverage of scientific and medical issues has often made two significant assumptions, firstly that the audience has a passive role and secondly that the responsibility for poor coverage lies with the journalistic community. Recent studies have highlighted the need for greater consideration of how scientific and medical media coverage impacts on audiences (Condit et al. 1998, Condit 1999a, Miller 1999). There has also been an increased recognition of the scientist's role as a source of poor communication, 'the reporter will probably feature rosy forecasts if the scientist is willing to offer them, yet such forecasts may all too often come to be seen as broken promises' (Condit 2004a). Studies considering journal coverage, press releases, and networks of expertise tracing communication through professional channels to the wider publics are emerging (Kitzinger and Reilly 1997, Nelkin 1998, Conrad 1999a, Schenk and Sonje 2000, MORI 2001, Nerlich and Clarke 2003, Nisbet and Lewenstein 2002, Smart 2003, Kua et al. 2004). The research presented here contributes to these debates, but further explores audience and contributors views on the media coverage of science and medicine, establishing that not only are appreciations of the publics' use of scientific and medical
coverage naïve but that further, the scientific and medical communities are more involved in perpetrating poor media coverage than is often recognised.

New genetics has become an area of prominence amongst coverage of science and medicine, as one aspect of the wider cultural trends towards geneticisation where genetic images have become stylised metaphors amongst popular culture (Lippman 1992, Katz Rothman 1995, Nelkin and Lindee 1995, Condit 1999b, Lewontin 2000). Coverage of genetic science and technologies suffers from many of the difficulties of more general coverage, though analysis has established a number of unique features in these types of items like the tendency towards genetic determinism for example where causation is frequently reduced to ‘the gene for...’ (Conrad 1997, Condit et al. 1998, Henderson and Kitzinger 1999).

Coverage has been found to be both supportive and unsupportive of the scientific and medical communities, while the quantity and interest in science in the media, along with the numbers of specialist health and science correspondents has increased (Conrad 1997, Nerlich et al 1999, Hargreaves and Ferguson 2000, Petersen 2001, Smart 2003). Numerous studies have contributed to a better understanding of how the media conveys scientific and medical information, yet relationships between experts and the media remain strained. Thus there is a need to ask more about why the media is portrayed as contributing so strongly to the public crisis in confidence, and the political motives behind this (Dornan 1999, Miller 1999) This thesis explores this issue by examining the role of the media in its wider contexts.

1.3 Measuring Public Attitudes Towards Science, Medicine and Genetics

As highlighted at the beginning of this introduction the relationships between science and the public have changed in recent decades, shifting from a strict segregation to an
awareness of public understanding, and more recently a trend towards participatory approaches and dialogue between these communities. In the UK policy makers have increasingly called for public participation in fields including healthcare, the environment, and transportation at both a local and national level (Dunkerley and Glasner 1998, Coulter 1999, Prior 2003, Rowe and Frewer 2004). Politically there are a number of incentives at play. There is the democratic incentive to include public or ‘citizen’ views towards science, technology and healthcare as a form of empowerment (Mulkay 1979, Irwin 1995, Michael 1998, Fuller 2000, Nowotny et al. 2001, Irwin and Michael 2003, Jasanoff 2003, Sturgis and Allum 2004). This has become more focused under the labour government as public confidence in the political system has declined and participation decreased (Bromley et al. 2001). Industry has also recognised the value of engaging with public concerns during the research and development process, though profit, confidentiality, patent and intellectual property law, and the lack of definition of the terms ‘engagement’ and ‘public’ provide significant obstacles to present attempts (RSA 2004, Wilsdon and Willis 2004).

The incentive for dialogue has come as traditional ideas regarding public understanding of science, or PUS, lose favour. The movement towards PUS, originating from the 1985 ‘Bodmer report’ in the UK, was hindered by a series of problems, not least in defining any of the three concepts it entailed, the public, understanding or science (The Royal Society 1985, Wynne 1995, Rose 2000, Turney 2002). Rather then opening science up to democratic involvement, it sought to define appropriate questions, concerns and issues with its primary reliance on scientific expertise (Irwin 1995, Collins and Pinch 1998, Hilgartner 2000). With its ‘deficit’ framework, linking factual knowledge to understanding, some approaches to PUS inappropriately inferred understanding and education would result in support (Evans and Durant 1995, Gregory and Miller 1998, Michael 2002, Irwin and Michael 2003).
Much of the research into public attitudes towards new genetics were thus coloured by these traditional conceptions regarding public understanding. The data gathered in the Eurobarometer surveys for example, and by key theorists in the area like Durant and Miller, largely concerned itself with a tripartite focus on interest, information and knowledge (Miller 1986, Durant et al. 1996, Pardo and Calvo 2004). Surveys like the Eurobarometer have provided detailed, comparative, cross-national data on issues such as genetic testing, alongside broader issues like regulation but have been restricted by their large scale and methodologies that have continued to focus on cognitive knowledge (Commission of the European Communities 1993, European Commission 2001, Wagner et al. 2002a, Gaskell et al. 2003, Pardo and Calvo 2004).

Accessing and conceptualising 'the public' is difficult in this context. At this point I would like to highlight that in using this term I recognise members of the public as *publics*, as has become theoretically accepted in work within this area.¹ Irwin and Michael (2003) provide the most complete explanation of thinking about these 'publics'; they are knowledgeable, with legitimate concerns and questions, that are informed by prior experience, ethics and values, and they are multiple and diverse. During this research I use the term 'public' more frequently than lay and am referring to the public respondents who contribute to my research as representing multiple voices, as opposed to one homogenous group.² Past studies have qualified members of the public that are attracted to science into special statuses like 'engaged', 'interested' or 'attentive', focused on them as consumers or simply sought to measure their opinion rather than the underlying issues for the formation of these (Miller 1986, Grove-White et al. 2000, Gaskell et al. 2003). Such definitions add credence to deficit principles and suggest that the public are exceptional if they are conscientious. This research contributes to broader definitions of lay voices and explores neglected groups in prior studies, while incorporating qualitative dimensions to researching the

¹ Defining the public and expertise will be discussed further, see chapter three page 59.
² See chapter three page 59.
attitudes of the public that provide a more successful manner in which to appreciate the variety and depth of viewpoints expressed by members of the public (Kerr et al. 1998, Iredale and Longley 2000, Michael and Carter 2001, Shaw 2002, Glasner and Rothman 2004b).

Recognising the diversity of public views, dialogue, upstream communication, public engagement and science and society programmes have attempted to move away from old-styles of public understanding aiming to be more deliberative, and inclusive in their approaches. Interaction with the public takes a range of forms in these approaches with methods like deliberative opinion polls, citizen juries, consensus conferences, internet dialogues and focus groups (POST 2001). However as the extract below demonstrates, dialogue continues to reinforce a number of traditional concepts.

The dialogue between the public and researchers and experts will be all the more rewarding...when it has a thorough knowledge and understanding of science and technology, of scientific facts, the results of research, of scientific action and of the way in which research operates in practical terms (Commission of the European Communities 2000:16).

Changes in how the scientific communities communicate with the public remain reliant on expert advice and technical detail, struggle to balance the differing viewpoints of planner and participant as to the aims of the participation and continue to define the quality of ideas presented using value judgements (Hilgartner 2000, Irwin 2001, Rowe and Frewer 2004). Scientists continue to frame questions for dialogue, typically focusing on specific issues like privacy, equality, cost and rights, as opposed to the concerns that many lay people have about new genetics that are typically broader (Barns et al. 2000, Irwin and Michael 2003, Wilsdon and Willis 2004). As such this research further contributes relevant information regarding the manner in which both experts and lay persons interact and perform identities, important within this present context.
1.4 Scientific and Medical Expertise; Interactions with the Public

It is often said that trust in scientists is lower now than in previous decades, though in reality there is virtually no evidence that the public is generally anti-science (Greenpeace 2002:3).

Empirical and theoretical studies of public attitudes continue to find that the public are not anti-science and remain largely supportive of scientific and medical communities despite the widespread message that the sciences lack public support or interest (MORI 1999, MORI 2001, OST and The Wellcome Trust 2000, Corrado 2001, Irwin and Michael 2003). However areas of science and medicine have always been controversial, and typically the focus of social science has been drawn to the controversial areas where expertise has ultimately been proved incorrect (Nelkin 1995, Irwin 1995, Lewenstein 1995, Glasner and Rothman 2004b).

Scientific advice continues to hold enormous influence but equally it has become challenged by the increased participation of environmental, consumer, feminist, religious and patient activists (Hilgartner 2000). Few studies have considered the role scientists actively play in communication but those, which have, are beginning to emphasise the important role of experts (Kitzinger and Reilly 1997, Nelkin 1998, Henderson and Ferguson 2000, Schenk and Sonje 2000).

There has been a noticeable convergence between the paths of basic research and the potential; of future technological applications...The frequency with which researchers adopt 'sales' techniques in their attempt to obtain funding for what, in fact, are mere 'options', possible 'futures' fallouts or spin-offs of unknowable research results, is increasing (Nowotny et al. 2001:38).

There has also been little focus on the industrial and privatised sectors of scientific or medical research, with the exception of local studies of industrial risk. However as the emphasis on public dialogue continues and the controversy surrounding genetic modification suggested commercial and financial impacts originating from public disquiet, research is emerging that suggests there is a significant 'mismatch' between the attitudes of science-based companies and government recommendations for dialogue (RSA 2004).
Medical sociology, emboldened by the medicalisation process that expanded the range of conditions and issues defined as medical, has sought to examine the nature of relationships between modern medicine and the lay populace (Williams and Calnan 1996). Media coverage of the healthcare system in the UK has further suggested healthcare 'crises'. Controversy surrounding MMR, organ scandals, waiting lists, and the MRSA super bug are just some of the issues generating media attention. Furthermore the impact of malpractice or compensation mechanisms, trends towards complementary or holistic medicine, and the incorporation of lay and patient voices in healthcare settings have created an increased sense of 'disillusionment' with scientific medicine and its professionals (Gabe and Bury 1996, Williams and Calnan 1996, Lupton 2003).

This may imply that there is widespread public distrust with the health service or its professionals but while individual patient interactions with expertise have undoubtedly been influenced by such factors there continues to be widespread support for the NHS in the UK and for healthcare professionals (Corrado 2001, MORI/BMA 2001, Mulligan and Appleby 2001). Medical provision has been an area both affected by an increasingly questioning public, and one, which is now actively seeking to acknowledge the views of the layperson with the emergence of 'lay experts', 'clients' and 'consumers' in medical settings (Coulter 1999, Hardey 1999, Henwood et al. 2003, Prior 2003). There have been alterations in healthcare interactions with the introduction of services like NHS Direct and the Patient Advice and Liaison Service, while the Department of Health routinely discusses the need for patient-practitioner involvement in care, treatment and regulatory bodies (HMSO 2000b, Mulligan and Appleby 2001, Prior 2003).

1.5 Communicating science with the public: discourse, dialogue or discord?
We now have a long history of studying the social aspects of science. Despite the increased recognition of the role and responsibility of scientists in science communication, the
increased respect and improvement in scientific coverage, and the privileging of public accounts of science, medicine and technology relationships between expertise, the media and public continue to be sites of struggle.

My thesis explores the relationships and mediations between these three groups, the media, 'general' public and experts from the scientific and medical communities. The research questions are: How do members of the media, public, scientific and medical communities view and construct new genetic discourses? How is this influenced by communicative relationships with the other respective groups? And what impact does this have on future interactions between the media, public and expertise? I consider the convergences and divergences in how these three groups experience communication, understanding and expertise, both in their attitudes to new genetic technologies and their perceptions of each other. In studying these existing forms of 'dialogue' I offer empirical insights into the present communication experiences of scientific and medical experts, the mediatory role of the media and finally public reactions to these communications. Given the present utilisation of new genetic techniques and the continued potential of genetic research, accompanied by other developing controversial sciences, this provides valuable information on communicating complex, ambiguous and socially significant science to and with the public.

Chapter Two examines the present theoretical and empirical literature. This chapter includes a discussion of the contribution of classical social theories, the sociology of scientific knowledge and studies that have examined public understanding and media representations of science and medicine. Chapter Three outlines the methodology of the research discussing the research aims and strategy employed. Sampling procedures and their implications for defining the public and expertise are considered, before outlining the design and implementation of the research methods.
Chapters Four, Five and Six each examine the primary data collated for this thesis. Chapter Four considers media perspectives including textual analysis of scientific and medical journals, and UK national newspaper coverage of new genetic issues. This is followed by the results of a questionnaire designed for national and local journalists, and a case study involving a national broadsheet science correspondent. In Chapter Five a range of quantitative and qualitative data derived from questionnaires and interviews, contribute to a discussion of public attitudes towards the media, expertise and new genetics. Chapter Six examines scientific and medical experts’ attitudes discussing data gathered through a questionnaire aimed at this group, as well as information generated from semi-structured interviews carried out with medical and scientific experts.

Chapter Seven intersects the information gathered from the three respective groups, the media, public, and scientific and medical experts. It begins by considering the data specifically related to new genetics and continues to discuss the implications for examining the role of the media, public, scientific and medical experts. Finally Chapter Eight concludes this thesis. The chapter considers the impact of the research in light of the present political climate encouraging participation, establishing that this negatively impacts on experts’ confidence to engage with the media and is a poor reflection of present public confidence to participate. Members of the public and medical and scientific communities create and maintain a variety of identities. These have impacted on their discourses of new genetics and the roles they identify themselves as performing.
Chapter Two: Literature Review

This chapter examines the differing sociological standpoints from which science, the media, the public and new genetics have been considered and the implications for the framing of this research. Firstly, classical and critical sociological perspectives of scientific knowledge are examined. While I have grouped together a number of theorists here I recognise that amongst these two groups there are also strong divisions in arguments (Bucchi 2004). The division of classical and critical rather, represents the shift from examining science as an outcome of modern society to examining its social settings, constructions and processes. Secondly, in light of this theoretical context, the chapter discusses traditional views of public understanding of science and how these have been politically shaped and influenced by recent ‘crises’ in scientific support. The influence of the media is centrally important and the chapter also considers media portrayals of scientific and genetic issues. The chapter finally examines public attitudes towards science and genetics, and critically the methodologies, which have framed these interpretations, before assessing the impact these broad discussions have had on the present context of scientific, media and public understandings and the call for a ‘third wave’ of studies in the sociology of scientific knowledge.

2.1 Classical Theories of Scientific Knowledge

A sociological interest in science was apparent in classical enlightenment thinking however it was largely confined to a ‘standard view’ of scientific knowledge, which perceived the natural world as real. To assess scientific methods while concurrently formulating and defending the empirical and positivistic aims of the social sciences restricted the extension of sociological thought to their inclusion. In this sense sociology originally placed ‘science on the pedestal from which it is now being knocked’ (Fuller 2000:99). However while theorists such as Durkheim and Marx were cautious and
intermittent when examining scientific knowledge, there were indications of recognition that the success of science as a knowledge system was of credible sociological interest.

Durkheim (1915) recognised that the subject's basic forms of reasoning and rules of logic, related to culturally variable conceptions of time, space and force, suggesting the emergence of science was socially linked.

'It is not at all true that between science on the one hand, and morals and religion on the other, there exists that sort of antinomy which has so frequently been admitted, for the two forms of human activity really come from the same force (Durkheim 1915:445).

However the objectivity of scientific method was a cleansing force on such socially produced subjective knowledge, 'he [sic] can affirm nothing that it [science] denies, deny nothing that it affirms, and establish nothing that is not directly or indirectly founded upon principles taken from it' (Durkheim 1915:431). Durkheim as the most stringent promoter of scientific methodologies in the social sciences was reluctant to fully characterise modern science as a belief system, socially influenced and negotiable (David 2005:5). The reality or accuracy of science was instead confirmed by peoples' belief in science's objectified notions, and their creation from the 'physical' and 'real' world. While Durkheim fails to critically examine scientific knowledge claims, assuming their accuracy, scientific knowledge was one strand of his other extensive works.

Marx similarly offered only brief declarations regarding science, and thus is open to wider interpretation. In particular the extent to which Marx suggests the content of scientific knowledge is socially formed as opposed to sciences representation to the external social world, is open to question (Mulkay 1979). Marx described an objective natural world, a setting transformed by human actions, and specifically the technological demands of capitalist society. The development of science and technology was thus an inevitable result of the growth of capitalist society, though at times Marx suggested science and technology may also drive capitalism through providing means for social control and intensified
productivity (David 2005). Marxist analysis more definitively related scientific knowledge to social groups and time periods, and furthermore added a dimension of critical thought in identifying science as a place of social conflict as opposed to criticising its potential for progress. The significance of economic interests and the ideological framework of social thought was a theme continued in the work of Mannheim (1936) who also extended the relevance of class to broader social groupings, including generation and occupation.

Mannheim (1936) distinguished scientific principles as objective, measurable and constant with priority given to the most credible evidence-based argument. In developing the sociology of knowledge and in particular his three theories of ideology, the ‘Particular Theory of Ideology’, ‘Total Theory of Ideology’ and ‘General Theory of Ideology’ his theorising represented a credible step to examining the social construction of scientific knowledge, though it was one which Mannheim himself refrained from taking (David 2005:6-7). Rather than identifying scientific knowledge as an ideology of a particular social grouping, Mannheim again excludes the ‘natural world’ from discussion, suggesting that certain ‘knowledge’s’ and the ‘intelligentsia’ that have helped them to develop are appropriately privileged.

While there was a continued contribution to examinations of the social development of science, in particular with the work of Bernal, it was Robert Merton who first actively focused on the ‘sociology of science’ and developed earlier intermittent thought in the area (Merton 1973, Baber 2000, David 2005). Like Marx and Mannheim, Merton suggested the development of scientific thought could be linked to social factors, and specifically to wider seventeenth century puritan values; ‘puritan principles undoubtedly represent to some extent an accommodation to the current scientific and intellectual advance’ (Merton 1973:229). Science was not discredited by unfounded contributions it made, instead for Merton (1973) the normative methodological structure of science, its ‘ethos’, standardised,
legitimised and regulated its claims. Merton further distinguished the four scientific values which effectively cleansed science of its potential to be socially influenced; universalism, ‘communism’, disinterestedness and organized scepticism. While Merton’s extensive theorising examined scientific knowledge in new detail, his continued association of scientific methods to strong methodological principles preserves knowledge claims and idealized science (Bucchi 2004). Social influences, be they the deviant behaviour of individuals or political influence, in particular at the time of Merton’s writing, were effectively managed by the normative structures science imposed (David 2005:12).

As such the antithesis to Merton’s positivistic claims regarding science has been the work of Thomas Kuhn (1970), which suggested that scientific knowledge claims were in themselves social and paradigm dependent (Baber 2000). Kuhn (1970) suggested the nature of facts were not external to the theories by which they were conceptualised but were justified by the paradigm via which they had emerged. The norms of science, its rules of observations and measurement are also paradigm dependent but we are typically blind to these interpretative channels that are only revealed in the event of controversy (Collins 1983). To clarify a scientific paradigm is both ‘the entire constellation of beliefs, values, techniques and so on shared by the members of a given community’ and a consistent reappraisal of tacit knowledge; how to do experiments, which apparatus to use, what theories to apply, ‘learning from problems to see situations as like each other, as subjects for the application of the same scientific law or law sketch’ (Kuhn 1970:175,190, Bloor 1976). As a paradigm grows, becomes successful, a ‘normal’ science, it does not simply remain in a fixed set of normative progress.

Normal science consists in the actualisation of that promise [of success], an actualisation achieved by extending that knowledge of those facts that the paradigm displays as particularly revealing, by increasing the extent of the match between those facts and the paradigm’s predictions, and by further articulation of the paradigm itself (Kuhn 1970:24).
Science is largely characterised by these periods of ‘normal science’. If knowledge cannot be integral to a paradigm it is not simply rejected, it is assumed it will one day find a place, and new knowledge and models are generated (Kuhn 1970). The mapping and sequencing of the human genome has in itself been identified as a possible paradigm shift within biotechnology (Glasner 2002, Glasner and Rothman 2004b). At times then the continuity of science can be fractured, broken by new knowledge and a dramatic revolution in understanding occurs. Kuhn’s work has been open to a number of criticisms, primarily due to its lack of normative framework or recognition of science as discriminated from non-science (Barnes 1982). Kuhn continues to portray scientists as an exclusive community leaving its authority unchallenged and is bound to a notion of scientific progress, which reflects his own interests in the area, but despite this his account offered credible description of scientific processes at work (Bloor 1976).

These theorists while often reluctant to attack scientific method lay the foundation for present sociological studies of science and this research. They inextricably linked science to social processes and began to consider, in particular with Kuhn’s definition of the scientific paradigm, that social relations may also be incorporated into scientific knowledge production itself. In light of the criticism levelled at these theorists’ views of the normative claims of science, new studies emerged which were prepared to more critically assess science in all its capacities.

2.2 Critical Theories of Scientific Knowledge

The shift to theorising concerning the knowledge claims, epistemological structure and institutions of science as opposed to merely the activities or reception science receives, has become a well-established and at times controversial area where ‘nerves are touched’ (Bloor 1976). Examining the social underpinnings of the natural sciences offers a range of quite different interpretations, as Helen Longino (2002:11) states
‘Science is socially constructed’ has become both a rallying cry and a banal comment, but this motto does not mean the same thing to all who use it. And the difference makes a difference.

Thus the likes of Barnes and Bloor, Collins and Pinch, Gilbert and Mulkay, Knorr-Cetina and Latour, are arguing quite different things both in terms of perspective and methodology, about the way that science can be linked to society; ‘from why particular individuals or groups believe in a set of propositions... to the question whether and how these propositions in themselves embody social factors’ (Knorr-Cetina 1983:116).

The Strong Programme, most significantly represented by the work of Barnes (1977) and Bloor (1976) but also Shapin (1982) explicitly linked science to the interests of those within the scientific community, to open the black box. Drawing upon the ‘hints’ of Durkheim and Mannheim, it incorporates four strands of approach to open both ‘good’ and ‘poor’ scientific knowledge to examination. These principles are:

1. Causality; the conditions, social or otherwise that create knowledge or belief.
2. Impartiality; regarding truth or falsity, rationality or irrationality, success or failure.
3. Symmetry; in its style of explanation all beliefs are to be examined in the same way.
4. Reflexivity; the patterns must also apply to sociology and other theories of knowledge (Bloor 1976).

The strong programme’s symmetry thesis is the most significant issue for this research, as it specifically rejects prior attempts to explain the reality of good scientific knowledge as rational and true, and poor scientific beliefs as irrational or social, and therefore open to sociological study (Longino 2002). As Bloor (1976:143) states,

What constitutes the very existence of science is its status as an ongoing activity. It is ultimately a pattern of thought and behaviour, a style of going about things which has its characteristic norms and values. It does not need any ultimate metaphysical sanction to support or make it possible. There need be no such thing as Truth, other than conjectural, relative truth, any more than there need to be absolute moral standards rather than locally accepted ones.
With its rejection of a priori argument, and of the ability of inference to secure universal 'truth', the strong programme has been said to inspire a meaningless state of relativism (Wolpert 1992). It highlights the significance of locally based knowledge and that 'the generalizations and associated probabilities on actual, existing networks never in themselves stand opposed to experience' (Barnes 1983:39, Longino 2002). Rather than accepting the normative and factual status of scientific knowledge claims they are open to systematic examination.

Continuing the 'interest's perspective', Collins and Pinch (1998) focus attention upon areas of scientific controversy, suggesting science is a 'golem'. The 'golem', a mythical human-made creation, seeks truth but at times is destructive in its mistakes. This conceptualisation recognises scientific knowledge as fallible and uncertain, scientific consensus occurs when social negotiations conclude rather than when methodological perfection occurs. The empirical programme of relativism makes three significant points. Firstly that experimental results are open to interpretive flexibility, secondly there are social mechanisms within the scientific community, which offer 'closure' to these interpretations, and thirdly that, these mechanisms are related to wider social processes (Collins 1983, David 2005:63-64). Collins and Pinch (1998) stress that it is not the scientific knowledge which is falsified by such an approach as theirs, but rather the mythology that surrounds the methodological privileging of scientific methods, a mythology where errors become externalised, presented as the work of deviant scientists who have not adhered to scientific principles. It is this political and cultural content of science, that masquerades scientific controversy, which Collins and Pinch (1998) suggest the public should become more aware of.

Challenging the interest's perspective, a further discursive approach emerged in the sociology of science. For Gilbert and Mulkay (1984) social studies of science were to open 'Pandora's box' and make visible the constructed, contextual and variable nature of
scientific discourses which attempt to homogenise the contested nature of certain scientific knowledge claims and present only singular statements. Rather than label variations in scientist’s accounts as ambivalent or untypical, Gilbert and Mulkay (1984) demonstrate their significance. Scientific consensus is not reached when a specifiable point of evidence is maintained but is a process of employing empiricist and contingent discourses in a range of contexts. ‘Versions’ of science alter depending on the surrounding climate. Empiricist repertoires used in formal settings like journal publications, operate with a strict level of de-personalisation and are closed to negotiation. They do not acknowledge any form of social setting in which the research has occurred, and in a sense represent the public face of scientific study. Contingent repertoires recognise that professional and scientific principles are affected by the personal and social context; as such they are used only informally and typically to reject the claims of a different scientist in the presentation of one’s own argument. Thus at times both repertoires may be used simultaneously. In particular in informal settings there exists a third repertoire known as ‘The Truth Will Out Device’. Reminiscent of Kuhn’s description of subtle shifts in knowledge, this allows the conjunction of these two repertoires while suggesting that the empiricist knowledge or ‘facts’ will speak for themselves in time, while the contingent repertoire is a temporary matter, as indeed are the social settings which it would have acknowledged (Gilbert and Mulkay 1984).

Given this complex series of presentations Gilbert and Mulkay (1984) question the point of ethnographic studies.

It will be quite impossible to establish the nature of action unequivocally by being present at and directly observing the original laboratory experiment. For the social character of the original laboratory work will continually change as participants interact in different settings and there by generate different kinds of linguistic gloss upon their initial activities (Gilbert and Mulkay 1984:9).

However the work of Knorr-Cetina (1981), Latour (1987), and Latour and Woolgar (1979) suggests this is exactly where social observers, naïve to a degree of natural scientific
understanding should be focused. 'Our entry into science will be through the back door of science in the making, not through the more grandiose entrance of ready made science' (Latour 1987:4). It is important to stress that Latour and Woolgar (1979) primarily argue that science is socially constructed not in a political or economic sense but in the sense that it is a multitude of social interactions and associations, a point highlighted by Knorr-Cetina (1981:13)

We must reject such equations as that between the individual and innovation on one hand, and between the social group and validation on the other...both the products (including those considered innovative) and the ideas of the laboratory are social occurrences which emerge from interaction and negotiation with others.

Science in the making is closed not because of the level of accuracy reached but because of social uptake and acceptance, 'the construction of facts and machines is a collective process' (Latour 1987:29 emphasis in original, Knorr-Cetina 1981). Scientific argument is strengthened by the support of fellow scientists, peer reviewers, institutions and funding bodies. While debate persists amongst scientists, with their 'fusion of interests', this is effectively shielded from public view. The outcome of research is recognised as a natural rather than selective process (Latour and Woolgar 1979, Knorr-Cetina 1981). This is illustrated very effectively by the professional channels of journal publication where layers of arguments, references, notes, legends and figures are created to attempt to determine the most unpredictable point of the chain, the audiences' reaction (Latour and Woolgar 1979, Latour 1987). Latour (1987) describes this as 'fact-writing' where the reader can either give up, go along or work through. The more controversial the area the more layers. When closer to closure fewer layers are deployed.

Significantly Latour (1987) later went on to describe the reaction of science if the audience chooses to follow its beliefs as opposed to these carefully constructed 'facts'. As an example he cites meteorology. Notoriously it is only a small number of the public who accept the claims of meteorologists, the remainder of the population have their own strong beliefs regarding the state of the weather on any particular day. However it remains this
majority of people who are ‘unlearned’ and as such irrational. Latour (1987) suggests instead that the beliefs of the ‘unlearned’ should be recognised as existing within their own conditions and contexts, ‘people do not anymore than scientists live in a world of fiction, representation, symbol, approximation, convention: they are simply right’ (Latour 1987:206 emphasis in original). Scientists are equipped with stronger tools for rhetorical argument but this should not overshadow the validity of other views. Thus the clash occurs when these knowledges’ intersect, and seek to become more credible than others by linking points and arguments, making associations and speaking out, all relationships that can be examined sociologically.

From the observer’s point of view none of these people ever think either illogically or logically, but always sociologically; that is they go straight from elements to elements until a controversy starts. When this happens they look for stronger and more resistant allies, and in order to do so, they may end up mobilising the most heterogeneous and distant elements, thus mapping for themselves, for their opponents, and for the observers, what they value most, what they are most dearly attached to (Latour 1987:205).

The sociology of scientific knowledge has then recently encouraged a number of studies regarding the localised nature of knowledge and the significance of cultural settings. ‘Rather than local knowledge being routinely inferior and defective, it has commonly proven more sensitive to local realities’ (Irwin 1995, Michael 1998, 2002, Yearley 2000:105, Lee and Roth 2003). The most significant of these studies remains Wynne’s (1996a, 1996b) work with Cumbrian sheep farmers following the 1986 Chernobyl nuclear accident. Wynne (1996a) highlighted the influence of social and institutional settings on ‘objective’ knowledge claims presented by the scientific experts involved in the incident. The lay-local sheep farmers recognised methodological weaknesses in the scientist’s arguments, and as such Wynne highlights the danger of disguising scientific uncertainty with the type of technical layering described by Latour and Woolgar (1979). Wynne (1996a:39) established instead that the publics’ ways of assessing the credibility of scientific arguments are:
...structurally identical to the factors shaping the logics of dispute and development within science; it is just in public situations the prior mechanisms of social closure are, by definition, less powerful.

In this case the scientists did not recognise the value of the advice of the local expert nor with their institutional and methodological pre-conceptions could they acknowledge it, and in protecting their own identities they threatened that of the public lay-local experts. Further local community based studies have linked public views to the significance of prior experiences, cultural contexts and contributory expertise in their everyday use of technologies, suggesting it is more a case of science 'misunderstanding' both their own epistemological limitations and the significance of these public views (Irwin 1995, Irwin et al. 1996, Irwin and Wynne 1996, Michael 1998, 2002, Collins and Evans 2002). Stephen Hilgartner (2000) has also extensively examined scientific advice, specifically in the US context of the National Academy of Sciences, as a form of 'stage-management'. This carefully polices the information performed 'front-stage' and those processes, which are concealed 'back stage'. While the authority this creates 'offers only limited opportunities for members of the audience to participate in the performance' (Hilgartner 2000:147).

The sociology of scientific knowledge has demonstrated beyond question that the normative claims of science, its observations, factual claims and theoretical underpinnings, are indeed open to sociological study. Science itself, in its social relationships, both internal and external, remains of significant interest. Science, in particular in research that is aimed at application is a socially and contextually framed knowledge (Nowotny et al. 2001). However by opening scientific knowledge to the same range of interpretations as any other knowledge system we are left with some serious questions,

What is called knowledge cannot be defined without understanding what gaining knowledge means. In other words, 'knowledge' is not something that could be described by itself or by opposition to 'ignorance' or to 'belief', but only by considering a whole cycle of accumulation: how to bring things back to a place for someone to see it for the first time so that others might be sent again to bring other things back (Latour 1987:220).
Thus now our concern must be how scientific knowledge has been opened to the public in practical terms, if scientific knowledge is not predestined but contextual, how can we evaluate the validity of public understanding of such contested knowledge? If scientific objectivity is not given how can it be used as an outright rejection of public claims? (Irwin 1995, Wynne 1996a)

2.3 Traditional Public Understanding of Science

In the context of the emerging sociological interest in scientific knowledge, there has been widespread attention regarding how the public ‘understands’ science. While trends for communicating science to the public in Britain and the United States can be identified since the nineteenth century, it was only during the post world-war period that a public lack of support was suggested (Irwin and Wynne 1996, Nelkin 1987, Wynne 1992, Edge 1995). C.P. Snow (1964) described the existence of ‘two cultures’; the scientific with ‘the future in their bones’, versus the ‘traditional culture’ typified by literary individuals. Some two decades later the same situation was identified with the 1985 Royal Society or ‘Bodmer’ report, entitled the ‘Public Understanding of Science’ (Royal Society 1985). The report stressed that public understanding of science must improve as technological and scientific interventions increased, that scientists had a duty to communicate with the public and resulted in a number of direct policy implications including the creation of the Committee for the Public Understanding of Science (COPUS) whose work is ongoing.

The history of PUS begins with a number of assumptions. Firstly that educating the public is politically important, the success of science has long been linked to its existence in democratic societies, and providing voters with information necessary to assess scientific and technological issues when they appear on the political agenda seems unproblematic (Mulkay 1979, Michael 1998, Fuller 2000, Nowotny et al. 2001, Jasanoff 2003, Irwin and

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1 Coincidentally Sir Walter Bodmer the author of the report was a Geneticist.
Michael 2003, Sturgis and Allum 2004). In fact it has been suggested that such PUS exercises, carried out by the ‘public understanders’ merely reproduce acceptable arguments leaving the public as passive rather than active participants (Irwin 1995, Collins and Pinch 1998). Similarly when there is a duty to provide scientific information, for example to residents who live in industrial areas where hazardous materials are stored, the information must again balance industrial and public needs (Irwin 1995). The provision of education in a democratic society is complex due to these conflicting requirements, there is a duty to provide information regarding science, but concurrently a reliance on scientific experts for information that ultimately promotes their authority (Epstein 1996, Yearley 1996, Locke 1999, Turner 2001).

Secondly traditional PUS has continuously reiterated that education is linked to support. An obvious indication is the manner in which PUS has become ‘politically correct’ in scientific institutions, and furthermore linked to encouraging people to enter scientific careers, fulfil industrial needs and increase the ‘national resource’ of scientific knowledge (The Royal Society 1985, PUSET 1995, Nelkin 1987, Pollock and Steven 1997, Nowotny et al. 2001, Allan 2002, HMSO 2002, POST 2002). Individual scientists have recognised the value of public visibility, marketing themselves to increase their likelihood of gaining future funding, to raise the profile of their work, and gain governmental support (Dunwoody 1999, Nowotny et al. 2001, Paul 2004). However the claim that education will result in support is not empirically justified and the minimal research which has been carried out suggests quite the opposite (Evans and Durant 1995, Grove-White et al. 2000, Hampel 2004).

Popularising science may not necessarily make science more popular: if no publicity is bad publicity, then science must be the exception that proves the rule...To know science is not necessarily to love it, and the publics that repeatedly tell survey researchers they want more information about science are as likely to be working out what to criticise or avoid as to what to applaud or embrace (Gregory and Miller 1998:52).
Despite this, mechanisms of PUS such as ‘café scientifique’, exhibits, centres and
museums reiterate the perception that the more colourful, mainstream and entertaining
science becomes the more popular it will be. PUS is frequently validated through the
success of such ‘want to know’ initiatives, visitor numbers to a museum for example or the
sales figures of ‘popular’ science books, which do not detail the process or success of
2004).

Finally traditional models of PUS, and many have argued this is the most significant
shortcoming, suggest that the public starts with a ‘deficit’ regarding science and related to
this that there are inherent, characteristic differences between scientists and the public
(Michael 2002). Miller (2004) defines understanding as being capable of reading and
understanding the Tuesday science section of The New York Times. The deficit model
advocates the principle that a factual knowledge of science infers understanding, treats the
public as ‘faulty scientists’, has legitimised ‘appropriate’ scientific facts restating a reliance
on expertise, and is simply impractical, which scientific facts are uncontested and how
many equate to understanding? (Barr and Birke 1998, Locke 2002, Michael 2002)
Presenting a gap between science and the public reinforces the notion that scientific
expertise is superior (Yearley 1994, Bensaude-Vincent 2001).

By assuming a standard level of ignorance where the public is conceived as generalised
‘outsiders’, deficit models fail to acknowledge that the public have any forms of relevant
contextualised understandings that they are likely to value more than legitimate scientific
1998, Michael 2002). Deficit models are sociologically naïve. For example Bodmer and
Wilkins (1992:7) in the launch perspective for the journal Public Understanding of
Science. state that the middle classes and men know more about science compared to
women who work in unskilled jobs (or whose husbands do, if the women do not work).'

While there is an interesting gender dimension to this statement, Bodmer and Wilkins attribute this to British research that is not cited, and go on to recommend that PUS should attempt to reach its audiences via tabloid newspapers and celebrity magazines, or even a 'fascinating' soap opera focused on a team of scientists. While here there is some attempt, if questionable, to account for variations in public needs, the failure to effectively define the public understanding of science has led to widespread rejection of deficit models and criticism of organisations like COPUS (Rose 2000, Allan 2002, Turney 2002).

While there is a continued interest in the public, in particular as 'scientific crises' such as the controversy around BSE and mobile phones have highlighted the issue, the language has shifted from understanding to terms such as awareness, access or engagement, and most recently, dialogue (Gilland 2002, POST 2002, Turney 2002, Sturgis and Allum 2004).

It is essential to establish an effective dialogue between Government, science-based organisations and the public. Such dialogue should help to ensure that the public is well-informed about the nature, potential benefits and risks of developments and that those engaged in these developments take public views fully into account in establishing their priorities (BA 2002:3).

In 2000 The House of Lords Select Committee on Science and Technology published their report, Science and Society (HMSO 2000a). Reminiscent of the Bodmer report it suggested public support for science was polarised and decreasing in light of the aforementioned crisis points, but that it could be salvaged before the public became anti-science as public issues largely involved confidence in regulation. The report states 'we need better, stronger, clearer ways of science and people communicating' and suggests the need for a 'sea change' in UK science with more open and positive communication with the media which 'will pay for itself many times over in renewed public trust' (HMSO 2000a:9). Thus despite talk of dialogue the report continues to link understanding and appreciation.
We need, therefore, a robust, engaging dialogue with the public. We need to re-establish trust and confidence in the way that science can demonstrate new opportunities and offer new solutions (HMSO 2000a:10).

Moves to present scientific communication as 'dialogue' are viewed sceptically when public concerns continue to be depicted as emotional or irrational and there is a lingering framework of 'deficit' (Irwin and Michael 2003). The mechanisms of dialogue; referenda, focus groups, consensus conferences and so forth are under-researched, lack centralised monitoring and continue to reflect provider aims (Iredale and Longley 2000, OST and The Wellcome Trust 2000, Rowe and Frewer 2000, Irwin 2001). As Irwin and Michael (2003:62) state ‘although the case for public dialogue has been convincingly made, there is a substantial gulf between such discussion and particular examples of practical engagement’. Despite this there remains a political motivation to encourage PUS, to understand the impact of its exercises and public perceptions towards science. In a 2002 speech by the Prime Minister, *Science Matters* he stressed the importance of science to prosperity, and the significance of public awareness about what science is trying to achieve. Tony Blair stated,

Science is just knowledge. And knowledge can be used by evil people for evil ends...The answer is that with scientific advance, we need greater moral fibre; better judgement; and stronger analysis of how to use knowledge for good not ill (HMSO 2002:2).

To draw the current debate regarding PUS to some form of conclusion there are a number of points to make. Trends towards public understanding and dialogue have been politically motivated, attempts by scientists to carry out 'lay political science', promoting professional ideologies under the guise of democratisation (Locke 1999, Michael and Brown 2000, Turner 2001). While it is easy to identify deficit models as the most obvious publicity exercises for these messages, we must be careful that shifts towards dialogue, consultation or upstream communication are as critically received. Instead of privileging scientific understanding over other forms of knowledge we should remember that 'universal scientific literacy is not feasible...a significant portion of the population is not attracted to
science and technology’ (Miller 1986:62). There is a need to draw into dialogue more of the issues the public are concerned with (Field and Powell 2001). Recognising that deficit models were inherently ineffective rather than merely had negative associations, and focusing more on the needs of the public than the aims of the scientists, would also have a significant impact. Traditional formulations of PUS instead places,

All the critical research attention on the public and the media. The only problems with science are to do with inducing scientists to communicate more clearly and entertainingly in lay terms. Questions such as those about whose interests are served by different kinds of science and scientific representations and about the basis of trust and social accountability of different institutional forms of control and ownership of science, are effectively deleted. Yet it is these unacknowledged dimensions which shape the public uptake or ‘understanding’ of science (Wynne 1992:38).

2.4 The Media Role, Communicating Science and Genetics to the Public

As communicating science to the public has become more popular, theoretical and empirical research regarding media accounts of science has increased. These have largely concentrated on coverage in newspapers, where science now permeates across features, business, environmental and medical pages, as opposed to coverage on the internet, television and in magazines (Friedman et al. 1986, Nelkin 1987, Pellechia 1997, Hargreaves and Ferguson 2000, Allan 2002). As may be suggested by the prior discussion of PUS, the media coverage of science has been a controversial issue for scientists; it has been an area of disquiet since the post world war period (Dorman 1999).

To summarise media coverage has been vocally criticised for framing science negatively, over-representing minority views, and somewhat consequentially given these two points, encouraging poor relationships with scientists (Kitzinger 1999, Stocking 1999, Ali et al. 2001, Bartlett et al. 2002). Scientific controversy and uncertainty

...are still regarded as things that should be kept within the scientific community. If there is a leak – as there often is – to the media, and hence to the public, there is often much wringing of hands. ‘Not in front of the children’ is still the attitude (Miller 2001:118).
Alternatively, positive depictions are seen to sensationalise and are also problematic when ‘continual progress – new fixes, new devices, new cures – are promised and yet, not infrequently, today's exaggerated promises become tomorrow’s sensationalized fears' (Nelkin 1987:72). The continuum between these two issues, positive and negative representations, is the claim that the media is inaccurate; this largely concerns what is left out of media coverage, qualifiers, details, or methodological contexts, as opposed to the status of that which is included, but is further questionable as it raises the issue of what constitutes acceptable scientific knowledge claims (Nelkin 1987, Evans and Priest 1995, Pellechìa 1997, Gunter et al. 1999).

A number of these criticisms result from the unrealistic expectations of scientists. A further criticism that routine research is over-looked, fails to recognise the media’s need for a ‘news angle’ which can be difficult when research is complicated, unpredictable or developing (Nelkin 1987, Allan 2002). Related to this, the definition of specialist science correspondents can lead scientists to assume that scientific stories have a foregone claim and may not recognise that science correspondents ‘are, in their practices and professional beliefs, journalists first and specialists second’ (Hansen 1994:111). These expectations are likely to come from the quality of communication training scientists receive, the infrequency with which they deal with journalists and their comparison to other forms of publishing, in particular professional journals (Dunwoody 1986). While scientist’s views regarding communication have been particularly under-researched, they have been found to believe that the public trusts the media but has a poor image of scientists. This ‘creates a barrier to dialogue between the scientists and the general public – in that scientists feel the public relies on sources of information in which they themselves have little faith’ (MORI 2000). Further studies of those involved in communication exercises suggests the experience is enjoyable and conveying information to the public is not difficult as is often suggested (Lewenstein 1995). However while it raises the profile of scientist’s work, it is
time consuming, and scientists often lack departmental encouragement, it was not so long ago that communicators were ‘sanctioned’ (Pearson et al. 1997, Gunter et al. 1999, Peters 1999, Hargreaves et al. 2003).

That said, a number of institutional factors have been identified as impacting on the quality of science coverage, including the pressurised structure of news environments, audience needs, the ‘news hole’ available, and editorial constraints, though there is some evidence that science correspondents have a higher degree of self-regulation (Friedman et al 1986, Nelkin 1987, Kitzinger and Reilly 1997). Interpreting technical terms and defining accuracy are also difficult (Kitzinger and Reilly 1997, Pellechia 1997). Somewhat predictably there are differences in the coverage offered by science correspondents and general news reporters but less obviously this has been interpreted both positively and negatively (Hansen 1994, HMSO 2000a, Allan 2002, Science Media Centre 2002). As Nelkin (1987) highlights science correspondents can ask technical methodological questions but they may write too technically or be reluctant to ask obvious or critical queries. Either way it can be difficult for journalists to avoid ‘hero worship’ when dealing with scientists, in a similar vein to sports correspondents (Nelkin 1987).

If we are to accept that scientists have been encouraged to communicate to the deficient public then surely they have some form of role here? As Miller (1995:280) states ‘scientists and other critics should stop bashing the media and patronizing the public’.

Indeed the role of sources has also been identified as significant. Russell (1986) defines two types of scientists; ‘reluctant scientists’ who must be pressured or pursued, and ‘overly cooperative’ scientists who wish to popularise their work for personal, political or financial reasons. Our concern should not be with reluctant scientists, just as there are members of the public who are uninterested there will be scientists that are simply uncommunicative and ‘charismatic teachers don’t win the Nobel Prizes...scientists don’t need the media to
advance in their fields' (Dunwoody 1986:9 emphasis in original). Instead it is those who are motivated by the current climate for PUS that may raise issues.

For example, optimistic genetic coverage has been traced back not to the tabloid press but to official reports, while journals have begun to publish 'provocative editorials and articles with catchy titles intended to capture media attention' (Macintyre 1997, Nelkin 1998:8126). Reporters can become dependent on a small number of accessible sources, who may then be misquoted or reprinted leading to 'anonymous' experts, as such the dominance of articles presented via a 'news hook', a press release, conference or public relations exercise is also somewhat inevitable (Kitzinger and Reilly 1997, Friedman 1999, Petersen 2001, Nisbet and Lewenstein 2002, Smart 2003). One of the few surveys of journalists, and specifically their coverage of genetic engineering in Germany, found scientific experts were the most popular source and significantly that the knowledge of the journalist varied depending on the quality of the network they had developed (Schenk and Sonje 2000).

More specifically, coverage of genetic issues has been an area of sociological interest as research and thus media coverage has increased. Petersen (2001) describes the media as operating at the 'interface' of genetic research and public understanding, studies have been carried out on the media coverage of a range of genetic issues from cloning techniques to areas such as genetic modification in agriculture, the announcements that have surrounded the human genome project and the portrayals of specific conditions including homosexuality, alcoholism, mental illness, and breast cancer (Miller 1995, Conrad 1999a, Henderson and Kitzinger 1999, Nerlich et al 1999, Priest 2001, Petersen 2002, Nerlich and Clarke 2003, Smart 2003, Bubela and Caulfield 2004). Reiterating the deemed significance of the media on public opinion, the government has also commissioned research on media coverage of areas such as GM foods (POST 2000).
Like more general science reporting, the tendency for either positive or negative coverage has again been noted; ‘hope’ or ‘horror’, ‘the discourse of concern’ versus the ‘discourse of great promise’ (Durant et al. 1996, Nerlich et al. 1999, Smart 2003). Genetic coverage as ‘good’ news has been evident particularly when scientific reporting continues to favour ‘heroic feats’ where the geneticist becomes an ideal ‘hero’ (Woolgar 1988, Conrad 1997, Petersen 2001). Negative reporting has concerned the macro level possibilities of genetic research as opposed to personal implications, and focused on the more novel ethical, legal and social implications, contributing to the ‘discourse of concern’ (Mazumdar 1992, Macintyre 1997, Smart 2003). Issues have also been found to commonly traverse both positive and negative coverage, and most obviously genetic modification in agriculture has been positioned as either ‘good or bad’, diverging between a destruction of nature to the saviour of the Third World (Arntzen et al. 2003).

Whilst this theorising has evidentially covered every eventuality of genetic reporting, a number of these studies have considered specific reporting techniques employed in genetic stories, including the choice of headlines, metaphors, sources and the emphasis placed on genetic causes (Condit et al. 1998, Henderson and Kitzinger 1999, Conrad 1999a, Condit et al. 2001, Liakopoulos 2002). A common complaint is that coverage reduces causation to single genes, or uses words like ‘cure’ inappropriately (Katz Rothman 1998, Conrad 1999b, Stockdale 1999).

Over the past decade front page news stories announced the discovery of the ‘gay gene’, ‘breast cancer gene’ and ‘obesity gene’. The imagery of language suggested that a specific gene had been identified. In each instance, such an interpretation was at best misleading, if not downright wrong (Conrad, 1999b:233).

Research has shown that coverage of specific genetic issues, like biotechnology has increased in recent decades, that more emphasis is placed on inherited or genetic factors in coverage of illnesses like breast cancer, and that the range of physical conditions genetic causes are applied to has extended (Condit et al. 1998, Henderson and Kitzinger 1999, Gutteling et al. 2002, Condit 2004b).
While this may present a hospitable news environment for coverage of genetics again there are some institutional factors to consider, and in particular the origin of this coverage.

Genetic ‘media events’ have been a focus of attention, providing a framework of risks and benefits, while furthering stereotypical representations of genetics. It is scientists themselves who have often been identified as the sources of metaphors, and science-fiction type scenarios that are then filtered through the media (Nerlich et al. 1999, Nerlich and Clarke 2003). Considering the problems of some PUS exercises the media can be positively reflected. For example research carried out by Miller (1995) suggested that press coverage of genetic causations, specifically for homosexuality, offered more complexity and implications than prior coverage in scientific journals due to the journals reluctance to discuss political, moral and financial contexts. Similarly Priest (2001) suggested press coverage of cloning in the United States had opened press coverage for the first time to social, ethical and legal issues.

The cloning debate served to illustrate how critical events can sometimes pierce through dominant representations to reshape the boundaries of legitimate discourse and produce novel areas of consensus. Such new areas of consensus, in turn, become part of the context that frames public understanding of subsequent related issues long after a specific controversy has receded. This kind of systematic self-correction is unlikely to have much visible impact on the existing distribution of institutional power and may even help prop it up, but it may also represent a process with the potential for producing more lasting ideological change (Priest 2001:59).

Thus it is easy to attack the media for their coverage of science and genetics but again we must bear in mind the motives of those who wish to criticise, the area has remained largely uncritical and sparse with a number of inbuilt assumptions that privilege the informed citizen as beneficial for democracy and do not question larger motives for media criticism and moves towards improved public understanding (Doman 1999).

It is significant that little research has gone on to consider how the audience react to these messages regarding science, and specifically genetics. Instead it has ignored the contextualised nature of audience reception and that the public rarely identifies the media...
as reflecting their own viewpoints but those of ‘other’ members of the public (Kitzinger 1999, Miller 1999, Petersen 2001, Gunther and Christen 2002, Amtzen et al. 2003, Condit 2004b). As Condit et al. (1998:979) state ‘none of the other scholars writing about genetics has provided even that [anecdotal] level of research with regard to the contents of public discourse about genetics’. While Condit et al. (1998) have been criticised for this rather aggressive claim, the point they make is important. The media is often inferred as representing the public. A study of scientists and journalists regarding science coverage, found the majority agreed that the media should speak for the public or powerless, promote correct public behaviour and influence public opinion (Gunter et al. 1999). Thus it is too easy to assume media coverage reflects public attitudes.

Despite widespread media coverage, the public may not be well informed about genetic discoveries. Media stories may omit important facts that can lead to misconceptions about research...Since much of the public’s knowledge about genetics will probably continue to come from the media, it is important to understand the factors that influence how media reports are generated (Geller et al. 2002:773 emphasis added).

The studies that have ‘belatedly’ considered audience interpretations of genetic coverage have found interactions to be far more subtle and unpredictable. Coverage has not determined public issues, there had to be a resonance with public concerns as audiences arrive with their own interpretations and pre-attitudes and significantly the public will disagree with scientific media coverage regardless of content on the basis of these prior assumptions (Evans and Priest 1995, Condit 1999a, Miller 1999, Peters 2000, Michael and Carter 2001, Hails and Kinderlerer 2003, Ceccarelli 2004).

Media coverage of science and genetics is both complex and problematic. Viewing the media in light of PUS and despite shifts to dialogue, it would appear that a ‘canonical’ or ‘popularization’ model exists in terms of communicating science to the public. Such

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2 See Nelkin and Lindee (1998) who disputes Condit et al. (1998) claims as reflecting their own methodological preference for quantitative data, which is also open to questioning. Condit (1999b) herself has also extensively written of the societal impact of genetics where the ‘public’ was used as terminology over ‘popular’ as is the tradition in rhetoric studies.

3 Further studies, which have considered audience reactions to a varying degree, include Kerr et al. 1998, Priest 1999, Henderson and Kitzinger 1999, Condit 1999a, Condit et al. 2001 and Gutteling 2002.
models suggest the increased specialisation of pure scientific knowledge requires a mediator between the scientist and the public, and that mediator is the journalist (Bucchi 1998). However it is clear we must reject this notion on a number of bases, we have seen that scientists do not simply input normative scientific knowledge into the communication process, the role of the journalist is highly variable, the audience is also likely to include fellow scientists, and the public is not operating in a ‘blank slate’ of popular culture (Phillips et al. 1991, Beacco et al. 2002, Myers 2003, Paul 2004). However if we accept that communication is not a one-way process we must be cautious that blame for misunderstanding and miscommunication is not simply placed on audiences and their pre-conceived irrational or emotional ideas about science. This tendency to blame the media is again occurring in a certain political climate (Miller 1999). In 2002 for example, the independent Science Media Centre was created in Britain to link journalistic and scientific communities, it is in its mission statement ‘unashamedly pro-science’. The representations of science and genetics we receive in the media are neither the entire responsibility of the media, nor received uncritically by the public.

At present genes are newsworthy and virtually any theorizing about them is taken seriously. This is not the fault of the media. Science, government and business are all hailing genetics and biotechnology as the wave of the future (Hubbard and Wald 1997:6).

2.5 Public Views Regarding Science and Genetics

As the last section suggested public attitudes to science and genetics are often assumed to be largely reflective of the media coverage of issues such as cloning and genetic modification. However in the increasing climate for public dialogue, with the presence of scientific crisis, and given a recognition that the common claim that the public is merely ‘apathetic’ may not be empirically supported, the views of the public regarding scientific issues are increasingly sought (Almas 1999, Fowler 1999, Franklin 2001a).

While industrial donations are capped at five per cent. sponsors include BP-Amoco, British Energy and Merlin Biosciences (Science Media Centre 2002).
In Europe the primary form of measurement has involved the Eurobarometer surveys (Pardo and Calvo 2004). Since 1991 these have included questions regarding biotechnology. As such they have provided a basis for both longitudinal analysis and further studies examining either specific variables of attitudes, such as relationships to education or country, or more focused interest in the issue itself (Allum et al. 2002, Bauer and Bonfadelli 2002, Midden et al. 2002, Wagner et al. 2002b). Eurobarometer 58.0, 52.1, 46.1, 39.1 and 35.1 have all included supplementary analysis of biotechnological issues, with the most recent 58.0 including a further report *Europeans and Biotechnology in 2002*. This report suggested the European public were either ‘unsure’ or ‘optimistic’ regarding biotechnology, a reversal in trends from prior surveys, which had steadily monitored an increase in pessimism (European Commission 2002, Gaskell et al. 2003).

The data drawn from Eurobarometer 58.0 highlights a number of key issues of relevance. Most significantly public support varies depending on the technology and whether it is intended for medical or agricultural use. There is widespread support for genetic testing for inherited diseases and generally for GM crops but not when transferred to food use (Gaskell et al. 2003). Public trust remains high in doctors, university scientists and in the media ‘doing a good job’, but not in industry or government (Gaskell et al. 2003). Thus public views resonate with broader social and political concerns and the perceived risk or benefit associated to a specific technology. The problem of distrust in regulatory bodies has been regularly highlighted, and furthermore used to explain why citizens in countries such as the United States, where there is a high degree of trust in bodies such as the United States Food and Drug Administration (FDA), are less concerned by issues such as genetic modification (Marris et al. 2001, Arntzen et al. 2003).

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5 Notably the confidence displayed to all of these groups was significantly lower when the public was asked if they trusted them to ‘tell the truth’ (Gaskell et al. 2003).
Significantly Gaskell et al. (2003:2) also suggest that members of the public that are ‘engaged’, ‘people who are more aware, knowledgeable and behaviourally involved with the subject’ are more supportive of the moral and use value of biotechnology than the less engaged. As the discussion earlier in this chapter emphasised, the link between knowledge and support for scientific research is questionable and here we come to one of the major criticisms of the data provided in Eurobarometer surveys. In the case of this data, ‘engagement’ was measured via questions on general prior knowledge of biotechnology, behaviour (if for example they would discuss it with friends) and finally, the truth or falsity of a number of factual-based questions, such as ‘it is impossible to transfer animal genes into plants’ (Gaskell et al. 2003). The problems of the deficit model and the need for public dialogue are strongly recognised by the report, but despite this it states ‘scientific knowledge, like knowledge of the political system for example, is a resource with which citizens may understand scientific developments and contribute to public debates on such issues’ (Gaskell et al. 2003:19).

Similar issues may be drawn from data gathered in Eurobarometer 38.1 in 1993 and Eurobarometer 55.2 in 2001 where public knowledge of science is also measured according to a series of relatively closed questions (Commission of the European Communities 1993, European Commission 2001). In both reports these included; defining ‘scientific areas’ of study such as biology, psychology and history, completing a quiz of ‘objectively true or false’ assertions where nine out of eleven ‘correct’ was defined as good scientific knowledge, and completing questions regarding ‘best’ scientific methods, including a question on probability (Commission of the European Communities 1993, European Commission 2001:19). As the 2001 report states,

As to whether ‘GMO-based food is dangerous’, this is an open question for more than a quarter of Europeans (26.5% of don’t knows)... 58.0% of those who left school aged 15 or under answered negatively, whereas this figure was 53.2% among those who had studied beyond age 20 (European Commission 2001:26).
The value or aim of asking the public such a question when it remains a controversial area of scientific debate, regardless of technical competence, seems questionable (Collins and Pinch 1998). Especially given that in the case above the variation in opinions are relatively narrow.

Thus while the Eurobarometer surveys provide a rich and large-scale range of information on public attitudes to a number of genetic technologies, and in particular confirm that the public are in fact much more supportive of science than is often depicted, they must be considered cautiously with an awareness that dialogue currently remains a rhetorical rather than practical claim (European Commission 2001). As such some studies have sought to supplement Eurobarometer data with supplementary methods or analysis (Bauer et al. 2000, Pardo and Calvo 2002, Hampel 2004).

The Eurobarometer data has highlighted the national and even regional variations in attitudes, and studies have also been commissioned which specifically consider the British public or sub-groups (Martin and Tait 1992, MORI 1999, The Wellcome Trust and MRC 2000a, HGC 2001, Stratford et al. 2001). The British Social Attitudes Survey has featured questions regarding genetic causality, privacy, diagnosis and manipulation. Like the Eurobarometer data such questions have been quantitative in nature and restricted to a measurement of attitude (Stratford et al 2001). A report jointly sponsored by the Office of Science and Technology and the Wellcome Trust, Science and the Public, further stressed the need for dialogue, including with members of the public that are scientifically unconfident (OST and The Wellcome Trust 2000). While rejecting deficit models, the report aimed ‘to stimulate and inform debate’ and to ‘increase public understanding of scientific facts, and more importantly, scientific and engineering processes’ (OST and The Wellcome Trust 2000:10 emphasis added). Significantly the report once more recognised wide scale public support for science, with distrust of governmental abilities, and by
incorporating more qualitative methods recognised that people placed science and technology in the context of their own lives. However the report referred to the public as consumers, and broke them down into typical groups, including for example ‘concerned’ who were largely female, and ‘confident believers’ who happened to be well educated and with good incomes (OST and The Wellcome Trust 2000). Such definitions may distort public attitudes and add to links between concern and irrationality (Irwin and Wynne 1996).

Further surveys of public attitudes regarding scientific, biological and genetic research, commissioned by organisations such as The Office for Science and Technology (MORI 1999) The HGC (2001), and The Wellcome Trust and MRC (2000a) have also suggested public views are generally supportive with trust in individual scientists and doctors remaining high. However attitudes vary according to technology, who it is funded by and who will have access to it, with the transparency of regulatory practices a significant concern. The link between public information and the mass media has also been reiterated by these studies and significantly it has been suggested that the public feel information is being kept from them (Commission of European Communities 1993, MORI 1999).

There was not an overwhelming feeling...that there is a lack of honesty about developments in the biological sciences. Rather, there was a feeling that the public receives little information about this complex area of science and that things are conducted without the opportunity for the public and other key groups to express their opinion (MORI 1999:81).

Again such studies while attempting to move away from deficit models must be viewed with an awareness of the commissioners’ motivations, in particular in light of statements such as ‘the more informed and positive view was that it [genetic research] could be of great importance in identification of genetic predisposition to and prevention of disease’ (The Wellcome Trust and MRC 2000b). Thus government measures of public attitude both at the national and European level have largely taken on board the problematic issues of deficit models, shifted to dialogue but have significant methodological weaknesses due to
their continued reliance on principles originating from the National Science Foundation indicator surveys (Bauer et al. 2000, Pardo and Calvo 2002, 2004). Such wide-scale public attitude surveys have become negatively associated with consumerist views of the public that offer one-dimensional surface attitudes, and with consistent findings that suggest either public acceptance or ambivalence, they are criticised for reflecting the needs of interested parties; the government and industry (Schibeci et al. 1997). In reflection 'the public has not been examined too closely...the public turns out to be rather too complicated' (Gregory and Miller, 1998:8). At this point we may then reflect on what can be contributed by sociological studies that have sought to give a clearer account of public perceptions.

Sociological studies incorporating qualitative methods, and talking with the public about issues such as genetically modified foods or biomedical science, have reinforced a number of issues highlighted in Eurobarometer data including the significance of trust in agencies, the variation in attitudes between technologies, and the complex and sophisticated ways the public thinks about issues (Kerr et al. 1998, Frewer et al. 1999, Barns et al. 2000, Iredale and Longley 2000, Michael and Carter 2001, Condit et al. 2002, Shaw 2002). They also reiterate as was suggested by the studies of audience reaction to media portrayals, that the public draws on a range of sources, and are primarily critical in their viewpoints, as such it has been suggested there should be more acknowledgement of public attitudes that 'do not look like science' (Edwards 2002).

Here, work that has originated from medical sociology has been particularly important. Like the sociology of scientific knowledge this has been an area of significant development in recent decades that I will now very briefly outline. Sociologists originally displayed some reluctance in critically attacking scientifically based medical knowledge just as they had broader scientific developments. Functionalist perspectives, particularly illustrated by
the work of Parsons (1951) suggested medical communities preserved social order by reducing the disruptive impact of illness. Parsons 'sick role' isolated ill persons from their social responsibilities, removing blame from the sick person, while emphasising their need to return to the normality of a well state, with each of these aspects requiring official conformation and care from a medical professional (Lupton 2003). Publics or patients were depicted in a highly passive role, with clear suggestions of dishonesty requiring regulation by external expertise. In more recent years however the medicalisation thesis has suggested that medical professionals may have their political and economic motivations in maintaining and extending such relationships. Social constructionist perspectives and particularly the work of Foucault (1967, 1973) have questioned the neutrality of medical knowledge, intervention and professionals. Foucault does not account for resistance or challenge to medical authority, however social constructionist perspectives represent a shift to a more critical focus in medical sociology where the continued process of social renegotiation of medical knowledge is accounted for (Turner 1995, Lupton 2003).

Thus reminiscent of SSK considerations of local knowledge, recent sociological studies which have examined specific patient communities have also, rather than depicting a passive or reluctant public, recognised that individuals are often critical, self-taught and active in their knowledge, using it to inform their behaviours, choices and manage their conditions but also to drive or criticise research (Williams and Popay 1994, Epstein 1996, Gabe and Bury 1996, Lambert and Rose 1996). They are capable of rejecting available medical and scientific expertise, and in reflection of the familial nature of genetic conditions, often utilise informal networks rather than simply institutional expertise, with patients frequently developing an awareness of the partial and contradictory nature of scientific or medical advice (Williams and Popay 1994, Epstein 1996, Gabe and Bury 1996, Lambert and Rose 1996).
Despite this and while new genetics has been heavily depicted as promoting individualised choices, with non-directive and client-centred approaches in its counselling and medical interactions, the continued presence of discrete expert advice is well recognised (Petersen 1999, Pilnick 2002, Kerr 2003a). Studies of communication, for example between genetic counsellors and their clients, suggests that counsellors continue to agenda-set but that this is often as a result of the suggested reluctance of clients to raise relevant issues or due to barriers of communication (Petersen 1999, Rowe and Frewer 2000, Pilnick 2002). The impracticality of non-directive approaches is only likely to increase as more genetic information, testing and surveillance becomes available. Thus in practice professionals continue to present an association between understanding and factual deficit and furthermore that improved education of scientific knowledge also results in better ethical and moral capacities dependent on the expert for information and moral frameworks (Kerr et al 1997, Ettorre 1999, 2002, Henwood et al. 2003, Kerr 2003b).

In genetic terms an awareness of these issues is significant. Kerr and Shakespeare (2002) suggest that a preoccupation with public fears and ignorance has led to an industry of genetic education along deficit lines regardless of its insufficiencies. This has happened under the misgiving that given the correct information about aspects such as probability the public will surrender their fears. This allows genetic policy makers to ignore the voices of pressure groups, in favour of the wider public who are treated more as consumers than citizens, their views accessed via quantitative survey data.

When the statistics are supportive this is used to counter criticism and underlie scientist’s democratic mandate. When support is less apparent, the media are often criticized for misrepresentation, and better education is advocated... at worst, surveys on genetics have little to do with democracy and empowerment of the public, and are closely linked with ‘manufacturing consent’, stifling dissent and promoting the interests of commerce and industry (Kerr and Shakespeare 2002:175).

Significant attempts have been made to access public attitudes towards science and new genetics but these have largely been typified by large-scale survey methods criticised for
their significant weaknesses or sociological studies, which again highlight the significant range of public knowledges. While the ESRC has recently commissioned the ‘Attitudes to Genomics’ project combining data from 60 genomics related questions on the 2003 British Social Attitudes Survey and qualitative elements including focus groups, interviews and textual analysis this research is ongoing and has yet to publish significant results (Shepherd 2004). Thus qualitative considerations, particularly in areas such as new genetics should be recognised as more valuable than merely ‘splashes of technicolour’ to quantitative approaches and to examine the public, a balance found between the local and the general (Irwin and Wynne 1996, Irwin and Michael 2003, Glasner and Rothman 2004b).

2.6 The Third Wave of SSK: Where do we go from here?

If we are to take ‘lay knowledge’ seriously, does this mean that scientific rationality has effectively been downgraded? Alternatively are we moving away from a singular form of rationality and truth towards a more pluralistic understanding where ‘multiple rationalities’ co-exist? (Irwin and Michael 2003:13).

At this point we are left with a number of considerations, science as an area of sociological study has been legitimised, public understanding has become a politicised term, and the media portrayals of science criticised, at times it appears unjustly. The public have also been clearly illustrated as viewing science and the media critically, referring to their prior knowledge and beliefs, while remaining largely supportive and trusting of certain scientific and medical groups. In such a climate, Collins and Evans (2002) suggest it is time for the Third Wave of Science Studies.6

Accepting that some form of interaction is necessary when science and technology enter the political domain, Collins and Evans (2002:236) suggest SSK has dealt with the problem of legitimacy, by broadening notions of expertise, but not the problem of extension, ‘if it is no longer clear that scientists and technologists have special access to the

6 Collins and Evans (2002) distinguish the first wave as the positivistic, classical theories of scientific knowledge up to and including the work of Kuhn. The second wave has been distinguished by the opening of definitions to relative expertise typified by the work of Wynne or Latour.
truth, why should their advice be specially valued?’ In particular we can relate Collins and Evans concerns to the increased use of the ‘precautionary principle’ in a number of political policies, chiefly those with a European dimension (Levidow and Carr 2000).

The precautionary principle is set to play an ever-increasing role in decision-making. But as it necessitates examining worst case scenarios and also demands the inclusion of public opinion into the consideration of issues, regardless of whether a scientists would take seriously the concerns raised, it contains the potential to marginalize expertise (Durodie 2002:27).

The use of the precautionary principle where focus is placed on risk rather than safety, around new, controversial or uncertain issues such as genetically modified organisms, has actively extended the dimensions of expertise (Levidow and Carr 2000). Rather than distort the cultural and environmental structures in which science evolves the precautionary principle acknowledges scientific uncertainty (Levidow and Carr 2000).

The precautionary principle is a principle of how to act in the face of scientific uncertainty...the ultimate aim has to be to reduce scientific uncertainty as far as possible and achieve the intended level of protection. Decisions have to be based on the latest knowledge and that knowledge has to be complete, certain and accurate (Commission of the European Communities 2000:12).

Thus in certain contexts this extension of expertise can be problematic. ‘The attack on expertise has made ‘expertise’ itself a field within which one now needs to become an expert’ (Durodie 2002:23). When science is popularised, reduced in both time and scale, the apex of certainty is extended to the public prior to sufficient resolution amongst the core-set of scientists involved in experimentation and theorising, thus the arguments and debates of the core-set become visible and open to the public. In resolution to this predicament Collins and Evans (2002) suggest new definitions of expertise are necessary referring to this development as ‘Studies of Expertise and Experience’ (SEE). These include ‘interactional expertise’ to network, ‘contributory expertise’ to the science or technology itself, and ‘referred expertise’ with a recognition of contributions to an area, ‘the boundary is no longer between the class of professional accredited experts and the rest; it is between groups of specialists and the rest’ (Collins and Evans 2002:270).
It is important to highlight that Collins and Evans (2002) raise a number of key points, in particular that the views of these newly defined experts should not be seen as versus the core-set, the point that any other form of expertise should not be seen as opposing science is important to make and is one that Collins has made well on a prior occasion (Collins and Pinch 1998). Also that some degree of 'translation' and 'discrimination' is needed between fields of science, it cannot be stressed enough that even amongst scientists specialisations are so great that no comparable knowledge may be apparent, as Locke (1999:75) states 'even scientists are members of the public with respect to those sciences and disciplines they do not practice'. Despite Collins and Evans (2002) stressing the value of second wave approaches to the sociology of scientific knowledge and the knowledge of some areas of the public they have been criticised on a number of their suggestions.

Most significantly for this research, Collins and Evans (2002) set scientific knowledge as the technical standard to which other expertises are to be compared, suggesting the core-set while not free of social contexts are more appropriately able to judge than others. Further they are accused of oversimplifying prior distinctions between expert and other expertises, and for failing to recognise the ways in which the public both as a group, and their interpretations, and meanings are framed and the motivations for this (Wynne 2003, Jasanoff 2003). It is worth highlighting that bioethics and ethical boards have been identified as a way of legitimising the concerns of specified public groups, for example pro-life interest groups, IVF users and the wider public while continuing to preserve the autonomy of science (Kelly 2003). Collins and Evans (2003) do not consider the implications of public expertise, and while any further conceptual tools for understanding expertise are likely to be useful, such a normative and rigid framework appears questionable (Rip 2003). Collins and Evans (2003) have defended their claims largely under the principle of interpretative flexibility but continue to defend the methodological standards of science. The need to privilege scientific expertise as a way of knowing is
necessary. If not ‘then there is a danger that a critique of scientism becomes a moral crusade against science’ (Collins and Evans 2003: 438).

However the points made by Collins and Evans (2003) highlight issues, which have been raised elsewhere and are significant in light of this growing literature (Collins and Pinch 1998, Miller 2001). As Nowotny et al. (2001:225) states,

A decline of deference towards science and it demands that science should be more responsive to public expectations can be regarded as a process of emancipation. But the diffusion of expertise is not unproblematic. A key issue is quality control.

In response to this issue, the work of Michael (1998, 2000, 2002) seems particularly relevant. Michael stresses the need to recognise the variations in expertise amongst lay-local groups, to consider the ‘micro-sociological characterisations of public responses’ and the increasing technological aspects of these relationships, questions of the public and understanding are thus multi-dimensional and by no means answered (Michael et al. 1997, Michael 1998, 2002, Michael and Brown 2000). Michael (2002) highlights the need for a new paradigm of public understanding which recognises the publics contextually framed knowledge of both a scientific and non-scientific basis, and their prehension of issues that, ‘connotes both a message that travels to an existent subject (or receiver or actor) and a message that partly (re)constitutes the subject, which serves in its emergence or becoming’ (Michael 2002:368). Michael’s account is thus more inclusive as it does not measure the public against science, it highlights the politicised manner by which definitions of ‘publics-in-particular’ have legitimised scientifically acceptable public voices, for example those that are informed or rational, while scientists keenness to represent themselves also as the ‘public-in-general’ has further sought to highlight their democratic and moral principles (Michael and Brown 2000).
2.7 Summary

To conclude this chapter there are a number of points to make. Science is a social process, social interactions construct knowledge claims and examinations must now be extended to how the public constructs knowledge and interacts with science in defining them. We must question, as Locke (1999) suggests, why the presence of conflict in media and public accounts should be a source of worry for scientists? The answer appears to be that public understanding of science has been used as a political weapon of boundary maintenance and the legitimisation of credible public knowledge. This has filtered through to the regular examinations or claims made regarding the media representations and public attitudes. Rather than accept that expertise has been devalued or widened to a meaningless state, it appears that attempts at public dialogue are all talk. In an area like new genetics, which is novel enough that professional boundaries are still being defined, these issues appear of particular relevance. ‘Although there are many voices, some have more influence than others’ (Cook et al. 2004:433). The role of these voices, scientific and medical experts, the media and public will be examined across the following chapters.
Chapter Three: Methodology

As outlined in the literature review this research originates from a perspective which questions the processes and values involved in the scientific method. The following chapter considers the implications this placed on my research design, first discussing the aims and objectives of the research, and its overall research strategy, which sought to combine quantitative and qualitative techniques. Next the chapter examines the sampling methods and conceptualisation of the three communities focused on; media professionals, members of the public and scientific and medical experts. It continues to outline the research design in more detail including the specific methods used, textual analysis, questionnaires, semi-structured interviews and a case study. Finally the chapter discusses the collection, management and analysis of data, before reflecting on ethics and my choice of research methods.

3.1 Research Aims

The objective of the research to compare and contrast media, public, scientific and medical expertises required the use of a number of research methods, adapted to the three groups that made up the sample. The aim of the project was to examine not only how these three groups viewed their own understandings and attitudes but to reflect on those of the other groups. The research questions were: How do members of the media, public, scientific and medical communities view and construct new genetic discourses? How is this influenced by communicative relationships with the other respective groups? And what impact does this have on future interactions between the media, public and expertise? The research aimed to examine media depictions of scientific and medical expertise and new genetics, explored through textual analysis, questionnaires and interviews, and the opinions and experiences of journalists, members of the public and scientific and medical experts, also examined using a combination of questionnaires and interview techniques.
3.2 Research Strategy

To access and trace the relationship between these various sample groups a combination of research methods was required that utilised a predominately inductive and exploratory research strategy. It was clear from the prior literature review that while valuable contributions have been made to the area, links between scientists, the media and public are under-researched, with the majority of research focused on only one or two aspects of this relationship.

Technology and society are thus presented as two distinct domains: the formulation presumes an exclusive demarcation between those experts who develop and administer new medical techniques (the technology) on the one hand, and on the other the pool of people form which patients and clients come and the pool from which public opinion about the new technologies will also come (Society) (Strathern, 1999:10).

My research strategy incorporated quantitative and qualitative methods, while specifically tailoring these methods to the respondents targeted. Figure one illustrates this combination of techniques, textual analysis, questionnaires, interviews and case study. For the purpose of discussion and illustration the various methods have been stratified into three research stages. The first stage of my research involved textual analysis of British scientific/medical journal and national newspaper coverage of new genetic issues. This
generated 291 journal and newspaper articles to be analysed. While it specifically targeted two of the experts groups, the media and scientific and medical professionals in its sampling methods, it also gave an indication of the types of new genetic coverage presented to the public. Analysis of textual content is a commonly practised method both in communication research and social research more widely. Rather than 'meaningless' counting it seeks to trace the relationships between a number of units of analysis, compiling and interpreting what at first may seem abstract indicators (Hansen et al. 1998:98).

As texts were selected on the basis of containing a genetic keyword, which will be considered in greater detail when I discuss sampling, at this point it is important to clarify what was defined as 'new genetic' in the design of the research tools. New genetics is a term, which has increasingly been used to describe developments in a range of genetic technologies (Marteau and Richards 1996, Macintyre 1997, Conrad and Gabe 1999, Glasner and Rothman 2004a). Kerr and Shakespeare (2002) break down this term to include the human genome project, genetic screening, gene therapy, cloning and behavioural genetics. Throughout the research these areas of genetic development were used to further define the aspect of new genetics referred to, though the research was generally more focused on medical and human genetics, than animal or plant. As genetic modification in agriculture is also an area of high press and research interest, this was also included as a new genetic theme with a high cultural presence (Gilland 2002, Shaw 2002, Arntzen et al. 2003, Hails and Kinderlerer 2003, Cook et al. 2004). As Pilnick (2002) observes experts may disagree as to how relevant or realistic some of these areas are to scientific research, but it was important that the research cover the relevant areas of public or media representations and these are issues which have all been highlighted by past research (Iredale and Longley 1997, Condit et al. 1998, Conrad and Gabe 1999, Fowler 1999, Priest 2001, Petersen 2002, Smart 2003).
Returning to the research strategy, the findings of the textual analysis went on to contribute to my development of the second stage of the research and the design of three separate questionnaires, aimed at media professionals, the public, scientific and medical experts.

Questionnaires were distributed to 571 individuals and combined a range of quantitative and qualitative questions. Questionnaires provided a practical means to assess the wide and diverse sample groups, while potentially generating a large amount of data. As I anticipated that two of the sampled groups, the media and scientific and medical experts, were likely to be geographically dispersed this was a particularly important consideration. In terms of the public sample a questionnaire was also likely to be more convenient for members of the public to complete, important as the respondents were sampled on the basis of having no significant relationship to the subject they were being questioned about. The anonymity of this approach, while it may be argued made asking practically complicated and morally sensitive issues difficult though this can also be a problem in interviews, gave respondents a sense of confidentiality or confidence to discuss issues without concern. Questionnaires have been criticised as promoting a deficit model of understanding in research in this area while representing the motivations of those carrying out research into public understanding.

Rather than drawing upon lay people's more complex and ambivalent relations with science, scientific institutions and expert knowledge, the questionnaire format imposes a one-dimensional framework (Irwin and Michael 2003:24).

The use of a questionnaire was problematic but proved useful in providing contextualising data, which I was then able to expand upon in the more qualitative aspects of the research strategy.

During the third stage of the research I carried out nine semi-structured interviews with members of the public and six semi-structured interviews with scientific or medical experts. These interviews while utilising an aide memoir were qualitative in nature and all lasted between 45 minutes and one hour, regardless of the group from which the
interviewee originated. Prior data collection with the public on similar issues has largely
conzentrated on using questionnaires and focus groups for similar research questions (Kerr
et al. 1998, HGC 2001, Midden et al. 2002, Allum et al. 2002). Exceptions to this has been
the research of Schibeci et al. (1997) and Shaw (2002) who have both extended
conceptions of public understanding with the use of more qualitative techniques. However
given that prior studies have largely measured public opinion and have often been
restricted by their extensive sample sizes, using semi-structured interviews appeared to
offer an opportunity to develop a more subtle account of the beliefs and relationships

A qualitative research interview seeks to cover both a factual and a meaning level,
though it is usually more difficult to interview on a meaning level. It is necessary to
listen to the explicit descriptions and meanings as well as to what is 'said between
the lines' (Kvale 1996:32).

While it may have seemed ambitious to expect a member of the public to become involved
in a semi-structured interview on subjects such as these, the interviews aimed to achieve
the level of 'richness', that is possible with face-to-face interviewing (Gillham 2000a).

During the third stage of the research I also carried out a case study with a media
professional, this included a semi-structured interview that lasted approximately one hour.
Though originally I had planned to interview a number of members of the media, issues
over sampling this group made this impractical as will be explained later. Instead a case
study was carried out using a science correspondent based at a national broadsheet
newspaper. Here, a case study involves the use of a single community, organization,
family, event or person; as such the generalizability of the method is clearly limited
(Bryman 2001, Gillham 2000b, Yin 2003). However the data provided via this method
illustrates the importance of such an inductive approach in exclusive communities such as
that of the professional journalist, and furthermore health or science correspondent
(Gillham 2000b). Rather than being a 'sample of one' the science correspondent was the
focus of interest, an interest that was supplemented by data gathered through the other
discussed means, including the textual analysis that also formed part of the case study (Bryman 2001:50, Aldridge and Levine 2001). As Yin (2003:27) states case studies have developed a reputation for their exploratory nature which can appear ‘sloppy’ however as the case study followed both textual and questionnaire analysis, as well as significant study of prior literature, it fulfilled the requirement that ‘case study investigators be well informed about the topics of inquiry and not simply dependent on a methodological tool kit’.

Thus the research strategies incorporated quantitative and qualitative methods in order to most appropriately and practically access the three groups of interest.

Researchers should not only consider which is the most appropriate method for the study of their chosen topic or problem but also what combination of research methods will produce a better and deeper understanding of it (Hansen et al. 1998:1).

The division of quantitative and qualitative methodologies in the context of research on media and public understanding of science has been described as unhelpful and unnecessary, ‘the costs of these methodological straightjackets are incomplete and inaccurate knowledge’ (Irwin and Michael 2003, Condit 2004b:404, Sturgis and Allum 2004). While quantitative methods have been criticised for prescriptively measuring public understanding and simplifying media portrayals of science they offered a practical and effective means to monitor media coverage and access the sample groups (Schibeci et al. 1997, Nelkin and Lindee 1998). They also offered context to the qualitative research of the later stages to avoid these findings lacking methodological rigour or context (Condit et al.1998, Nelkin and Lindee 1998).

3.3 Sampling

The groups I aimed to examine; the media, public and scientific or medical experts required a complex sampling strategy to effectively recruit respondents. During the textual analysis it was necessary to select both the professional journals and the national
newspapers to be sampled. At stage two and three, the questionnaires, interviews and case studies required samples of media professionals, the public, scientific and medical experts to be identified. Further to selecting the sample, I also reflected at various points of the research on my own definitions of groups such as the public and medical or scientific ‘experts’. The problems of these groupings are considered intermittently during the following sections.

**Sampling for Textual Analysis (Stage One)**

The journals sampled during the textual analysis were *Nature, New Scientist*, the *British Medical Journal* (henceforth *BMJ*) and the *Journal of Medical Genetics* (henceforth *JMG*). These journals were selected on the basis of their impact ratings and publication in the UK. I selected a sampling period for the journal and newspaper coverage that contained no significant ‘genetic events’ like the birth of Dolly the Sheep or the announcements surrounding the Human Genome Project. While general studies regarding media coverage have often provided extensive longitudinal data, recent UK analysis of media coverage has tended to focus on ‘genetic events’ while average, day to day coverage, has less often been considered (Kitzinger and Reilly 1997, Condit et al. 1998, Priest 2001, Gutteling et al. 2002, Nisbet and Lewenstein 2002, Petersen 2002, Nerlich and Clarke 2003, Smart 2003). I sampled the journals during a four-week period between the 6th August 2001 and the 2nd September 2001. During this period, *Nature, New Scientist* and the *BMJ* each published four issues, while the *JMG* published on a monthly basis, had one issue. Articles were selected on their inclusion of one of three keywords. The keywords used were ‘gene/s’, ‘genetic/s’ or ‘DNA’. These had been selected deductively prior to the analysis by carrying out a broad and generalised search of newspaper and journal coverage and noting frequently occurring terms. Two further keywords ‘human’ and ‘expert’ were also

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1 Further details of these journals including impact rating and circulation can be found in the appendix one, table 12, page 251.

2 Further details of sampling procedures can also be found in appendix one, table 12, page 251.
originally used, however during the process of data collection it was apparent that these terms were not necessary to select relevant items and were disregarded. In total 110 journal articles contained the keywords during the time period of the 6th August to the 2nd September 2001.

In recognition of the potential mass media interest in journal items, I selected a slightly later time period for the analysis of newspaper coverage. Again it contained no significant genetic 'events'. I searched the national daily newspapers, The Times, The Guardian, The Daily Mail, The Express, The Mirror and The Sun during a two week-period in 2001, between the 20th August and 2nd September. I also examined their Sunday counterparts The Sunday Times, The Observer, The Mail on Sunday, The Sunday Express, The Sunday Mirror and The News of the World during a four-week period, the 12th August to the 2nd September 2001. The inclusion of tabloid newspapers in this study was novel; other studies concerning scientific coverage have largely studied the opinion-leading press and suggested their coverage sets the tone more widely (Nisbet and Lewenstein 2002, Nisbet et al. 2003). As a distinction is often also made between the quality of broadsheet and tabloid health and scientific coverage, this also seemed to warrant further investigation. The newspapers were also searched for three keywords, 'gene/s', 'genetic/s' and 'DNA'. In the case of newspaper coverage certain items were irrelevant and filtered out, however items where the keyword was used symbolically or metaphorically, as a linguistic choice in a book review for example remained in the sample. 181 newspaper articles during these periods included the keywords 'gene/s,' genetic/s' or 'DNA'.

Sampling for Questionnaires (Stage Two)

I sent questionnaires to 69 national newspaper journalists and 12 local regional journalists in January 2003. The journalists were selected for the sample as they had either written

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3 Such disregarded articles largely involved the use of 'Gene' as a name, for example 'Gene Hackman' or 'Gene Kelly'.
articles from the initial newspaper textual analysis, or were the medical, science or health correspondent on a national or local newspaper at the time of questionnaire distribution. While this sampling approach assumed some level of journalistic familiarity with the issues, indicators were also developed on the questionnaire to account for variations in the journalist's qualifications and experience. Prior research had indicated the impact factors such as qualification or editorial quality can have on coverage (Nelkin 1987, Hansen 1994, Allen 2002). The first questionnaire was distributed by post in January 2003. This was followed by an electronic distribution to non-responding journalist's email accounts in April 2003. 12 per cent of journalists (n=10) returned completed questionnaires across the postal and electronic distribution. Four journalists returned incomplete questionnaires with a reason. These included lack of time or desire to complete the questionnaire or that they did not personally reply to correspondence. Despite this low response rate, which I had anticipated given the nature of the profession targeted, the questionnaires with their combination of open and closed questioning, provided access to a rarely researched group.

The public questionnaires were distributed in three areas of the South-West of England. Samples were selected in the cities of Plymouth and Exeter, and the more rural areas of Totnes and the South Hams, using a cluster sampling approach. In these areas samples were further stratified by electoral ward, in Plymouth 220 questionnaires were distributed (approximately 11 questionnaires to each of the 20 electoral wards), in Exeter 130 (approximately seven questionnaires to each of the 18 electoral wards) and in Totnes and the South Hams, 50 questionnaires were sent out (approximately eight questionnaires to each of the six electoral wards). An initial distribution took place in October 2002, followed by a second distribution to non-respondents in April 2003. The public questionnaires were sent to 'the occupier' of addresses within the electoral ward, despite the impersonal nature of this approach the response rate was encouraging and allowed members of the household to self-select the person to complete the questionnaire. While
this sampling procedure can potentially be problematic for achieving a representative sample; it did not appear to impact significantly on the gender distribution of respondents, and in one case the questionnaire was photocopied allowing for its completion by more than one household member (Fowler 2002). Targeting a ‘blind’ public in this way was a risk, but the return rate was encouraging despite the lack of financial motivation or acknowledged interest in the sample group, as has occurred with other surveys of the public (BA 2004).

I had a number of concerns in defining ‘the public’ as a group. To define or research ‘the public’ is problematic, as ‘the public’ ‘people’ or ‘lay’ persons connotes non-professionals or those without expertise, while at the same time it has come to represent a special reference of capability (Williams and Popay 1994, Schibeci et al. 1997, Collins and Evans 2002, Irwin and Michael 2003). I used both terms throughout this research with some caution, as they appear to clash with my theoretical standpoint, which recognised the qualities of non-professional viewpoints regarding science. As Michael (2002:322) states:

The discourse and the techniques of the social sciences, as applied in the public understanding of science whether they be in the form of questionnaires or ethnographic studies, (re)produce particular versions of the ‘lay public.’ They are parts of a circuit or nexus of activities that feeds back to the ‘public’ visions of itself.

Using the term ‘local’ or ‘lay local’, as other research has favoured, did not extend the examination of the influences on public views as far as I intended. Such terms suggest there are ‘special’ members of a wider public, be they consumers, communities or those equipped with practical skills, and this segregates further the local from the global or general (Irwin and Wynne 1996, Michael 2002, Irwin and Michael 2003). Thus despite my difficulties with the terms ‘public’ or ‘lay’ it was an identifiable group for analytical purposes, indeed the public as ‘anti-science’ has developed into something of a rallying cry in recent years (Barr and Birke 1998, MORI 2000, Mayer 2002, Irwin and Michael 2003,

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4 58 per cent (n=88) of were female and 41 per cent (n=63) of public respondents were male.
Sturgis and Allum 2004). In using the terms 'lay' or 'public' I anticipated that the group would not have exclusive boundaries, there were likely to be some members of the public who had more in common with journalists or scientific and medical experts and vice versa (Nelkin 1995, Wynne 1995, MORI 1999, Fuller 2000, Nisbet and Lewenstein 2002, Gaskell et al. 2003). Nor did I intend to discuss them as representing one view or understanding, or to be 'anyone who is not a scientist' (Zehr 1999:7). Thus I focused attention on this group, 'the public' or 'lay' without preconceptions of expertise or non-expertise.

153 members of the public returned completed questionnaires; this was a response rate of 38 per cent. A further five per cent (n=20) returned the questionnaire uncompleted, these were either left blank or had attached comments saying they did not have the time or desire to complete the questionnaire. The return rate was consistent across the three areas, 37 per cent (n=82) were returned in the Plymouth area, 42 per cent (n=42) in the Exeter area and 46 per cent (n=23) from Totnes and the South Hams. Six questionnaire respondents removed their address identification from their questionnaires. The response rate, accompanied by the random nature of the respondent's selection suggested some degree of public interest regarding the issues it involved.

Scientific and medical experts were identified, like the media sample, on the basis of the original textual analysis of national newspaper and journal articles. Each UK based scientific or medical expert that was mentioned in or that authored a news or journal item was added to a database of experts. Five further experts of international standing, who regularly appear in press coverage but who had not appeared during the period of textual analysis were also included. In total this resulted in postal questionnaires being sent to 90 members of the scientific or medical community at their place of work, from Research Fellows to Professors and Directors of Research Institutes. A primary postal distribution
took place in December 2002. This was followed by a further electronic distribution to non-respondent’s email accounts in April 2003. 41 per cent of scientific and medical experts returned completed questionnaires (n=37), a further five returned uncompleted questionnaires.

It is important I further clarify some points about the definition of scientific and medical ‘experts’. Other research has noted problems with definitions like the public and expert. The distinction between ‘experts’ and ‘non-experts’ in our own research design reflects the same simplistic binary division between ‘scientists’ and ‘the public’ which our findings led us to question...as our project progressed, all four terms became harder rather than easier to define. However we found that for our informants the scientist/public opposition was generally treated as real and relatively unproblematic (Cook et al. 2004:435).

Creating a database of experts through their prominence in journal and newspaper coverage provided a practical and effective means to access this group. However in doing so I recognised that there were both likely to be scientists and medical experts with greater genetic expertise that were not included in the sample, and that there were also likely to be considerable differences in the opinions of these two types of expert. Prior research suggested that medical experts with their greater patient interactions might have differing experiences than scientific experts (Kerr et al. 1997, Ettorre 1999, Petersen 1999, Pilnick 2002). In light of the theoretical standpoint of this research I was also sensitive to the concept of ‘expertise’. As science and medicine has become increasingly specialised, expertise has become less transferable, epistemologically challenged and credibly extended to include, as I have already suggested, that of the lay local or patient group (Williams and Popay 1994, Irwin 1995, Epstein 1996, Irwin and Wynne 1996, Lambert and Rose 1996, Locke 1999, Wynne 1999, Fuller 2000, Novas and Rose 2000, Irwin and Michael 2003, Cook et al. 2004). As such ‘experts’ in the case of this research were defined as one form of expertise rather than the definitive. Expertise is not a case of ‘either-or’ and it was with some reluctance that I labelled this group as experts alone (Jasanoff 2003).
The characteristics of respondents from each of the three groups, the media, public, medical and scientific experts are discussed in detail in the next three chapters.\(^5\) However overall 49 per cent (\(n=97\)) were male and 50 per cent (\(n=101\)) were female. 46 per cent (\(n=89\)) were aged between forty-one and sixty. 25 per cent (\(n=49\)) were between twenty-six and forty, and 25 per cent (\(n=49\)) over sixty-one. 59 per cent (\(n=118\)) of the sample were married and 74 per cent (\(n=147\)) had children. Finally 96 per cent (\(n=191\)) of the sample described themselves as white, and 34 per cent (\(n=67\)) stated that they were not religious.

**Sampling for the Interviews and Case Study (Stage Three)**

Questionnaire respondents from all three groups, the media, public, scientific and medical experts, were asked if they would be willing to take part in a further interview. Originally I planned to interview a number of media professionals however due to the low questionnaire response rate from this group this proved problematic. Despite a number of journalists agreeing to be interviewed, indeed the media professionals appeared more open to informal dialogue than contributing to quantitative research, my proximity to London and the professional constraints of the journalists in question necessitated a different approach. Instead a science correspondent from a national broadsheet newspaper who had completed a questionnaire and whom I had remained in email contact with became the basis of a case study.

As the response rate to the public questionnaire was much higher it was possible to carry out interviews with this group as I originally intended. 14 members of the public indicated on their questionnaire that they were willing to be interviewed though five of these did not respond to the researcher’s request to be interviewed at the time of the fieldwork. Nine members of the public did take part in semi-structured interviews.

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\(^5\) Summaries of respondent characteristics can also be found in appendix one, tables 10 and 11, page 249-250.
Ten of the 37 scientific or medical experts that completed the questionnaires also initially agreed to be interviewed. At the time of the fieldwork six of these were available to take part; three could no longer be interviewed as they were unavailable or had other commitments. The tenth respondent had emigrated to Australia in the six months since the initial survey. Again my proximity to London impacted on my ability to be flexible when arranging interviews, and keeping track of respondent’s employment was also problematic at times. Six interviews were carried out with scientific or medical experts during June 2003.

Those that took part in the case study and interviews were self-selecting, which had implications for the representativeness of the data. Particularly in the case of the journalist and scientific and medical experts, there was a willingness to discuss issues such as the media or public understanding from the outset. However as Gillham (2000b:30) states ‘in any area some kinds of information, some people, are more accessible than others’, being conscious of this and supporting the qualitative insights with wider quantitative data, reduced the potential impact of this issue.

3.4 Research Design and Collection

Having selected the samples to be examined, the research methods had to be further tailored to the characteristics and research questions specific to the three groups, the media, public, scientific and medical experts. In this section I will discuss the specificities of these research tools; the design of two coding schedules for the textual analysis, and the characteristics of the three questionnaires and aide memoirs. I also detail the process of data collection.
Coding Schedules

Two separate coding schedules were designed for the textual analysis of the journal and newspaper articles in the sample. Included in both coding schedules were a range of basic categorical questions. These included categorising the date of publication, the journal or newspaper it was published by, and the section it appeared in. There were some minor variations between my journal and newspaper coding schedules; I noted headlines for example in the case of the newspaper items.

I piloted the coding schedules on a sub-sample of ten newspaper and journal articles. This highlighted a number of further specifications that I incorporated into the final schedules. In the case of the journal schedule it was clear that I would need to recode page numbers, as issues do not begin on page one. Defining the author was problematic, particularly in the publication of research papers. On some scientific papers it was not uncommon to see a list of between five and ten authors. As such I listed the author as the first listed by the journal items byline. While I recognised that this author may not have been the main or most senior contributor to an item, this is an approach that has been taken by other researchers (Wilkes and Kravitz 1992). In the case of the newspaper coding schedule piloting highlighted that articles, particularly those from the broadsheet newspapers, appeared in supplementary sections and I adjusted the coding schedules to account for these details.

Both coding schedules, though largely taken up with quantitative variables, also incorporated a number of more qualitative questions regarding the framing and tone of the articles. The designation of frames to media coverage is a common aspect of content analysis, though it is one, which must be undertaken cautiously (Scheufele 1999, Nisbet and Lewenstein 2002, Murdock et al. 2003).

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6 The coding schedules for both the newspaper and journal articles can be found in the appendix two, figures 18 and 19, pages 242-243.
7 Tone was defined as 'supportive', 'unsupportive' or 'neither' where appropriate.
Frames can take into account changes in the appearance of the already defined frames, but probably not the arising and formation of new frames. There might be a tendency to press an article into an already existing frame category, apart from the methodological rule that you cannot introduce new categories while coding (Kohring and Matthes 2002:145).

In an attempt to overcome this potential problem highlighted by Kohring and Matthes (2002), I left coding of frame and tone until all other coding had been completed in order that it accurately represent the data available. Using framing techniques has attracted criticism for the vagueness of the method, however in this case I assigned frames according to ‘media frame’ the package or storyline of an item, as opposed to ‘individual frame’, the clusters of ideas, pre-conceived long-term or short-term ideas which act to help interpret an issue (Scheufele 1999). The frames which developed in the case of the journal coverage were; original genetic research, original general research, original bioethical research, genetic news report, general news report, editorials/comments/features or ‘other’. The term ‘original’ indicated that research was being published by its authors rather than reflected or commented on. The newspaper frames similarly developed during familiarisation with the data and included medical research, scientific research, genetic modification, forensic science, genetic language use, hereditary accounts and ‘other’. While further coding an item’s tone as ‘supportive’ or ‘unsupportive’ where applicable, may appear controversial, it is common in content analysis to classify the values or ideological stance of an item. However this point required the deepest level of interpretation on my behalf, as such it would be the one most open to criticism for subjectivity (Einsiedel 1992, Hansen et al. 1998).

As the textual analysis made up only one stage of my research strategy I was able to analyse only two forms of textual data during this study. My coding schedules were limited. I was not able to explore other interesting aspects of the data like the images accompanying text nor contrast or compare coverage from other mediums that would

8 These frames are discussed in more detail in chapter four.
undoubtedly have been useful (Hansen et al. 1998, Kitzinger 1999, Wagner et al. 2002b, Murdock et al. 2003). However newspapers are the most commonly examined form of media in communication research and this supplemented by journal coverage provided a significant amount of data and background for further research (Lewenstein 1995, Murdock et al. 2003, Bubela and Caulfield 2004).

As I have already discussed the journals sampled were Nature, New Scientist, the BMJ and the JMG. I searched the journal issue’s web editions electronically in the case of Nature, New Scientist and the BMJ. At the time of the research electronic searching was not possible for the JMG and instead I searched this journal for the keywords manually.⁹ As it involved only one issue this was not impractical. There were 110 journal articles in the sample. The daily newspapers in the sample were The Times, The Guardian, The Daily Mail, The Express, The Mirror and The Sun. The Sunday newspapers analysed were The Sunday Times, The Observer, The Mail on Sunday, The Sunday Express, The Sunday Mirror and The News of the World. I searched all newspapers, with the exception of The Sun and The News of the World electronically via the NewsBank service; I searched The Sun and The News of the World archives manually at the National Newspaper Library in London, again this was only practical due to the low amount of coverage in these publications.¹⁰ There were 181 articles in the newspaper sample.

Questionnaires

It was necessary to design three separate questionnaires to survey the attitudes of journalists, members of the public, scientific and medical experts.¹¹ While the three questionnaires had a number of distinctive features, they had common questions. All

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⁹ Electronic searching has subsequently become available for the JMG and results of the original data collection cross-referenced. It was possible to search Nature electronically though articles were sourced in hard copy.

¹⁰ Seven articles in the sample came from The Sun and four from The News of The World. Electronic searching has subsequently become available for these newspapers and results of the original data collection cross-referenced.

¹¹ The three questionnaire designs are illustrated in appendix three, figures 23 to 28, pages 247-267.
combined a number of closed and open questions with opportunities for the respondent to add comments. Although the questionnaire designs were each original, questionnaires used by Wertz and Fletcher (1998) and Lauren et al. (2001) gave some initial ideas, which helped with the eventual questionnaire formulation.

Each of the three questionnaire designs began with seven to ten questions regarding the respondent's gender, age, ethnicity, religiosity, qualifications and familial status. I included these questions due to their possible relevance to genetic issues, as well as to assess how representative the sample was in the case of the public questionnaire. I also included a question regarding the respondent's income, intended to be used in conjunction with their qualifications and occupation. As it turned out this question was interesting for further reasons, some respondents' were reluctant to answer this particular question and there were also some significant variations between respondents from the three groups. In the questionnaire aimed at members of the public I also asked respondents if they or any members of their family worked in science or healthcare, with room for brief details to be stated.

The three questionnaires all had two questions regarding personal experiences the respondent or their relatives had regarding genetic conditions or testing. These questions were left open in order that the respondents could define their condition as 'genetic' and also the 'family' member it had effected. While it may be argued this affects the reliability or interpretation of this question to stringently define 'genetic' or 'family' may also have been contentious. The questionnaires asked all respondents about their media habits, which newspapers they read and how often. Also, more specifically, how reliable they thought different forms of media coverage, including television, are when covering issues like new genetics. The three separate questionnaires all involved between two and six questions.

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12 This point is discussed further in chapter six.

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around the issue of media reliability and the sources through which they had gained information regarding, science, genetics, or the public, dependent on the group the questionnaire was aimed at.

To consider briefly some unique characteristics of each questionnaire design, the questionnaire aimed at journalists involved nine questions regarding professional status, confidence and 'ideal' stories. Six of these questions were of closed format but Likert scales were also used to measure the journalist's attitudes towards professional statements like for example, 'a scientific story is still good, even if it promises no immediate practical applications.' Also asked the media respondents about their relationships with scientific and medical professionals, and their general thoughts and trust regarding science, medicine and the media.

The questionnaire aimed at the public incorporated extracts from newspaper coverage. These were not referred to specifically in the questions but acted as an introduction to the theme of the questionnaire. This is an approach that has been used in other studies (The Wellcome Trust 1998, Edwards 2002). The public questionnaire had four open questions. These included questions concerning the respondent's thoughts on which conditions, illnesses and behaviours are hereditary and their attitudes towards recent developments in genetics. In this questionnaire I also asked public respondents, as I had journalists, seven questions about their general attitudes to science and medicine and persons whom they would trust. Members of the public were specifically asked in a closed question to measure their own understanding of genetic issues.

Finally the questionnaire designed for scientific and medical experts had a range of distinctive questions regarding the expert's professional activities and their attitudes towards public understanding of science and genetic issues. Five of these questions were
open with opportunities for the professional to suggest for example, ways in which public understanding could be improved. At the end of all three questionnaires, I asked journalists, members of the public, scientific and medical experts if they would undergo genetic testing if it were offered to them. This question did not specify the type of testing and it is likely that different responses would clearly be drawn depending on what the test aimed to achieve. However I thought the opportunity to compare expert, public and journalists attitudes to this point was important. All respondents were also given the chance to add any further comments they wished to make at the end of each questionnaire.

It was clearly important to my research that the questionnaire results remain comparable to the information from the other groups data while at the same time used the appropriate specialized wording for the group it was aimed at (Fowler 2002). All three questionnaire designs included a range of closed attitudinal questions that used Likert scales to measure respondent’s attitudes to certain genetic statements. There are a number of points to stress regarding these questions. Firstly it was made clear to respondents that a number of the questions on the questionnaires had no correct answer or had deliberate ‘sketchiness’ (Fuller 2000). While respondents were asked for example whether they agreed or disagreed with a statement such as ‘in the future gene treatments will treat an illness’ I recognised that these were opinion rather than factual statements at the present time, ‘science is frequently full of controversy and disagreements over detail’ (Yearley 1994:247). I used such questions as measures of social relations, beliefs and attitudes rather than scientific fact. Secondly and perhaps more importantly given the theoretical framework of this research, questions in particular those using Likert scales on the three questionnaire designs, were included which would appear to measure public understanding from a deficit standpoint. I asked members of the public for example, ‘if an individual has about 30,000

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13 For each questionnaire design the statements were grouped into separate questions but respondents were asked for their thoughts on between 16 for the media and expert, and 22 statements for the public.
14 Deficit standpoints associate scientific understanding to factual knowledge and are discussed more fully in chapter two, page 27.
genes’. However I did not use such questions as a measure of understanding. I did not intend to investigate whether a certain percentage of the public ‘do not understand’ a scientific statement which may in itself be contested, but used such questions to compare the attitudes of the public to those of experts and journalists. As Fuller (2000:136) states ‘comparable data are lacking for scientists...we have a more finely-grained sense of the level of general scientific literacy among non-scientists than among scientists’. Asking experts and journalists about their thoughts on the same or similar statements and measuring the consistency of their attitudes, rather than a suggesting public ‘misunderstanding’ allowed for comparison between the three groups (Gregory and Miller 1998, Aldridge and Levine 2001). Finally a number of the questions, three on the expert design, six on the media design, and ten on the public questionnaire offered the respondent the opportunity to write that they ‘did not know’ or were ‘not sure’. Including these options has been questioned in research design, however the abstract nature of the subject made it important to recognise that some respondents were likely to ‘not know’. In the case of the public this was accompanied by a ‘screening question’ regarding their understanding of the area (Fowler 2002). ‘Don’t know’ responses have also contributed significantly to actual analysis in similar research on public understanding (Wynne 1995, Wagner et al. 2002a, Irwin and Michael 2003).

Each questionnaire was drafted on three separate occasions. Comments from my research supervisors were very useful in this process but with hindsight it may have been helpful to have consulted media or scientific and medical expertise during the design process. Given the limits of the sample sizes of these two groups, and also the conflicting perceptions amongst experts, it is difficult to assess what impact this would have had on the designs. It may have made the process more complex and less practical given the disputed nature of

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15 The Human Genome Project estimated the human genome to contain 30,000 to 40,000 genes at the time of the questionnaire distribution, recent estimates have decreased to 20,000 to 25,000 (The Sanger Institute 2001, The Sanger Institute 2004).

16 Respondents also had the option to leave out any of the questions.
some scientific issues. However it was possible to pilot the public questionnaire. 15 members of the public were sent or given questionnaires during piloting. This process resulted in a number of minor changes to the questionnaire design. In particular it was highlighted that questions which could draw more than one response, for example ‘can you name any living scientists?’ would have to be carefully coded. While this proved a time-consuming task these questions were important and an open format was the only practical way to include them. Other problems largely involved formatting and piloting did not highlight any further significant problems.

I initially distributed the three questionnaires as a postal package to all respondents between October 2002 and April 2003. Packages included a covering letter. This briefly detailed the research project, contact details for the researcher, sample selection methods and directions on how to complete the questionnaire. Given the sensitive nature of some of the issues the questionnaire concerned, respondents were reassured that they could leave out any questions they were uncomfortable answering and that all questionnaires would remain confidential. The package also included a freepost envelope for its return and a small form if the respondent was willing to take part in a further interview. I distributed postal questionnaire packages only to the public, with a further package sent to non-respondents six months after the first mail out.

The first distribution to the media and scientific or medical experts was also postal, though I sent these packages to their work addresses. The second distributions to non-responding journalists, scientific and medical experts however, were sent electronically. In the electronic distribution using work email addresses, the covering letter was placed at the beginning of the questionnaire. Respondents were given the opportunity to print the questionnaire and return by post, or to return it to my email address. This would obviously

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17 The covering letters can be seen in appendix three, figures 23 to 28.
18 This is discussed in further detail in the sampling section of this chapter.
highlight their identity. As such it was important to reiterate confidentiality in the questionnaires themselves, and that all data would be anonymised. As all members of these two samples had access to email, though it could not be assumed that they used it actively, this did not significantly impact on the sampling of the population as can be the case with internet or email survey design (Coomber 1997, Fowler 2002). In total 200 questionnaires were returned from the three groups that made up the sample. This was an overall response rate of 35 per cent.

*Interview and Case Study Aide Memoir*

The interviews with scientific and medical experts, and members of the public were all face-to-face and semi-structured. I designed an aide memoir to use with each of these groups incorporating between 11 and 13 questions, the first two of which were largely designed to introduce the area and were always asked first.\(^9\) I could ask the remaining questions in any order, disregard or replace them depending on the responses of the interviewee. While it is recommended that questions in interviews are logically ordered, this allowed me to tailor the questions more flexibly to the interviewee’s arguments than would have been possible in a highly structured interview (Gillham 2000a). As such I designed the aide memoirs to allow optimal flexibility, while offering the support of questions and prompts for myself were the interview to falter. The semi-structure allowed ‘people to express themselves in their own words, highlighting their own feelings, preferences and priorities rather than those of the researcher’ (Aldridge and Levine 2001:6).

Certain questions in the aide memoir may have seemed quite complex. To take the public aide memoir for example, one question regarded the strategies respondents employed to judge the quality of a media item. This may have appeared quite a difficult question to

\(^9\) The aide memoir’s can be found in the appendix two, figures 21 and 22, pages 245-246.
suggest to a member of the public. However a willingness amongst members of the public to reflect on this type of question and similar questions regarding the authoritative nature of sources had been successfully measured in earlier research (Irwin and Michael 2003, Murdock et al. 2003). This illustrates the usefulness of semi-structured interviewing in this context.

Semi-structured interviews, in particular, have attracted interest and are widely used. This interest is linked to the expectation that the interviewed subject’s viewpoints are more likely to be expressed in a relatively openly designed interview situation than in standardized interview or questionnaire (Flick 1998:76).

Other questions raised in the public interviews developed points introduced in the questionnaire surrounding opinions of science, the media and the respondents own understanding. In the case of the public aide memoir there was also an extensive range of ‘prompt’ genetic subjects that I could use to develop questions further were the interviewee not to suggest their own examples. So, for example when I asked a member of the public ‘what sort of ethical issues surrounding genetics concern you?’ I could supplement this with ‘do you have any ethical concerns around genetic databases?’ if the interviewee was not forthcoming.20 Having said this I found that interviewees were often prepared to introduce their own genetic issues to explain the point they were making and I rarely found it necessary to refer to these prompts.

I presented fewer questions to the scientific and medical experts; the aide memoir covered the relevant topics while again allowing the flexibility to react to the interviewee. I asked scientific and medical experts about media coverage and their professional experiences in dealing with the media. In this case it was not necessary for me to use any prompts, the interviewees at their discretion raised genetic subjects such as human cloning, though I consistently inserted spontaneous probing questions to develop the interview or clarify points made. Using the aide memoir I also introduced questions regarding the public’s understanding and opinions towards science, expectations and responsibilities to the

20 The genetic subjects for introduction where needed are also shown in appendix two, figure 21, page 245.
experts. The aide memoirs were each piloted on two interviewees from each of the samples; the public, scientific and medical experts. Both worked well and only limited changes, such as the choice of words, were made.

During the case study, which involved a science correspondent based at a national broadsheet newspaper, I also carried out a semi-structured interview that again used an aide memoir as its basis.\textsuperscript{21} In this case the interview was enhanced by face-to-face conversation and also some email correspondence as the journalist involved had been particularly helpful throughout the fieldwork. While it was not possible to pilot this aide memoir it was loosely structured in the same way as the public, scientific and medical experts designs. It covered issues such as, professionally communicating with the public, scientific and medical experts, and the interviewee’s professional experiences of coverage. I again informally inserted probing questions at relevant points for clarification or to develop comments made by the interviewee. Again it was unnecessary to introduce genetic issues as prompts during this interview due to the interviewee’s obvious familiarity with the area.

I had contacted all interviewees and the member of the case study, on prior occasions via email or telephone to arrange meetings. I gave all interviewees some notes prior to the interview detailing the title of the project and reiterating confidentiality. They also completed consent forms to continue to take part in the project. While few further details of the research were given at this point, to avoid influencing the interviewee’s responses I stressed to interviewees that they may ask me a question at any time. Due to my ethical considerations I also informed interviewees that they may stop the interview at any point and asked for their permission to record the interview. All interviewees gave me permission, though one interviewee asked for a specific personal comment to be removed.

\textsuperscript{21} This aid memoir can also be found in appendix two, figure 20, page 244.
from the transcript of the interview. I was of course happy to disregard this comment from my data.

Semi-structured interviews with the public lasted between 45 minutes and an hour on average, though one particularly keen interviewee discussed the issues for 90 minutes. I invited members of the public to university sites in Plymouth and Exeter or local libraries to take part in the interviews, with their travelling expenses reimbursed. For some interviews an invite to the university appeared to add credibility to their opinions but I also recognised that some interviewees may have found their lack of familiarity with the environment intimidating (Gillham 2000a). My interviews with scientific or medical experts and the journalist who took part in the case study, all occurred at their place of work. I carried out the interviews during May and June 2003 in London, Edinburgh, Leeds and Oxford. The interviews all lasted between 45 minutes to an hour. At the end of the interview I reminded interviewees of my contact details, thanked them and in the case of the public, gave them some further sources of information if requested. After each interview I also sent a formal letter to all interviewees, reiterating my thanks for their taking part in my research.

I found the aide memoires useful during the interviews for a variety of reasons. In the case of the public having the support of the specific questions allowed complex issues to be discussed, and with the scientific and medical experts prevented the interviewee’s agenda taking over. With both the scientific and medical experts, and the journalist who took part in the case study, there were some added dimensions to interaction. As Fowler (2002:120) states

A special complexity is introduced when the interviewer and respondent come from different backgrounds in society. In this instance, communication may not be as free and easy as when backgrounds are similar.

22 Visiting work environments could be expanded to include observation in further research following the examples of Latour and Woolgar (1979) and Knorr-Cetina (1981).
When I was interviewing the scientific and medical experts it was important I stayed focused as they were clearly advanced in their own academic careers and familiar with teaching students. The interview with the journalist was also an unusual experience as she was undeniably used to following her own schedule in such settings. As Gillham (2000b) suggests such 'elite interviewing' is unique in that the interviewee is likely to have a greater knowledge than that of the interviewer, to structure their knowledge accordingly and at best respond to themes that the interviewer introduces rather than answering specific questions. However in this research I found the use of the aide memoir was possible despite these potential problems, indeed it offered both a verbal and physical reminder as to the context of the discussion, and avoided the tendency for the interviewee to start 'interviewing' or 'teaching' me. That said in my interviews with scientific and medical experts I often found myself feeling that they were in some ways attempting to encourage my own empathy or enthusiasm for their subject, or 'selling science' to me.

3.5 Data Management and Primary Analysis

During the textual analysis each journal and newspaper article was analysed using the coding schedules as have been discussed. Original journal articles from *New Scientist* and the *BMJ* were electronically imputed into an N5 database. This was not possible for *Nature* and the *JMG* articles, in these cases hard copies were used and stored separately. All newspaper articles apart from those taken from *The Sun* and *The News of The World* were also electronically transferred into an N5 database. As *The Sun* and *The News of The World* were not available electronically at the time of the research, these items were copied manually due to the low numbers in the sample and then stored in the N5 database. I also took hard copies of each article, or photocopies where electronic versions were unavailable. While taking hard copies may have appeared an unnecessary and laborious process it proved useful in providing a 'feel' of the original article, which can sometimes be lost with electronic versions (Hansen et al. 1998). The quantitative information gathered
using the coding schedules was stored in an SPSS 11.5 data file, though the search facilities available using N5 also provided some assistance in this process to count keywords and define the framing of the articles. N5 was particularly valuable for extracting relevant sections of text and generating a broader view of an extensive range of data. However, the statistical output and N5 analysis were used with a continued referencing to the original articles so as to not lose the essence of the data. Univariate descriptive analysis generated a number of frequencies in the data, which were interesting in themselves. Subsequent bivariate analysis allowed for further consideration of relationships between variables.

The information generated by the three separate questionnaires were also collated and stored using an SPSS 11.5 data file. Using the facilities available on SPSS 11.5 frequencies were run, and cross-tabulations drawn to examine the data more fully. As all of the questionnaire designs incorporated some open questions, this data was separately transcribed and inputted into an N5 file to be supplemented at a later point by the qualitative data drawn from the interviews and case study. The questionnaires were designed with SPSS in mind, so the quantitative questionnaire data was simple to input. However a number of the open questions were post-coded, which was time consuming but unavoidable, and added to the SPSS 11.5 data. All data was stored confidentially in accordance with my ethical guidelines, which will be discussed further. Despite the completion of 200 questionnaires there were limitations to the statistical analysis that could be carried out due to the variations between the three separate sample groups. However as quantitative analysis made up one aspect of the research and supplemented by qualitative data from the outset, this was not problematic given the wealth of data to be drawn from at the point of analysis.

Each interview, including that carried out during the case study had been recorded. I transcribed recordings verbatim, and these alongside notes taken during interviews were
again managed using N5. In this case three separate files were used to store the media, publics, scientific and medical expert's qualitative data. This information was kept strictly confidential, and tapes of interviews erased after transcription. N5 proved invaluable in storing this range of data, taken from the three separate samples. However once again it is important to highlight that it was primarily used to manage the data. Hard copies were taken of all interview transcripts, and this coupled with my personal participation in all interviews, avoided the potential to de-contextualise the data. Interviews were thus analysed at a personal level, how an interviewee structured their thoughts across the entirety of the interview, which stressed a number of the subtleties and variations in their opinions. Using the 'explore' and 'node' features of N5 the qualitative interviews were furthermore compared thematically between each interviewee. The use of these features developed the themes and interviews into a further cross-tabulation or matrix, possible due to the relatively low number of interviews undertaken.23

3.6 Ethical Issues

The research design adhered to the ethical guidelines set out by the British Sociological Association and was approved by The Human Ethics Sub-Committee at the University of Plymouth. Due to the sensitive nature of a number of issues covered in the questionnaires, case study and interviews, ethical considerations were particularly significant when planning the research. Given the medical implications of a number of the areas referred to, including the human genome project, genetic screening and behavioural genetics, it was important that participant's protection from harm was fully appreciated. It was highlighted to participants that they may withdraw themselves or their prior comments from the project at any time. In the covering letter and email supplementing the questionnaires, the research title and objectives were stated. A sheet detailing the project, its funding and objectives was also given to participants prior to all interviews, as was a consent form for the

23 The interview data matrix's can be found in appendix four, table 14 and 15, pages 270 to 274.
interview to take place. The participant’s confidentiality was assured at all times. Questionnaires and interviews were identified numerically, and the participants contact details segregated from the data.

I recognised that the sensitive nature of the research questions may draw reactions from respondents that could not be anticipated. For example, one scientific expert returned the questionnaire with strong objections to its design; including the definitions of ethnicity and use of a questionnaire. The categories of ethnicity had loosely been based on the national census, and I had specifically sought advice on this variable prior to design. Their objection to my using a questionnaire regarded its suitability as a method for these types of issues, again an issue I had previously recognised. They also objected to the research question suggesting public understanding was an area of research already exhausted. I recognised the validity of this expert’s point. Were I to design my research tools again, I would have highlighted the overall research strategy more clearly and also sought more advice on the ethnicity issue. The only other negative feedback I received came from a Clinical Geneticist who wrote that he did not like filling in ‘stupid surveys’ next to the question regarding professional activities, however completion of the questionnaire was voluntary so the value of this point seems questionable. As these were the only directly unsupportive responses I received, and such comments have also been recorded in similar research, I do not think the overall research strategy was unsuccessful.

In terms of public reactions I anticipated that some might develop further questions in response to the questionnaire or interview. While the questionnaire and interviews did not cover a personal medical history, I sought details of genetic counselling, diagnosis and support groups prior to stages two and three of the research. If respondents requested details they were available. Some public respondents did ask for further information as

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24 See chapter three, page 53.
25 See for example Hargreaves and Ferguson (2000).
they were interested in the issues of the research but no one asked for information regarding personal health.

3.7 Summary

There were a variety of factors, which influenced the research design of this project. The significant contribution of prior research regarding public understanding and media coverage, not least indicted that both quantitative and qualitative methods have consequences when examining issues of this type. Dividing the sample into three communities raised conceptual issues and also added to the level of design necessary to operationalize and define indicators. This required the research strategy to utilise a range of methods; textual analysis, questionnaires, interviews and a case study, each of which had to be specifically tailored to the sub-sample it aimed to survey while continuing to offer a comparable level of data.

Were I to carry out the research again I would have extended the qualitative aspects of the research strategy. The content analysis and questionnaires were very useful in contextualising my qualitative data but allowing room for more open responses may have been valuable. Related to this, sampling the media, scientific and medical communities may have been aided by more flexibility on my part. In terms of the design of our discussions I think these groups may have been open to less structured conversation. In developing contacts, had I developed more networks with media professionals this may have been a simpler group to sample. However I am now a more experienced researcher and there may have been the potential for my respondents to ‘take over’ the research had I recognised these and utilised these points at an earlier stage of my research. The three stages of the research drew interesting, comparative and detailed information from the media, public, scientific and medical experts. In the following three chapters I will discuss
the data from each of these groups respectively, before comparing these findings in chapter seven.
Social studies of the new genetics have often concentrated on the significant role of the media in portraying a deterministic model of science which verges from 'hope' to 'fear', 'promise' to 'concern' (Durant et al. 1996, Smart 2003). The following chapter considers the media role in reporting science, medicine and new genetics using research collated from three perspectives.

- Content analysis involving a sample of British-based journals during 2001.
- Content analysis concentrating on a sample of British-based national newspaper reports during 2001.
- A survey of a sample of national and regional journalists.
- A case study involving the work and experiences of a science correspondent on a leading British newspaper.

4.1 Journal Content Analysis

Content analysis was carried out on four British journals, Nature, New Scientist, the British Medical Journal and the Journal of Medical Genetics. Nature contained 51 per cent (n=56) of articles published during the sampling period in 2001, followed by New Scientist that contained 21 per cent (n=23) of articles that included the keywords 'gene/s'.

![Figure 2. Frequency Articles Containing Keyword By Journal](image)

Source: Journal Content Analysis August-September 2001

1 The main characteristics of the four journals can be found in appendix one, table 11, page 240. A discussion of the sampling procedures and content analysis can be found in chapter three.
'genetic/s' or 'DNA'. The British Medical Journal (henceforth BMJ) featured 15 per cent (n=17) and The Journal of Medical Genetics (henceforth JMG) 13 per cent (n=14) of articles published during the sample period, as figure two illustrates. The JMG was the only journal which had one issue across the sample period. Nature, New Scientist and the BMJ each published four issues during the month. Nature consistently featured articles containing the keywords, publishing between 13 and 15 articles across all four issues of the month. This is shown in table 1. The BMJ published more articles towards the beginning of the month, publishing on average four articles in each issue. New Scientist published more in the later issues of the month and on average published six items containing the keywords in each issue. The JMG published 14 items in its one issue.

<table>
<thead>
<tr>
<th>Journal</th>
<th>Issue No.</th>
<th>Publication Date</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nature</td>
<td>6847</td>
<td>9 August 2001</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>6848</td>
<td>16 August 2001</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>6849</td>
<td>23 August 2001</td>
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</tr>
<tr>
<td></td>
<td>6850</td>
<td>30 August 2001</td>
<td>15</td>
</tr>
<tr>
<td>New Scientist</td>
<td>2303</td>
<td>11 August 2001</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>2304</td>
<td>18 August 2001</td>
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<td>2305</td>
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</tr>
<tr>
<td></td>
<td>2306</td>
<td>1 September 2001</td>
<td>9</td>
</tr>
<tr>
<td>BMJ</td>
<td>7308</td>
<td>11 August 2001</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>7309</td>
<td>18 August 2001</td>
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</tr>
<tr>
<td></td>
<td>7310</td>
<td>25 August 2002</td>
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</tr>
<tr>
<td></td>
<td>7311</td>
<td>1 September 2001</td>
<td>3</td>
</tr>
<tr>
<td>JMG</td>
<td>8</td>
<td>August 2001</td>
<td>14</td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
<td></td>
<td>110</td>
</tr>
</tbody>
</table>

Table 1. Distribution of articles – All Journals
Source: Journal Content Analysis August-September 2001.

Authors came from a range of professional backgrounds. As discussed in the prior methodology chapter, authors were coded by the primary author stated in the by-line, despite an acknowledgement that they may not have been the senior or primary contributor to an item (Wilkes and Kravitz 1992). 54 per cent (n=59) of the items within the sample were written by 'academics' including professors, readers and research fellows. 26 per cent (n=29) were written by 'science writers', a number of whom were freelance and/or had PhDs. The journals' 'editorial teams' accounted for just four per cent (n=5) of the sample. One item was written by a Member of Parliament. Nine items were not credited to any author; all of which were brief news or advertisements. Across the journals there were
variations in the types of authors used. For example 73 per cent (n=16) of items in *New Scientist* were written by science writers, whilst 73 per cent (n=36) of articles originating from *Nature* were authored by academics.

42 per cent (n=46) of the journal articles were placed in the first one to twenty pages of the journal, with a further 24 per cent (n=26) appearing on pages twenty-one to forty. The prominence of articles in the primary pages of the journals is likely to reflect the dominance of ‘news’ coverage. While the articles appeared in a range of journal sections, 40 per cent (n=44) came from ‘news’ sections. The *JMG* was the only journal that did not have a news section, reflecting its more specialised nature. A further 31 per cent (n=34) of items containing the keywords were placed in ‘Letters’ sections, seven per cent (n=8) appeared as ‘papers’ and seven per cent (n=8) of the articles were ‘reviews’, frequently related to books or publications specifically concerned with genetic science. The distributions of articles across the journals are shown in table 2. *Nature* had items featuring the keywords in the greatest range of sections. The *BMJ* also featured a range of articles including news, papers, letters and reviews. The *JMG*, with its more specialised

<table>
<thead>
<tr>
<th></th>
<th>Nature</th>
<th>New Scientist</th>
<th>BMJ</th>
<th>JMG</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>News</td>
<td>24 (42%)</td>
<td>14 (61%)</td>
<td>6 (35%)</td>
<td>0 (0%)</td>
<td>44</td>
</tr>
<tr>
<td>Papers</td>
<td>2 (4%)</td>
<td>0 (0%)</td>
<td>3 (18%)</td>
<td>3 (21%)</td>
<td>8</td>
</tr>
<tr>
<td>Letters</td>
<td>18 (32%)</td>
<td>2 (9%)</td>
<td>4 (23%)</td>
<td>10 (72%)</td>
<td>34</td>
</tr>
<tr>
<td>Editorials</td>
<td>2 (4%)</td>
<td>0 (0%)</td>
<td>1 (6%)</td>
<td>0 (0%)</td>
<td>3</td>
</tr>
<tr>
<td>Reviews</td>
<td>4 (7%)</td>
<td>0 (0%)</td>
<td>3 (18%)</td>
<td>1 (7%)</td>
<td>8</td>
</tr>
<tr>
<td>Feature/Special Report/Interview</td>
<td>2 (4%)</td>
<td>7 (30%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>9</td>
</tr>
<tr>
<td>New Products/ Advertisements</td>
<td>3 (5%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>3</td>
</tr>
<tr>
<td>Corrections</td>
<td>1 (2%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>56 (100%)</td>
<td>23 (100%)</td>
<td>17 (0%)</td>
<td>14 (100%)</td>
<td>110</td>
</tr>
</tbody>
</table>

Table 2. Location of Article By All Journals.
Source: Journal Content Analysis August-September 2001.

2 *Nature* and the *JMG* both published a number of original papers under their ‘letters’ sections explaining the frequency of this type of article.
content consisted mainly of papers and 'letters to the editor', with the exception of one review piece. Thus the sections the pieces appeared in did not necessarily give an indication as to the actual article; letters sections in both Nature and the JMG often featured novel research papers. The journal pieces were thus further coded by the specific content of the articles.

21 per cent (n=23) of the articles in the sample involved the publication of original genetic research. Original genetic research was distinguished on the basis of a significant genetic content, stated findings or the professional department of the author/s. These included papers on the identification of genotypes, genetic mutations, and autosomal disorders. The extent of genetic factors involved was variable across such research. For example work on the genetic factors for hearing impairments stated 'fifty to eighty percent of autosomal recessive congenital severe to profound hearing impairment result from mutations in a single gene, GJB2, that encodes the protein connexin 26' (Van Laer et al. 2001:515). But during this period genetic links were made to a number of conditions including Type 1 diabetes and agoraphobia (Stene et al. 2001).

12 of the published papers on genetic research appeared in Nature and the remaining 11 in the JMG as figure three illustrates. Nature also published the most general research papers, which mentioned the keywords but were not specifically concentrated in the area. Such

![Figure 3. Research Content by All Journals. Source: Journal Content Analysis August-September 2001.](image-url)
papers were coded as original general research, as they were focused on an area other than genetics and made up 14 per cent (n=15) of the journal articles published during the period. The BMJ also published a number (n=4) of such research papers, which whilst concerned with other issues briefly mentioned for example the possibility of a genetic link. The complex and highly technical nature of the research papers highlighted the difficulties science correspondents are faced with in interpreting such information for public audiences. A research paper in the JMG, ‘Complex and segmental uniparental disomy (UPD): review and lessons from rare chromosomal complements’ illustrates the intricacies of such findings as its summary of conclusions suggest.

Research in the field of segmental and/or complex UPD may help to explain undiagnosed non-mendelian disorders, to recognise hotspots for meiotic and mitotic recombinations, and to show that chromosomal segregation is more complex than previously thought. It may also be helpful to map autosomal recessively inherited genes, genes/regions of genomic imprinting, and dysmorphic phenotypes. Last but not least it would improve genetic counselling (Kotzot 2001:497).

Thus understanding, reducing and simplifying such information is likely to be problematic. As such some research papers themselves attempted to demystify information. A research paper describing the latest bacterial genome sequencing stated ‘differences in G + C content between accessory genes [needed for specialist functions such as nodulation] and housekeeping [essential] genes are common in bacterial genomes’ (Downie and Young 2001:598). The paper noted that such concepts ‘made life a little easier for generations of students’ (Downie and Young 2001:598).

Two pieces of original research reflected on some of the ethical and social issues involved in genetics. These were coded as original bioethical research and both were published in the JMG. The two pieces of research considered the emotional impact of genetic testing for familial adenomatous polyposis (FAP) in children and adults, and the intentions of women undergoing predictive genetic testing for hereditary breast cancer (Michie et al. 2001, Welkenhuysen et al. 2001). Both pieces of research reflected on the extent of factors
involved in both the undertaking and outcome of genetic testing, including for example the implications for insurance, parental choices and individual psychologies, and recommended more awareness of such factors in genetic counselling.

However, the technologies involved in these items were largely unquestioned, represented as neutral tools with the potential to provide challenges in the context of a social setting, 'public concern, pessimism, or fear about the new genetic technology may discourage interest in applications like predictive genetic testing' (Welkenhuysen et al. 2001:540). The article suggested that such consideration of the bioethical implications of genetic technologies were thus orientated in overcoming public resistance to their use. Other writers of journal articles acknowledged ethical implications in their more general news pieces and publishing of research. Ian Wilmut (2001) for example in a letter to Nature called for 'informed public debate' on human reproductive cloning, expressing concern that the cloning of children to overcome infertility or replace a dead child would impair a child’s development. Here 'the views of those who have studied child development would be very welcome' (Wilmut 2001:583). Cunningham-Burley and Kerr (1999) suggest such discussions by scientists regarding the social consequences of their work seek to maintain boundaries between different types of science and more widely reinforce the distinction between science and society.

30 per cent (n=33) of the journal articles reported on genetic research that had been published elsewhere. These reports were coded as genetic news reports and were restricted to New Scientist, Nature and the BMJ. They included reports on research into genetic mutations and gene therapy and were more similar to mass media reporting in that they often used terms such as 'hope', 'visions' and 'prospects' (Cohen and Young 2001, Gottlieb 2001, Graves 2001, Motluk 2001). The word 'fight' frequently appeared in reference to disease, as did 'hunting' and 'angle of attack' (Chicurel 2001, Cohen and Le...
Page 2001, Vogelstein and Kinzler 2001). The p53 protein, of potential use in cancer treatment, was described as a 'guardian of the genome' (Vogelstein and Kinzler 2001:865). Yet news pieces also cautioned scientists regarding the use of such terms that could be misconstrued or misunderstood by the media and public. One pathologist specifically stated, 'I have a word of advice for geneticists: don't label a predictive mutation a cancer gene, or you will create an almost intractable communication barrier' (Foucar 2001:514).

An additional report indicated a further incentive for alert language choices suggesting that supporters of therapeutic cloning used the term 'blastocyst' in preference to 'embryo' (Hopkins Tanne 2001).

The reflective nature of news pieces allowed for the use of qualifications. An article in the BMJ described the discovery of a group of genes known as DUP25 as opening 'a new era for the understanding of psychiatric disorders, which should lead to new definitions of the biological, genetic and clinical basis of anxiety disorders' (Bosch 2001:360). At the beginning of the item the gene played a 'fundamental role', by the end it 'probably' had an effect. The same research reported in New Scientist described 'hope for those whose lives are ruled by terror’ but added that,

While having DUP25 greatly increases the risk of anxiety disorders, it doesn't necessarily condemn you to a life of fear...In the affected families, for instance, 20 per cent of people with DUP25 had no anxiety illness at all (Cohen and Le Page 2001:9).

The research discussed by the four journals as news thus often highlighted other likely factors or stressed that research would not see results for some time. A further article stated it was 'a little too early to chill the champagne’ when highlighting new research on a gene aiding the resistance levels of certain crops, it remained 'the $64,000 question’ if knocking out a single gene would boost inducible defences (Day 2001:35).

22 per cent (n=24) of the journal pieces involved more general news reporting. Nature, New Scientist and the BMJ all featured a number of articles which whilst not centrally
focused on genetics made some mention of it. Such reports for example discussed institutional aspects of science or social issues with some mention of the term genetic. The prominence of these articles, as figure four demonstrates, suggests that the inclusion of a genetic term in journal coverage may also contribute to how newsworthy an item is. This has previously been indicted in mass media coverage. (Conrad and Weinberg 1996, Conrad 1997, Petersen 2001) These general news items also reflected on criticism directed at specific scientists. Dr Severino Antinori’s work in one article in the BMJ was described as both ‘scientifically unsound’ and ‘dangerous’ (Barratt 2001:406). A news piece in Nature reported on the charging of two molecular biologists in the US, Takaski Okamoto and Hiroaki Serizawa, for conspiring to steal DNA samples (Nature 2001). Similarly a news piece in Nature cited the publication of an article in another journal, Langmuir, published by the American Chemical Society. An addendum was necessary to this article stating that the supervising scientist disputed the content, ownership and methods of the work, following a series of disagreements between a physicist and chemistry professor (Adam 2001:669). Such journal articles thus acknowledged the disputed and controversial nature of some areas of science; scientists had ‘always disagreed’ and some findings were described as ‘irresponsible’, ‘dangerous’ and ‘ludicrous’ (Cohen 2001a, Coghlan 2001).
Amongst this more general reporting there was also criticism of the mass media. The announcement by Dr Severino Antinori and his two colleagues at that time, Dr Panos Zavos and Dr Brigitte Boisellier that they intended to impregnate up to 200 women with ‘cloned’ embryos inspired a number of news pieces across the journals. *New Scientist* described the interest it had generated, ‘with the world’s media in attendance—at one stage camera crews even pursued Antinori as far as the toilets—it was more like a Hollywood event than a staid scientific inquiry’ (Cohen, 2001a:6). The *BMJ* also monitored the reaction to the announcement amongst the world’s media.

This is a story in which clichés of scientific hubris have abounded. *Time* magazine, in a special issue (7 August) devoted to the question ‘Is human cloning an inevitability?’ asked, ‘Can this genie be put back?’ Andorra’s *La Vanguardia* (9 August) was not sure: ‘Pandora’s box is half open’ (Barratt, 2001:406).

Whilst the *BMJ* criticised the ‘economic’ reporting of the scientific technicalities of cloning, it blamed much of this on the ‘blurring’ and inaccuracies of Antinori’s descriptions.

A further report considered media coverage of the Sally Clark murder conviction in November 1999 for the murder of her two children under the guise of sudden infant death syndrome (Jackson 2001). The article was particularly balanced in its reporting of the controversy around her conviction and the criticism of an expert witness, Professor Sir Roy Meadow. Aware of the difficulties of communicating expertise it highlighted the media reaction shifting from criticism of the defendant to support for her appeal. ‘Post-trial newspaper reports paint a picture of pathological mayhem, with medical experts disagreeing and changing their opinions’ (Jackson 2001:347). Professor Sir Roy Meadow declined to talk to the media in anything but live debates, ‘he was worried that if his responses were taped and inserted into a documentary programme he would be in danger of being ‘stitched up’’ (Jackson 2001:347). At the time of the Jackson (2001) article Sally Clark remained convicted. However in 2003 both Sally Clark, and a further mother,
Angela Cannings, had their convictions overturned at the Court of Appeal on the basis that they were unsafe. In light of this the GMC is investigating Professor Sir Roy Meadow’s involvement, while the cases of five further parents convicted in similar contexts have also been sent to the Court of Appeal (GMC 2003, Goldsmith 2004). This does not reflect on the stance of this item, as it is only with hindsight that we may recognise the expertise provided as insufficient. However it has opened definitions of expertise to further interesting questions. Professor David Southall who subsequently made accusations regarding Sally Clark’s husband’s involvement has since been found guilty of serious professional misconduct by the GMC. This case and that of Professor Sir Roy Meadow are presently ongoing (GMC 2003, 2004).

<table>
<thead>
<tr>
<th>Journal</th>
<th>Nature</th>
<th>New Scientist</th>
<th>BMJ</th>
<th>JMG</th>
</tr>
</thead>
<tbody>
<tr>
<td>Original Research Genetic</td>
<td>12 (21%)</td>
<td>0 (-)</td>
<td>0 (-)</td>
<td>11 (79%)</td>
</tr>
<tr>
<td>Original Research General</td>
<td>10 (18%)</td>
<td>1 (4%)</td>
<td>4 (24%)</td>
<td>0 (-)</td>
</tr>
<tr>
<td>Original Research Bioethical</td>
<td>0 (-)</td>
<td>0 (-)</td>
<td>0 (-)</td>
<td>2 (14%)</td>
</tr>
<tr>
<td>Genetic News Reports</td>
<td>16 (29%)</td>
<td>12 (52%)</td>
<td>5 (29%)</td>
<td>0 (-)</td>
</tr>
<tr>
<td>General News Reports</td>
<td>14 (25%)</td>
<td>7 (31%)</td>
<td>3 (18%)</td>
<td>0 (-)</td>
</tr>
<tr>
<td>Editorial/Comment/Features</td>
<td>1 (2%)</td>
<td>1 (4%)</td>
<td>1 (5%)</td>
<td>0 (-)</td>
</tr>
<tr>
<td>Other including letters</td>
<td>3 (5%)</td>
<td>2 (9%)</td>
<td>4 (24%)</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>Total</td>
<td>56 (100%)</td>
<td>23 (100%)</td>
<td>17 (100%)</td>
<td>14 (100%)</td>
</tr>
</tbody>
</table>

Table 3. Article Content by Specific Journals
Source: Journal Content Analysis August-September 2001.

Like news pieces the editorials, comments and features were more able to reflect on genetic issues, discussing, supporting or criticising points, though they contributed to only three per cent (n=3) of the sample across the four journals. Again such items were not present in the JMG during this time period as is illustrated in table 3. One such feature was critical of possible influences on scientific research. An interview with Richard Peto a leading expert on smoking described how British American Tobacco recently gave three million pounds to Nottingham University to fund a professorship in corporate responsibility, calculating that
Every cigarette sold makes a profit for the company of about 3p. To get its donation money back, which we have to assume BAT wants to do, it has to sell 100 million extra cigarettes. Every million cigarettes causes roughly one death. So to break even, they've got to sell enough cigarettes to cause about 100 deaths (Pearce 2001:44).

Finally nine per cent (n=10) of the journal articles featuring the keywords were coded as other this included letters in response to prior issues raised by the journal or mass media. The critical responses of some scientists to prior research again emphasised the disputed nature of some scientific findings (Wilcox and Subramanian 2001, Lowell 2001). There were also a number of advertisements or recommendations for scientific products or new technologies, and book reviews (Palumbo 2001).

In summary, genetic issues continued to feature in the British journals during August to September 2001, both as a focus of original research and as scientific ‘news’. This suggests the interest in genetic knowledge generated via scientific research remained ‘newsworthy’ to the professional journals. The highly specialised content of the journal items reflected the difficulties presented to journalists in reducing, both in terms of content and language choices, such information for public readers. The journal articles, particularly the papers presenting original research were often reluctant to specify the exact role of genetic causes, representing an awareness of criticism towards genetically deterministic approaches and also the disputed nature of evolving scientific research. As such the journals presented a self-regulating image of science. They actively criticised ‘bad’ science, including specific scientists whom interestingly were often those that are seen to court publicity. They also stressed the significance of external factors on the success of ‘neutral’ technologies, publishing bioethical work or producing critical items on funding influences colouring scientific research.

3 Letters which contained original research in response were coded under original genetic research or original general research dependent on their content.
4.2 Journals and Newspaper Relationships

The national media picked up a number of the items, which appeared in the journals. Prior to a detailed discussion of the newspaper content analysis these provide an interesting focus to link the two sample areas. Research establishing associations between genes and prostate cancer published in *Nature* was reported on by *The Daily Mail*, *The Mirror* and *The Times* (Dhanasekaran et al 2001, Kendall 2001a, *The Mirror* 2001, Henderson 2001a). Similarly research on gingko biloba and pregnancy that featured in *New Scientist*’s news section was reported on by *The Daily Mail* (Nielsen 2001, Chapman 2001a). A news piece in *New Scientist* that critically reported on both the implications and scientific feasibility of a US business attempting to copyright ‘celebrities’ DNA also featured in *The Daily Mail* and *The Sun* (Cohen 2001b, *The Daily Mail* 2001, *The Sun* 2001). Whilst *New Scientist*’s news report effectively admonished both the scientific and financial credibility of the US company planning to do this, the newspaper reports whilst critical of the potential of the research, ignored the journals assertions that it would be scientifically impossible (Cohen 2001b).

A number of the journal articles, like that from *New Scientist*, were depicted in the mass media as peer-reviewed and published research by a reliable journal when in fact they had featured as news pieces or opinions. As such they often lacked the balance or critical aspect of the original journal piece and gave credibility to questionable research using this technique. Newspapers suggested research was published in peer-reviewed journals such as *Nature* when in fact they may have only referred to or commented on the work, and often critically so. Research into the impacts of laboratory settings on research animals reported on as a news item in *Nature* was also the basis of a story in *The Guardian* (Knight 2001, Meek 2001). The previously mentioned letter written to *Nature* by Ian Wilmut inspired an article in *The Observer* headlined, ‘The cloning controversy: Human cost of toying with life’ (Wilmut 2001, McKie 2001). This type of reporting ignored the context of
the original journal coverage, suggested credible research had been undertaken or was ongoing and frequently mis-represented the emphasis of the original journal item.

As such it was interesting to note that it was the ‘news stories’, which are often brief and explanatory, that a number of the newspapers reported on during this sampling period, as opposed to the more complex original research papers. In doing this certain newspaper reports not only mis-represented the original publication research had featured in, but also choose to focus on more controversial aspects of journal items. This ignored the rejection or credibility of scientific claims, which would effectively have rendered the story unfeasible.

4.3 Newspaper Content Analysis

A sample of British national newspaper coverage was examined using a slightly later sampling period that allowed stories to be traced between the journal and newspaper coverage. Six daily newspapers were sampled between 20th August 2001 and the 2nd September 2001, while six Sunday newspapers were sampled between the 12th August 2001 and the 2nd September 2001. The same keywords, ‘gene/s’, ‘genetic/s’ and ‘DNA’, were used to select relevant articles. Across the two-week period for the daily newspapers and the four-week period for the Sunday newspapers, 181 articles were present which featured the keywords. 68 per cent (n=123) of these articles appeared in the daily national news, with 32 per cent (n=58) appearing in the Sunday newspapers. The Guardian featured the largest number of articles with 19 per cent (n=34). The Daily Mail had 13 per cent (n=24) closely followed by The Times that also had 13 per cent (n=23). The Daily Express featured ten per cent (n=18) of the articles and The Mirror nine per cent (n=17). The Sun had just four per cent (n=7) of the total articles throughout the two-week period. These frequencies are detailed in figure five. In terms of the Sunday newspapers, The Guardian featured the largest number of articles with 19 per cent (n=34). The Daily Mail had 13 per cent (n=24) closely followed by The Times that also had 13 per cent (n=23). The Daily Express featured ten per cent (n=18) of the articles and The Mirror nine per cent (n=17). The Sun had just four per cent (n=7) of the total articles throughout the two-week period. These frequencies are detailed in figure five. In terms of the Sunday newspapers, The

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4 The main characteristics of the newspapers can be found in appendix one, table 12, page 241. Again there is further discussion of the sampling procedure and methods used in chapter three.

94
Sunday Times featured the most stories and had 12 per cent (n=22) of articles, whilst The Observer had eight per cent (n=15) of reports featuring the keywords. These were followed by The Sunday Mirror and The Sunday Express. The Mail on Sunday and The News of the World had two per cent (n=4) of articles each throughout the four-week period.

The keyword that appeared most frequently was ‘DNA’. 51 per cent of the articles (n=93) used the term and it appeared in total on 163 occasions. 45 per cent (n=80) of the articles used the word ‘genetic/s’, it appeared in total 137 times. Finally 34 per cent (n=61) of the articles used the words ‘gene/s’. ‘Gene/s’ appeared 152 times in total. Just ten of the articles used all three keywords in combination, indicating the high proportion of articles that did not use the terms due to a scientific or medical focus but simply mentioned the terms in passing or as a metaphor.

Articles were present on each day of the time period, across the newspapers and their distribution was relatively consistent. The distribution across the daily newspapers is illustrated in figure six. The least number of articles appeared on the 31st August 2001 when four articles were found across the six daily newspapers. The largest number of articles appeared on Monday the 27th August 2001 when 17 items featured across the six
daily newspapers. This day was particularly popular for numerous reasons. Firstly there were reports on a range of 'controversial' health related genetic announcements. Research was published to suggest our lives could be lengthened using genetic therapies, and it was reported that a woman having IVF treatment intended to use her biological brother's sperm. Predictably both announcements generated a number of articles and journalistic comments (Chapman 2001b, Johnston 2001, Loudon 2001, Meikle 2001). Secondly, it being a Monday, a number of the stories related to articles that had appeared in the previous day's press. Stories regarding research into human longevity had previously appeared in The Sunday Express and The Sunday Times. The Sunday Times had also reported on the IVF case. However it was not always the case that a large number of reports on a specific day would inevitably lead to a high number in the following days. The 28th August, 2001 had a number of stories (n=16), only one of which refereed back to the issues of two days previously, yet it was followed by one of the days with the least number of reports, the 29th August, 2001 when just five articles appeared which contained the keywords. In contrast the Sunday newspapers appeared somewhat more evenly spread, however there was a single day that dominated. Sunday the 12th August 2001 had 25 articles, which made reference to the keywords gene, genetic or DNA illustrated in figure seven. This was also the day, which featured the most pieces, 14 per cent of the total sample, across both the daily and Sunday newspapers.
22 per cent (n=39) of the articles appeared on pages one to ten of the main newspaper, with a further 18 per cent (n=32) of articles appearing on pages eleven to twenty. Articles featuring in the supplements of newspapers, for example ‘Times2’ in The Times, ‘Culture’ or ‘Style’ in The Sunday Times, or ‘G2’ in The Guardian were coded into separate page categories. 16 per cent (n=29) of the articles appeared in such supplements. In both cases, whether in the main body of the newspapers, or in the supplementary features, the trend appeared for such articles to appear at the beginning of the newspaper or supplement and to decrease later in the publication. It is difficult to assess whether this relates to the newsworthiness of a genetic feature, or simply the average length of the differing newspapers or indeed the layout of their sections. There was for example, a slight rise in the number of articles on pages 41 to 50, all of which were in The Daily Mail or The Mail on Sunday and this may be explained by the fact that in these papers such pages account for the health and ‘femail’ sections. The appearance of articles containing the keywords in later pages can largely be accredited to a forensic science story concerning a ‘hate campaign’ against a football manager which was covered in The Sunday Mirror, The Sunday Express, and The Mail on Sunday (Mills 2001).

The headlines of the newspaper articles were also considered and in this case searched for any further general scientific references. 19 per cent (n=35) of the articles involved in the study had a reference to one or more of the following words in their headlines; gene/s,
genetic/s, DNA, Clone/Cloning/IVF, GM/Modification. The newspapers most likely to use such terms in the headline of a piece were *The Sun* and *The Mirror*. 29 per cent (n=7) of articles also appearing in *The Daily Mail* and 27 per cent (n=6) of those in *The Sunday Times* included such terms in headlines as can be seen in table 4. DNA appeared in 13 headlines across the newspapers, gene/genetic appeared in nine headlines, IVF/Cloning or Clone appeared in eight headlines and GM/modification appeared in seven headlines.5

<table>
<thead>
<tr>
<th>Newspaper</th>
<th>Word featured in headline</th>
<th>% of stories in individual newspaper</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Times</td>
<td>3</td>
<td>13%</td>
</tr>
<tr>
<td>The Guardian</td>
<td>6</td>
<td>18%</td>
</tr>
<tr>
<td>The Daily Mail</td>
<td>7</td>
<td>29%</td>
</tr>
<tr>
<td>The Express</td>
<td>2</td>
<td>11%</td>
</tr>
<tr>
<td>The Mirror</td>
<td>5</td>
<td>29%</td>
</tr>
<tr>
<td>The Sun</td>
<td>3</td>
<td>43%</td>
</tr>
<tr>
<td>The Sunday Times</td>
<td>6</td>
<td>27%</td>
</tr>
<tr>
<td>The Observer</td>
<td>3</td>
<td>20%</td>
</tr>
<tr>
<td>The Mail on Sunday</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>The Sunday Express</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>The Sunday Mirror</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>The News of the World</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>35</td>
<td>19%</td>
</tr>
</tbody>
</table>

Table 4. Scientific Reference in headline by Individual Newspaper


Headlines which contained the words gene or genetic largely determined single genes as crucially important with titles such as ‘HIV-protective gene’ and ‘At last, the gene that lets you live to 100’ (*The Sunday Times* 2001:35, Johnston 2001). They further emphasised scientist’s discoveries, ‘Scientists find genetic clues to a longer life’, as well as offering hope and elevating suffering, ‘Gene Test Hope for Thousands of Prostate Victims’ (Rogers 2001: 3, Kendall 2001a: 42). The headlines that contained references to DNA emphasised two points. Firstly that DNA was valuable both financially and as a resource; ‘£10,000 on offer for Archer DNA’ (Mowling 2001). Secondly that DNA is increasingly central to criminal investigations with science trapping and solving crime; ‘Dani Uncle’s House Combed By DNA Cops’ (Hepburn 2001:15). References to GM in the headlines drew attention to the familiarity the public now has with this concept, stating for example ‘Safe’

5 The headlines themselves and the newspapers they appeared can be found in appendix four, table 13, page 268.
GM tomato' (Henderson 2001b:7). All but one of the headlines used the abbreviation 'GM' displaying a confidence in the audiences understanding of this term.

There were also some headlines, which were not included in the above sample as they made no implicit reference to the terms, but which raised interesting points nonetheless. One headline similarly illustrated that terms like 'Dolly' are now assumed to have public recognition with little further explanation. The headline stated 'Wool gathering: Dolly firm wins £30m rescue backing' (Clark 2001:24). A further headline also highlighted the importance of expert advice, with the statement 'pregnant women are told' and depicted nature as dangerous; 'Naturally Dangerous: Pregnant Women Are Told To Avoid Herbal Cures' (Chapman 2001a:5). In the context of the articles themselves some metaphors were predictably used including the 'the blueprint for life', the 'Holy Grail', 'Frankenstein forests' and 'Genetic fingerprints' (Kendall 2001a, Marsh 2001, Thomas 2001). More unusually terms also appeared like, 'genetic booster rockets', 'genetic signatures', and drugs described as 'time bombs' (Chapman 2001c, Johnston 2001, Radford 2001a). The term 'Methuselah', applied to a combination of 'aging' genes by The Daily Mail spread across the two other newspapers that covered the story (Chapman 2001b).

The newspaper articles were coded by the dominant themes of the article content. These were reduced to seven categories the nature of which will now be discussed. 16 per cent (n= 29) of the newspaper articles concentrated on medical research related to some form of genetic issue. Genetic links were made to diabetes (Chapman 2001c), prostate cancer (Kendall 2001a), short-sightedness (Packer 2001), skin cancer (Dobson & Winnit 2001), polycystic ovary syndrome (Stuttaford 2001), and menopause (Chapman 2001a). One article alone linked genetic predisposition to heart disease, leukaemia, bunions, thyroid problems, obesity, osteoporosis, hernias, arthritis, colds and even freckles (Janes 2001).

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6 For further details of the textual analysis coding schedules see chapter three page 64.
A number of these reports described medical research in other areas whilst mentioning a genetic component. For example a report concerning deep vein thrombosis (DVT), at the time an area of considerable media interest, promoted the use of a herbal mouth spray and stressed contributing factors such as lack of movement and too much sleep. However by the last paragraphs of the lengthy article it stated, ‘10 per cent of the population carry genes which predispose you to DVT’ (Halle 2001:44). Articles highlighted complex preventative methods. A piece on tooth decay did not consider the importance of brushing teeth or avoiding sugary foods but that ‘genetic engineers reported last year that they were trying to develop apples and strawberries that would deliver a protein to stop decay bacteria from colonising tooth enamel’ (Radford 2001b:7).

Articles stressed support for preventative measures. One article criticised genetic screening for breast cancer as being a ‘postcode lottery’, demanding a more regionally distributed service. The report itself stated that a breast cancer patient’s operation had been cancelled four times and yet the overall emphasis of the article privileged the funding of genetic diagnosis as opposed to more urgent surgical and pharmaceutical interventions (Marsh 2001:32). The articles were further coded by the overall impression of the reporting; was it supportive or unsupportive of the research it described or neither. While this required some level of judgement on the part of the coder, such approaches have been used in other examples of content analysis (Hansen et al. 1998). As figure eight demonstrates the

![Figure 8. Medical Research Articles by Overall Impression. Source: Newspaper Content Analysis August-September 2001.](image)
reports, which concentrated on medical research were largely supportive of the research they described. 31 per cent (n=9) were negative, four of these reports concerned a case that was controversial in the press at the time, where a woman planned to use a donated egg inseminated with her biological brother’s sperm (Loudon 2001).

Scientific research was the most popular theme of the articles. 25 per cent (n=45) of the sample focused on some form of scientific research. Like medical research, scientific research was also often presented supportively with language used around research such as ‘cutting edge’, ‘breakthroughs’ and ‘miracles’ (Bright & Baker 2001, Cooke 2001, Walker 2001). 32 of the articles reporting on scientific research did so supportively. Genetic predispositions were again stressed and the development of technologies often promoted with little reflection of the consequences or the complexity of the technology itself. However a further nine articles discussed both positive and negative issues, often adding some form of disclaimer or reflecting uncertainties in the final paragraphs. The novel nature of the research meant some articles stated that scientific announcements had ‘ultimate goals’, would be operational ‘within five years’ or that ‘further work needed to be done’ (Hawkes 2001, Henderson 2001a). It was often the case that controversy occurring around a scientific announcement after an initial report, was followed up by further commentary. Three of articles covering scientific research were negative in their stance, for example around experimental drugs trials or commercial interests, though the depiction of the scientists as objective remained (Goldwin 2001).

Don’t blame the scientists: blame the system. Successive governments have declared that science is intimately linked with national wealth. Conservative governments, in particular, found ever more cavalier ways of forcing academic scientists to tout for funds from industry. But there is always the suspicion that those who pay the piper have the power to call the tune (Hoggart 2001a).

Seven per cent (n=12) of the sample specifically concentrated on genetic modification in food or agriculture and these were more unsupportive than the reports of scientific or medical research more generally. Five of the articles centred on GM were unsupportive,
three were neither supportive nor unsupportive and discussed possibly positive and negative implications of the research.

20 per cent (n=37) of the newspaper reports, were concerned with forensic science and specifically the use of DNA testing in solving crime. Often DNA 'evidence' was identified as being the central factor in a prosecution or case; 'The vital clue is that police found what appears to be the attacker's blood on Joanne's T-shirt' (Stalker 2001). In a case where a body had been discovered the overall negative outcome was over-shadowed by the positive DNA evidence it had provided.

Although West Yorkshire police described the find as 'the worst possible news for Leanne's family', detectives are optimistic that it may yield further clues and possible matching with DNA tests. Samples have been taken from 140 men in Bramley, where Leanne was last seen by her friend (Wainwright 2001:6).

Cases were reopened on the basis of 'fresh' DNA evidence or techniques; a strong emphasis was placed on science catching those responsible, particularly when they had gone undetected for so many years. As one article stated, 'a SEX killer who escaped justice for nearly two decades was finally jailed for life for murder yesterday after he was trapped by advances in forensic science' (The Express 2001 emphasis in original). DNA was also being used in Serbia, according to news reports, to confirm the identities of those who had been victims of ethnic cleansing. Family members demonstrated a need to know what had happened to relatives, no matter how shocking or potentially painful this proved (Carroll 2001). Such articles ignored the undoubtedly laborious working hours that had gone into cases, DNA testing becoming a positive angle on often highly negative or disturbing news stories. 36 of the articles that referred to forensic science were thus positive regarding these techniques. An exception to this was a report on the case of a parent who did not wish for their child's body to be exhumed, 'he begged the state coroner not to exhume his son's body. William Wade pleaded with authorities to "let my son rest in peace"' (Bray 2001).
Outside of crime the importance of genetic relationships were also highlighted. Three per cent (n=6) of the articles were hereditary accounts of how an illness effected a family, or concerned the significance of biological relationships. In one article headlined ‘Suddenly I had 10 brothers and sisters and it fell great’, the writer stated, ‘just knowing [my biological parents] is a tool which helps me make more sense, however little, of why I am the me I am’ (Rowson 2001:S). Five of the six articles ignored the potentially negative consequences of such findings, instead optimistically highlighting the significance of genetic information. Tutton (2004) has highlighted the impact of genetic knowledge regarding genealogies and identities and its effect on the way people view themselves and others.

17 per cent (n=31) of the articles that appeared in the sample were not specifically related to science or medicine, instead they contained a reference to the keyword or used what we may term genetic language. Such pieces demonstrate the extent to which genetic thinking has invaded popular culture. Genes were frequently refereed to in the singular sense or as a means of description, supporting the findings of prior research (Miller 1995, Condit et al. 1998, Condit 1999b, Conrad 1999). A writer on a shopping trip with four women observed ‘the shopping gene at work’, and a further columnist stated ‘she can’t help being fat, they’ll say, it’s all in the genes’ (Hoggart 2001b:12, Stoppard 2001). Genetics, genes and DNA were also used as metaphors for other concepts, for example political stances become ‘Tory genetic throw backs’, and a dance review had ‘giant genetic-code backlighting’ (Williams 2001:22, Bain 2001:18). Thus such articles restated the claims of science, accepting that such deterministic genes are realistic.

Finally 12 per cent (n=21) of the articles from the sample were not discussing genetic issues in a specific sense but instead had sporadically and un-contextually used the words genes, genetic or DNA like the following music review,
Mick Jagger's first solo album in eight years, Goddess in the Doorway, is set for release on November 6 ... which should leave ample time for a splendid catfight between the 397 women who are prepared to take a DNA test and supply candid photographs of hotel doorways to prove that the album is dedicated to them (Wright 2001:12).

These reports, which were coded as other, largely consisted of celebrities and the identification of their biological children. Newspaper articles also discussed crop circles (one shaped as DNA) at the centre of scientific and expert attention for a number of years; the culprits were two Southampton pensioners who had been making patterns with planks since the seventies (Kendall 2001b).

Overall 60 per cent (n=109) of the newspaper articles included direct quotes from individual sources, and 40 per cent (n=74) of the sample referred to between one and two individuals during their reports. Of the types of people referred to, as figure nine illustrates, the most popular were the official spokespersons of organisations. This for example, included representatives of medical trusts, individual hospitals and the police. 20 per cent (n=36) of the articles referred to a scientist, and 14 per cent (n=26) to a medical professional. 13 per cent (n=23) featured other experts, this included academics that were not natural scientists, politicians and those with legal expertise. 16 per cent (n=28) referred to a patient, relative or victim with experience of the topic referred to, while a further nine per cent (n=17) spoke to a general member of the public or other type of individual, for

![Figure 9. All Newspaper Articles by Individual Sources.](source)

example when the article was interviewing a public figure.7

The media reporting of genetics was both supportive and consistent during this sample period in 2001 but varied throughout the newspapers. Overall only 13 per cent (n=23) of the articles gave an unsupportive impression of the aspect of science and medicine they were reporting on and a further ten per cent (n=18) examined both positive and negative consequences of the developments they discussed. The remaining 67 per cent (n=122) thus framed recent developments supportively. There was a sense that genetics is 'science', with an omnipresent need to include the word 'gene', 'genetic' or 'DNA' regardless of the story or scientific claim. In particular forensic science was typified as single-handedly solving crime. Including such terms as 'DNA' or 'gene' in the headlines of items was also popular amongst certain newspapers like The Daily Mail, Mirror and The Sun, often inaccurately reflecting the actual article content. A number of articles privileged genetic methods of prevention, ignoring the other ways we cope and deal with illness, disabilities and disease. The reporting of scientific 'breakthroughs' was enthusiastic and promising, again focusing on genetic links and making this the headline or leading issue in the story. It became apparent only later in a story whether research was contested or underdeveloped.

Critical discussions of genetic research, or scientific issues more generally, came in the form of comment or reflection after the publication of an initial story. Arguably such reports which criticised the possible consequences of some scientific interventions added credibility to the scientists claims. Stories in The Sun or The Mirror, dedicating just a couple of lines to the 'gene found for' offered less authority to the scientific arguments than lengthy deliberations of social consequences which typified items in The Guardian. Thus the depictions of science and genetics from this period in 2001 where there were no highly controversial scientific announcements or genetic events illustrates the saturation of

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7 The term 'victim' refers to the crime stories that contributed to the sample.
scientific and genetic terminology and images in the British national press during this period.

4.4 Journalists Questionnaire and Case Study

While the content analysis of journal and newspaper publications highlighted a number of issues, questionnaires and a case study with media professionals allowed for the further consideration of a number of aspects of the data. In January 2003, a six-page questionnaire combining a selection of open and closed questions was circulated to 81 journalists on British national newspapers and South-West regional newspapers.8 Journalists were selected on the basis that they had featured in the original content analysis, had written a genetically focused piece in the regional press, or were the present science or health correspondent or editor at a newspaper. Completed questionnaires were returned by 12 per cent (n=10) of the sample across two distributions. The findings of this survey are now discussed, supplemented by a case-study carried out in June 2003 involving an in-depth interview with a science correspondent Emma, working on a national broadsheet newspaper.9 She had worked in the media for 10 years. Prior to this she had received a higher degree in a science-based subject and experienced working as a scientist in a professional capacity. Discussions with Emma were loosely formulated around a set of eight open questions, allowing for the coverage of a number of relevant issues whilst still offering some flexibility.10 Excerpts from Emma's case study are highlighted but interlinked with the more general survey of journalists.

Survey respondents were asked a number of questions about their personal characteristics including gender, age, marital status and religious preferences; these are illustrated in table nine in appendix one. Respondents came from a range of British national newspapers,

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8 For full details of this process see chapter three.
9 The journalist's real name has been changed to protect her identity.
10 The interview aid memoir is also discussed in chapter three and is shown in appendix two, figure 20, page 244.
including *The Times*, *The Guardian*, *The Sunday Times*, *The Observer*, *The Mirror* and *The Express*. Three journalists based on local South-West newspapers also responded. Two worked on *The Express and Echo* an evening newspaper based in Exeter, and one for *The Plymouth Evening Herald*. Eight of the respondents wrote primarily for the newspaper they were contacted at. Two worked on a freelance basis at the time of the survey. Four of the respondents described their professional title as reporter or journalist. Four were science or medical correspondents on their respective newspapers. One was a columnist and a further respondent, a freelance journalist, was also a psychologist. All of the journalists had experienced writing about genetic, scientific or medical issues. A comment made by Emma during the case study highlighted why.

> If you cover science and health you can't help but [cover genetics]. There are so many genetic stories about that you would really have to have your eyes shut and your ears closed to not come across them...journalists have got past that sort of fashion for doing 'there's been a gene discovered for such and such'...people are still quite interested in genes and genetics generally either for their own family or because it tells you, supposedly, it can tell you about personalities, about illnesses...possibly tell you about the future, in a way that hasn't been possible before (Emma IM001 National Newspaper Science Correspondent).

This statement highlights the presence of available genetic stories, Emma also described a public interest in the area, and was keen to stress in her choice of language, the 'possibility' of genetic research rather than inevitability. Four of the members of the media had been working in the field for less than 10 years, whilst two had worked in the media for eleven to twenty years and a further three for over twenty-one years. Nine of the respondents answered that 75 to 100 per cent of their professional activities were dedicated to media work; the tenth respondent did not answer this question. Three of the journalists had higher degrees; in one case this was a PhD in a natural science. A further two had been in full time education to degree level. The remaining respondents had a range of journalism diplomas specific to the profession or had been educated only to school level. Two of the respondents' highest levels of qualification were O-levels, CSEs or GCSEs, though this

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11 The average net circulation per issue of the *Express and Echo* was 26,848 in December 2002 to June 2003. The average net circulation per issue of the *Plymouth Evening Herald* was 43,553 in December 2002 to June 2003 (Audit Bureau of Circulations 2003).
was not related to the age or the type of newspaper, local or national that the journalist worked for.

The respondents expressed confidence in dealing with scientific or medical issues. Three felt 'very confident' when dealing with medical issues, though only one respondent felt 'very confident' dealing with scientific issues. A further four respondents felt 'quite confident' dealing with medical issues, and three felt 'quite confident' when dealing with scientific issues. Five respondents described themselves as 'neither confident nor unconfident' when writing about scientific issues, two of these were medical correspondents; the remainder were all reporters or journalists. One journalist was 'neither confident nor unconfident' but was not a science or medical correspondent. None of the respondents described themselves as unconfident.

Emma consistently raised the quality of science and medical reporting during the case study. She discussed the improvement of scientist's communication abilities, combined with a journalist's practical experience and the increasing prominence of scientific reporters as central to improvements in the area.

Science reporting has got a lot better, there's more of us doing it and so the quality has gone up because it's got quite competitive. Everyone is always chasing the best story ... Scientists have actually done incredibly well to change their own culture in trying to sort of popularise their work and talk about it to people outside their own academic communities...they ought to be praised for what they have done really. There are still the odd few that to be quite honest would never make good communicators but...its like learning a new skill...I only really got the hang of science writing after about three years...it took that amount of time to be confident about what was the story, why it was relevant, why it was interesting and writing it in a way that I was pretty confident would really draw in readers...its a knack (Emma IM001 National Newspaper Science Correspondent).

It is important to stress that Emma's comments were that of just one science correspondent but they valuably highlighted a number of the issues raised by both the content analysis and survey respondents. Returning to the survey, the journalists were asked which sources they would ideally like to include statements from when writing an article on genetics.
Nine of the respondents would like to include statements from a genetic scientist. Seven said they would also include comments by politicians and policy makers, and six said they would speak to Health Workers such as GPs and Nurses. Comments from individuals affected by a genetic condition were also popular, half of the journalists felt they would ideally include them. As one respondent stated however consultation would very much depend on the type of story involved. Only three respondents said they would include the comments of genetic counsellors.

The case study provided an opportunity to discuss with Emma her experiences of dealing with scientists whom had been identified in the survey as a favoured source. She depicted her experience as ‘variable’, dependent on the scientist you were communicating with, their experiences of dealing with the media and abilities in explaining their work.

Some scientists are very clued up and will know how to explain their work and will not be afraid of journalists and actually work quite hard with the journalist to make sure that the story comes across well and accurately and correctly...it’s very rare to come across a scientist who just won’t talk to you because its just not really the done thing now. It’s become a lot more acceptable to publicise your story and scientists nowadays are expected to engage with the public...also their grants, a lot of scientists when they are applying for grants, there's an element of how they disseminated their work to the public...some who are very practiced and very good at what they do, they can come up with good analogies, they can talk eloquently about the implications of their work, about the limitations as well, which are really important and others, others are not so good at disseminating their work or talking about their work to general lay audience. But you as a journalist, it’s your job as a journalist, to kind of tease it out of them and find out exactly what their works about and why it’s so important, you know why the paper that's just been published in some obscure journal actually matters (Emma IM001 National Newspaper Science Correspondent).

Emma highlighted that scientists were increasingly expected to communicate with the public; specifically she suggested this was an implication of the funding process. Whilst she appreciated some scientists were good communicators she recognised others were not, as this is not the primary facet of their profession 'their primary role is to actually do the research... scientists should spend part of their time thinking about what they do and how they would explain what they do' (IM001 Emma, National Newspaper Science Correspondent). However she suggested it is down to a ‘good’ journalist to actually
communicate the issues involved and was keen to stress that this move to communication was recent.

It's a bit of a culture change from what they're [scientists] used to... before, it was okay for scientists not to have to engage at all. It was seen as something a bit sordid if you were talking to the public and talking to journalist but it's really not seen like that anymore (Emma IM001 National Newspaper Science Correspondent).

Returning to the survey, when asked about the sources used in practice as opposed to theory, results varied. When covering a medical or scientific story, eight of the respondents said they would use professional contacts. Seven of the respondents described using internet or web-based material and six said they consulted scientific or medical journals. Five journalists that completed the questionnaire said they may look at other newspaper articles in the area, and two respondents stated that they would consult medical or scientific texts. Only one respondent indicated that they would utilise all of these sources when writing a scientific or medical item.

Nine of the respondents felt they were ‘always adequately informed about the issues they professionally reported or commented on’. One respondent disagreed with this statement. Five agreed or strongly agreed that ‘it is difficult to make scientific and medical information understandable for the public’. Four journalists disagreed or strongly disagreed with this statement and one ‘did not know’. Emma during the case study gave some further indication of the difficulties of writing about science for the public

No one is paying the reader to sit there and read what you have written. If you don’t make it easy for them and straightforward, then there’s no reason why they should read you. I mean why should I read something that’s dull...boring or really hard work...You want to draw the reader in and hold their interest and also make them feel as if they have got some grasp of the subject by the end of the article and if you manage to get them to the end then you have done well...it’s kind of ‘big brotherish’ to think that the media has any particular duty... no ones got a duty to read about science. I think the average interested citizen will want to read about genetics...I think scientists themselves have a duty to explain it and we are their sort of conduit (Emma IM001 National Newspaper Science Correspondent).

Eight respondents similarly agreed or strongly agreed that ‘the media acts at the interface between science and the public’, and likewise that ‘medical stories are most appropriately
supported by individual cases and stories'. Half of the respondents agreed that ‘a scientific story was still good even when it does not have any immediate practical applications’.

Asked ‘do you find it useful to make stories more attractive with catchy headlines or metaphors?’ Two journalists strongly agreed, and five agreed. Two journalists, from *The Guardian* and *Observer*, disagreed or strongly disagreed with using catchy headlines and metaphors to make a story attractive. The language choice of journalists was an issue more extensively discussed with Emma during the case study. She again described a change in the motivations of scientists and how this had impacted on the language she used when reporting scientific or medical issues.

Scientists themselves are getting better at telling us what they do... scientists are a lot less likely to use jargon. Before it was a bit of a protection mechanism. Very few people knew what they were on about and so they didn't really get questioned very much... nowadays scientists just can’t get away with jargon... they have to be a bit more open and that includes spelling things out in plain English where possible, even though there are limitations in that too (Emma IM001 National Newspaper Science Correspondent).

Emma suggested that at times using simple language could lead to a misinterpretation of scientific principles. However when specifically asked about her viewpoints on metaphors Emma was particularly supportive.

Well think of DNA, think of the human genome. It's very convenient and this is Matt Ridley’s metaphor, which is brilliant, which is that the genome is a book, the chromosomes are chapters, the genes are paragraphs. You know it's a really easy, straightforward and fairly accurate way of thinking about the human genome. I would be hard pressed to come up with a better analogy. I think that's the perfect example where people get a real feel for what you're talking about. I mean you can stretch the analogy too far... We have genes that don't appear to code for anything so called 'junk' genes and its very easy to think of those as completely redundant paragraphs in a chapter ...but I think that's a really useful analogy and I think it really gives people a hold and a feel for what we are talking about and that's really important when you are in science journalism (Emma IM001 National Newspaper Science Correspondent).

Predictably the journalists described newspapers as the most reliable source of genetic information in the media in comparison to television or the internet. Seven described newspapers as reliable, with only one respondent stating it was unreliable; again this person was based at *The Observer*. Five of the journalists described the television as reliable. Only two respondents felt the internet provided reliable information, despite the
journalists' prior description of using the internet when writing an item on science or medicine.

Six members of the media stated that there is not enough information on genetics in the media. Three of the respondents felt it was about right and one was not sure. This was an issue raised with the journalist involved in the case study, Emma stated:

I think it's about right [media focus on science] because I don't want to have it rammed down my throat any more than I want any more arts programmes or anything else...They are kind of self-balancing in a way, because you know the paper sells we are obviously getting some balance of stories right...stories need to compete on their merit. Just because something's a science story doesn't make it interesting...it shouldn't be there for the sake of it, it should be there because it's interesting and because it's more interesting than say a crime story that it knocked out of the paper. I don't think science has any particular claim on a certain portion of the paper...To be quite honest a lot of the science that we do get press releases about are deathly dull...we are looking for...stories that are interesting, relevant, timely, tell us something important that we didn't know before, you know illuminate some truth and actually, are interesting that people want to read after all they are buying a paper. The paper is a commercial commodity (Emma IM001 National Newspaper Science Correspondent).

Emma stressed that people choosing to purchase a paper was a key factor in measuring the balance, demand and understanding of articles by the general public.

The journalists surveyed were asked to select a word that best described their attitude to recent developments in genetics. Three examples were given including, optimistic, cautious and confused. The most popular word used was cautious, which three of the respondents felt described their attitude. Two felt optimistic, and one journalist used the word sanguine akin to optimism. The remaining respondents described their attitudes as hopeful, fascinated and 'cautiously excited'. One journalist did not complete this question.

Asked if they would undergo genetic testing if it were offered to them, three felt that they would undergo testing, three stated that they would not and four did not know.

Journalists were evenly split over how scientists and medical professionals viewed the media. Asked about scientists and medical professionals' attitudes, the journalists were
given five options ranging from very positive to very negative with the mid point being neither positive or negative. Three respondents felt scientists and medical professionals viewed the media positively. Three thought they viewed the media negatively and a further three felt their opinion was neither positive nor negative. Again one respondent did not provide a response. It was interesting that a range of views were represented with regards to this question. Support was also an issue extensively discussed by Emma, the journalist involved in the case study. She had already described a shift in scientists' views regarding communication and went onto describe how this influenced their attitudes to members of the media.

The attitude of scientists towards journalists has changed hugely. They're much less dismissive of you, scientists seem to take a lot more interest in what the public thinks about them and their work and also the other thing is that journalism itself has now become a kind of acceptable profession for scientists to move into...so the gaps get narrower (Emma IM001 National Newspaper Science Correspondent).

Emma described an increased willingness amongst scientists to communicate with journalists, but also described some of the difficulties she had experienced when dealing with scientists.

Sometimes I get letters or comments from scientists whose work I have covered...Most of the time they are pretty good and they tend to have a very good idea of what going in the paper just from conversation, it tends to be a good reflection of what we were talking about. But occasionally there will be some that may think that it may be a little to simplistic but sometimes we do have to take account that we can't mention every caveat... sometimes people are going to find it tough that their work has been simplified. We try to do as good a job as we can. (Emma IM001 National Newspaper Science Correspondent).

Members of the media were also asked about their viewpoints on a number of specific statements related to genetics. These were a selection of the statements taken from the public questionnaire that will be discussed in a later chapter. Four journalists, including two science or medical correspondents, stated that they did not know if 'the cause of an illness is always a combination of genetics, environment and lifestyle'. Two agreed or strongly agreed with the statement, and a further four disagreed or strongly disagreed. Six members of the media did not know if 'a human has about 30,000 genes'; again two of these were science or medical correspondents. Only one respondent agreed that 'in the
future gene treatment will treat all illness’, five did not know and four disagreed or
strongly disagreed. As such just two members of the media thought ‘genetic research
should be given priority in government funding’. Six respondents disagreed with this
statement.

As to the application of possible genetic innovations opinions were clearer. All ten agreed
or strongly agreed that ‘genetic testing should be voluntary in healthcare’ and just one
journalist felt that ‘women should not be offered pre-natal genetic tests’, nine being in
agreement with their use. Nine of the respondents also felt that ‘genetic researchers would
not be the best judges of what is ethically appropriate’, and all ten agreed or strongly
agreed that ‘geneticists’ professional conduct should be regulated by government
legislation’. Despite this the journalist involved in the case study drew a broader
perspective on those that were responsible for genetic research. Emma stated

> Scientists should spend part of their time thinking about what they do...not
> necessarily justify I think that's done by ethics committees and you know the great
> and the good ...I think its good for everyone if the scientists are not seen as just
> sort of academics in ivory towers but seen as human beings who are actually doing
> relevant work (Emma IM001 National Newspaper Science Correspondent).

There was also a range of questions concerning the implications of genetic advances.
Despite only two journalists agreeing with it being a priority in government funding there
was strong support for the work. When asked if ‘genetic researchers are intruding on areas
of life, which should be left untouched’, six disagreed with the statement and a further two
strongly disagreed. Seven of the respondents agreed or strongly agreed with a statement
regarding genetic privacy, stating that they were ‘concerned that genetic data could
become private property’. Whilst nine out of the ten respondents agreed that ‘genetic tests
and databases increases the power of experts’, they also felt it could increase the power of
individuals. Six agreed or strongly agreed that genetic testing will give ‘individuals more
control over their lives’. Two respondents disagreed with this statement.
Though there was support for genetic research some well-publicised implications remained controversial. The members of the media were asked if ‘human cloning would be acceptable in certain cases’. One respondent strongly agreed with the statement, one agreed but six disagreed or strongly disagreed. Equally when asked how they felt about genetically modified foods, three respondents felt they were acceptable, two did not know and five agreed or strongly agreed that they were unacceptable. During the case study Emma was asked about the difficulties of portraying scientific controversy to the public, she said

You would try and get both sides of the argument. That’s really important and if you don’t manage to get both sides then you have to say so. But it’s also important to communicate what the prevailing scientific opinion is...it’s important if you are covering controversy just to be upfront about it and to actually spell out for the reader where there might be an imbalance...sometimes it can be ninety nine percent of the scientific lobby who thinks one thing and one percent who thinks the other. That’s not to say that the one percent is always wrong just like...at the end of the day you have to go very much as scientists do, you have to go for a balance of peer reviewed literature (Emma IM001 National Newspaper Science Correspondent).

The journalists involved in the survey were also asked for their opinions on the publics’ understanding of the issues, science medicine and genetics at a general level. Asked to rate the publics understanding of science eight of the journalists felt it was poor, though one respondent described it as good and one described it as adequate. They were more optimistic regarding the publics understanding of medicine, three described it as good but six respondents thought the public understanding of medicine was poor. Where genetics was concerned, public understanding was only described as adequate to very poor. One journalist thought it to be adequate, six thought the public understanding of genetics is poor and three described it as very poor. Emma however was keen to stress that successfully communicating to the public was a satisfying aspect of her job.

Most readers are great actually. The best letters to get are from people, who have got no scientific background at all, and you have written something and they will write to you and say, I have understood it for the first time in my life and that’s really rewarding (Emma IM001 National Newspaper Science Correspondent).

Whilst the media in their reporting of science and medicine often identify risks, the individual members of the media had very high levels of trust in both science and medicine.
when asked specifically. Nine of the respondents said they mostly trusted doctors, one said they totally trusted doctors while all ten of the media respondents said they mostly trusted scientists. Their level of trust in these professions was high, regardless of their own professional role. Similarly nine of the respondents felt medicine was useful, and eight of the journalists said science generally was useful. Six respondents thought genetics was useful generally, two respondents said it could be more useful than harmful and a further two respondents thought it may be useful and harmful.

4.5 Summary

It was important that this study considered how journals covered new genetic issues, as professional journals are the legitimised, public face of science. As Mulkay (1979) has highlighted the scientific journal is a social site through which scientific knowledge-claims are legitimised though rarely are experiments replicated, they are accepted by the scientific community at a ‘superficial’ level. The content analysis of journal coverage thus highlighted a number of issues regarding representations of science. Genetic issues are newsworthy not only amongst the mass media but also amongst the audiences of professional publications. Only 36 per cent (n=40) of the sampled journal articles, containing the keywords gene, genetic or DNA appeared in the publication of original data, research and papers. The remaining coverage involved news reports, editorials, comments, features or letters. As such a high amount of the coverage in journals like New Scientist were not authored by academics but were written by science writers, with only 54 per cent (n=59) of the total sample authored by academically based researchers.

The research papers themselves were predictably highly technical and dense in comparison to the style of writing in the news items of the various journals. This highlighted the difficulty in translating such pieces to a general audience and a comparison to the press releases distributed to journalists by the journals themselves may have been useful to
develop this angle of thought. Nevertheless, the comparison of journal and national newspaper coverage drew attention to the use of professional journals by the print media. In particular it highlighted the reliance during this sample period on journals' news items rather than original papers, and also the discrete use of source attribution. Using journal news stories inappropriately sensationalised issues which had been rejected in the journal coverage, suggested sometimes wrongly that research was ongoing or finalised and gave credibility to research or ideas which may have originally featured in far more obscure or less credible publications. The timing and extent of comparison possible in this study however means that a more extensive survey of journal to newspaper coverage would be necessary to reflect on these points in more detail.

This inevitably raises questions over the responsibility for sensationalised or inaccurate coverage in mass media coverage. The journals or rather the authors of specific pieces were not unfamiliar with both the purpose and use of metaphors or language of explanation in their own writing, as was particularly highlighted by Downie and Young (2001:598) and their defence of concepts such as 'housekeeping genes' in aiding student understanding. The journals news coverage in particular used words like 'hope', 'vision', and 'fight' adding to the progressive stance towards genetic science. However at the same time, there were notes of caution both about the use of such terms and the certainty with which they could be applied, and the frequent appearance of doubt or disclaimers by the end of sampled coverage.

The image presented by the professional journals was undoubtedly one of ethically neutral and objective science and technology where problems were created only by the externalised and abstract environment, carefully segregated from science itself. The ethical, legal or social implications were for 'other' experts to consider or study, and to be
negotiated or overcome for a technology to be accepted. In this sense the journal coverage emphasised a point made by Nowotny et al. (2001:2).

Much of the attention remains focused on science rather than society. The latter impinges on the argument only when it touches the former... The perspective is still mainly that of the scientific community(ies)... In other words the relationship is viewed principally from one, still dominant, perspective.

In cases where the public representation of science had been disturbed, where the intervention of scientific certainty or expertise was questioned this was personalised to an individual level, or attributed to powerful external influences like private corporations.

The broader media coverage in national newspapers suggested a continued interest in genetic 'news' during this period in 2001, in particular amongst newspapers like The Times, The Sunday Times, The Guardian and The Daily Mail. The frequent appearance of keywords in articles with little or no scientific or health content and the use of concepts like 'Dolly' or 'GM' in headlines emphasised a public awareness of such terms. The more general language use in such articles, talk of hope, breakthroughs, and miracles also continued the theme and reproduction of geneticisation in popular culture (Lippman 1992, Nelkin and Lindee 1995, Condit 1999b, Franklin 2001b). In coverage that was health related emphasis was placed on genetic factors in causation, prevention and cure. During the two-week period links were made to genetic factors contributing to conditions like cancer, diabetes, colds, tooth decay and DVT, which continued the tendency to emphasis the determining role of genes in human biology (Franklin 2001b). The reporting of scientific research which was presently ongoing or in preliminary stages highlighted its possible future applications in a supportive manner, the exception to this being coverage of genetic modification in agriculture which was predominantly unsupportive as other studies have already indicated (POST 2000, Shaw 2002, Arntzen et al. 2003). Notably the coverage of crime stories supported forensic science without question, and here the term DNA and its linkage to success, problem solving, and benefits, were some of the most
strongly made. Media coverage thus contrasts with public concern regarding the impact of such data collection on civil liberties (Glasner and Rothman 2004b).

While only small samples of journalists were involved in the survey, their responses when supplemented by Emma’s comments provided contextualised information regarding the media coverage of science and medicine. The journalists clearly felt accountable to both their public ‘consumers’ and the scientists who cooperated with them. Experiences varied, specialist science and medical correspondents had greater expertise than those journalists who wrote about research or controversy as news items. This emphasises that it cannot be assumed that those who write about science, medical or genetic issues, in the range of articles suggested by the newspaper content analysis, are informed widely about such issues. Instead their expertise is likely to represent the specific issue that is newsworthy at the time. The proliferation of genetic research, highlighted in the journal and newspaper content analysis, and by Emma the science correspondent clearly impacts on coverage in the area. The scientific community has become more conscious of the role of the media, and the constraints of reporting, whilst there is a clear necessity for trust in the scientist-journalist relationship, particularly as they are a key source, this is balanced by the problematic nature of representing the disputed nature of scientific research. The media is often criticised for treating science poorly but the findings of this aspect of the research suggests that like members of the public, individual journalists continue to view science and medicine supportively. Thus they question the claims of science and medicine not in the vein of being ‘anti-science’ but in their professional role as a ‘journalist’.
Chapter Five: Public Responses to Science and Genetics

Public attitudes towards science and in particular genetic developments are frequently depicted as unsupportive (HMSO 2000, BA 2002, POST 2002). However as the literature review and methodology suggests the viewpoints of the public have largely been examined from two opposing perspectives, quantitatively examining the deficit in public understanding, or qualitatively focusing on specialised local or patient groups (Condit 2004b, Sturgis and Allum 2004). Recently it has been recognised that such divisions are unhelpful, and that the public generally, rather than exclusively, may have interesting and informative views on science, genetics, and in particular controversial issues like GM in agriculture. As such this chapter incorporates the findings of two research methods,

- The outcomes of nine semi-structured interviews with members of the public.

5.1 Public Questionnaire and Sample Characteristics

A six-page questionnaire was distributed to 400 members of the public living in the South West of England. As discussed in the methodology, the sample was selected using a cluster sampling approach. Home addresses were selected in three areas, Plymouth, Exeter and the South Hams, and further stratified by electoral ward. Two postal distributions took place, the first in October 2002, with a further distribution to non-respondents in April 2003. 38 per cent (n=153) of the members of the public sampled returned their questionnaires completed.

Like the media survey sample, and the expert respondents discussed in the next chapter, the public respondents were primarily asked questions regarding their personal characteristics. While the value of these attribute questions at the outset of a questionnaire is disputed, the sensitive nature of many of the areas covered meant they were not only a
necessity, gender for example may impact on pre-natal genetic issues, but also acted as an introduction to the more sensitive issues to follow (De Vauss 1996). These public sample characteristics, including, gender, age, marital and parental status, qualifications and income, can be seen in appendix one, table ten in detail but will now be briefly discussed.

A range of individuals formed the sample, despite the anonymity of the initial questionnaire sent to 'The Occupier' of a household. 58 per cent (n=88) of public respondents were female and 41 per cent (n=63) were male. 44 per cent (n=67) were aged between 41 and 60, and 29 per cent (n=44) were over the age of 61.1 In the lower age groups, 20 per cent (n=31) were aged between 26 and 40, and six per cent (n=9) of respondents were aged between 18 and 25. 57 per cent (n=87) of the public sample were married or remarried and 75 per cent (n=115) had children. 99 per cent (n=151) of the public respondents classified their ethnic origin as white. As the South West is generally an area of low ethnic diversity this was not unpredictable. 28 per cent (n=42) were not religious.2

Respondents were asked about their occupations and income for the purpose of later cross tabulation. 28 per cent (n=43) of respondents had a personal income of less than £10,000 per annum, with a further 30 per cent (n=46) earning between £10,001 and £20,000. Five per cent (n=8) of the public sample earned over £35,000 per year. These questions in themselves generated some interesting outcomes. 16 per cent (n=25) of respondents left out the question regarding income, compared to six per cent (n=9) of respondents that left out a question concerning abortion at a later point of the questionnaire. The respondents came from a range of occupational backgrounds, as can be identified in table 5. The questionnaire respondents were asked for their occupation in an open question and the Office for National Statistics Standard Occupational Classification 2000 was

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1 The remaining one per cent had not completed the questions regarding gender or age.
2 See appendix one, table ten, page 239 for further comparison of the public sample characteristics and 2001 Devon census data.
utilised to classify the occupations stated (ONS 2003a). While a number of the members of the public were in professional occupations and the sample was slightly over-represented in this category, the survey reached a broad range of people from a variety of backgrounds. Process, plant and machine operatives, and those from skilled trade, or sales and customer service occupations were however, slightly under-represented.

The public sample were asked if they or any members of their close family worked in science or healthcare due again to the possible influence on responses. 22 per cent (n=34) did work themselves or have a family member in science or healthcare fields. A large number were parents of recent science graduates. However there were also pharmacists, nurses, dentists, doctors, midwives, carers, ward clerks and practice managers.

All three sample groups were asked if they themselves or any members of their family had undergone genetic testing, or been diagnosed with a genetic illness. This question was again included due to its possible influence upon responses. Nine per cent (n=14) of the public sample answered yes to the question ‘have you or any member of your family undergone genetic testing, or been diagnosed with a genetic illness’. This was an open question as the respondents were left to interpret their own definition of genetic and asked to provide brief details of the condition. Four public respondents or their family members...
had conditions like diabetes, while a further respondent had experienced cancer screening which did not necessarily involve sophisticated genetic testing. Eight respondents had children who had conditions which health professionals had said were 'likely' to be genetic, such as visual impairment and autistic disorders but there were also some cases of diagnosed genetic conditions. These included diagnoses of Tay Sachs, PKU, Tourettes Syndrome, ADHD, and Aspergers Syndrome. It is not possible to confirm if the presence of those with genetic conditions amongst the sample is an indication of their proliferation amongst the population, or simply due to these respondents feeling more equipped or motivated to respond.

5.2 Public Respondent's Media Choices

Views of the media were asked for in various forms. The most popular daily national newspaper amongst respondents was *The Daily Mail*, read regularly by 29 per cent (n= 45) of participants as is illustrated in table six.³ *The Daily Telegraph* and *The Mirror* were also popular choices. The least favoured daily newspapers were *The Express*, which nine per cent (n=13) of the sample read, and *The Independent*, which just seven per cent (n=10) read regularly. When asked which Sunday newspapers they read, respondents displayed a similar pattern. *The Mail on Sunday* was the most popular, 19 per cent (n=29) of respondents regularly read this newspaper. This was followed by *The Sunday Times*, which 11 per cent (n=17) read. The least popular Sunday papers were *The Observer* that five per cent (n=8) of the sample read and *The Independent on Sunday*, regularly read by three per cent (n=4). There were some indications that those from different educational backgrounds read different types of newspaper, 35 per cent (n=8) of those with a first degree read *The Times* compared to ten per cent (n=4) of those educated to O-level, CSE or GCSE. Similarly 22 per cent (n=5) with a first degree read *The Guardian* compared to seven per

³ 'Regularly' was defined as more than once a week for daily newspapers and once a month or more for Sunday newspapers.
Table 6. Question 14 Which newspapers do you read regularly?
Source: Public Questionnaires

<table>
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<tr>
<th>Newspaper</th>
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<tr>
<td>The Times</td>
<td>20</td>
<td>13%</td>
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<tr>
<td>The Guardian</td>
<td>16</td>
<td>11%</td>
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<td>The Independent</td>
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<td>7%</td>
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<tr>
<td>The Daily Telegraph</td>
<td>29</td>
<td>19%</td>
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<tr>
<td>The Daily Mail</td>
<td>45</td>
<td>29%</td>
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<td>The Express</td>
<td>13</td>
<td>9%</td>
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<tr>
<td>The Mirror</td>
<td>21</td>
<td>14%</td>
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<tr>
<td>The Sun</td>
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cent (n=3) qualified to O-level, CSE or GCSE. For other newspapers the variations were less defined, 33 per cent (n=5) of those with higher degrees read The Daily Mail for example, as did 31 per cent (n=13) of those with O-levels, CSE’s or GCSE’s. Three of the 19 respondents who stated that they regularly read The Sun had higher or first degrees.

36 per cent (n=55) of the public sample thought they read articles concerning health and/or science on a weekly basis, and 19 per cent (n= 29) of the sample on a daily basis. While eight per cent (n=12) of respondents stated that they never read such articles, this did not necessarily indicate a lack of interest or knowledge in health and science issues. A further question asked respondents how interested they were in health or science issues, and here only three per cent (n=4) of respondents stated that they were not interested in health and science issues. 54 per cent (n=83) of public respondents were quite interested in health and science issues, and 26 per cent (n= 40) felt they were very interested, over half of these (n=22) respondents were themselves or had members of the family working in science or healthcare. There was however little variation in expressed interest and the level of occupation respondents came from. 91 per cent (n=32) of those from professional backgrounds described themselves as very interested or quite interested in health and science issues, as did 100 per cent (n=13) of those from elementary occupations.
As figure ten indicates the most popular source for gaining information on genetics was television, which 73 per cent (n=112) of the sample said they had used.⁴ 65 per cent (n=99) had seen information in newspapers. Friends or relatives had been a source of information for 23 per cent of respondents (n=35); only four of these respondents had been diagnosed with a genetic condition themselves or within their families. 78 per cent (n=7) of eighteen to twenty-five year olds attributed some of the information they had received on genetics to their education, compared to two per cent (n=1) of those aged sixty-one plus. In terms of occupation there was little variation in the types of sources utilised, though those from professional backgrounds and students were more likely to have used the internet as an information source.

Regarding the reliability of such sources respondents were most trusting of genetic information they had seen on the television. 43 per cent (n=65) said this was a reliable source, 22 per cent (n=33) felt it might be unreliable. Less than one per cent said that they had not seen any information on genetics on the television. The public respondents were less trusting of newspaper coverage. Only 21 per cent (n=32) believed it was reliable and 37 per cent (n=57) stated that it was unreliable. 35 per cent (n=54) were unsure, and again only one per cent had not seen any information.

⁴ See page 66 chapter three as to why television analysis was impractical.
Respondents were then asked whom specifically they would trust when reading an article on a genetic issue. This question provided some interesting results. The person whom most respondents stated they would trust was a genetic scientist. 60 per cent (n=91) of respondents stated that they would trust a scientist when reading a piece about genetics. 49 per cent (n=75) said they would trust people with genetic conditions, their friends or a relative as is shown in figure 11. Health workers, including GPs or Nurses, and genetic counsellors were also put at a high regard. More predictably journalists were trusted by only six per cent (n=9) of respondents and only two respondents said they would trust a politician or policy-makers comments in an article on genetics.

5.3 The Public Respondents, Scientists and Medical Professionals

The questionnaire then moved into areas more specifically related to genetics. Asked 'in general do you trust scientists and doctors?' the levels of mistrust remained relatively low. 64 per cent (n=98) of the public sample said they mostly trusted scientists and 78 per cent (n=119) said they mostly trusted doctors. At the extremes of the responses, seven per cent (n=10) said they totally trusted doctors though only one respondent totally trusted scientists. Only three respondents stated that they did not trust scientists or doctors. There was an interesting gender dimension to these responses. 74 per cent (n=45) of the male
respondents said they mostly trusted scientists, while 59 per cent (n=52) of the female respondents said they mostly trusted scientists.

In two separate questions members of the public were asked to name any diseases or characteristics that they thought were hereditary. Both questions were open, with no examples given to respondents. All responses to this question were coded and included, regardless of their medical or scientific accuracy. The question aimed to measure the public samples perception of conditions that were hereditarily linked, rather than measure them as correct or incorrect. 74 per cent (n=113) of respondents named at least one characteristic, disease or illness, though on average respondents stated at least two conditions. Two respondents named over ten conditions, neither of whom came from occupations specifically linked to science or healthcare. It cannot be assumed that the remaining 26 per cent (n=40) of respondents were unaware of any hereditary factors. Responses included ‘yes’ but giving no examples, stating that they could not spell the illness, disease or characteristic, or that their mind had ‘gone blank’.

The most popular disease named as hereditary was cancer. 31 per cent (n=47) of people stated that some types of cancer were hereditary. They often referred to a specific type such as breast or prostate cancer where genetic predispositions have been found. Following this was heart disease, which 23 per cent (n=35) claimed was hereditary and where again genetic links have been reported. 22 per cent (n=34) of respondents stated that certain mental illnesses had hereditary links, those mentioned included schizophrenia, manic depression and conditions such as Alzheimers and dementia. 18 per cent (n=28) of people knew that Cystic Fibrosis was a hereditary condition, whilst 16 per cent (n=24) were also conscious that Haemophilia was hereditary. 13 per cent (n=20) referred to Huntingtons Disease, 12 per cent (n=18) mentioned eye problems such as glaucoma and 11 per cent

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5 Given the controversy around certain genetic links this would have been a problematic task. Genetic links have for example been found to conditions such as homosexuality or alcoholism only to be refuted by other scientists, or in the process of continuing research (Miller 1995, Conrad and Weinberg 1996).
(n=17) stated that diabetes was hereditary. Between five and ten per cent of the public sample also cited conditions such as Sickle cell anaemia (n=14), allergies (n=11), Downs Syndrome (n=11), Multiple Sclerosis (n=8), Tourette's Syndrome (n=8) and Parkinson's (n=8). These responses represent the social proliferation of these diseases as opposed to those with the medically strongest genetic and hereditary links.

16 per cent (n=24) of respondents described personal characteristics such as eye, hair, and skin colour as inherited. Some respondents also hereditarily linked syndromes such as Autism, Asperger's and Dyslexia. Issues such as alcoholism and obesity, were mentioned as hereditary conditions. This highlights not only the medicalisation of such problems but also suggests the resonance of media reporting, 'genes for' alcoholism, homosexuality and obesity have drawn interest in past media coverage (Conrad and Weinberg 1996, Friedman 2004). Finally there were a number of further conditions, referred to only once or twice. These included Epilepsy, Lupus, Phenylketonuria/PKU, Polycystic Kidney Disease/PKD, amyloidosis, Crohn's Disease, Tay-Sachs, Hurlers Syndrome, Muscular Dystrophy and Motor Neurone Disease.

In the majority of cases the illnesses, conditions or diseases have been linked to genetic factors by scientific research or the media, however there were also cases where the combination of genetic and environmental factors is complex. Two respondents for example stated that AIDS was hereditary and as the HIV virus can be passed on to an unborn child we may recognise the motivation for this response. Similarly apoplexy, a stroke or seizure due to thrombosis or the rupturing of a brain artery, was mentioned as a hereditary condition. Again such ideas indicate that public understanding of 'factual' science may not always be simplistically defined. The tenuous links made between the impact of multiple genes, single-genes and the impact of the environment and behaviour,
means public ideas regarding the role of genes and hereditary factors are likely to be uncertain (Parrott et al. 2004).

A further open question asked respondents to give a word that would best describe their 'general' feelings towards recent developments in genetics. 14 respondents did not complete the question. The remainder were given three examples of words these being 'optimistic', 'confused' and 'cautious'. Whilst most respondents picked one of these three words, the question received in total 22 different responses. A number of respondents used unsupportive terms to describe their feelings, choosing words such as 'frightened', 'horrified', 'disgusted', 'fearful', 'anxious' and 'worried'. The most commonly selected word was 'cautious', 68 respondents selected this word to describe their feelings. A large number of respondents also applied more indifferent terms, 19 choose the word 'confused', but phrases like 'cautiously optimistic' and 'guarded excitement', and words like 'detached', 'bewildered' and 'overwhelmed' were also popular. 26 respondents used supportive terms, like 'excited', 'hopeful' and 'optimistic' to express their feelings toward recent developments in genetics.

As figure 12 demonstrates, when asked about more general thoughts on medicine, science and genetics the results were largely supportive. 79 per cent (n=122) of the public sample

![Bar chart](https://example.com/chart.png)

**Figure 12. Question 28 In general do you think medicine, science, genetics is...**

*Source: Public Questionnaires Note: 4 people did not complete question.*
thought medicine was useful, or more useful than harmful. Interestingly 23 per cent (n=20) of female respondents said medicine was useful and harmful compared to 8 per cent (n=5) of male respondents. 76 per cent (n=115) of respondents generally felt science was useful, or more useful than harmful. There was slightly less support for genetics generally, but 53 per cent (n=81) still felt it was useful or more useful than harmful. As this question did not distinguish between types of genetic innovation, support for pre-natal testing for example is likely to differ to GM in agriculture, six per cent (n=9) thought genetics was more harmful than useful, or harmful in general.

5.4 Public Responses to Genetic Issues

A section of the public questionnaire asked respondents to complete a Likert scale to measure their attitudes towards a number of genetic statements. In many of the questions there were no ‘correct’ answers, though in some cases there has been ethical concurrence, the construction of legislative frameworks or scientific agreement regarding the ‘factual basis’ of the statement. However it was stressed to all respondents that answers were not being measured for validity, instead the questionnaire simply required respondents to indicate their agreement or disagreement with a statement.

Initially the respondents were asked some brief scientific and medical questions. 89 per cent (n=136) agreed or strongly agreed with the statement ‘the onset of certain diseases is a combination of the genes, environment and lifestyle’. In the case of this question only 9 per cent (n=13) of the respondents were not sure, however when the questionnaire moved on to ask if ‘an individual has about 30,000 genes’ 69 per cent (n=106) were not sure. 13 per cent (n=20) of the public agreed or strongly agreed that recent estimates have been in this region.
The questionnaire included a number of statements regarding the implications of genetics. 48 per cent (n=73) of the public sample agreed that 'genetic tests may increase peoples quality of life', and only six per cent (n=10) disagreed. Similarly 43 per cent (n=65) agreed or strongly agreed that 'with genetic and DNA testing individuals have more control over their lives'. However, while recognising these possibly positive influences there was an awareness that others may benefit through genetic interventions. 76 per cent (n=117) of the public sample agreed or strongly agreed that 'genetic tests/databases increase the power of experts' and 66 per cent (n=101) stated that they were 'concerned that genetic data will become public property'.

The respondents were unclear about scientists’ capabilities, either at present or in the future. 38 per cent (n=58) agreed or strongly agreed that 'in the future gene treatments will treat an individual's illness', but 50 per cent (n=77) of the members of the public were not sure. 34 per cent (n=51) were also not sure about the statement 'scientists are not able to alter an individual’s DNA', 26 per cent (n=40) thought that they could alter human DNA, and 37 per cent (n=57) thought they could not.6

Public views were more acute when considering familiar information or issues that have received higher levels of publicity. Asked if 'all diseases are hereditary' only 20 per cent (n=30) of the public sample were not sure and only one respondent left out the question. Similarly, asked if 'human cloning might be acceptable in certain cases' only 20 per cent (n=30) of the public sample were not sure of their response as figure 13 illustrates. However areas of high press coverage or public interest did not necessarily settle debate or draw agreement as the case of genetically modified foods illustrates. Regarding the statement 'genetically modified foods are not acceptable' 30 per cent (n=46) remained not sure. 22 per cent (n=34) felt GM foods are acceptable, while 43 per cent (n=66) agreed or

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6 A number of the statements appear as double negatives, this is due to the original questionnaire design where a positively phrased question was followed by a negatively phrased question regardless of its content, see appendix three, figure 26, page 255.
strongly agreed that GM food products are not acceptable. There were therefore
moderately higher levels of support for GM foods than found in other studies, but as has
also been shown in other surveys of this type, public indecision regarding this issue
remains high (MORI 2003). While the data cannot assess whether the high levels of
divergent coverage has impacted on this confusion, it may be a factor contributing to the
public respondents doubt (MORI 2003).

Returning to genetic medical interventions, 56 per cent (n=91) of respondents said they
disagreed or strongly disagreed with parents being told the sex of their unborn baby,
though 54 per cent (n=83) agreed or strongly agreed that it is appropriate for women to be
offered pre-natal genetic testing. 15 per cent (n=22) of the public sample disagreed or
strongly disagreed with the use of pre-natal testing. Many members of the public supported
the use of genetic testing even if there was no treatment for an illness. While 26 per cent
(n= 40) were not sure if ‘genetic tests should be performed on an individual when there is
no treatment for the illness’, only 29 per cent (n=44) disagreed or strongly disagreed with
using genetic testing when there was no treatment available.

The variability of views depending on the context of the question phrasing was notable.
Respondents were asked two similar questions regarding compulsory genetic testing. 74
per cent (n=113) of the public sample agreed or strongly agreed that 'genetic testing should be voluntary in healthcare'. During a prior question, where respondents were asked if 'in the future genetic tests should become compulsory', 51 per cent (n=78) disagreed or strongly disagreed. Thus support for voluntary testing was strengthened when healthcare was placed into the equation. Likewise when asked about abortion issues, 7 per cent (n=11) strongly agreed or agreed that 'abortion is never acceptable' but 5 per cent (n=7) disagreed or strongly disagreed with the statement that 'abortion is appropriate if the health of the parent/child is at risk'.

As already briefly mentioned, the public respondents appeared aware of the use of genetic knowledge to empower not only the individual but also those of other interest groups. 82 per cent (n=126) of the public sample agreed or strongly agreed with the statement 'geneticists should be regulated by government legislation for their professional conduct', and 80 per cent (n=123) disagreed or strongly disagreed that 'genetic researchers are the best judges of what is ethically appropriate'. However this caution did not diminish the public’s support for scientific research and 39 per cent (n=59) of the sample felt 'genetic research should be given priority in government funding'. Conversely in a similar question, when asked if genetic researchers are intruding on areas of life 'which should be left untouched'.

![Figure 14. Question 19g 'genetic researchers are intruding on areas of life, which should be left untouched'. Source: Public Questionnaires Note: 6 people did not complete question.](image)
untouched’, 41 per cent (n=62) agreed or strongly agreed with the statement as figure 14
highlights. 22 of the respondents who agreed or strongly agreed that scientists are intruding
in areas of life that should be left untouched, none the less agreed that genetic research be
given priority in government funding. Interestingly 65 per cent (n=26) of those aged over
sixty-one agreed or strongly agreed with this statement, compared to 11 per cent (n=1) of
those aged between eighteen and twenty-five. 48 per cent (n=49) of Christian respondents
also agreed or strongly agreed with this statement compared to 27 per cent (n=11) of non-
religious respondents.

Finally when asked would you undergo genetic testing if it were offered to you, the
responses were evenly divided. 34 per cent (n=52) of the public sample did not know, 31
per cent (n=48) said no and 33 per cent (n=51) said yes, they would undergo genetic
testing. Two respondents did not complete this question. While the question did not specify
the type of genetic test and this would impact on an individual’s decision, it still illustrates
considerable public support given that it came at the end of a questionnaire discussing
ethical and social ramifications. 61 per cent (n=94) of the public sample also stated at this
point that yes; they felt they understood some of the issues, whilst 24 per cent (n=37)
stated no they were not confident in their own understanding. 34 per cent (n=9) of the
sample with no qualifications said they understood some of the issues, compared to 87 per
cent (n=20) of those with first degrees.

5.5 Public Qualitative Questionnaire Data and Interviews

The public questionnaires offered a number of opportunities to answer open questions or
add further detail. A number of the respondents took the opportunity to add further detail to
the often-complex issues, and this was further supplemented by nine in-depth interviews
with members of the public. Those who took part in the interviews were self-selecting, the
five women and four men, had all completed a questionnaire and agreed to be contacted for
a further semi-structured interview. Interviews were carried out during February and April 2003. On initial analysis of the questionnaire and interview data it became clear that in an area such as science, medicine and genetics individuals often hold ambiguous and complex viewpoints. Thus the qualitative interview data has been considered holistically, how an individual interviewee responded and thematically, the links across the qualitative aspects of questionnaires and interviews. An illustration of these links in demonstrated in table 14 in appendix four. However I will now discuss the issues raised by the public interviews and questionnaire comments.

5.6 Public Qualitative Data, Scientific and Genetic Support

Throughout the questionnaires and interviews it became apparent that respondents often expressed supportive viewpoints when thinking about the term ‘science’ generally. Six of the interviewees when asked how they would describe their general attitude towards science began with notions of progress, separating the institution of ‘science’ from its potential developments, consequences and individual experts. The following extract is typical of the types of viewpoints interviewees and questionnaire respondents expressed when thinking about science at its most general.

'It's marvellous actually science...when you think of man going to the moon... I'm amazed at all the technology in science not that I know anything about it but just the way it helps the world generally (John P003 41-60 NHS Support Worker).

Science was identified as positive, ‘helping the world’, determining our standards of living for the ‘good of mankind’. Words were used such as ‘excited’ and ‘amazed’. In most cases these supportive viewpoints were a reflection of the interviewees association of science to technology, as John expresses above. One interviewee also considered science to be the ‘best method we have’ and defended its use from the standpoint that scientific methods were a valuable way to gain knowledge.

Science as a means of finding out about nature, our environment and the way things work, and what things are, and how they have evolved it’s probably the best.

7 Interviewee’s names have been changed to protect their identities. The questionnaire data is coded only through the data labels I; Interviewee, or Q; Questionnaire, P; Public, 001; number.
method that you have. Because it works on the scientific principle of observation, experimentation, and repeatability (Andrew IP004 41-60 Engineer).

Andrew was a qualified engineer and his links to this field were clear in a number of his responses. Methodologically he was very supportive of the principles of science and generally optimistic about advances such as pre-natal screening and stem-cell research, recognising the individual scientist's incentive for knowledge and progress. Scientists were poor communicators according to Andrew; the 'dumbing down' of scientific information under-estimated the public, though some guidance is needed in areas with ethical ramifications. It was the external factors which were of most concern to this interviewee, government and commercial factors, unintended consequences, inadequate regulation and control. Other interviewees, even with regards to scientific advances that have negative associations, shared this viewpoint supportively viewing the progress of science during initial questioning.

I believe...in trying to push science as much as possible... science is the answer more or less to everything. We can only learn by science and the more we put into it the more we get out of it. Mostly I feel for the good of mankind but obviously not always, with nuclear bombs and things but that's progress anyway (Susan IP002 41-60 Clerical).

In some questionnaire responses this need for scientific progress was starkly portrayed. In the further comments section of the questionnaire one respondent provided a list.

1. Genetic funding is not supported by most governments.
2. Genetic treatment could cure most disease.
3. Thus NHS would not be overloaded with sick people (QP115 Female 41-60 School Assistant).

Other questionnaire respondents included statements summarising their views, though these were not typical, 'genetic engineering should be used only to eradicate mental and physical abnormalities' (QP075 Male 41-60 Engineer). Respondent QP075 did not go on to describe what they thought 'mental and physical abnormalities' were. Whilst a few respondents came to such specific conclusions without detailed argument over the intricacies of the area, the majority of respondents and all of the interviewees actively played out their arguments, describing some of the complex ethical dilemmas and the
contradictions in their arguments as ‘knowledge is itself construed in the process of discursive exploration’ (Edwards 1999:87). The overall emphasis was that the technologies and methods of science are neutral. It was the handling of these developments where concerns began to be drawn and this was first apparent in a number of further questionnaire responses. Support for genetic advances often involved a disclaimer, an acknowledgement that there were possible problems but that these would be reduced by the overall benefits. Comments included, ‘I support the study and use of genetics both in food promotion and medicine so long as it is carefully and responsibly used’ (QP018 Male 61+ Environmental Health Officer). Similarly this questionnaire respondent stressed the need for ethical frameworks.

Genetic research should pursue in the hope to help save lives, help people have a better standard of life when faced with a disease. Ethics and caution should remain at the forefront to help prevent any wrong turn to our society (QP077 Female 26-40, Librarian).

Both questionnaire and interview respondents were generally supportive of the aims of scientific, medical and genetic research. They viewed the institution of ‘science’ optimistically, appreciated its technological implications, and supported its progressive goals. Recognising that there were possible negative repercussions, concerns were raised regarding the social motivations, regulation and utilisation of such technologies, which largely neutralised the science and demonstrated a greater concern with social settings.

5.7 Public Qualitative Data and Scientific Governance

The roles of scientists, doctors and ‘vested interests’ was an issue raised by a number of the questionnaire respondents and was discussed further with all nine interviewees. Three interviewees in particular discussed the role of funding in scientific research. The most common issues were that scientific research in the UK is under-funded, and over-reliant on topical themes.

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8 Questions seven and eight on the interview aid memoir gave interviewees the opportunity to discuss these issues without directly asking for views on governmental or commercial interests. See figure 21 in appendix two, page 245.
They [scientists] probably don't play as great a role as I would like. It depends on how marketable their research is. I honestly think if some poor person doing some really interesting research into the genome of some plant or the other, they are not going to get the funding that some person who is doing work on the cystic fibrosis gene. It's where the money is isn't it? (Lisa IP008 41-60 Writer).

Liz was an academic based in the human sciences, she thus had a greater knowledge of funding processes but echoed the more general concerns expressed by other interviewees.

I think a lot of the funding bodies...I'm not convinced they're as objective in their decision making...you get the person that, the few people who maybe started something and they like requote, quote and requote themselves and its like this mesh. I hate to use the word incestuous but it is almost like that. So anybody new trying to get in can find it very, very difficult (Liz IP005 41-60 Academic).

Liz's attitudes to science were not as positive as she 'would have liked'. Like Andrew, she identified with the scientists quest for knowledge but for her, this was conflicting, her main concerns surrounded ambitious science ignoring potential impacts and constantly extending what is morally appropriate. She also found scientific depictions 'patronizing', believing the public were more equipped to deal with genetic information than is recognised. Returning to her discussion of funding, for Liz, genetics has become a 'hot topic'. Liz feared other research was neglected because of this, a point also made in the first extract by Lisa. More generally the demands of finding funding were identified as a negative mechanism in science, a further interviewee David suggested it was partly to blame for scientists publicising their work prior to concrete findings.

They [scientists] don't get the funding, it's a rat race isn't it you know? If they don't get in there and get the funding from whatever area by announcing that they have got somewhere then they can't continue the research (David IP007 41-60 Teacher).

A consistent theme throughout the interviews and questionnaires involved the body funding the research. The role of industry and particularly pharmaceutical companies in scientific and medical research, was a controversial issue as these extracts illustrate.

They are major players [the pharmaceutical industry]...they are irresponsible, I could just shoot some of them I really could. On the genetics side I am not so sure but I suspect the pharmaceuticals are in there as well (Lisa IP008 41-60 Writer).

I support really the relatively small science teams doing their own thing...if you get into the situation where you have got maybe a huge drugs company and they are pushing for something it's a slightly different sort of research (David IP007 41-60 Teacher).
This reinforced that it was factors external to 'science' that would determine negative impacts of genetic advancement. The high levels of trust in scientists and doctors demonstrated in the questionnaire results continued with the interviewee's discrimination between scientist's motivations and institutional settings.

People who do pure research, I have a very high regard for them...scientists who are doing research on behalf of government organisations or on behalf of a commercial organisation then, not really so much respect... I really do feel they are biased too produce the results that they are expected too (Marion IP001 61+ Clerical).

Marion provided the clearest illustration of the contradictory nature of some public attitudes. Genetics was an area where she had clear interest. Marion described reading newspapers, looking things up on the internet, watching science fiction programmes and her enthusiasm for projects such as the RI Christmas Lectures. She criticised those pressure groups that attempted to sideline science, admonishing the public's low interest in science. Marion described herself as 'amazed' by the Human Genome Project but horrified by GM in agriculture. She had ethical concerns over sex selection but was excited by the potential impact of stem cell techniques. Marion was the most obvious example of the complexity of public views on these issues. However returning to more general public viewpoints, these were balanced between a view of the individual doctor or scientist and the external pressures they faced, both for professional recognition and personal gain.

Inevitably your going to have those few people in scientific spheres who are not wholly driven by the scientific endeavour...they either want to make their mark and they may choose to actually colour things in a way that they think is going to get them recognition or influence other people and there are those who are driven by commercial aspects as well...that can be very dangerous (Andrew IP004 41-60 Engineer).

A scientist's quest for knowledge was appreciated, though this was accompanied by fears over their individual determination and ambition. Whilst scientists and doctors were privileged for their significant professional commitment, they were also perceived as 'only human' and as capable of making mistakes, as stressed in a number of the questionnaire responses. One respondent stated 'I am fearful of scientists whose curiosity gets the better of them' (QP065 Female 61+ Teacher). A further respondent added that while he
appreciated the advances of medical science and the improvements to quality of life this had brought, it was balanced with 'a healthy scepticism with regard to the all-knowing' scientist who remains human and thus all too fallible' (QP089 Male 41-60 Teacher).

There was also doubt expressed by some public respondents and highlighted in the following extracts, regarding the honesty of certain scientists, discussing scientific advances with hindsight, and motivated to keep the public un-educated.

Things are thrown up that quite possibly they [scientists] have been working on for years and no one knows anything about them (Carol IP006 61+ Sales Assistant).

They [scientists] never seem to want to [make science clearer to understand]... A lot of it does seem to be hush, hush and then suddenly you get it... it's like any work that you do you don't want people looking over your shoulder all the time...asking questions (John IP003 41-60 NHS Support Worker).

It was clear that the public respondents felt external regulation was needed. This was two fold, firstly the nature of individual doctors and scientists meant observation was necessary but secondly for some, the regard with which they held doctors and scientists meant giving them ultimate responsibility for the outcomes of their work was seen as unfair as the following interview extracts stress.

Years ago people used to say 'oh the doctor knows best' but then... 'These are my rights, why isn't this happening' they [the public] don't understand that things take time (Susan IP002 41-60 Clerical).

If I go to my GP, whom I trust and people in the medical and scientific profession... I've got respect for people that do that in life... it's not just about politicians making decisions, its got to be with the people on the floor so to speak that do the scientific work and the medical work (John IP003 41-60 NHS Support Worker).

Furthermore the public respondents were able to give some clear indications as to where these issues around trust, commercial interests and individual motivations had emerged.

Whilst it is anticipated that the GM in agriculture debate has been damaging to science and the government in the UK and has had a high degree of public resonance, this was demonstrated by some responses (POST 2000, Arntzen et al. 2003, Cook et al. 2004). In particular the following interviewees had felt manipulated.
It was 'moral blackmail' saying that it [genetically modified crops] would benefit third world countries and they would have a really good crop every year. Accept of course that crop would be sterile, the seeds would not germinate and the people would have to go back to the same, I think it was Monsanto... I think that's a very, very cynical use of genetic modification (Marion IP001 61+ Clerical).

However again reiterating the contradictions in public attitudes both generally and amongst individual interviewees, these images had resonated with others and their opinions of science and medicine.

If you were an African or an Indian and not living all that well and you had the possibility of increasing your crop yields through GM, I don't think you would hesitate to long when you have got a starving family (David IP007 41-60 Teacher).

Whilst the publics' viewpoint towards the institutional setting of science and the motivations of its professionals varied, there were a number of consistent issues. Respondents highlighted funding as a key criticism, identifying it as biased toward certain individuals, subjects, and commercial interests, increasing pressure to publish findings prematurely. Individual doctors and scientists were generally held in high regard with empathy for the pressures they face. However this was a balancing act between a positive view of individuality, the quest for knowledge and the vocational qualities of such careers, and a negative view of individuality, the quest for money, status and ambition. Individual doctors' and scientists' humanity is identified as a safety mechanism, to keep them on the appropriate ethical route, and a hazard warning of the fallibility of human nature. Certain members of the public were sceptical as to the transparency of most science, with issues such as GM in agriculture clarifying these concerns and leaving a particular distaste for the pharmaceutical industry and commercial motivations generally.

5.8 Public Qualitative Data and Media Depictions

Some of the strongest reactions in both the questionnaires and interviews came when the words 'the media' were raised. General responses included, 'the media? I would use a rude word except! A load of ...' (Marion IP001 61+ Clerical), 'Oh god, rubbish, sorry about that, I'm not, not very enamoured with the media at all' (Carol IP006 61+ Sales Assistant).
A number of members of the public sample seemed aware of common criticisms, that the media sensationalised the area and that scientific and activist arguments lacked balance and exaggerated claims.

I support the study and use of genetics both in food promotion and medicine so long as it is carefully and responsibly used. Unfortunately both sides use exaggerated arguments to try and influence public opinion (QP018 Male 61+ Environmental Health Officer).

Lisa went into further detail during her interview. Again her initial education was scientific though she now worked in a different career. Whilst supporting science generally and again appreciating the motivations for research she had grown critical and unhappy. Like others her concerns surrounded the partial and mechanistic views of science, be it with regard to the human or natural environment. She described an instinctive reaction by the public, which would allow them to understand genetic developments, suggesting many of the concerns are related to ethical and religious frameworks. However her particular concern was with controversy surrounding mobile phone safety that had led her to a complete lack of trust of the government, commercial interests and portrayals of scientific expertise. Returning to her opinions of the media, Lisa was sceptical of the media handling of scientific information.

That's been very interesting, the way that [mobile phones] has been dealt with in the media...you will find an article on about page 20 or something of The Times... they don't want that information to be out there. Somebody decides where it goes in the paper...the same with genetically modified food and they do come out with, make these bold statements. 'There is no problem with this'...and its absolute rubbish because it's obvious it hasn't been studied. I really don't know how they can even put it in the press... I found it really frustrating, the audacity some people must have when they must know the truth...They put it across as science and it just irrelevant and yet that is shoved at the public as fact (Lisa IP008 41-60 Writer).

Respondents made clear distinctions between different types of media stating that the quality of information was dependant on who produced it, who had written it, what channel it was on or if it was on the radio. Further distinctions were made between journalists, newspapers and the tabloid and broadsheet press.

The journalists involved in the scientific press I am sure are doing a perfectly good job but there's a difference between someone like that handling a story and the sort of tabloid stuff really. It's the sort of scare mongering headline isn't it, 'GM's going
to finish the world' and whatever it is and everyone, because its easier to believe that than sort of, I don't know if people believe it we've got a slightly cynical world really and that's not good news for science (David IP007 41-60 Teacher).

Whilst it was evident some members of the public recognised the sensationalised tactics of the media this had two further influences. One interviewee had found the ‘media event’ of the birth of Dolly the Sheep confusing but recognised that in this sense the media or scientists may use it to their advantage.

Dolly the sheep... I never could see the point of it... I'm thinking right there must be a purpose it can't be as simple as that. But the way that it is presented in the media it's almost like a game. So therefore I guess the media does have some role in how we, the public, perceive a scientific event (Liz IP005 41-60 Academic).

In contrast for Marion this connection to science fiction had clearly influenced her enthusiasm for science.

I think it's [Human Genome Project] a hugely exciting thing actually. When I found that they had discovered the whole genome about six months before that I had watched the episode of the X-Files where they discover this alien thing washed up on the beach in Africa with weird writing on it from an alien species... They had discovered the whole genome and a few months later they had actually done it (Marion IP001 61+ Clerical).

However in both the questionnaires and interviews the public respondents were aware that scientific coverage is frequently criticised. Some interviewees blamed the scientists themselves for poor coverage, reiterating that they publicise findings too soon, do not communicate effectively or promote an image that can be taken seriously.

I don't think they are great friends of science [the media] but then I don't think that science has managed the media very well... because they are all bidding for funding so they start shouting about things before they have really finished their work... then they excite the media who generally get it wrong... [scientists] could do a whole lot more in terms of managing their own press and make it simple so that people can understand it... we still have a, you know comic strip vivid sort of image...of a sort of slightly batty bloke in the back of a laboratory somewhere beavering away (David IP007 41-60 Teacher).

It's very difficult for somebody who's immersed in something at such, at such the level of detail and technicality. It's very difficult for the average scientist to begin to start telling anybody else, anything about it that's meaningful to them (Andrew IP004 41-60 Engineer).
In some ways some members of the public recognised that scientists are in a vulnerable position with journalists and the public, which was interesting. Interviewees made numerous suggestions as to how the communication of scientific ideas could be improved.

[Communication] has to be done in a way that's not patronizing but equally not to much jargon and high fallibility, and also in a sense, in a way, that makes it relevant to people so that it would be interesting (Liz IP005 41-60 Academic).

If you could get someone to produce a really good programme with the right kind of images and I hate to say it, but the right kind of people presenting it...whether that's enough to bridge the gap into the world of genetics...the basic questions are so basic that anybody can understand how you should value the natural world and how you should value human life (Lisa IP008 41-60 Writer).

There was an emphasis that the public were capable of dealing with genetic information if it was contextualised and that there were costs if information was merely simplified or promoted.

Over the last ten years in particular, any kind of technological or scientific programme is dumbed down...at the lowest level and you go through perhaps an hour of a programme and you could write down on a piece of paper five lines which summed up the whole lot in terms of any new information that you have just got...The trouble is you see, that they're [science programmes] put on television for the majority of people and the majority of people like lots of whiz...If they stopped treating people like idiots and started to say we are going to give you some information here...to give you the facts in a digestible way, at a level at which you can understand them, people would start to listen to the programmes (Andrew IP004 41-60 Engineer).

Rather than demanding a greater basic scientific educational information the public respondents suggested that at present they often felt 'patronized' by the information available to them. Thus these members of the public seemed more critically engaged with the media images than they are often credited for, whilst other issues brought a range of often contradictory comments, there was broad agreement amongst respondents that the media and journalists are problematic. The main criticisms involved journalists sensationalising findings and offering unbalanced arguments, the fictionalised quality of some reporting both inspired excitement and confusion. Though the public respondents criticised scientist's management of their own publicity and image, they recognised the difficulty in simplifying their work, whilst at the same time they clearly felt it was
‘dumbed down’ too much. The public respondents indicated an interest in further information and a curiosity regarding science, medicine and genetics when contextualised.

5.9 Public Qualitative Data and Common Sense/Holistic Approaches

The public sample often under-estimated their own understandings but also demonstrated a confidence to discuss certain areas in detail without any specific technical understanding, as the following extract demonstrates.

I watch people’s children. I have taught so long in this one school I am now teaching children of ones I taught before...I can see the same genes coming up again and again. I’m a Darwinian... genetics just comes through again, and again (David IP007 41-60 Teacher).

Like the rest of those interviewed, David was supportive of science generally; though he went on to clearly promote this in his viewpoints. As the statement above suggests he strongly agreed with genetics and was encouraged by its potential, which he hoped, would not become restricted by the public controversy surrounding some issues. Though he recognised some areas were ethical ‘minefields’ he was convinced the positives would outweigh the negatives. He compared current scepticism to past scientific developments, stating ‘it’s very easy to be a Luddite, no I am pro science.’ David put forward the strongest argument for scientific neutrality, his criticisms were of ‘other’ pressures on scientists, stating that ethical stances should frame science not drive it. However he was not the only interviewee who took to using science to explain some of their concerns or understandings.

Five of the nine interviewees confidently discussed genetic modification in agriculture, and in particular field trials. Whilst the information they gave was often scientifically questionable, it remained interesting, demonstrating the high level of press coverage but also with their conviction in sharing their knowledge, that it was an area they were assertive in tackling. The following extracts are examples of these types of explanations.

We used to be beekeepers years ago...a bee’s flight is perhaps two miles from its hive. Therefore planting crops is all right within two miles of each other? Its absolute rubbish... bees can fly more than two miles, secondly a bee one side can
fly one mile and bee from the other side flying a mile and they meet in the middle, thirdly bees rob other bees' hives an so they can spread the pollen for miles and miles and miles, fourthly what about the wind? (Marion IP001 61+ Clerical).

I am very, very concerned about the arbitrary introduction of genetically modified plants into the environment. I think it's a big mistake and it's highly dangerous, especially those that have got genes from micro-organisms placed into them, perhaps markers or labels or whatever else. Where you are introducing traits of resistance, there's various things that could be passed on. The field trials that have been going on in the UK and elsewhere are very worrying...I think that they are being totally inadequately controlled...the pollen from them...its carried on the wind for great distances so you have got to be in a position where all of your so-called organic crops are contaminated, when there isn't any way back (Andrew IP004 41-60 Engineer).

I don't know what scientists think about but it did cross my mind that, don't think you can stop birds and bees and animals by putting a fence round a field...sometimes I think its common sense completely lacking (Carol IP006 61+ Sales Assistant).

In many of these excerpts interviewees dismissed the scientists due to their perceived lack of 'common sense'. This dissatisfaction had spread to other issues, there appeared to be general agreement that scientists are becoming over-confident in their knowledge. Four of the interviewees perceived that to work against 'nature' would come at a price.

Scientists are changing so much... we have strayed so far from anything that's natural, and again, its where science and medicine maybe in some cases has got a bit to clever for its own good. That doesn't mean to say that I totally reject it, because I think it does do amazing things that help a lot of people (Liz IP005 41-60 Academic).

To go throwing this great big boulder into the pond is bound to cause big waves...The scientists, who are acting irresponsibly, they are treating themselves as god and they seem to be under the impression that when they introduce the organism into the environment, the environment isn't going to respond and evolve...they don't know what could happen out there and once it's done its done (Lisa IP008 41-60 Writer).

Whilst there were few 'slippery slope' type comments in the interviews as they dealt with more complex and sustained discussion, in the questionnaire data there were a number of such comments about 'playing god' or 'interfering with nature' (Katz Rothman 1998). Statements included, 'genetics is a relatively new 'thing'...I feel a lot more work should be done before it is generally applied to the populace' (QP058 Female 61+ Clerical) and, 'too many people are dabbling into the unknown and more time should be spent on investigating causes of and cures of serious illness' (QP007 Male 41-60 Surveyor).
In particular the death of Dolly the sheep during the interview period had resulted in a confirmation of scientist’s perceived lack of ‘common sense’ and a clear lack of belief that scientists are taking into account all of the relevant issues.

It’s all very clever doing this [animal cloning], but in the end I don’t honestly believe they can buck nature. Nature will hit back in the finish...well this with Dolly the sheep, I mean she didn't live a normal life did she after all? She didn't live as long as normal sheep (Carol IP006 61+ Sales Assistant).

The death of Dolly appeared to induce a sense of sympathy amongst some respondents, ‘I’m aware that they are doing cloning, you know Dolly the Sheep has finally popped her little hoofs and that sort of thing’ (Lisa IP008 41-60 Writer) said one interviewee, similarly another stated ‘I've been broadly interested in genetics. I've not taken it any further but um obviously Dolly, poor Dolly who was put down’ (Susan IP002 41-60 Clerical). It did not necessarily mean that they were against cloning, in fact the same respondent who described ‘poor Dolly’ being put down, also stated,

Dolly of course because that was really terrific...that was important... because the papers were there with Dolly and we [work colleagues] all said oh how sad it was but how we thought it was a breakthrough (Susan IP002 41-60 Clerical).

The dissatisfaction of these members of the public, aside from their emotional ‘attachment’ to the sheep involved, recognised these potential problems which were perhaps not highlighted enough by the scientists.

There's been a lot of coverage about Dolly the sheep again because she has died which I think they have rather expected. I mean it certainly seems from what has been published that the methodology used in the cloning process is very hit or miss and you get a great number of failures before you get anything which can be deemed success at all and even then, I mean if all of these are dying of almost immediately or their living for a very short period of time then that even reduces the success rate even further doesn't it?...It’s clear from that particular example and other examples that there is a lot we don't understand about the process. Because there seems to be quite a lot built into the normal reproductive process where you are using cells from two parents, that insures against the kind of things going wrong, that you can't avoid when its monoclonal (Andrew IP004 41-60 Engineer).

Dolly’s death made these members of the public critical; it seemed a common sense issue to some that she would die ‘young’ which the media coverage had not stressed enough.

Reducing the information to positivistic ‘breakthroughs’ surrounding her birth had avoided obvious implications.
A theme also returned, which had emerged during the media content analysis concerning the importance of biological and genetic relationships. The concept of hereditary relationships was something that the interviewees clearly resonated with, and in particular appeared to value their DNA in an objectified sense.

I'm interested in family history...one side of the family had a bit of a heart problem...so I just wondered if it was [genetic]...if people wanted to take my blood to investigate, I wouldn't mind that (Susan IP002 41-60 Clerical).

I was very interested in programmes on the Vikings and as I come from the Wirral it did occur to me that...I would very much like someone to look at my DNA and tell me whether I came from Viking stock; it would just be very, very interesting (Marion IP001 61+ Clerical).

In the case of this interviewee thinking about her 'Viking blood' led her to spontaneously think about some other issues, that testing may draw attention to diseases and how you would deal with the potential impact of this information.

Do you tell people that they might have a tendency for a certain disease...a tendency towards something is not the same as saying you are defiantly going to get this? That could be very cruel to people could wreck their lives...[if] they could be advised as to what to do and what not to do to avoid it then I feel that would be very helpful but then again where do you draw the line? And then you come to the practical thing of people with certain DNA are not going to ever be able to get any insurance (Marion IP001 61+ Clerical).

These types of unprompted discussions were typical of a number of the interviews. The public respondents were also well equipped to talk about parental choices. All but one of those interviewed had children themselves and 75 per cent of those that completed the questionnaire had children. There was thus an emphasis that decisions resulting from genetic interventions should ultimately be placed with parents whilst recognising the significant dilemma this would be. Seven interviewees discussed in detail the appropriateness of parental decision-making, the following examples display the key concerns raised.

People who have a genetic history of disease...can you tell that couple that they can't have children because there's a 1 in 3 1 in 5 or an 80% chance that the child will have the same problem...There is still a life there...at whatever stage that child dies (Leonard IP009 41-60 Water Resources Planner).

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9 See chapter four page 103 for further details.
10 Interviewee IP001 Marion was however a step-parent.
It [screening] would save a lot of heartache, you know for people that have had children that [they] don't know about these things until their children are quite old...Then they find out that they passed a gene on and it must make parents feel awful. So I'm not adverse to that but its where the lines drawn that I'm adverse to (Carol IP006 61+ Sales Assistant).

It's entirely up to them [parents]... If they discover that their child is going to be developing cystic fibrosis, they have got to decide whether they want it to carry on, are they going to have child who is going to die before 13? Probably before that and have that life and give the child the best they can, or whether they are going to treat it as a throw away item. Doing screening does encourage the throwaway option but as a woman, I know the trauma it must be for people to have to deal with a sick child and know that that she's going to die. It must be awful (Lisa IPO08 41-60 Writer).

Whilst there was a general consensus amongst these interviewees that it should be up to the parents, a further interviewee was conscious, like Carol that lines should be drawn, and discussed the potential problems if they were not.

Whilst I think that's [genetic screening] good in respect of illnesses...you can't have yes we will screen it out cause its satisfies one person and you won't screen it out because stuff doesn't satisfy another...Its very difficult because you have got to be down the line...otherwise you are going to have push and pull all the time. You know it can be very difficult but I mean life's like that and so has history shown (Susan IP002 41-60 Clerical).

Interviewees recognised the complexity of these issues, demonstrating particular confidence in talking about them. Whilst there was no direct reference to eugenic fears in any of the questionnaires or interviews, there was the very occasional mention of 'history'. However on the whole questionnaire respondents and interviewees largely supported individual choice, though recognising that this could have social consequences. How would individual decisions impact on society if they were not ethically and socially appropriate? As such the public sample made tentative links between genetic choices and weak eugenic practices.

Scientists were pressed to consider issues more holistically. Three interviewees were critical of reductionism by both scientists and medical professionals.

The scientists are trying to... say that genetics is going to be the be all and end all, and resolve and solve all the problems of anything that's wrong with human beings and its almost like there's that slight element of, we can create the certain type of people we want, who will be fine, healthy, beautiful... I don't think we can just go
down the genetic road without also looking at so many other factors and that's the cultural, the environmental...we might create a super race but if we make them miserable by overworking them and neglecting their children and abusing them, you are going to actually end up with another load of problems (Liz IP005 41-60 Academic).

A number of the questionnaire respondents and those involved in the interviews, clearly related to genetic issues through their perceptions of nature, familial relationships, ethical and religious practices. At times their own understandings made them draw criticisms of the scientist's public appraisals of consequences. Their concerns centred around two main issues here, firstly that scientists and medical professionals are arrogant in their appreciations of 'nature' and secondly that they are overly reductionist. However in discussing these concerns the public respondents again demonstrated confidence in their understanding of certain issues, how did this continue into their appraisal of public understanding more generally?

5.10 Public Qualitative Data, Regulation And Education

In the qualitative information there was a clearly expressed lack of confidence in respondent's knowledge of genetics. Respondents excused themselves for their perceived lack of understanding, 'Confused' perhaps best describes my largely ill-informed state' (QP089 Male 41-60 Teacher), even when they had demonstrated knowledge as the previous theme illustrated. Whilst all interviewees recognised that their abilities to think about many genetic advances were restricted by a lack of technical scientific knowledge, they indicated that their strengths lie in certain areas.

I don't know enough about it...it's from a layperson's point of view. I know how it would affect me and people with certain diseases...more than that I don't really know enough about it (Susan IP002 41-60 Clerical).

I do tend to read things you know about that [genetics]... its interesting to see how things have developed over the years and which I consider yes there very good, and some things I think, hang on a minute, you know this shouldn't be happening its taking it too far...I mean I left school at fourteen dear so I've never, you know I'm not very well educated (Carol IP006 61+ Sales Assistant).
Carol stressed that her age and education meant she had little understanding of the area; though she had raised a number of relevant issues and discussed them in detail. She described science as ‘fantastic’ and was very positive about attempts to reduce genetic conditions, though like other respondents she criticised the shortsightedness of genetic modification in agriculture. Carol was also concerned by the changes in views towards health and the body, like the increasing medicalisation of childbirth. She described a recent visit to a doctor,

They say, 'have you got any aches and pains?' and I think I’m flipping seventy three years old, I’m entitled to have aches and pains...people are expecting things that twenty, thirty years ago weren’t even on the agenda (Carol IP006 61+ Sales Assistant).

Overall she felt the public were equipped to observe science, as it is their moral rather than educational levels that are challenged. Interestingly Carol was the only interviewee who reflexively recognised her own contradictions, stressing this when inconsistencies with earlier points occurred. Whilst she had no scientific qualifications she was interested, keen and prepared to build on the knowledge her life experience had clearly provided. Similarly though the public respondents often felt they lacked scientific understanding this did not mean they could not learn or were not prepared to, one respondent described their use of journals in the area.

*New Scientist* I find quite good, I read that every week. If you go and read journals, the professional journals...they are highly technical. It’s very difficult for a lay person, which I am, to actually understand them ... If you do read about them enough and you read about them regularly, you gradually learn and you gradually get a picture and you can understand what their talking about and see the significance and the advantages, the possibilities, the dangers (Andrew IP004 41-60 Engineer).

Interviewees did not reject the idea of learning about genetics and took responsibility for their own understanding. Unlike some of the experts and journalists they did not attribute their lack of understanding to scientist’s communication, reporting in the media or their own science education. Instead they looked to themselves for not having enough time or interest. However even in the case of simplistic, closed questions the public sample demonstrated a more detailed understanding or opinion than they often gave themselves.
credit for. When asked in the questionnaire about their agreement with the statement 'an individual has about 30,000 genes' one respondent stated, 'current thinking that this figure is effectively much higher as so-called 'junk' DNA does have a vital role' (QP110 Male 41-60 Teacher).11

Whilst the interviewees recognised that the public had certain abilities which they could use to apply genetic knowledge be it their ability as parents, their understanding of inherited characteristics or their motivation and interest there was a clear distrust, that 'others' would misuse the technology. In some cases interviewees suggested it was 'other' members of the public they distrusted but it was also again, 'other' ruthless scientists that were distinguished from the ethically sound majority. Two interviewees used the example of sex selection to illustrate this concern.

It will be the thin end of the wedge and the more unscrupulous people who will use it for their own advantage. Whether they be scientists or whether they be the general public... If enough people did it then you are in big trouble. People only see a very small picture of themselves and their immediate surroundings (Marion IPO01 61+ Clerical).

There's always that moral problem for anyone, individual choice whether the individuals make the choice or somebody else makes the choice for them but potentially you could end up with 95 per cent of the population choosing to have a boy as a child (Leonard IP009 41-60 Water Resources Planner).

While the public sample was generally sceptical about their own levels of knowledge they were highly critical of other members of the general public and their perceptions of genetic advances. In both the questionnaires and interviews, respondents criticised members of the public who merely rejected science, comparing public fears of genetics to past controversies. Two interviewees were particularly critical of 'vocal groups', pressure groups or protestors.

I think its [genetics] one of the big things of the future actually...if its not going to be sidelined and stopped in its tracks by groups of very vocal minority groups who seize on things, which have been done which are really wrong and use that against it, to stop the whole thing (Marion IPO01 61+ Clerical).

11 The Human Genome Project estimated the human genome to contain 30,000 to 40,000 genes at the time of the questionnaire distribution, recent estimates have decreased to 20,000 to 25,000 (The Sanger Institute 2001, The Sanger Institute 2004).
I'm not one to stand up and go ripping up fields...going around not letting people get on and try these things...if we don't give people chance to try things then we're just stuck then, we don't move on. Life is about chances (John IP003 41-60 NHS Support Worker).

So whilst cautious views were shown towards aspects of science and genetics no interviewees actually recommended a ceasing of the research and there were some interesting depictions of those concerned by genetic developments. As one interviewee stated 'some people do have strong concerns but they’re probably the people who have strong concerns about everything' (Leonard IP009 41-60 Water Resources Planner). Just as certain interviewees felt the 'other' could not be trusted not to misuse the technology, they also felt that the 'other' public had less information, education or ability than themselves, while often estimating that their own knowledge was poor.

I wouldn't say we are a well-educated nation, in terms of science and I can see the problems of putting that across to the vast majority of the public. It would be virtually impossible to do well (Lisa IP008 41-60 Writer).

At this point it would be easy to assume that respondents felt the role of the public was limited but here an added issue became obvious. The first interviews with members of the public took place in the build up and during the war with Iraq. References to the government during interviews drew sceptical responses in all of the interviews but are illustrated by the following extract.

You would like to think it would be your government [decision making], I'm afraid to say that I don't trust the government one iota with regard to making any decisions in that respect...I wouldn't trust this government as far as I could throw it (Andrew IP004 41-60 Engineer).

Two interviewees went on to suggest that MPs were no more adequately equipped to play a part in making scientific decisions, than other members of the public.

I don't think the government actually are the group of people who are as knowledgeable as they should be... scientists again have to be careful what they do because they are in a position of massive power and people with power often get corrupted...they get so caught up with this kind of ideal and actually the ideal can become very warped (Liz IP005 41-60 Academic).

Politicians making the decisions, especially when the vast majority of them...have got no scientific training the majority of them and no technical training of any kind...nothing...I don't trust them to make the decisions (Andrew IP004 41-60 Engineer).
Again it was the individuals, which were most clearly attacked by the interviewees rather than the institutions. Though Andrew went on to link the governmental problems to commercial interests that were again clearly problematic and identified as influencing the objective scientist.

[The government] have a role, but they’re increasingly dependant on these companies...they use the weapons of employment, the weapons of keeping technology in our country for those kind of things that are international. They cultivate politicians...It’s not been done by independent scientists who are doing things from, experimental purely research basis...it’s motivated by finance, commercial, commercial considerations (Andrew IP004 41-60 Engineer).

As a compromise between the dissatisfaction interviewees expressed with both public and government relationships to science, all interviewees described panels of decision makers favourably. However there was little consensus about the types of people and negotiations these should involve.

It has to be panels of people that are comprised in the majority of scientific people...but there has to be lay people on there, who are intelligent lay people...otherwise they are going to be totally ineffective and they have to be totally independent of government...and they have to have some group means of communication with the public (Andrew IP004 41-60 Engineer).

There should be a balance, a panel of people...the more people you have got making the final decision, the less likely you are to get a very, very bad decision theoretically...you should have the scientists that are doing the work and yes, you should have that balance with people representing the ethical side and sanctity of life, religious possibly or philosophical side...If you have got money and you have got your own lab and you can do what you like and nobody will know (Lisa IP008 41-60 Writer).

Lisa, though agreeing with panels as a forum for regulation, reiterated the lack of confidence as to how effective any step could be. Those interviewed felt that people had a responsibility to find out about science and genetics to their best ability. Their dismissive attitude of what ‘other’ members of the public would be capable of often seemed to represent a worry that the issues were not being taken seriously.

Generally speaking the general public just seems to let things slide... I just wonder where it’s all going to end? You can get a bit frightened really if you think about it (Carol IP006 61+ Sales Assistant).

The most ambiguous views were therefore implied when it came to discussing the public, government and regulation. Whilst interviewees and questionnaire respondents were highly
critical of their own understanding, for which they took full responsibility, they also
recognised that some personal characteristics and issues could lead to a different type of
appreciation. They distrusted the educational capabilities of other members of the public,
and the public’s abilities not to misuse the technology. While cautioning against
'hysterical' or activist groups halting scientific research, they appeared concerned by the
lack of public interest or understanding in genetic developments. Less ambivalence was
shown towards the government, though again there was distrust regarding the abilities of
individual MPs, the government itself was completely distrusted.

5.11 Public Respondent’s Genetic Perspectives

The opinions of the public respondents with regards to science, medicine, genetics and the
media became strongly themed to these directions when considering the issues in their
broader terms. It is important to stress that at times the questionnaire and interviews could
not emphasise the intricacies of some of the issues as was recognised by a number of
respondents.

It’s really, really difficult for us as ordinary human beings just to get a sort of black
and white answer too. A lot of it depends on our own personal experiences...if you
have had any contact with some very severely disabled children and you know that
their quality of life is practically zilch...then you would think yes if you can screen
someone...maybe an abortion is the morally accepted way to go, choice... But I’m
a little bit on the fence...that’s horrible really. Use a nice lay person’s word (Liz
IP005 41-60 Academic).

As such some of the most interesting responses came from those who had some personal
experience, a number of questionnaire respondents wrote detailed explanations of the
implications of genetic conditions. In certain cases genetic developments had been
something they had actively used or were optimistic that they would benefit from in the
future, as the example below shows,

We have had a son with a rare genetic disease so we do feel that genetics are
important for us. We were lucky that because of recognised screening we were able
to have further unaffected siblings, fortunately I did not need any terminations but
though a termination would have been painful it would have been devastating to
lose another precious child after years of watching them suffer. So for health
reasons we agree. Don't know if stopping ageing etc. would be selfish (QPO01 Female 41-60 occupation missing).

Their own genetic situation had led them to feel that genetic advances had a positive influence on their lives. It was worthy of note that the individual concerned had written ‘fortunately I did not need any terminations’ acknowledging that her viewpoints may have been affected had the outcome been different. Nonetheless it was clear that in this case, the family involved believed they would have undergone that unpleasant decision rather than watch ‘another precious child suffer’ and that their own experience led them to question the use of genetic technology in other areas. Other respondents suggested that having a child with a genetic condition made it difficult to imagine situations differently. To welcome techniques which effectively would have meant the abortion of a child they now have, was understandably difficult for two families.

We have a disabled child (aspergers) but we wouldn't want him to go through any tests to discover if he could be different. God is the only person who should chose whether a baby is born disabled/different (QP153 Female 41-60 Carer).

We are all individuals with our own strengths and weaknesses. This creates a diverse world. 'Different' in most ways is ok every child must be a wanted child. My view on abortion, they do not all wait for an invitation before being created. The only safe contraception is 'no' (QP037 Female 41-60 Carer).

A further questionnaire respondent suggested their experiences with experts in the area had clouded their thinking, expressing difficulty answering the questions due to a variety of reasons.

Found some questions difficult to answer objectively because of issues surrounding our children. Both [have] autistic spectrum disorders, but were fine until MMR vaccination which we feel triggered disorder - probably underlying genetic susceptibility but all genetic testing inconclusive and nothing anywhere else in either of our large extended families. Have developed somewhat cynical view of Department of Health, most politicians and 'experts' in field over the years! That said I do try to be objective!! (QP129 Female 41-60 Academic).

Interestingly all four of these questionnaire respondents, where genetics had clearly had a considerable impact, used the words 'we', 'our family', 'myself and my husband' in describing their thoughts highlighting the familial links of these issues.
5.12 Summary

In summary the public reactions to science, medicine, genetics and the media were variable, indicating the depth of the issues involved and reiterating the need to understand the public in broader senses than simply as a single audience or group. In a climate where the public has been attacked for its lack of support or interest in the scientific and medical communities, the public respondents illustrated a continued interest and trust in certain aspects of these professions. 80 per cent (n=123) of the public sample described themselves as ‘quite’ to ‘very’ interested in health and science issues and as the interviewees specifically demonstrated in their comments regarding ‘other’ members of the public it was an area they felt some responsibility to be aware of. While some degree of interest was likely to influence a participant’s choice to complete a questionnaire, they rarely recognised this interest, concurrently admonishing the lack of interest or concern of ‘other’ members of the public, while underestimating their own interest or understanding.

When I speak to other people they hardly know what it is... I don’t think a lot of people go beyond the emotional reaction. ‘Oh wouldn’t it be wonderful if a baby could cure that little brother or sister’... You do feel very frustrated sometimes as an ordinary member of the public when you see certain things you think you know they’re wrong and you can’t do anything about it (Marion IP001 61+ Clerical).

The public respondents trusted the individualised professionals, 78 per cent (n=119) of questionnaire respondents ‘mostly’ trusting doctors and 64 per cent (n=98) ‘mostly’ trusted scientists. They were generally supportive of the scientific principles of progress and just three stated that they did not trust scientists or doctors. A continued trust in scientific and particularly medical professionals has been indicated in prior research (Corrado 2001, MORI/BMA 2001). In the interviews in particular, negative attitudes were associated to funding bodies, political interventions and commercially funded research and development.

The reliance on the television and newspapers for past information regarding genetic issues, 73 per cent (n=112) of the respondents had gained information about genetics from
the television, confirms that this is an important arena for the public to gain knowledge about scientific and medical issues. The public respondents and in particular those who took part in the interviews, stressed their critical attitudes to such information and gave the impression they were far from passive in terms of their media utilization. 21 per cent (n=32) of the public sample described newspaper coverage as reliable. When explored further, sensationalism, lack of balance and accuracy were all expressed concerns by members of the public.

Although I believe the information provided in the media (i.e. newspapers/TV) re-genetics to be broadly correct, both of these media might occasionally mis-represent the truth by their tendency to highlight the sensational and oversimplify matters which are inherently complex (QP089 Male 41-60 Teacher).

Despite recognising the difficulties of communicating science, and also the variations in coverage, it was clear that a number of the public respondents felt insulted by the level of some scientific coverage, not because they did not understand it but because they understood it too easily.

In terms of the coverage itself the disparity between the level of trust regarding politicians and policymakers comments, whom just one percent (n=2) stated they would trust, and genetic scientists, whom 60 per cent (n=91) of public respondents said they would trust, was very apparent. The impact of the media was emphasised by the range of conditions public respondents suggested were hereditary, a number of these conditions were in the respondent’s families, but only nine per cent (n=14) of the sample had stated that they had such conditions in their backgrounds. This coupled with the high reliance on the television and newspapers for information, would suggest some impact of geneticisation on public knowledges. The qualitative interviews suggested a high level of public salience around issues like genetic modification in food and agriculture, and Dolly the Sheep. The public respondents confidentially discussed these issues, though not necessarily with clearer conclusions of appropriateness, highlighting the role such ‘genetic events’ can play in public perceptions and attitudes towards science, governmental intervention and regulation.
In terms of genetic developments there were a broad range of viewpoints both supportive and unsupportive, so that at times the public respondents' thoughts could appear contradictory. However these contradictions more often represented the complex thought processes involved in such sensitive issues as opposed to apathy. Terms such as ambivalence thus infer that the public cannot offer a cut and dried answer to many of the ethical, social and governance issues around science and new genetics rather than suggest a lack of opinion. That said the public respondents expressed greater certainty regarding specific aspects of the questionnaire. It was for example notable that respondents more frequently expressed defined opinions around issues of regulation and governance than the use of genetic applications. For example ten per cent (n=15) of public respondents were 'not sure' if geneticists should be regulated by government legislation, while 26 per cent (n=39) of respondents were 'not sure' if it is appropriate for women to be offered pre-natal genetic testing. There was also uncertainty regarding the capabilities of scientists and the potential of genetic interventions both at present and in the future. Despite this the public was generally supportive of governmental funding for genetic research, even when this appeared to raise moral questions for the same respondents.

While the public respondents ascribed some level of understanding to themselves in the survey, 61 per cent (n=94) stated that they felt they understood 'some' issues related to genetics, it would be a mistake to assume widespread public confidence on the part of the public. Strengths in understanding were recognised in particular related to life experiences, as parents for example, or to 'common sense'. However the public reiterated that their experiences made the social and ethical dilemmas no simpler to define, suggesting they are looking for more mutual contributions of knowledge than an outright rejection of expertise.
Chapter Six: Expert Approaches to the Public and Media

As discussed in the methodology chapter definitions of expertise may be disputed, while contextualised studies of scientific knowledge have demonstrated the relevance of locality and experience. As a final strand of data collection this chapter examines the views and experiences of both medical experts and scientific researchers to provide the third dimension of this research. The following chapter discusses these findings, including

- The results of a questionnaire distributed to scientific and medical experts.
- The findings of six semi-structured interviews carried out with UK-based medical and scientific experts.

6.1 Experts Questionnaire and Sample Characteristics

In December 2002, a six-page questionnaire combining open and closed questions was circulated to 90 UK-based scientific and medical experts who were selected for the sample on the basis that they had written or appeared in one of the journal or newspaper articles featured in the original content analysis. Five further experts were included as they frequently appear in the media, but had not featured during the period of content analysis. 41 per cent (n=37) of the scientific and medical experts returned completed questionnaires across two distributions, one postal in December 2002, and one electronic in April 2003.

The experts were asked about a number of personal characteristics, including, gender, age, parental status, qualifications and income. Distributions of responses to such questions were less even than was the case with the public or media respondents. 78 per cent (n=29) of experts were male, and 51 per cent (n= 19) of the total respondents were in the forty-one to sixty age group. 76 per cent (n=28) of the experts had children and were married or

1 For full details of this process see chapter three.
2 Full details of expert respondent’s personal characteristics including gender, age, marital status and religious preferences can be found in appendix one, table nine, page 238.
cohabiting. In terms of religion and ethnic group, experts were more dispersed than the media and public respondents. 49 per cent (n=18) of the experts described themselves as 'not religious', and 84 per cent were white (n=31). The income levels of the experts were considerably higher than members of the public sample. 83 per cent (n=29) of experts earned over £40,000 per annum.

The scientific and medical experts were asked if they or any member of their family had undergone genetic testing or been diagnosed with a genetic illness. All expert respondents completed this question and 16 per cent (n=6) answered yes, they or a member of their family had undergone genetic testing or been diagnosed with a genetic illness. Two cases of Dyspraxia had been diagnosed amongst respondents or their families, and a genetic link had been diagnosed in a case of deafness. Two further experts or their families had cases of depression and diabetes. One expert respondent had undergone genetic testing as a part of their own research.

The 37 medical and scientific experts had a range of professional titles. 14 were Doctors, 17 were Professors and two were Consultants. There were also two Directors of Institutions or Research Institutes, and one Press Officer. One respondent held the honour of Sir. Expert respondents worked in a wide range of institutions as table seven illustrates. 43 per cent (n=16) were NHS based, including those working for regional genetic services. 41 per cent (n=15) worked for a university, including those based in a clinical setting. Asked how much of their professional time they spent actively working in the field of genetics, 46 per cent (n=17) of respondents spent 75 to 100 per cent of their professional time in activities related to genetics, with a further eight per cent (n=3) spending over half of their time in such activities. It was interesting to note that eight per cent (n=3) of the experts spent none of their professional time working in genetics. The sample for the
Organisation

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<th>Organisation</th>
<th>N</th>
<th>%</th>
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<tr>
<td>University including hospital based research units</td>
<td>15</td>
<td>41</td>
</tr>
<tr>
<td>NHS including regional genetic services</td>
<td>16</td>
<td>43</td>
</tr>
<tr>
<td>Medical Research Centres including government based</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Research Institutes including public commercial laboratories</td>
<td>4</td>
<td>11</td>
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<tr>
<td>Total</td>
<td>37</td>
<td>100</td>
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Table 7. Where do you conduct the majority of your work?
Source: Expert Questionnaires

expert questionnaires was selected on the basis that the individual had featured in a journal or newspaper article, which by the nature of its inclusion in the content analysis had discussed genetics. This in itself raises interesting questions regarding the relevance of these experts to the original item they had featured in regarding their own professional field, and their abilities to comment in light of the increasing specialisation of science.

The experts were further asked about the types of activities their work entailed and figure 15 displays the types of activities they were involved in. Research was the most popular activity with 50 per cent (n=18) spending all or most of their time in research activities. 64 per cent (n=23) of the sample spent at least a little of their time in educational activities, though only 6 per cent (n=2) spent all their time teaching. 28 per cent (n=10) of respondents were involved in direct patient care.

Figure 15. Question 12 Of the time you spend working in genetics, what amount of time relates to...
Source: Expert Questionnaires Note 1 person did not complete question
6.2 Experts Media Choices

As a primary facet of the research question concerned the media it was important that experts were asked about their personal media choices, rather than assuming that they would have an inevitable interest in the area, or favour certain types of coverage. The most popular newspaper to be read by expert respondents was The Guardian, which 46 per cent (n=17) read on a regular basis. The Times was read regularly by 32 per cent (n=12) of the sample, The Independent by 27 per cent (n=10) and The Telegraph by 16 per cent (n=6). Eight per cent (n=3) of respondents regularly read The Daily Mail or Express. None of the expert respondents read The Mirror or The Sun. Their reading of the Sunday newspapers followed a very similar pattern, with 30 per cent (n=11) reading The Observer and 24 per cent (n=9) reading The Sunday Times. Again no respondents read The Sunday Mirror or News of the World, both popular newspapers with the public.

Health and science issues were of interest to many of the experts. 83 per cent (n=30) of the expert respondents read pieces concerning science or healthcare on a daily or weekly basis. 16 per cent (n=6) of respondents stated that they read such pieces on a monthly basis, or less often than that. As to the other forms of communication that they engaged with, the most popular resource was professional journals, which 87 per cent (n=32) read regularly. 68 per cent (n=25) had viewed or listened to TV and radio programmes that had covered genetics. 62 per cent (n=23) regularly used professional networks, and 57 per cent (n=21) utilised email updates and the internet. Respondents cited reading a broad range of journals, the most common of which were, Science, BMJ, Nature, New Scientist, NEJM, Nature Genetics, American Journal of Human Genetics, and Human Reproduction. 54 per cent (n=20) of the expert respondents said that they read material concerning genetics from disciplines other than their own such as the social sciences, healthcare, law or politics. When asked for further details, material included articles and books on risk perception and

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3 Regular was defined as more than once per week for daily newspapers and once per month for Sunday newspapers.
assessment, confidentiality and consent. Others mentioned drawing material from ethics, law, healthcare policies and the history and philosophy of science.

Discussing the reliability and forms of information available in the media, 46 per cent (n=17) of the experts thought that the media provides about the right amount on information on genetics. Eight per cent (n=3) thought it provides too much information on genetic issues, and 33 per cent (n=12) of the experts thought it should provide more. Asked about the tone in which genetics was depicted, there was an exact 50/50 split in respondent’s answers between positive and negative viewpoints as figure 16 illustrates. Nine per cent (n=3) of the experts described media reporting as ‘positive’, and 41 per cent (n=14) felt it was ‘more positive than negative’. 38 per cent (n=13) described media reporting as ‘more negative than positive’, and 12 per cent (n=4) described it as ‘negative’.

Specifically the expert respondents rated television as the most reliable source compared to newspapers or the internet. 65 per cent (n=24) regarded it as reliable or mostly reliable. Likewise 64 per cent (n=23) believe newspapers to be reliable or mostly reliable. The internet was the resource which experts were most sceptical of. 38 per cent (n=14) said they did not know if it was reliable or not, again this is likely to reflect the differing nature of internet resources, but 33 per cent (n=11) felt it was reliable or mostly reliable.

![Figure 16. Question 21 Do you think the media reporting of scientific and genetic issues is largely...](image)

Source: Expert Questionnaires Note: 3 people did not complete question
6.3 Experts and the Public

A number of questions sought the expert’s views on the general public. Initially this line of questioning began with a number of specific areas like genetic carrier testing and human reproductive cloning. With each statement the experts were given a Likert scale with choices, ranging from ‘very good’, to ‘very poor’.

This brought a range of responses from the medical and scientific experts sampled. Asked about public understanding of genetically modified foods, 14 per cent (n=5) of experts felt the public had a good understanding and 62 per cent (n=23) felt it was poor or very poor. 14 per cent (n=5) thought the public had a good understanding of human reproductive cloning, though 72 per cent (n=27) of the sample felt public understanding of this issue was poor to very poor.

These points are highlighted by table eight. The complex issue of stem cell techniques was also seen as a difficulty for public understanding. 84 per cent (n=31) of the expert respondents thought that public understanding of stem cell techniques was poor or very poor, 6 per cent (n=2) of respondents thought it good. The experts were least optimistic about the public’s understanding of genetic databases. No experts described it as good or very good, 89 per cent (n=31) described public understanding of genetic databases as poor or very poor. Where genetic innovations were less novel and more widely utilised, experts were more optimistic. 20 per cent (n=7) for example rated the public’s comprehension of

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<th>Very Good</th>
<th>Good</th>
<th>Neither Good Or Poor</th>
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<th>Very Poor</th>
<th>Total</th>
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<tbody>
<tr>
<td>Genetically Modified Foods</td>
<td>0 (0%)</td>
<td>5 (14%)</td>
<td>9 (24%)</td>
<td>11 (30%)</td>
<td>12 (32%)</td>
<td>37 (100%)</td>
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<tr>
<td>Human Reproductive Cloning</td>
<td>0 (0%)</td>
<td>5 (14%)</td>
<td>5 (14%)</td>
<td>19 (51%)</td>
<td>8 (21%)</td>
<td>37 (100%)</td>
</tr>
<tr>
<td>Stem Cell Techniques</td>
<td>0 (0%)</td>
<td>2 (6%)</td>
<td>3 (8%)</td>
<td>21 (58%)</td>
<td>10 (28%)</td>
<td>36 (100%)</td>
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<tr>
<td>Genetic Databases</td>
<td>0 (0%)</td>
<td>0% (0%)</td>
<td>4 (11%)</td>
<td>20 (57%)</td>
<td>11 (32%)</td>
<td>35 (100%)</td>
</tr>
<tr>
<td>Genetic Carrier Testing</td>
<td>0 (0%)</td>
<td>7 (20%)</td>
<td>7 (20%)</td>
<td>15 (43%)</td>
<td>6 (17%)</td>
<td>35 (100%)</td>
</tr>
<tr>
<td>Pre-natal Genetic Testing</td>
<td>1 (3%)</td>
<td>7 (20%)</td>
<td>10 (25%)</td>
<td>14 (40%)</td>
<td>3 (9%)</td>
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Table 8. Question 23 How would you rate the general public’s understanding of the following areas?
Source: Expert Questionnaires Note: 2 people did not complete all of the questions

165
genetic carrier testing as good. Similarly in the case of pre-natal genetic testing actively practised in healthcare at present, 23 per cent (n=8) of the experts felt public understanding was good to very good and only 49 per cent (n=17) described understanding as poor or very poor.

More generally the scientists and medical professionals rated the public's understanding of 'science and medicine' as poor. Eight per cent (n=3) said that the public's understanding of science and medicine was good. 30 per cent (n=11) said it was neither good nor poor. 49 per cent (n=18) described it as poor and eight per cent (n=3) described it as very poor.

Experts were asked to give a word which they thought most accurately described the public understanding of genetics. No examples were stated in the questionnaire and the question generated twenty different responses. The most popular word was 'poor', which 27 per cent (n=10) of the sample used to describe the public's understanding of genetics. Other words with negative connotations included woeful, hysterical and abysmal. Eight per cent (n=3) used the term 'limited' and a further eight per cent (n=3) described it as 'confused'. A number of the words pointed to a lack of effective communication rather than understanding, words such as 'confused' and 'muddled' or 'misguided'. The public was also described as wrongly apprehensive and over optimistic. Two respondents described the public as interested and a further expert described public understanding of genetics as emerging, which were more encouraging or optimistic choices.

Asked if they felt it was necessary to improve public understanding of genetics, 89 per cent (n=33) of the medical and scientific experts agreed that public understanding should be improved. 11 per cent (n=4) did not know. Suggestions as to how it could be improved in an open question had a consistent theme. Education at primary school to college level was most often identified as the way that public understanding of genetics could improve. Some experts suggested that educational reform was needed, and even that paying
teacher's better wages would improve public understanding. More generally making
information more accessible and easier to understand was recommended. The experts
suggested the media could be more straightforward, that there should be more dedicated
series on TV or in the newspapers, better science journalism and recommended both more
and less coverage. A couple of the experts suggested scientists learn to communicate more
effectively with the media. Finally one expert suggested a form of governmental education,
1-2 minute films like 'adverts', while another expert suggested the public needed to learn
more about how science is objective.

6.4 Expert Responses to Genetic Issues

During the media and public surveys, respondents were asked for their opinions regarding
a number of statements related to science, genetics, healthcare and ethics. A section of
similar questions were included on the expert questionnaire to compare both levels of
agreement and general standpoints between the three groups. In some of the more
contentious and ethically challenging areas it was clear that technical expertise and
understanding did not result in consensus. For example when asked if 'people knowingly
carrying a recessive disease gene should avoid having children with another carrier',
opinions between the experts were well distributed. 43 per cent (n=16) of the experts
strongly agreed or agreed with the statement. 36 per cent (n=12) of the experts strongly
disagreed or disagreed. A question regarding the statement 'withholding any requested
service from individuals is unethical' brought a similar range of responses. 22 per cent
(n=8) of experts agreed or strongly agreed with the statement but 54 per cent (n=20)
disagreed or strongly disagreed. 19 per cent (n=7) expressed no opinion.

More agreement was apparent regarding questions likely to affect current practices or
where there had been more bioethical debate. 87 per cent (n=32) of experts agreed or
strongly agreed with the statement, 'genetic testing should be voluntary in healthcare'. 75
per cent (n=28) of the experts agreed or strongly agreed that 'a woman's decision about abortion should be her own, without external pressure'. Only 11 per cent (n=4) agreed with the statement 'healthcare professionals are not responsible for the public using genetic services appropriately'. There were also strong viewpoints regarding external factors influencing developments. 84 per cent (n=31) of the experts thought that insurers do not 'have a legitimate claim to a person's genetic data' and 81 per cent (n=30) disagreed or strongly disagreed with employers accessing a person's genetic data. Whilst the experts were more open to the judicial system accessing peoples genetic data, 51 per cent (n=19) still disagreed with the information being used in this way.

In areas of science that have often drawn controversy or media attention, expert's views were in more agreement. Asked whether 'human cloning may not be unacceptable in all cases' 58 per cent (n=19) of the experts agreed or strongly agreed. In comparison when asked the same question only 20 per cent (n=30) of public respondents agreed or strongly agreed. In the context of relationships only 11 per cent (n=4) of the expert sample felt that a person's partner or blood relative should have access to their genetic information without their consent. 78 per cent (n=29) disagreed. 65 per cent (n=24) of the experts also disagreed or strongly disagreed with the statement 'parents must never be told the sex of an unborn baby'. Only one expert agreed with the statement that parents should never be told the sex of an unborn baby, thus in this case the medical and scientific experts largely supported the present regulatory context.

4 Interestingly 8 per cent (n=3) of experts disagreed with this statement. Termination of a pregnancy in the UK requires the consent of the women and the agreement of two medical practitioners. There are some exceptions, for example in the case of those who are defined as ‘non-competent’ minors, however the woman’s spouse or the biological father has no rights to demand or refuse an abortion. Professionals advising on termination must provide verbal advice, which is supported by accurate and impartial information (RCOG 2000).

5 In the UK parents presently have the option to find out the sex of a foetus through ultra sound techniques. Selective termination is not permitted on the basis of sex of the foetus alone. HFEA which regulates any clinic offering IVF, PGD, sperm storage or donation does not permit sex selection for non-medical purposes. Sperm sorting techniques are however available at 3 unlicensed clinics, further regulation is presently being considered (HFEA 2003a, POST 2003).
Asked about some of the possibilities of genetic research and applications the experts viewpoints returned to a more differentiated nature. 27 per cent (n=10) of the experts agreed that 'genetic counselling should reduce the number of harmful genes in the population' but 49 per cent (n=18) felt it should not. 51 per cent (n=19) agreed with the statement that 'genetic research should be given priority in government funding', while 16 per cent (n=6) disagreed. Similarly 40 per cent (n=15) of the experts agreed or strongly agreed with the statement 'genetic therapies and preventative measures should be given priority in health budgets' but 32 per cent (n=12) disagreed or strongly disagreed. This reluctance to see genetics become a scientific and medical priority is likely to represent the variety of experts consulted and the differences between those working in a clinical, healthcare or laboratory setting. As such 30 per cent (n=11) of the experts agreed or strongly agreed with the statement 'gene treatments are the future of medicine'. 43 per cent (n=16) disagreed or strongly disagreed.

Whilst many of the expert's had quite different opinions regarding a number of these questions, and this was likely to be effected by their own professional field, there was also disagreement as to regulation of their work in ethically challenging genetic fields. When asked if a 'geneticist's professional conduct should be regulated by government legislation', 57 per cent (n=21) of the experts agreed or strongly agreed. However 24 per cent (n=9) of the expert respondents disagreed or strongly disagreed with geneticist's professional conduct being regulated by government legislation. Considering the range of opinions across this group of experts it is difficult to see how self-regulation would be feasible.

The final closed question involved public participation. As noted previously 89 per cent (n=33) of the experts agreed that public understanding of genetics should be improved. However when asked if 'the general public should be consulted when developing policies
governing genetics’, 73 per cent (n=27) agreed or strongly agreed. Only 8 per cent (n=3) of experts had previously stated that they felt public understanding of science and medicine was good and yet 73 per cent agreed that they should be consulted in policy-making. This raises interesting issues regarding the terminology and language choices around such exercises. If this question had asked if ‘the general public should be listened to when developing policies governing genetics’ it seems likely the responses would have been quite different.

6.5 Experts Qualitative Questionnaire Data and Interviews

The expert respondents were given the opportunity to add further observations to both a number of the open questions and in the further comments section of the questionnaire. This brought some qualitative responses to the survey, further enhanced by six in-depth interviews with experts in the area. These included three experts, whose work was medically based, involving some degree of patient interaction, and three experts who were based in scientific research in a non-clinical setting.

Like the public questionnaire the outcomes of these interviews were considered separately and thematically with the main points of each interview organised in figure 2.18 in appendix four. The interviews were transcribed in full, as discussed in the methodology chapter, and stored electronically using an N5 dataset. The benefits of using electronic and hard copies of the interviews were numerous, as was my own involvement in all of the interviews. This allowed for the data to be examined broadly, comparing interviewee’s responses, and singularly comparing the views of separate interviewees at varying stages of the interview. Thus while the expert interviews could also be compared using a matrix formation as was the case with the public, they are also followed by a more focused consideration of the qualitative information gained in the interviews.
6.6 Expert Interviewees and their Experiences of the Media

The experts involved in the interviews had relationships with the media at two levels. As observers, like members of the public, they had witnessed depictions of genetics in the media. However unlike the public they also had relationships and interactions with news stories and journalists themselves. All of the experts involved in the interviews had experienced coverage of their own work. Five of the interviewees had directly been involved with the media, one interviewee Lara, had however only experienced her work being disseminated widely via patient groups and internet sites. The experts most commonly stated that the media had contacted them to find out information about their field, or that the institution they worked for encouraged them to contact the media when for example, funding was secured or research published. The following descriptions are typical of these types of experiences.

There has been quite a lot of stuff about genetic variation in human populations... I have had a couple of phone calls from newspapers asking me for comments on it but it's not directly my own research (Geoff IE005 Research Professor).

I try and avoid dealing with the media if I can possibly help it... we were involved in some research... a big Cancer Research UK thing so I was on the radio saying that we were starting to do that study... We actually wrote just a little piece for the paper saying we were delighted with this money (Judith IE003 Consultant Geneticist/Clinical Director).

Though the experts often communicated with the media some displayed reluctance due to the inconvenience it involved. There was also an unwillingness to comment for this expert and the institution they represented if the area was sensitive or controversial.

Well certainly we do have relationships with media... about three years ago we did have somebody contacting us but we actually weren't very keen to get involved in any discussion relating to sensitive issues, in particular related to genetics (Maria IE002 Consultant).

When first discussing their media involvement a primary difficulty involved the response time necessary, a number of the experts described the difficulty in summarising a controversial area, with a journalist effectively waiting on the phone. This suggested firstly, that the onus for simplification is often placed with the expert and secondly, that

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*The interviewee's names have been changed to protect their identities. The data is coded I; Interviewee, E; Expert, 001; Interviewee number.*
responses by scientists on some controversial areas are often a quick solution rather than pre-planned discussion. If an expert’s name is published, it appears to invite a series of phone calls from journalists, which the expert must then discriminate between as well as keeping up with their research or patient demands.

The difficulty is they phone you up and they want a sound bite and you don't really have an awful lot of time to prepare and you don't know what questions they are going to ask you, it is quite difficult (Judith IE003 Consultant Geneticist/Clinical Director).

One of the experts interviewed, Steven had the most experience of dealing with the media. In the past he had acted as a media officer for the research institute he worked for and as such had some of the strongest ideas about the media’s relationship with science. He emphasised that the specialised nature of much scientific work meant a scientist would normally deal with the media on one or two occasions across their career and that this could be problematic. He strongly argued that it was scientists’ expectations that often affected their relationships with journalists.

[The] first thing is not to have very high expectations and also to recognise what journalists are trying to do and the timescales they are up against... the responsibility for making sure that the information is transmitted correctly, not the interpretation but the information, is very much the scientist’s and once you accept that a journalist is going to write an interesting article not the article you think they should have written... I don't think we have been particularly disappointed. We have only been let down on two or three occasions by journalists... we have only been misrepresented on two significant times over probably thousands of interviews in five or six years (Steven IE006 Research Institute Director).

Steven suggested a need simply to communicate your argument, and emphasised the scientist’s responsibility to do this effectively, in contrast to the experts who avoided speaking to the media. He feared that if more scientists did not stand up and defend their work the anti-science momentum created by GM in agriculture could create a tide of such feelings. The institution he worked for had actively encouraged its relationship with the media to influence the 'quality of debate' and because it allows such broad communication with the public.

The media have been intensely interested in our work, because we have been accessible we have been able to reflect on other aspects of our research programme and we have involved ourselves in ethical debate and discussion... we wish to
maintain that relationship because it's the only way you can communicate with large numbers of people at a formal level (Steven IE006 Research Institute Director).

The strength of caution displayed by other experts involved in these interviews suggested Steven was correct in his depiction of a lack of confidence amongst other experts. Maria described her experience of interviews for the press, pre-recorded and live television.

My personal experience is that when [interviewing me]...it does not reflect what I have said realistically. Certainly I have given an interview on the television and again after it’s been edited, it kind of does not reflect at times, what the message you’re trying to give is...I have been also in live television interviews and that is, from my point of view, a little bit more satisfactory because the question has been asked and I have given an answer but things like a recorded interview and then edited and then shown on the television or somebody asking me questions and trying to write an article, I am rather sceptical about what I have said and what has been published or shown (Maria IE002 Consultant).

Maria thought she had been mis-represented in both print and pre-recorded interviews, which had made her cautious of this type of media interaction. More generally the experts suggested they were able to recognise such cases, expressing a clear difference between research they were familiar with, perhaps having read a journal paper or communicating with colleagues, and media depictions. A common criticism was that research had been significantly mis-represented or sensationalised.

The media tend to make more out of things than is really there and the solid evidence. That's a frequent complaint I think from scientists... if you actually look at the paper the evidence is by no means as solid as that interpretation (Geoff IE005 Research Professor).

The media always want [to] sort of sensationalise things. They’re saying 'this could be the cure for ovarian cancer' rather than saying we don't know what it does, this is a study to try and find out and so there always putting a very positive spin on things as opposed to saying what's really happening (Judith IE003 Consultant Geneticist/Clinical Director).

The interesting point of these statements is that they criticise the journalists for taking the research too literally and over-emphasising its possibilities, for being too supportive of the scientific claims. The following interviewee also criticised the genetic determinism of some media reporting.

There's definitely a major problem with the way people talk about genetics... the idea that somehow you could just introduce a gene and make somebody into like a superhuman or a super intelligent person or have a particular characteristic and it
often ignores some quite major complexities about genetics. Actually modern genetics shows that it's very difficult just to change one thing like that...So in that sense there is often a misperception in peoples minds about what is and isn't going to happen... we should have a bit more acknowledgement of the fact that genetics is actually far more complex than the media often portray (Mark IE004 Non-Clinical Research Fellow).

The experts emphasised that the media should depict scientific complexity more accurately, that not every piece of research becomes a dramatic technology or application.

Steven again highlighted this tendency to over-emphasise the significance of research and simplify findings to wider concerns intrinsic to the British press.

It's very much a news agenda... that reflects the very competitive nature of print media in the UK. We have thirteen or fourteen national newspapers all of which are competing head to head and the emphasis is very much on news on breakthroughs and I don't think that fits very easily with how science actually progresses (Steven IE006 Research Institute Director).

Where as Maria identified the journalist's professional qualifications as central to the problem.

I don't believe 90% of what I hear in the news because the journalists are just scratching the surface and have very limited knowledge. How can they have in-depth knowledge when they haven't got the background?... sometimes I look at the interviews being conducted on scientific matters and the journalist... has read maybe one article and he's just insisting and sticking to this, which quite frankly, people who know a lot, its very irritating (Maria IE002 Consultant).

Maria was the most critical of the experts involved in the interviews. As already highlighted she strongly felt she had been mis-represented in the past, which had clearly influenced her views. She felt a need to communicate, in particular, as she was involved with patients in her work. Patients' tendencies to increasingly appear with information emphasised to her the need for accuracy in public arenas. She described a 'cultural attitude', which created expectations that science and medicine would always offer solutions. Whilst she defended the need for the public's trust it was clear that unreasonable patient demands were also a pressure. The media evidently offended Maria. She described it as 'irritating' and 'ignorant'. However other experts also noticed these over-simplifications, which extended to the depiction of the scientific community. A number of the experts described receiving phone calls for comments and Mark had been interested
and amused by media portrayals of 'expertise' regardless of your relationship to the field you may be commenting on.

One of the things I found quite weird...was I found you get presented, when you’re quoted in these things, as being an expert. Where as I'm sure people who work in cloning would not consider me in any way an expert but in the public's eye you become an expert just by having a voice and being a scientist. It's a kind of really interesting distinction that a scientist themselves would not see you as an expert but the public might (Mark IE004 Non-Clinical Research Fellow).

The degree of specialisation in science and medicine may indeed be something that the public fails to perceive and the media utilises to gain controversial or convenient quotes from scientists that are willing to communicate most readily. However it was not just the general media, which the experts criticised for these types of simplifications and sensationalising tactics. Geoff had been particularly disturbed by the manner in which New Scientist had described some research he was involved with.

The point of the research was that you can improve a lifespan of Drosophila...this got written up as, by the New Scientist, as the case of the middle-aged baby with a picture on the front of a baby with a bowler hat. It just didn't really to me, convey the proper interpretation of what we were trying to say...they tried to make it funny and grab people's attention. I guess that's what the media want to do. (Interviewee laughs) It's not quite what scientists see themselves as doing, we see ourselves as trying to get at the truth (Geoff IE005 Research Professor).

Mark, Geoff and Steven all began to voice criticisms of the scientific community and their relationships with the media.

There is a kind of culture clash. The media basically want to sell papers or get an audience for their TV programmes or whatever and so they tend to go for the more sensational side of science... When you see the kind of papers, which get media attention...any article with sex in the title, gets a lot of attention. Where as some may be good, some may be much more important but are more technical, they just get no attention at all...There's a sort of difference in attention of what scientists see as [important] and what the media see as [important], which just isn't going to go away (Geoff IE005 Research Professor).

There's a lot of scientists think that the media is something that misrepresents science... scientists sometimes miss is the fact that news has to be presented in a way that's entertaining and that engages people...presenting a much more black and white picture than maybe scientists view it...skimming over some of the complexities, in favour of the more direct approach. That's why its very difficult to do good news without to some extent misrepresenting science in the way that scientists see science...what would make very objective, very factual accurate science wouldn't necessarily make good news (Mark IE004 Non-Clinical Research Fellow).
Whilst these interviewees could understand some of the media’s difficulties and indeed in the case of Geoff and the depiction of a middle-aged baby, even laugh off some of their experiences, for others the consequences of media reporting were more complex. This was particularly the case for experts Lara, Maria and Judith who worked more actively with patients. Judith described how sensationalised, genetic determinist stories in the media ignored quite common preventative measures whilst alarming viewers and readers.

They [media] always go to extremes. There was a series of programmes where they had certain genetic conditions...a gentleman had Gorlin's Syndrome and one of the problems was that he was at the very far end of extreme, really bad. So that might of actually scared people to death rather then promoting the fact that this is something that we can perhaps do something about by avoiding the sun but he was so badly disfigured I think it was quite upsetting for a lot of people (Judith IE003 Consultant Geneticist/Clinical Director).

She went on to describe how such ‘positive’ stories about the potential impacts of genetics could ignore the depth of the issues involved, demonstrating a genuine concern that both her patients were being misinformed and that possible implications of genetic interventions were being ignored. She talked specifically about the press handling of the Hashmi case.

It’s been very emotive because they have been filming the child... I don't think it’s been completely balanced because there are ethical dilemmas about starting down that route really...what would happen if that child in the future needs a kidney transplant? You've already got a sibling that you know is a tissue match (Judith IE003 Consultant Geneticist/Clinical Director).

The experts involved in the interviews had a range of experiences with the media and already at this stage it is clear that the motivations of ‘scientific’ and ‘medical’ experts differ when it comes to communicating with the media. Some experts assertively involve themselves with the issues; others provide commentary only when it is required of them. The consistent issue however was that of reduction and simplification, even though the majority of the experts recognised that some degree of summary and interpretation is required for media audiences, this had consequences. The positive emphasis in media portrayals of genetic advancement was seen as inaccurate generally and problematic for those working in patient care. What is less clear is who is responsible for this.

7 The Hashmi family have successfully fought for preimplantation genetic diagnosis in the UK in order for their present son to undergo a bone marrow transplant on the birth of a sibling (HFEA 2003b).
experts themselves describe a pressure to summarise who is responsible for accurate communication?

6.7 Expert Interviewees And Their Responsibilities To Communicate

All of the interviewees agreed that scientific and medical experts have a responsibility to communicate, though there were clear variations between the scientific and medical experts as to how this should occur.

The responsibility is to communicate, to get the message to the public... there is a responsibility that if you carry out the research then you carry it out for a purpose...obviously it might effect people and then people should, people effected, should know about it but I don't know if it would be for me to communicate through the media or I don't know the media to pick it up (Lara IE001 Clinical Research Fellow).

Lara had not experienced any direct reporting of her own research. Her research had however been of interest to certain patient groups and as such distributed via support groups and internet sites. Like the other medical experts whose opinions were dominated by the implications of media coverage for patient care, her opinions were balanced between an encouragement for a more knowledgeable public and the practicalities of having more informed patients. Her more medically based background appeared to influence her responsibility to communicate. Medical experts perceived that their knowledge was there to be consulted at the media's request, where as the scientific experts seemed to more actively encourage interest. As the following extract illustrates the medical experts were conscious that direct communication could be perceived as a conflict of interests.

I'm not sure whether I personally have a responsibility but I think there is a responsibility for the genetic community as a whole to communicate what we do. But it's difficult to do that because as a geneticist the basic tenet of what we do is that we are non-directive, promoting ourselves goes against everything that we actually stand for... A lot of the work that we do is saying to people you don't have to know this information if you don't want to, you have to think about the effect it would have on the rest of your life. So it is difficult then to kind of promote what

8 The expert sample were selected as they had authored or appeared in either a journal or news item in the original content analysis. It was not a prerequisite for interviewees to have had media coverage of their own work, though this was the case with the further five interviewees. Chapter three has further details of sampling methods see page 57.
we do in a public way but the public do need to know more about what we do...the perception is that we leap upon people and test them as they come in the door and tell them things that they don't want to know and I think that's counterproductive a lot of the time (Judith IE003 Consultant Geneticist/Clinical Director).

Interestingly Judith in the above extract raised the point of non-directive roles, the emphasis on which has been recognised in other research (Petersen 1999, Ettorre 2002, Pilnick 2002). All of the experts, both medical and scientific, stressed that communication is just one facet of their role. 'It shouldn't be a criteria for being a good scientist that you have to communicate well. There is going to be brilliant and bad communicators and vice versa' (Mark IE004 Male Non-Clinical Research Fellow). However it was clear that the constraints on those based in scientific research and those who also had responsibilities in patient care, were different. The medical experts, Lara, Maria and Judith were more conscious of the dangers of misinformation, keen to correct inaccuracies which they perceived would effect patients outside of their own care, and aware that public understanding could potentially make their 'lives more difficult' (Maria IE002 Female Consultant). At times there was even a hint of annoyance at their patient's reliance on the media over their own advice but the following extract was typical of these aims.

I certainly feel I have a responsibility to communicate with my patients and their families. I may occasionally feel if something has been misreported then I may as a physician, as a consultant in a hospital, I'd probably get advice regarding that but I would feel that it is important that the public should know the truth (Maria IE002 Consultant).

Judith, a consultant geneticist, demonstrated throughout the interview a concern that her patients were being needlessly upset, receiving incorrect information, or having their expectations unrealistically raised. She described the difficulty of explaining to patients the implications of a genetic test in such a media context.

One of the problems is it gives people a false impression of what's actually available. For instance there was a television programme about Huntington's disease saying about the research that's going on into that and it gave the impression that the cure is round the corner. That's far from the truth and it makes it very difficult when your counselling patients who are wanting to go for a test to see whether they are going to develop something in the future, if their perception of it is that's there is going to be a cure round the corner. When in fact there may not and may never be...we frequently get patients phoning up saying that the papers said such and such and why can't we have it and why isn't it there? It gives them a false
idea of what they are going to have to live with if they get this information (Judith IE003 Consultant Geneticist/Clinical Director).

The medias enthusiasm for genetics was thus impacting on Judith's interactions with her patients, and this also extended to those who had experienced genetic testing in the past, as Judith continued to discuss.

There was recently an article...about Huntington's and there was a doctor talking about it and she actually gave some false information in that magazine article and we actually wrote and said no this is not true. Basically she said that the test wasn't 100% and that's not true...that came to light because one of our patients phoned us having had a test for it, which said she wasn't going to develop it... what she [the doctor] had done was read some old books...what we do nowadays is 100%...She gave this information which was false and it upset a lot of people and that's the problem that people get these things from the media and they tend to rely more on what it says in the magazine than necessarily how they rely on us which is a problem (Judith IE003 Consultant Geneticist/Clinical Director).

Interestingly it was an error by the doctor consulted in this article, which caused the claimed misinformation and the experts interviewed underlined their desire to consult others before they spoke to the media. Maria on the prior page makes a similar comment.

Having so critically examined media reporting the experts were cautious in their involvement, aware that judgement in public arenas is likely to have differing implications than those within the privacy of professional networks and peer review. However this emphasis on scientist's communicating inaccurate or poor information to the public was most keenly emphasised by Mark.

The real problem is that you have actually got leading scientists that somehow come out with... quite similar simplifications. You have people like James Watson the discovery of the DNA helix, he has come out with quite crude views on genetics... There is a general problem about the way in which we think about genes and the relationship to the body. I'm completely against the idea for instance, that there is going to be a gay gene, or a gene for aggressiveness. It's a massive oversimplification of what we really expect to find...there are going to be far more complex traits than would be coded by a single gene...you even get some scientists who work in these areas that seem to be saying that it is going to be simple. I don't think its necessarily always the media's fault or even the publics fault that there's misconceptions in this area, some scientists are to blame as well...I mean a guy I won't name him...he claimed that we would soon know the gene that made Mozart a genius and that is a complete oversimplification because although Mozart no doubt was a musical genius there were so many other factors in his life...it is a ridiculous thing to say actually. I was quite surprised to hear a leading geneticist come out with that... they probably believe it themselves that's the worst of it. You can be a good geneticist and still have very crude idea about how genes come together (Mark IE004 Non-Clinical Research Fellow).
Thus there were some similarities in how the scientific and medical experts viewed the responsibilities to communicate, most obviously that you must be correct and accurate, though as the last statement illustrates some scientific concepts remain contentious in areas of science and medicine. Whilst those in medical fields had a sharper awareness and experience of some of the ethical complications, those carrying out research in ethically sensitive areas of science also described this as a motivation to communicate.

Steven describes having ‘no choice’ but to discuss potential impacts with the public, indicating some wider responsibility for the knowledge they were producing, though his statement also emphasises an educational role in this discussion.

We work in a range of controversial areas... we have no choice but to participate in the ethical debate on these areas and try, not be able to influence the outcome but you can influence the quality of the debate. In particular the debate should focus on what is possible, what scientists are likely to do, would like to do, as distinct from what other people say that scientists are likely to do... we have got a responsibility to ourselves to create a climate in which the sort of research we do is publicly acceptable, is accepted by the government and regulatory bodies and so on. We have to engage in this whole area of society that surrounds our work (Steven IE006 Research Institute Director).

Steven discussed the issue of funding and other interviewees raised the point, that when research has an ongoing need for public monies it should aim to have public support. The scientific experts linked the need to openly communicate to wider peer review. Why does science appear wary of criticism when debate, argument and disagreement are such an influential part of the scientific process? Mark expanded this theme.

Although it can be quite a difficult thing to let down the barriers and let people scrutinise your work I think it's a positive thing to have a debate and therefore even on things like animal experimentation, where maybe people feel under threat, maybe they are going to get blown up... I still thinks its better to have a debate and an honest debate, than not... scientists have to wake up to the fact that these days you can't simply hide away you have to let the public know why you do what you do (Mark IE004 Non-Clinical Research Fellow).

While the motivations of Steven and Mark appeared honourable it is important to consider their motives for these comments. Firstly the need for public support was linked to a need for continued funding, and secondly talk of debate exists in a rhetoric where public communication and dialogue remain key. Steven described influencing ‘the quality of
debate’, while Mark needed ‘honest debate’, both comments suggest that even amongst experts who have a high opinion of the public, it remains easy to label views as wrong or inaccurate, depending on the expert’s perspective. Steven went on to stress the importance of a scientist simply defending their work.

There is a sense almost that a scientist standing up and being seen to defend a piece of work is as important as exactly what they say. Here’s somebody who says ‘my experiments are essential’ and the fact that somebody is standing up and saying that is the most important issue. If their argument is good, they present their case well that’s an added bonus. Just actually simply standing up and saying ‘I'm sorry but this criticism is nonsense’ is worth you know its 80% of the way (Steven IE006 Research Institute Director).

Again in this statement criticism was related to ‘nonsense’. The responsibility to communicate was thus deemed necessary by all interviewees though attitudes and motivations for it were variable. The most obvious differences were between the opinions of the scientific experts, those carrying out research in environments largely removed from the public or patients, and the medical experts, those interacting with people where the repercussions of poor communication are clearly more acute. The medical experts wanted to be consulted and to provide accurate information to ‘patients’ in the broadest sense. There was also some indication that they hoped to influence information in the media which patients inevitably, if not appropriately in their view, rely on. The scientific experts wanted to instigate communication, gain public support for their funded research and encourage scientific transparency. While it is not possible to determine their motives for doing this it is obvious that these exist in a context of education, communication and dialogue amongst the scientific community. Where there was agreement was that communicating is a risk, a number of the key inaccuracies highlighted by experts themselves were attributed to other expert’s errors. The notion of promoting correct scientific and medical knowledge was therefore also highlighted as difficult in contentious areas such as new genetics.
6.8 Expert Interviewees and Views of Public Understanding

Having established some of the challenges facing the media and communicating expertise, how did the experts perceive the public? The interviews specifically raised the concept of ‘public understanding of science’. Some of the interviewees who were aware of the general themes of the research introduced the concept whilst others were specifically asked what it meant to them. It became apparent that for some interviewees this concept had a political form. Promotion of public dialogue or understanding remains appropriate, aiding funding; as such it was sometimes difficult to identify how sincere certain experts were about their commitment towards it.

The public, the public yes would benefit from it [PUS] and researchers as well in getting grants’ (Lara IE001 Clinical Research Fellow).

The public would probably benefit because it’s a nice thing to know about. We would probably decide that the community would benefit because we might get some more money for our research (Geoff IE005 Research Professor).

We are an institute in the public sector, we are expected to include public understanding of science, yes we can go and talk to groups of people all over but even if all of us spent all our time doing it, it would be a tiny fraction of the population. On the other hand if you get a good story in the media, a positive story, an accurate story you are dealing with potentially millions (Steven IE006 Research Institute Director).

They have had kind of a thing now you have in all the research grants, where you have to write in kind of lay persons English a summary of your work. But to be quite honest it is a bit like window dressing really because everybody does it and yet at the end of the day I don’t know who reads it but it’s not the main decider (Mark IE004 Non-Clinical Research Fellow).

Whilst here Mark appears rather sceptical of the realities of public understanding exercises he was the most positive of all the experts interviewed with regard to engaging and communicating with the public. He was keen to become more involved with the media, though stressing that not all scientists are naturally good communicators, he found such experiences rewarding. Mark felt the public was often more supportive of science and sophisticated in their thinking and appraisals of media reporting then they were credited for. Like Steven he stressed that scientists should become more realistic about the role of
the media to educate and inform in an attractive way. His personal interest had led to a good awareness of the present assumed 'hostility' between scientists and the public.

There is this tension going on between the public and the presentation of science to the public. There's big debates in science communication about what is the public communication of science and there used to be this very simple idea that you just tell the public about science and educate them about science and that was enough. Now there is a much more critical angle which is the public need to be involved, engage, that they have a voice (Mark IE004 Non-Clinical Research Fellow).

However the more general views of PUS by the other interviewees had remnants of the deficit model, the following expert stated 'I think public understanding probably is dependent on where they got the knowledge from...its relative to people, to their education and intellectual abilities as well' (Maria IE002 Consultant). Geoff stated,

'It's a good thing for a scientist to try and get science across to the general public...I don't think that necessarily means that everybody should be telling the media about the results of their various research because...you undergo a lot of training, there's whole levels of background which obviously you can't expect from anybody outside of your own area of speciality in science, I'm not just talking about you know the public 'Joe' on the street...so you have to simplify everything (Geoff IE005 Research Professor).

Geoff also highlighted a point made earlier, that the intricacies of scientific research means levels of expertise are variable outside ones own field. Geoff had previously discussed the sensationalising and simplified depictions of science in the media 'clashing' with the aims of scientists. However he understood some public apprehensions, including those over GM in agriculture and government and commercial interventions, whilst also stressing that such fears were often a reflection of the novelty of genetic approaches. Though Geoff linked public understanding to education, he and other interviewees encouraged emphasis on the methodological and institutional issues around science. The most necessary of these issues was seen to be educating the public that not all science is a 'breakthrough', a point of 'consensus' or practical application.

It's [PUS] more of a particular appreciation for how science is done. That people accumulate evidence and try and interpret ideas in the light of that evidence and often, scientists involved in the research, they haven't got solid conclusions and some of the evidence goes one way and some of the evidence goes the other way ...At the cutting edge of research there is a lot of debate whether this idea is right or that idea is right. I'm not sure that comes over to the public...You can't tell what discovery, in a subject like genetics, will be of use in twenty years time... science
isn't just about making new crops or generating electricity or whatever, its also about understanding (Geoff IE005 Research Professor).

There are broader issues particularly about the idea of risk...scientists can't be sure of anything, the probabilities, the likelihood or whatever...so you can't say something's safe, absolutely safe but that's apparently what the public seem to want (Steven IE006 Research Institute Director).

Thus communicating the often-indeterminate nature of progress in science, the levels of probability involved and fulfilling public expectations were continuing issues. Geoff's recognition that there is often no consensus was an important point in light of prior expert comments regarding guiding the public towards 'correct' debates. While Steven went on to stress in the following extract that it was important scientists realised that increased public understanding would not necessarily lead to a less critical and more supportive public, whilst reiterating that PUS had become a motivational concept.

I don't subscribe to the idea that increased public understanding necessarily means that the public will support science anymore. They might decide I didn't realise that was happening and I'm defiantly against it...public understanding of science is a phrase that trips off everybody's tongues...I don't think it [support] would change, the sort of quality of debate would improve (Steven IE006 Research Institute Director).

The interviewees did however share some understanding of how public fears could become exaggerated in the media context of genetics, this related to their awareness of the ethical complications of many of the issues. Again for Judith this could prove a clinical complication.

[Reporting] has an impact on public awareness and they then feel a bit more weary about the things that we do. Even medical students think that we sit here and clone people and animals...that's one of the biggest problems that people think that we are seeing them because there is some underlying agenda from us rather than as a service to them (Judith IE003 Consultant Geneticist/Clinical Director).

There is an element of interfering with nature on a different level than simple intervention. Surgery even could be viewed as 'playing god' after all the person would die so that's pretty serious intervention. On the other hand genetics does have this eugenics element to it in the public perception and there is the idea that you are tinkering, not just with this patient or this generation but with the future generations...there seems to be something special in the public consciousness around genes, which I don't think that many scientists share, are they my genes? Are they my kid's genes? (Steven IE006 Research Institute Director).
Interestingly certain experts highlighted their own concerns, two of the scientific experts justified public doubts over GM in agriculture.

I have my reservations about GM crops as well. For people to be a bit suspicious and a bit worried about developments that could, have quite major knock on effects is a good thing actually. Even though I would do my utmost to say defend IVF and all these things I don't think there is anything wrong with people being challenging and critical (Mark IE004 Non-Clinical Research Fellow).

Judith was also suspicious of the government’s emphasis on genetic applications.

This particular government is very dedicated to promoting genetics and having widespread genetic testing. Alan Milburn...his view, his vision of the world would be that everybody has a smart card which has there genetic profile... the concern is that the government seem to be placing a lot of emphasis on preventive strategies by changing peoples behaviour and I’m not sure that there is anything proven that telling people things are bad for them actually changes their behaviour at all (Judith IE003 Consultant Geneticist/Clinical Director).

There were thus some minor variations in the way that medical experts viewed developments, whilst their views towards the public were very similar to the scientific experts there were again some issues specifically related to their fields. For example all three medical experts mentioned the pro-active nature of patients in finding information.

People are more questioning. They are becoming more aware...I think it's the internet with people having access to all sorts of websites, not all of them necessarily correct...they question, they want to know what the alternatives are, exactly we are doing, how its going to benefit, what are the alternatives and how this is more beneficial (Maria IE002 Consultant).

There's a lot of misinformation now. People will arrive with sheets of notes from the internet and that's a big problem as well. That they kind of expect all sorts of things because of stuff they have read, again that's not the media as such but you know there's a lot of false information (Judith Consultant Geneticist/Clinical Director).

These issues were intrinsic to the medical experts and clearly affected their relationships with patients. Having already discussed the impact of genetic promotion on patients, the medical experts went on to describe further implications of these approaches, describing a more general perception of health, illness and death. Whilst agreeing high expectations and demands of healthcare in developed societies are appropriate, with one medical expert stating, ‘its not frivolous to look at science to answer a number of questions’ (Lara IE001 Clinical Research Fellow) there were again wider issues involved.
The cultural attitude is that there is always a solution to your problem and in most cases there is but unfortunately there are still certain situations where there isn't a cure for a disease (Maria IE002 Consultant).

People think that you can do a lot more than you actually can do and in some ways there's sort of a public perception that death is a failure...this is a major difficulty in the perception of what medicine is. It can't stop people dying it can only prevent it for a while sometimes not even then...they have too much faith really, in the fact that you know it can cure all ills and stop people dying and make you live a happy healthier life, go on well forever really, which is obviously not possible (Judith IE003 Consultant Geneticist/Clinical Director).

While these expert’s felt public trust had been affected by developments and their reporting all did not share this opinion. Mark and Steven anticipated that public mistrust lie more with the funding process, government regulation, and the commercialisation of science and medicine.

What people maybe more distrust is the big corporations and the government announcements about science...people are becoming so cynical about government and some big business companies...when things are presented by those people, then people are cynical. I don't know if it does extend to the individual scientists much, I would like to hope it doesn't but its incredibly important that we do have trust because it would be really bad for the public not to know what we are doing, and not to be appreciative of what we are doing. After all we pay vast amounts of money really to do research (Mark IE004 Non-Clinical Research Fellow).

I don't know whether the public’s trust in science [is important], I think in the regulatory framework. Scientists basically don't trust other scientists. The whole purpose of science is to question and if you get a single study that says there's cold fusion then somebody comes along and challenges it. That's what science is about. Scientists generally are a suspicious lot (Steven IE006 Research Institute Director).

These extracts suggest that distrust is with regulation processes rather than science itself, re-clarifying the need for public support when research is centrally funded. The scientific experts highlighted that the public generally appreciated the mechanisms of science.

Even though...people sometimes link things like the atomic bomb, and pollution and all these sorts of negative things...I still think people really are aware, that science plays quite a central role in our lives. It’s very difficult to create drugs and have operations and antibiotics, even use washing machines or televisions without being aware of it somehow... People are aware that technology develops and there is a positive side to technology as well as what can sometimes seem like the more negative side, we will probably end up destroying the planet...people are often much more sophisticated, ordinary people...than they are given credit for (Mark IE004 Non-Clinical Research Fellow).

Public understanding of science was thus a concept, which was actively supported by both the medical and scientific experts, with differing implications for those who experienced
direct patient interaction. For the scientific experts in particular public education, understanding of dialogue had become a politicised concept, the appropriate thing to support and an unavoidable part of the funding process. That said it was clear that the experts involved in the interviews had some understanding and appreciation of the principle of public involvement, remnants of the idea that public understanding is about simple education gaining support were balanced with a hesitation to view the concept that simplistically. Instead the scientific experts encouraged a wider public appreciation of the complexity of scientific processes and the methodological basis of science. For the medical experts a more questioning and informed public stressed to them the inaccuracies of medical and genetic positivism in public settings. Whilst the medical experts felt poorly informed public expectations were influencing the trust they received, the scientific experts were more optimistic. Public trust was seen to largely remain, with some public concerns be it GM in agriculture, interventionist approaches to healthcare or ethical issues over genetic ownership, recognised as warranted.

6.9 Summary

Scientific and medical experts did not provide consensus viewpoints regarding the communication of science, the role of the media or the social and ethical questions associated to new genetics. The data and findings presented in this chapter suggest that attitudes can be as divergent and inconclusive amongst experts as the public respondents, and that in thinking about scientific and medical communities we must recognise the variations in views that these groups incorporate.

Past research has suggested scientific and medical experts are dissatisfied with the media coverage they receive and taken as granted the experts knowledge to inform such opinions. Scientific and medical experts were indeed familiar with certain media coverage as audience members. This included the broadsheet, and to a lesser degree mid-market
newspaper coverage and television features. The experts were confident in the reliability of
the television and newspaper coverage; in fact they were considerably more confident than
the public. 64 per cent (n=23) of the scientists and medical experts described newspaper
coverage of genetics as reliable or mostly reliable, compared to 21 per cent (n=32) of the
public respondents. However the views of the experts often conflicted and did not portray a
common aim of what scientific and medical experts hoped to see in media coverage.
Genetic coverage was deemed positive or more positive than negative by 50 per cent
(n=17) of the scientific and medical experts, and negative or more negative than positive
by the remaining 50 per cent (n=17) of respondents. Similarly 46 per cent (n=17) thought
the media had about the right amount of genetic coverage, while 33 per cent (n=12)
suggested there should be more.

In terms of practical experiences in dealing with journalists, the interviewees suggested
that there were a number of constraints. Some were attributed to the expert; their
inexperience in dealing with the media, poor communication skills, unrealistic expectations
and accessibility. Others were attributed to the journalist; their expectation for quick
responses, qualifications, simplified explanations, ‘sound-bites’, editing practices and their
focus on controversial areas of science and applications as opposed to continual
developments. More widely, an increased recognition of the methodologies, and processes
of research and development involved in scientific and technological development, was
recommended on a number of occasions.

57 per cent (n=21) of the expert respondents described public understanding of science and
medicine as poor to very poor. Despite the low estimation of the publics’ understandings of
issues related to new genetics, 73 per cent (n=27) of the experts agreed or strongly agreed
with public consultation when developing policies, and this was despite 89 per cent (n=33)
of expert respondents suggesting there needed to be improvements to the public
understanding of genetics. Thus what for the experts are the purposes of such exercises and how would they improve understanding?

The medical experts had a clear motivation to communicate with their patients and wider affected communities; in particular they were concerned by the misrepresentation of conditions or treatments in the media, which had a far more acute effect on their work and patients, than those scientists involved in research and development. Geneticisation blurred the realities of treatments and conditions while adding to the overall cultural expectation that death is no longer a possibility. However more widely the experts continued to (unintentionally) promote a deficit view of the public, and suggested that acknowledging public dissemination was a form-filling process or expectation in funding applications within the scientific and medical communities. Despite largely identifying the media as reliable, this and the educational system were commonly identified as ways to improve the public's understanding, suggesting they had always played some role in generating, or not as the case may be, poor understanding. Educational improvements, accessible media coverage, more skilled journalists, even scientific adverts, were recommended more frequently than a better understanding on the part of experts, as to how they could communicate with the public.

As for the responsibility to communicate, the sample selection method and the professional backgrounds shed interesting examples on the types of scientists that communicate. Three of the expert respondents spent none of their time working in genetics, and eight spent under 24 per cent of their time working in the area, yet each had featured in a journal or newspaper item that had discussed genetic issues. Given that the sample period for the newspaper item was a maximum of four-weeks, we may question the prominence of certain scientists in media coverage. What determines a scientist's inclusion in the media? Is it their scientific expertise or their ability to communicate? The interviewees discussed at length the importance of improving communication and how the media can play a role in disseminating accurate information. The experts agreed that educational improvements and better media coverage are necessary, but they also highlighted the need for more skilled journalists and the potential of scientific adverts to enhance public understanding.
length their responsibilities to communicate. This frequently involved communicating accurate information to patients, and wider patient communities. While for scientists there was an ethical responsibility to engage if you were working in controversial fields, and a need to question why good scientists would be wary of their work being communicated more broadly. Being a good scientist is not about being a good communicator as one interviewee highlighted, but good scientists should be confident that their methods and evidence can stand up to questioning, debate and challenge.

The expert’s responses to the questions regarding some of the issues surrounding new genetics further emphasised the problematic nature of the concept ‘understanding’ if it is taken to infer conclusion or agreement. A range of the questions displayed disagreement and variations often with no correlation to any specific professional backgrounds or experiences. Similar numbers of experts agreed or disagreed with statements like ‘genetic counselling should reduce the number of harmful genes in the population’, ‘genetic therapies and preventative measures should be given priority in health budgets’ and ‘gene treatments are the future of medicine’. While these questions over-simplify a number of complex issues they are the types of question often asked of the public to infer understanding or interest.
As chapters four, five and six have illustrated, extensive and detailed data was provided by the textual analysis, questionnaires, interviews and case study. The information contributed by each of the three samples had a number of distinctive features but equally there were related areas, which became evident as the research developed. This chapter considers the convergences in the attitudes of each of the sampled groups, alongside variations in their opinions. The issues have been broken down into four areas;

- New genetic issues; the specific issues of communication and understanding related to the science and technology of new genetics.
- The media's role in communication; perceptions of the role of the media and journalists.
- The role of the public; how the public discuss and understand medical issues, science and technologies.
- The expert's role in communication; what role do scientists and medical professionals play?

7.1 New Genetic Issues

The textual analysis of scientific and medical journals contextualised the research with members of the journalistic, public and expert communities and illustrated a continued interest in genetic issues amongst professional publications, the print media and their related audiences. The coverage of new genetics in the journals Nature, New Scientist, the BMJ and the JMG, suggested that the research and development of genetic science continues not only to be funded and thus to secure exposure through the publication of original research, but also to be a 'newsworthy' area for professional publications.
Genetic news appeared in the national newspaper coverage, and 41 per cent \((n=74)\) of the newspaper articles from the sample were focused by scientific or medical research. These articles were frequently supportive. 59 per cent \((n=17)\) of those discussing medical research were largely supportive in their tone and 71 per cent \((n=32)\) of the articles concerned with scientific research were also predominantly supportive in tone. Bubela and Caulfield (2004) found that the majority of newspaper articles covering genetic research emphasise benefits. The textual analysis presented in this thesis similarly suggested a greater focus on ‘hope’ associated with new genetic techniques than ‘fear’ during its limited sampling period (Conrad 1997, Petersen 2001). This contrasts with the portrayal of the media as critical and unsupportive of scientific and medical research, and their respective communities (Kitzinger 1999, Hargreaves and Ferguson 2000, Ali et al. 2001, Bartlett et al. 2002, Harrabin et al. 2003, McQuail 2003). The exceptions to this amongst the coverage were those articles that discussed genetic modification in agriculture. As prior studies have indicated this continued to be an area of more vocal media criticism (POST 2000, Shaw 2002, Arntzen et al. 2003).

The impact of new genetic issues was most acute when the range of articles genetic concepts appeared within is highlighted. These included for example; articles focused on crime where the reliance on forensic science was highly praised and portrayed as certain to items focused on familial relationships, where understanding biological heritage was also privileged without question. There were also a number of passing references to new genetics, in television and film reviews, without context or using metaphors, which also illustrates both cultural privileging and an assumption by author-journalists that they will be recognised and meaningful to audiences (Lippman 1992, Katz Rothman 1995, Nelkin and Lindee 1995, Condit 1999b, Lewontin 2000, Glasner and Rothman 2004b). Headline writers made this assumption in particular, utilising terms like ‘Dolly’, ‘GM’ or ‘DNA cops’. This not only suggests confidence that the audience will be aware of and understand
the relevance of these terms, but also that they will be of significant interest to act as a
'hook' to the reader (Nerlich et al. 1999, Henderson and Ferguson 2000).

The potential of the scientific, medical and technological research remained largely
unquestioned in this sample of media reporting from 2001. It provided hope, potential
breakthroughs and cures without question, while genetic causation provided the clue or
single impetus for a condition or disease (Condit et al. 1998, Katz Rothman 1998, Conrad
1999b, Stockdale 1999, Condit 2004b). In this small sample of journal and newspaper
articles alone genetic predispositions were made to diabetes, heart disease, a range of
cancers, osteoporosis, arthritis, hearing and sight impairments, but also to recently
medicalised issues like obesity and agoraphobia.

The resonance of genetic explanations with the public was indicated by some comments
made by the public respondents when discussing how the public understands new genetics,

If it was pointed out from granddad you pick up the eye and it's coming through all
these generations that is a way that would jog people's imaginations... Relating it
to their personal circumstances. People know that if your grandmother had breast
cancer you're more liable to get it then the lady next door (Susan IP002 41-60
Clerical).

Genes have become the focus of an increasing number of health promotion, care and
counselling messages, however prior surveys have suggested that the public has not
become more deterministic in their thinking (Parrott et al. 2004). Instead as Priest
(1999:108) states,

The foundation of the information climate for genetic science is popular belief in
the heritability of various human characteristics and the related popular notion that
'blood is thicker then water'. We believe in the importance of biological heritage.

While prior surveys have not then shown significant changes in the way the public
attributes pre-defined conditions like heart disease to genetic causes, openly asking the
public about the types of conditions they thought were hereditary did illustrate, like
Susan's comments, the resonance of genetic pre-dispositions, in particular related to
As far as genetically modified plants and animals are concerned that was just a kind of safety mechanism? I pricked up my ears and thought this isn't good and these are the things that could go wrong with it...I couldn't see in the long run that it could be safe. That was my instinctive thing (Lisa IP008 41-60 Writer).

Practically at the moment to try and clone human beings seeing what's happened to the animal clones it's wicked, if they are going to have so many medical problems...but I'm not a scientist. When your cloning you start off with a cell, if you start of with a cell from an animal or person whose already X number of years old then to me that is obvious...It didn't surprise me in the slightest that Dolly the sheep when tested showed symptoms of being a lot older then the chronological age (Marion IP001 61+ Clerical).

At least enable parents and their medical advisors to consider whether or not they ought to be bringing a child into the world...There are horrible ethical questions about that because who has the right to play god and say you mustn't be born...You can't say we are not going to do screening because I think the imperative is you have got to do that but what you have got to have is an intelligent way of dealing with the answers you are going to get (Andrew IP004 41-60 Engineer).

Each of these statements highlight a number of further points regarding the way that public respondents discussed genetic developments; the lack of 'common sense', the application of scientific understanding, and the ethical considerations involved in genetic screening and manipulation.
of scientific arguments to their own concerns, and the suitability of other types of experiences, like being a parent, to think through genetic issues. These issues will be discussed later in this chapter. To return to the extracts, these controversial genetic issues for the public raised further specific points regarding their relationships with expertise.

Statements made by the public respondents were often replicated, albeit with more scientific terminology or fluency, during the expert interviews. This highlights not only that scientists are members of the public regarding areas in which they are not specialists but equally that to dichotomise between ignorant public opinion and out of touch scientists over-simplifies a more complex relationship (Edwards 1999, Locke 1999). To take as an example arguments around genetic modification, statements made by some scientific experts raised similar issues to those made by public respondents.

There is this concern about potential problems from genetic manipulation either of people or crops. In some ways this sort of reflects the novelty of something, which has just become possible and we don't know really what the long-term implications of it are. So it's perfectly reasonable for there to be a debate or concern... It's not clear to a lot of people how useful GM crops are likely to be or what their benefits and disadvantages are and I certainly have very mixed feelings about them myself... It is right to be talking about this (Geoff IE005 Research Professor).

While it therefore may appear that the expert and public respondents were making the same claims and arguments, caution appears necessary in considering the experts' statements. Frequently such claims of concern or precaution were accompanied by an externalising of responsibility for such issues as Kerr et al. (1997) similarly found and as this expert questionnaire respondent illustrates.

Genetics is moving faster than the government is keeping up with discussion and legislation - there needs to be more debate about the ethics of using genetics otherwise it will be possible to do so much and there will be no way of controlling it - that seems a situation that is likely to be unethical and very scary (QE011 Female 26-40 Senior Postdoctoral Research Fellow).

Furthermore, Irwin and Michael (2003) suggest scientists actively attempt to incorporate public views into their explanations to assert their own reasoning practices, while continuing to discreetly draw boundaries under the guise of transparency. 'Scientists
represent themselves not only as members of the public, but also as members of its best (most ‘logical’) fraction’ (Irwin and Michael 2003:126). Likewise Hilgartner (2000), using Goffman’s concepts of identity and self, suggests scientists and science advisors interchange their identities, both deceptively and honestly, across contexts.

Performers often experience a profound need to be a certain kind of character, such as a good scientist or public servant, and to act in keeping with this role even when no one else is watching (Hilgartner 2000:14 emphasis in original).

While the expert accounts and in particular their keenness to compare their own views to the public supports these points, so to can they be extended to the publics identities, which fluctuated from confident, to self-ascribed ignorance, to parent, to patient and so on. These issues are also returned to later in this chapter.

Thus experts and members of the public at times appeared to express similar views regarding genetics, and Irwin and Michael (2003) suggest this was a conscious assertion. In which case how did they view each other’s ideas regarding new genetics specifically, as this would suggest some knowledge of each other’s understanding and attitudes? Public and expert respondents had considerably different ideas about each other’s views towards geneticisation and the consequences of the widespread cultural emphasis on genetic cure, treatment and disease. To take specifically the medical experts involved in clinical work, the impacts on patients were frequently discussed. The experts suggested the media and cultural focus on genetics made treatments appear imminent, this could impact on a person’s choice to have a genetic test without a full appreciation of the implications and have an emotional impact on those diagnosed with or without a condition. The medical experts further suggested media sources and information from the internet were now influencing their interactions with patients, ‘there’s a lot of misinformation now, people will arrive with sheets of notes from the internet and that’s a big problem as well’ (Judith IE003 Consultant Geneticist/Clinical Director). Prior studies have suggested that patients bring media resources to medical contexts as a mediatory resource bridging their
‘unorthodox’ account with the professionals ‘orthodox’ views (Britten 1996:70). The views of the medical experts appear to support this account but suggest that this form of empowerment for the public is an irritation for experts, raising further questions about the realities of increased dialogue, interaction or mediatory tools. Judith’s comments infer a lack of ability on the part of her patients to assess the reliability of sources. This contrasts research in this area that has suggested the general public are aware of possible inaccuracies or unreliability, rarely volunteer their ‘informed’ status prior to medical advice and use their commonsense to regulate the information they utilise (Hardey 1999, Henwood et al. 2003). Hardey (1999) suggests the use of the internet as a resource for health information is a new site for struggle over expertise, one which healthcare professionals are now seeking to regulate and define and the attitudes expressed by the medical experts in this research would appear to emphasise similar difficulties.

The medical experts suggested that the emphasis on genetic prevention and treatment had contributed to the wider cultural expectation that a certain quality of life and expectancy is always achievable and this had impacted on the expectations they now felt from patients (Lupton 2003). The public sample was not from a specific patient group, and views from such individuals may have been beneficial to this research. However there was an obvious gap between the expectations of these medical experts and some public respondents involved in the research. The gap and variations between expert and lay ideas about pain, suffering and death has been highlighted in prior work but the data collated during this research in fact indicates a lack of appreciation of each other’s views as opposed to a dissimilarity or conflict (Bendelow 1996, Rajan 1996). Public respondents actively resented being ascribed a ‘sick role’, be it the Doctor asking them if they had aches or pains, an invitation for cancer screening at their local clinic or the use of available medical treatments.

Sometimes science is taking us into very dangerous areas, like keeping premature babies alive. In principle it sounds like an amazing, fantastic thing to do, in practice
it's ended up that there's an awful lot of children who are seriously handicapped and will never have a good quality of life... just because people can do something its questionable whether they should actually use it (Liz IP005 41-60 Academic).

Members of the public encouraged more holistic views.

I do not believe 'particular 'characteristics are hereditary but believe that individuals may have a propensity to develop certain characteristics given general biological make-up AND other factors (QP023 Female 41-60 Teacher emphasis in original).

Again these attitudes were similar to some expert opinions.

There's definitely a major problem with the way people talk about genetics, which is the idea that somehow you could just introduce a gene and make somebody into like a superhuman...modern genetics shows that it’s very difficult just to change one thing like that (Mark IE004 Non-Clinical Research Fellow).

Thus while Irwin and Michael’s (2003) claims are substantiated, experts do replicate public concerns in their thinking regarding geneticisation, there is a lack of appreciation of each others views. Experts perceive the public to accept genetically deterministic ideas obediently, contributing to higher expectations regarding science and healthcare. While members of the public perceive scientists and medical professionals to over-promote the role of genes, also unrealistically reinforcing the capabilities of science and medicine.

7.2 The Role of the Media

The textual analysis of professional journals raised a number of issues regarding science and medical communication with the wider media and their audiences. Only 54 (n=59) per cent of the journal items were authored by those presently working in academic settings, this reflects not only the high amount of coverage given to genetic news in such publications but also leads to questions regarding the print media’s utilisation of such sources and the role of those within the scientific community amongst wider media coverage. The technical, complex and lengthy nature of the journal papers indicated that journalists are likely to be more attracted to the summaries of news in professional journals or to the press releases accompanying them.

It is hard to popularise science because it is designed to force people out in the first place. No wonder teachers, journalists and popularisers encounter difficulty when we wish to bring the excluded readership back in (Latour 1987:52).
The fact that such journal items frequently included genetic metaphors and language, as was recognised by some cautious scientists themselves, led me to question how involved experts are in circulating simplistic or inaccurate explanations? Emma, the science correspondent involved in the case study favoured Matt Ridley’s description of the Human Genome, while items from the journals used language like ‘fight’ or ‘hunting’ to describe relationships between genes, and ‘hope’ or ‘visions’ to explain the potential impact of genetic information.

The data indicated a number of further focuses for research interested in the media and its relationships with the scientific and medical communities and the public. Examining coverage which featured in both journals and newspaper coverage, highlighted that newspapers often misrepresent the journal which research has featured in, or suggest research is credible that may have been admonished by the original journal coverage it received. Though it is only relatively recently that research has considered scientific reporting in more qualitative detail, examinations of the relationships between mass coverage and its origins within the scientific community are emerging (Nisbet and Lewenstein 2002, Bubela and Caulfield 2004, Kua et al. 2004). The public respondents indicated that they utilised the media a great deal for scientific and medical information, and considerably more than educational resources, medical professionals or friends and relatives but the journalists relationship with public audiences is one which is at present under-investigated (Condit et al. 1998, Kitzinger 1999, Condit 2004a). Lewenstein (1995) suggests science writers place more focus on the views of scientists reading their work, than members of the public. However as Emma highlighted, the public, her readers, regulate her role and work to some degree. As this research focused on the media, public and medical and scientific expertise it was able to explore such relationships. Evading an exclusive focus on any one of these three communities reduced the tendency to blame one, if not both, of the other groups for miscommunication and misunderstanding.
The textual analysis of newspaper coverage included tabloid content and this has also frequently been avoided in media studies of science, simply because it is not identified as opinion leading (Nisbet and Lewenstein 2002, Nisbet et al. 2003). Not only do the daily tabloids attract a considerably larger share of the audience, they are often the most frequently criticised. Though accused of ‘dumbing down’ they pay a considerable amount of attention to scientific and medical issues and provide some interesting data (Hargreaves and Ferguson 2000, Bubela and Caulfield 2004).^ 50 per cent (n=75) of the public respondents in this survey regularly read a broadsheet paper, and 64 per cent (n=98) regularly read a mid-market or tabloid newspaper, yet tabloid coverage was continually criticised as poor by public respondents.\(^2\)

If you actually want to try and get some well laid out information, that's been thought about and researched properly, and is written in a considered kind of way you need to go to the broadsheets. The tabloid press...it's all hyped up in one direction or another, because they want to sell newspapers (Andrew IP004 40-61 Engineer).

Are we justified however to criticise tabloid coverage of science and medicine purely on the basis of other features in these newspapers? Are the motives of tabloid, mid-markets and broadsheets really so differentiated when it comes to scientific and medical coverage? On what grounds can experts criticise these types of coverage, given that none of the expert respondents in this survey read tabloid coverage at all?

As an example we may consider coverage of the same scientific research, genetically modified elm trees resistant to certain fungal infections, by *The Mirror* and *The Times*.\(^3\)

Both had somewhat sensationalised headlines, ‘GM trees to beat fungus’ in the case of *The Mirror* and ‘GM elms ‘immune to killer disease“ in *The Times* coverage (Harris 2001, Walker 2001). Both headlines used the abbreviation ‘GM’, and language like ‘beat’ and ‘killer disease’. The reports were clearly based on the same information and covered many

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\(^1\) See appendix one, table 12 page 241 for a comparison of circulation figures.

\(^2\) See chapter five page 123 for the specific newspapers public respondents read regularly.

\(^3\) These articles can be seen in full on page 269 in appendix four.
of the same details. These included details of the immunity provided by the scientific research, the wider positive consequences of the research, its association with biotechnology and a statement from a scientist. Both reports included the assertion 'this is an example of environmentally friendly biotechnology' and were largely supportive in tone (Harris 2001, Walker 2001). *The Times* did include some reflection on the possible negative consequences of the research with a statement from The Forestry Commission that emphasised the developmental nature of the science. It also highlighted that the scientists' comments were from a member of the study. In terms of length *The Times* article was three times that of the item in *The Mirror*, thus it is not unpredictable that the broadsheet coverage was able to go into a greater amount of background detail. However there were few significant differences in the coverage of this issue between the tabloid and broadsheet coverage and the textual analysis instead highlighted questions as to which type of coverage has a more negative impact on science, a brief story in tabloid coverage or a lengthy article in a broadsheet which considers the various implications, social, legal, ethical, environmental, that may never materialise on the basis of the present research? It has been argued that social studies of new genetics add credence to claims that it will be a revolutionary science and we may draw similar conclusions about this type of newspaper coverage.

The public in past studies have often been assumed to accept media depictions of science and views like Andrews on the prior pages were interesting (Gunter et al. 1999, Gellar et al. 2002). The public respondents' estimates towards the reliability of newspaper and television coverage were considerably lower than experts. 21 per cent (n=32) of the public sample stated that newspapers were reliable and 43 per cent (n=65) thought that television was reliable. In contrast 64 per cent (n=23) of the expert respondents believed newspapers were mostly reliable, and 65 per cent (n=24) stated that the television was similarly reliable. The public respondents were critical of the media coverage of science and health,
its sensationalising tactics, over-simplification, and misrepresentations and frequently expressed these concerns. The few studies which have examined how the audience relates to media coverage have similarly suggested more reflexive audiences than are commonly credited (Hornig 1993, Grove-White et al. 2000, Hampel 2004, Levitt 2004).

I don't have a generally good impression of journalists. They are out there to make people sit up and pay attention and that might involve sort of, being radical and getting people to commit themselves, just going over the top (Lisa IP008 41-60 Writer).

Rather than stressing their lack of understanding or confusion, the public respondents had high expectations of the types of coverage they hoped to receive. It had to be entertaining but at the same time there was a clear demand for relevant information and they recognised the difficulties of fulfilling these multiple requirements. The public respondents demonstrated reflexivity in their media choices, attitudes and uses. Hargreaves et al. (2003) suggest people often claim to receive the media critically and it is often difficult to assess how objective they are about actual media use but these views did appear to indicate some prior thought around these issues.

To take as an example 'entertaining' science, some of the data gained from the public respondents supported the positive emphasis of these types of coverage. When Apollo 11 landed on the surface of the moon in 1969 science fiction 'coming true' was a common feeling identified by members of the public (Allen 2002). Marion with her account of The X-files 'coming true' made a similar point regarding The Human Genome Project.\(^4\)

Concurrently there was a fine line between providing entertainment and patronising the public. The quality of science coverage was rarely stated to be 'confusing' or 'difficult' by members of the public, instead 'over-simplified' and 'patronizing' were common statements.

If you are not already interested in a thing it's very difficult [to communicate], unless you sensationalise it and to a large extent trivialise it, you make it so easy.

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\(^4\) See chapter five page 143 for Marion's account.
Public disappointment in the quality and detail of coverage was unrecognised by certain experts involved in the study. These expert responses to a question regarding improving the public understanding of genetics illustrate this point. ‘Back to basics. Take out the ‘scare factor’. They need simple explanations with no strings attached (QE010 Female 26-40 Clinical Geneticist). ‘I don't know 'how' but it needs to be clear, accessible, non-scary, nothing like science fiction etc.’ (QE011 Female 26-40 Senior Postdoctoral Research Fellow).

Returning to the expert’s more general opinions, there was a lack of agreement regarding the present amount of media coverage genetic research receives and whether the media is supportive or unsupportive of science and medicine. There was a 50/50 split amongst the experts as to whether coverage was positive or negative. 33 per cent (n=12) wanted to see more genetic coverage while 46 per cent (n=17) thought there was about the right amount. Relevant points were raised regarding the issue of coverage by the experts who suggested media attention was there for newsworthy issues or good communicators, and by Emma who stressed that as genetic research is an area of significant funding it will inevitably draw attention. This suggests a media interest in new genetics originates from the scientific and medical communities themselves.

In terms of the more personal relationships between journalists and scientific and medical experts there appeared to be little personal dissatisfaction with such relationships. The experts who choose to communicate with the media appeared to separate those journalists they had decided to work with, from their more general opinions about the profession. This has not been an area of significant past research though it has been suggested that scientists actively involved in an article are rarely dissatisfied with coverage they receive (Bubela and Caulfield 2004). The exception to this was Maria who clearly felt she had been
significantly misrepresented stating; ‘I don't see why the media’s trust in science and medicine is important because frankly they are not scientific and medical people’ (Maria IE002 Consultant). This statement highlights a number of points. Firstly Maria draws a significant distinction between ‘scientific and medical people’ and others, in this case media professionals. Secondly it suggests that the views of her peers are important and may impact on how she hopes to be represented in media coverage. Thirdly this coupled with a number of other statements Maria made, suggested her involvement with the media had been disappointing for her. Other experts highlighted the issue of over-expectation on the part of the expert, suggesting scientists expected special treatment, had expectations which were too high or did not understand the professional constraints and requirements of the media. Mark a Non-Clinical Research Fellow raised a number of issues, and also highlighted that mixed-views do not inevitably denote confusion.

Scientists sometimes grumble too much...there's an important role for the media in actually exposing scientific statements that are made in the guise of science, like about GM crops, things like that which are not necessarily as black and white as science would like to think. Sometimes the media go over board and they do misrepresent things simply because they don't get their facts right but its often a kind of confusion about what the media is really there for in scientists eyes that's the problem. I've got mixed views, I probably sound a bit confused but I see it both ways (Mark IE004 Non-Clinical Research Fellow).

There were however practical irritations regarding the manner by which journalists approached experts; cold-calling them, requiring immediate responses and ‘sound-bites’. Prior research has highlighted these difficulties and equally their inevitability in a pressurised environment like the media (Friedman et al. 1986, Nelkin 1987, Kitzinger and Reilly 1997, Gunter et al. 1999, Hargreaves and Ferguson 2000). These comments did though highlight the role of the scientist in providing simplified accounts, and their role in inaccurate media coverage. The blame for inaccuracy is often placed on the journalist and their failure to interpret a scientist’s work appropriately but if the journalist has required an

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5 See chapter six, page 173 for further comments made by Maria.
explanation from a scientist, the failure in interpreting the work inevitably involves both parties.

Maria, the expert who was most sceptical of the media interpretation of her work suggested journalists lacked the education or knowledge to report on areas like science. This is an issue that has occurred in prior studies, and one which though lacking merit, I will discuss briefly (Friedman et al.1986, Nelkin 1987, Hargreaves and Ferguson 2000, Hotz 2002).

Emma the science correspondent involved in the case study had come from a scientific background; though she suggested it sometimes made scientists more willing to talk with her she clearly identified herself as a journalist and not a scientist. Similarly other studies have continually shown that experience can be as much a hindrance to a science correspondent as ignorance, ‘biting the hand that feeds you’ can be a considerable constraint, and though a number of science correspondents have scientific qualifications they themselves do not identify them as essential (Nelkin 1987, Hargreaves and Ferguson 2000, Hotz 2002). Yet the view that correspondents are unqualified persists amongst some experts in the present context and this ‘deficit’ in journalistic understanding remains a convenient excuse for scientists to use if media coverage is not to their liking.

7.3 The Role of the Public

The results of the public questionnaires suggested a wider interest in science and medicine than may have been anticipated. 80 per cent (n=123) of the public respondents were ‘quite’ to ‘very’ interested in health and science issues. Though this would have been affected by their self-selection to complete a questionnaire, the sampling method, which had targeted members of the public with no prior agenda, illustrated some broader interest in the issues.6 Some public respondents had experience of genetic conditions but this had little impact on their specific responses, other than that they appeared more often to add explanatory

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6 See chapter three page 55 for more discussion of the sampling methods used.
comments to their statements. Regarding the qualifications of the members of the public, there were also those with scientific and medical skills or a good education. Andrew for example, a member of the public sample was an engineer, while Lisa also a public respondent was a writer. The 153 questionnaire respondents came from a range of educational and occupational backgrounds, as did the interviewees. There were limited variations in attitudes correlated to educational or occupational background, hindered by the relatively small sample size. Some occupations were moderately over-represented but accessing typical and representative samples has been a problem in similar qualitative research (Glasner and Rothman 2004b). Though the attitudes expressed by the public respondents may then seem educated or well developed at times, the sample was largely representative and again this points to issues in labelling the expertise of 'the public'. It is important to remember that when discussing 'the public' we do not simply assume them to be under-educated, unskilled or inexperienced. Engineers, teachers, writers are as much members of the public, as clerical workers, sales assistants and electricians.

Traditionally consulting with the public has drawn only 'predictable' voices and accessing the 'uncommitted' or general public has been difficult and rare (Irwin 2001, POST 2002, Irwin and Michael 2003, Poortinga and Pigeon 2004). This was one of the major criticisms of the 2003 GM Nation debates, which were accused of being 'hijacked' by anti-GM campaigners (GM Nation? Steering Board 2004, Macmillan 2004, Poortinga and Pigeon 2004). Participatory approaches can in the act of inclusion be an exercise of power, by legitimising the views of certain excluded groups the strength and scope of their views can be confined (Kothari 2001). As Hilgartner (2000:9) states,

Vocal members of the audience stop being mere spectators and become another set of performers, who (like advisors) also face the challenges of assuming creditable characters and presenting credible messages. Public debates over science advice are

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7 The occupations of questionnaire respondents can be found in chapter five page 121. Further details of the public interviewees can be found in table 14, appendix four, page 270. Each interviewee is discussed in detail during chapter five.
therefore theatrical contests in which the protagonists perform opposing dramas before audiences that include (but are not limited to) one another.

The image of science in the UK 'completely overrun by protestors and pressure groups which used emotion to drive out reason...a small band of people...who genuinely want to stifle debate' makes it easy for scientists to stereotype any public reaction as dramatic or emotional (HMSO 2002:2-10). Therefore the selection of a public sample unmotivated by a particular interest or financial incentive, often used when the views of 'blind' publics are targeted, was an unusual aspect of this research (BA 2004).

Attending events aimed at the public it is often noticeable that much of the audience are quick to declare themselves as professional scientists. The approach of my research was somewhat risky and assumed prior attitudes or interest in issues existed (Flynn 2004). However the successful response rate helps us to move away from ideas that members of the public that are concerned or knowledgeable regarding science, medicine or technology are 'special', while also attempting to acknowledge the views of members of the public that may become sidelined by the strength and inclusion of activist groups. Huniche (2003) describes learning from the 'voiceless' and Lawton (2003) similarly suggests the presence of 'missing voices'. By targeting those without incentive to be active in their knowledge, vocal or participant, public respondents distinguished both their ability to discuss issues and their roles from 'activist' publics as will be considered later in this chapter.

The extracts from members of the public demonstrated both an interest in science, medicine and genetics and some well-developed narratives of such developments. Public views were clearest in their opinions regarding regulation, control and access to genetic techniques airing on the side of precaution. The public respondents were predictably clearer about policing ethically problematic decisions than concluding on appropriateness but were generally unaware of what the government was doing with regards to scientific and medical legislation (Hargreaves et al. 2003). The focus on a deficit in public
understanding of science may have ignored the issue that a greater awareness of regulation and control may better address public concerns. Issues of high press coverage like genetic modification in food and agriculture, and Dolly the Sheep drew the most defined public narratives, suggesting that 'the consistent telling of a story - particularly one with echoes of other stories - clearly influences public understanding' (Hargreaves et al. 2003:51).

Further the public reactions to genetic modification in food and agriculture and the cloning of Dolly raise other issues. The public sample was drawn from three areas of the South-West, two cities and one more rural community. The locality of knowledge can often award it special merit and as agriculture remains prominent both visually and economically in the South-West this raises further considerations (Collins and Evans 2002). As John a public respondent stated, 'in my case, my in-laws are farmers and they talk about genetic this and that but then they go out and spray all sorts and they don't know what they're spraying on' (John IP003 41-60 NHS Support Worker). Though John was the only interviewee to mention a specific link to the farming community, and no questionnaire respondents stated a related occupation, the interest and confidence to discuss the issue of genetic modification cannot be distinguished as either an indication of the general level of press coverage or the insight of regional interest. The relative acceptance of genetically modified products in the United States for example has been in part attributed to the small percentage of the public that are engaged in agricultural production (Amirzen et al. 2003: 840). However it seems likely that the geographical context of the public respondents did influence such views, as Crisp (1986:74) suggests

Small communities that fall by geographical accident into the forefront of the nation's search for the solutions to its most haunting problems should be first in line to get the most complete and accurate information possible.

Again the association between science, technology and context may be reinforced by the familiarity with agriculture amongst members of the public in these geographical areas,

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8 Chapter three, page 55 has further details of sampling.
relating to their ideas about ‘naturalness’ in a similar fashion to their understandings of familial or hereditary links (Pilnick 2002).

The public concerns that naturalness was being destabilized involved the only personalised lack of respect shown towards scientists and doctors. While the public rarely expressed dissatisfaction with individual scientific and medical experts, instead the commercial, professional and political pressures they faced concerned them, the ‘absurdity’ of some scientific ideas was a source of humour for some respondents (Irwin 1995). ‘Don’t they know that birds and bees can fly’ was a comment expressed by at least two of the public interviewees. Here we can draw comparison with Latour’s (1987) discussion of the popular misconceptions around meteorology, the public respondents had not only developed their own beliefs but further suggested the experts were irrational.

The interviews with members of the public existed in a wider political context illustrating that ‘science disappears within everyday life’, both in how they [the public] relate to it and the influences they perceive as acting upon it (Irwin et al. 1996:52). Infrequently public respondents mentioned basic scientific understanding or the methods of science in their justifications or criticisms, but reflected more generally on issues motivating the sociology of science; detecting ‘when scientific knowledge has actually been influenced by other political or ideological agendas to the extent that its content has been affected by those other commitments’ (Yearley 1994:253). These types of details however, as the content analysis of journal and newspaper coverage indicates, are often lacking or depicted as untypical, conflicting with present public demands (Nelkin 1987, Rogers 1999, Kua et al. 2004).
The public respondents used and demanded scientific thinking in some of their arguments, expecting rationality and objectivity, criticising methodologies or risk factors, but they also related their understanding to their experiences, both professional and personal.

The selection of children specifically to help other children...who are sick already. I can understand on the one hand their anxiety, if it were me I think I would do it, but standing back at the same time I'm uneasy at that being the reason for having a child...that's an emotional reaction, and I can't really justify it anymore than that. Your emotions at some point take over and cloud your judgement. I would say basically it's wrong but then if it was me I would probably go do it (Marion IP001 61+ Clerical).

We knew a couple who adopted a child who had Huntington's disease and they accepted that the child they were adopting might be dead by the time he's twenty or something but they said well so what?...There is still a life there and all that sort of thing at whatever stage that child dies (Leonard IP009 41-60 Water Resources Planner).

The public respondents appeared more confident in their responses to issues where there has been high media coverage, longer public familiarity or where they were questioned on social and ethical issues. For example 69 per cent (n=106) of respondents were 'not sure' when asked if an individual has around 30,000 genes, while only five per cent (n=6) were 'not sure' if abortion is appropriate if the health of the parent or child is at risk. What do such 'not sure' responses tell us about the public? Prior surveys have included analysis of this type of 'don't know' response. Wagner et al. (2002a:328) state 'in questionnaires self-ascribed ignorance is expressed as a 'don't know' response' however this over-simplifies public attitudes which are as likely to be confused or undecided, as unaware.

Large proportions of people are unable either to agree or disagree...a likely reflection of widespread uncertainty in the face of expert disagreements as well as lack of information and understanding (Christie and Jarvis 2001:136 emphasis in original).

The public respondents held defined opinions on certain issues; they were not ambivalent as they lacked thought or understanding but because they recognised the complexity of the area and sought to explore the issues more extensively (POST 2002, Brown 2004). The issue for public engagement strategies is to recognise that resolution or definition of attitude is not always possible, and to be capable of incorporating such varying responses (Irwin and Wynne 1996).
The inclusion of comparative questions in the expert survey provided further illustration that public consensus and consent might be an unrealistic aim. Science incorporating debate was a point itself raised by a few of the experts, some of whom also suggested that opening science to more criticism and revealing scientific uncertainty would make it more rigorous (POST 2002). Figure 17 illustrates that the experts themselves were undecided or lacked consensus on a range of issues. While these questions are overly-simplistic, as some experts highlighted in the further comments sections of the questionnaire, they illustrate the problem of assuming that non-consensus infers a lack of understanding, clear viewpoints or opinion. Wynne (2003) suggests experts, governments and commercial interests will often reject such generalisations as they seek the ‘narrowest possible definition’ of a question, anything further may be dismissed as irrelevant, imprecise, or subject to unreliable sources, which does not allow for a more realistic and comprehensive framing of science. Despite then, the sometimes negative reactions to these questions this was an important aspect of the questionnaire.

Returning to the public respondents, in some cases they suggested an opinion was difficult unless you had experience of a situation, with attitudes such as ‘there are no black and white answers’, or it ‘should be up to parents’. Barns et al. (2000:300) similarly found that

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9 See Marks comments on page 180 for further support of this point.
10 See chapter three page 70.
in focus groups discussing genetic medicine, lay persons expressed 'communal moral reasoning' that is to say 'even where participants expressed views critical or sceptical of developments in gene technology, they nonetheless displayed an awareness of the complexity of the issues involved'. The narratives public respondents created interacted with their existing 'frameworks' and utilised information already available to them; their opinions towards science, medicine and the media, their family histories of disease, their understandings of nature and religious beliefs, even their experiences with their own GPs (Edwards 1993, 1999, Franklin 2004). The public undertook these 'coping strategies' when dealing with scientific innovation, accepting images and representations that they can adapt to their everyday thinking and common sense notions not only to interpret but also to understand and explore (Wagner et al. 2002a). Furthermore as nine per cent (n=14) of the public respondents had themselves or had family members that had undergone some form of genetic testing, the frameworks on which the public build their knowledge are only likely to increase assuming genetic science fulfils its promises.

Despite their own interest or understanding public respondents distinguished themselves from 'other' members of the public. Those who lacked interest or would utilise genetic developments for their own means, were externalised.

I would like it to be a well informed [public] opinion rather than listening to the tabloids and that's another issue. I don't think dare I say it, that some, well really quite a lot of people in this country are particularly well informed (David IP007 41-60 Teacher).

In an ideal world, yes it would be nice if we could have that kind of dialogue [between scientists and the public] but it would mean a very well educated public (Lisa IP008 41-60 Writer).

Henkel and Stirrat (2001:175) chart the social history of participatory practices which have emerged not only through political and economic developments but spiritual, religious and moral duties; 'participation is not only – in some senses not even in the first place – a right, but also a duty'. Public participants thus admonished others who were not informed or
active in debates in a similar fashion to that described by Huniche (2003) in her research on persons with Huntington's disease.

Persons who do not voice themselves publicly with respect to being at risk... are broadly spoken of by others as persons who avoid the subject, repress the facts, and act irresponsibly (Huniche 2003:259 emphasis in original).

Huniche (2003) makes the point that such non-active persons do indeed speak and think about issues but not in active ways, which others may be aware of or recognise. In my research the public suggested that 'poor' and disinterested members of the public were in the majority, and externalised themselves from this group, the 'wider public'. This contrasts with Michael's (1998) suggestions on the basis of work carried out by Wynne (1996a, 1996b) that homogenised lay communities emerge. The public respondents in my research isolated themselves, though their explanations were often similar, they lacked recognition of their comparison to other members of the public.

Concurrently the public respondents displayed very critical attitudes to those groups who held up scientific and medical research, also segregating themselves from these types of campaigners, as the following extracts suggest.

We should be aware of those who thought that the printing press and microwaves would be the end of civilisation (QP018 Male 61+ Environmental Health Officer).

I suppose there are some dangers but I have got a feeling people have said that through every scientific development through all time. They weren't very pleased with Galileo when he suggested the world was round (David IP007 41-60 Teacher).

Some people do have strong concerns but they're probably the people who have strong concerns about everything...you can't get too concerned (Leonard IP009 41-60 Water Resources Planner).

Often in these cases they discussed the historical context of prior scientific research. This was a tactic also utilised by scientists and journalists but further it illustrates what Brown and Michael (2003) have termed 'retrospecting prospects', where we recollect past futures or how the future was at one time represented. Experts and members of the public drew comparison to prior scientific controversy suggesting that public controversy is an integral part of science, which is inevitably resolved (HMSO 2002). Of more interest is the
somewhat contradictory manner in which the public respondents define themselves; they like to take an interest but not too much, again an indication of the complications in public views.

While the public respondents then often suggested they had a greater awareness of new genetics, than the generalised ‘other’ public, this did not translate into a particular confidence in their knowledge or the contributions they could make to public dialogue (Hargeaves et al. 2003, Hampel 2004). As Michael (1996:108) states, ‘people are very adept at reflecting upon this manifest absence of knowledge, that is upon their ‘ignorance’’. Though relatively confident that they understood some of the issues related to new genetics, 61 per cent (n=94) of the questionnaire respondents stated that they thought they understood some of the issues; this was not in a pro-active or challenging sense. The public instead sought to reduce or apologise for their lack of understanding.

I just don't think we know enough about it at the moment and they [the public] just touch on it in passing but it doesn't affect them yet. So I don't think they feel it's that they can do anything about it or that their opinion counts (Susan IP002 41-60 Clerical)

I think I have a very superficial knowledge of genetics (QP010 Female 41-60 Teacher).

Despite their understandings or attitudes they were unsure of their role in debates about scientific and technological progress, reinforcing ‘the tension between wanting to be involved yet simultaneously feeling unable to participate’ (OST and The Wellcome Trust 2000:26, Hargreaves et al. 2003, Irwin and Michael 2003, Franklin 2004). While the public respondents blamed other members of the public ‘for believing the tabloids’, they strikingly placed no responsibility for their own perceived deficit on the media, communication or experts. All was placed on themselves, their own lack of education, interest or understanding. Though the public respondents struggled to identify their role or relationship with other members of the public, they also used their ‘knowledgeability’ (or perceived lack of) to perform the identity of a ‘lay person’ (Michael 1998).
The experts similarly rated public understanding poorly. 57 per cent (n=21) of the scientific and medical experts rated the public understanding of science and medicine as poor to very poor, and 30 per cent (n=11) rated their understanding as neither good or poor. Unsupportive views, though rare, were apparent; one expert described the public as ‘limited, they are more interested in game shows on the whole’ (QE017 Male 41-60 Clinical Geneticist). This raises the question why are the public identified as a credible threat to expertise? The experts largely held the view that there was a deficit in understanding, and while they accepted there was a responsibility to communicate with the public, particularly in health related or socially controversial areas, they segregated this from the responsibility to improve how the public understands scientists. This responsibility was primarily placed on the education system, the media and mechanisms to help ‘sell science’ to the public, reiterating the emphasis on old-style PUS. Despite this, and as previously mentioned, they perceived an expectation amongst the scientific community to listen to the views of the public, there was an apparent level of keenness amongst experts to promote public understanding. The link made between such activities and funding mechanisms by a number of respondents suggests a somewhat cynical motivation for this, while concurrently suggesting a number of the public concerns regarding commercial or governmental influences may be accurate.

Confidence in public support is rarely recognised in the current climate but other studies have suggested that the public are willing to embrace new technologies and are in favour of some aspects of new genetics in particular those with medical potential (MORI 2001, MORI/BMA 2001, RSA 2004). Despite the concern over public understanding and suggesting the need for improvement experts, like the public respondents, did not recognise a widespread crisis in public trust for their role. The public respondents remained largely trusting of science and medicine and supportive of its generally progressive stance,
thus some statements made by each sample were again similar, as Geoff’s comments
demonstrate when compared to John and David’s views.

The ordinary public appreciate that you know much of their everyday life now is
dependent on some sort of electricity and modern medicine and so on...that aspect
of their life they kind of take for granted...there are some people who seem fairly
hostile to scientific activity. I think that’s a minority, most people do have a
reasonable trust in what science is about (Geoff IE005 Research Professor).

I think it’s marvellous actually science. I mean the technology about. Like this
morning when I put my washing in the washing machine and just press some
buttons, that sort of thing (John IP003 41-60 NHS Support Worker).

Science and technology...its responsible for our standard of living today...I’m more
optimistic about science and GM and all these sorts of things that get people
excited, than taking the other view. I mean it’s very easy to be a Luddite. No I am
pro science (David IP007 41-60 Teacher).

In this broad sense there was little questioning of the wider motivations and aims of
science, medicine and technology, overall there was a genuine sense of enthusiasm
amongst the public for scientific developments and it was only at a more detailed level that
cconcerns were raised. When public respondents were actively critical they often sought to
reiterate an overall level of support; ‘science and medicine maybe in some cases has got a
bit to clever for its own good. That doesn’t mean to say that I totally reject it’ (Liz IP005
41-60 Academic). As in other studies, the views of the public respondents suggested they
were not ‘anti-science’ (MORI 1999, MORI 2001, MORI/BMA 2001, OST and The
Wellcome Trust 2000).

7.4 The Role of Expert’s

The textual analysis and discussion of the media coverage with journalists, medical and
scientific experts suggested that the link between scientists and media coverage is often
under-estimated or distorted. The technical nature of journal coverage and professional
writing in science leads to the assumption that the metaphors or simplifications of media
coverage occur at the level of the journalists interpretation, that there is a need to change
‘how’ something is said (Kua et al. 2004). However the data collated suggests the scientific
and medical communities themselves have a much more active role in these types of explanations.

At times 'experts' that communicate science and medical issues can appear on the periphery of a field of expertise, a concern expressed by Mark during the interviews. Here it is worth repeating a point regarding sampling. Of the ten journalists that completed the questionnaire, four were specialist science and health correspondents, and of the 37 scientific and medical experts that responded 46 per cent (n=17) spent over 75 per cent of their professional time in genetic activities. These journalists, scientific and medical experts had all authored or been cited within an item on new genetics appearing in a journal or newspaper during a two-to-four week period in 2001. Regardless of their professional experiences, qualifications or peer esteem these were the people writing about or discussing genetic issues. 'Experts' are licensed to become involved in such issues by their segregation as non-members of the public, they are legitimised by their general role as scientist or doctor, not only to discuss other areas of science and medicine but also wider social concerns, it is thus somewhat predictable that the public find it difficult to distinguish the core of expert knowledge (Nelkin 1987, Turner 2001, Prior 2003).

While misrepresentation was an issue for some of the experts as has been discussed earlier in this chapter, the balance of scientific coverage was also of concern. Emma the science correspondent discussed the problem at length. It's not fifty/fifty, sometimes it can be ninety nine per cent of the scientific lobby who thinks one thing and one per cent who thinks the other. That's not to say the one per cent is always wrong...it is beholden on the journalists to spell out where controversy is accurately (Emma IM001 National Newspaper Science Correspondent).

10 per cent (n=18) of the newspaper articles were neither supportive nor unsupportive as they attempted to 'balance' half the article with positive associations to science or medical

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11 See chapter six, page 175 for Mark's comments.
12 For Emma's comments see chapter four, page 115.
research and half to negative implications. Steven, the director of a research institute made a number of points,

The timing of interventions in the media are important. If you allow a momentum to be built up against the technology, rational or not...its very difficult to change and you really need the government to act or create some sort of honest broker to try and act as a focus for a debate...If the argument for GM crops fails...on illogical grounds, then the pressure groups will just move on to the next target...the scientists try and argue on logical grounds and the opposition say 'well we are not bothered about factual details' we just don't like it...So the scientific community has got to be aware that there is a potential domino effect if you start losing small battles then you could end up with almost an anti-science agenda (Steven IE006 Research Institute Director).

There are numerous issues here, the separation of scientists versus anti-scientists, the definition of scientist's arguments as factual and 'the oppositions' as illogical or a matter of taste, and this distinction between categorically 'for' or 'against' science. According to Steven if you are against science you have the potential to contribute to the destruction of science in the UK but Stevens comments further remind me of a point made by Yearley (1994:248)

As science becomes more expensive and government (even universities) choose to back certain lines of enquiry for their possible economic pay-off, there is more pressure on scientist to come to solutions quickly and not to engage in interminable disputes.

Such attitudes, as that expressed by Steven, continue to define science as accurate, to use it to 'silence people', and depict other opinions as value judgements; the ascription of right or wrong knowledge can potentially always be used against public concerns (Katz Rothman 1998). These issues begin to illustrate the problematic nature of balance in science coverage and debates around science more broadly (Nelkin 1987, Evans and Priest 1995, Irwin and Michael 2003, Condit 2004a).

If objectivity is not interpreted as accuracy, then it is interpreted as 'balance'...it leads to the temptation to report only polarized opinions and interpretations, leaving out the broad territory in the middle. It is a special problem in science journalism, where reporting only polar ideas can result in too much attention to 'fringe' ideas held only by a few maverick scientists (Evans and Priest 1995:329).

Objectivity is a problem when the argument of one scientist is just that, one scientist, while scientific consensus largely rests elsewhere and this is not made clear. In such cases
however as Hargreaves and Ferguson (2000) highlight the minority view should be recognised, as it may be correct in the face of scientific consensus. In defence of this view, Emma drew similar historical analogies.

There’s the example of Stanley Prusiner who discovered prions and everyone thought he was crazy for years, decades actually people thought he was crazy and actually now prions are accepted, they are a new infectious mechanism like a bacterium or virus (Emma IM001 National Newspaper Science Correspondent).

Furthermore, Nelkin (1987) suggests there is little room in scientific coverage for uncertainty and this was also a strong, if impractical, recommendation of the experts involved in the study. Research has previously shown that open-ended scientific uncertainty or ignorance is problematic to define or communicate though there has been an increased focus on conveying it to the public (Grove-White et al. 2000, POST 2004, Wilsdon and Willis 2004).

You can’t tell what discovery, in a subject like genetics, will be of use in twenty years time. Nobody would have imagined that Mendel growing his peas in his garden would have led you know, ultimately to recombinant DNA, cloning and all that sort of stuff. We do need to foster science which to the public might seem quite irrelevant, pie in the sky sort of stuff because down the line that can be something which factors as tremendously important in the view of practical applications. We can’t tell that at the time... it’s important that sort of message gets across (Geoff IE005 Research Professor).

There’s often this idea that people who are against GM crops are on the grounds of ignorance and yet if you look at a lot of the people who are against GM crops they use what I would call scientific arguments. They use arguments about the fact there is a real risk of genes passing between organisms, now whether or not you agree with these oppositions is a kind of debate in itself but they are not ignorant and I think that sense of using facts to actually create debate and actually make them more aware that scientists are not black and white and actually sometimes there are hazy areas where there is a real debate going on, that in itself, that’s the sort of public understanding of science I would like to see (Mark IE004 Non-Clinical Research Fellow).

Mark’s comments are thus strikingly different to Steven’s on the previous page. For Steven public arguments against science are invalid and potentially damaging, for Mark they incorporate scientific arguments and are potentially positive, as expectations around science will become more realistic. As Nowotny et al.(2001:208) state, ‘public contestation almost never leads to demands to dispense with scientific objectivity. Rather the reverse; it intensifies the search for better science’.
However the use of opposing voices and argument in scientific and medical coverage is not without advantage. This was illustrated by certain aspects of the journal coverage, where the potentially negative implications of scientific research and technologies were either externalised to other experts or attributed to maverick individuals and corporate interests. Experts like Takashi Okamoto, Hiroaki Serizawa and Severino Antinori were framed as individual deviants, with little reflection on the underlying causes of the scientific or medical expert's actions (*Nature* 2001, Barratt 2001). The depiction of Professor Sir Roy Meadow was particularly interesting as at the time of this largely balanced journal item he received a sympathetic description, in contrast to present opinions regarding his expertise (Jackson 2001, GMC 2003, Goldsmith 2004). The work of Nelkin (1987) remains relevant, suggesting there are two approaches to scientific fraud in press coverage.

The first [approach] suggests that fraud is simply the deviant behaviour of individuals, the second that it is a larger phenomenon with underlying causes that are basic to the present organisation of science. Yet both convey a mystique about science, idealizing it as a sacrosanct, if vulnerable profession (Nelkin 1987:24).

Despite, or perhaps due to such cases, public trust in the explanation, citations or comments of scientists was extremely high, particularly in comparison to their attitudes towards the trustworthiness of journalists, politicians and policymakers. As public trust in the comments of friends, families or relatives of those with genetic conditions was also lower, this suggests that while expertise has been affected by changes in patient communities, the voice of experts remain significant for the public. 78 per cent (n=119) of the public questionnaire respondents ‘mostly’ trusted doctors and 64 per cent (n=98) ‘mostly’ trusted scientists. Trust in doctors and scientists also remained high amongst the journalists surveyed. Prior studies have suggested that controversies like the BSE crisis have led to scientists no longer being ‘a trusted partner’ in debates over scientific issues, however the data collated from the public in this study reiterates that trust is most lacking in government and commercial organisations, with public trust in the views of academic researchers, scientists and medical professionals remaining high (Grove-White et al. 2000, Christie and Jarvis 2001, Hails and Kinderlerer 2003).
More widely there was also public support for scientific and genetic research. When the public questioned how it would be regulated and its social and ethical implications their questioning of the scientists motives for such research further segregated the general aims of 'science' from the behaviour of individual scientific and medical deviants; those motivated by personal financial or professional gain. The externalising of 'poor' scientists from the generalised 'good' scientific community was in contrast to the public respondents ideas about 'poor' and disinterested members of the public who were identified as being the majority. As Andrew a member of the public stated,

> It strikes me that the majority of scientists are...for getting at the truth behind things and trying to do it in an objective way and reach some kind of understanding...other people are trying to direct things, because they have their own agenda, political agenda...vested interests that they try to steer you in (Andrew IP004 41-60 Engineer).

Thus questioning why research was being carried out largely remained at a simplistic stage probing commercial, financial or professional motivations at an individual or corporate level. While some members of the public queried the wider aims for developing such technologies, often when concern was raised over dabbling with 'nature', this was more unusual (Barns et al. 2000, Wilsdon and Willis 2004).

> The world is created and it works very well, it worked for centuries and a millennium or whatever it was, before we came on the scene and yet within the few short years in terms of human history, scientists are changing so much (Liz IP005 Academic 41-60).

The negative attitudes associated to funding bodies, political interventions and commercially funded research and development, in particular pharmaceutical companies suggests commercial groups should focus more strongly on issues of public communication. Research which has been carried out with the private industrial sector suggests they barely consider social impacts beyond health and safety issues, are unsure who the public are or what constitutes engagement, lack any standard processes to engage with the public and are vague about handling uncertainty or ignorance in their communication strategies (Grove-White et al. 2000, RSA 2004). If true dialogue is to be effective in science, corporate interests must also address these issues.
Conjuring up the example of Monsanto is usually enough to make the point that the failure to participate openly in, or the intention to subvert, processes of public debate around new technologies can have disastrous consequences for the profitability or even survival of a firm (Wilsdon and Willis 2004:51).

The attitudes expressed by the public respondents towards companies like Monsanto, and pharmaceutical companies more broadly, illustrate the potential commercial impacts of poor public dialogue and engagement in an already high risk area (Wilsdon and Willis 2004, Glasner and Rothman 2004a). Consider Andrews comments,

Another worrying aspect is when you have large companies like Monsanto... where they are totally dominating, or trying to totally dominate the world seed market and force farmers. They're trying to bribe them into buying their seed, knowing full well that each year they are going to have to totally re-buy there seed. They can't put 10 per cent buy and grow next years crop from it, its infertile, the seed that's produce from the plants that grow from the seed, won't germinate (Andrew IP004 41-60 Engineer).

Whilst there was some approval of committees and boards being set up to regulate the area, particularly by the public and with public involvement, there was a lack of faith in both politicians and the public's abilities. The public continued to view such government interventions with suspicion and distrust (Grove-White et al. 2000). While public support was high for government regulation of science, 82 per cent (n=126) of the public respondents agreed or strongly agreed that geneticists conduct should be regulated by government legislation, only one per cent (n=2) of the public sample said they would trust the comments of policy-makers or politicians and particularly negative comments were associated to such individuals.

I'm very cynical about politicians and government and their motives. I have come to the point where I suspect everything they do. I've become paranoid about their motives...there's always got to be some other reason behind it (IP001 Marion 61+ Clerical).

One would like to say a government should be involved but...I don't trust this government but in an ideal world it would be very nice if there was a decent government who would do what they should (Lisa IP008 41-60 Writer).

Thus it is also clear that governmental policy-making and recommendations in the area of public engagement and dialogue have significant bridges to build, not in gaining trust for the science or technology alone but in their role as conduit, funder and regulator.
The scientific and medical experts had a number of reasons or responsibilities to communicate with the public; to promote 'correct' medical information, become involved in ethical and social implications, stand up for scientific and medical communities and to receive continued funding for their research. Whether these were a responsibility or a motivation is disputable given the varying attitudes of the expert sample. However it was also notable that members of each three sample groups; journalists, members of the public, and scientific and medical experts highlighted that communication was neither an essential or necessary role for the majority of scientists.

7.5 Summary

Genetic news continued to have a high profile in professional journals and the print media, with public salience around genetic terms, language and metaphors. The public related to these types of depictions, in particular due to their relationships with family members, community settings and wider experiences than simply cognitive knowledge, education or understanding. They confidently applied narratives in areas of high press coverage, or where there were wider experiences to draw from. Both experts and members of the public were concerned by the emphasis on genetic prevention and cure, each assuming the other to promote and believe in the prominence of genetic factors.

Print media coverage was often generated by the scientific community, and reliant on those on the peripheries of expertise. Simplifications, metaphors and explanations were as likely to be produced by the expert communities, as reproduced by the journalist, though misunderstandings in these interpretations were evident. Public audiences not only made demands of media coverage but were the most critical towards it; while they hoped to be interested or entertained they found some coverage patronizing. Scientific and medical experts were concerned by the role of the media, though largely expressed satisfaction with personal the coverage they had received.
The media, scientific and medical communities had low expectations of the publics understanding and interest, in contrast to the data gathered from public audiences which suggested some confidence and interest on their part. Though there were concerns regarding regulation, motivations and the aims of some genetic developments, there was little evidence of 'crisis' amongst the public who remained largely trusting of scientific and medical professionals. Public respondents did not recognise themselves as either members of a 'lay community' or equipped or informed, and took clear responsibility for their own lack of knowledge.

The scientific and medical experts often expressed similar concerns to the public but this requires further insight as to their motives in doing this. Experts were as likely as members of the public to offer non-defined opinions on some areas of ethical concern, suggesting that such 'uncertain' responses need to be analysed within their broader contexts. Scientific and medical experts recommended better ways to deal with balance, uncertainty and risk in media coverage and public understanding, while concurrently externalising those who eroded such relationships from the scientific community. Despite the low expectations experts had regarding members of the public, and their continued expectation that they have public support their relationships with the public were still identified as an area for improvement, with the wider potential to act as a credible threat to the scientist and medical professional's role.
Chapter Eight: Conclusions

In this conclusion I summarise the various interpretations of expertise and communication contributed by journalists, members of the public, scientific and medical experts during my research. I discuss their similarities and differences and the problems respondents faced in identifying their own roles and responsibilities. Further I discuss the broader needs for communication, and the difficulties varying aims are bringing to the context of engagement between different groups. Throughout this chapter I consider the wider setting of the political emphasis on mutual communication and the realistic possibilities of such an approach in light of the attitudes expressed during this research.

8.1 Multiple Identities, Multiple Experts?

The accounts brought to this research by the three sampled groups; members of the media, public respondents, scientific and medical experts, brought unanticipated results concerning the formulation and depictions of identity both of oneself and of others. In the attitudes shown to the other respective samples there was an apparent distinction made between individuals and communities in a number of senses. Journalists segregated the scientists they networked with from their attitudes to science in general, members of the public segregated their opinions of individual doctors and scientists from their attitudes to these communities more broadly, and experts segregated the journalists they worked with from the wider media. There was a sense of criticism directed at such communities, which was not reflected in the actual experiences or relationships of the groups involved. In these senses not only were boundaries drawn around such communities but also they were strongly drawn within them.

As highlighted throughout this thesis, it is no longer acceptable to refer to the public as a homogenised group in relation to their attitudes towards science, medicine and technology
The range and complexity of views provided by public respondents did not simply relate to variables like, age, education or parental status, supporting a point made by Irwin and Michael (2003:138):

The Saturday afternoon animal rights activist is a Monday morning filing clerk, the politically active citizen is also a couch potato...old essentialist notions of citizenship and scientific awareness give way to more flexible, partial and, at times, contradictory forms.

Further it was obvious that the same variations in identity could be applied to scientific and medical experts, and journalists, who expressed transient identities and beliefs throughout their discourses. The temptation to discuss each of the unique experiences and contributions of Marion, Leonard, Emma, Geoff, Steven and each of the other respondents, as 'one story among many', was balanced by the necessity to relate their viewpoints to wider relationships in communication between the media, public and expertise (Irwin 1995).

The experts were keen to highlight that they were 'just people' with the same concerns and attitudes as other members of the public. The discussions by members of the public suggested this type of emphasis could be useful in building relationships between experts and the public as the personal respect shown to professionals illustrated. While as already highlighted this may be a 'tactic' of professionals to represent themselves as not only an expert but also as the most 'logical' of citizens, this research contributes further insight to this issue (Irwin and Michael 2003). To take as an example the trust shown towards the media, experts were considerably more confident in its reliability than public respondents reversing the common perception that scientists suggest the public relies too much on sources of information in which they lack confidence (MORI 2000). The discussions by members of the public regarding the coverage of scientific and medical issues were frequently more developed and aware of the multiple difficulties impacting on this type of
coverage. Not only are experts highlighting their abilities to generate trust, but so too are the public subtly and occasionally reasserting their abilities and identities.

Through each of the sampled groups there were incidences of ambivalence where views varied or were diametrically opposed on both practical issues like media coverage, and the ethical, legal and social implications of new genetics. Irwin and Michael (2003) suggest new ethno-epistemic assemblages exist where the blurring and interrelations of science and society may be explored, through recognising other forms of situated knowledge and that such knowledges continue to remain contestable, evolving, dynamic and processual.

‘Instead of arguments that are ‘largely scientific’ or ‘largely lay’, there is a series of statements that weave in and out of expert and lay domains’ (Irwin and Michael, 2003:113). The research presented here strongly supports this point, the views of the respondents were rarely static either in comparison to other members of sample groups or in the attitudes expressed by one respondent across the course of an interview.

The public respondents however refrained from fully embracing their participatory roles, seeking instead to concurrently reduce their knowledge while privileging it over the wider publics, recommending a public interest which at the same time is ultimately regulated by scientific, medical and policy making communities. The public involved in this study appeared displaced and uncertain of either their influence or responsibility.

It is by the otherness that the self is productively transformed. The very capacity to escape the fixity of one’s own views and homogenous community is through seeking the other- that which is different... The notion of communication as ‘to make common’ has all too often been read as to make alike, rather than to understand the productivity of mutually holding our differences in relation to each other (Deetz 1997:129).

For communication with the public to be improved there is a continued need to operate with a better understanding regarding perceptions of the public and a shift away from the continued presentation of ‘us and them’ amongst the scientific and medical communities.

At present the low confidence members of the public have in their understandings
represent little threat to the knowledge's of expertise and this could be a considerable advantage to expert communities in continuing to monopolise interactions which are depicted as mutual.

8.2 Roles, Responsibilities and Risks in Communication

While the views expressed by the media, public and scientific and medical experts suggested a reciprocal need to improve communication, the present context is one of 'crisis' (HMSO 2000a, HMSO 2002, POST 2002). Shifts to dialogue and the emphasis placed on encouraging communication with the public, exaggerate this sense of crisis and suggest that the representations of the media and views of the public represent a credible threat to expertise.

Science and scientists have not been used to the context speaking back, so it is not surprising that they see contextualization as a challenge to their cognitive and social authority. Caught on the defensive, they blame contextualisation, and the *agora* in which it emerges, for the rise of anti-science sentiments, for the subversive influence of social scientists and other 'relativists'. They fear that irrationality will break through the fragile crust of scientification. There is hard evidence that such fears are exaggerated (Nowotny et al. 2001:207).

The data collated from the experts suggested this attitude existed amongst some members of the scientific and medical community. Scientific experts for example discussed anti-GM campaigners contributing to the destruction of science in the UK, while medical experts appeared threatened by notes from the internet which now accompanied medical consultations. This supports the existence of a 'cultural pessimism' amongst the scientific community about their role in society, and the impact this will have on teaching in schools, universities, public policy and ultimately the future of science, which has made scientists unnecessarily reactive and defensive (Hargreaves and Ferguson 2000, Bateson and Cookson 2001). Public respondents recognised this issue, reiterating their general support for science and medicine and expressing caution at the potentially damaging impacts of activist publics. Amongst policy documents recommendations of dialogue often appear following lengthy discussion of scientific and technological developments and the 'crisis'
in science, thus it is somewhat inevitable that these attitudes are expressed. As MacMillan (2004:6) states ‘public engagement should be treated as an asset to innovation, not a damage limitation strategy’ but it appears scientists, medical experts and the public are conscious of this wider political emphasis and we may question the motivations for this. A crisis suggests not only that communicating with the public is a problem to overcome, but also that it is an emergency, in which case mechanisms for engaging with the public may be reactionary and ineffective.

The public respondents were not aggressive or unsupportive in their attitudes to science and medical advice. While relating to certain issues they were not overly confident in their understanding of science, medicine and genetics and though they defined themselves as having a greater understanding than other members of the apathetic public they were quick to reduce their own ideas and segregate themselves from activist publics of which they were extremely critical. This supports prior research suggesting the public though increasing in propensity and knowledge to question expertise continues to rely on its ultimate support (Hardey 1999, Prior 2003).

The public respondents are thus immediately on the back foot regarding roles in engagement as they are so readily perceived as being a threat to expertise, particularly as recent theorising suggests increased challenge to the expert role which does not appear replicated in practical interactions. It seems difficult to relate Collins and Evans (2002) conception of the ‘Third Wave’ to the experiences of the expert and public respondents contributing to this research. Though a number of theorists have suggested that expertise is no longer ‘specially valued’, an attitude that was at times expressed amongst the expert respondents, this does not appear to translate to a greater respect being shown towards public views (Collins and Pinch 1998, Collins and Evans 2002, Durodie 2002). Rather than use Collins and Evans (2002) suggestion as an argument for excluding public or lay views
from the few opportunities they have to communicate, this approach would be better applied if experts improved the quality and access to scientific and medical communication. In particular as the experts continued to take little responsibility for contributing to improvements in relationships between science and the public, which instead were attributed to educational and media organisations. If 'allowing everyone to speak is as bad as allowing a single group alone to speak...as bad as having no-one speak at all', then relevant experts taking inconvenient phone calls from journalists would better tackle this issue (Collins and Pinch 1998:146). Expertise continues to frame exercises in public dialogue, with the public rarely structuring or prioritising the issues they are concerned by (Irwin and Michael 2003, Franklin 2004). For medical experts in particular communication was an essential aspect of their role, the impacts of media confusion on patient communities is also an aspect of audience interpretation that remains under explored and it was a weakness of my research that I did not explore this further.

The voices of the public are legitimised only in strictly controlled settings, unnerving for a public generally lacking in confidence. The questionnaires and interviews carried out with members of the public were in themselves a form of engagement and as my methodology discusses framing the views of the public is problematic, though qualitative approaches do seem to contribute to improving identifying public concerns rather than enclosing them. It would have benefited the research if I had made greater attempts to access public voices intimidated by such methods, as such my interviewees for example were relatively educated and confident in their views. Traversing the theorising and research around scientific and medical communication it was striking that such areas themselves enforce strict ways of regulating readers (Latour 1987). Though I have used abbreviations occasionally throughout this thesis, the language of science and technology studies and policy makers in the science and society field is notably inaccessible and disseminating the
social sciences to the public, or public understanding of the social sciences, is presently under theorised (Fenton et al. 1997).

Public distrust and concern was expressed towards very specific new genetic research and development, and to broader issues of regulation and control. Though improved communication strategies go some way to dealing with this lack of confidence in regulation a greater focus on this issue may be necessary to improve public confidence.

In pushing forward the boundaries of science and breaking new ground in technological progress, the public needs to have confidence in the ethical and regulatory framework within which these advancements are being made (HMT/DfES/DTI 2004:14).

The present depiction of an overtly critical media and public audience is distorting the true issues involved. This research suggests there remains continued support, trust and confidence in scientists and doctors amongst the public respondents and the journalistic community sampled. The scientific and medical professionals further suggested that there was general public empathy towards their role. The public do have concerns regarding the objectivity of science, commercial influences, funding pressures, and public activism suggesting such influences have a negative impact on the quality and direction of scientific research. Concurrently they suggest scientific and medical experts must pay more attention to external social concerns, local populations and ethical consequences. These are thus conflicting issues as befits the complex and ambiguous nature of public views around developing science and technology but they also suggest that the emphasis on public understanding of science has neglected the greater need for public understanding of regulation. The present policy context suggests public trust can reach a goal of restoration but neglects to recognise that 'lay judgements of trust are not set in concrete or even necessarily apply in all circumstances. Rather they are conditional, and open to continual renegotiation' (Wynne 1996a:20). Trust should not be the goal, it should be the conditions through which it can develop; honesty, accountability and mutual respect (Grove-White et al. 2000).
Criticism of the media and public (mis)understandings of science have neglected the role of the expert communities in utilising and contributing to such problems. The research presented in this thesis suggests expert’s criticism of the media should be examined with an awareness that professionals are familiar with selected areas of the media and this is rarely the mid-market or tabloid coverage the community is quick to criticise. The textual analysis illustrated the impact professional journals have on the coverage of science, medicine and genetics, while the views of journalists and experts suggested a mutual role in the depiction of such areas amongst newspaper coverage. Thus amidst talk of dialogue it is unsurprising that the media role is rarely analysed bar a footnote indicting its negative impact on public views. Continuing to suggest the media is poor in quality and unsupportive of the scientific and medical communities allows media and public concerns to remain neglected aside from the legitimised channels of dialogue. As Cunningham-Burley and Kerr (1999:648) state,

Scientists and clinicians are powerful players in such discussions [of the social aspects of new genetics] and seem able to direct attention towards the social implications of new genetics, especially its beneficial applications. Where concerns are expressed these tend to be narrowly focused on issues such as the commercialisation of genetic testing or threats to individual autonomy. This limits more fundamental and critical discussion about the social values embedded in the knowledge and practices of the new human genetics itself.

Public discussions often circulated around such broader issues, the motives for developing new genetics, the processes for regulation, the funding mechanisms for scientific research. The role of the public as an audience for scientific and medical communication has also been significantly neglected. The success of coverage related to new genetics while undoubtedly influenced by its current prominence amongst scientific and medical research, is also popular amongst audiences who interpret it using their situated knowledges. These include the science educations they have received and their general interest in the area but considerably more attention is needed on their experiences as family members, community members and political citizens in thinking about how the public is developing its views.

Inviting the public to communicate with scientists and the media to develop their coverage of health and scientific issues is one way in which such communities are seeking to 'evoke a sense of transparency' (Irwin and Michael 2003:127). It was telling that while 57 per cent (n=21) of the expert respondents described public understanding of science and medicine as poor to very poor, 73 per cent (n=27) agreed or strongly agreed with public consultation when developing policies. While the public, journalists and scientific and medical experts who formed my sample largely suggested an interest in the communication of scientific, medical and genetic developments this took place within a political climate where such opinions are actively encouraged (Mulkay 1979, Irwin 1995, Michael 1998, Fuller 2000, Nowotny et al. 2001, Irwin and Michael 2003, Jasanoff 2003, Sturgis and Allum 2004). As such there are two points to make. Firstly these individuals were likely to have a predefined interest in choosing to complete a questionnaire, but secondly and perhaps more importantly these were the individuals who were likely to be already supportive of the trends for improved communication. As such these views, which often continued to promote a deficit approach to the public and medias knowledges, to privilege expertise and support the continued presence and role of the scientific and medical communities, were made by those predominantly supporting increased interaction. Accessing the views of those who do not want to see increased dialogue or engagement would thus be an interesting dimension of further work and an aspect this research may have considered further.

8.3 Divergent Discourses? Divergent Dialogues?

Some of the more naive proponents of public engagement seem to assume that the way to resolve difficult issues is by bringing together the concerned parties, adding a mix of methods and a family pack of post-it notes, and then allowing the facilitators to save the day (Wilsdon and Willis 2004:45).
A number of discourses were constructed throughout this research around communication, expertise and new genetics. At times there were convergences in attitudes, indeed perhaps more than would be anticipated, but there remained confusion regarding how and why relationships between the media, public and expertise can or need to develop. There was a continued sense that communication between experts and the public should lead the path not only to enlightenment but also to agreement, and that this agreement would emerge when the deficit in the public and media understanding was improved. Despite a number of experts suggesting there are significant social influences on the methodologies and cultural contexts of the scientific and medical communities the need for public recognition of this was disputed. Some emphasised that if the public were more aware of the uncertainty of science and the methodological structures that seek to cleanse it they would have more realistic expectations. Others recommended a restoration of respect and trust in science would only occur if such influences were ignored. Either way these views reiterated that experts felt an ability to listen to or ignore public attitudes dependant on their own pre-conceived ideas of relevance.

The views expressed by the public respondents in this and other research continue to suggest that consensus is not always possible or even preferential. 'As a rule, the same person will both approve of some applications and reject others' (Hampel 2004:49). Experts continue to frame or 'gate-keep' the questions raised as relevant, and these often avoid the deeper sociological queries or 'unknown uncertainties' that members of the public in this research have suggested they are interested by (Yearley 1996, Turner 2001, Glasner and Rothman 2004b, Wilsdon and Willis 2004). How will it be regulated, who is funding the research, what will it ultimately aim to achieve? Wilsdon and Willis (2004:29) suggest that these are some of the questions that need to be forced 'back on to the negotiating table' in recognising public concerns, and the data from this research would support this claim.
Not only may consensus be an unrealistic expectation but so are the more general aims of the public and experts in their communication with each other (Irwin 2001). It was clear that the public respondents had few expectations that their views were of interest or credible. Inviting public views in areas of technological and scientific concern and continuing to admonish them may thus be potentially more damaging to the public’s trust in scientific and medical communities. Just as the implications of ethical, legal and social studies in new genetics are questioned regarding their impacts on scientific research and development, the communication strategies between experts and the public may remain all talk, and politically impotent (Cranor 1994, Kerr et al. 1997, Katz Rothman 1998). In particular this seems possible as the privatised research and developments sectors have barely engaged with this agenda (RSA 2004, Wilsdon and Willis 2004). For expertise to be proved wrong after ignoring the concerns of the public is one thing, to be proved wrong after it has ‘listened’ to the views of the public has the potential to be even more damaging.

There was also evidence that the public are capable of becoming conscious of such hidden agendas. They had for example felt manipulated by some coverage of genetic modification, were distrustful of government, policy makers and regulators, and anticipated that some scientific and medical research remained concealed from them, reproducing continued inequality and exclusion (Franklin 2004). As Grove-White et al. (2000) caution communication influenced by the political emphasis on spin should not assume public ignorance to its motives.

Institutionalised in this fashion, ‘communication’ relates overwhelmingly to the projection of deliberate, explicit propositional knowledge [the facts]...people are able increasingly to ‘read’ and ‘interpret’ such communication products in the light of a host of subtler and more indirect clues, most crucially based on experience of the provider bodies themselves...feeding evermore intense public scepticism, rather than generating the increased confidence and respect aspired to so earnestly (Grove-White et al. 2000:34).

There were clearly a number of indications that communicating with the public has become politically appropriate. Though negative attitudes to such moves were occasionally
apparent these were shrouded by an overall emphasis that communication was necessary and unavoidable. Some attitudes suggested that ‘public engagement is no more than a process box that civil servants and scientists have to tick when drawing up a policy or applying for funding’ but there were some exceptions to this (Wilsdon and Willis 2004:40). Mark, a non-clinical research fellow appeared to be genuinely enthusiastic about engaging with the public (whether for professional or personal gain) and was making steps to achieve this within his own career. More clarity is needed as to what communication hopes to achieve; argument, defence, the search for common answers and recognition that, ‘instead of knowledge being a product, it is a process; indeed a collective performance of contingency and movement where no singular discourses/interpretative repertoires predominate’ (Irwin and Michael 2003:86).

At the beginning of this thesis I asked how members of the media, public, scientific and medical communities view and construct new genetic discourses. Discourses of new genetics have developed and interacted within a broader context. A context influenced strongly by existing notions of expertise, responsibility and regulation. As such the various constructions of new genetics by the media, public, scientific and medical communities have been inherently tied to the perceptions and identities of ‘others’. The opinions created of other forms of expertise are frequently not maintained by actual interactions and this research has added further dimensions to the transient nature of identities of expertise. As to future impacts, the present political context of engagement suggests that the public are a risk to science, with potential commercial impacts and the ability to negatively influence the future of science in the UK. However relationships between expertise and the public have evolved, trust has been built and broken, but their remains continued support both amongst the public and media. Thus communication between the public and expertise is attempting to further public trust and support under a guise of crisis. While these moves may improve communication in the area it is unlikely such mechanisms will ever achieve
absolute success. Aims of communication continue to be unrealistic and divergent and ignore the mutual experiences and understandings that already exist between the media, public and expertise.
### Appendix One: Sample Characteristics

<table>
<thead>
<tr>
<th>Sample</th>
<th>Members of Media</th>
<th>Scientific And Medical Experts</th>
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</thead>
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<tr>
<td></td>
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<td>Frequency (%)</td>
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<tr>
<td><strong>Gender</strong></td>
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<td>Divorced</td>
<td>0 (0%)</td>
<td>2 (5%)</td>
</tr>
<tr>
<td>Missing</td>
<td>0 (0%)</td>
<td>5 (14%)</td>
</tr>
<tr>
<td><strong>Do you have children?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>4 (40%)</td>
<td>28 (76%)</td>
</tr>
<tr>
<td>No</td>
<td>6 (60%)</td>
<td>7 (19%)</td>
</tr>
<tr>
<td>Missing</td>
<td>0 (0%)</td>
<td>2 (5%)</td>
</tr>
<tr>
<td><strong>Religious Preference</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Christian</td>
<td>3 (30%)</td>
<td>10 (27%)</td>
</tr>
<tr>
<td>Muslim</td>
<td>0 (0%)</td>
<td>2 (5%)</td>
</tr>
<tr>
<td>Jewish</td>
<td>0 (0%)</td>
<td>2 (5%)</td>
</tr>
<tr>
<td>Hindu</td>
<td>0 (0%)</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Greek Orthodox</td>
<td>0 (0%)</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Not Religious</td>
<td>7 (70%)</td>
<td>18 (49%)</td>
</tr>
<tr>
<td>Missing</td>
<td>0 (0%)</td>
<td>3 (8%)</td>
</tr>
<tr>
<td><strong>Ethnic Group</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>9 (90%)</td>
<td>31 (83%)</td>
</tr>
<tr>
<td>Indian, Pakistani or Bangladeshi</td>
<td>1 (10%)</td>
<td>3 (8%)</td>
</tr>
<tr>
<td>Black-British, Black-African or Black-Caribbean</td>
<td>0 (0%)</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Chinese</td>
<td>0 (0%)</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Missing</td>
<td>0 (0%)</td>
<td>1 (3%)</td>
</tr>
<tr>
<td><strong>Personal Income Per Annum</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>£15,000-£30,000</td>
<td>3 (30%)</td>
<td>£15,000-£40,000</td>
</tr>
<tr>
<td>£30,001-£55,000</td>
<td>3 (30%)</td>
<td>£40,001-£80,000</td>
</tr>
<tr>
<td>£55,001+</td>
<td>4 (40%)</td>
<td>£80,001-£150,000</td>
</tr>
<tr>
<td></td>
<td></td>
<td>£150,001+</td>
</tr>
<tr>
<td>Missing</td>
<td>0 (0%)</td>
<td>Missing</td>
</tr>
<tr>
<td><strong>Have you or any member of your family undergone genetic testing/ have been diagnosed with a genetic illness?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0 (0%)</td>
<td>6 (16%)</td>
</tr>
<tr>
<td>No</td>
<td>10 (100%)</td>
<td>31 (84%)</td>
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</table>

Table 9. Main Characteristics of Journalists, Scientific and Medical Experts Samples.

Source: Media and Expert Questionnaires. Note: Other variables were available in original questionnaires.
<table>
<thead>
<tr>
<th>Sample</th>
<th>Members of The Public</th>
<th>2001 CENSUS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency (%)</td>
<td>Devon N (%)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>63 (41%)</td>
<td>340,013 (48%)</td>
</tr>
<tr>
<td>Female</td>
<td>88 (58%)</td>
<td>364,480 (52%)</td>
</tr>
<tr>
<td>Missing</td>
<td>2 (1%)</td>
<td></td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-25</td>
<td>9 (6%)</td>
<td>58,017 (8%)</td>
</tr>
<tr>
<td>25-40</td>
<td>31 (20%)</td>
<td>130,068 (18%)</td>
</tr>
<tr>
<td>41-60</td>
<td>67 (44%)</td>
<td>192,198 (27%)</td>
</tr>
<tr>
<td>61+</td>
<td>44 (29%)</td>
<td>172,391 (25%)</td>
</tr>
<tr>
<td>Missing</td>
<td>2 (1%)</td>
<td></td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>25 (16%)</td>
<td>144,083 (25%)</td>
</tr>
<tr>
<td>Living With Partner</td>
<td>6 (4%)</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>87 (54%)</td>
<td>314,364 (55%)</td>
</tr>
<tr>
<td>Divorced</td>
<td>15 (10%)</td>
<td>51,360 (9%)</td>
</tr>
<tr>
<td>Separated</td>
<td>4 (3%)</td>
<td>12,014 (3%)</td>
</tr>
<tr>
<td>Widowed</td>
<td>13 (8%)</td>
<td>55,218 (10%)</td>
</tr>
<tr>
<td>Missing</td>
<td>3 (2%)</td>
<td></td>
</tr>
<tr>
<td><strong>Do you have children?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>115 (75%)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>38 (25%)</td>
<td></td>
</tr>
<tr>
<td><strong>Religious Preference</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Christian</td>
<td>106 (69%)</td>
<td>527,209 (75%)</td>
</tr>
<tr>
<td>Muslim</td>
<td>0 (0%)</td>
<td>1,496 (0.2%)</td>
</tr>
<tr>
<td>Jewish</td>
<td>0 (0%)</td>
<td>652 (0.9%)</td>
</tr>
<tr>
<td>Hindu</td>
<td>0 (0%)</td>
<td>337 (0.05%)</td>
</tr>
<tr>
<td>Greek Orthodox</td>
<td>0 (0%)</td>
<td></td>
</tr>
<tr>
<td>Spiritual</td>
<td>4 (3%)</td>
<td></td>
</tr>
<tr>
<td>Not Religious</td>
<td>42 (27%)</td>
<td>114,498 (16%)</td>
</tr>
<tr>
<td>Missing</td>
<td>1 (1%)</td>
<td>55,624 (8%)</td>
</tr>
<tr>
<td><strong>Ethnic Group</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>151 (98%)</td>
<td>696,590 (99%)</td>
</tr>
<tr>
<td>Indian, Pakistani or Bangladeshi</td>
<td>1 (1%)</td>
<td>1,116 (0.2%)</td>
</tr>
<tr>
<td>Black-British, Black-African or Black-Caribbean</td>
<td>0 (0%)</td>
<td>1,502 (0.2%)</td>
</tr>
<tr>
<td>Chinese</td>
<td>0 (0%)</td>
<td>4,354 (0.3%)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (1%)</td>
<td></td>
</tr>
<tr>
<td><strong>Personal Income Per Annum</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under £10,000</td>
<td>43 (28%)</td>
<td></td>
</tr>
<tr>
<td>£10,001-£20,000</td>
<td>46 (30%)</td>
<td></td>
</tr>
<tr>
<td>£20,001-£35,000</td>
<td>31 (21%)</td>
<td></td>
</tr>
<tr>
<td>£35,001+</td>
<td>8 (5%)</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>25 (16%)</td>
<td></td>
</tr>
<tr>
<td><strong>Qualifications</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>27 (18%)</td>
<td>134,114 (27%)</td>
</tr>
<tr>
<td>O-levels/CSEs/GCSEs</td>
<td>42 (27%)</td>
<td></td>
</tr>
<tr>
<td>A-levels/AS Levels</td>
<td>15 (10%)</td>
<td>237,409 (47%)</td>
</tr>
<tr>
<td>GNVQs/NVQs</td>
<td>11 (7%)</td>
<td></td>
</tr>
<tr>
<td>First Degree</td>
<td>23 (15%)</td>
<td></td>
</tr>
<tr>
<td>Higher Degree</td>
<td>15 (10%)</td>
<td>93,500 (18%)</td>
</tr>
<tr>
<td>Other</td>
<td>17 (11%)</td>
<td>38,189 (8%)</td>
</tr>
<tr>
<td>Missing</td>
<td>3 (2%)</td>
<td></td>
</tr>
<tr>
<td><strong>Have you or any member of your family undergone genetic testing/diagnosed with a genetic illness?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>14 (9%)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>137 (89%)</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>2 (2%)</td>
<td></td>
</tr>
</tbody>
</table>

Table 10. Main Characteristics of Public Sample.

Source: Public Questionnaires, ONS 2003b. Note: Other variables were available in questionnaire.
<table>
<thead>
<tr>
<th>Journal</th>
<th>Place of Publication</th>
<th>Worldwide Circulation 2001</th>
<th>Impact Factor Rating&lt;sup&gt;1&lt;/sup&gt;</th>
<th>Issues Per Year</th>
<th>Sample Size</th>
<th>Sample Publication Dates</th>
</tr>
</thead>
<tbody>
<tr>
<td>Journal of Medical Genetics (JMG)</td>
<td>London England</td>
<td>1,540</td>
<td>5.098</td>
<td>12</td>
<td>14</td>
<td>August 2001</td>
</tr>
</tbody>
</table>

Table II. Main Characteristics of Journal Sample.

<sup>1</sup> The impact factor rating is based on the frequency with which a journal's papers are cited.
<table>
<thead>
<tr>
<th>Newspaper</th>
<th>Place of Publication</th>
<th>Average Net Circulation August 01 - January 02</th>
<th>Sample Size</th>
<th>Publication Dates</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Daily Mail</td>
<td>London England</td>
<td>2,480,374</td>
<td>24</td>
<td></td>
</tr>
<tr>
<td>The Express</td>
<td>London England</td>
<td>961,754</td>
<td>18</td>
<td></td>
</tr>
<tr>
<td>The Mirror</td>
<td>London England</td>
<td>2,179,236</td>
<td>17</td>
<td></td>
</tr>
<tr>
<td>The Sun</td>
<td>London England</td>
<td>3,469,196</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>The Sunday Times</td>
<td>London England</td>
<td>1,398,220</td>
<td>22</td>
<td></td>
</tr>
<tr>
<td>The Observer</td>
<td>London England</td>
<td>472,673</td>
<td>15</td>
<td>12th August 2001</td>
</tr>
<tr>
<td>The Mail on Sunday</td>
<td>London England</td>
<td>2,371,967</td>
<td>4</td>
<td>19th August 2001</td>
</tr>
<tr>
<td>The Sunday Express</td>
<td>London England</td>
<td>855,275</td>
<td>6</td>
<td>26th August 2001</td>
</tr>
<tr>
<td>The Sunday Mirror</td>
<td>London England</td>
<td>1,832,787</td>
<td>7</td>
<td>2nd September 2001</td>
</tr>
<tr>
<td>The News of The World</td>
<td>London England</td>
<td>4,033,812</td>
<td>4</td>
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</table>

Appendix Two: Coding Schedules and Interview Aide Memoirs

**Coding Schedule: Journal Items**

<table>
<thead>
<tr>
<th>Journal</th>
<th>Nature (1)</th>
<th>News Scientist (2)</th>
<th>BMJ (3)</th>
<th>JMG (4)</th>
</tr>
</thead>
</table>

**Issue Date:**

<table>
<thead>
<tr>
<th>Journal Page Number:</th>
<th>Recoded Page Number:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1-20 (1)</td>
</tr>
<tr>
<td></td>
<td>21-40 (2)</td>
</tr>
<tr>
<td></td>
<td>41-60 (3)</td>
</tr>
<tr>
<td></td>
<td>61+ (4)</td>
</tr>
</tbody>
</table>

**Volume Number:**

<table>
<thead>
<tr>
<th>Issue Number:</th>
</tr>
</thead>
</table>

**Item Length (number of pages):**

**Author (first author stated in item):**

**Author professional background:**

<table>
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<th>Academic</th>
<th>Science Writer</th>
<th>Editorial Team</th>
<th>Other</th>
<th>No stated author</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
<td>(4)</td>
<td>(9)</td>
</tr>
</tbody>
</table>

**Section appearing in:**

<table>
<thead>
<tr>
<th>News</th>
<th>Papers</th>
<th>Letters</th>
<th>Editorials</th>
<th>Reviews</th>
<th>Feature/Special Report/Interview</th>
<th>New products/Advertisements</th>
<th>Corrections</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
<td>(4)</td>
<td>(5)</td>
<td>(6)</td>
<td>(7)</td>
<td>(8)</td>
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</tbody>
</table>

**Article Theme:**

<table>
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<tr>
<th>Genetic Research (original)</th>
<th>General Research (original)</th>
<th>Bioethical Research (original)</th>
<th>Genetic News Report</th>
<th>General News Report</th>
<th>Editorials/Comments/Features</th>
<th>Other (including letters)</th>
</tr>
</thead>
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<tr>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
<td>(4)</td>
<td>(5)</td>
<td>(6)</td>
<td>(9)</td>
</tr>
</tbody>
</table>
**Coding Schedule: Newspaper Items**

**Newspaper:**

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<th>4</th>
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<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
</tr>
</thead>
<tbody>
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<td>The Times</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(1)</td>
<td></td>
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</tr>
<tr>
<td>The Guardian</td>
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<td></td>
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</tr>
<tr>
<td>The Daily Mail</td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>The Express</td>
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<td>(6)</td>
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<td>The Sunday Times</td>
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<td>(7)</td>
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<tr>
<td>The Observer</td>
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<td>(8)</td>
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<td></td>
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<tr>
<td>The Mail on Sunday</td>
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<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>The Sunday Express</td>
<td></td>
<td></td>
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<td>(10)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The Sunday Mirror</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(11)</td>
<td></td>
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</tr>
<tr>
<td>The News of the World</td>
<td></td>
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<td></td>
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<td>(12)</td>
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**Daily (1) or Sunday (2):**

Date of publication:

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<td></td>
<td>11-20</td>
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<tr>
<td></td>
<td>21-30</td>
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</tr>
<tr>
<td></td>
<td>41-50</td>
</tr>
<tr>
<td></td>
<td>51+</td>
</tr>
<tr>
<td></td>
<td>Supplement 1-10</td>
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<tr>
<td></td>
<td>Supplement 11-20</td>
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<td>Supplement 21+</td>
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**Keyword/s featured:**

**Source/s**

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<thead>
<tr>
<th>Source/s</th>
<th>Number of Source/s:</th>
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<tr>
<td>Scientist</td>
<td>(1)</td>
</tr>
<tr>
<td>Doctor/Surgeon/Medical Professional</td>
<td>(2)</td>
</tr>
<tr>
<td>Patient/Relative/Friend of person/victim</td>
<td>(3)</td>
</tr>
<tr>
<td>Spokesperson of Organisation</td>
<td>(4)</td>
</tr>
<tr>
<td>Other Expert (i.e. legal, judicial, political)</td>
<td>(5)</td>
</tr>
<tr>
<td>Other (i.e. fitness expert, 'crop circle expert')</td>
<td>(9)</td>
</tr>
</tbody>
</table>

**Article Theme:**

<table>
<thead>
<tr>
<th>Article Theme</th>
<th>Number of Article Theme:</th>
</tr>
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<tr>
<td>Medical Research</td>
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</tr>
<tr>
<td>Scientific Research</td>
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</tr>
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<td>Genetic Modification</td>
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<td>Forensic Science</td>
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<tr>
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</tr>
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<td>Hereditary Accounts</td>
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<td>Other</td>
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</tbody>
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**Article Frame:**

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<thead>
<tr>
<th>Article Frame</th>
<th>Number of Article Frame:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supportive</td>
<td>(1)</td>
</tr>
<tr>
<td>Unsupportive</td>
<td>(2)</td>
</tr>
<tr>
<td>Neither Supportive or Unsupportive</td>
<td>(3)</td>
</tr>
</tbody>
</table>

**HEADLINE:**

Figure 19. Newspaper Coding Schedule 243
1. Have there been any major genetic stories that you have written about or been aware of in recent months?

2. What has been your experience when talking to people from a scientific or medical background in a professional capacity?

3. In your experience what role do scientists play in communicating their knowledge to the public?

4. Does the frequently changing and complex nature of medical and scientific information make your work more interesting, more challenging, more…?

5. How do you cover controversy in a scientific area, for example in the case of the recent Clonaid announcements?

6. Do you think that metaphors or anecdotes are useful when writing a scientific or medical piece?

7. Do you regularly receive reader's responses? If so how do you respond/reply/react?

8. In your experience what role should the media have in helping the ordinary person understand science?

Is there anything else you would like to add?

Figure 20. Media Interview Aide Memoir
Members of the Public Interview Aide Memoir

1. How would you describe your general opinion of 1) science, 2) medicine and 3) the media?

2. In the course of the last year which genetic issues have caught your attention? Are there areas where you have noticed high press coverage?

3. Where do you think you get most of your scientific/genetic/medical knowledge?

4. When you see a scientific or medical piece in the newspaper or on the television how do you assess its validity?

5. What sort of ethical issues surrounding genetics concern you?

6. In your opinion is it appropriate for us to be moving into these areas?

7. Who, in your opinion, makes the decisions about what scientific and medical research is carried out and which is not?

8. Who do you think should make the final decisions about appropriate scientific and medical advances?

9. Are any of the issues related to genetics particularly confusing in your opinion?

10. In your opinion how could 1) scientists, 2) doctors and 3) journalists make genetics clearer to understand?

11. In your opinion do you think you are more or less interested in genetics than other members of the public?

12. Are you aware that people have concerns or strong opinions in this area?

13. Do you think these issues are relevant to the public? Are they things you have raised or discussed with friends or family?

Is there anything else you would like to add?

Prompts: CLONING, GENETIC MODIFICATION, GENETIC DATABASES, GENETIC CARRIER TESTING, STEM-CELL TECHNIQUES, PRENATAL GENETIC SCREENING

Figure 21. Public Interview Aide Memoir

245
Scientific and Medical Expert Interview Aide Memoir

1. Has there been any media reporting of a scientific or medical issue, which you have been, particularly aware of or involved with in recent months?

2. Have you had media coverage of your own work?

3. Describe in your own words how you think the media covers scientific and medical advances?

4. Do you think that you have a responsibility as a scientist or medical professional to communicate with both the media and/or public?
   If yes, what form should this communication take?

5. In your opinion is the public’s ‘trust’ in science and medicine important?

6. In your opinion is science’s ‘trust’ in the media important?

7. What does the term ‘public understanding of science’ mean to you?

8. In your opinion, what do you believe society expects of science?

9. Where do you think these expectations come from and how have scientists responded to them?

10. Who do you think would benefit from an increased public understanding of science?

11. Do you think genetics is reported or commented on any differently in the media than other aspects of science or medicine?

Is there anything else you would like to add?

Figure 22. Scientific and Medical Expert Interview Aide Memoir
Appendix Three: Questionnaire Designs

Re: GENETICS AND THE MEDIA QUESTIONNAIRE

Dear Sir or Madam,

I am currently carrying out PhD research at the University of Plymouth looking at the way in which the public understands science, medicine and specifically genetic advances. Your name has been selected due to your position on a local newspaper. I would very much appreciate it if you could take around fifteen minutes of your time to fill in the enclosed questionnaire. The questionnaire is a chance to comment on some very significant issues.

It does not require ANY previous knowledge. If scientific or medical issues are not your specific field, your response is still valuable. In a number of the questions THERE ARE NO RIGHT OR WRONG ANSWERS. The questionnaire is laid out in manageable sections and mainly consists of tick boxes. You may stop filling in the questionnaire at any time or leave out any questions you do not wish to answer.

Your answers are strictly confidential. Your identity will not be linked to the answers, or the survey results. If you find the questionnaire interesting and would like to take part in a further interview, simply complete the consent form at the end of the questionnaire. If you would rather take part in an interview only please contact me directly. If you have any questions or would like to see the survey results I am available on 01752 233293, or cewilkinson@plymouth.ac.uk.

When you have completed your questionnaire please return it in the FREEPOST envelope provided.

Thank you for your help

Clare Wilkinson
Research Student

Figure 23. Media Covering Letter
**Genetics and the Media Questionnaire**

**Section One - About You - Please remember the questionnaire is confidential**

1. Are you, Male □ Female □
2. Are you, 18-25 □ 26-40 □ 41-60 □ 61+ □
3. What is your current marital status? (please specify e.g. married, widowed, same-sex relationship etc.)
4. Do you have any children? Yes □ No □ If yes, how many? What ages?
5. What is your religious preference? (please specify e.g. Christian, Hindu, Muslim, Jewish etc.)
6. What is your Ethnic Group? White □ Asian or Asian British □ Black or Black British □ Chinese □ Other (please specify) □
7. What is your estimated personal income per annum (please remember this questionnaire is confidential)
   - £15,000 - £30,000 □
   - £30,001 - £55,000 □
   - £55,001+ □
8. Have you or any member of your family undergone genetic testing, or been diagnosed with a genetic illness? Yes □ No □
9. If Yes, please give details

**Section Two - About Your Professional Activities**

10. What is your professional title/s?
11. Which publications do you regularly write for?

12. What qualifications do you hold?
   - O-levels/CSEs/GCSEs
   - A-levels/AS levels
   - NVQs
   - First Degree
   - Higher Degree
   - Other (please specify)

13. How long have you been working in the media?

14. What percentage of your professional activity is dedicated to media work?
   - 75-100%
   - 50-74%
   - 25-49%
   - Under 24%

15. What percentage of your professional writing is medically based science?
   - 75-100%
   - 50-74%
   - 25-49%
   - Under 24%
   - None

16. How confident do you feel when covering Medical Issues?
   - Very Confident
   - Quite Confident
   - Neither Confident or unconfident
   - Unconfident
   - Very Unconfident

17. Which sources would it likely be for you to consult when covering a scientific or medical story?
   - Medical or Scientific Journal
   - Medical or Scientific Texts
   - Professional contacts in the area
   - Internet sites/ web-based information
   - Newspaper articles written by others
18. When you are writing an article on genetics, which of the following sources would you ideally include statements from? Please number 1-7 in order of preference, 1 being favourite to use, 7 being least likely to use.

- Genetic Scientist
- Genetic Counsellor
- Health worker including GP/Nurse
- Health Service providers, NHS trusts
- Politicians/Policy Makers
- Journalist
- Individuals with genetic conditions, their friends or relatives

19. What is the extent of your agreement with the following statements?

a. I am always adequately informed about the issues I professionally report or comment on.
   - Strongly Agree
   - Agree
   - Don't know
   - Disagree
   - Strongly Disagree

b. It is difficult to make scientific and medical information understandable for the public.
   - Strongly Agree
   - Agree
   - Don't know
   - Disagree
   - Strongly Disagree

c. Do you find it useful to make stories more attractive with catchy headlines or metaphors.
   - Strongly Agree
   - Agree
   - Don't know
   - Disagree
   - Strongly Disagree

d. A scientific story is still good, even if it promises no immediate practical applications.
   - Strongly Agree
   - Agree
   - Don't know
   - Disagree
   - Strongly Disagree

e. A medical story is most appropriately supported by individual cases and stories.
   - Strongly Agree
   - Agree
   - Don't know
   - Disagree
   - Strongly Disagree

f. The media acts at the interface between science and the public.
   - Strongly Agree
   - Agree
   - Don't know
   - Disagree
   - Strongly Disagree

20. How would you describe scientific and medical professional's feelings toward the media generally?

- Very Positive
- Positive
- Neither Positive or Negative
- Negative
- Very Negative
21. Do you think that the media provides enough information on genetics?
   - Too much
   - About right
   - Not enough
   - Don’t know

22. Do you think that information on genetics in the media is?
   - Reliable
   - Unreliable
   - Don’t Know

23. Do you think the public’s understanding of science is?
   - Very Good
   - Good
   - Adequate
   - Poor
   - Very Poor

   Medicine is...
   - Very Good
   - Good
   - Adequate
   - Poor
   - Very Poor

   Genetics is...
   - Very Good
   - Good
   - Adequate
   - Poor
   - Very Poor

Section three – ethical issues, science and medicine

24. Do you agree, don’t know, or disagree with the following statements?

   A. The cause of an illness is always a combination of genetics, environment and lifestyle.
   - Strongly Agree
   - Agree
   - Don’t know
   - Disagree
   - Strongly Disagree

   B. In the future gene treatment will treat all illness.
   - Strongly Agree
   - Agree
   - Don’t know
   - Disagree
   - Strongly Disagree

   C. A human has about 30,000 genes.
   - Strongly Agree
   - Agree
   - Don’t know
   - Disagree
   - Strongly Disagree

   D. Scientists are not capable of altering human DNA.
   - Strongly Agree
   - Agree
   - Don’t know
   - Disagree
   - Strongly Disagree

   E. With genetic and DNA testing individuals have more control over their lives.
   - Strongly Agree
   - Agree
   - Don’t know
   - Disagree
   - Strongly Disagree

   F. Genetic tests/ databases increase the power of experts.
   - Strongly Agree
   - Agree
   - Don’t know
   - Disagree
   - Strongly Disagree

   G. Genetic testing should be voluntary in healthcare.
   - Strongly Agree
   - Agree
   - Don’t know
   - Disagree
   - Strongly Disagree

   H. I am concerned that genetic data will become private property.
   - Strongly Agree
   - Agree
   - Don’t know
   - Disagree
   - Strongly Disagree
I. Parents should be told the sex of an unborn foetus.
J. Women should not be offered pre-natal genetic tests.
K. Genetically modified foods are not acceptable.
L. Human cloning might be acceptable in certain cases.
M. Genetic researchers are intruding on areas of life, which should be left untouched.
N. Genetic researchers are the best judges of what is ethically appropriate.
O. Genetic research should be given priority in government funding.
P. Geneticists professional conduct should be regulated by government legislation.

25. Which single word would best describe your attitude to recent developments in genetics? (for example, Optimistic, Cautious, Confused)

26. In general do you think,

<table>
<thead>
<tr>
<th>Medicine is...</th>
<th>Science is...</th>
<th>Genetics is...</th>
</tr>
</thead>
<tbody>
<tr>
<td>Useful</td>
<td>Useful</td>
<td>Useful</td>
</tr>
<tr>
<td>More useful than harmful</td>
<td>More useful than harmful</td>
<td>More useful than harmful</td>
</tr>
<tr>
<td>Useful and harmful</td>
<td>Useful and harmful</td>
<td>Useful and harmful</td>
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<tr>
<td>More harmful than useful</td>
<td>More harmful than useful</td>
<td>More harmful than useful</td>
</tr>
<tr>
<td>Harmful</td>
<td>Harmful</td>
<td>Harmful</td>
</tr>
</tbody>
</table>

27. In general do you trust,

<table>
<thead>
<tr>
<th>Scientists</th>
<th>Doctors</th>
</tr>
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<tbody>
<tr>
<td>Totally</td>
<td>Totally</td>
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<tr>
<td>Mostly</td>
<td>Mostly</td>
</tr>
<tr>
<td>Don't Know</td>
<td>Don't Know</td>
</tr>
<tr>
<td>Not much</td>
<td>Not much</td>
</tr>
<tr>
<td>Don't trust at all</td>
<td>Don't trust at all</td>
</tr>
</tbody>
</table>
28. Would you undergo genetic testing if it were offered to you?

Yes ☐  No ☐  Don't know ☐

29. Finally do you have any comments you would like to add with regard to any of the issues raised in this questionnaire?

Thank you for your information, please return the questionnaire in the envelope provided.

If you would also like to take part in an interview please complete the details below.

I agree to take part in an interview on the way in which the public understands science, medicine and genetics with Clare Wilkinson. All interview data will be confidential.

My Name is ________________________________________________

My Address is ________________________________________________

___________________________________________________________

___________________________________________________________

___________________________________________________________

___________________________________________________________

Email/ Telephone No. ________________________________________
Re: GENETICS AND YOU: QUESTIONNAIRE

Dear Sir or Madam,

I am currently carrying out a piece of PhD research at the University of Plymouth looking at the way in which the public understands science, medicine and specifically genetic advances. Your name has been randomly selected from your postcode and I would very much appreciate it if you could take around fifteen minutes of your time to fill in the enclosed questionnaire.

It does not require any previous knowledge of science or genetics, and your contribution is valuable. In a number of the questions there are no right or wrong answers. The questionnaire is a chance to comment on some very significant issues. The questionnaire is laid out in manageable sections and mainly consists of tick boxes. You may stop filling in the questionnaire at any time or leave out any questions you do not wish to answer.

Your answers are strictly confidential. Your identity will not be linked to the questionnaire. However, if you find the questionnaire interesting and would like to take part in a further interview, simply complete the consent form at the end of the questionnaire. If you have any questions or would like to see the survey results please contact me on 01752 233847 or cewilkinson@plymouth.ac.uk.

When you have completed your questionnaire please return it in the FREEPOST envelope provided.

Thank you for your help.

Clare Wilkinson
GENETICS AND YOU: QUESTIONNAIRE

SECTION ONE. Please remember that the questionnaire is anonymous.

1. Are you, Male □ Female □

2. Are you, 18-25 □ 26-40 □ 41-60 □ 61+ □

3. What is your current marital status? (please specify e.g. married, widowed, same-sex relationship etc.)

4. Do you have any children? Yes □ No □ If yes, how many? What ages?

5. What is your religious preference? (please specify e.g. Christian, Hindu, Muslim, Jewish etc.) Not religious □

6. What is your Ethnic Group? White □ Indian, Pakistani or Bangladeshi □ Black-British, Black African or Black-Caribbean □ Mixed Origin □ Chinese □ Other (please specify) □

7. Which of the following qualifications do you have? None □ O-levels/CSEs/GCSEs □ A-levels/AS levels □ GNVQs/ NVQs □ First Degree (e.g. BA, BSc) □ Higher Degree (e.g. M.A, PhD, PGCE) □ Other, (please specify) □

8. What is your income before tax? What is your households income before tax?

Less than £10,000 □ £10,001 - £20,000 □ £20,001 - £35,000 □ £35,000+ □ Less than £10,000 □ £10,001 - £25,000 □ £25,001- £40,000 □ £40,000+ □

9. What is your occupation (If not working please give previous occupation)
10. Do you, or any member of your family work in science or healthcare?  
   Yes ☐  No ☐

11. If yes, please specify job and relationship to yourself.

12. Have you or any member of your family undergone genetic testing, or been diagnosed with a genetic illness?  
   Yes ☐  No ☐

13. If Yes, please give details.

SECTION TWO. The Media

14. Which newspapers do you read?  
   How often per week 1-6x (please specify)  
   The Times  ☐  The Guardian  ☐  The Independent  ☐  The Daily Telegraph  ☐  The Daily Mail  ☐  The Express  ☐  The Mirror  ☐  The Sun  ☐  Other (please specify)  ☐  Do not read newspapers  ☐
   How often per month 1-4x (please specify)  
   Sunday Times  ☐  The Observer  ☐  Independent On Sunday  ☐  The Sunday Telegraph  ☐  Mail on Sunday  ☐  Sunday Express  ☐  Mirror on Sunday  ☐  News of The World  ☐

15. How often do you read articles concerning health and/or science in newspapers?  
   Daily  ☐  Weekly  ☐  Monthly  ☐  Less Often  ☐  Never  ☐

16. How interested would you say you are in health and science issues?  
   Very Interested  ☐  Quite Interested  ☐  Indifferent  ☐  Not Very Interested  ☐  Not interested  ☐

SECTION THREE. Reporting Genetics

Please read the following extracts and answer the questions that follow them. The questions do not relate to the extracts specifically, they are designed to raise issues. Please remember that in a number of the questions there are no right or wrong answers.
"THE greatest mystery of medical science is about to be revealed - a gene which allows people to live beyond 100. Scientists will soon reveal the magic gene - named the 'genetic booster rocket' - which stops people developing age-related diseases. Until now scientists have believed that it is nurture, not nature which influences how long we live. But new research shows environmental factors such as diet, income and exercise have little or no bearing on long-term survival and that ultimately it is all down to a gene." (Johnston, A. August 26th 2001: 'At last, the gene that lets you live to', The Express Newspaper.)

17. Do you strongly agree, agree, not sure, disagree, or strongly disagree with the following statements?

A. All diseases are hereditary.
B. The onset of certain diseases is a combination of the genes, environment and lifestyle.
C. In the future gene treatment will treat an individual's illness.
D. An individual has about 30,000 genes.
E. Scientists are not able to alter an individual's DNA.
F. Genetic tests should not be performed on an individual when there is no treatment for the illness.
G. Gene tests may increase people's quality of life.

"Forensic experts yesterday began a painstaking search of the home of missing Danielle Jones. The operation seeking DNA clues to the 15 year-old's disappearance will last for three days. Then a specialist police team will move in to lift floorboards and search the garden of Stuart Campbell's semi in Grays, Essex." (Hepburn, I. August 21st 2001: 'DANI UNCLE'S HOUSE COMBED BY DNA COPS', The Sun, p.15)

18. Do you strongly agree, agree, not sure, disagree, or strongly disagree with the following statements?

A. With genetic and DNA testing individuals have more control over their lives.
B. Genetic tests/databases increase the power of experts.
C. In the future genetic tests should become compulsory.
D. Genetic testing should be voluntary in healthcare.
E. I am concerned that genetic data will become public property.
F. Genetic research should be given priority in government funding.
THE Italian fertility expert whose plans to clone a human being provoked intense controversy last week, claims to have refined a technique that will reduce the risk of abnormalities to a minimum. Professor Severino Antinori, who runs a clinic in Rome, intends to start a cloning programme in November with 200 infertile couples - some British - who are desperate for a child. He believes work he has carried out on goats and mice using a method known as 'recloning' will enable him to screen out any deformities. (Follain, J. August 12th 2001 'Cloner promises 'perfect' babies' The Sunday Times, p.22)

19. Do you strongly agree, agree, not sure, disagree, or strongly disagree with the following statements?

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Not Sure</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
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<tbody>
<tr>
<td>A. Women should not be offered pre-natal genetic tests.</td>
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<td>B. Parents should be told the sex of an unborn baby.</td>
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<td>C. Abortion is never acceptable.</td>
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<td>D. Abortion is appropriate if the health of parent/child is at risk.</td>
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<tr>
<td>E. Genetically modified foods are not acceptable.</td>
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<td></td>
<td></td>
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<tr>
<td>F. Human cloning might be acceptable in certain cases.</td>
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<td></td>
<td></td>
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<tr>
<td>G. Genetic researchers are intruding on areas of life, which should be left untouched.</td>
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<tr>
<td>H. Genetic researchers are the best judges of what is ethically appropriate.</td>
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<td></td>
<td></td>
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<tr>
<td>I. Geneticists should be regulated by government legislation for their professional conduct.</td>
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</table>

SECTION FOUR. Genetics and You

20. Can you name any diseases that to your knowledge are hereditary?

21. Can you name any characteristics that to your knowledge are hereditary, for example psychological or behavioural characteristics?

22. Can you name any living scientists?
23. From which sources have you gained any information concerning genetics?  
Friends or relatives  
Physicians or nurses  
Television  
Newspapers  
The Internet  
Scientific publications  
Educational institution  
Elsewhere, (specify)  
Don't know

24. Do you think that the media provides enough information on genetics?  
Too much  
About right  
Not enough  
Don't know

25. Do you think that information on genetics in the media is?  
Newspapers  
Reliable  
Unreliable  
Don't know

TV  
Reliable  
Unreliable  
Don't know

Internet  
Reliable  
Unreliable  
Don't know

Have not seen information on genetics in the media.  

26. Whom of the following would you trust if reading an article on genetics?  
(please feel free to choose more than one)  
Genetic Scientist  
Genetic Counsellor  
Health worker including GP/Nurse  
Health Service providers, NHS trusts  
Politicians/Policy Makers  
Journalist  
People with genetic conditions, their friends or relatives  
None  
Other, (please specify)  

27. What word would best describe your feelings to recent developments in genetics? (e.g. Optimistic, Cautious, Confused)

28. In general do you think, Medicine is... Science is... Genetics is...  
Useful  
More useful than harmful  
Useful and harmful  
More harmful than useful  
Harmful  
Don't know

Useful  
More useful than harmful  
Useful and harmful  
More harmful than useful  
Harmful  
Don't know
29. In general do you trust,

Scientists
- Totally
- Mostly
- Don't know
- Not much
- Don't trust at all

Doctors
- Totally
- Mostly
- Don't know
- Not much
- Don't trust at all

30. Do you feel you understand some of the issues related to genetics?
- Yes
- No
- Don't know

31. Would you undergo genetic testing if it were offered to you?
- Yes
- No
- Don't know

Finally do you have any comments you would like to add?

Thank you for your information, please return the questionnaire in the envelope provided. If you would also like to take part in an interview please complete the details below.

I agree to take part in an interview on the way in which the public understands science, medicine and genetics with Clare Wilkinson. All interview data will be confidential.

My Name is

My Address is

Contact Number

Signature

Figure 26. Public Questionnaire
Re: GENETICS, THE MEDIA AND PUBLIC

Dear Sir or Madam,

I am currently carrying out PhD research at the University of Plymouth looking at the way in which the public understands science, medicine and specifically genetic advances. You name has been selected as it appeared in a journal article or media piece concerning genetics during August and September 2001. I would very much appreciate it if you could take around fifteen minutes of your valuable time to fill in the enclosed questionnaire.

It is laid out in manageable sections and mainly consists of tick boxes. If genetics is not your specific area of expertise, your response would still be appreciated. The questionnaire is an opportunity to comment on increasingly important issues in society, and to understand and develop the publics' understanding of science. You may stop filling in the questionnaire at any time or leave out any questions you do not wish to answer.

Your answers are strictly confidential. Your identity will not be linked to the answers, or the survey results. If you find the questionnaire interesting and would like to take part in a further short interview, please complete the consent form at the end of the questionnaire. If you have any questions or would like to see the survey results please contact me on 01752 233293, or cewilkinson@plymouth.ac.uk.

When you have completed your questionnaire please return it in the FREEPOST envelope provided by 1st March 2003.

Thank you for your time and help

Clare Wilkinson
Research Student
the public and media's relationships with genetics – expert questionnaire

**Section One: About You**

Please remember the questionnaire is confidential.

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Are you,</td>
<td>Male ☐ Female ☐</td>
</tr>
<tr>
<td>2. Are you,</td>
<td>18-25 ☐ 26-40 ☐ 41-60 ☐ 61+ ☐</td>
</tr>
<tr>
<td>3. What is your current marital status? (please specify e.g. single, married, widowed, same-sex relationship etc.)</td>
<td></td>
</tr>
<tr>
<td>4. Do you have any children?</td>
<td>Yes ☐ No ☐ If yes, how many?……... What ages?………...</td>
</tr>
<tr>
<td>5. What is your religious preference? (please specify e.g Christian, Hindu, Muslim, Jewish etc.)</td>
<td></td>
</tr>
<tr>
<td>6. What is your Ethnic Group?</td>
<td>White ☐ Indian, Pakistani or Bangladeshi ☐ Black-British, Black-African or Black-Caribbean ☐ Mixed Origin ☐ Chinese ☐ Other (please specify) ☐</td>
</tr>
<tr>
<td>7. What is your estimated personal Income per annum (please remember this questionnaire is confidential)</td>
<td>£15,000 - £40,000 ☐ £40,001 - £80,000 ☐ £80,001 - £150,000 ☐ £150,000+ ☐</td>
</tr>
<tr>
<td>8. Have you or any member of your family undergone genetic testing, or been diagnosed with a genetic illness?</td>
<td>Yes ☐ No ☐</td>
</tr>
<tr>
<td>9. If Yes, please give details</td>
<td></td>
</tr>
</tbody>
</table>
10. What is your professional title/s?

11. What percent of your professional time do you spend in activities related to genetics?
   - 75-100%
   - 50-74%
   - 25-49%
   - Under 24%
   - None
   If none, please move to question 13

12. Of the time you spend working in genetics, what amount of your time relates to?
   - Direct patient care
   - Patient services
   - Research
   - Educational activities
   - Administration
   - Other (please specify)

13. Where do you conduct the majority of your work?
   - University-based clinical genetics programme
   - Hospital-based clinical genetics programme
   - Private commercial laboratory
   - Independent prenatal diagnosis centre
   - Office (solo practice)
   - Office (group practice)
   - Community Health Clinic
   - Other (please specify)

14. How often do you read articles concerning health and/or science in newspapers?
   - Daily
   - Weekly
   - Monthly
   - Less Often
   - Never
15. Which newspapers do you read? (please specify)  

<table>
<thead>
<tr>
<th>Newspaper</th>
<th>How often per week (0-6)</th>
<th>How often per month (0-4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Times</td>
<td></td>
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<tr>
<td>The Guardian</td>
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<tr>
<td>The Independent</td>
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<td>The Daily Telegraph</td>
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<td>The Daily Mail</td>
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<td>The Express</td>
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<td>The Mirror</td>
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<tr>
<td>The Sun</td>
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<tr>
<td>Other (please specify)</td>
<td></td>
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</tbody>
</table>

16. Which other forms of communication do you engage with that cover genetics? (please specify or give brief examples)  

- Television/ Radio  
- Films/ Theatre  
- Internet sites/ Email updates  
- Professional networks  
- Professional Journals  
- Other (please specify)  

17. Which professional journals do you regularly subscribe to?  

18. Do you ever read material concerning genetics from disciplines other than your own (e.g. social sciences/ healthcare/ law/ politics)?  

- Yes  
- No  

19. If yes, please give brief examples  

264
20. Do you think that the media provides enough information on genetics? 
   Too much 
   About right 
   Not enough 
   Don't know

21. Do you think the media reporting of scientific and genetics issues is largely....
   Positive
   More Positive than Negative
   More Negative than Positive
   Negative

22. Do you think that information on genetics in the media is?
   Newspapers
     Reliable
     Mostly reliable
     Don't Know
     Rarely reliable
     Unreliable
   TV
     Reliable
     Mostly reliable
     Don't Know
     Rarely reliable
     Unreliable
   Internet
     Reliable
     Mostly reliable
     Don't Know
     Rarely reliable
     Unreliable
   Have not seen information on genetics in the media.

section four – the public

23. How would you rate the general public's understanding of the following areas?
   Genetically modified foods.
   Human reproductive cloning.
   Stem cell techniques.
   Genetic databases.
   Genetic carrier testing.
   Pre-natal genetic testing.

24. Which one word do you think most accurately describes the public understanding of genetics?
25. Do you think that the public's understanding of science and medicine is?

<table>
<thead>
<tr>
<th>Very Good</th>
<th>Good</th>
<th>Neither Good or Poor</th>
<th>Poor</th>
<th>Very Poor</th>
</tr>
</thead>
</table>

26. Do you think it is necessary to improve public understanding of genetics?

- Yes ☐
- No ☐
- Don't Know ☐

27. If yes, how do you think the public's understanding of science could be improved?

---

**Section Five – Ethical Issues**

28. Please indicate the extent to which you agree or disagree with the following statements:

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neither Agree or Disagree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
</table>

- a. People knowingly carrying a recessive disease gene should avoid having children with another carrier.

- b. A woman's decision about abortion should be her own, without external pressure.

- c. Parents must never be told the sex of an unborn baby.

- d. Gene treatments are the future of medicine.

- e. Withholding any requested service from individuals is unethical.

- f. Healthcare professionals are not responsible for the public using genetic services appropriately.

- g. Genetic counselling should reduce the number of harmful genes in the population.

- h. Human cloning may not be unacceptable in all cases.

- i. Genetic testing should be voluntary in healthcare.

- j. With genetic and DNA testing individuals have less control over their lives.
k. Whom of the following have a legitimate claim to a person's genetic data.  
   a) The judicial system  ☐ ☐ ☐ ☐ ☐ ☐  
   b) Insurers  ☐ ☐ ☐ ☐ ☐ ☐  
   c) Employers  ☐ ☐ ☐ ☐ ☐ ☐  

l. A person's partner or blood relative should not have access to that person's genetic information without their consent.  ☐ ☐ ☐ ☐ ☐ ☐  
m. Genetic research should be given priority in government funding.  ☐ ☐ ☐ ☐ ☐ ☐  
n. Genetic therapies and preventative measures should be given priority in health budgets.  ☐ ☐ ☐ ☐ ☐ ☐  
o. Geneticists professional conduct should be regulated by government legislation.  ☐ ☐ ☐ ☐ ☐ ☐  
p. The general public should be consulted when developing policies governing genetics.  ☐ ☐ ☐ ☐ ☐ ☐  

29. Finally do you have any comments you would like to add concerning any of the issues covered in this questionnaire?  

Thank you, please return the questionnaire in the envelope provided. If you would like to take part in an interview please complete the details below. 

I agree to take part in an interview with Clare Wilkinson. All interview data will be confidential. 

My Name is... 

My Address is... 

Email/ Telephone No... 

Figure 28. Scientific and Medical Expert's Questionnaire 267
## Appendix Four: Supplementary Qualitative Data

<table>
<thead>
<tr>
<th>Gene/s Genetic/s</th>
<th>DNA</th>
<th>Clone/Cloning/IVF</th>
<th>Modification/GM</th>
</tr>
</thead>
</table>
| **The Times**    | 'New prostate gene tests may save thousands' | | 'GM elms 'immune to killer disease”  
Safe' GM tomato' |
| 'The shopping gene: how to spend ages not buying anything' | 'DNA tests 'to predict decline in fertility' | 'IVF to give woman a baby by brother' | 'Scientists modify elm to resist disease that killed millions of trees in Britain’, ‘Global GM market starts to wilt’, ‘Feeding prejudice: With hunger and malnourishment set to spread, it's vital that we stop demonising GM food’ |
| **The Guardian** | 'The Methuselah Genes: Discovery Could Unlock Secrets Of Living To Over 100, Say Scientists’, ‘Gene Test Hope For Thousands Of Prostate Victims' | 'Life For Strangler Trapped By His DNA After 18 Years’  
'DNA May Trap 1977 Murderer’ | 'Copyright' On Cloning Celebrities’  
'Woman To Have Her Brother's IVF Baby' |
| **The Daily Mail** | 'At last, the gene that lets you live to 100' | '300 men in DNA testing to solve killings’, 'DNA clue to '70s murder  
'£10,000 on offer for Archer DNA’ | 'Gm Trees Created To Resist Elm Disease' |
| 'Genetics: Double Trouble Nina and Sam get sick within hours of each other and feel the other's pain’ | 'DNA to identify 5 Stardust Dead Calls for the remains to be exhumed after 20yrs’, 'Don’t dig up victims of Stardust Inferno: Dad fights plans to exhume 5 bodies for DNA tests’, 'DNA science traps murderer after 18yrs’ | | |
| **The Express**  | | | 'GM trees to beat fungus’ |
| **The Mirror**   | | | |
| **The Sun**      | | | |
| Sunday Times     | | | |
| The Observer     | | | |


268
‘GM trees to beat fungus’

SCIENTISTS have grown the first-ever genetically modified trees, it was revealed yesterday. The research team has created a batch of elm trees which can fight the deadly fungus that causes Dutch elm disease. The disease has killed 20 million trees in the UK since 1970.

Experts say the breakthrough means elm trees could now be re-introduced back into their natural habitat across Britain. Professor Kevan Gartland of the University of Abertay, Dundee, said: "This is an example of environmentally friendly biotechnology."

Researchers used minute DNA-coated ball-bearings to transfer genes into the elm trees. There are 40 species of elms, some living for 300 years.

Figure 29. GM trees to beat fungus The Mirror newspaper extract. (Walker 2001).

‘GM elms ‘immune to killer disease’

Scientists have produced the world’s first genetically modified elm trees, which could lead to the native species being reintroduced to the British countryside. The project at the University of Abertay Dundee has grown saplings that scientists believe are resistant to deadly fungal infections including Dutch elm disease. Kevan Gartland, the head of molecular and life sciences at the university, said he hoped that the GM trees would eventually be used to tackle damaged landscapes and restore ecosystems blighted by fungal diseases.

"This is an example of environmentally friendly biotechnology," Professor Gartland said. "Our work in elm trees could be used to help damaged landscapes caused by diseases such as Dutch elm disease and chestnut blight throughout the world." The Forestry Commission gave a "cautiously open-minded" response to the development. A spokesman said that further tests needed to be carried out, but if the trees proved viable they could be a significant step forward for forestry.

Dutch elm disease has destroyed more than 20 million elm trees in the United Kingdom since 1970. In the United States 70 per cent of mature elms have fallen victim to the devastating disease since 1930. First identified by scientists in The Netherlands, Dutch elm disease is carried by elm bark beetles, which breed beneath the bark. Once the disease is contracted, fungal growth spreads throughout the tree, preventing water and minerals from reaching the branches and leaves. The tree can take weeks or years to die.

Traditional breeding approaches to the problems of the disease in Europe have failed, while non-GM biotechnological methods have had limited success. Professor Gartland, who headed the study, said that researchers used minute ball bearings coated with DNA to transfer genes into the elm trees. The saplings are being monitored in a university laboratory. "Some of the trees have reached one-and-a-half metres (4ft 7in) in height already. When the time is right, the trees will undergo rigorous testing in an effort to establish their resistance to Ophiostoma novo-ulmi, the Dutch elm disease fungus," Professor Gartland said. Elms, of which there are at least 40 different species, first grew about 40 million years ago and can live for up to 300 years.

Figure 30. GM elms immune to killer disease The Times newspaper extract. (Harris 2001:7)
<table>
<thead>
<tr>
<th>Theme 1: Scientific and Genetic Support</th>
<th>Theme 2: Scientific Governance</th>
<th>Theme 3: Media Depictions</th>
<th>Theme 4: Common Sense/ Holistic Approaches</th>
<th>Theme 5: Regulation/ Education</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>IP002 Female 41-60 Clerical 'Susan'</strong></td>
<td>Quest for knowledge outweighs negative consequences. In favour of genetic screening for illness.</td>
<td>Doctors face commercial pressures. Anti-committees but drew distinction between scientists working commercially.</td>
<td>Some media useful as provides information. Genetics should have more positive coverage.</td>
<td>GM in agriculture needs more careful confinement. In support of genetic databases at a national level for easier access to medical data.</td>
</tr>
<tr>
<td><strong>IP003 Male 41-60 NHS Support Worker 'John'</strong></td>
<td>Positive view of technology and drug applications. More trust in scientists than government regulation.</td>
<td>Sceptical of claims by certain 'scientists' that human cloning is near. Individual scientists grow resentful of policing.</td>
<td>Media sensationalist but source of knowledge. Ambivalent due to depictions of argument.</td>
<td>Identifies positive (third world uses)/negative impact of GM in agriculture.</td>
</tr>
<tr>
<td><strong>IP004 Male 41-60 Engineer 'Andrew'</strong></td>
<td>Methods of science 'the best we have'. Medicine if better funded could more utilise technology. Potential of cloning, pre-natal screening, stem cells, positive if methodology improved.</td>
<td>Empathised with individual scientist/sdoctors quest for knowledge. Against political/commercial pressure but recognised this as a motivation for some individuals. Scientist's poor communicators due to the depth of technicality their work involves.</td>
<td>Highly critical of media 'dumbing' down and sensationalism. Need to recognise public interest and capabilities when familiarised. Disagreed with GM depictions of third world support.</td>
<td>GM in agriculture inadequately controlled. Ethical ramifications of cloning so wide, un-anticipated and consequential that must be prior debate and regulation.</td>
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</table>

- Ethical guidelines problematic. Critical of media 'dumbing' down and lack of public knowledge. Should not be 'sidelined' by uneducated.
<table>
<thead>
<tr>
<th>Theme 1: Scientific and Genetic Support</th>
<th>Theme 2: Scientific Governance</th>
<th>Theme 3: Media Depictions</th>
<th>Theme 4: Common Sense/ Holistic Approaches</th>
<th>Theme 5: Regulation/ Education</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>IP005</strong> Female 41-60 Academic 'Liz'</td>
<td>Concerned by individual scientists quest for knowledge ignoring actual use of technology. By concentrating on genetic influences other research will be lost. Funding system lost objectivity privileging topics, individuals and commercialism. Responsibility beyond scientist doing research.</td>
<td>Media distorts possibilities of scientific research. Media provides good information on genetics for those that are interested but it must be accessible, jargon free and not patronizing. Publicly relevant as may effect all of us.</td>
<td>GM worrying interference with nature/ uncontrollable. Scientific advances must be contextualised by broader consequences and abilities to deal with them. Concerned by extension of genetic interventions until morally acceptable.</td>
<td>Any person/scientist/journalist is open to bias and prejudice. Public deals with issues on basis of own experiences and are equipped to understand the ethical problems. Government lack knowledge to regulate and are generally untrustworthy.</td>
</tr>
<tr>
<td>Science is excellent; some advances are 'fantastic'. Sees nothing wrong with some advances, e.g. selecting embryos but recognises own contradiction. False expectation of 'health'.</td>
<td>Older people are frightened and unquestioning of doctors/scientists. Distrustful of commercial motivations as aim to make money must colour objectivity. Personal dealings with doctors, including own GP very positive.</td>
<td>Media exaggerate, gloss over, glorify or criticise. When done well it can be very interesting. Need to discuss issues now not after something has happened.</td>
<td>Nature is unpredictable doubtful how much we can control it, confirmed by death of Dolly. GM shows lack of common sense, concerned scientists will be equally short-sited elsewhere. Potential to go against 'nature' for example IVF and genetic screening dependent on motive.</td>
<td>Specific reasons for intervention, lines drawn. With parents making ultimate decision over risk. Government cannot be trusted to regulate. Moral stance, not education needed for understanding.</td>
</tr>
<tr>
<td><strong>IP006</strong> Female 61+ Sales Assistant 'Carol'</td>
<td>High opinion of science, technology and medicine. Responsible both for our longer lives and standards of living today. Genetic research seems to have a lot of potential. Science always criticised by public.</td>
<td>Funding pressures mean scientists publicise work too soon. Scientists have not worked well with media or promoted own image and thus have suffered politically. Science produces knowledge, aware of how it may be used but laws must ultimately regulate. Scientists should pursue knowledge not be market led.</td>
<td>Media can be inaccurate, sensationalist, ignorant and need to 'read between the lines'. Generally are not pro-science. GM debate full of scare-mongering. Great respect for establishment publications, journals and scientific journalists.</td>
<td>All research open to abuse. Regulation will evolve due to many of the financial implications and our 'litigation' society. Ethics/Committees should come into play after research, not drive it. Government role to represent public views, which are largely ill-informed.</td>
</tr>
<tr>
<td>Male 41-60 Teacher 'David'</td>
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<tr>
<td>Theme 1: Scientific and Genetic Support</td>
<td>Theme 2: Scientific Governance</td>
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<tr>
<td>From a science background (did undergraduate degree) ‘Pretty’ positive about it but does not accept science at face value. Understands motives for genetic research but consequences initially seem huge. In fact they are attackable as they relate to intrinsic questions about life which the public understands.</td>
<td>Science as dependent on whose ‘hands’ it is in. Research is probably already occurring behind closed doors, human ‘clones’ probably exist. Some scientists act irresponsibly and like ‘god’. Pharmaceuticals highly irresponsible and influential, reducing scientists control when research is marketable. Scientist’s agendas influenced by types of research they will receive funding for. Distrusting due to expert/ politicians maintaining safety of things like GM and mobile phone masts.</td>
<td>Though are some good journalists who ‘ask the right questions’, others radicalise, sensationalise or campaign for support. Interest in mobile phones led to complex questioning of media portrayal of controversy. We hear about breakthroughs but not the problems and errors that occur with them. Media responsible for much public education.</td>
<td>Described natural need to pay attention to genetic interventions as ‘instinctively’) cannot see how will be safe in the long-term. Using ‘guinea pigs’ it seems obvious issues won’t end when an advance occurs. Favourites traditional medicine but would prefer more holistic view of body particularly in medication use. Concerned by release of genetic organisms unchecked, permanently into environment, they would evolve if they were meant to be there and it does not allow for a reaction by the natural habitat.</td>
<td>All decisions should be made by individual/ parents, whilst concerned reduces the sanctity of life would be very difficult choices. ‘Hysterical’ individuals could be very concerned by genetic predictions. Should be some governing of science, with financing you can go unchecked. Government untrustworthy ideally should have role. Public generally un-interested and poorly educated.</td>
</tr>
<tr>
<td>IP008 Male 41-60 Writer ‘Lisa’</td>
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<td></td>
</tr>
<tr>
<td>IP009 Male 41-60 Water Resources Planner ‘Leonard’</td>
<td>Holds science in high regards generally though concerned with scientists responsibility and the irreversible nature of interventions.</td>
<td>Scientists make a lot of decisions but there is a higher level of government and commercial interest. At times such groups stop research only after the event. Scientists are too involved to objectively police their research but other regulators lack competitive level of scientific knowledge. Some are good communicators but do they really want the public to be aware of their research?</td>
<td>Science comes across poorly in media. Interprets what is available superficially. Aware of conclusions of science rather than processes. Appreciate difficulty of reporting science but disagrees with way both broadsheets and tabloids hype science, highlight or ignore scientific research.</td>
<td>Questions point of some genetic interventions including GM and the possible effects on the natural process of evolution. Public involvement necessary and often links to personal experiences though some members of public are over the top in their reactions. Global disparity in medical treatment led to question why need expensive genetic interventions before equality in health.</td>
</tr>
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Table 14. Public Interviews Thematic Links  Source: Public Interviews.
<table>
<thead>
<tr>
<th>Theme 1: Media Experiences</th>
<th>Theme 2: Responsibilities To Communicate</th>
<th>Theme 3: Public Understanding Of Science</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>IE001 Female Clinical Research Fellow University Based “Lara”</strong></td>
<td>Media representations generally comprehensive and immediate. Coverage of own work extended only to journal publications. However work had been picked up by patient groups and various internet sites, it is important these are correct and balanced as patients rely on them.</td>
<td>Research is relevant to patients and public. Confused as to whether own role to communicate that or media's role to identify relevance. Public expectations of science and medicine are high, in a developed society such as this that is appropriate.</td>
</tr>
<tr>
<td><strong>IE002 Female Consultant NHS Public Practice “Maria”</strong></td>
<td>Media portrayals generally ‘ignorant’. Journalists not equipped with necessary depth of knowledge, rely on one argument or do not ask relevant questions. Often contacted by media though not always keen to get involved in discussions. Own experience ‘variable’ with overall messages edited and not a true reflection of points, making hesitant of media. As such had found ‘live’ TV most satisfying experience.</td>
<td>Clear responsibility to communicate with patients. As such would intervene if something was misreported but only after seeking advice. Public trust in science and medicine extremely important. Strongly argued against a media trust in science and medicine. Media does not have the depth of knowledge needed to judge science. As such it often depicts completely the wrong message to the public. Arguments should be led by medical professionals or scientists in the same way that they would chair a meeting or board.</td>
</tr>
<tr>
<td><strong>IE003 Female Consultant Geneticist/ Clinical Director NHS Public Practice “Judith”</strong></td>
<td>Some media reporting very emotive e.g. case of the Hashmi family. Reporting with ‘sound bites’, sensationalism and simplification allows for no in depth consideration of issues at stake. They also put very positive ‘spin’ on things, often finding cures which does not reflect true research. Tries to avoid dealing with media but has publicised past research with announcements of funding. Difficult as often unable to prepare for questions and media expects summaries of complex areas. Most people are very cautious of the media and fear misrepresentation.</td>
<td>Positivism of media reporting can give people ‘false hopes’, difficult when dealing with patients who may not have a true understanding of the potential impact or likelihood of cure. Some ‘experts’ give incorrect information which can have significant effects on patients. Responsibility for scientific/medical community as whole to communicate but difficult when geneticists role is non-directive. Concerned by government emphasis on genetics which ignores the significance of preventative advice.</td>
</tr>
</tbody>
</table>

Some patients rely more on information given in media than by doctors. To make issues interesting to public media often goes to extreme levels of illness e.g. Gorlins Syndrome. If publicity is particularly controversial will experience come back from patients. Public is generally not distrusting, though death has become a ‘failure’ in public/cultural perceptions. Also see geneticists having an underlying dangerous agenda. PUS has become a ‘buzz’ word.
<table>
<thead>
<tr>
<th>Theme 1: Media Experiences</th>
<th>Theme 2: Responsibilities To Communicate</th>
<th>Theme 3: Public Understanding Of Science</th>
</tr>
</thead>
<tbody>
<tr>
<td>IE004 Male Senior Non-Clinical Research Fellow University Based 'Mark'</td>
<td>Presented own work in media, and journalists ‘phone up’. Found media portrayal of ‘experts’ which does not represent what would be seen as ‘expertise’ by the scientific community. Scientists criticism of media for misrepresenting science misses fact it must be direct, entertaining, and engaging. Media also has important role in exposing bad ‘science’. Overall confusion as to what the media is there for. Public more sophisticated in their thinking than given credit for, probably view most media with a ‘pinch of salt’. Major problem with genetic determinism in media but many scientists are responsible.</td>
<td>Increased interest in genetics by the media, from HGP, scientists are beginning to communicate more. Many scientists identify no need for communicating with the public, but very important personally. Being a good communicator should not be interpreted as being a good scientist. Public mistrust in science is done, more likely to be in corporations or government role. In educating public of scientific facts must also ask whose ‘facts’ they are. Not all public fears are unfair, also has reservations about GM for example.</td>
</tr>
<tr>
<td>IE005 Male Research Professor University Based “Geoff”</td>
<td>Media tendency to make more out of interpretations than research supports, experienced in depiction of research was involved with. Has phone calls from journalists for comments. Media want to get attention, scientists want to get at ‘truth’, creating a culture clash. Media sensationalises exciting developments over more routine but significant research. Controversy reflects novelty of genetics advances. Also has mixed-feelings over GM.</td>
<td>Communicating science positive step but not all science suitable, some fields are too specialised. Government pressure to provide applied/economic benefits wrongly puts demands on funding bodies but an important message for the public is that most science, not motivated by governmental/commercial aims. Science should be open, using public funds and has ‘nothing to be ashamed of’.</td>
</tr>
<tr>
<td>IE006 Male Director Research Institute ‘Steven’</td>
<td>Competitive nature of British news privileges ‘breakthroughs’ in conflict to how science progresses. Some scientists have to high an expectation, need to recognise pressures on media. Only disappointed by media slant few times and misrepresented on couple of occasions. Most scientists work attracts attention very occasionally thus can be difficult for them, but more acceptance now of scientists who do communicate and simplify their work. Scientists must stand up and defend their work, respond to journalists quickly recognising the timescale of news or a momentum against science started by GM will grow. Relationship between genetics, and ethical stances has special ‘yuck’ factor.</td>
<td>Working in ethically controversial areas no choice but to communicate. Maintains relationship as the only method to communicate with public large scale. Danger of not communicating is someone don’t agree with i.e. pressure groups, do it instead. Cannot influence outcomes of debate but can influence quality. Public must trust regulatory framework, not science. Scientists do not trust other scientists, purpose of science to question thus public should. More scientists should communicate, not just same old faces.</td>
</tr>
</tbody>
</table>

Table 15. Expert Interviews Thematic Links. Source: Expert Interviews
Abbreviations

BA - British Association for the Advancement of Science
BMA - British Medical Association
BMJ - British Medical Journal
BSE - Bovine Spongiform Encephalopathy
COPUS - Committee for the Public Understanding of Science
DfES - The Department for Education and Skills
DNA - Deoxyribo Nucleic Acid
DTI - The Department for Trade and Industry
DVT - Deep Vein Thrombosis
ELSI - Ethical, legal and social implications
GM - Genetic modification
POST/OST - Parliamentary Office for Science and Technology
PUS - Public Understanding of Science
PUSET - Public Engagement with Science and Technology
HGC - The Human Genetics Commission
HMSO - Her Majesties Stationary Office
HMT - HM Treasury
JMG - Journal of Medical Genetics
MRC - Medical Research Council
MMR - Measles, mumps and rubella vaccine
MRSA - Methicillin Resistant Staphylococcus aureus
NHS - National Health Service
RI - Royal Institution of Great Britain
RSA - The Royal Society for the encouragement of Arts, Manufactures & Commerce
SEE - Studies of Expertise and Experience
SSK - Sociology of Scientific Knowledge
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283


284


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287


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