
by

Jane Denise Hendy

Submitted for the award of Doctor of Philosophy

Department of Psychology
School of Human Sciences
University of Surrey

November 2003

© Jane Denise Hendy
Abstract

This thesis explores how general groups of people think about predictive genetic testing. Psychological research into individual decision-making prior to the consulting room is scarce, with our knowledge of the types of factors that influence the decision to request this service barely investigated. The research presented undertakes this task by identifying salient factors influential in the contemplation of this new health choice. The research then examines how these factors impact on genetic-testing decision-making processes and intentions in more detail. The aim is to increase scientific understanding of early decision-making in this area, by exploring the motivations of individuals who intend to request this service and also the decision-making of those individuals who will never be seen at a genetic clinic.

The thesis is comprised of four studies. The first study uses an exploratory qualitative methodology, gathering focus group data to discover how groups of people who have not directly experienced predictive genetic testing think about this service. The findings suggest that people are primarily concerned with their perceived control over genetic testing decision-making processes and their risk of genetic diseases. The second and third studies use repeated measures experimental designs to manipulate perceived control (self-efficacy) over genetic-testing decisions and perceptions of disease risk. The findings revealed a complex relationship between self-efficacy in these domains, global self-efficacy, perceptions of risk and intention to undergo testing. Study two showed that when specific efficacy in these domains was experimentally decreased global perceptions of self-efficacy also reduced, alongside the desire to maintain control over these domains. Study three showed that a lack of intention to undergo genetic testing was predicted by perceptions of high disease risk, high levels of health-specific self-efficacy and the importance of this efficacy – but not levels of general self-efficacy. Additionally the results from the third study revealed that intention to undergo testing was higher when people were given no information about the genetic inheritability of a disease, indicating
that as a disease becomes 'geneticized' both control over that disease and general control may become eroded.

The final study again uses a qualitative methodology, using interview data from individuals at high and low risk of disease to further examine the role of risk and self-efficacy in genetic testing decision-making, and to identify which areas of self-efficacy have most impact on intentions. The study also examines how people make sense of their 'genetic risk', how they conceptualise self-efficacy within this domain, and how they perceive these two concepts to be related. Findings from the last study suggest that levels of general self-efficacy may be relevant to decision-making when the individual's confidence is extremely high, in that the person feels confident to cope with the test result regardless of any possibility of cure or prevention. Attitudes and intentions towards genetic testing also appeared to be strongly determined by levels of disease-risk anxiety, with the attraction of testing appearing to wane when the emotional consequences of genetic testing were reflected upon.

To conclude, these findings suggest that a lack of perceived control over genetic testing decision-making and disease risk has wide-reaching consequences in negatively impacting on overall perceptions of competence and well-being. The findings also suggest that for people at extremely high risk of disease, who feel both in control of any potential symptoms and value this control, genetic testing is unattractive, in robbing them of the potential for control in the future. Diseases perceived as being genetic were largely viewed as immutable and uncontrollable. On deeper reflection, decision-making in this area was often perceived as anxiety provoking and conceptualised by ambivalent and complex thinking.
Contents

Chapter One

The thesis outline
1.1 Introduction ................................................................. 1
1.2 Summary of chapters ..................................................... 2

Chapter Two

Background literature
2.1 A brief overview of predictive genetic testing ..................... 9
  2.1.1 The public’s attitudes towards predictive genetic testing ...... 11
  2.1.2 Clinical research into the psychological consequences of predictive genetic testing ................................................. 16
  2.1.3 Factors influencing the public’s interest in genetic testing .... 21
  2.1.4 Actual rates of uptake of genetic testing ....................... 24
  2.1.5 The public’s decision-making when contemplating testing .... 26
2.2 Health psychology research ................................................ 29
  2.2.1 The Health Belief Model .............................................. 29
  2.2.2 Protection Motivation Theory ....................................... 34
  2.2.3 Theory of Planned Behaviour ........................................ 37
  2.2.4 The self-regulation model of illness behaviour ............... 40
  2.2.5 Illness representations of genetic disease ....................... 43
2.3 Perceived behavioural control and perceived self-efficacy .......... 47
  2.3.1 Self-efficacy theory .................................................... 48
  2.3.2 Self-efficacy research .................................................. 50
  2.3.3 Generality of self-efficacy ........................................... 52
  2.3.4 The importance of self-efficacy ...................................... 56
2.3.5 Self-efficacy as moderator of coping ................................................................. 57
2.4 Genetic susceptibility to disease and health behaviour ........................................ 59
  2.4.1 General risk research ......................................................................................... 62
  2.4.2 The concept of genetic risk .............................................................................. 66
2.5 Conclusions ........................................................................................................... 70

Chapter Three

Epistemological and methodological issues
3.1 Introduction ............................................................................................................ 72
3.2 The researcher’s epistemological position ............................................................. 72
3.3 The research strategy ......................................................................................... 74
3.4 Developing the methodology ............................................................................... 75
3.5 Demonstrating good research .............................................................................. 77
3.6 Grounded theory – the analytic process ............................................................... 78
3.7 Personal reflexivity ................................................................................................ 80

Chapter Four

Lay responses to predictive genetic testing: A focus group study
4.1 Research Aims ........................................................................................................ 82
4.2 Meeting with experts .............................................................................................. 84
4.3 Method - Pilot study ............................................................................................... 85
  4.3.1 Aims .................................................................................................................. 85
  4.3.2 Sample .............................................................................................................. 85
  4.3.3 Procedure ......................................................................................................... 85
4.4 Method - Main study ............................................................................................. 86
  4.4.1 Design ............................................................................................................... 86

iv
Chapter Five

Genetic Testing and the relationship between Specific and General Self-efficacy

5.1 Research Aims ................................................................. 123
5.2 Research hypotheses ........................................................... 126
5.3 Method - Pilot study.............................................................. 127
  5.3.1 Aims .................................................................................. 127
  5.3.2 Sample ............................................................................... 127
  5.3.3 Procedure ........................................................................... 128
  5.3.4 Measures ........................................................................ 128
  5.3.5 Analysis ............................................................................ 129
  5.3.6 Textual Messages ................................................................. 132
5.4 Method - Main study.............................................................. 133
  5.4.1 Design ................................................................................ 133
  5.4.2 Sample ............................................................................... 133
  5.4.3 Procedure ........................................................................... 135
  5.4.4 Measures ........................................................................ 136
5.5 Results .................................................................................. 136
  5.5.1 Initial data analysis ............................................................. 136
  5.5.2 Main data analysis .............................................................. 139
5.5.3 Comments recorded from the message questionnaire ........................................ 146
5.6 Discussion ........................................................................................................... 149
  5.6.1 Conclusions and future directions ............................................................ 152

Chapter Six

The intention to undertake genetic testing: The relationship between perceived risk, disease controllability and self-efficacy

6.1 Research Aims .................................................................................................. 153
6.2 Research hypotheses ........................................................................................ 156
6.3 Method - Pilot study ....................................................................................... 157
  6.3.1 Aims ............................................................................................................... 157
  6.3.2 Sample .......................................................................................................... 157
  6.3.3 Procedure ..................................................................................................... 157
  6.3.4 Measures ....................................................................................................... 157
  6.3.5 Analysis ......................................................................................................... 158
6.4 Method - Main study ....................................................................................... 161
  6.4.1 Design ........................................................................................................... 161
  6.4.2 Sample .......................................................................................................... 161
  6.4.3 Procedure ..................................................................................................... 162
  6.4.4 Ethical considerations .................................................................................. 163
  6.4.5 Measures ....................................................................................................... 163
6.5 Results ............................................................................................................... 164
  6.5.1 Initial data analysis ...................................................................................... 164
  6.5.2 Main data analysis ....................................................................................... 166
6.6 Discussion ........................................................................................................... 181
  6.6.1 Conclusions and future directions ............................................................. 186
Chapter Seven

The prospect of predictive genetic testing for participants at low and high perceived risk: analysis of intentions

7.1 Research Aims ................................................................. 187
7.2 Method - Pilot study ............................................................ 189
  7.2.1 Aims ......................................................................... 189
  7.2.2 Sample ....................................................................... 189
  7.2.3 Procedure ................................................................. 190
7.3 Method - Main study ............................................................ 190
  7.3.1 Design ....................................................................... 190
  7.3.2 Sample ....................................................................... 190
  7.3.3 The interviews ............................................................ 191
  7.3.4 Procedure ................................................................. 192
  7.3.5 Ethical considerations .................................................. 193
  7.3.6 Method of analysis ....................................................... 193
7.4 Results .................................................................................. 193
  7.4.1 Initial data analysis ....................................................... 193
  7.4.2 Main data analysis ....................................................... 206
7.5 Discussion ............................................................................ 221
  7.5.1 Conclusions and future directions ................................... 225

Chapter Eight

Overall discussion

8.1 Brief overview ............................................................... 227
8.2 Summary of the findings ................................................... 228
8.3 Wider implications .......................................................... 232
8.4 Limitations of the research and methodological issues .......... 235
Index of tables

Table 1  Pilot study - Pattern matrix of structural coefficients - Two-factor solution specific efficacy ................................................. 130
Table 2  Main study - Pattern matrix of structural coefficients - Two-factor solution specific efficacy .................................................. 138
Table 3  Independent samples t-test - Media report questions.................................................. 140
Table 4  Means and standard deviations - Specific efficacy scores............................................. 141
Table 5  Means and standard deviations - Specific efficacy scores - divided by whether participants felt efficacy in this domain was of low or high importance............................. 143
Table 6  Means and standard deviations - General Efficacy Scores............................................ 144
Table 7  Means and standard deviations - General Efficacy - divided by whether participants had low or high levels of general efficacy .......... 145
Table 8  Frequency of response (percent) - Risk of Arthritis Index........................................... 159
Table 9  Pattern matrix of structural coefficients - Two-factor solution specific-efficacy scale.................................................................................. 160
Table 10 ANOVA Significant Results - Multivariate within-subjects effects.................... 167
Table 11 ANOVA Significant Results - Multivariate between-subjects effects ................ 167
Table 12 t-tests Specific Self-Efficacy Scores - Time 1 and time 2................................. 171
Table 13 t-tests General Self-Efficacy Scores - Time 1 and time 2 ............................... 172
Table 14 t-tests Importance of Specific Efficacy Scores - Time 1 and time 2...... 173
Table 15 ANOVA - Experimental condition by intention to undergo testing...... 173
Table 16 One way ANOVA - Intention to undergo testing.......................................... 174
Table 17 Bivariate correlations - Efficacy and risk factors with intention ............... 175
Table 18 Multiple regression - Participants with perceived low risk......................... 179
Table 19 Multiple regression - Participants with perceived high risk..................... 180
Table 20 Multiple regression - Specific efficacy and the importance of efficacy.. 180
| Figure 1  | Basics of the Health Belief Model | 30 |
| Figure 2  | Basics of Protection Motivation Theory | 35 |
| Figure 3  | Basics of the Theory of Planned Behaviour | 38 |
| Figure 4  | Leventhal's Self-regulatory Model of Illness Behaviour | 42 |
| Figure 5  | Summary of the themes and relationships uncovered from the second stage of the analysis | 112 |
| Figure 6  | Scree plots - Pilot data | 129 |
| Figure 7  | Specific Efficacy - Scores of participants who felt efficacy in this domain was of high or low importance | 142 |
| Figure 8  | General Efficacy Scores | 144 |
| Figure 9  | Scree plot - Risk of Arthritis Index | 159 |
| Figure 10 | Scree plot - Specific-efficacy Scale | 160 |
| Figure 11 | Means - Importance of specific-efficacy | 168 |
| Figure 12 | Means - Specific efficacy | 169 |
| Figure 13 | Means - General efficacy | 169 |
| Figure 14 | Means - Perceived risk | 170 |
| Figure 15 | The relationship between intention to undergo testing and perceived risk | 176 |
| Figure 16 | The relationship between intention to undergo testing and specific efficacy | 176 |
| Figure 17 | The relationship between intention to undergo testing and the importance of specific efficacy | 177 |
| Figure 18 | The relationship between intention to undergo testing and risk | 178 |
Acknowledgements

I would like to express my deepest thanks to my supervisor Evanthia Lyons for her personal understanding, guidance, professional support and friendship. I am also thankful to Prof. Glynis Breakwell for inspiration at the beginning of the project.

This thesis has been a professional endeavour but also a time of healing and I would like to thank those who helped me survive the journey. This thesis would not have been possible within my husband Mark, who has always only wanted the best for me. I’d also like to thank my family, especially my Mother and Sister Jackie, whose faith in me, and pride has been unwavering. Thanks also to Pete. Much gratitude also goes to Stuart and Shirley, for all their help and support. I’d also like to thank my friends especially Nihat, Donna, Suzanne, Theti, Irene, Anastasia, Natasha and Julia. Thanks to Barbara, Carol and Dawn.

A special thanks to all the participants who gave me their time and showed interest in the project, especially Dad and his gang, staff at the medical centre, ‘Edinburgh Woollies’, and the all parishioners of Midhurst Parish Church.
This thesis is dedicated to my oncologist Desmond Barton,

also to Audrey & Jim who sadly didn’t make it.
Chapter One

The thesis outline

1.1 Introduction

As genetic research quickens, asymptomatic genetic testing for a range of common adult onset diseases is likely to increase with predictive genetic testing for conditions such as bowel cancer, diabetes and arthritis becoming routinely available in the next few decades. Understanding the pathogenic mechanisms of these genes is likely to have a huge impact on preventative health care and bring dramatic changes to how we define ourselves, our health and society. Yet psychological literature concerned with understanding how people make sense of these discoveries is surprisingly scarce. The research that is available primarily consists of surveys sponsored by government to examine the general population’s attitudes towards genetic testing and biotechnology (see Hietala, Hakon, Aro, Niemela, Pelton & Aula 1995; Singer, Corning & Lamias 1998; Cabinet Office 1999; National Science Board 2000; Stratford, Marteau & Bobrow 2001). Overall the results from these surveys indicate that people are largely in favour of the medical possibilities offered by this new technology, with the potential for improved health care welcomed. However, alongside this support is a lack of confidence in the ability to control these new developments. Research suggests that perceptions of control - over the target disease, over disease worry and over future outcomes - are likely to be relevant to the decision to take up predictive genetic testing services, although deeper understanding of the reasoning behind these concerns is hard to elucidate. A major limitation within this body of research is the large number of survey-style studies undertaken. Although the study design allows the views of a large number of people to be gathered, the methodology does not necessitate deeper exploration of the type of factors that influence differences in perception, or possible reasons for people’s ambivalence towards genetic testing. Several quantitative studies have begun to explore how the public’s attitudes to predictive genetic testing might be shaped or changed, but more research is needed before any major conclusions can be reached (Durant, Hansen, Bauer & Gosling 1993; Kerr, Cunningham-Burley & Amos 1998).
Another body of psychological and medical research examines the psychological consequences of genetic testing for specific diseases in high-risk clinical populations, and uptake and interest in genetic testing within these populations. Again this body of work suggests that perceived control is a pivotal issue, with control over the target disease, control over future uncertainty and perceptions of risk are important factors in people’s interest in predictive genetic testing. Although informative, this second body of research is also limited by its narrow sampling. By primarily using individuals already attending medical clinics, or the relatives of such individuals, there has been a failure to consider the decision-making of those people who never reach a clinic, the motivation of the vast majority of high-risk individuals who choose not to attend genetic screening, or participate in clinical research (see Bowen, Patenaude & Vernon 1999). The aim of this thesis is to address this gap, to discover how more general groups of people who have not had direct contact with this procedure think about predictive genetic testing. The research will then examine how salient factors identified within the research influence the decision-making process and intentions to uptake these services in more detail.

1.2 Summary of chapters

Chapter two

In approaching this task the researcher began by reviewing both medical and psychological research concerned with psychological aspects of predictive genetic testing. The goal was to summarise the findings from literature in this area and gain a broad overview of the type of factors identified as being influential in people’s decision-making and intentions towards genetic testing. As discussed, the literature reviewed suggests that perceived control is a pivotal factor in steering attitudes toward testing and influencing testing uptake. Other factors identified as likely to influence interest in this health choice concern perceptions of risk, although the relationship between levels of risk and intentions was far from clear.

Specific theories of health behaviour were then examined, with the four most frequently used models - the health belief model (Rosenstock 1966), protection motivation theory
(Maddux & Rogers 1983), the theory of planned behaviour (Ajzen 1985) and the self-regulation model of illness behaviour (Leventhal, Meyer & Nerenz 1980) - reviewed in detail. Much of the research on predictive genetic testing is sociological or medical in origin, so it was useful to examine how these psychological theories explain why people may or may not decide to undertake predictive genetic testing. The intention was not to conclude which if any theory was better than another, rather the aim was to clarify the strengths and weaknesses of these theories, and examine general problems, when considering their usefulness to the research question proposed. It was concluded that health theories reviewed had applicability problems, in assuming that the motivation to act arises from the expectation that action can reduce the likelihood or severity of harm (Weinstein 1993), with health behaviour the direct response to some kind of health threat. However we do not know if the majority of people perceive genetic testing as threatening, with asymptomatic predictive genetic testing seemingly characterised by a lack of concreteness.

The review went on to investigate factors already identified in the literature as influential to testing decisions and intentions. Firstly, psychological literature on perceived control was evaluated. Perceived control can be conceptualised in several ways, but, within health psychological research, perceived self-efficacy appears most useful, being the strongest predictor of health decisions, intention and behavioural change (Armitage & Conner 2001). Therefore it is Bandura’s (1997) definition of self-efficacy that is addressed when considering how perceptions of control influence genetic testing decision-making. Psychological literature on risk was then reviewed. The aim was to evaluate how people might perceive self-efficacy and genetic risk in the context of testing. Additionally the review examined the role of these constructs in shaping the decision-making process and coping with the perceived outcome of this choice. Overall the research suggests that the reciprocal relationship between perceived risk, risk communication, and the individual’s sense of personal control, in being able to manage their risk, is likely to influence responses to testing. The research also suggests that people’s understanding of their ‘genetic risk’ cannot be determined solely using
mathematical probability, that subjective experience and contextual factors have a role in how risk is personally conceptualised and managed.

Chapter three
The research undertaken and type of evidence being sought were all influenced by the researcher's epistemological stance, so the aim of the third chapter was to make this position explicit and explain the philosophical framework within which the research was undertaken. The researcher's paradigmatic position and the implications of combining both qualitative and quantitative research methodologies within the thesis as a whole are discussed. This is followed by a more detailed exploration of the research methodologies adopted and the criteria used to assess rigour, specifically in regard to the qualitative approach used. Finally, the researcher's personal motivation for embarking on the work is explored.

Chapter four
As discussed earlier, psychological understanding of how more general groups of people perceive predictive genetic testing is scarce, hence the first study in the thesis uses an exploratory qualitative focus group methodology to explore this question. Data from six focus groups were analysed using grounded theory. From the analysis two main topic areas of debate emerged. The first of these topics concerned personal family related issues such as experiences of illness and the benefits or disadvantages attached to having predictive genetic-testing information. The second main area of discussion concerned the actual process of testing and the wider social implications attached to this new health choice.

On examining the data in more detail the findings suggest that individual perceptions of genetic testing are divided. Firstly, people appeared concerned with personal factors regarding their risk of genetic diseases and their perceived control over possible outcomes. Secondly, there was a wider societal concern regarding the control of genetic testing decision-making, and dissemination of information that may result from this procedure. The research did not directly address why some participants felt more in
control of these concerns than others, although the data suggests perceptions of self-efficacy - the belief in one’s personal ability to perform specific behaviours in order to achieve a set outcomes - may be influential. In the next two studies the thesis follows up these tentative conclusions by examining the two factors identified in more detail. Firstly the role of self-efficacy within the decision-making process is explored; then perceptions of disease risk and control over this risk are examined.

Chapter five
As discussed within the focus group conversations, perceived control over genetic testing decision-making appeared to be a salient concern, with some participants feeling choice over genetic testing decisions was illusory and others feeling confident and optimistic about their ability to control their future destiny. The aim of study two was to try to elucidate possible reasons for these apparent differences in perception. To achieve this aim it was decided to further investigate the impact of general self-efficacy on coping with testing decision-making, and to try to unravel the relationship between specific and general self-efficacy. The research questions were investigated using a repeated measures quantitative experimental design. Firstly, the study set out to determine the extent to which perceived efficacy over genetic testing decision-making could be manipulated via different presentations of information. The research then examined whether a lack of efficacy in this domain would generalise to other areas of personal control, as measured by a decrease in general self-efficacy. The relationship between specific and general self-efficacy was examined. Additional potential factors thought to be influential in the process of generalisation were explored, particularly the importance of specific and general self-efficacy and initial levels of general efficacy.

The results showed that perceived efficacy over testing decision-making could be successfully manipulated with the use of alleged media reports. The results then indicated that changes to specific-efficacy did impact on levels of general self-efficacy. The research hypothesised that the importance of efficacy would be influential in the process of efficacy generalisation, as would initial levels of general efficacy. Results were mixed. Significantly both the threat and the enhancement to specific-efficacy had more impact.
when levels of general efficacy were low, suggesting high general efficacy acts as a buffer, in diluting the impact of any potential change. However, this change occurred regardless of the importance of general efficacy, although the importance of efficacy did appear relevant at a domain specific level. Overall the results suggest that both the negative and positive effects of having to decide whether to take a genetic test are complex, with a lack of self-efficacy over the decision to undertake testing having wider implications in serving to lower levels of general self-efficacy.

Chapter six
The aim of this study was to investigate the second major theme to emerge from the earlier focus group study - people's perceptions of genetic risk and their control over this risk. This study set out to answer this question by determining how perceptions of disease risk and self-efficacy interact, and whether and how these constructs affect people's intentions towards undertaking predictive genetic testing. The study also aimed to clarify issues raised in the last study by further investigating the relationship between health-specific and general self-efficacy. The study examined these questions by manipulating perceived control (over the management of disease symptoms and genetic risk) of a common disease. The impact of this action was then examined using a repeated measures experimental design. Specifically the study investigated whether participants at high perceived risk of arthritis had decreased self-efficacy after reading information stating that arthritis was uncontrollable and genetically inherited. The study also aimed to replicate the previous findings by again demonstrating that a decrease in specific efficacy could transfer to produce a significant decrease in general self-efficacy. In addition we aimed to clarify the role of importance (of specific-efficacy), and investigate whether changes in specific or general self-efficacy would impact on intentions to undergo genetic testing.

The results showed that the experimental interventions (disease information) successfully manipulated both perceived specific efficacy and disease risk, with these changes occurring regardless of the importance of self-efficacy in this domain or the level of risk. Although importance did not appear to influence changes in specific-efficacy, the results
showed that importance of specific-efficacy was affected by the experimental interventions, in being significantly lower after the intervention threatening control. The results additionally showed that after exposure to the experimental conditions perceptions of risk were increased, with this increase most pronounced after the intervention threatening control.

In line with the previous findings, changes to specific-efficacy did impact on levels of general self-efficacy, with general efficacy significantly reduced after the condition threatening control. Somewhat surprisingly, decreased levels of general efficacy did not affect the participant’s intention to undergo genetic testing. The analysis revealed that intention to undergo genetic testing was affected by perceptions of high risk, high arthritis-specific efficacy and the importance of this efficacy, suggesting that for people at extremely high risk, who feel both in control of any potential symptoms and value this control, genetic testing is unattractive. Additionally the higher levels of intention we found in the control group suggest that just reading about arthritis, in terms of the disease being genetic, reduces the intention to undergo genetic testing.

Chapter seven
The aim of the final study was to further investigate the perceived consequences attached to being diagnosed with a genetic predisposition, and the subsequent intention towards genetic testing for individuals at low and high perceived risk of disease. Findings from the previous study suggest the motivational processes underlying intention to be tested is different across these two groups. The study also aimed to further examine the role of self-efficacy, by investigating which factors determine whether predictive genetic testing is perceived as decreasing or enhancing control. The study also set out to identify which areas of self-efficacy were important to the participants when considering whether or not to undertake genetic testing.

Data for the study was collected by conducting interviews and analysing their content with grounded theory. The analysis offers an explanation for the previous finding - that general self-efficacy was not influential in testing intentions - by suggesting that levels of
general self-efficacy may be only relevant to decision-making when the individual's confidence is extremely high, so the person feels confident to cope with the result regardless of the outcome. The findings also suggest that levels of health specific self-efficacy determine decision-making and intentions, with those individuals active in protecting their health and coping with their risk expressing more positive attitudes about the possibility of testing. The analysis also showed that attitudes and intentions towards genetic testing appeared strongly determined by levels of disease-risk anxiety. Interestingly, the attraction of testing appeared to wane when the consequences of genetic testing were reflected upon.

Chapter eight

The final chapter examines whether the research has achieved its initial aims, with the main findings resulting from the thesis as a whole briefly summarised, and broader themes and new conceptual links made. The wider theoretical and practical implications arising from the main findings are then explored. In particular the relationship between specific and global self-efficacy is discussed, and the link between these constructs, risk and intention examined. The wider implications of the results are then explored, with the impact of the findings in relation to policy-making and the health and well-being of the nation considered. The implications of the results are also examined in relation to other main theories of health behaviour. In particular the findings are examined in relation to Bandura's (1995) self-efficacy theory, with the theoretical process of efficacy generalisation debated. Methodological issues and limitations are addressed, with the strengths and weakness of the sampling identified. Useful future areas of research are then suggested and overall conclusions are made.
Chapter Two

Background literature

2.1 A brief overview of predictive genetic testing

The recent and rapid expansion in molecular genetics means a growing number of predisposing disease genes have been identified (see Marteau & Lerman 2001). In 1995 alone 60 new disease genes were isolated (see Cunningham-Burley & Boulton 2000). A gene is a ‘string’ of nucleotides at a defined location on a chromosome that has been associated with a specific trait and its associated variants. The different variants of a gene are known as alleles, and these variants produce disease, termed ‘gene mutations’. Disease gene mutations are inherited through parents, with genetic testing identifying whether an individual’s genes harbour such mutations. A person identified as having a mutation is referred to as a ‘carrier’. Whilst some genetic disorders such as Huntingdon’s disease are caused by the inheritance of a single mutation, most disease is polygenic - caused by a number of genes - or multi-factorial - the product of an interaction between genetic, environmental and social factors. Another important distinction within the classification of genetic disease is the issue of penetrance. Genetic disorders such as Huntingdon’s disease are fully penetrant, with the inheritance of the genetic mutation associated with this disease always leading to development of the condition at some point in the individual’s life (Lerman 1997). Other gene mutations have reduced penetrance, so they give the affected individual a greatly increased risk, but actual development of the disease is not inevitable (see Hopwood 1997). Genetic testing for most common diseases such as breast cancer, hereditary nonpolyposis colorectal cancer, Alzheimer’s disease and heart disease fall into the reduced penetrance category (Lerman 1997; Roberts 2000; Evers-Kiebooms, Welkenhuysen, Claes, Decruyenaere & Denayer 2000).

Until recently, the advances made in identifying biological markers had mostly been used by obstetricians and paediatricians, to provide antenatal and reproductive testing (see Croyle, Achilles & Lerman 1997; Lerman, Croyle, Tercyak, & Hamann 2002). This type
of testing informs individuals of the risk of passing a genetic disorder on to their children, and so allows them to make family planning choices (Marteau & Croyle 1998). The early ability to define and diagnose the molecular basis of single gene, penetrant disorders, such as cystic fibrosis, muscular dystrophy, and Huntington's disease (Connor & Ferguson-Smith 1993) was an important step forward for families carrying these diseases and planning their families, but the incidence of these conditions within the population as a whole is relatively small. However, the rapid progress made in identifying more complex genes (in terms of penetrance and aetiology) means that pre-symptomatic genetic testing for adult-onset diseases, such as hereditary forms of breast, ovarian and colon cancer, are now increasingly available and viable (see Lerman 1997). An estimated 135,000 women in the UK aged between 25 and 60 are likely to be effected by the BRCA1 gene mutation associated with breast cancer (Hopwood 1997). Searches for susceptibility-conferring genotypes for rare early-onset forms of type II diabetes and Alzheimer's disease have also been successful (Roberts 2000; Holtzman, & Marteau 2000), and wide-scale genetic testing for conditions such as heart disease, many forms of cancer, and increased risk from smoking and obesity, is becoming increasing likely (Marteau & Lerman 2001). This chapter will concentrate on reviewing psychological research into this new area of predictive genetic testing; which specifically informs a healthy adult about his or her chances of developing a disease, such as breast cancer, in the future.

Asymptomatic predictive genetic testing has a number of unique aspects that differentiate it from other forms of health screening (see Lerman 1997). Firstly, genetic information is highly probabilistic. Often no clear indication of, if or when the disease in question will develop is given. This is especially true for conditions with reduced penetrance such as Alzheimer's disease and the BRCA1/2 gene mutations associated with breast and ovarian cancer. Current estimates of developing breast cancer range from 55% to 85% for a BRCA1 gene carrier, compared to 10% for women in the general population (Cappelli, Surh, Humphreys, Verma, Logan, Hunter & Allanson 1999; Lerman, Croyle, Tercyak, & Hamann 2002). Other factors also influence a person's susceptibility to breast cancer and complicate the picture, for example reproductive history, age, obesity and diet (Denton,
1996). Unfortunately science knows relatively little about how these environmental and lifestyle risk factors and genetic susceptibility to disease combine to effect disease onset, but it is conjectured that an interaction of these processes will account for a much larger proportion of breast cancer cases than inherited dominant gene mutations alone (Schneider, Stopfer, Peters, Knell, & Rosenthal 1997). Secondly, unlike testing for the HIV virus, a person with the BCRA1 gene mutation may remain disease free for decades or even for life, suffering no ill effects themselves, but passing on the impact of their genetic make-up to their children (Lerman 1997). Even genetic testing for total penetrance diseases such as Huntingdon’s disease cannot give accurate information about time of onset. The disease can begin at anytime from 2 to 75 years, although the mean age of onset is 40 years (see Tibben, Timmen, Bannink & Duivenvoorden 1997). Thirdly, current technology for mutation screening is imperfect; if a mutation is not found this may mean it remains undetected (Richards 1999). This lack of certainty regarding onset, and the limited value of available screening and intervention strategies, means that the value and benefit of genetic testing for many conditions such as Huntingdon’s disease and breast cancer, is highly contentious (Croyle, Achilles & Lerman 1997; Cunningham-Burley & Boulton 2000; Huibers & Spijker 1998).

2.1.1 The public’s attitudes towards predictive genetic testing

As stated, the progress made in mapping the Human Genome has been rapid, however the early promise attached to this project has not led to the revolution in health care predicted in some quarters (see Durant, Hansen, Bauer, & Gosling 1993). Science is still a long way from offering ‘ordinary’ people the chance of a ‘disease-free’ future (see Richards 1999; Lerman, Daly, Masny, & Balshem 1994; Cunningham-Burley & Boulton 2000). This said, media interest and public debate regarding the development of genetic technology has been intense and widespread. A systematic review of newspaper coverage in 1995 found over 1000 articles in British newspapers about the ‘new genetics’ - a term which specifically refers to the body of knowledge and techniques arising from the invention of recombinant DNA technology in 1973 (Kerr, Cunningham-Burley & Amos 1998; also see Durant, Hansen, Bauer, and Gosling 1993). Even the most casual viewer
cannot fail to notice the huge media attention this topic has attracted (see Hutton in Vogue 2002).

Psychology's apparent lack of parallel interest in these developments is more surprising. Advances in human genetics have been based on enormous financial and technological efforts, but there appears to be little sign of any comparable effort to understand and deal with the social and psychological impact of these new discoveries. Psychological studies examining the opinions of lay people regarding predictive genetic testing are scarce (see Evers-Kiebooms, Welkenhuysen, Claes, Decruyenaere, & Denayer 2000). The research that is available can be broadly divided into two overlapping categories. The first body of work primarily consists of surveys sponsored by governments to examine the general population's attitudes towards genetic testing and biotechnology (see Hietala et al. 1995; Singer, Corning & Lamias 1998; Cabinet Office 1999; National Science Board 2000; Stratford, Marteau & Bobrow 2001). The second group of studies examines the psychological consequences of predictive genetic testing in high-risk medical populations, and examines uptake and interest in this procedure within these populations.

Findings from the first body of research suggest that the public's attitudes to genetic technology are ambivalent, and largely reflective of media coverage. The new medical genetics have been reported as being able to 'unravel the mysteries of human disease and life itself' (Durant, Hansen, Bauer & Gosling 1993), and as the forerunner of a 'Frankensteinian' threat to humanity (see Milewa 1999). Errors such as Thalidomide, Chernobyl and more recently BSE, provide the public with fuel for debate and concern (Frewer 1999). In a recent piece of research on attitudes to genetics by Stratford, Marteau & Bobrow (2001) it was reported that only one fifth (19%) of the British population were classified as 'enthusiastic' towards genetic manipulation, with another half classified as 'cautious' (48%), and the remainder classified as 'restrictive' in their attitude (33%). Another British opinion poll examined both the public's attitudes to insurers' use of genetic test results, and genetic testing in medical research. Out of the 1000 respondents questioned 280 said they would not take a genetic test if they were required to disclose the results, and nearly 700 of the respondents indicated that they would object to tissue
samples being used without their knowledge or consent (Brunner, Sheppard & Ravetz 1997). A European survey of attitudes found that the majority of respondents felt that, irrespective of regulation, scientific research in biotechnology could not be controlled, with only 23% of Europeans feeling that current legislation, regarding the safeguarding of genetic engineering, was sufficient (Eurobarometer 1997). Results from a large nationwide Finnish survey (Hietala, Hakon, Aro, Niemela, Pelton, & Aula 1995) demonstrate similar findings. Although both the population and family members carrying a severe genetic disease had favourable attitudes towards testing, people were concerned about the possibility of discrimination, regarding employment and insurance.

Overall the public appears to characterise genetic technology as something positive but also as something the individual needs protecting from, and that needs to be controlled, with the future possibility of gaining this control considered doubtful (see Frewer, Howard & Shepherd 1997). A large follow up study by Jallinoja, Hakonen, Aro, Niemela, Hietala, Lonnqvist, Pelton, & Aula (1998) again surveyed the attitudes of 1169 Finnish people, and serves to further consolidate these findings. The study focused on the approval of genetic testing as an individual choice, and people’s confidence in controlling the processes attached to testing. Although over half of the respondents (52%) expressed total support for genetic testing as an individual choice, only 35% felt completely confident in being able to decide for themselves whether or not to attend genetic testing, and how the results would be used. A high 95% of respondents went on to express concerns about the independent decision-making processes attached to testing, and expressed worries about the three genetic issues presented to them - the possibility of eugenics, lack of informed consent regarding testing usage, and lack of confidentiality. The public’s apparent ambivalence towards genetic testing is further illustrated in a telephone survey conducted in the U.S by Bosompra, Flynn, Ashikaga, Rairikar, Worden, & Solomon (2000). In the survey 92% of the respondents said that undergoing genetic testing would be beneficial for their family, whilst at the same time 70% of the sample also believed that genetic testing would have a negative impact on their family.
Overall the results from these surveys indicate that people are largely in favour of the medical possibilities offered by this new technology, with the potential for improved health care welcomed. However, alongside this support is a lack of confidence in controlling the ways in which genetic information may be used, although the reasoning behind this concern is harder to elucidate. Abstracting more detailed conclusions from the research reviewed is difficult. Survey studies gather the views of a large number of people, and are useful in providing an overview of the public’s attitudes, but they do not inform us about how these attitudes are formed or changed (see Davison, Barns & Schibeci 1997; for critique). The research design does not address how people tackle and articulate the complex issues involved in decision making around genetic testing. By design, there is little awareness of the social context in which the views gathered are placed. Psychological studies that take a qualitative approach are useful when the research topic is concerned with a novel and complex domain, such as understanding why the public appears to be ambivalent towards genetic technology. Such research is available, but limited, with only a small number of projects currently undertaken.

In 1993 Durant, Hansen, Bauer, & Gosling conducted a series of 12 focus groups (which included special interest groups, such as anti-abortionists, and members of the public) to examine public and media representations of the Human Genome Project (HGP). The data was analysed using social representations theory. In line with the earlier studies discussed, the researchers found a high level of interest in the ‘new genetics’, but again people expressed concerns about the appropriate regulation of these discoveries, with scientists and politicians distrusted. There was a general worry that people were being ‘kept in the dark’ about current developments in biotechnology, although media reports were often felt to be ‘over the top’, with a tendency to invoke fear rather than inform. The discussants were very interested in the possibilities offered by genetic technology, with generally a positive attitude expressed towards medical research aimed at treating or curing genetic disease. However, the discussants’ attitudes towards genetic screening were distinctly ambivalent. The reliability of the test results was questioned, as was the ability to cope with a genetic-risk assessment and the ethics of abortion. Other concerns again concentrated on the ethics of tampering with nature, and the possibility of eugenics
and discrimination. A major concern was the control of human genetics. It was felt that commercial pressures might push genetic research into illegitimate areas.

The impact of social and commercial pressures on the development and use of genetic technology were further raised as concerns in a focus study conducted by Kerr, Cunningham-Burley & Amos (1998). The researchers gathered people together to talk about the genetic research in order to determine where people felt the line should be drawn in the development of this technology. The discussions involved 20 focus groups using a mixture of people from the local community. People expressed feelings of discomfort with the idea of conducting genetic testing to determine trivial physical characteristics. From the discussions, there also emerged a general unease about genetic testing for more ‘serious’ conditions. As mentioned, there was talk of the social pressures attached to testing that might compromise individual autonomy, such as the pressure to abort a disabled child. Personal control was seen as both an appropriate brake, and an undesirable pressure, with a concern that these ‘new’ developments would rob people of choice and responsibility.

The aim of this thesis is to explore factors that may influence the public’s decision-making when contemplating undertaking predictive genetic testing. The research reviewed suggests that the need to safeguard personal autonomy is likely to be highly influential in the decision-making process. People appear to see the potential benefits of medical genetics, and are positive about the possibilities of improved health care, cures and treatments for genetic diseases. Alongside this positive outlook is concern over the possibility of eugenics and discrimination, commercial pressures and a lack of government regulation. The public appears to be distrustful of governments’ ability to control genetic testing developments, and concerned about the possible loss of personal autonomy, resulting from a lack of regulation over these discoveries. The confusion emerging from the research reviewed appears indicative of the dilemmas this technology has created, for professionals and the lay public alike. On the one hand testing appears to offer many considerable benefits and positive choices, yet the potential negative side-
effects and longer-term implications of this health choice are still largely unknown, with the regulation of this technology still being debated.

2.1.2 Clinical research into the psychological consequences of predictive genetic testing

As stated, the majority of psychological research into predictive genetic testing is contained within two broad categories; survey studies of public attitudes, and studies examining the psychological consequences of genetic testing for target diseases, and uptake and interest in genetic testing within these populations. Having discussed the first category, I shall now turn to the second. A ‘typical’ study within this category of research is a piece of work conducted by Coyne, Benazon, Gaba, Calzone & Weber (2000), into distress and psychiatric disorder in 464 women enrolled in a hereditary breast cancer registry. Perhaps surprisingly, the researchers found that women at high risk of breast cancer were remarkably free of psychological distress and psychiatric morbidity, being no more likely to be depressed than a random selection of unscreened women in the general population. This finding, that people at risk of ‘genetic diseases’ are not particularly depressed or psychologically vulnerable, has been widespread and suggests that many people seeking genetic-testing may not require extensive psychological counselling (see Shaw, Abrams & Marteau 1999).

A recent review of the majority of work undertaken in this area was conducted by Broadstock, Michie & Marteau (2000), and serves to support this conclusion. From 899 abstracts and 15 papers reviewed, which concerned genetic testing for Huntingdon’s disease, hereditary breast and ovarian cancers, familial adenomatous polyposis and spinocerebellar ataxia, the researchers concluded that genetic testing results were rarely predictive of distress one month or more after the event. Broadstock, Michie & Marteau found that both carriers and non-carriers showed decreased distress after testing, and although this decrease was more rapid amongst non-carriers, any distress in both groups of patients soon wore off. It was concluded that subsequent distress was not predicted by the test results but by the patient’s pre-test emotional state. Another review undertaken in
1999 by Shaw, Abrams & Marteau, to determine the frequency and circumstances under which genetic predisposition to illness could lead to adverse psychological effects, reports similar findings. Fifty four studies informing individuals of a range of disease risk - such as cancer, Huntingdon’s disease and AIDS - were examined. It was found that in the case of a positive result (indicating increased risk) any adverse effects quickly dissipated, and were not evident one month later.

The findings from these studies are given added weight by the work of DudokdeWit, Tibet, Duivenoorden, Niermeijer, & Passchier (1998) in the only comparative long-term study looking at predictors of post-testing distress across HD, cancer syndromes and BRCA1 gene mutation testing. Variables were measured at two pre-test interviews, 1 week and 6 months after testing. Data was collected from 25 HD patients, 23 familial adenomatous polyposis (FAP) cancer patients and 10 BRCA1 patients. The highest predictor of potential distress 6 months after testing was being female, having children and pre-test intrusion. Participants who were depressed before testing were more distressed after testing, although those participants who were anxious before testing were less distressed post-test. Again the researchers found that the test result itself did not additionally contribute to post-test distress.

The three studies reviewed (Broadstock, Michie & Marteau 2000; Shaw, Abrams & Marteau 1999; DudokdeWit et al. 1997) give a convincingly positive view of the psychological consequences of predictive genetic testing, suggesting that psychologically well adjusted individuals remain so, even after discovering that they are gene carriers. However, a percentage of patients may not be psychologically well adjusted before testing, with the research reviewed suggesting that these participants will not fare well, reacting to receiving genetic risk results with more significant and profound levels of distress (see Horowitz, Sundin, Zanko, & Lauer 2001). The findings from the DudokdeWit et al. (1997) study suggest that a more negative reaction is likely if the tested individual is female or has children. These people may be doubly affected by the thought of passing on their risk to their offspring, and if they are female, fearful of
leaving their children motherless, due to testing bringing the increased possibility of early
death.

The positive image presented by the research reviewed leaves room for caution for a
number of other reasons. Firstly, psychologically vulnerable individuals may be ‘weeded
out’ within the confines of a research protocol, where most participants received
extensive counselling and education (see Croyle, Achilles & Lerman 1997; Meiser &
Dunn 2000). In the future, the possibility of automated and widespread genetic testing via
the internet or ‘drop in’ medical centres suggests that people will not experience these
safeguards. Secondly, the studies reviewed all used existing measures to gauge
psychological well-being. These traditional measures may not be specific or subtle
enough to detect the true impact of genetic testing (see Lerman, Croyle, Tercyak, &
Hamann 2002). Thirdly, the research-based nature of most of the studies may induce
participants with particularly negative effects to minimise these. Lastly, genetic testing
was offered at no charge. When testing moves out of the research arena, the availability
and desirability of this service may change. Insurance companies and the NHS may not
be willing to pay for either testing or counselling, with people thinking differently about
receiving bad news from a test they have paid for.

A large, mainly descriptive study by Lynch et al. (1997) serves to reinforce the need for
cautions, in assuming that people do, and will cope well with genetic test results. The
study involved 388 people undergoing genetic testing for breast cancer (181 of the
participants actually received genetic test results for the presence of the BRCA1 gene
mutation). The participants’ immediate and emotive reactions to testing were recorded by
Lynch et al. (1997) during post-test counselling sessions. Data was collected through
open-ended questions prior to, and subsequent to discussion of patients’ DNA results.
Those patients who tested positive - with an increased risk of cancer - had more
emotional responses of sadness, whilst those with negative results expressed relief. Many
participants had profound responses. One woman, whose sister had tested positive,
experienced guilt and severe shock. Another woman who had chosen not to marry and
have children, because she believed she was going to develop cancer, on finding she had
tested negative said 'I have wasted my entire life' (Lynch et al. 1997, p. 2225). One woman who was a gene carrier decided she would not have children, and leave them motherless; with another patient on hearing she had the gene, undergoing a prophylactic mastectomy at the age of 21. Several individuals, who strongly believed they had the gene mutation, did not trust or believe their negative test results, and still felt they would inevitably develop cancer. Many of the women reported having a strong fear of breast cancer and would not let their partners touch their breasts, did not perform breast self-examinations, or attend further screening. This study suggests that people can experience profound and life changing experiences following genetic testing, and suggests that taking a more qualitative approach to exploring individual reactions to this new health choice may be a useful way of uncovering these responses.

It is important to point out that all the studies reviewed including the latter (Lynch et al. 1997) have investigated immediate or short-term reactions to genetic testing (6 months or less). Psychological studies into the long-term consequences of predictive genetic testing are rare and have only just begun. Even mid-term follow-up of psychological morbidity after testing for diseases, such as breast cancer, are scarce (see Evers-Kiebooms, Welkenhuysen, Claes, Decruyenaere, & Denayer 2000) with qualitative research into the longer term consequences of genetic testing appearing to be non-existent. Most long-term psychological studies undertaken are quantitative in design, and concern carriers of Huntingdon’s disease (HD), as this was first adult-onset disorder for which at risk persons could be genetically tested. HD is an incurable, progressive neuropsychiatric disorder characterised by involuntary movements, cognitive deterioration, and affective symptoms, with a slow progression of these symptoms, and eventual death, averagely occurring 15 years post-onset (see Evers-Kiebooms, Welkenhuysen, Claes, Decruyenaere, & Denayer 2000).

A major study examining the psychological effects of pre-symptomatic testing for HD over a 3 year period was undertaken by Tibben, Timmen, Bannink, & Duivenvoorden (1997). Measures of psychological distress were collected 1 week, 6 months, and 3 years post-testing from 20 identified carriers, 29 non-carriers, and 37 partners of carriers. At 1
week hopelessness and intrusion scores differed significantly, decreasing for non-carriers and increasing for carriers and their partners. At 6 months the differences had been maintained, with an additional significant increase in avoidance found in the carrier group and their partners. At 3 years comparisons revealed no differences between the groups, although the partners of carriers were significantly more hopeless, and reported more intrusive feelings and avoidant thoughts. The partners of non-carriers showed the opposite change. This finding appears positive, although people who feel particularly ill-equipped to know they will develop this fatal disease may not present at a genetic clinic to request testing. As the authors point out, one quarter of the sample of the initial study was lost at follow-up, with some of this loss due to patients’ severe reactions of depression and suicidal behaviour.

A second study by Codori, Slavney, Young, Miglioretti, & Brandt (1997) into the long-term impact of genetic testing for Huntingdon’s disease (HD), assessed predictors of psychological adjustment at 3, 6, 9 and 12 months after testing. Hopelessness and depressive symptoms were measured in 52 genetically positive and 108 genetically negative candidates. Average hopelessness and depression scores were recorded as being within normal limits. At all the time points, married candidates with the gene mutation were more hopeless than unmarried carriers. Carriers closer to the age of onset were more hopeless than those further away. Positive carriers with children were more hopeless than carriers without offspring. As with the earlier studies examining the short term consequences of testing, baseline adjustment was the strongest predictor of follow-up adjustment in both groups.

These studies suggest that being married and having children increases the impact of having a positive test. These candidates must not only deal with their own issues, but cope with the wider impact of the diagnoses on their family members. Partners of carriers seem to have more difficulty coming to terms with the situation than carriers themselves, perhaps due to the dual prospect of having to care for their partner, and being left alone to cope. Mood before testing appears to be the strongest predictor of adjustment, regardless of the test result, suggesting that individuals who are distressed prior to testing may be at
high risk of an adverse psychological outcome post-testing. The findings are further verified in a recent review of literature investigating the long term psychological impact of Huntingdon’s disease by Meiser & Dunn (2000). The researchers conclude that the test results do not in themselves determine distress. The situation is more complex. Over time carriers appear to find resolution, balancing the reality of their situation with living their life, although this gets harder as the onset of the disease gets closer. The emotional difficulties faced by participants contemplating genetic testing for Huntingdon’s are further illustrated in a study by Decruyenaere, Ever-Kiebooms, Boogaerts, Cloostermans, Cassiman, Dom, Fryns, & Van den Berge (1997). The study examined psychological differences in at-risk participants who underwent genetic testing from those at-risk individuals who did not. One of the most startling findings to emerge from the study was the low response rate of non-tested individuals. Taking part in the study appeared to be too stressful, with non-tested at-risk participants stating it was too threatening to talk about or even think about the disease. This reluctance, along with the restricted number of patients currently receiving genetic testing, and high attrition rates, means any generalisation from the studies reviewed should be treated with a degree of scepticism.

2.1.3 Factors influencing the public’s interest in genetic testing

The public’s interest in undertaking predictive genetic testing for cancer syndromes is reported to be somewhere in the region of 70% to 80%. Tambor, Rimer & Strigo (1997) asked women aged over fifty, who received regular mammograms and were enrolled in a breast screening program, whether they would wish to be tested for the presence of the breast cancer gene. Sixty nine percent of the 475 women surveyed said they would be tested. Although high, this figure is substantially lower than the figure found in other studies examining interest in genetic testing for cancer susceptibility (see Donovan & Tucker 2000). In a random telephone survey conducted in the USA by Croyle, Achilles & Lerman (1997) nearly all the respondents (82%) said that they were ‘somewhat’ or ‘very’ interested in genetic testing for colon cancer susceptibility. Lerman, Daly, Masny & Balshem (1994) determined the attitudes to genetic testing in 121 female first-degree relatives of ovarian carcinoma patients registered with a national cancer centre. Seventy
five percent of the subjects said they definitely wanted testing, 20% said they probably would, 2% said they would not be tested, and 3% were uncertain.

In the Lerman, Daly, Masny & Balshem (1994) study cited, the authors examined factors related to interest in genetic testing services. The most commonly cited reasons for wanting genetic testing were: to learn children’s risk (76% rated this as very important), to increase screening practices (71%), to be reassured (70%), and to take better care of oneself (52%). Making childbearing decisions was also important (48%), with marital decisions less so (20%). Demographic factors associated with higher interest were having an education beyond high school and being younger (marginally so). Several psychological variables were additionally measured and associated with interest. The degree of mood disturbance (as measured by the POMS) and the perceived likelihood of being a gene carrier were strongly associated with interest (four times greater). The perceived risk of developing cancer was also associated with increased interest, although interestingly, actual levels of ovarian cancer risk were not. This finding suggests that increased risk is important to genetic testing decision-making, although it is subjective perceptions of risk rather than objective risk levels that are relevant. A vigilant information-seeking coping style, psychological disturbance and younger age also predicted the perceived negative impact of testing. These findings raise concerns, by suggesting that women who want to undertake genetic testing for breast and ovarian cancer represent a psychologically vulnerable sub-group (Lerman, Daly, Masny & Balshem 1994) in being younger, having heightened perceptions of risk, suffering more psychological distress and attaching more negative consequences to testing.

The suggestion that psychological disturbance may predict testing uptake is further verified in a follow up study conducted by Lerman, Schwartz, Lin, Hughes, Narod, & Lynch in 1997. This time the participants were 149 men and women from hereditary cancer families who were asked to provide blood samples for genetic-testing research. The authors found that individuals with high levels of cancer-related intrusive thoughts were three times more likely to request their genetic test results, although 42% of the 149 participants did not want to be informed of their genetic status because of fear of
discrimination and difficulties gaining insurance. Concerns about life insurance and job
discrimination have also been cited as reasons for rejecting testing in a study by
Armstrong, Calzone, Stopfer, Fitzgerald, Coyne & Weber (2000). Participants were
women with a family history of breast cancer, enrolled in a clinical research program.
The researcher found only 50% of the women in the program chose to undergo testing
(even though all the women had received genetic counselling and were attending a
clinical cancer risk evaluation program) because of a fear of discrimination. These
findings confirm that the public’s concerns about discrimination noted in the studies
reviewed earlier (Durant, Hansen, Bauer, & Gosling 1993; Hietala et al. 1995; Kerr,
Cunningham-Burley & Amos 1998) are translated into a potent reason for declining
genetic testing.

Although studies examined so far have concentrated on factors related to interest in
genetic testing for cancers (primarily the BRCA1/2 gene), research is emerging that is
gauging the public’s interest in genetic testing for other types of diseases. In 2000
Roberts gauged interest in genetic testing for Alzheimer’s disease (AD) in 203
participants of first-degree relatives with the disease. The participants were enthusiastic
about genetic testing for this condition, with men expressing greater interest than women,
and the benefits of testing being rated as more important than the limitations, or the risks.
The most significant predictor of testing intentions was the balance between the
perceived pros and cons, with increased information for future planning the most
important benefit, and concern over the effects of testing on loved ones, the most
important reason for declining. Despite the generally positive responses noted by
Roberts, in line with the earlier findings discussed (Lerman et al. 1997; Armstrong et al.
2000), a significant subset of the participants were concerned about the effects of testing
on insurance rights, employment prospects and the family’s emotional well-being.
Interest in AD has also been investigated by Frost, Myers, & Newman (2001) this time
using undergraduate students. The researchers found that contrary to the keen interest
noted by Roberts (2000), only 2% of their sample definitely intended to undertake testing
for AD, suggesting - perhaps unsurprisingly - that demand for this service is unlikely to
be high among young people.
2.1.4 Actual rates of uptake of genetic testing

As stated, the public’s interest in genetic testing appears to be high, although research suggests that this level of interest may not be translated into actual rates of uptake (Lerman et al. 1997; Armstrong et al. 2000; Roberts 2000). Cappelli, Humphreys, Verma, Logan, Hunter & Allanson (1999) examined the demand for BRAC1 testing, together with factors predicting the intention to be tested, and the degree to which the women acted on their intention. The participants were 110 Canadian women under age fifty, 60 of the women were diagnosed with breast cancer, with the rest of the women drawn from a population index group. Overall 60% of the participants indicated they would like a genetic test for the breast cancer gene, 29% were uncertain and 11% did not want to be tested. In the breast cancer group 72% wanted to be tested, but only 49% actually contacted the genetic counsellor 3-15 months later. Cappelli et al. (1999) did not continue follow-up after 15 months, but at this time only nine women in the at-risk group had actually had undergone genetic testing. As in the earlier study by Lerman, Daly, Masny & Balshem (1994), intention to be tested was again associated with the perceived presence of breast cancer, and with greater perceived benefits, fewer perceived costs and higher levels of concern for relatives. Actually arranging to meet the genetic counsellor was associated with fewer perceived costs, although any conclusions, based on the small number of participants who actually undertook this procedure, must be tentative. Overall the study suggests a moderate interest in testing, with the intention to be tested not translated into uptake.

The wide gap between interest and uptake of testing is clearly illustrated in a review of genetic testing uptake rates undertaken by Meiser, Gleeson & Tucker (2000). In the study genetic testing uptake rates for Huntingdon’s disease among people at risk are reported as being as low as 10%-20%. In contrast, uptake rates for families identified with mutations predisposing them to hereditary breast cancer or nonpolyposis colorectal cancer were much higher, at around 40%-60%. For individuals at risk of FAP uptake rates were the highest at around 80% (also see Clarke & Flinter 1996; Hopwood 1997). Currently the motivation behind these large differences in uptake, for those in high risk groups is
unknown (Bowen, Patenaude, & Vernon 1999; Lerman, Croyle, Tercyak, & Hamann 2002). Meiser, Gleeson & Tucker (2000) suggest that the most likely reasons for the disparity is the possibility of medical intervention. In the case of Huntingdon’s disease, there are currently no medical interventions to slow down the onset of this incurable and very unpleasant condition. In the case of breast cancer, for a healthy young woman learning that she has an 80% chance of developing the disease (see Lerman 1998), the option of a prophylactic mastectomy, or regular breast screening, appears in the first case extreme and in the latter inadequate (see Eisen & Weber 1999; Huibers & Spijker 1998 for discussion), whilst the case of FAP screening and effective interventions are highly effective in slowing down the disease. This said, in the case of hereditary nonpolyposis colorectal cancer effective interventions to prevent onset of disease are available, yet the uptake of genetic testing has still been lower than anticipated (Holtzman & Marteau, 2000). On more actively contemplating testing, or after receiving genetic counselling, people may become more aware of the limitations of testing. Women who show an initial interest in genetic testing for breast cancer may decide against the test once they learn that following a negative test, they still have a 1 in 11 population risk for developing breast cancer (Tambor, Rimer & Strigo 1997). People may decide there is no point in testing if knowledge of their genetic risk involves making behaviour changes they feel unable to action, or simply do not want to action. Alternatively people may feel any preventative action is useless in the face of a disease they are ‘genetically’ predisposed to.

A difficulty in attempting to investigate the gap between interest and uptake of testing is the almost exclusive focus on understanding the decision-making of individuals already attending specialist cancer centres. In a recent review of the literature on predictive genetic testing decision-making Lerman, Croyle, Tercyak, & Hamann (2002) argue that those individuals who decide to pursue genetic testing probably make the decision to commit long before they participate in any form of counselling or education program. Huibers & Spijker (1998) further point out that people within clinical settings are not neutral. Why would people be there in the first place if they were not already interested in discovering more about their genetic make-up? The fact that participants are within a
research setting or a medical clinic indicates that they have already made a large step in their decision to pursue this option. In a rare study that does attempt to contact participants at risk of Huntington’s disease, who had no previous contact with a research centre, the results are disappointing (Decruyenaere et al. 1997). The researchers asked participants who had been tested for HD whether they could contact their at-risk relatives. Of the 112 possible participants only 50 people responded. The researchers found that people at-risk (who had chosen not to participate in screening) did not want to think about the disease, talk to the researcher, or want the researcher to contact their families. The anticipated inability to cope with a bad result was the largest reason reported for deciding against testing, although the low response rate makes any conclusions difficult. Lerman, Croyle, Tercyak, & Hamann (2002) argue that researchers need to examine the decision-making process pre-counselling and consider disease representations, comprehension and motivation in more general groups of people within the community, not just self-selected counselling attenders - or the relatives of high-risk participants.

2.1.5 The public’s decision-making when contemplating testing

As stated, few studies have been conducted which examine the public’s decision-making when contemplating undertaking genetic testing, although the research that is available provides further evidence that perceptions of control - over the target disease, over disease worry and over future outcomes - is likely to be relevant. In the Tambor, Rimer & Strigo study (1997) cited earlier women who believed that having regular mammograms gave them a feeling of control over their health were almost three times more likely to be interested in testing than those who did not agree that mammograms gave them a feeling of control. Another recent study by Shaw & Bassi (2001) aimed to probe the public’s knowledge, attitudes and desire to undergo testing, using responses from 228 individuals randomly selected from the population in Pennsylvania. Apart from standard attitudinal measures, participants were presented with 12 hypothetical situations concerning the possibility of treatment, the probability of a positive result, and the severity of the disease. The participants were asked to indicate how likely it would be that they would want to be tested in each hypothetical situation. Overall the responses were very
optimistic concerning the potential benefits of genetic technology, but as with the earlier survey research, alongside this feeling ran the acknowledgement that testing could cause problems if it was conducted by the ‘wrong people’, with the need for privacy and autonomy stressed. The respondents’ decision to pursue testing appeared to be affected by the predictive value of the test, the availability of any cure, and the severity of the disease. The desire to know the future was also highly correlated with interest in testing, especially if the disease did not have a cure. The respondents stated that they would be more likely to take a genetic test if they felt the results would lead to high levels of certainty (also see Croyle, Dutson, Tran & Sun, 1995). Controllability and predictability were particularly identified by the researchers as being two distinct motivations for engaging in testing. These results suggest that even when genetic testing does not offer control, in terms of disease prevention, people may still be interested in genetic testing in order to reduce any ambiguity over their future health. A third study, investigating the public’s decisions-making regarding using predictive genetic testing was conducted by Wroe, Salkovskis & Rimes (1998). The researcher recruited a mixed sample of both students and individuals who had previously contemplated undertaking predictive genetic testing. In giving reasons for pursuing testing, 67% of the participants who had contemplated testing stated emotional or anxiety related reasons, compared to just 13% of the students. The results again imply that for people intending to undergo this procedure freedom from uncertainty and worry is a strong motivator (Wroe, Salkovskis, & Rimes 1998).

To conclude, the first body of research reviewed examines the general population’s attitudes towards genetic testing and biotechnology, and suggests that genetic technology is viewed as something that the individual has little personal control over (Frewer, Howard & Shepherd 1997). A lack of government regulation, fear of discrimination, and the need for personal autonomy over genetic testing decision-making, emerge as particular concerns. A major limitation within this body of research is the large number of survey studies. Although this research design allow the views of a large number of people to be gathered, the methodology does not necessitate any deeper exploration of the type of factors that influence differences in perception, inform us about the possible
reasons for people's ambivalence towards genetic testing, or tell us about how the public's attitudes might be shaped or changed. Quantitative research that attempts this task is limited, with currently few studies undertaken in the United Kingdom.

The second group of studies reviewed examines the psychological consequences of genetic testing for specific diseases, in high-risk medical populations, and uptake and interest in genetic testing within these populations. From initial research it appears that most people do cope well with the results of genetic testing, although there is room for caution, with qualitative and long-term studies into psychological adjustment post-testing, currently not available. The research reviewed suggests that perceived control over the target disease, and control over future uncertainty are important factors in people's interest in predictive genetic testing. The perceived ability to protect one's family, plus perceptions of increased disease risk also appears relevant to people's interest in this health choice. However, the relationship between perceived risk and actual uptake appears more complex, a point that will be expanded later. The relationship between concerns over discrimination and lack of uptake appears straightforward, with this fear translating into a reason for declining testing.

One of the biggest limitations of the second body of research is the narrow focus of the sampling. By using individuals already attending medical clinics, or the relatives of such individuals, there is a failure to consider the decision-making of those people who never reach a clinic, the motivation of the vast majority of high-risk individuals who choose not to attend screening or participate in clinical research (see Bowen, Patenaude, & Vernon 1999). The thesis presented attempts to bridge this gap by investigating factors that influence genetic testing decision-making prior to the consulting room and exploring the motivations of individuals who intend to request this service and also the decision-making of those individuals at high risk of disease who will never be seen at a genetic clinic.
2.2 Health psychology research

Health psychology has proposed many theories to help explain the adoption of health-protective behaviours (see Ogden 2000). In this paper I shall review four of the most frequently used: the health belief model (Rosenstock, 1966), protection motivation theory (Maddux & Rogers 1983), the theory of planned behaviour (Ajzen 1985) and the self-regulation model of illness behaviour (Leventhal, Meyer & Nerenz 1980). The intention is not to conclude which theory is better than another, the goal is to identify which might be most applicable to the problem of explaining why people may or may not decide to undertake predictive genetic testing.

2.2.1 The Health Belief Model

In 1966 Rosenstock presented a model aimed at helping professional health workers better understand and explain why, and under what conditions, people take action to prevent, detect and diagnose disease. From this seminal work the health belief model (HBM) was developed. The model predicts that health behaviour is the result of a core set of beliefs. The original core beliefs outlined by Rosenstock (1966) concerned the individual’s perception of:

- susceptibility to illness (my chances of getting breast cancer are high),
- the severity of illness (breast cancer can be fatal),
- the costs involved in carrying out the behaviour (breast screening will be uncomfortable),
- the benefits involved in carrying out the behaviour (breast screening will help to catch the cancer early and save my life) and
- cues to action, which may be internal (finding a breast lump) or external (seeing a TV program on breast cancer)

Criticisms of Rosenstock’s (1966) original model have led to some revisions (see Maiman & Becker 1974) with the construct ‘health motivation’ being added to reflect the
individual's readiness to be concerned with health matters (I now admit that I am at risk of breast cancer). Becker & Rosenstock (1987) have also suggested adding perceived control, see figure 1 below.

**Figure 1.** Basics of the health belief model

Research into health behaviours using this model have been numerous and widespread (see Sheeran & Abraham, 1995), although research using this model to predict genetic testing decision-making is relatively scarce. One early study conducted by Rosenstock and colleagues (Becker, Kaback, Rosenstock & Ruth, 1975) used the HBM to explain differential voluntary decisions relating to future cooperation in a genetic screening program for Tay-Sachs disease. The results from the study indicated a significant positive relationship between the desire to have children, perceived susceptibility to Tay-Sachs disease and intention to be tested. Perceived severity of the disease was also related to intention, but negatively, with the higher the perceived severity the lower the intention.
The authors explain that perceived severity acts ‘independently’ of the other constructs studied, although this claim appears unfounded as the authors did not report examining the relationships between the variables studied. The ‘two tailed’ hypothesis testing of individual variables that was employed by Becker, Kaback, Rosenstock & Ruth, (1975) appears useful for identifying potential areas of interest, but inadequate in terms of model building. Interestingly, the authors also found no relationship between a general measure of health motivation and the desire to be tested. The authors explain that, in retrospect, the result was ‘unsurprising’ because genetic testing is probably unrelated to how a person thinks about their health. This rationale appears far from obvious, and again serves to demonstrate the limitations of presenting a theory without investigating how component parts relate and interact as a whole.

Unfortunately, the testing of individual variables, as opposed to model testing and theory building, appears typical in much current psychological research, across all the theories of health behaviour discussed in this review, with often mixed or poor results. This ‘cherry picking’ approach is demonstrated in a study by Cappelli et al. (2001). The researchers used a selection of constructs contained within the HBM to predict interest in genetic testing for breast cancer susceptibility. The constructs thought to be relevant to the research question were perceived risk, benefits (reasons for taking the test) and costs (reasons for declining testing). Participants were 58 volunteers at high-risk of breast cancer and 50 women from the general population. The results were mixed. Unlike the previous studies reviewed earlier (Cappelli et al. 1999; Lerman, Daly, Masny & Balshem 1994), risk perception was not related to interest in genetic testing, although perceived benefits and fewer perceived costs were associated with increased intent. Another larger study investigating health screening behaviour was conducted by Macrae, Hill, St. John, Ambikapathy, Garner, & the Ballarat General Practitioner Research Group (1984). The results were again disappointing. The researchers used components of the HBM (including cues to action and health motivation, but excluding perceptions of control) to predict colon cancer screening behaviour in 581 people visiting their GP. Using multiple regression analysis the combined variables were found to account for 12% of the variance in screening behaviour. Macrae et al. (1984) found that patients susceptible to the disease
- having a first-degree relative with colorectal cancer - were more likely to take home the screening test (a ‘do it yourself’ testing kit), however this did not mean they were actually any more likely to use the test than participants at low risk.

A rare study testing the usefulness of the whole model (rather than combining the predictive value of separate variables) was conducted by Bosompra et al. (2000). The HBM was applied to predicting the likelihood of undergoing genetic-testing for cancer-risk within the general population. In the study 622 adults were interviewed by telephone, and asked whether they would undertake genetic testing (if available). The reported likelihood of uptake was surprisingly low. Only 20% of the participants said they would probably or definitely undergo genetic testing, increasing to 62% if recommended to do so by their doctor. The structural equations produced confirmed that perceived benefits of testing (the perception that testing would be beneficial to the family), perceived barriers (the perception that testing would have a negative impact on the family), perceived susceptibility (lifetime risk) and perceived pessimism, together predicted 34% of the variance in intention. This raises the question of what other variables account for the 66% of variance not explained by the model. Overall the studies reviewed suggest that the HBM may have limited usefulness, when applied to the question of investigating factors that influence the public’s decision-making when contemplating genetic testing.

Another problem with using the HBM to study interest in predictive genetic testing is highlighted by Harrison, Mullen & Green (1992). The authors point out that the inclusivity of constructs such as perceived benefits makes valid operationalism of variables extremely difficult. For example, is the certainty offered by predictive genetic testing for Huntington’s disease (development of the condition is inevitable if the gene is detected) a perceived benefit of undergoing this test, a perceived barrier to testing or alternatively, does it concern the perceived susceptibility or severity of the disease. The factors outlined by the HBM appear to allow an infinite number of measures to be applicable, and constructed in an infinite variety of ways, making the interpretation of results and comparison of findings across studies problematic (Janz & Becker 1984). In a meta-analysis of the HBM conducted by Harrison, Mullen & Green (1992) the authors
state that a lack of homogeneity across different studies makes it difficult to form any
strong conclusions about the usefulness of the HBM. Many studies appeared to be
measuring different constructs, but naming them under the same headings. This problem
is clearly demonstrated in a study by Decruyenaere et al. (1997). In the study HBM
variables were used to differentiate participants who underwent genetic testing for
Huntingdon’s disease from those who declined. Participants who declined testing stated
that the perceived inability to cope with a bad test result was the most important reason
for their decision. The researchers conceptualised this perceived inability as a ‘cost’ of
testing, and as such it was separated from the other personality variables measured in the
study, such as coping strategies and anxiety, a research position which appears highly
subjective.

A different but equally important difficulty in applying the HBM to the problem of
genetic testing decision-making is the lack of focus on the actual development of the
decision-making process. The model offers no temporal order and, as shown, health
psychology research often fails to conceptualise any relationships between the main
variables (see Sheeran & Abrahams, 1995). The potential value of the model would be
greatly enhanced if the origins and development of health beliefs were more clearly
specified and placed within a broader theoretical framework that account for responses to
a wide range of stimuli (see Rosenstock 1974). This lack of specificity leads to criticisms
of circularity regarding cause and effect, and raises the question of whether the HBM is
really a model or a short list of variables (see Weinstein 1993; Sheeran & Abraham
1995). Another question raised by Rosenstock in 1974 is whether the constructs within
the HBM are monotonic, uni-dimensional or have cut-off threshold points. Unfortunately
since this time little psychological research can be found which offers an answer. The
model implies that certain levels of readiness are optimal in stimulating health behaviour,
but neither theory nor research has disclosed what these levels are. The resulting lack of
theoretical depth makes any explanation of alternative relationships difficult, with the
inclusion of idiosyncratic or alternative forms of evidence unworkable. For example a
study by Lerman et al. (1993) into mammography adherence found that increased worries
regarding susceptibility to breast cancer acted to inhibit not encourage breast screening
activities. Similarly a study by Lipkus, Biradavolu, Fenn, Keller & Rimer (2001) examined whether women's intentions to seek mammograms would reduce, if their risk of developing breast cancer was reduced. The researchers found that in contrast to HBM predictions, giving women a lower risk-estimate of developing breast cancer had no impact on their breast screening intentions. Currently the HBM offers no explanation for these findings.

Several studies into HIV risk behaviour gives weight to the suggestion that an awareness of increased susceptibility often fails to promote behaviour change (see Edgar, Freimuth, & Hammond 1998). Variables such as perceived self-efficacy, descriptive norms and contextual factors, such as drug use, have been shown to be more important predictors of HIV-preventive behaviour than HBM specified variables (see Sheeran & Abraham 1993; Kelly, St. Lawrence, Hood & Brasfield, 1989). This lack of success again implies that the model may have limited applicability. Predictive genetic testing is similar to HIV risk behaviour, in that there is a delay between the risk-preventative behaviour and the appearance of any illness. Psychological research on sexual behaviour suggests this delay often produces a lack of acknowledgement regarding personal susceptibility (Edgar, Freimuth, & Hammond 1998). As noted in HIV research, increased perceptions of genetic risk, among those individuals who already acknowledge their susceptibility to disease, may lead to denial, not increased risk perceptions or motivation (see Holztn & Marteau 2000).

2.2.2 Protection Motivation Theory

Protection motivation theory (PMT) was developed by Rogers (1975), and helps to address some limitations of HBM. According to Rogers the intention to adopt health behaviours is mediated by the amount of protection motivation aroused. Protection motivation is described as an intervening variable that has the typical characteristic of a motive, in that it arouses, sustains and directs activity. A basic premise is that protection motivation arises from the cognitive appraisal of a depicted event, specifically the individual's perceived:
• Severity of a disease,
• Susceptibility to disease,
• Response effectiveness (having breast screening would be good for my health),
• Self-efficacy (see Maddux & Rogers 1983) and more recently,
• Fear, (see figure 2 below).

Figure 2. Basics of protection motivation theory

PMT describes perceived severity, susceptibility and fear as threat appraisals. Self-efficacy and response effectiveness are described as coping appraisals. According to PMT two types of information serve to activate these appraisals – environmental information (such as media campaigns on breast cancer) and intrapersonal experience (prior personal experience of disease). The five components of the model then elicit either adaptive or maladaptive coping responses, such as intending to take better care of one's health or ignoring the problem. Rogers (1975) argues that PMT is advantageous over other health models in that the theory can be applied to automated forms of coping, in which no emotional state or fear is aroused such as crossing the street or wearing a seat
belt. It is important to note that the components in the model predict behavioural intentions, not actual behaviour.

The effectiveness of PMT has been demonstrated in predicting health screening intentions (see Rippetoe & Rogers 1987). In the study the authors examined whether PMT variables would have an impact on intention to practice breast self-examination (BSE) in 163 female students. Individuals were randomly assigned to a number of different experimental groups where they were given information about breast cancer. The information emphasised either a low or high levels of health threat, and encouraged low or high levels of self-efficacy - in being able to conduct BSE. The results provided support for the model. Both the threat and the coping-appraisals increased intentions to undertake BSE, although the threat alone did not determine how people coped. Both maladaptive and adaptive coping was reported as being higher in the high-threat condition.

In the Rippetoe & Rogers (1987) study adaptive coping was classified as rational problem solving and the intention to perform BSE, whilst maladaptive coping was classified as not intending to perform BSE. This labelling of responses does not appear appropriate in the case of predictive genetic testing, and illustrates one of the limitations this model presents. Declining genetic testing for Huntington's disease - a disorder that is incurable, progressive and extremely unpleasant, with currently no effective medical interventions available - is difficult to classify as either a maladaptive or protective response. No clear or correct response is available. The answer appears dependent on individual moral judgements and standpoints (see Smith, Michie, Stephenson & Quarrell, 2002). Equally when considering the applicability of both the HBM and PMT to the question of predictive genetic testing the absence of social or historical factors appears limiting. As previously discussed, psychosocial research suggests the population's attitudes towards this new technology are emotive, ambivalent and entrenched within both historical and social dialogues (Milewa, 1999).
Another limitation of both the HBM and PMT is the assumption that people process information in a rational manner. There is considerable evidence that people do not act like optimal problem solvers (Weinstein 1993), that decision-making may be more automatic (Smith, Michie, Stephenson & Quarrell 2002), or influenced by concrete short term costs than a hypothetical reduction in future vulnerability (Edgar, Freimuth, & Hammond 1998). In the case of predictive genetic testing, research suggests that perceptions of risk to disease are influential in people's intentions to undertake testing (see Lerman, Croyle, Tercyak & Hamann 2002; Marteau, Kidd, Cook, Michie, Johnston, Slack, & Shaw 1991). Yet perceptions of risk appear to be partly based on emotional considerations, such as the person having an intuitive feeling that they will develop a disease, not just rational information processing of the facts (Hopwood 1997; Lynch et al. 1997; Smith, Michie, Stephenson & Quarrell 2002).

2.2.3 Theory of Planned Behaviour

The theory of planned behaviour (TPB) (see Armitage & Conner, 2001) is a revision of the earlier theory of reasoned action, with the addition of perceived and actual control as factors in both behavioural intention and behaviour (Ajzen, 1983). In the theory, behaviour is assumed to be determined by intention, with intention determined by three basic constructs: attitudes, subjective norms and behavioural control. The TPB assumes that people usually behave in a 'sensible manner' (see Ajzen 1983, p. 12). However, unlike both the HBM and the PMT, the model does include a degree of irrationality, in the form of personal evaluations, and addresses to some extent social and environmental influences, in the form of normative beliefs. In addition it includes a role for past experiences, in the form of perceived behavioural control (see figure 3 below).
A recent meta-analysis of psychological research conducted using this model by Armitage & Conner (2001) concluded that TPB variables account for between 27% and 39% of the variance in behaviour and intention respectively, with the variable subjective norm being the weakest predictor of intentions, but the addition of perceived behavioural control serving to greatly increase the models predictive value. The levels of variance quoted by Armitage & Conner (2001) appear moderate rather than impressive, and raise the question of what other constructs influence the 60% to 70% of variance not accounted for. Another comment is that although the health models discussed aim to predict the
likelihood of behaviour, they do not predict the amount of ‘precautionary’ behaviour that will occur; whether 20%, 50% or 80% of the population will want to undertake genetic testing (Weinstein 1993).

Components within the TPB have been used to assess a variety of health-related behaviours, such as eating a low fat diet (Povey, Conner, Sparks, James & Shepherd 2000), testicular examination (Brubaker & Wickersham 1990), and weight loss (Schifter & Ajzen 1985). TPB variables have also been used to predict intention to take a genetic test for Alzheimer’s disease (AD) (Frost, Myers, & Newman 2001). In the study 449 undergraduate students were asked about their willingness to have genetic testing for AD, with only 2% responding that they definitely intended to make use of this service, when available. The authors found that 50% of the variance in intention was related to TPB variables, with negative beliefs (not wanting to know if they would develop the disease) and subjective norms (regarding other people’s approval of this procedure) accounting for the vast majority of this figure (30% and 11% respectively).

The Frost, Myers, & Newman (2001) study is useful in illustrating some of the difficulties in applying current theoretical models of health behaviour to the problem of understanding predictive genetic testing intentions. From the study we know that only 2% of the sample definitely intended to undergo genetic testing for AD, with negative beliefs (not wanting to know about whether they would get this disease) being identified as the most influential TPB variable in people deciding to reject this service. However, what the study fails to tell us is why; what underlying factors or variables differentiate those individuals who want to know about their likelihood of developing Alzheimer’s disease, from those who do not. Another problem highlighted by the study is that only two variables within the TPB appeared to have any major influence on testing intentions, suggesting that the other variables within the model are redundant. All the health behaviour models discussed are framed with the assumption that the concepts used represent how people actually think about health behaviour.
As discussed, in the case of predictive genetic testing psychology knows relatively little about how the general population perceives this procedure. Unlike the other behaviours examined by the health models discussed, predictive genetic testing is differentiated by the distance between the health behaviour (genetic testing) and any potential threat to well-being, as any disease may not develop for decades or even for life. Actual ill health is something that may completely bypass the individual, as can be the case for men who carry the BRCA1 breast cancer gene; they may suffer no ill affects themselves but can pass their genetic status to female children or grandchildren (Lerman 1997). This lack of certainty regarding onset, and the variable availability of screening and effective intervention strategies means that the value and benefit of genetic testing for many conditions such as breast cancer is highly contentious (Croyle, Achilles & Lerman 1997; Cunningham-Burley & Boulton 2000; Huibers & Spijker 1998). Psychological research on genetic testing suggests that the relationship between perceptions of disease risk and the intention to undertake testing are highly complex, a point that will be expanded shortly (see Shiloh, Petel, Papa & Goldman 1998). These unique aspects of predictive genetic testing, and our lack of knowledge regarding the public’s perception of these issues, suggests a qualitative approach is required to ascertain the answers to these questions before proceeding further. It appears logical to investigate the mental representations people actually use when contemplating predictive genetic testing, before trying to fit the end result of these deliberations into a predictive model. To achieve this task, the self-regulation model (SRM) of illness behaviour (Leventhal, Meyer & Nerenz, 1980) appears useful.

2.2.4 The self-regulation model of illness behaviour

The SRM differs from the other types of health-decision models discussed in attempting to conceptualise the processes involved in the construction of judgements about vulnerability to disease, severity of disease and effectiveness of actions. The model aims to understand how people define and represent an illness, and then go on to cope with it. The SRM is based on a problem-solving approach, which assumes that a person is motivated to solve health problems and re-establish their state of normal health - hence
the term self-regulation. The model proposes that health-related decisions evolve through a series of stages, beginning with the formation of a health threat representation. The threat to health is received in two ways, through the perception of symptoms or from social messages - such as having a younger sister diagnosed with breast cancer. The health threat will then be given meaning via constructed representational attributes (which include both reasoned perceptions and emotional information) regarding the -

• cause of illness - what factors led to disease onset
• consequences - the short and long term effects of the disease
• cure & control of the disease - what can be done to get over the disease, plus the
• development and duration (time-line) of the disease, and
• disease identity - the labels and symptoms associated with the disease (see Leventhal, Meyer & Nerenz 1980).

In the second stage of the model these ‘common-sense’ illness representations guide the formation and enactment of coping behaviours aimed at resolving the health problem and reducing the emotional distress induced by the threat (see Cameron 1997; Leventhal, Idler, & Leventhal 1999). Two broad categories of coping have been identified within the model; approach coping (such as attending health screening) and avoidance coping (ignoring your health risk and choosing not to attend health screening). Hence non-compliance may emerge because people generate their own representations of danger and their own coping reactions in order to deal with the potential health threat. In the final phase the effectiveness of these strategies is appraised, and the individual decides whether to continue with this solution or opt for an alternative strategy - see figure 4 below.
While the composition of the concept of predictive genetic testing has not been widely explored, researchers have addressed the prototype of illnesses, and the meanings of common diseases (Leventhal, Meyer & Nerenz 1980). Lau, Bernard, & Hartman (1989) used the five disease components contained within the model to examine representations of illness in 1,628 respondents, over a period of 3 years. The research confirmed that respondents used these cognitions to describe recent periods of illness ranging from the...
common cold to cancer, with the five components appearing reasonably stable over time. Identity appeared to be the strongest representation of illness, followed by time-line, cause, cure and consequences, with 11.3% of respondents mentioning all five components in their descriptions of two or three recent illnesses (also see Lau & Hartmen 1983).

2.2.5 Illness representations of genetic disease

Within the SRM, illness representations are described as guiding coping, and being constructed to permit coping. However, exactly how these five representations might relate to coping with the decision to pursue predictive genetic testing is unknown. Psychological research has not directly investigated this question, although Shiloh & Berkenstadt (1992) have used the concepts developed by Leventhal and colleagues to study representations of genetic disorders. In the study the researchers found that people did not conceptualise time-line associations when considering genetic disorders. The 3 most frequently mentioned associations were the symptoms of a disease, the cause of onset, and the emotional consequences attached to a medical diagnosis. The participants' answers contained specific emotional responses and social information about the perceived consequences of a genetic disorder. This suggests that the representations reflected both generalisations from specific illness experiences, and information from cultural norms.

Marteau & Senior (1997) have used the illness representation paradigm to review the content and structure of causal beliefs attached to genetic testing. The researchers concluded that whilst the word 'genetic' does automatically imply a hereditary cause most people do perceive diet and exercise as having a role in causing illness. What is unclear is the relationship between these perceived factors. Research by Michie, McDonald & Marteau (1996) may offer some insight. The study examined how families affected by familial adenomatous polyposis (FAP) conceptualised the cause of this condition. FAP is primarily genetic in origin, although the majority of participants in the study considered the disease to be multi-factorial. In a follow up study by Michie et al.
the researchers found that this belief - in the multi-factorial nature of the condition - led to reluctance to abandon bowel screening in some patients who had received a low risk test result. Lack of certainty over the accuracy of the test, and increased perceptions of risk and disease worry were additionally identified as influencing the desire to continue with screening (Michie et al. 2002). The desire to maintain screening may also be due to this behaviour providing a strong source of self-efficacy, in giving the patients a reassuring and formalised means of preventing further development of the condition. A negative genetic test result would serve to invalidate this source of control, something patients may have dealt with by ignoring the facts.

Psychology has not investigated how the identity, cure, control or consequences of a genetic disease might be conceptualised within the illness representation paradigm. Neither has research examined how illness representations affect people's decision-making, in relation to undertaking genetic testing services. People's representations of genetic testing may provide a focus for self-regulating behaviour, that expands or decreases the individual's sense of self-determination or control over their health and future life (Leventhal, Meyer & Nerenz 1980). A small body of research is emerging that does suggest that labelling a disease as 'genetic' results in lower perceptions of control, and that these constructs are strongly linked. In an analogue study by Senior, Marteau & Weinman, (2000), two groups of students (n=212) were asked to imagine that they were undergoing a test for heart disease or arthritis. When the test was represented as a new 'genetic' test as opposed to another procedure, the disease (regardless of type) diagnosed by the genetic method was seen as less preventable. The researchers followed up this finding by conducting semi-structured interviews with the parents of 24 children at risk of familial hypercholesterolaemia (FH), a condition that predisposes an individual to coronary heart disease. When the test for FH was perceived as detecting cholesterol, the parents perceived the problem as familiar, dietary in origin, controllable and less threatening. When the results of the test were perceived as detecting a genetic condition, the results of the test were seen as more threatening and less controllable. Senior, Marteau & Peters (1999) conclude that the threat posed by a genetic diagnosis may lead to fatalistic behaviour, to people taking less active measures to improve their health.
Research by Henderson & Maguire (1998) into lay representations of genetic testing adds further weight to the suggestion that people are deterministic about the treatment of 'genetic' diseases. In the study members of the general public were interviewed and asked to state how they felt about genetic diseases and genetic testing. The researchers found that only one of the 20 participants mentioned treatment and prevention issues, and referred to genetic diseases as 'avoidable'. A sociological analysis of the media coverage of genetic testing and its impact on the public's perception of the 'new genetics' was conducted by Conrad (1997) and helps to elucidate this apparent trend for 'genetic determinism'. From the analysis the researcher concluded that media constructions of genetic research such as the 'gay gene' have served to 'overgeneticize' the issues they describe, and reinforce the idea of both genetic essentialism and determinism. These beliefs give strength to the idea that people are fundamentally products of their DNA, and have no control over their biological destiny (see Petersen 1998).

To summarise, the SRM has been the most widely used to study how people perceive genetic-testing, and appears to address many of difficulties raised when discussing the other models presented. The complex and dynamic self-regulatory processes outlined by the SRM appear intuitively sensible and useful, in starting from a position of describing cognitions or representations. The model also can be applied to explore the relationships between these representations and coping, and is useful in predicting and understanding health decision-making in more depth. However, the five disease representations outlined (identity, cause, consequences, time line, cure & control) may not represent how people actually think about predictive genetic testing. As the authors point out (Leventhal, Meyer & Nerenz 1980, p.19), people often find it difficult to conceive of an asymptomatic illness threat, with predictive genetic testing seemingly characterised by a lack of concreteness.

The HBM, PMT and TPB also suggest limitations. Firstly, although psychological research investigating the models discussed is widespread and numerous, much of this work concentrates on the predictive value of specific variables, with little attention placed
on the development of theory, or the actual process of decision making. Secondly, models such as the HBM assume that the relationship between disease susceptibility and behaviour is linear and straightforward, with again an assumption that the constructs presented represent how people actually think about health behaviour. Thirdly, the social cognitive models examined largely assume that when people are given available information on risk, or an assessment of liability, the individual will weigh up all the options and arrive at the most rationale decision. This denies the complexity of social action, and the fact that no single objective factor or combination of factors will necessarily be influential; that people's responses to 'genetic risk' and predictive genetic testing are often based on their emotional needs (see Wroe, Salkovskis, & Rimes 1998).

It is also important to note that all the models discussed assume that the motivation to act arises from the expectation that action can reduce the likelihood or severity of harm (Weinstein 1993), so health behaviour is the direct response to some kind of health threat. However we do not know if the majority of people perceive genetic testing as threatening. Unlike the threat of say breast cancer, or even tooth decay, the possibilities offered by genetic testing may be viewed as a positive way of improving one's health. It appears likely, from the poor rates of uptake of this service, that the issue is divided, but psychological research does not yet provide this answer. The health models discussed often fail to allow for the inclusion of alternative or idiosyncratic forms of evaluation or evidence, making the adoption of behaviours contrary to the models' predictions difficult to explain. Hence the first study in the thesis uses an exploratory qualitative methodology to answer this question. The aim is to discover how people think about predictive genetic testing, before going on to examine how the factors identified might influence the decision-making process in more detail.

As discussed, all of the models of health behaviour presented appear to have limited applicability when considered in their entirety - in presuming a simplicity to people's genetic testing decision-making that is unsubstantiated. However research does suggest common factors found across these models may be useful. From the literature reviewed earlier it can be concluded that perceptions of disease risk and perceptions of control over
this risk are likely to have an important role in shaping genetic testing intentions. Some of the studies reviewed suggest that increased perceptions of risk increase testing intentions and screening behaviour (Cappelli et al. 1999; Lerman, Daly, Masny & Balshem 1994; also see Clavel-Chapelon, Joseph & Goulard 1999), whilst other studies show the opposite trend (Cappelli et al. 2001; Macrae et al. 1984; Lipkus et al. 2001). Certainly the perceived ability to control disease appears to be pivotal (Meiser, Gleeson & Tucker 2000; Shaw & Bassi 2001), although how this factor interacts with risk to influence genetic-testing intentions is currently unclear.

2.3 Perceived behavioural control and perceived self-efficacy

Psychological literature on both perceived control and perceived risk in relation to health protective behaviours is numerous. I shall address each topic in turn, starting with perceived control, as this construct has probably received more research attention than any other (see Wallston, Wallston, Smith, & Dobbins, 1987). In relation to health psychology research, perceived control is primarily conceptualised in one of two ways. Firstly, Ajzen (1985) defines perceived behavioural control (PBC) within his theory of planned behaviour (TPB) (see Armitage & Conner 2001), secondly perceived control is conceptualised by Bandura (1997) as self-efficacy, within social cognitive theory. The definition of PBC outlined by Ajzen (1985) includes the person’s perceived ability to exercise control over their own actions, and real world environmental events or circumstances that may prevent control from being possible. In contrast, Bandura’s self-efficacy is less inclusive and is firmly centred on the person’s belief that he or she can engage in a specific behaviour. In defining this difference Bandura argues that self-efficacy is concerned with cognitive perceptions based on internal control factors, whilst PBC reflects more general external factors (see Armitage & Conner, 2001). As Schiaffino & Revenson (1992) point out, in many instances the distinction is probably more theoretical than actual, however the relationship between these two constructs, and the superiority of each in terms of their predictive value has been widely investigated.
In a review of research on the theory of planned behaviour, Conner & Armitage (1998) concluded that across health psychology research there is a strong relationship between perceived self-efficacy and behavioural intention - people intend to engage in behaviours which they feel capable of performing. In addition, from the research reviewed, Conner & Armitage go on to state that self-efficacy is a more consistent predictor of health behaviour than PBC. Further confirmation of the predictive superiority of self-efficacy over PBC was obtained by Armitage & Conner in 1999. Over a period of three months 344 hospital workers completed questions regarding factors associated with eating a low fat diet. Both self-efficacy and PBC were assessed separately, with the former emphasising the perceived ability to eat a low fat diet, and the latter emphasising perceptions of personal control. The researchers found evidence for discriminant validity between the two constructs, with self-efficacy not PBC emerging as the most useful predictor of food choice. On evaluating this research (also see Armitage & Conner 2001; Povey, Conner, Sparks, James & Shepherd 2000) we agree with Conner & Armitage (1998) that within health psychology research self-efficacy is a stronger predictor of health decisions, intention and behavioural change than PBC. Therefore it is Bandura’s (1997) definition of self-efficacy this thesis is concerned with when discussing perceptions of control.

2.3.1 Self-efficacy theory

Self-efficacy theory was originally presented to explain and predict changes achieved by different modes of psychotherapeutic treatment (Bandura 1977). The theory predicted that the success of a range of psychological procedures would be mediated by the participant’s personal sense of mastery. The individual’s belief in their ability to perform a specific behaviour in order to achieve a set outcome would determine and explain the end results (Bandura 1977). More recently, self-efficacy has been expanded to include a wider range of personal resources and beliefs. The definition of self-efficacy now incorporates people’s “beliefs in their capabilities to mobilize the motivation, cognitive resources and courses of action needed to exercise control over task demands” (Bandura
1990, p.316). Hence self-efficacy is not concerned with the skills a person has, but with the personal perception of what they can do with those skills.

For the social learning theorist, self-efficacy is the primary cognitive mechanism by which all human behaviour is regulated and formulated. Self-efficacy has a complex, reciprocal and dynamic role within the cognition, behaviour and affect triad. People feel, think and behave according to their perceived potential effectiveness, at any given moment, about any given situation or object. An individual will process available information and assess the adequacy of their resources, in order to cope. A person high in perceived self-efficacy will be motivated to undertake a difficult task and persist in the face of obstacles, whilst an individual low in self-efficacy will view problems or tasks as formidable and slacken or give up. The outcome of this behavioural action is cognitively reassessed and determines perceived self-efficacy judgements in the future. Although seemingly straightforward, the action following on from this assessment is not automatic. Failure does not necessarily mean self-efficacy is lost. Research suggests self-efficacy and intrinsic interest in tasks can be positively and adversely affected, according to different types and levels of feedback; with the use of goal setting, and with evaluative rewards (Bandura & Schunk 1981).

The sources of available information on which efficacy judgements are made fall into four main categories; performance attainment, vicarious experience, verbal persuasion and physiological states (Bandura 1982). Less emphasised within self-efficacy research, but still important, are imaginative experiences and emotional states (Maddux 1995). Bandura additionally emphasises that self-efficacy judgements can be measured along three dimensions; magnitude, generality and strength (Bandura 1977). Magnitude refers to the ordering of tasks in terms of level of difficulty, generality is the applicability of efficacy across a variety of scenarios, and strength refers to the resoluteness of the person’s convictions. Although this distinction is made in Bandura’s early work, research into self-efficacy (including Bandura’s own) appears to ignore these multi-dimensional elements, preferring to measure self-efficacy across the strength dimension only (see Maddux 1995).
Bandura's theory clearly states that the origin of self-efficacy rises from diverse sources of information conveyed by directed or mediated experience (Bandura, p.203; 1977). Self-efficacy is information and situation specific; it cannot exist in a vacuum, distinct from contextual factors. A person may be high in efficacy when dealing with a naughty child, but low in efficacy when attending a conference. Each social situation and its stages of perceived efficacy must be considered separately. Successfully studying and predicting specific levels of efficacy and the resulting outcomes requires a detailed 'microanalytic' methodology, which must reflect the specific nature of the task, across different activities, levels of activities and situations (Bandura 1982). This idea has important implications for studying and measuring self-efficacy, and is pivotal to the difficulties the theory faces, particularly when attempting to measure self-efficacy in regard to larger areas of living, such as interpersonal relationships, and areas of decision-making, a point that will be returned to.

2.3.2 Self-efficacy research

For reasons of surmised simplicity, early self-efficacy research primarily concentrated on the testing and treatment of participants with phobias (snake or spider phobias and agoraphobia) under controlled conditions in the laboratory (Bandura 1982; and Bandura, Reese & Adams 1982). These studies involved guided participation and controlled exposure to the object or situation causing anxiety (enactive mastery). As hypothesised, the interventions led to higher levels of self-efficacy, with treated subjects successfully executing new tasks that fell within their enhanced range of competence. Despite the success of these experiments the choice of topic is debatable. Kirsch (1986) rather successfully argues that these 'snake-approach' experiments do not measure levels of self-efficacy but levels of fear, and although self-efficacy may be linked to fear, particularly in the case of aversive outcomes associated with phobias (see Bandura, Reese & Adams 1982), self-efficacy and fear cannot be assumed to be the same thing. Another pressing problem for researchers is the micro-analytic method proposed by Bandura. This level of specificity may be ideal for researching phobic behaviours and their attached
cognitions, being isolated, specific and extreme areas of profound inefficacy, but the methodology renders the study of broader social issues difficult. A fear of snakes, a dislike of math or a fear of sexual attack (Ozer & Bandura 1990), although serious, appears to encompass relatively small areas of an individual’s sense of self.

Research using specific areas of self-efficacy to predict a much wider diversity of behaviours and outcomes has been successfully conducted, particularly in the field of health psychology. A study by Goh, Primavra & Bartalini (1996) examined variables that predicted AIDS-preventative behaviour in 251 high school students. The authors found that self-efficacy was significantly related to AIDS-preventative intentions, perceived knowledge and measured knowledge about AIDS. The results also suggested that these intentional measures led to actual AIDS-preventative behaviours. The role of self-efficacy has also been studied by Viela & Iraurgi, (2001) as a predictor of abstinence from alcohol. The sample consisted of 198 recovering alcoholics who were followed over a six month period. Of the psychological variables measured only self-efficacy - those participants who had highest confidence in resisting drinking, no matter what risk situations they were involved in - predicted abstinence after 6 months. Somewhat unexpectedly other variables which included measures of drinking status, coping, locus of control and avoidance, independently failed to predict abstinence. The further importance of self-efficacy in regard to preventative health behaviours is strongly demonstrated in a study by Rimal (2001). In an impressive study lasting nine years, 6,149 members of the public who were thinking about taking action, and currently taking action to prevent cardiovascular disease, were assessed regarding their long term use of health information. The primary hypothesis stated that levels of self-efficacy would determine whether risk appraisals were translated into health behaviours. The results confirmed this, those respondents with greater self-efficacy were more likely to think about their risk of heart disease and engage in information-seeking behaviours.

A review of the role of specific measures of self-efficacy within health literature psychology was conducted by Strecher, McEvoy DeVellis, Becker & Rosenstock in 1986, and serves to confirm the predictive power of self-efficacy, and the importance of
this construct when developing treatment programs. The review focused on self-efficacy in regard to quitting smoking, predicting weight control, contraceptive use, alcohol abuse and adherence to exercise programs. The studies reviewed suggested strong relationships between self-efficacy and health behaviours, with perceived self-efficacy consistently predicting long and short-term success in regard to adopting new health behaviours and maintaining these changes. The authors also suggested that levels of self-efficacy are particularly important when the health practice is believed to lead to desired consequences, but that the change itself is difficult to make.

Finally a study by Stacey, Sussmen, Dent, Burton & Flay (1992) suggests self-efficacy may have uses beyond the prediction and maintenance of behavioural change. The authors examined factors influential in the genesis of adolescent smoking in 1,245 high school students in Southern California. In regard to taking up smoking, self-efficacy regarding the perceived ability to resist the social influence of peers was the only significant moderator. Surprisingly other moderators such as self-esteem, latchkey status and stress were not significant regarding the ability to ignore social pressure from peers. These findings suggest that self-efficacy has a significant effect on the ability to adopt healthier behaviours, and also that a strong sense of self-efficacy can provide a buffer against potentially harmful social influences, allowing the individual to maintain their own position, even when pressured or threatened, a point that will be returned to.

2.3.3 Generality of self-efficacy

As demonstrated, self-efficacy has been successfully used to predict a wide range of health behaviours and outcomes. However, work by Bandura investigating the relationship between specific areas of self-efficacy and broader social outcomes is rare. One such study was conducted by Bandura and his colleagues into homelessness (Epel, Bandura & Zimbardo 1999). The study hypothesised that individuals high in self-efficacy (regarding searching abilities), with a future time perspective, would initiate more proactive behaviours, and be more likely to find housing and work. Results did not support this, painting a more complex picture. As predicted, individuals high in self-
efficacy were more active in their search, but this made no difference to outcome, they did not obtain more housing or employment than those low in efficacy. The paper is perhaps useful in illustrating the difficulties of trying to predict more general, broad based issues such as the obtainment of housing or employment, using a single, specific measure of self-efficacy.

A research question posed by this thesis appears to face a similar problem. One of the main aims was to investigate the impact of lack of perceived self-efficacy over genetic-testing decision-making, in terms of that specific area and any wider consequences. To achieve this task, efficacy regarding genetic-testing decision-making needed to be measured, as well as any areas of self-efficacy likely to be influenced by this specific area of control. However, achieving this task is problematic. Self-efficacy over genetic-testing decisions may be similar to the dissemination of genetic information, to the societal consequences of biotechnological advances or to perceived efficacy over life decisions in general. The identification of a specific number of distinct and salient domains similar to genetic-testing decision-making, and the delineation of these within workable operational boundaries appeared limitless (see Williams 1992). The work of Sherer, Maddux, Mercandante, Prentice-Dunn, Jacobs & Rogers (1982) and Schwarzer & Jerusalem (1995) on measures of general self-efficacy offers a solution. The global measures of general self-efficacy developed by Sherer et al (1982) and Schwarzer & Jerusalem, (1995) measure a person’s broad and stable belief in their competence to respond to, control, and efficiently deal with a variety of stressful situations and challenges. For the purposes of our research the measure appears useful in allowing us to determine whether changes to perceived efficacy over genetic testing decision-making have any wider impact, as measured by changes in the person’s overall perception of competence. However the construct of general self-efficacy provides a junction, where Bandura’s opinion and that of other prominent theorists researching in this field divide.

As noted earlier, Bandura (1997, p.52) states that self-efficacy must be contextualised and measured against each and every unique activity (see Bandura, 1997 p.41). Bandura acknowledges that the ‘generalization’ of perceived efficacy across multi-domain
measures exists (Bandura, 1990; p.102), but he is against general measures of self-efficacy, stating that the socio-cognitive approach “provides profiles of efficacy beliefs across diverse domains of functioning rather than evading the distinctive patterning of human belief systems by using general measures” (Bandura 1997, p.51). In concordance with Bandura we accept that “measures of perceived self-efficacy tailored to given domains of functioning have much more predictive power than do omnibus measures of perceived control” (Bandura 1990, p.102; also see Schwarzer, 1994). Having said this, research suggests that various and numerous experiences of failure or success in different domains can generate a generalized set of expectations about the individual’s ability to deal with life in general, that are carried forward into new situations (see Wallston, Wallston, Smith, & Dobbins, 1987).

Work by Smith (1989) has demonstrated that efficacy learnt in one situation can generalise to dissimilar situations, to give the individual a sense of overall personal competence. In the study, college students were enrolled in a coping-skills training program. Although the program was heavily orientated towards test-anxiety, at the end of the course the students showed a significant reduction in general trait anxiety and an increase in generalised self-efficacy. Another study by Williams, Kinney & Falbo (1989) reported similar findings, with a performance-based treatment program again producing generalised change. In the study patients found they improved in areas of agoraphobic disability not directly treated by the program, or related to overt behaviours, but in regard to their thoughts and feelings about coping with other activities as well. Research by Bandura and colleagues (see Bandura, Adams, Hardy & Howells, 1980) into the generality component of self-efficacy found that in the treatment of agoraphobics there was evidence of generality across different areas of functioning, with notable improvements in coping behaviours corresponding with changes to self-efficacy. In a review of studies into the generalization of self-efficacy, Kirsch (1986) concludes that there is evidence to support the idea that self-efficacy generalises along dimensions other than similarity. These studies suggest that beneficial changes in domain specific areas of efficacy are not limited to narrow, similar areas of functioning, but can be generalised across a broad range of thoughts and feelings.
As stated, it is acknowledged that the concept may not have the same level of precision as specific task-situation measures, but general self-efficacy scales have demonstrated considerable predictive value, and high reliability (Bosscher & Smit, 1998; and Weinman, Wright, & Johnston, 1995). The scale developed by Schwarzer & Jerusalem (1995) has proved extremely useful when trying to make predictions across a wide variety of situations (see Schwarzer, 1994; Fournier, de Riddler, Bensing, 1999). This measure has been used in more than twenty large scale German studies, and has demonstrated that generalized self-efficacy is a better predictor of subjective well-being, self-reported illness and coping than other concurrent measures, such as self-esteem or trait anxiety (Schwarzer 1994). In a study comparing the health practices of group of health fair attenders and grocery shoppers Waller, Crow, Sands & Becker (1988) found that levels of general self-efficacy were the best predictors of the health attenders behaviour, with the attenders having greater perceived control over their health than the shoppers. A study into psychological variables predicting the health-promoting behaviour of ‘blue collar’ workers by Weitzel (1989) also found that the General self-efficacy scale developed by Sherer et al (1982) emerged as one of the most powerful predictors of health behaviour, faring better than the health locus of control scale, or a measure of the perceived importance of health. Taken collectively, self-efficacy research suggests that people can and do hold different beliefs about their personal effectiveness across different situations, but also that there is a degree of stability across time and situations. Self-efficacy does successfully emerge as a powerful predictor of both health decisions and behavioural change, when applied at both specific and general levels (see Wallston, Wallston, Smith, & Dobbins, 1987; Schwarzer 1994).

If, as discussed, changes in self-efficacy can transfer from one domain to another and also generalise to impact on wider levels of competence, the next question raised concerns about the mechanism of this transfer. Bandura (1997) states that similarity between one domain and another is fundamental to efficacy transfer, however social cognitive theory outlines at least five other processes through which experiences can produce some generality in personal efficacy. These include the sharing of similar sub-skills, the
generalisation of self-regulatory and coping skills, through cognitively structuring communalities and through the co-development of skills (see Bandura 1997, p.51). These other means of efficacy transfer have received scant psychological attention, although in discussing co-development - as a process that builds generality - Bandura states that efficacy beliefs can vary widely in perceived importance. Some forms of personal efficacy will be more vital to one’s life pursuits and fundamental life structure than others, with individual differences attached to the perceived value of control (Bandura 1997, p.51). Bandura states that the level of importance placed on an area of efficacy by the individual will serve to determine the pattern of any generalisation process, with efficacy generalisation organised around these patterns. It makes sense to assume that a threat to or failure in a valued area of competence will have a larger impact than a threat to self that is of little consequence. Equally the individual will be more motivated to maintain control over an area of self-efficacy that is highly valued and central to one’s self-concept.

2.3.4 The importance of self-efficacy

The importance of self-efficacy beliefs outlined by Bandura (1997) raises some interesting questions, although empirical research examining how this construct might impact on the generalisation process is lacking. In the thesis we set out to explore this question further, firstly by investigating whether an individual who highly values self-efficacy over genetic testing decision-making is more affected by a threat to this control, than a person who places no importance on this choice. Secondly we investigate whether the perceived importance of efficacy moderates the generalisation process, as measured by changes in general self-efficacy. Specifically, we plan to investigate whether decreased levels of self-efficacy, regarding genetic-testing, will transfer to impact on levels of general self-efficacy, particularly when general self-efficacy is highly valued. Leading from this rationale is another question - whether higher levels of general self-efficacy also moderate this process. Whether, as in the Stacey, Sussmen, Dent, Burton & Flay (1992) study cited earlier, a strong sense of self-efficacy can provide a buffer against
potentially harmful influences, with individual’s high in general self-efficacy better able to cope with any dilemma or threat posed by genetic testing decision-making.

2.3.5 Self-efficacy as moderator of coping

Social cognitive theory predicts that individuals low in levels of self-efficacy will view any potential threats to genetic testing decision-making as unmanageable, often exaggerating the impact of change and fretting over events that may not happen (Bandura 1995, Ozer & Bandura 1990). Psychological research adds weight to these claims, and has demonstrated that self-efficacy affects how much stress and depression people experience when faced with threatening or difficult situations (Bandura 1989). A study by Beckham, Burker, Lytle, Feldman & Costakis (1997) found that cancer specific self-efficacy (control over pain, function and other symptoms) explained a significant proportion of the variance in measures of cancer adjustment, psychological distress, positive effect, negative effect and behavioural dysfunction in male outpatients attending a cancer clinic. Further studies by Cunningham, Lockwood & Cunningham (1991), Cozzarelli (1993) and Jerusalem and Mittag (1995) further confirm that self-efficacy is a powerful cognitive resource in managing illness and coping with difficulties. In the first study (Cunningham, Lockwood & Cunningham, 1991) the researcher’s examined psychological well-being in 273 cancer patients. They found a strong positive correlation between high levels of self-efficacy (as measured by The Stanford Inventory of Cancer Patient Adjustment), quality of life measures, and mood. Cozzarelli (1993) examined the responses of 336 women after abortion. The researcher found that self-efficacy over coping with an abortion was a strong proximal predictor of adjustment, both preceding and 3 weeks after the procedure. Jerusalem and Mittag (1995) found that young East German migrants and refugees with a high sense of coping self-efficacy adapted better to the challenge of integrating into a new society. The researchers followed the migrants over a period of eighteen months. Those with high coping self-efficacy experienced less anxiety, better health, and fewer health complaints than their counterparts low in self-efficacy. The latter group tended to view social change as threatening and stressful and felt it had a negative effect on their physical well-being.
As shown, specific measures of self-efficacy can predict the ability to cope with stress; however the third question raised by the thesis is the impact of a more general sense of competence on the ability to cope with the dilemmas posed by predictive genetic testing. Within health psychology, the use of global measures of self-efficacy has grown, with generalised self-efficacy emerging as a major psychological factor relating to coping with stress. Fournier, de Riddler, & Bensing (1999) used Schwarzer and Jerusalem’s measure of general self-efficacy to explain the role of optimism in the management of chronic disease, finding that positive efficacy expectancies were related to better mental health in multiple sclerosis patients. A study by Boer, Elving & Seydel (1998) examined the relationship between psychosocial variables, such as self-efficacy and social support, in regard to the mental health of cancer patient survivors. A total of 480 patients participated in the study. Multiple regression analysis found that levels of generalized self-efficacy, along with feelings of loneliness, were major predictors of variations in mental health. A study by McClanahan & Weinman (1998) examined variables associated with carer's well-being in people looking after stroke patients, again finding that low levels of generalised self-efficacy emerged as the most powerful determinant of carer distress.

To recap, the concept of self-efficacy, at both specific and general levels, is receiving increasing recognition as a predictor of health behaviour, and as a moderator of coping with stress, illness and social change, with an increasing number of psychological texts devoting large sections of discussion to the concept’s application (Petrie & Weinman 1997; Conner & Norman 1995). The research reviewed suggests that perceived efficacy may be influential in the public’s decision-making when contemplating undertaking predictive genetic testing. The thesis aims to examine this suggestion, and determine whether a lack of perceived control over genetic-testing decisions has the power to impact more widely, as measured by a change in general self-efficacy. Research has not examined the heuristics underlying efficacy generalisation from one area to another, or more globally across situations, however Bandura suggests the perceived importance of efficacy may be influential in this process. This thesis also aims to investigate these
questions by examining the relationship between specific and general self-efficacy, the perceived importance of self-efficacy and genetic testing decision-making in detail.

Before leaving self-efficacy and addressing the psychological literature on perceptions of risk, an issue that encompasses both these domains needs mentioning. The models of health behaviour reviewed, that include self-efficacy, assume that increased levels of self-efficacy combined with increased perceptions of risk (conceptualised as perceptions of vulnerability or susceptibility to disease) serve to positively impact on coping, and serve to motivate behaviour change. In regard to predictive genetic testing, evidence suggests this might not the case (see Kash, Holland, Halper & Miller 1992 below). In addition, it has been acknowledged that psychological research into how risk and self-efficacy might interact and operate, to explain alternative outcomes, is scarce (see Bandura 1990, p.101). The question of how perceptions of risk might diverge, interact with, or override self-efficacy perceptions appears to have been overlooked. Similarly, the issue of whether any combined effects are additive or multiplicative appears unaddressed. These limitations are clearly demonstrated in a study by Kash, Holland, Halper, & Miller (1992) which examined the impact of having a heightened risk of breast cancer on surveillance behaviours. In the study the researchers found that contrary to HBM predictions increased disease anxiety led to decreased health-care behaviours, and that increased perceived susceptibility to disease and increased personal efficacy also led to less health-care behaviours. The models of health behaviour reviewed offer no theoretical explanation for these outcomes.

2.4 Genetic susceptibility to disease and health behaviour

The limitations outlined are again highlighted when attempting to explain why increased perceived susceptibility to ‘genetic’ diseases are not often associated with increased surveillance behaviours, or lifestyle changes aimed at lowering risk (see Clavel-Chapelon, Joseph & Goulard 1999). A study by Becker & Levine (1987) using the siblings of patients recently hospitalised with coronary heart disease (CHD) illustrates this. The researchers studied risk perceptions, risk factors and lifestyle factors related to
CHD in the siblings. They found no differences in lifestyle behaviours, such as smoking, diet or exercise, between the sibling group and a comparative control group in the four months preceding the CHD event. This lack of behaviour change existed even though levels of perceived risk in the CHD group were higher than the control group, and risk was related to current lifestyle behaviours.

Similar findings were noted by Audrain et al. (1999), when examining the behaviour of smokers given genetic susceptibility testing. Smokers who were given biomarker feedback about their increased susceptibility to lung cancer were initially more likely to attempt to quit smoking. But 12 months on they were no more likely to have actually stopped smoking than participants who received minimal contact quit-smoking counselling. In an analogue study, Hicken & Tucker (2002) examined whether levels of risk based on a positive genetic test result would be perceived differently from risk based on the participant’s family history. Members of the public were randomly grouped to receive either positive or negative genetic test results indicating the presence of a fictitious enzyme which predisposed them to disease. Participants who received a risk-estimate based on a positive genetic test result indicated no more motivation to follow health-care recommendations than participants who received a family-history risk, suggesting that genetic testing may not be a potent motivator of protective health care behaviours.

Research into the screening behaviours of individuals with a hereditary risk of cancer presents a similar picture. A recent study by Lerman et al. (2000) into breast cancer screening found that women who tested positive for the BRCA1/2 gene mutation attached to ovarian and breast cancer did not change their behaviour, being no more likely to participate in health screening than non-carriers of the gene. A study of colorectal cancer screening behaviours, risk perceptions and willingness to receive genetic testing by Yeomans-Kinney, Choi, DeVellis, Kobetz, Millikan & Sandler (2000) found similar results. Unsurprisingly risk perceptions among the 95 participants were high; all the participants had first-degree relatives with colorectal cancer. Willingness to undergo genetic testing was also high, with 84% stating that they would take a genetic test if
offered. However, the participants' current adherences to screening recommendations were disappointingly low. The work of Bratt, Damber, Emanuelsson, Kristoffersson, Lundgren, Olsson & Grönberg (2000) sheds some light on these findings. The researchers studied 110 men at high-risk of prostate cancer. They found that high perceived risk of cancer was associated with cancer worry, anxiety and depression. Again, nearly all the participants said they would be interested in genetic testing for prostate cancer (98%), but only two-thirds regularly attended screening, with participation in screening lowest among those men with high levels of cancer-specific distress. This suggests that the perception of high-risk and the distress associated with this perception may lead to avoidance behaviours.

In a review of studies examining genetic-risk assessments and health-care behaviours, Holtzman & Marteau (2000) conclude that people feel less in command of their destiny, and more fatalistic about their ability to decrease their risk of disease, if they feel the cause is genetic. Most adult-onset diseases for which predictive genetic testing is available are caused by a complex combination of environmental, behavioural & biological processes. Yet research suggests that 'genetic' risk is commonly perceived as serious and immutable, with DNA-derived information serving to decrease people’s motivation to change, rather than acting as a catalyst for improving one’s lifestyle (Marteau and Lerman 2002). People tend to believe that if their DNA can not be changed, then they are powerless to help themselves (see Marteau, 1997; transcript National Radio Australia). This conclusion is tentative. It may not be powerlessness in the face of one’s genes that explains people’s apparent lack of action. As Schwarzer (1999, p. 118) points out, a strong sense of self-efficacy may allow the individual to perceive they can cope with the challenge of increased risk, allowing them to discount the need for change. Alternatively beliefs and representations about particular diseases may lead to fatalistic thinking and behaviour, whilst other diseases are approached with more confidence. An interesting thought is whether people who are reassured that they are not genetically predisposed to a target disease develop a false sense of security, and begin to feel invulnerable to the adverse effects of their risky behaviour (see Tymestra and Bieleman, 1987). These questions are exploratory, but the findings do suggest that more research is
needed to ensure that the huge efforts made in eradicating human disease do not unintentionally undermine rather than enhance the human spirit. The thesis aims to explore these questions, through an in-depth examination of the relationship between both health specific and general measures of perceived self-efficacy, risk perceptions and intentions towards predictive genetic testing.

2.4.1 General risk research

Assessing risk has become a major issue in health management, with public health discourse roughly divided into two main areas (see Gabe 1995; p.3). The first body of research concentrates on effective risk communication (Renn, Burns, Kasperson, Kasperson and Slovic 1992; Johnson 1993; Fischhoff 1995), with the gap between lay and expert risk assessments discussed (Slovic, Fischhoff and Lichenstein 1985). The second body of research appears more ‘person centred’, with risk constructed as a personal lifestyle choice, and an emphasis on the need for personal control (see Bandura 1995). In attempting to link the first body of research to the issue of predictive genetic testing, there is the problematical focus on the public’s support or opposition to environmental and hypothetical risks and hazards (nuclear power, nuclear waste, radon gas) (see Fischhoff, Bostrom and Quadrel 1993 for review; Johnson 1993). The distinction between a specific risk to oneself, risk to others and more abstract societal hazards and concerns appears huge (see Frewer 1999; Frewer, Howard and Shepherd 1997), yet within this body of literature the issue often appears blurred or ignored (see Sjöberg 2000; Wåhlberg 2001). Another difficulty in linking research that concentrates on environmental or social assessments of risk to predictive genetic testing is the suggestion that lifestyle risks, such as being susceptible to a disease, involve a tendency to deny personal vulnerability, whilst notions of general risk are more realistic (Sjöberg 2000).

This phenomenon of minimising personal risk or ‘unrealistic optimism’ has been widely researched and described in health psychology as means of coping with health threats (Weinstein 1987). One such study was conducted by Fontaine and Smith (1995) to gauge
how people judged their personal likelihood of developing cancer. In line with Weinstein’s theory, the researchers found that people judged their risk of cancer as less than average. Yet this bias does not appear in participants involved in genetic testing protocols (see Lipkus et al. 2001). Within these groups there is a tendency to overestimate not underestimate one’s personal risk of cancer (Bratt et al. 2000; Lerman, Croyle, Tercyak and Hamann 2002). The distinction is difficult to explain, and perhaps highlights the differences present in research conducted on self-selected individuals attending medical clinics and the population at large. Weinstein’s (1987) optimistic bias may be a phenomenon primarily associated with the high proportion of subjects who consider themselves at average or low risk of disease, with individuals who perceive themselves at high disease risk, such as those attending medical clinics, replacing optimism with pessimism (see Shiloh, Petel, Papa and Goldman 1998). Unfortunately most of the work on optimistic bias has involved the aggregation of group scores, so a small pessimistic sub-group would be difficult to detect (see Harris and Middleton 1994). Similarly optimistic bias may be attached to perceptions of control, with those at low risk feeling confident in their ability to control illness. Individuals at high-risk may be more ‘realistic’ about perceived self-efficacy, because of their family history or biographical experience of disease (see Foster, Watson, Moynihan, Ardem-Jones and Eeles 2002; Smith, Michie, Stephenson and Quarrell 2002). Alternatively those at high risk may acknowledge their risk, but downplay the impact, setting their risk within a manageable, controllable context (see Senior, Smith, Michie and Marteau 2002).

Whatever the explanation, research by Shiloh, Petel, Papa and Goldman (1998) suggests psychologists need to consider the implication of having a low or high perception of disease risk, when conducting research into genetic testing decision-making and intentions. In the study, women attending an outpatient breast-care centre in Israel were asked to explore their motives behind the decision to undertake genetic testing for breast cancer susceptibility (Shiloh, Petel, Papa and Goldman 1998). Fifty four women at high-risk and 96 women at average risk of breast cancer participated. Shiloh, Petel, Papa and Goldman (1998) reported that women at average risk displayed ‘unrealistic optimism’ regarding their cancer risk, whilst women at high-risk were pessimistic by comparison.
Interestingly the researchers found testing was more strongly rejected amongst women at high-risk. In giving a reason for intending to undertake testing, only women at high risk mentioned ‘control-related’ reasons, whilst women at average risk often had ‘no concern and interest’ in testing. These findings suggest that perceived control over disease is a motivating factor for women at high risk, but is not influential for woman at average risk, and indicates that the motivational processes underlying intention to be tested are different across these two risk groups.

Another problem with most of the risk research discussed is the underlying premise that knowledge about risk is a matter of people having more or less or it. Hence the goal of risk communication is to give people more information and education, because it is assumed that individuals who are more aware of their risk will be motivated to take preventative action (Slovic, Fischhoff and Lichentein 1986; Edgar, Freimuth and Hammond 1988; Rimal 2001). Yet, research on genetic risk assessment and health screening practices suggests that this is incorrect, with research strongly indicating that an educational approach is insufficient to change behaviour in this area (Bowen, Patenaude, and Vernon 1999). The limitations of this assumption are further demonstrated in regard to AIDS prevention. Huge efforts were made to inform and educate the public about the risk of AIDS, regarding transmission of the virus and safeguarding against infection (Scott and Freeman 1995; Kitzinger, 1990). Research has shown that this effort was successful in communicating this knowledge to the public, yet adults and adolescents aware of the seriousness and prevalence of HIV infection and the advantages of safe sex still continued to place themselves at risk (see Edgar, Freimuth and Hammond 1988; Goh, Primavera, Bartalini 1996; Dinoff and Kowalski 1999). It appears that people perform risky behaviours in spite of their awareness of the potential negative consequences; that people are capable of ‘tuning out’ or ignoring potential health threats (see Gerrard, Gobbons, Reis-Bergan and Russell 2000).

The lack of success with AIDS suggests a different focus is required, when considering more intimate and personal risks that involve making specific behaviour changes, such as those associated with genetic risk assessments. Questions such as how and why different
internal and external dimensions and pressures interact to determine people’s response to risk need addressing (see Edgar, Freimuth and Hammond 1988). This approach encompasses the second body of risk research mentioned earlier. The emphasis within this paradigm is on risk as an individual cognitive choice. According to social cognitive theory (Bandura, 1990) it is conceivable that a person could have risk information but still engage in risky behaviour. Behaviour is not the direct result of knowledge or skills, but is mediated by a process of cognitive appraisal, by people forming a judgment about their abilities and motivations to change. The usefulness of this approach has been successfully demonstrated by Kelly, St.Lawrence, Hood and Brasfield (1989). In the study, the frequencies of high-risk sexual practices of 104 gay men were reduced. The researchers used a range of interventions aimed at increasing perceptions of self-efficacy, which included cognitive-behavioural self-management training, building sexual assertion and the development of self-affirming social support networks.

In a review of research on self-efficacy and AIDS prevention, Bandura (1995) concludes that the weaker the individual’s perceived self-efficacy, the more easily social and affective factors will increase the likelihood of risky sexual behaviour, with the belief in one’s personal capabilities to exercise control over sexual behaviour emerging as a strong predictor of risk taking (see Mckusick, Coates, Morin, Pollack and Hoff et al. 1990). However, it should not be assumed that increased self-efficacy always leads to decreased risk. A study by O’Leary, Goodhart, Jemmott, and Boccher-Lattimore (1992) into student responses to HIV risk found that among the 923 students sampled, those highest in self-efficacy - in regard to their ability to assess prospective partners HIV risk-related history - had more risky sexual encounters. It appears that the perceived confidence to assess another person’s sexual history led to decreased perceptions of personal risk.

In an impressive and rigorous study by Rimal (2001), the interaction between perceived self-efficacy and perceived risk was examined. Participants were people thinking about taking action, and currently taking action to prevent cardiovascular disease (CVD). In the study the responses of 6149 members of the public were followed for a period of 9 years. Participants were divided into 4 groups depending on whether they had high or low
perceived self-efficacy regarding CVD prevention, and high or low levels of CVD risk. In support of the hypothesis the researcher found that levels of self-efficacy did determine whether risk appraisals were translated into health care behaviours. When risk perceptions were high, those with greater self-efficacy were more likely to think about heart disease, and were more likely to engage in information-seeking behaviours. Furthermore the effects of heightened risk perceptions were more pronounced among those with lower self-efficacy. What can be concluded from this study is that the communication of genetic risk alone is unlikely to strongly influence health behaviour or genetic-testing intentions (see Lipkus et al. 2001). It is the reciprocal relationship between perceived levels of risk, information regarding what can be done to reduce this risk and the individual's sense of personal control in being able to manage their genetic risk of disease, that is likely to influence response.

2.4.2 The concept of genetic risk

A separate but important issue in understanding the public's perception of predictive genetic testing is determining how people conceptualise genetic risk. Research on the perceived risk of various technologies and activities suggests that risk is a multidimensional concept (Slovic, Fischhoff and Lichenstein 1985). Across all genetic-testing research, a common theme is that participants' decisions about testing are influenced less by their actual risk and more by their subjective risk and emotional factors (see Lerman, Croyle, Tercyak and Hamann 2002, Marteau et al. 1991; Smith, Michie, Stephenson and Quarrell 2002). Overall research suggests that perceived susceptibility to disease cannot be understood as a single probability statistic (Fischhoff and Bruine de Bruin 1999; Fischhoff 1995; Schapira, Nattinger and McHorney 2001). However, within this body of research, little is known about the mechanisms by which risk perceptions and emotional factors influence the decision-making process. Testing for most reduced penetrance diseases such as breast cancer is extremely complex, with risk assessment statistics extremely difficult to grasp even for experienced clinical practitioners.
In order to manage this problem, Cancer Risk Counselling (CRC) (or Genetic Counselling, as it is sometimes called) has been developed (Schneider, Peters, Knell and Rosenthal 1997). The central elements of CRC are gathering a detailed medical, family and lifestyle history, followed by a discussion of individual factors contributing to elevated risk, the presentation of individualised risk figures and screening recommendations such as mammograms and breast self-examination (see Lerman et al. 1996). The goal of CRC is to provide risk information to assist the individual in making more informed and thoughtful decisions about cancer surveillance and prevention and genetic testing (Schneider, Peters, Knell and Rosenthal 1997). The psychological ramifications of risk information and medical management options, and the need for support are also addressed, with counselling provided.

The impact of CRC on risk perception has been measured by Evans, Blair, Greenhalgh, Hopwood and Howell, (1994). New patients attending a family history breast cancer clinic were divided into two groups, women who were given prior information about their risk (n=209), and women who were given no information (n=308). The groups were asked to assess the population risk and their personal risk of breast cancer. Sixteen percent of women in the uninformed group chose the correct population risk, compared with only 26% in the informed group. Personal risk was retained more accurately post-counselling, with 41% giving the correct figure compared to 11% pre-counselling. These figures demonstrate that although the women self-referred to a family cancer clinic, the vast majority had no idea of their level of lifetime risk for breast cancer. The results of informed group are particularly worrying, with only 26% getting the population risk right, even after being given literature on the subject. Another study by Lerman et al. (1996) evaluated the impact of CRC on breast-cancer specific distress and general distress in 239 women with a family history of breast cancer. The participants were randomly assigned to either individualised CRC with personalised risk information, or a general health education program. Only women with less formal education appeared to benefit from CRC, in having significantly less breast cancer distress than the other group. However CRC did not reduce the perceived risk of breast cancer, or improve the accuracy of subjective risk estimates. The researchers offer no concrete explanation of
why CRC should perform so badly. Overall the results of the studies presented question
the benefits and value of risk counselling, and suggest there is a need for a more
experiential approach to understanding the meanings attached to genetic risk.

Research by Hopwood (1997) further suggests that genetic risk information may be
conceptualised in ways other than mathematical probability (see Teigen 1988; Schapira,
Nattinger and McHorney 2001). A subtle but important distinction may exist between
perceived susceptibility and vulnerability to disease, and evaluations of risk. In the study
Hopwood (1997) found that women were able to give an accurate estimate of their risk of
breast cancer, however some women still thought that they would inevitably get cancer
on the basis of personal factors, such as their family history. The influence of this
personal interpretation of risk on testing uptake is further demonstrated in a study by
Decruyenaere et al. (1997), examining factors influencing the uptake of genetic testing
for Huntingdon's disease. Nearly half of the at-risk carriers accurately knew their 50% risk
as a statistic, but individuals who had decided not to be tested often did not
experience their risk as fifty-fifty. They reported feeling that they would inevitably get
the disease, stating reasons such as 'I look like my affected father' or 'There are six
affected persons in the family; I have the feeling that I cannot escape'. These finding
suggests that risk perceptions are not rational, but entrenched within the individual's
biography.

The social construction of genetic testing and the role of contextual factors in risk
perception are featured in the work of Parsons and Atkinson (1993). The work illustrates
that for women living with the risk of Duchene Muscular Dystrophy an awareness of
being 'at risk' was related to significant life events and social encounters during their life
course. The women did not retain their carrier risk as a statistic; mathematical probability
appeared meaningless in the light of personal experience. Risk was translated into
descriptive categories - meaningful everyday statements - that became integrated into
their reproductive behaviour. The researcher's found that these perceptions of risk were
shown to influence whether the women were risk takers or risk refusers, alongside other
biographical factors such as prior reproductive desire and the structuring of genetic
information. Biographical experience and personal family context have also been shown to be an intrinsic part of risk perception in a study by Smith, Michie, Stephenson and Quarrell (2002). In the study interpretative phenomenological analysis was used to examine risk perceptions and genetic testing decisions-making in women at risk of HD. The researchers found that each of the five participants had their own perception of risk, and that this account was often complex, contradictory and extended to cover the risk status of other family members. The women knew their risk as a 50% statistic but this fact was difficult to assimilate. Other lay beliefs - such as the disease being more likely to affect women, or the sibling most physically similar to the affected parent - appeared to override more 'rational' thinking. A further study by Senior, Smith, Michie and Marteau, (2002) again used qualitative phenomenological methods to investigate perceptions of familial hypercholesterolemia and its genetic basis, in patients and families diagnosed with the condition – which predisposes the individual to heart disease. The authors discovered that when participants’ risk of heart disease was discussed, it was often in terms of how the risk was ‘controlled’ or ‘managed’, with risk perceptions minimized, often using downwards social comparisons. Specifically, individuals appeared to deal with their risk by comparing themselves favourably to others who were perceived as having a higher risk. Again these findings suggest that the concept of risk is personalised and dealt with according to the individuals own experiences and resources.

To sum up, genetic research and genetic screening have largely proceeded on the assumption that the potential benefits of genetic testing will advance the health and welfare of ‘the public’. However, results from the studies reviewed imply these assumptions need revising, with predictive genetic testing not emerging as a potent motivator in terms of increasing health protective behaviours. In attempting to apply current risk research to the unravelling of this question, several problems arise. Firstly, a large section of this work focuses on risk in terms of the public’s support or opposition to environmental and hypothetical hazards. The potential differences between this level of risk and risk to oneself, in terms of an inherited disease, appear huge yet often overlooked. Likewise, there is a suggestion that lifestyle risks such as being susceptible to a disease involve a tendency to deny personal vulnerability, whilst notions of general
risk are more realistic (Sjöberg, 2000), however in the case of genetic disease risk this phenomena of unrealistic optimism is not apparent. Perhaps most telling is the apparent lack of success of traditional risk research in changing sexual practices associated with AIDS. Research has shown that the goal of risk communication, information and education, is not enough to motivate people to take preventative action to reduce their risk of HIV infection.

Bandura’s social cognitive theory (1990) takes a more ‘person centred’ approach to risk, with the emphasis not on communication, but on risk as an individual cognitive choice. This approach has shown to be effective in preventing HIV risk behaviour, and serves to demonstrate that the communication of genetic risk alone is unlikely to strongly influence health behaviour or genetic-testing intentions. Research suggests it is the reciprocal relationship between perceived risk, risk communication and the individual’s sense of personal control, in being able to manage risk, that is likely to influence response. Research also suggests that people’s understanding of ‘genetic risk’ cannot be solely determined using mathematical probability that subjective experience and contextual factors have a role in how risk is personally conceptualised and managed.

2.5 Conclusions

Wide-scale predictive genetic testing is yet not available, so it is difficult to conduct large scales studies with enough power to judge the impact of factors such as perceived self-efficacy, disease information and risk perceptions on actual uptake of these services, and perhaps to do this would be premature. It seems sensible firstly to examine the motivations and decision-making of people not informed about testing. To consider factors that might influence a person’s decision to become informed, and approach their general practitioner about this service, before evaluating the reasons for undertaking testing in the small number of patients already attending genetic clinics. Our aim is to increase scientific understanding of early decision-making in this area, by exploring both the motivations of individuals who intend to request this service in the future and also the decision-making of those individuals will never be seen at a genetic clinic.
In approaching this task the thesis will begin to unravel people's decision-making regarding pursuing predictive genetic testing by conducting focus groups. The aim is to discover how people think about predictive genetic testing. The thesis then examines two factors identified as having an important role in shaping decision-making and intent; perceptions of disease risk, and perceptions of control - both over this risk, and the decision-making process itself. Gaining this understanding is hugely important. The actions stemming from these judgements will have significant personal consequences, and wider societal consequences, in terms of managing the public's health. Failure to consider these questions will at best result in the positive potential offered by this technology not being realised.
Chapter Three

Epistemological and methodological issues

3.1 Introduction

The research design, definition of concepts and type of evidence being sought were all influenced by the researcher’s epistemological position, so it is useful to make this explicit. The following chapter sets out to explain the philosophical framework within which the research was undertaken. The first section concentrates on the research questions being addressed and the researcher’s epistemological view and its implications for choosing and developing the research methodology. This is followed by a more detailed exploration of the research methodologies adopted and the criteria used to assess rigour, specifically in regard to the qualitative approach used. Finally, the researcher’s personal motivation for embarking on the work is explored.

3.2 The researcher’s epistemological position

As stated earlier, the aim of the research is to gain an understanding of factors that might influence the general population’s decision-making when contemplating the possibility of undertaking predictive genetic testing - to provide both a descriptive and causal account of events. In approaching this task the researcher takes a pragmatic position, with the research process primarily seen as a practical rather than political activity. Understanding the internal world of the individual is not tied to an epistemological preference, but to the job of uncovering of new understandings (see Hammersley 1995). Therefore the researcher is open to using both qualitative and quantitative research methods, with context and purpose of the study situation judged and considered, alongside the type and level of information required to address each stage of the research process, and each research goal (see Rossman and Wilson, 1985; Greene, Caracelli and Graham 1989).
This lack of absoluteness is not a naïve position aimed at minimising or ‘glossing over’ epistemological or technical differences between qualitative or quantitative methods, although it is believed that considering research methodology in terms of competing paradigms is unhelpful (Smith, 2000). Qualitative methods are not a single method set in opposition to quantitative research, with recent developments in psychology recognising the artificiality of this distinction. This change in stance is based not only on the reality of increasing cross-disciplinary projects but also on the growing recognition that complex interactions mutually influence the relationship between the individual and their environment (Hammersley 1995). It is also more readily accepted that a strict distinction between methodological positions is not necessary, that psychological understanding of a new area of research can be significantly enhanced by exploring convergences in stories generated from alternate paradigms and sources of data (Hammersley 1995).

In adopting a ‘mixed method’ approach, it should be made clear that the researcher’s intent is not to resolve difficult epistemological and ontological issues about the nature of research and which method offers a better understanding of social phenomenon. It is acknowledged that challenging and complex empirical differences exist, but dualistic demarcation and amplification of the scale of these differences stops new, more fluid, interchangeable ways of approaching research from emerging (see Smith, Harré and Van Langenhove, 1995; Henwood and Pigeon, 1993). Moreover adopting a rigid methodological position can give the impression that empirical difficulties are resolved simply by taking a paradigmatic stance (see Hammersley 1995). The belief is that psychological theory is open to correction and modification, in the light of what is learnt in practice (Hammersley 1995); the aim is to provide a common-sense case for the power of combining quantitative and qualitative methods. Hence the quality of the research will demonstrate that both the numerical and verbal findings presented have value in being able to cement and develop particular theoretical arguments.
3.3 The research strategy

In approaching an, as yet, little-understood research area, the researcher is faced with where to begin, and how to develop psychological understanding in a way that is rigorous and credible. In addressing this problem, it was decided a qualitative approach would be most useful, in facilitating a more elaborate understanding of individual beliefs and responses to the possibilities offered by predictive genetic testing. In choosing a qualitative methodology the primary concern was to choose a method that allowed ideas to be generated, in an area of research without a strong theoretical history, in a manner that was both transparent and systematic. Grounded theory (GT) is a ‘bottom-up’ inductive approach to the conceptual analysis of qualitative data that fits these requirements. Another project requirement was to use a qualitative method that was complementary to the epistemological position espoused by the researcher. In GT there is “no fundamental clash” between the purposes and capacities of qualitative and quantitative methods or data (Glaser and Strauss 1967, p.17). Each is considered useful in the verification and generation of theory, with the main point of emphasis being the continued generation of new ideas.

Grounded theory fits well with the social cognitive stance taken by the researcher, in assuming that previous experience and personal understanding influence the emotional and cognitive reactions displayed in talk, and that exploration of these reactions allows attitudes and behaviours to better be understood. Thus, talk is seen as representing the cognitive content of people’s minds. Additionally within grounded theory there is an implicit assumption that a set of cognitive or psychological relationships exist objectively in the world, awaiting discovery or generation (see Pigeon 1996). This ‘realist’ assumption has received criticism from more ‘constructivist’ approaches (see Henwood and Pigeon 1993) but the philosophy bonds with the researcher’s own epistemological stance. The researcher assumes a ‘modest realism’ in supposing that constructs such as self-efficacy - although not directly visible - exist and can be measured. It is also believed that, through the study of such phenomena, the social framework that underlies individual and social life can be better derived.
Recent developments in the evolution of grounded theory have led to a number of theoretical and methodological disagreements (Robrecht 1995; Melia 1996 and Annells 1996). The methodological stance used in the analysis below utilises the analytical coding framework set out by both Glaser and Strauss (1967) and Strauss and Corbin (1990), but does not incorporate a strict adherence to conceptually distinct stages of analysis as suggested by Strauss and Corbin (1990). The aim was to achieve flexibility and freedom, allowing the process to be fluid rather than formulaic, and allowing each stage of analysis to emerge and then merge with the next stage, without forcing the data into prescriptive or rigid boundaries.

Strauss and Corbin (1990, p.38) state “the research question in a grounded theory study is a statement that identifies the phenomenon to be studied. It tells you what you specifically want to focus on and what you want to know from this subject”. In contrast, Glaser (1992) states that “all categories and properties are discovered, not forced by preordainment”, and argues that the problem must emerge from the data (see p.25 and 97). In this analysis we are applying grounded theory to identified research questions, but this does not mean the answers are predetermined, they remain open to revision and discovery. Our analytical approach although intensely focused, is firmly grounded in discovery, rather than a ‘conceptual description’ of conversation (see Benoliel, 1996).

3.4 Developing the methodology

The idea behind the research strategy was to build a complementary and sequential process, not to measure the same phenomenon at the same time, but to use the findings of one methodology to inform and enhance the clarity of issues being addressed in the next stage of the research. This interactive and iterative process would allow the researcher to develop a detailed theoretical account of the public’s contemplation of predictive genetic testing.
Arising from the grounded theory analysis was a salient but complex theme concerning the participant’s personal control over genetic testing decision-making. Some participants felt choice in this matter was illusory, while other participants expressed feeling confident that they could control these decisions. It was decided to investigate this theme further by examining the impact of general self-efficacy on coping with genetic testing decision-making. The aim was to try and unravel the relationship between specific and general self-efficacy, by examining the effect of being given or denied the choice of undertaking a predictive genetic test. In achieving this aim, a quantitative experimental model that could test causal relationships between domains of self-efficacy, was considered most appropriate. In making this choice, the primary consideration was how useful the methodology would be in developing the research story. Few psychologists would disagree that the question must be “which methodological approach is most suited to the research question or problem at hand” (Henwood and Pigeon, 1995, p.115). There is also the belief that different methodologies pitched at different levels of analysis and types of research question, can uniquely contribute to measuring different facets of a given question. Pragmatically, the research question also involved factors such as self-efficacy that could be operationalised into measurable variables and tested statistically (Rossman and Wilson 1989).

The same considerations influenced the choice of methodologies used in the third and fourth studies. In the third study, we decided to investigate the relationship between specific and general self-efficacy further, and additionally investigate another salient theme to emerge from the focus group study, perceptions of disease risk. The primary aim was to examine how specific and general self-efficacy interact with perceptions of disease risk to influence people’s intentions towards predictive genetic testing. It was felt this question would again be best answered by testing causal relationships between the constructs outlined, using a quantitative experimental design (see study chapter for details). The results from the two quantitative studies found that whilst levels of general efficacy were affected by changes in health specific efficacy, surprisingly there was no relationship between levels of general efficacy and people’s intention to undergo testing. The relationship that emerged between levels of self-efficacy, disease-risk and intention
was complex and theoretically difficult to explain. In the last study we decided to further investigate these apparent inconsistencies, by specifically examining how control and risk are constructed within the context of genetic testing. For this task a qualitative study, incorporating semi-structured interviews with participants at different levels of disease risk, was felt to be most suitable, in facilitating a more complex understanding of the relationship between self-efficacy, perceptions of disease risk and the contemplation of predictive genetic testing. Again the results were analysed with grounded theory (see below).

3.5 Demonstrating good research

In order to demonstrate that the complementary use of grounded theory and multivariate statistical techniques can have equal value in corroborating, elaborating and initiating findings and successfully shed light on factors that influence the public contemplation of genetic testing (see Pigeon 1996), good research practice must be demonstrated. The criteria for judging quantitative research is familiar to most psychologists, and is placed within the positivist tradition of experimental manipulation and the quantification and control of subsets of variables on the basis of prior theory. Obviously in undertaking quantitative research a statistical approach is an important tool in the accurate testing of theory so large numbers of cases are used to eliminate individual variation. The researcher’s commitment is to the rules of objectivity, generalisability, replicability and validity - with the criteria for assessing these clearly defined.

In contrast qualitative researchers use constructivist criteria to define the quality of the work undertaken. In adopting a constructivist stance the researcher locates the observer and the observed in the world, taking into account that people do not respond to the world in a mechanical fashion, that people actively shape their environment, their sense of life differs and that complex multiple realities and truths exist (Hammersley 1995). This is not to say that quantitative approaches do not take into account the social context in which the research is being carried out, but consideration of this factor is less pivotal. This ‘relativism’ within qualitative research means no absolute certainty is possible,
however this does not mean any attempt at forming conclusions is doomed, or any view is as good as any other. The researcher does make value judgements about what is relevant, and does present these as scientific findings, although whether these judgements do successfully construct the participants 'reality' is not always clear (Salmon 2003). No methodological criterion exists that is capable of guaranteeing the absolute accuracy of any qualitative research, however grounded theory (the method used in this project) does have a number of practice guides, such as the importance of fit, adequate documentation, reflexivity and theoretical sampling, which will be discussed below (see Henwood and Pigeon 1993).

3.6 Grounded theory – the analytic process

Originally Barney Glaser and Anselm Strauss (1967) devised GT because in their view sociology was stagnating in deductive theorising, with researchers forcing data to fit within existing theories rather than refining or creating new ideas. The term ‘grounded’ refers to theory that is generated in the course of close inspection and analysis of qualitative data. The aim of GT is to uncover meanings and describe the main issues, problems and structures that may arise within a given situation and build a conceptually rich, dense and contextually grounded account of life. Pre-determined hypotheses are not tested. New hypotheses and theories are discovered and developed, through the emergence of phenomenon within the data, and the labelling and description of relationships between these phenomena. Hence, as the name suggests, the first practice guide within GT is the importance of ‘good fit’ - the resulting theory must fit or be grounded in the data collected.

Grounded theory advocates that good fit is more likely if the researcher works systematically through the data, following a number of analytical stages. Firstly the researcher closely studies the data, and through a process of inductive categorisation allows low level concepts and abstract features, ideas and textual labels to emerge. This process should be done with maximum flexibility and creativity (Glaser 1992). As the analysis progresses the findings are integrated into larger coherent theoretical statements
or accounts (see study 1 and 4 for details). The final success of the analytic process largely depends on choosing the appropriate level of abstraction for the concepts in question, and the ability to demonstrate the ‘reality’ of this abstraction with examples taken from, and grounded within the data gathered. At every turn the researcher must return to the original text and ensure that the conclusions and relationships being developed do exist, and are grounded within the text presented (Henwood and Pigeon 1993). In terms of our research findings, we have demonstrated ‘good fit’ at each stage of the analytic process by supplying detailed illustrations taken from the original text which summarise how and why the data has been labelled in certain ways with, at each stage of the research process, this evaluation is clearly and transparently laid out for the reader to assess (see study 1 and 4 for details).

Another important feature of grounded theory is an emphasis on the constant interplay between the data and the emerging account. The active ‘flip-flop’ or constant comparison between the data and developing concepts demands a dynamic iterative process of change and adjustment. This fundamental idea has been applied to the grounded theory studies undertaken within thesis and to the research project as a whole. In study 1 the transcripts were divided into two batches and analysed at two separate time points, with different levels of analysis and types of process applied to each stage. This separation allowed developing categories to emerge, and be compared, contrasted and developed in the first stages of analysis. The emerging themes were then tested against the data in the final batch of texts. The texts used in the initial stages of the analysis involved transcripts from groups 1, 2, 3 and 4. Once the analysis of these texts was completed the researcher went on to gather and analyse data from another 2 focus groups (5 and 6).

A third element of ‘quality control’ within GT is theoretical or active sampling. Grounded theory is seen as a continuously ongoing process. The analytic strategy requires that the data collection and analytic interpretation proceed simultaneously with sampling conducted as the analysis proceeds. After each stage of the analysis the researcher returns to the text and actively collects more data, which serves to further confirm or refute the emerging theory. This active toing and froing, from data collection,
analysis and sampling, continues until the researcher feels a point of impasse or theoretical saturation is reached - that no significant or new theoretical ideas are likely to emerge. After the sixth focus group it was felt that theoretical saturation was reached with no new significant categories emerging, so the gathering of discussants ceased (see Willig, 2001).

In study 4 data from the interviews was also collected and the transcripts analysed at three separate time points, with different levels of analysis and types of process applied to each stage. Again this separation allowed developing categories to emerge in the first batch of texts, these ideas to be further compared, contrasted and developed in the second batch of texts, and the emerging theory to be tested against the data collected in the third batch. The first 8 interviews used in the initial stage of the analysis resulted in 3 transcripts from participants with low perceived risk of disease, 2 transcripts from participants with high perceived risk of cancer, 2 transcripts from participants with high perceived risk of heart disease and 1 transcript from a participant with high perceived risk of both cancer and heart disease. Once the analysis of these texts was completed the researcher went on to interview and analyse data from another 8 participants, with the same levels of perceived risk as the earlier group. In the final stage of analysis the researcher conducted four more interviews with 2 participants at low perceived risk of disease, and 1 interview with a participant at high risk of cancer and 1 interview with a participant at high perceived risk of heart disease. This active toing and froing - from data collection, to analysis, to further sampling - continued until again the researcher felt theoretical saturation had been reached, with no significant or new theoretical ideas likely to emerge.

3.7 Personal reflexivity

Pigeon and Henwood (1997) recommend that grounded theory researchers’ document and carefully detail each phase of the research process in order to increase personal reflexivity. It is important to acknowledge that aspects of the researcher’s personal identity will influence the types of questions raised, the participant’s particular responses
to these questions, and the resulting findings. The researcher’s motivation for embarking on this work is embedded in her personal and family health history. Throughout the period of study the researcher was being treated for and recovering from cancer, and the work undertaken formed a large part of this recovery. The researcher’s experiences of being treated for this disease were documented in a diary. These thoughts have not been included or implicated in any particular piece of research, although at each stage of the research process the researcher’s assumptions, values, sampling decisions, analytic techniques and interpretations of context were noted. These deliberations and experiences also allowed the researcher to reflect on her own biases, and, where possible and appropriate, add useful insights to the research process. For example, in study 4 the researcher was able to recognise and further investigate the participant’s anxieties concerning their risk of disease, and explore ways of dealing with this with the interviewees. This process also allowed the researcher to be more aware of how her perceptions might inappropriately shape the research, and prevent the participants’ views from being developed and fully represented. In particular how her experiences of risk and illness may differ from those expressed by the participants. Research is an inescapably selective process, so the transparency of the research process aims to allow the reader to make their own conclusions concerning the veracity of the final conclusions drawn.
Chapter Four

Lay responses to predictive genetic testing: A focus group study

4.1 Research Aims

As stated earlier, psychological studies that examine the opinions of lay people regarding predictive genetic testing are scarce, with studies examining the public's decision-making regarding the contemplation of using this technology, rarer still (see Evers-Kiebooms, Welkenhuysen, Claes, Decruyenaere, and Denayer 2000). The research currently available primarily consists of survey studies sponsored by governments to examine the general population's attitudes towards genetic testing and biotechnology (see Hietala et al. 1995; Singer, Corning and Lamias 1998; Cabinet Office 1999; National Science Board 2000; Stratford, Marteau and Bobrow 2001). Alongside this survey work a few qualitative projects exist which examine the lay public's attitudes to genetic technology in more depth (Durant, Hansen, Bauer, and Gosling 1993; Kerr, Cunningham-Burley and Amos 1998). The combined results of this research suggest that the public is largely in favour of the medical possibilities offered by genomic technology. People see the potential benefits of genetics, and are positive about the possibilities of new cures and improved health care, but alongside this positive outlook worries exist (Hietala et al. 1995; Bosompra et al. 2000). The public appears to lack confidence in controlling the ways in which genetic information may be used and is distrustful of governments' ability to control biotechnical developments. There appear to be concerns about the possibility of eugenics, discrimination, commercial pressures and a loss of personal autonomy attached to predictive genetic testing (see Brunner, Sheppard and Ravetz 1997; Jallinoja et al. 1998).

These findings provide an interesting starting point in understanding public attitudes towards genetic technology. However, they tell us little about how people's specific concerns regarding predictive genetic testing, may inform the decision to undertake or
decline this procedure. Psychological research specifically examining decision-making around genetic testing uptake has up to now concentrated on sampling medical populations or the relatives of individuals at high-risk of target diseases (see Lerman, Daly, Masny and Balshem 1994; Lerman et al. 1997). In reviewing this work, the research suggests that perceived control over the target disease, and control over any future uncertainty, are important factors in people’s interest in predictive genetic testing. The perceived ability to protect one’s family, plus perceptions of increased disease-risk also appear relevant to people’s interest in this new health choice. These findings, although informative, are limited regarding any wider generalisation, due to the narrow sampling employed. As Lerman, Croyle, Tercyak & Hamann (2002) point out, individuals in research settings have probably already decided to pursue genetic testing, or commit to a research program, long before they are selected to participate. Huibers & Spijker (1998) further point out that people within clinical settings are not uninformed. Why would people be there in the first place if they were not already interested in discovering more about their genetic make-up? The fact that participants are within a research setting or a medical clinic indicates that they have already made a large step in their decision to pursue this option. Psychological research into individual decision-making prior to the consulting room, and our knowledge of the types of factors that influence the decision not to request genetic testing, have been barely investigated.

The first study of the thesis attempts this task. Using focus groups, the study was designed to explore how more general, non-clinical groups of people perceive predictive genetic testing. The aim was to elicit factors that influence how the public responds to the possibility of undertaking this procedure. As stated earlier, unlike other health behaviours, predictive genetic testing is differentiated by the distance between the health behaviour (genetic testing) and any potential threat to well-being, as any disease may not develop for decades or even for life. Secondly, unlike the threat of say heart disease, the possibilities offered by genetic testing may be viewed as a positive way of improving one’s health. Thirdly as Leventhal, Meyer & Nerenz (1980) point out, people often find it difficult to conceive of an asymptomatic illness threat, with predictive genetic testing seemingly characterised by a lack of concreteness. Hence, the first study in the thesis
used an exploratory qualitative methodology to elucidate some of these complexities, before going on examine how the factors identified might influence the decision-making process in more detail.

4.2 Meeting with experts

Prior to commencing the pilot study the researcher met with members of a genetic counselling team based at Guy's & St. Thomas' Hospital London, (22.3.2000). The aim of this meeting was to brainstorm, to discuss issues the genetic counsellors felt were relevant to their clients and consider why these issues may or may not entirely represent the concerns and views of more general groups of people, when contemplating predictive genetic testing. The meeting allowed the researcher to gain greater insight into why the opinions of people, gathered in a non-clinical environment, may not correspond with clinical responses to this new health choice. For example, clients attending the genetic clinic have mostly made the decision to investigate their genetic background before presenting for testing, with genetic counselling focusing on the outcome of that choice rather than the factors that shaped the decision to obtain this information. Equally many clinical patients have been actively involved in genetic research programs. They have had contact with support groups and counselling over a period of time, perhaps years, so their decisions may have been made some time ago - whilst waiting for the technology to become available. The meeting also focused the researcher's thinking and allowed the researcher to remain mindful of how people's social and medical location - their current state of health and experience of health care and science generally - was likely to shape their contemplation of genetic testing. For example, patients with a strong family history of a disease will be influenced by how well the family copes with the condition, and the perceived impact of the condition on family life.
4.3 Method - Pilot study

4.3.1 Aims
Before commencing the main study, four semi-structured pilot interviews were conducted. Interviews were conducted for practical reasons - it was felt that recruitment would be straightforward, with the data generated suitable for identifying themes and generating useful areas of questioning in the focus groups. For example, the participants talked about how knowing their risk would make them feel, the possible anxiety attached to gaining this information and how this would affect their lives. These topic areas were then included in the interview schedule for the main study. Data from interviews also ensured that any questions posed were relevant and easy to understand, and that the discussions would be directed with the correct amount of researcher intervention. The data from each interview was analysed before actively choosing the next participant and commencing the next interview.

4.3.2 Sample
Each participant was approached personally by the researcher (through acquaintances) and chosen with the aim of generating data that contained both comparisons and contrasts with the previous interview data, and range of experiences regarding the contemplation of genetic testing. With this in mind the first interviewee was a married woman with children, who felt at risk of a genetic disorder. The second interviewee was also a married woman, who had undergone genetic testing, and who had no children. The third interviewee was a single man without children or any genetic history of disease and the last interviewee was a married man with children and no genetic history of disease. After the fourth participant interview, it was felt that enough information had been generated, so interviewing ceased.

4.3.3 Procedure
Prior to the commencement of the pilot interviews, the study was presented to each participant both verbally (Appendix I) and through an information sheet (Appendix II). In this verbal presentation the researcher gave a brief overview of current advances in
genetic testing, explaining how testing is conducted and its current availability for diseases, such as breast cancer and heart disease. The researcher also explained the likelihood of testing being available in the future, for conditions such as Alzheimer's disease, alcoholism and mental illnesses (manic depression/bipolar disorder). Respondents who wished to participate were asked to sign a consent form (see Appendix III). After a short period for questions, the interviews began by the researcher asking the interviewee whether they would consider taking a genetic test. Topics covered in the interviews concerned the participant's beliefs and concerns regarding genetic testing, whether they would consider undertaking a genetic test and their reasoning behind this answer. The researcher used a number of questions to shape or redirect the discussion as necessary (see Appendix IV), although the structure of the interviews was left as open as possible. The duration of the pilot interviews was approximately twenty-five to forty minutes and conducted at offices supplied by the University of Surrey. The conversations were audio-taped but not transcribed.

4.4 Method - Main study

4.4.1 Design
This was a qualitative study concerned with gathering the views of a cross section of people within the community, regarding their responses to the future possibilities offered by predictive genetic testing.

4.4.2 Sample
Participants in the focus groups were recruited to represent a range of ages, occupations, interests and educational levels, and religious, moral and familial viewpoints. We wanted to include a broad range of people, thus moving away from the focus on clinic-based samples that has dominated much of the in-depth work in this field. Each group had between 6 and 8 participants (n = 42), and contained at least one individual with a strong family history of either breast cancer, heart disease or both (the current availability of predictive genetic testing for these conditions was explained to the groups before commencement of the discussion). This criterion was included to ensure that the group
discussions, regarding the availability of predictive genetic testing, moved beyond the purely hypothetical. Demographic details of each group were recorded. We asked the participants to state their age, whether they had children, their religious faith, any family history of disease and any genetically inherited condition within the family. The answers are summarised below:

**Group 1**
Female undergraduate university students
Ages - 18, 18, 32, 19, 19, 21 years old
Children - none
Religious faith - 1 discussant was a Roman Catholic, 5 were atheist (self-classification).
Genetic history - 1 discussant had a family history of breast cancer

**Group 2**
Male (2) and female (6) shop workers
Ages - 35, 42, 50, 58, 52, 49, 36, 62 years old
Children - 7 discussants had children (2 with children under age 5)
Religious faith - 4 discussants were Church of England, 4 were atheist.
Genetic history - 2 discussants had a living relative with Alzheimer’s disease
1 discussant had a family history of Breast Cancer
1 discussant had a young disabled child

**Group 3**
Male (2) and female (5) health support workers
Ages - 45, 57, 45, 54, 38, 46, 61 years old
Children - all discussants had children (1 had a child under age 18)
Religious faith - 1 discussant was Anglican, 2 were Church of England, 4 were atheist.
Genetic history - 1 discussant had undergone BRCA1 testing for breast cancer
1 discussant had a family history of Alzheimer’s disease
2 discussants had a family history of heart disease
Group 4
Male postgraduate university students and university staff
Ages - 26, 37, 35, 29, 32, 30, 34, 27 years old
Children - 2 discussants had young children
Religious faith - all discussants were atheist.
Genetic history - 1 discussant had a family history of heart disease

Group 5
Male (4) & female (3) Christian parishioners
Ages - 65, 80; 71, 75, 43, 51, 47 years old
Children - 6 discussants had children (1 with a child under age 18)
Religious faith - all discussants were Church of England
Genetic history - 1 discussant had a family history of alcoholism
2 discussants had a family history of heart disease
1 discussant had a deceased child with Down’s syndrome

Group 6
Mothers (6) of young children at a playgroup
Ages - 25, 31, 28, 35, 22, 33 years old
Children - all discussants had children
Religious faith - 1 discussant was a Christian, 5 were atheist.
Genetic history - 1 discussant had a family history of Alcoholism
1 discussant had a family history of a hip disorder
1 discussant had a strong family history of breast cancer
1 discussant had a child with a genetic disorder (fragile X)

4.4.3 The focus groups
It was decided that focus groups were an appropriate method of collecting the data. A focus group methodology is particularly useful when wanting to gain insight into the negotiations behind people’s accounts of their attitudes, beliefs and values. Focus groups also allow the articulation of a breadth of views as well as detailed exploration of relevant
issues (see Krueger 1994) and actively encourage people to defend and expand on their opinions, developing a wider range of discussion that might arise in individual interviews (see Johnson 1996). We also felt that sensitive issues such as abortion and stigma might arise in group conversations about the new genetics, and that these topics would be more difficult to discuss on a one to one basis. Six focus groups were conducted in total.

4.4.4 Procedure

Prior to the commencement of the focus groups, the study was presented to each participant both verbally (see Appendix I) and through an information sheet (see Appendix V). In the verbal presentation the researcher gave a brief overview of current advances in genetic testing, explaining how testing is conducted, and its current availability for diseases such as breast cancer and heart disease. The researcher also explained the likelihood of testing being available in the future, for conditions such as Alzheimer's disease, alcoholism and mental illnesses (manic depression/bipolar disorder). Respondents who wished to participate were asked to sign a consent form (see Appendix VI). After a short period for questions, the focus group discussions began by the researcher asking the group whether they would consider taking a genetic test. Prompts were developed from the pilot interviews, with open ended questions developed to encourage the discussants to explore their thinking and feelings surrounding this topic (see Appendix VII). However these prompts were little used, with the structure of the discussions largely left open. As stated earlier, the methodology used - grounded theory - is mindful of the dangers of overly-directing the discussion or cutting off interesting theoretical leads or rich data. The material should be left to emerge, not be overly driven by the researcher's prior assumptions about what is theoretically important (see Pigeon & Henwood 1996).

The duration of the focus group discussions lasted between one and two hours. The conversations were audio-taped and later transcribed. Finally, an informal debriefing period was held to answer any further questions, and thank the discussants. The groups were conducted at their usual meeting place.
4.4.5 Method of analysis

The 6 transcribed focus group discussions were analysed, using grounded theory procedures and techniques as laid down by Glaser & Strauss (1967) and Strauss & Corbin (1990). See the earlier chapter on epistemological and methodological issues for a detailed explanation of the research process and a description of the research strategy.

4.5 Results

4.5.1 Initial data analysis

The aim of the first stage of the analysis was to break down the data into conceptual labels, and then to categorise the data into groupings that appeared to belong together. This involved an intense line by line analysis of the texts. At this stage the analytical process was both broad and minute. General reflections and thoughts were recorded in a memo diary, with idiosyncratic conceptions and images drawn and debated. Additionally, each piece of text was intensely studied, with words, phrases and sentences picked out, sorted and grouped together to form conceptual descriptive labels. The labels were clustered and further developed into analytical categories with shared properties, attributes and dimensions. Theoretical sensitivity was enhanced by constantly comparing and verifying the categories to the actual text, and with the use of constant questioning. This ‘flip-flop’ between the data and the researcher’s developing conceptualisations was an important part of the dynamic process of developing emerging concepts (see Pigeon & Henwood 1996). The researcher additionally used diagrams to map patterns of interactions and conceptual relationships, and looked for the meaning of inconsistencies within the data. Through a detailed analysis of words, sentences and phrases, and by making different level comparisons, broader themes emerged from within the categories, to aid the next stage of analysis. This process is partially illustrated below, using excerpts of text taken from the first stage of analysis (see Appendix VIII and Appendix IX for two complete examples of the transcribed interviews). For ease of illustration only the words highlighted are used as examples, in terms of forming part of a descriptive label or category. Other phrases and words included in the excerpt are not redundant or ignored but form parts of other labels and categories not illustrated.
In the first series of examples, the discussants are concerned about possible
discrimination resulting from predictive genetic testing, with the consequences discussed
in terms of increased insurance premiums, new social pressures and an increasing
numbers of abortions. A sample of one of these conversations is shown below:-

*02/104-9: You've only got to be smoking, not to be insured. That's the first question they
ask you, and if you say yes, the premium goes way up. 
So this testing thing, this is going to have even more of an effect. And the drugs as well,
because certain types of drugs they will think you are unsuitable for because if you have
a certain gene. 
It would just stress you out, so much pressure.

*denotes text is taken from group 2, lines 104 to 109

The text was broken down and labelled for each particular concern. Examples highlighted
were labelled as –

- Higher premiums or no insurance cover
- Exclusion from health care

Leading to

- New social rules and pressures

These labels were then clustered under the larger category of 'Discrimination', and
finally placed under the heading 'Negative consequences of genetic testing' (see
summary of results below).

In another discussion the theme of discrimination is expanded, but the conversation is
steered towards the lack of confidentiality attached to genetic testing, and the pressure
exerted from society resulting from this knowledge.

01/212-222: I know it will be supposedly confidential with your work or with your
doctors, but I think they will emerge - prejudices against people. Without having to say
you’ve got it, you’ve got an 80% chance of getting this disease, and saying directly to that person. It’s going to come out and the same kind of things when you’re talking about getting pregnant. I mean you’re going to not have to tell people whether you’ve got this disease, but it’s going to be known, the general public view of whether you should have that kid. They’re going to look down on you cause you’re having a kid and knowing you’ve got a chance of passing on the disease. So you’re going to have that social pressure about it all, about it all coming out in the full, and being against you.

This section of text was similarly labelled, with the labels developed concerned with the -

- Lack of confidentiality attached to testing

Leading to

- New social information

Leading to

- New social rules and pressures
- Social exclusion

These labels were again placed within the category ‘Discrimination’. Within this piece of text, there was also a strong concern with the perceived ‘future pressure to have perfect children’, and this concern was labelled accordingly (see summary below) and put within the category ‘Frankenstein society’ and under the heading ‘Tampering with nature/playing God’.

In a third example, the health support workers are again concerned with the emergence of new social norms surrounding genetic testing information, although in this discussion the emphasis is on the possibility of testing leading to more abortions and to eugenics.

03/208-214: You will have a superior race, it may be even come to people who are not genetically up to scratch... Being knocked off.

Eventually.

Oh yeah.
What going to happen to the educationally subnormal? You get your genes tested as you say, it's like you're going to have a genetically abnormal child of some form, or get aborted, so you are streamlining the human race.

This section of text was primarily labelled as –

- Social pressures to have perfect children

and

- More abortions

Leading to

- Eugenics
- Streamlining of the human race

and placed under the category 'Tampering with nature/playing God', but additionally the text was labelled as social norms = leading to exclusion, and again placed within the category label 'Discrimination'.

In the second series of examples the conversations are concerned with the reasons why some of the respondents would want to undertake genetic testing. In this piece of conversation -

04/51-56: Well for things like cancer there are some proactive things you can do. And um, things that we perhaps don't know - how to reduce the symptoms. I guess you've got a certain amount of time to start looking into how you'd do it for yourself, and perhaps for other people. Yeah I think there are certain things you can do and if you do have a family as well you can take sort of planning action, in relation to them.

the discussant feels genetic testing would be beneficial, and the text is labelled:

Genetic testing allows you to be

- More prepared
- More proactive

and to
• Plan for your future
• Plan for you families future

The labels were then put in the heading ‘Positive consequences of genetic testing’. However the participant is also concerned with insurance, so part of the conversation (not shown) is labelled in relation to this concern and was later placed under the category ‘Discrimination’.

In the next section of text, below, the woman talking also feels genetic testing would be beneficial, but this respondent is more directly concerned about health planning in terms of her existing children:

06/103-109: \textit{We've got a hip disorder in our genes, and I would have known} (with testing). My eldest daughter had to have an operation, and I didn't know she was going to have that, cause the other children never did, so. So I would have had a test for that definitely. I think it's good for children - definitely.

\textit{If you had known in advance how would that have been helpful?}

\textit{If I had of known, well I'd have still got scans and things, but maybe I'd have been more prepared for it, that's it. As a mother I'd have been prepared for it.}

This piece of text is labelled genetic testing ‘Allows you to make children’s life better’ and put in the category ‘Genetic testing allows you be more prepared and proactive, and plan for the future’. The conversation additionally addresses the discussant’s understanding of how disease is passed on through her family and although not shown, this dialogue was given a label which describes this understanding.

Similarly in the next piece of text, a woman (a mother) feels genetic testing would be beneficial to her, in planning to have future children:

06/154-161: \textit{Oh yes, I would have it} (genetic testing) \textit{next time, for myself, to know for the next child. And also if I thought there was a possibility of something else. If I'd had}
genetic testing before I had T and found out that I was a carrier I could have made an informed choice about what to do. I don’t know what I would have done, happily I’m not in that situation and I’ve got two lovely children, and I wouldn’t change that for the world. I would have still had T, because as a Christian I think it wrong to take away life. I wouldn’t do it. But it just explains things - it prepares you.

This piece of text is labelled -

Genetic testing allows you to

- Plan for a family
- Be more prepared,
- Make your child’s life better

Genetic testing gives you

- Choice (in terms of knowingly passing on a genetic disorder to your child).

In the conversation the participant also talks about having the opportunity to make an informed choice and this is part of the text is additionally labelled and later categorised under the heading ‘Personal and social control over genetic testing decision-making’ (see below).

A summary of the overall findings, and the labels and categories developed and extracted from this initial stage of the analysis are shown below.

Summary of findings – labels and categories extracted from the initial stage of analysis

1. Identity of genetic disease

- Seriousness
- How curable or preventable
- How common
- An immediate risk or more distant risk
2. Cause of genetic disease

*Genetic cause*
- Known family history = risk to oneself & family

3. Cure and treatment of disease

*Testing allows you to*
- Seek medical interventions
- Make lifestyle changes
- Be cured
- No cure or treatment = no control =

*Lack of intention*
- 'No point testing for diseases that cannot be cured or treated’

4. Personal and social control over genetic testing decision-making

- Testing is an individual choice
- Testing should be an informed choice =
- With counselling provided
- With more public information provided
- Need for governmental controls and regulation =
- 'Halt' - put the breaks on genomic research until we know more

*Concerns over*
- Lack of informed consent
- Compulsory testing *specifically*
- Compulsory testing prior to marriage
- Lack of Confidentiality = discrimination
- 'Like 'AIDS' testing’

5. Positive Consequences of genetic testing

- Gives you freedom from worry – if a negative result

*Allows you to*
• Be more vigilant
• Be more prepared/proactive
• Live life to the full
• Plan for your future
• Plan for your families future
• Plan for a family
• Get a diagnosis, an assessment of the problem
• Make your child’s life better
• Prevents children with serious genetic disorders begin born =
• ‘It’s wrong to knowingly pass on a genetic disorder to children’

_Gives you, creates_

• Choice
• Certainty
• Responsibility

_Therefore testing is a good thing_

• Especially in regard to protecting children’s health
• With legislative safeguards in place

6. Negative Consequences of genetic testing

_Create_

• Stress and worry over your own health
• Stress and worry over your children’s health
• Too much certainty, uncertainty =
• Illness
• False sense of security (a wrong or inaccurate result)
• Prevents you from getting on with life
• Restricts your child’s life

_Discrimination_

• Lack of confidentiality
• Higher insurance premiums or no cover
• Lack of employment
• Exclusion from health care
• Lack of confidentiality attached to testing

Leading to
• New social information

Leading to
• New social rules and pressures =
• Social exclusion

Commercial exploitation
• Power of drug companies
• Power of money (to make from testing)
• Financial cost of testing

Leading to
• Lack of availability for all

7. Distrust of science

Confusion over
• How genetic testing works

Concern over
• Accuracy of tests
• Lack of public knowledge
• Lack of scientific care and knowledge (over long-term outcome)
• Lack of scientific morality
• ‘New’ unknown elements of technology

8. Tampering with nature, playing God

Frankenstein society
• ‘It (science) will go too far’
• It’s (genetic testing) too deterministic
Leading to

- Social pressures to have perfect children =
- More abortions
- Eugenics
- Streamlining of the human race

Morally wrong to

- Take away life (of foetus)
- Create a super-race (designer babies)
- Alter the human race - Hitlerian eugenics
- Create a genetic underclass

Current 'too far' comparisons made =

- GM foods
- BSE
- Cloning

Therefore testing should be available for

- ‘Serious’ health condition
- Assessing risk to children
- For determining quality of life
- For everyone

9. Genetic fatalism

- You can’t stop progress (it’s coming anyway)
- The choices are too difficult =
- So just accept what comes – nothing you can do
- You can get ill anyway
- Just take precautions anyway
- Just hope for the best
- What you don’t know doesn’t hurt you
- Disease is not preventable if it’s genetic
4.5.2 *Main data analysis*

In the second level of analysis the researcher's aim was to allow the relationships between and within the labelled concepts, categories and headings to be seen from different and fresh perspectives. The focus was on considering the conditions that gave rise to a category, and on examining the specific context of a set of properties. Additionally, available actions or interactional strategies were explored and reconsidered, by investigating the possible ways in which these strategies are handled and managed, and the consequences of these actions (see Strauss and Corbin, 1990).

As the categories became more integrated, the emerging themes were continuously validated against the data set, and compared to different pieces of text within the data (see Glaser 1992). Relationships between the categories were expressed in the form of coherent theoretical statements. Specifically the aim was to discover new and unexplored themes surrounding the participants' representations of predictive genetic testing. In this stage of analysis the data from the transcripts was unpacked and then put back together, a 'flip-flop' process characterised by comparing and contrasting categories and linking them together. This was done in a multitude of variations that identified and verified relationships that were strongly presented and widely repeated within the data. It attempts to find and examine incidences of variation, and examine these alternative dialogues. The results were recorded in a memo file, with flow charts and diagrams used to provide a concise illustration of the function of different relational concepts (see final diagram below).

The first theme to emerge from this stage of the analysis was the discussants' belief about the cause of illness. The theme – 'illness runs in families' was very strong across all the groups, with heredity perceived as the major determinant of illness. Overall it appeared that the more people affected in a family, say parents, siblings and grandparents the greater was the perceived family history of disease, and the stronger the perceived genetic risk:
03/5-8: I would (have genetic testing). I would certainly consider it because I have a very strong family history of heart disease. My Mum died at 48; my sister had two lots of open-heart surgery at under fifty and a stroke, so therefore I would be very happy to take part in the test.

05/30-34: We have alcoholism in my family and I have long held the belief that there was a genetic predisposition cause I can see the pattern that has gone through my family. As far back as I can see it, which is my great grandparents, which I didn't see until my mother became an alcoholic...

If the respondent had no family history of disease then generally no genetic predisposition to disease was perceived and there was no perceived risk, which appeared to render genetic testing personally irrelevant and unnecessary:

01/5-10: I don't know, cause the thing is, I don't know of any serious illness in the family. So, if I knew that there was some sort of, that my dad had died of a heart attack, my granddad blah, blah, blah I think I might consider it. ... Because as... I said, I find it hard to say whether I would or not (have testing). I've got no family history or anything in that sort of nature, so I also find it hard. For me it's like well that's what someone else would do.

02/96-99: If you've got nothing in your family, if nothing ever goes wrong you'd think no I would never have it done. But if you had a problem you can't say what you'd do, if you were given the choice or opportunity. It only when it comes very close to home that's it's a different outlook.

The second theme to emerge from the data was the identity of disease. The majority of the discussants appeared to identify 'genetic disease' as predetermined - if you had the genes for a disease within you then you were probably going to get ill:
01-63-4: I don't know if they are preventable cause they're genetic... Don't think so, not really, if it's in your genetic makeup how can you stop it?

03-11: I mean you can't cure it, if it's hereditary, you can't cure it....

04/39-41: For many things that's it, you've got it. You've got a one in twenty chance of having the cystic fibrosis gene; there's nothing you can do to reduce that. Once you've taken the test there's nothing you can do after that...

The identity of the disease appeared to be linked to perceptions of how curable and controllable the disease was, with the issue of control and cure appearing to determine attitudes towards genetic testing (whether this type of health assessment was the best way to deal with the possibility of future ill health). If the target disease could not be cured, or controlled, and no outcome options were perceived, then many discussants expressed that they would probably not undertake genetic testing:

01-45-48: Yes, I don't know if it's the same thing, but the AIDS thing for example. You know how they say they haven't got a cure for it, I guess you'd rather not know. If it's not curable and you're going to die, you'd rather just not know about it, until it actually happens.

02/19-25: If someone asked me tomorrow do I want to go and have a test for breast cancer my answer would be no, I don't want to know...what's the point of knowing something there's no cure for. It's just your own abuse, and I wouldn't want the worry... I think you only want to know if there was a cure. I mean I only want to know if they cure me. If they said I'll give you a test for breast cancer, but they can cure you if you've got the gene, I'd be first in the queue. If they couldn't 100% cure me then afraid not.

03/101-105: If I want to be genetically counselled, I mean tested, no I wouldn't, definitely.
But what if something develops when they're twenty, twenty-five and had you already known about it, you could have done something about it. Not if there is no cure. If you can be genetically counselled and there is a cure I might, but not to be genetically counselled and there is no cure.

The consequences of genetic testing if there was no perceived cure, control or outcome options were seriously considered. In these circumstances many of the discussants felt testing could only bring them worry and stress, and a lack of hope in the future. This dialogue was most clearly demonstrated when the respondents discussed the issue of genetic testing for Alzheimer's disease and breast cancer:

02/29-32: What the point in worrying about it now cause they can't eradicate it now. If you went for a test to find out if you were predisposed to breast cancer and they said yes, 'you are, you've got the gene', you'd spend the next ten years worrying you're going to get breast cancer.

05/229-233: But I mean I would be very unhappy if I could take the test and be told, 'yes you are going to develop Alzheimers. Cause at the moment there isn't anything that can be done about that, and I would be very unhappy to know that I am going to degenerate like that. It would not allow me to look forward to old age with hope, whereas at the moment I can.

The feeling expressed by some discussants was 'out of sight, out of mind' - it was better to just get on with life, and hope for the best. Too much certainty regarding the future prospect of illness was considered worrying, both for the discussant and for their children:

01/158-168: ...I know I'd just always be waiting for it to happen, it would be like a shadow there, I think. I won't be able to get on with my life. I think, anytime you got ill, or if you found a lump or something, you'd immediately think it was cancer. ...I'd be
much more inclined to just get on with it, and fit as much as I could in my life, while I didn’t have cancer.

03/112-114: No, I don’t think so. I just don’t particularly want to do it (have testing). I’m all for living for the moment I don’t particularly want to grow old. I certainly don’t want to end up in a nursing home; I’d just would rather live a short but happy life.

03/109-110: No I wouldn’t (have my child tested) cause I wouldn’t want to put that limitation on his life really. I rather that he had a short but enjoyable life, rather than drugged up worried life.

However, a number of other participants viewed the development of illness as more multi-factorial, in that they felt the development of disease might be changed with diet or exercise. Similarly some participants felt that even if they could not access a cure, positive personal consequences resulting from predictive genetic testing might be possible. For these individuals the future certainty over their health offered by genetic testing was seen more positively. These participants saw the knowledge gained from genetic testing as a means of making lifestyle changes, perhaps seeking medical interventions, being prepared, planning for the future and generally improving the future for themselves - and their children:

02/441-446: They thought I had a brain tumour a few years ago, and they were talking about the scan results, but I lived though that. But I wanted to know, so I could plan my life, so I knew what I wanted to do. Um, certain things in my life I’d love to do, and if I had a limited time I’d go and do them. You’d do it if you have something coming. A little bit of preparation can go an awful long way, mentally and physically.

06/163-169: Yes I would have it done (genetic testing). It would just give you that knowledge. My mother-in-law had breast cancer at a very young age. I would like to know if that was genetic. I would like to know for my daughter’s sake so she would know whether she has this, this genetic predisposition. I think anything that makes you more
aware is a good thing. She can be more vigilant and be prepared. If there’s a slight worry to seek medical help right away. Because a lot of women get it and die.

Another strong positive personal consequence of testing, expressed by many of the discussants, was the ability to choose not to have future children with serious health problems:

01/51-53: That’s what I was going to say, if when it comes to having children, and there was the possibility of a disease that I could pass it on to my children, then it’s something I seriously consider doing.

06/154-157: Oh yes, I would have it next time, (genetic testing) for myself, to know for the next child, and also if I thought there was a possibility of something else. If I’d had genetic testing before I had X and found out that I was a carrier I could have made an informed choice about what to do.

Alongside the possibility of increased personal choice, the discussants expressed that it might be wrong, that it might be socially unacceptable to have children knowing you had the chance of passing on a genetic disorder, examples of these conversations is shown below:

02/244-248: I watched it on children’s hospital, where one child is badly disfigured and needs mega medical treatment and the parents have gone on to have another child who needed exactly the same, and I must admit, in that case I have thought ‘oh why have they had another kid’. I have put my opinion forward, and maybe that is wrong.

02/231-238: I think some people would disapprove, ‘how could you do this if you knew’. I should think it would be quite an issue, especially from family. When I was pregnant with my daughter, anything like that I knew, I don’t think I could have gone ahead, to be quite honest. Cause I’d be going ahead for reasons of my own, not for her... I think we are all influenced by what other people think all our lives aren’t we, even to the most
unimportant issue like you hair. So the opinions of others, regarding your child it's the ultimate isn't it. With my daughter, everyone wants people to say isn't she lovely, not isn't she ugly.

In the first part of the analysis, the conversations shown have primarily been concerned with the perceived identity, cure and control of specific diseases and the personal consequences of genetic testing. In the second part of this stage of the analysis the conversations illustrated are more centred on predictive genetic testing as a technological process. In these discussions the identity of genetic testing itself was discussed, and appeared to be strongly linked to other technological advances such as GM foods. An extract from one of these conversations is shown below:

01/292-301: It's like GM foods - just shovel loads of it out on the shelves and do a test after everyone's eaten a bit...I think too many schemes like GM foods they just dive ahead, go ahead, and then in a few years, it's like actually when we think about this it not such a good idea - like B.S.E.

01/279-283: Also just by using the word 'genetic' people become immediately concerned and a bit sceptical about it, the whole thing with genetically modified food and all that sort of stuff. I mean I kind of link the two, just because they bring, they use the same word and there's been a lot of scepticism about GM foods and there would be the same worry with this as well, I think.

Perceptions of personal control again appeared pivotal in the participant's perception of the merits of this new technology, with a general distrust of 'science' and new technologies being expressed in all the groups:

03/184-186: It's all stored on computer. They'll have everything they want, its big brother. Big brother watching you. Which is more or less what it is now. The more information they've got on you, the more they're going to use, they've got you.
04/84-86: To put it very crudely we’re going to get stuffed by it (genetic testing). Big companies will get what they want cause they are the big companies, they always have done. I’ll admit I’m very fatalist. It just seems to work out that way.

Like the perceived consumption of GM foods, a general lack of personal efficacy was expressed regarding the decision to undertake genetic testing. Many participants felt that this procedure was something they would have no personal control over or choice about, as personal control regarding their health was something they were already being denied:

02/301-306: I think L is right I don’t think we’ll have the choice. Even now without us realising it you don’t have the choice. When you’re pregnant you automatically have these scans. You don’t have the choice. You don’t ask for them, you don’t request them. And if you say you don’t want them they think you’re like the pits, so already you don’t have the choice, they’ve already put medical issues upon you...yon don’t have a choice in this. You’re just unaware of it.

03/190-203: I think for most people personal choice had already been taken away, so much. What have we got left really? Yes, even the testing we do at work I find it slightly - I find it - where you’re looking at people for heart problems and things like that. So do I. Yeah we beginning to do it here and I find it quite disturbing. I find it disturbing from their point of view. You know if they’ve got a heart problem you sort of bringing it to the forefront of their brain - therefore they are then dwelling - instead of getting on with their lives they’re focused on this heart.

So do you think genetic testing will be a choice?
probably at first, but it won’t be. But in the future there won’t be no choice. No choice. (Everyone agrees). Not in the future. Instead of the K injection of whatever they put in there with babies, it will be the genetic test. I think it is the way it’s going.

Leading on from the issue of control over genetic testing decision-making was a concern about informed consent. Many discussants expressed that they felt it was important that people fully understood the wider implications of this procedure. However there was a
general consensus that currently the public did not know enough, and were largely uniformed about genetic testing and biotechnological advances:

01/269-279: I think a lot of people don't know about any of the stuff that's going on, the majority of people in society. So they can just be carried along with the sweep of it, and they won't really know if it's a moral or social issue or not, cause they don't really know what's going on. It's a barrier between us and them..... It will get to a point where maybe they're tested, and yeah, this is the thing, then they'll get to a point ten years later where all this information about them is being used for drug testing and things like that. And they're not prepared and they didn't like that. But at the time they didn't know enough to be able to go against it.

06/120-124: I think they can do HIV, they can even do HIV tests on pregnant women, and it's not stipulated that they are going to do that. I think that's a bit wrong. That should be up to the individual as well. I think if you're informed you can make that choice. Yes, being informed. I think if you're informed you can make that choice.

The third area of discussion centred on discrimination issues – many of the discussants were worried that genetic information would not be confidential, with a lack of confidence expressed in the dissemination of genetic information. It was felt that a lack of confidentiality would result in unemployment, a loss of insurance and loss of finances:

01/191-195: Yeah, that was on the news last night already, about genetic testing being divulged to insurance companies. If you had, if they found that you had a predisposition then your life insurance could go sky high. Basically, it would cost a lot more to be insured than someone who didn't have a predisposition, and I think that's really unfair.

04/410-413: Mortgage companies are going to want this, health insurance companies are going to want this, nobody's going to be able to afford a house, nobody will be able to get a job, cause unless you have the perfect DNA nobody will have you. That's what it will come down to. We will end up in the movie Gatteca.
04/101-107: Another thing that really worries me is what happens to those records. That really worries me more than anything, because of all the implications on insurance, jobs and everything else. I mean who knows what will happen in the future, how much records can be looked into, how much they can be looked into now, sort of thing. That's the really scary thing, rather than knowing I've got something.

In discussing discrimination comparisons to HIV testing were commonly made:

02/135-138: It's only as confidential as the person putting it in, isn't it. If you got Aids or something and someone knows someone, who's coming to work for me, they going to say to you, 'oh did you know they've got Aids'. And you'd be like, 'Oh!'.... You've never going to keep that secret.

04/302-309: ...It's like HIV testing today. You know it's good for me to know if I'm HIV positive, but at the same time it's not good, cause if my employer knows I even went for a test they could possibly fire me. I think the HIV is a good candidate cause it's on your record, whether you want it on there or not. So the very fact that you've had an HIV test puts on your record that you're at risk of HIV and people will make assumptions about you and your lifestyle. So it's a really good example of why these things cut across what they are designed to do.

Finally the discussants expressed many concerns about where genetic testing developments should lead. There appeared to be a general unease that genetic testing might be taken 'too far', that humankind was tampering with nature and disastrous consequences might ensue:

05/261-273: It does worry me in a broader sense really, this sort of interference. That man is all-powerful, that man can fix everything and really we are not God. Um, and I'm just uncomfortable with that view. I'd like to know this and that, and I'd like to know if I do this, that I won't get this. In a broader sense, it doesn't quite seem right that man
should do this. That salutary story of Philip the Great of Masceden, he had one of his
chamber slaves come in every morning and say to him very loudly and clearly the
reminder, 'thou must die'. A sanitary story I think. We are mortal, and no matter how
clever and sophisticated we become we will always be mortal... We are also fallen
creatures and whatever controls are put on reproductive medicine or cloning it will go on
in the background won't it.

Many examples of going 'too far' were given, with the creation of a super-race through
eugenics and cloning considered unacceptable across all the groups:

01/255-256: Like in Sweden when they sterilised all those people under a certain I.Q.,
when they tried to do that. It still could be the same sort of thing.

02/286-289: If you going to get married there's a law that you're going to have to have
this genetic testing. If you're going to have children you got to have them perfect. And
that will be a curse, like Hitler again, perfect families, perfect people.

06/172-178: I don't like the idea of cloning, or of designing babies to fit certain
specifications, sex and things like that. Choosing the genes to develop the perfect human
embryo, it's a horror to me.... ...not testing for things like homosexuality or colour of
hair.

It was also expressed that the commercial exploitation of genetic testing, and the money
that could be made from this biotechnology, would contribute to genetic testing getting
out of hand and being taken 'too far':

01/302-307: And it's the whole money thing. Especially at the beginning cause less
companies will use it, so therefore they'll have more revenue from it, cause they won't be
vying for the same business, so they'll do it knowing they can make a mint before all the
problems come. Then they can pack up their business and go on to something else, when
all the profits have come and they've got lots of money in the bank.
Again I don’t think the people on the other side of this, the people who will be making the money out of this, will behave as honourably as perhaps you do. This has to be taken care of. They will give you the test, you walk out and they’ve made seventy quid that’s how they’ll see it. The manufacturers, the propagators don’t get involved in health care or mental care, they’re just into administering these tests and that’s the scary thing.

The negative social consequences of testing appeared to be less, and intention to undertake genetic testing appeared to be higher in those individuals who felt that appropriate governmental safeguards and legislation would address these concerns:

But predictive testing to find out what’s wrong with me, and how I can live with it - I might be convinced that’s a good thing, if the safe-guards were in place so insurance companies couldn’t get hold of them. If it was not held on medical records unless that’s what you wanted. I’m not sure, but that could be good news.

I think the government is going to have to lay down guidelines when it’s the right time to use it, and when it isn’t. To stop misuse, I think. It’s the same with any new thing, isn’t it? Yes, it’s like anything new, so...

But I think as long as it’s worked sensibility it’s a very good thing. It’s been a very positive experience for me. If it’s used within a sensible moral and ethical framework then it’s OK. Not testing for things like homosexuality or colour of hair.

The following diagram illustrates the final themes and relationships resulting from the analysis — see figure 5 below.
Figure 5. Summary of the themes and relationships uncovered from the second stage of analysis.
4.6 Discussion

Psychological research into lay perceptions of predictive genetic testing, and decision-making prior to the consulting room is scarce, with qualitative research addressing this issue rarer still. Given the paucity of previous work in this area, the aim of the study was to use a focus group methodology to discover new and unexplored themes surrounding the participants' representations of predictive genetic testing. Two main topic areas of debate emerged from the data analysis. Firstly, the participants' conversations were primarily concerned with personal family related issues, such as experiences of illness, and the benefits or disadvantages attached to having predictive genetic testing information. Secondly, discussions appeared to be concerned with the actual process of testing and the wider social implications attached to this new health choice.

In considering our findings in more detail, the first theme to emerge was the participants' beliefs about the cause of genetic diseases. This concern with the cause of illness is one of the common-sense representations identified in the Self-Regulation Model (SRM) of illness (Leventhal, Meyer and Nerenz 1980) examined in the introduction. In the SRM five representations (cause, identity, cure and control, consequences and duration) conceptualise the processes involved in the construction of judgements about vulnerability to disease, severity of disease and the effectiveness of actions. They guide the formation and enactment of coping behaviours, aimed at resolving the health problem and reducing the emotional distress induced by the threat of ill health (see Cameron, 1997; Leventhal, Idler, and Leventhal, 1999). In terms of our findings the belief that illness 'runs in the family' was strongly represented, with heredity perceived as the sole cause of having a genetic predisposition to illness. This finding is not surprising; the word 'genetic' denotes that a disease is passed on through family genes with the belief that 'genes' can cause illness well rooted in both medical and lay Western culture (see Marteau and Senior, 1997). The idea of genes being a primary cause of illness is further reinforced as genetic testing for disorders, such as cystic fibrosis and adult onset diseases such as breast cancer, become increasingly common.
The cause of genetic disease also appeared relevant to the construction of judgements about vulnerability to disease. If the respondent in the group had no family history of disease then any genetic risk was considered unlikely, with consequently no perceived need for testing, and no intention to undertake this procedure. The data from our study suggest that the more people affected in a family - say parents, siblings and grandparents - the greater the participant’s perceived family history of disease and the stronger the perceived risk. However, the relationship between risk and the degree of perceived genetic inheritance may have been a function of family closeness or physical similarity, rather than any actual genetic tie. The phenomenon of perceived family characteristics being substituted for genetic ties is illustrated in a study by Lynch et al. (1997) into women’s reactions to BRCA1 test results. Two sisters were tested, one positive and the other negative for the breast cancer gene. The results came as a shock to the ‘non-carrier’ sister; she could not believe she did not carry the gene as she resembled her affected mother so strongly, whilst the carrier sister did not. Research needs to gain a greater understanding of how people perceive their own risk in relation to the family connections they perceive as important, such as the influence of shared characteristics or sex-linked heredity. The fact that a woman is just as likely to inherit the BRCA1 breast cancer gene through her father (or paternal grandmother) as her mother is rarely considered, with this fact not evident in any of psychological research investigating lay perceptions of inheritance. Similarly, all the respondents in our focus groups discussed breast cancer as a disease that was inherited maternally.

For those individuals with a family history of illness and perceived vulnerability to disease, the contemplation of genetic testing and its usefulness appeared to be influenced by another representation outlined in the SRM by Leventhal, Meyer and Nerenz (1980) - disease identity. In line with other research the study found that lay representations of ‘genetic’ diseases were largely deterministic in content (see Henderson and Maguire, 1998; Senior, Marteau and Peters 1999). The majority of the respondents appeared to identify ‘genetic’ diseases as predetermined - if you had the genes you were going to get ill. Overall levels of perceived control regarding disease aetiology, or any cure, were low. As Petersen (1998) points out this cultural belief in genetic determinism is supported by
media reports. News reports tend to sensationalise and 'over-geneticize' the issues they describe, with genes being depicted as the sole determinates of more complex behavioural states, such as being 'gay'. This type of exaggerated reporting leaves the public with a lasting but incorrect impression of the dominant role 'genes' play.

This proposition is supported by research. In a study by Henderson and Maguire (1998), the five content categories of the SRM were used to investigate lay representations of genetic disease. Of the twenty participants interviewed, only one mentioned treatment and prevention issues. This finding implies people are fatalistic about genetic disease, thinking treatment options are not available. A 1996 study by Senior, Marteau and Weinman, into causal beliefs about illness, further indicates that people believe 'genetic' illness is unavoidable. The researchers asked two groups of students (n=212) to imagine they were undergoing a test for heart disease or arthritis. When the test was a new 'genetic' test, as opposed to another procedure, the disease (regardless of type) diagnosed by the genetic method was seen as less preventable. Recently this research finding was followed up. Senior, Marteau and Peters (1999) conducted semi-structured interviews with the parents of 24 children at risk of familial hypercholesterolaemia (FH). When the test for FH was not perceived as genetic the parents perceived the problem as familiar, dietary in origin, controllable and less threatening. When the results of the test were perceived as genetic the condition was seen as more threatening and less controllable. The authors suggest that providing people with genetic information may lead them to become fatalistic, taking less action to reduce their risk, such as changing their diet.

The idea of genetic fatalism does appear relevant to the data collected in our study. If the respondent felt the identity of the disease meant it was not curable or controllable - in that they could not gain access to medical interventions or take preventative action to stop the onset of the illness, or prevent deterioration - then testing was often considered detrimental. Many of the respondents did not mention outcome options or treatments, but instead suggested that the best way to deal with the threat of 'genetic illness' was to ignore it and 'hope for the best'. In these circumstances genetic testing meant
unnecessary and perhaps uncontrollable long-term anxiety and worry, for themselves and their children, and there appeared to be little intention to take up this service.

Whilst generally genetic diseases did not appear to be identified by our sample as particularly avoidable or curable, some respondents saw genetic diseases as more multifactorial in nature, with genetic testing perceived as offering the possibility of finding a cure or other outcome options. Those individuals who tended to be in favour of genetic testing for themselves also viewed testing for their existing children more positively, feeling that testing was an option that might enable them to make their existing child’s life better. Other participants felt the information would prevent their child leading a normal happy life, and blight the family. Although attitudes towards testing for existing children was divided, genetic testing in pregnancy, or before planning a family, in order to prevent children with serious health problems being born, was universally viewed by the groups as a positive consequence of the technology. In this situation intention and support for testing appeared universally high. This finding is not surprising. Currently genetic testing in the form of amniocentesis testing for Down’s syndrome is widely accepted and utilised by pregnant women in Britain. In a recent Mori poll (see Milewa, 1999) out of 1978 adults sampled, only 9% said they would attempt to conceive without a genetic test, if they knew they were at risk of passing a serious genetic disorder to their children.

The apparent split in perceptions regarding the consequences of genetic testing and the perceived ability to access outcomes for themselves and their children was surprising and pronounced. Even without any possibility of cure, some respondents expressed that they wanted the certainty offered by genetic testing. They felt this procedure would offer their family choices, in allowing them to prepare and plan for the future, take preventative action and access medical interventions. These participants appeared more optimistic about their ability to control the future and their intention to undertake genetic testing appeared much higher. Leventhal, Meyer and Nerenz’s (1980) original work on the self-regulation model of illness does not particularly focus on individual differences regarding the perceived ability to control future outcomes. Similarly, although both the health belief
model (Becker and Rosenstock 1987), and the theory of planned behaviour (Ajzen 1985) include perceived and behavioural control, the construct is defined more generally and is concerned with outside environmental events or circumstances that may prevent actions from being possible. Protection motivation theory (Rogers 1975) is the only health decision-making model that specifically addresses self-efficacy - the personal ability to perform a specific behaviour in order to achieve a set outcome. As discussed in the introduction, the role of self-efficacy has been most widely theorised and researched by Bandura (1977). Bandura (1982) suggests that high levels of self-efficacy can help to predict the ability to cope with stress, with individuals low in perceived efficacy often feeling helpless and powerless in the face of health threats. A review of the role of specific measures of self-efficacy within health psychology literature further supports this view (Strecher, McEvoy DeVellis, Becker and Rosenstock 1986) and serves to confirm the predictive power of self-efficacy in predicting long and short-term success in regard to adopting new health behaviours and maintaining these changes.

In terms of our data, the findings suggest that self-efficacy may have a pivotal role in determining intentions towards predictive genetic testing, with those participants who stated they are more in favour of testing appearing more optimistic and efficacious about their ability to control the future after a genetic test result. Individuals high in self-efficacy may perceive genetic testing as a positive way of accessing new outcome options and taking more control over their health and future life, whilst individuals low in self-efficacy may find genetic testing detrimental, with the lack of perceived ability to action outcomes resulting in feelings of powerlessness and fatalism. The proposal is tentative; research specifically addressing the question of self-efficacy and genetic testing decision-making is needed to determine the accuracy of this hypothesis.

Another interesting finding to emerge from the data was the participants’ discussion of their perceived risk of ‘genetic’ diseases. Although, as mentioned, protection motivation theory and the health belief model discuss the issue of control, they also address perceived risk, under headings of perceived susceptibility or vulnerability. Unfortunately what the models fail to do is theorise on how perceptions of risk and self-efficacy might
interact, override one another, or diverge, to influence health decision-making. Similarly, the issue of whether any combined effects are additive or multiplicative appears unaddressed. In our study the participants appeared to perceive genetic diseases as largely immutable, if you have the genes then you are at high risk. However differences in opinion were more divided regarding what the individual could do about this risk. Some participants expressed feeling helpless – it was best to ignore it and ‘hope for the best’- whilst other participants felt they could take positive action (regardless of whether a disease might be fatal), such as disease management and future planning. Research has shown that high levels of self-efficacy can determine whether risk is translated into actual health behaviours (Rimal, 2000). However the question of whether self-efficacy interacts with perceptions of risk, to change personal feelings of vulnerability and intentions towards genetic testing, has not been researched.

Having discussed the first main topic area we shall now move on to the second, the discussions concerned with the actual process of testing, and the wider social implications attached to this new health choice. In considering the processes attached to genetic testing, the identity of predictive genetic testing was widely discussed, and appeared to be linked to other technological advances. Overall there appeared to be a distrust of ‘science’ and new technologies. This distrust was most clearly centred on recent issues associated with genetic engineering such as cloning, BSE and, more particularly, the issue of GM foods. As one respondent pointed out just the word ‘genetic’ made people feel sceptical and brought in associations with GM foods. As Frewer (1999) comments, since the 1950s the impact of errors and accidents such as Thalidomide, Chernobyl, and more recently BSE provide the public with signals that biotechnology is ‘out of control’, with the public becoming increasingly concerned about the risks associated with emerging technologies, and a cultural shift towards preference for societal decisions which favour risk aversion (Frewer 1999).

In our sample perceptions of control appeared pivotal to perceived merits of predictive genetic testing as a technological process and new health choice. A major concern was the lack of perceived efficacy over the decision to have testing, with the feeling that this
procedure would become compulsory, with some participants expressing that free choice in this matter was already an illusion. It was felt that in the future insurers or employers may insist that people take genetic tests, and that people may be forced to take genetic tests before being allowed to marry or have children. This latter fear was strong, and may partly mirror the practices of other countries. Currently in China couples are 'not allowed' to have more than one child, and are compelled to submit to genetic testing before marriage for mental disorders, sexually transmitted diseases and serious hereditary diseases. If the couple are found to be suffering from any hereditary disease they may be forced to undergo sterilisation or long-term contraception (see Petersen 1998). Attached to this concern was the perceived lack of public information about the new genetics. People felt they did not know enough about this new biotechnology in order to make informed choices: this concern may prove difficult to address. One of the problems with genetic testing is its complexity. Genetic test results are often conveyed in terms of a risk percentage, something people find difficult to comprehend in real terms (Evans, Blair, Greenhalgh, Hopwood, Howell 1994). Another difficulty is that genetic practices are changing so rapidly. Even experts have different opinions regarding the meaning of genetic risk assessments (Schneider et al. 1997). Likewise the consensus on exactly what information the public needs to know is still being decided, with the goal posts constantly moving and changing (Human Genome Commission 2000).

Another main issue of control, for the overwhelming majority of respondents in the sample, was the possibility of discrimination. Many examples of discrimination were made, with HIV testing offered as a comparison. Generally concerns were centred on being discriminated against by insurance companies and employers, with a lack of faith expressed in the confidentiality of genetic information. This concern is firmly based in reality and again may prove difficult to address. The Association of British Insurers originally promised that people would not be asked to undergo genetic testing before receiving insurance, but this position is already being revised. The issue of confidentiality is equally complex. By its very nature genetic testing is about ‘family’ diseases. The Nuffield Council on Bioethics states that an individual with a genetic disorder has a
responsibility to inform other family members, and if they cannot be persuaded to do so, rights to confidentiality may be denied (see Petersen 1998).

Attached to the possibility of discrimination was the concern that genetic testing could 'get out of control'. Most respondents were happy with the idea of genetically testing children for serious health problems, but there appeared to be boundaries which science should not cross. Research by Urban (1996) using structural equation modelling techniques to analyse beliefs surrounding the new genetics, suggests that attitudes can be classified according to the constructs of 'genetic modifications' versus 'genetic testing', and 'child-related' versus 'adult related' issues. Findings from our study partly support this. Genetic testing applied to curing or preventing serious health conditions was viewed positively, whilst any form of 'unnecessary' genetic modification in regard to streamlining the human race was denounced. This fear is not surprising when considering the state-initiated eugenics programs in the recent past, in both the USA and Nazi Germany (Petersen 1998). Likewise the media has overwhelmingly focused on this issue, in its reporting of genetic biotechnology (see Milewa 1999; for review). Apparently the impact of this reporting has filtered down, with research into the public's opinion of this new technology demonstrating that issues such as eugenics and cloning are primary concerns (Durant et al. 1996; Jallinoja et al. 1998; Wellcome 1998).

Examples of unacceptable genetic applications were given, such as altering a child's eye colour or aborting on the grounds of sexuality, although where unacceptable modification and acceptable health prevention measures met was left unclear. This boundary issue was raised in several of the groups (did people think preventing children being born with breast cancer was acceptable) but answers were not forthcoming. This confusion, between the unacceptable and worthwhile, is indicative of the dilemmas this biotechnology has created, for professionals and the lay public alike. Related to this concern about genetic 'tampering', the commercial exploitation of genetic testing was raised. It was felt that the money that could be made from this technology would contribute to genetic testing 'getting out of hand' and being taken 'too far'. People felt the money to be made from the research was both morally wrong and would result in a
lack of care. The debate appeared to be concerned with issues of power, in that our sample expressed that industry and science had too much power, and that new technological developments would increase this imbalance. This finding supports research by Frewer (1999) which found that the public is far more accepting of new technologies and their attached risks when the benefits are perceived to accrue to the public or the environment, rather than to industry.

The respondents expressed that governmental legislation was the best way to address their concerns and fears regarding the future of genetic technology. This need for safeguards at a governmental level indicates that genetic biotechnology and its control are primarily seen as the responsibility of the government, a finding again supported by research (see Frewer and Shepherd 1995). The respondents' perceptions of whether governmental safeguards would be provided and would be sufficient were again divided. Some respondents felt that they would not be protected and were pessimistic about controlling their future, other respondents felt that genetic testing would be accompanied by sufficient legislation and that they would be protected by law. In our sample, intentions towards testing appeared strongly influenced by this issue of perceived safety; if the respondent felt that genetic testing would be controlled then the procedure was seen as a more viable choice.

As discussed earlier, the perception of future safety may again be linked to individual differences in perceived self-efficacy - at a general level. General self-efficacy measures the individual's global belief in their own competence, and ability to control their lives (Sherer et al. 1982; Schwarzer and Jerusalem 1995). A high level of self-belief may allow the individual to believe they have the personal resources to exert control over any threat posed by the introduction of this new technology. Similarly, a high sense of general self-efficacy may allow the individual to feel in control of any situation, if genetic testing confirms high risk of a disease, the individual will perceive being able to tackle this. Again this suggestion is tentative, further research is needed before more conclusions about the role of general self-efficacy can be reached with any certainty. Within health psychology, this concept has been shown to act as a powerful cognitive resource in
coping with new and difficult health choices (Schwarzer 1994). Currently the use of
general self-efficacy, as a major predictor of coping with the stress associated with
illness, is growing (see Fournier, de Riddler, and Bensing 1999; Boer, Elving and Seydel
1998). However the impact of general self-efficacy on coping with genetic testing, or the
role of this construct in genetic testing decision-making is unknown, and awaits further
investigation.

4.6.1 Conclusions and future directions
The aim of the research was to uncover representations and factors influential in people’s
conceptualisation and contemplation of predictive genetic testing, describing the concepts
that shape their decision-making. The research suggests that individual perceptions of
genetic testing are divided. Firstly, people appear concerned with personal factors
regarding their risk of genetic diseases and their perceived control over possible
outcomes. Secondly, there is a wider societal concern regarding the control of genetic
testing decision-making, and dissemination of information that may result from this
procedure. The research does not directly address why some participants felt more in
control regarding these concerns than others, although the data suggests perceptions of
self-efficacy - the belief in one’s personal ability to perform specific behaviours in order
to achieve a set outcomes - may be influential. This proposal is tentative, the
representations, relationships and potential factors uncovered by the research, will now
be investigated in follow-up studies.
Chapter Five

Genetic Testing and the relationship between Specific and General Self-efficacy

5.1 Research Aims

The previous study used a focus group methodology to explore how general groups of people perceive predictive genetic testing. The aim was to elicit factors that influence how the public responds to the possibility of undertaking this procedure. From the data analysis two main areas of interest emerged. Firstly, the respondents’ conversations were concerned with personal family related issues, such as experiences of illness and the benefits or disadvantages attached to having predictive testing information. Secondly, discussions appeared to be concerned with the actual process of testing and the wider social implications attached to this new health choice. In discussing these processes there appeared to be a distrust of ‘science’ and new technologies, with perceptions of control pivotal to the perceived merits of genetic testing.

The control of genetic testing decision-making appeared to be a salient concern. Many participants felt that predictive genetic testing would become compulsory, with some participants expressing that free choice in this matter was already an illusion. However not all the participants expressed this view, some participants felt confident and optimistic about their ability to control their future destiny. The focus group study did not directly address possible reasons behind this difference in perception, although the verbal data elicited suggested that perceptions of self-efficacy - the belief in one’s personal ability to perform specific behaviours in order to achieve a set outcome - were influential. Individuals high in self-efficacy, regarding genetic testing decision-making, may perceive genetic testing as a positive way of taking more control over their health and future life. Individuals low in self-efficacy may find genetic testing detrimental, with the lack of perceived ability to action outcomes resulting in feelings of powerlessness and fatalism. Perceptions of control may also be linked to individual differences in perceived self-
efficacy at a general level. A high level of self-belief may allow the individual to believe they have the personal resources to exert control over any threat posed by the introduction of this new technology. Similarly, a high sense of general self-efficacy may allow the individual to feel in control of any situation - if genetic testing confirms high risk of a disease, the individual will perceive being able to tackle this.

It was decided to further investigate the impact of general self-efficacy on coping with genetic testing decision-making, and to try to unravel the relationship between self-efficacy at a specific and general level by examining the effect of being given or denied the choice of undertaking a predictive genetic test for a common illness. In order to do this we first need to determine whether people's perceived self-efficacy over the decision to undergo genetic testing (specific self-efficacy) could be experimentally manipulated - via an alleged media statement. Psychological research examining the public's attitude towards, and interest in, genetic technology suggests that people are influenced by the information they receive (Wroe and Salkovskis 1999), and that this information has led to a perceived lack of personal and public control in this area (Milewa 1999). The public appears to be distrustful of the government's ability to control genetic testing developments, and people are concerned about the possible loss of personal autonomy resulting from a lack of regulation over these discoveries. This is most clearly illustrated in a survey by Jallinoja et al. (1998) which reported that only 5% of respondents felt fully confident in their ability to control the decision whether or not to undergo genetic testing.

Psychological research, exploring individual factors associated with the intention to undergo genetic testing, further suggests that the desire for maintaining control is a strong personal motivator. A study by Tambor, Rimer and Strigo (1997) examined factors associated with awareness and interest in genetic testing for breast cancer, amongst 473 of women of average risk of the disease within the general population. They asked women whether they would be interested in genetic testing to discover if they carried the breast cancer gene. Women who stated that regular mammograms gave them a sense of control over their health were more likely to say they were interested in being tested.
Although, as stated, the first task was to attempt to manipulate perceived control over testing, the focus of the research was to unravel the relationship between health specific and general self-efficacy. Research suggests that changes in domain specific areas of efficacy can have a wider impact and generalise across a broad range of thoughts and feelings (Bandura, Adams, Hardy and Howells 1980; Smith 1989; Williams, Kinney and Falbo 1989). The study aimed to investigate whether a reduction in self-efficacy over genetic testing-decision making (will be referred to as specific efficacy henceforth) would transfer to affect other areas of personal agency, as measured by changes in general self-efficacy. Investigating whether and also how testing decisions impact on perceptions of control furthers our understanding of the impact of these health decisions, and provides a useful starting point in understanding why some people may decide not to utilise predictive genetic testing in the future.

As debated in the introduction, psychological research has shown that specific efficacy can generalise from one domain to another, although the relationship between self-efficacy at a specific and more global level appears complex. Bandura suggests the perceived importance of efficacy may be influential (Bandura 1995), but research has yet to confirm or refute this theory. The research set out to determine the answer to this question in two different ways. Firstly, the study investigated whether the perceived importance of specific self-efficacy affects the perceived impact of the experimental manipulation (a media report) - as measured by a change in specific efficacy. Secondly, the study examined whether the perceived importance of general efficacy moderates the process of efficacy transfer, as measured by a change in general self-efficacy. Specifically we examined whether decreased levels of testing efficacy would transfer to impact on general efficacy, when general efficacy was highly important. Leading from these two questions a further issue emerged - whether levels of general efficacy could also act to moderate the process of efficacy generalisation. In the Stacey, Sussmen, Dent, Burton and Flay (1992) study cited earlier, a strong sense of efficacy was found to buffer against potentially harmful influences, raising the question of whether individuals high in general efficacy are better able to cope with any dilemma or threat posed by a lack of control over genetic testing decision-making. If levels of general efficacy do moderate
generalisation, then a person with high general efficacy will not experience any reduction in their perceived competence, when an area of specific efficacy is reduced.

5.2 Research hypotheses

We hypothesised that the effect of the experimental manipulation would be moderated by the level of importance placed on specific efficacy, so the experimental interventions would have little impact if efficacy over testing decisions were unimportant. However when specific efficacy was important a threat to this area of control (via the experimental manipulation) would significantly lower this efficacy domain. Similarly an enhancement to this control would significantly increase specific efficacy. We predicted that these changes to specific efficacy would generalise and impact on other areas of control, as measured by a change in the level of general efficacy.

Again we hypothesised that the process of efficacy generalisation would be moderated by the level of importance placed on general efficacy, and by the level of general efficacy itself. High levels of general efficacy would buffer any threat (our experimental manipulation) so a reduction in specific efficacy (over testing) would not reduce levels of general efficacy. General efficacy would only be lowered (by the threatening experimental manipulation) if existing levels of general efficacy were low and additionally if general efficacy was important. According to this rationale, in the case of an enhancement to efficacy, general efficacy would be universally increased - as the initial level of efficacy would be immaterial.

In summary when specific efficacy was important -

- *The threat would produce significant decreases in specific efficacy, and would generalise to produce*

- *Significant decreases in general self-efficacy (when the level of general self-efficacy was low and general efficacy was considered important).*
• The enhancement would produce significant increases in specific efficacy and would generalise to produce

• Significant increases in general self-efficacy – regardless of the level or importance.

The study’s success clearly relied on the participants’ response to the experimental manipulation, so the study design included a short questionnaire to directly measure this. In line with our earlier hypotheses, if the manipulations were successful they would have more impact when specific efficacy was important. We also predicted that the threatening manipulation would have less impact when levels of general efficacy were high, again because of the buffer effect discussed earlier.

In summary when specific efficacy was important -

• The threatening and enhancing intervention would have a significantly greater impact and

• The threatening intervention would have significantly less impact when the level of general self-efficacy was high.

5.3 Method - Pilot study

5.3.1 Aims
In order to generate valid and reliable scales for use in the main study the measures detailed below were piloted.

5.3.2 Sample
The pilot sample consisted of one hundred and twenty-three first year undergraduate psychology students at the University of Surrey. The mean age was 19, the median age
18, with ages ranging from 18 to 39. Eighty nine of the students were women and eleven were men.

5.3.3 Procedure
Participants were given an information sheet (see Appendix X) then asked to complete the pilot questionnaire (see Appendix XI). One hundred students successfully completed the questionnaire.

5.3.4 Measures
In order to test the research hypotheses scales were needed to measure:

- Genetic testing (specific) self-efficacy
- The importance of genetic-testing (specific) efficacy
- General self-efficacy
- The importance of general self-efficacy

Scales for measuring self-efficacy over genetic testing decisions, and the associated importance of this domain plus the importance of general efficacy, were not available, so they were developed by the author. The specific efficacy measure aimed to ascertain whether the participants believed they had control over decision to undergo genetic testing and consisted of 10 questions, answered on a five-point Likert scale (Appendix XI). For example, question 1 asks the participant to agree or disagree with the statement “I have complete control over the decision to undergo genetic testing”. The importance of specific efficacy mirrored the earlier scale and aimed to ascertain whether the participants felt it was important to have control over genetic testing decisions. Again it consisted of 10 questions answered on a five-point Likert scale (Appendix XI). For example question, 1 asks the participant to rate the importance of the statement “It is important to think of myself as a person who has complete control over the decision to undergo genetic testing”. The scale measuring general self-efficacy was Schwarzer and Jerusalem’s (1995) General Efficacy Scale. The scale has 10 items and a 4-point response, ranging from “not at all true” to “exactly true.” The importance of general self-efficacy mirrored this scale but asked the participants how important general self-efficacy was to them,
with again 10 items, and a five-point Likert response scale (see Appendix XI). For example question 1 asks the participant to rate the importance of the statement “It is important to think of myself as a person who can always manage to solve difficult problems if they try hard enough”.

5.3.5 Analysis
From the data, histograms were prepared for each scale with normal distribution curves superimposed. Skewness and kurtosis measures were calculated, (using SPSS frequencies). Testing efficacy scores were normally distributed (skewness divided by std. error of skewness = 0.87, kurtosis divided by std. of kurtosis = -0.27) as were scores measuring the importance of this domain (skewness divided by std. error of skewness = 0.13, kurtosis divided by std. of kurtosis = -0.78). General efficacy scores were slightly positively skewed (skewness divided by std. error of skewness = 1.82) but not peaky (kurtosis divided by std. of kurtosis = -0.02), with scores measuring the importance of this domain normally distributed (skewness divided by std. error of skewness = -0.86, kurtosis divided by std. of kurtosis = 0.14).

A principal components factor analysis with non-orthogonal oblique rotation was then performed (using SPSS) to examine the factor structure of new specific-efficacy scales. Scree plots were generated (see figure 6 below).

1. Specific self-efficacy
2. Imp. of Specific self-efficacy

Figure 6. Scree plots – pilot data
The scree plot produced for the specific-efficacy scale suggests the presence of two factors. The computer generated analysis (SPSS) reported factor I as explaining 30.96% of the variance, with factor II explaining 16.64% of the variance, with 47.61% of the total variance explained (for eigen values over 1). Factor I is made up from questions 1, 2, 3, 7, and 10. Factor II contains questions 4, 5, 6, and 9. Question 8 appears to load on both factors similarly, although slightly higher on factor I (see table 1 below).

Table 1. Pilot Study - Pattern matrix of structural coefficients – Two-factor solution specific efficacy

<table>
<thead>
<tr>
<th>Question</th>
<th>Factor I</th>
<th>Factor II</th>
</tr>
</thead>
<tbody>
<tr>
<td>Question 1</td>
<td>-.713</td>
<td></td>
</tr>
<tr>
<td>Question 2</td>
<td>.481</td>
<td></td>
</tr>
<tr>
<td>Question 3</td>
<td>.766</td>
<td></td>
</tr>
<tr>
<td>Question 4</td>
<td></td>
<td>.762</td>
</tr>
<tr>
<td>Question 5</td>
<td></td>
<td>.709</td>
</tr>
<tr>
<td>*Question 6</td>
<td>.323</td>
<td>.500</td>
</tr>
<tr>
<td>Question 7</td>
<td>.686</td>
<td></td>
</tr>
<tr>
<td>*Question 8</td>
<td>-.382</td>
<td>-.330</td>
</tr>
<tr>
<td>*Question 9</td>
<td>-.422</td>
<td>.722</td>
</tr>
<tr>
<td>*Question 10</td>
<td>-.512</td>
<td>-.394</td>
</tr>
</tbody>
</table>

*A lack of simple structure is indicated.

*Absolute values less than 0.3 suppressed. Rotation Method: Oblimin with Kaiser Normalization. Rotation converged in 14 iterations.

On examining the item content of the scale the two-factor solution makes theoretical sense. Questions 1, 2, 3, 7, and 10 are concerned whether the individual believes they
have control of the decision to undergo testing. Questions 4, 5, 6, and 9 are concerned with the personal difficulties an individual might perceive in controlling and coping with the decision to undertake testing. Question 8 is concerned with the individual’s perceived choice to receive testing, and appears to incorporate both perceived control over testing and possible personal difficulties in enacting this choice. The two factors correlate by 0.207. This suggests that the two concepts are moderately associated, with both factors measuring different elements of efficacy.

A reliability analysis was performed on each factor (after questions 1, 8, and 10 were re-coded so all items scored positively). Factor I had an alpha of 0.67 (0.55 if question 8 were excluded). Factor II had an alpha of .66 (regardless of inclusion or deletion of question 8). The scale had an overall alpha of 0.70. Factor I has an unacceptable alpha if question 8 is deleted, so it was decided to leave is question in the scale and review its presence after the main data collection. The results compare reasonably favourably with the alpha value of 0.6 recommended by Nunnally (1978) when using psychometric scales for basic research purposes, so it was decided to leave the questionnaire unchanged for use in the main study.

The last scree plot resulting from the analysis was for the importance of specific efficacy. Again the scree plot strongly indicates the presence of a single factor, with the analysis indicating that a single factor explains 55.76% of the total variance. These results suggest the scale is uni-dimensional in measuring only one construct. A reliability analysis was performed, with the scale scoring an alpha reliability coefficient of 0.91. These results suggest that the scale is highly reliable and is measuring a single concept, so it was decided to leave the questionnaire unchanged for use in the main study. The General Self-efficacy scale had an alpha reliability coefficient of 0.85, and the importance of general efficacy measure had an impressive alpha of 0.91.

Correlations between the scales were obtained. If, as argued, general mastery experiences generalise to other areas of behaviour, the scales should correlate moderately (see Becker et al. 1993). If general efficacy is highly important to a person, it is likely that the
The individual would work to keep their levels of general efficacy high. The results support this suggestion, with general efficacy and the importance of this construct correlating $r = 0.40$ ($P < 0.01$). Using the same argument, testing efficacy and its associated importance should also moderately correlate, and again the results support this ($r = 0.38$ $P < 0.01$ level). The two importance measures correlated $r = 0.52$ ($P < 0.01$ level), suggesting that the value of efficacy is universal, regardless of the domain. Levels of general efficacy and specific efficacy did not correlate ($r = 0.03$ n.s.), suggesting that, unlike psychological measures of importance, levels of specific and general efficacy vary widely.

5.3.6 Textual Messages

The media interventions aimed at enhancing or threatening efficacy over testing were piloted for their effectiveness. Twenty participants from an opportunity sample were asked to read one of the two media statements (see Appendix XII and XIII). The participants were then asked one of three questions:

1. ‘Are you satisfied with the amount of personal control you have over the decision to undergo genetic testing?’

Of the ten participants given the efficacy threatening media report: 6 felt partly dissatisfied, 3 participants felt completely dissatisfied, 1 participant felt neither satisfied nor dissatisfied. In contrast the ten participants given the efficacy enhancing report replied that: 1 participant felt partly dissatisfied, 4 participants felt partly satisfied, 5 participants completely satisfied.

2. ‘Did the statement make you feel that decisions regarding your health were being taken out of your control?’

Those participants receiving the threatening report replied that: 7 partly agreed, 1 participant completely agreed, 2 participants neither agreed nor disagreed. Those participants receiving the enhancing report responded that: 2 participants completely agreed, 5 participants partly disagreed and 3 completely disagreed.
3. 'Did the statement make you feel empowered, in being able to choose to do something active to improve your health?'

Those who had received the threatening report responded that: 1 participant completely agreed, 8 participants partly disagreed and 1 participant completely disagreed. Those who had received the enhancing report responded that: 8 participants completely agreed, 2 participants partly agreed.

These results indicate that the textual messages are effective, in serving to threaten or enhance efficacy over testing. The majority of respondents given the threatening report felt dissatisfied with the amount of personal control they had over the decision to undergo testing, whilst the majority of respondents who were given the efficacy enhancing report felt satisfied with the amount of control suggested by the intervention.

5.4. Method - Main study

5.4.1 Design
The study used a repeated measure 3 x 2 mixed design. All participants were randomly assigned to one of three experimental conditions. Efficacy scales in the form of a single questionnaire were then administered at two separate time intervals – before and after administration of the experimental interventions.

5.4.2 Sample
Prior to sampling a power analysis was conducted. The analysis stated that 390 participants were required for the main study with 95% power, small effect sizes (0.2) and a 5% Alpha. Three hundred and thirty three participants were eventually recruited for the main study, with 300 responses used in the final analysis. On examination 33 responses were spoiled because of partial non-completion. With 300 participants power is reduced to 87%. The 87% power is not optimal, but was considered sufficient, because of practicalities of recruitment. The final study required that each participant give up 25
minutes of their time, with each measure requiring personal administration by the researcher.

All the participants were an opportunity sample recruited from the local community and included -

- The Rotary Club (n = 39)
- The Berrylands Women's Group (n = 9)
- Kingston College of Higher Education ('A' Level students and mature students attending adult education classes) (n = 114)
- Midhurst Parish Church Group (n = 27)
- Post-graduate students attending a Management School (n = 55)
- Health centre administration workers (n = 14)
- Retail workers in a clothing store (n = 10)
- Executives and professionals (HM treasury, Visa International, The Children's Society, FaulknerBrowns Architects) (n = 45)
- Miscellaneous (personal acquaintances) (n = 7)

Given that the experimental manipulations concerned the availability of predictive genetic testing for heart disease, participants with a history of heart disease were excluded from the study on ethical grounds.

Of the 300 responses used, 141 were from men and 159 from women. The mean age was 32; the median age was 26, with ages ranging from 16 to 80. The majority of participants were single (68%), and had some form of higher education. Only 35 participants had received no higher education after age 16. The largest occupation was being in full time education (47%) with managers (6%), professionals (10%), administrators (12%), secretarial workers (10%) and sales staff (7%) making up the majority of other occupations (plus another of 8% of mixed occupations). Occupations were categorised in line with the Office of Population Census and Surveys (1990) standard occupational classification. Only four participants had actually undergone genetic testing (1.3%).
5.4.3 Procedure

A repeated measures design was used. Each participant was given an information sheet (Appendix XIV). The efficacy scales were then personally administered by the researcher in the form of a single questionnaire (Appendix XV). A short five-minute distraction task was then given to counteract carry-over effects (Appendix XVI). The experimental manipulation was then administered by the researcher in the form of a media report (Appendix XII and XIII). A media report aimed at threatening efficacy over testing was given to one third of participants; an efficacy-enhancing media report was given to the second third, with no information given to the last third - the control group. The media intervention was given out in a sequential order to avoid uneven distribution between the different samples of people taking part. The media report concerned the availability of predictive genetic testing for heart disease. In the threatening report (Appendix XII) it was stated that genetic testing for heart disease was available, urging people to attend, and suggesting non-attendance would risk increased insurance premiums, and poorer health care. The enhancing report (Appendix XIII) gave the same information, but stressed individual choice and the promotion of active health care. A three-item questionnaire followed, asking participants whether they felt the report took away their control, actively allowed them to improve their health, or had no affect on them (Appendix XVII). The participants were also invited to comment on the media statement they had read. The four efficacy scales were then re-administered (to all three groups), to measure the effect of the media statements on self-efficacy. On completion of participation all the respondents were personally debriefed by the researcher, and given a written statement confirming that genetic testing for conditions which increased susceptibility to heart disease, although feasible, were not yet widely available, and that the press report they had read was fictional (Appendix XVIII and Appendix XIX). Participation took approximately 25 minutes. For a summary of the running order see below:-

Order of administrative procedure

1. Information sheet
2. Pre-intervention efficacy questionnaire
• Genetic testing (specific) self-efficacy scale
• The importance of genetic-testing (specific) efficacy scale
• General self-efficacy scale
• The importance of general self-efficacy scale

3. Distraction task
4. Media statement – (not the control group)
   • Threatening intervention
   • Enhancing intervention
5. Media statement questionnaire – (not the control group)
6. Post-intervention efficacy questionnaire (scales as in 2. above)
7. Debriefing statement (not the control group)

5.4.4 Measures
After data analysis of the main study, the specific efficacy scale (and the associated importance measure) was shortened (see below). The specific efficacy scale now consists of 3 questions (numbers 1, 8 and 10) and investigates belief in the ability to control, and respond to the decision of whether or not to undertake genetic testing (Appendix XV). The items were answered on a 5-point scale varying from “completely disagree” to “completely agree”. The scale measuring the importance of testing efficacy mirrors this first scale (Appendix XV). The importance items were also answered on a 5-point scale varying from “of total importance” to “not at all important”. The scale measuring the importance of general efficacy remains unchanged from the pilot and is based on Schwarzer and Jerusalem’s (1995) General Efficacy Scale, but addresses the importance of general efficacy. The Schwarzer and Jerusalem scale has 10 items, and a 4-point response, ranging from “not at all true” to “exactly true.”

5.5 Results

5.5.1 Initial data analysis
Before the main analysis, frequencies were computed to check for inputting errors, odd numbers and ceiling effects. SPSS explore was then used to test for univariate normality.
For each of the four scales - 5% trimmed means, Kolmogorov-Smirnov statistic, normal Q-Q plots, detrended normal Q-Q plots, boxplots, histograms and skew and kurtosis were computed to check for score distribution. The specific efficacy scale was negatively skewed and slightly flat (skewness divided by std. error of skewness = -4.06, kurtosis divided by std. of kurtosis = -1.65). The associated importance measure was also negatively skewed and peaky (skewness divided by std. error of skewness = -6.01, kurtosis divided by std. of kurtosis = 4.53). The general efficacy scale was positively skewed (skewness divided by std. error of skewness = 2.83) and extremely peaky (kurtosis divided by std. of kurtosis = -20.02), with the associated importance measure negatively skewed (skewness divided by std. error of skewness = -5.45, and again peaky (kurtosis divided by std. of kurtosis = 6.74). When the sample is large, standard errors become quite small and trivial deviations from zero become significant. Because none of the histograms suggested bi-modal distribution, and large samples sizes are more robust to lack of normality it was decided not to transform the data for normality. Moreover, because scores on the scales were meaningful, transforming the data would make interpretation of the results difficult (Tabachnick and Fidell, 1996, p.82). Mahalanobis distance was computed to check for multivariate outliers and scatterplots were computed to check for linearity. Extreme outliers (n=2) were not included in the data set, as the researcher felt the questionnaires had not been answered honestly and carefully. Questionnaires with missing data were excluded from further analysis (n=18).

Principal components analysis with Oblimin rotation was computed for both the pre and post-intervention data (using SPSS) for the new specific efficacy scale and the associated importance measure. The results of the factor analysis for the ten-item testing specific efficacy scale appeared problematic with the analysis producing a three-factor solution for the pre-intervention scores and a two-factor solution for the post intervention scores (with eigen values exceeding 1). Item 6 of the scale was particularly problematic, loading equally well across two factors. See table 2 below.
Table 2. Main Study - Pattern matrix of structural coefficients – Two-factor solution

Specific Efficacy

<table>
<thead>
<tr>
<th>Pre-intervention</th>
<th>Factor</th>
<th>Post-intervention</th>
<th>Factor</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>I</td>
<td>II</td>
<td>I</td>
</tr>
<tr>
<td>Question 1</td>
<td>.785</td>
<td>Question 1</td>
<td>.776</td>
</tr>
<tr>
<td>Question 2</td>
<td>.794</td>
<td>Question 2</td>
<td>.532</td>
</tr>
<tr>
<td>Question 3</td>
<td>.771</td>
<td>Question 3</td>
<td>.583</td>
</tr>
<tr>
<td>Question 4</td>
<td>.671</td>
<td>Question 4</td>
<td>.648</td>
</tr>
<tr>
<td>Question 5</td>
<td>.811</td>
<td>Question 5</td>
<td>.776</td>
</tr>
<tr>
<td>*Question 6</td>
<td>.416</td>
<td>*Question 6</td>
<td>.700</td>
</tr>
<tr>
<td>Question 7</td>
<td>.508</td>
<td>Question 7</td>
<td>.548</td>
</tr>
<tr>
<td>Question 8</td>
<td>.470</td>
<td>Question 8</td>
<td>.861</td>
</tr>
<tr>
<td>Question 9</td>
<td>.868</td>
<td>Question 9</td>
<td>.693</td>
</tr>
<tr>
<td>Question 10</td>
<td>.830</td>
<td>Question 10</td>
<td>.816</td>
</tr>
</tbody>
</table>

Rotation Method: Oblimin with Kaiser Normalization. Rotation converged in 7 iterations.

Correlations between factors I and III for the pre-intervention data were 0.31, indicating a strong association. For the post intervention, factor I and II were correlated 0.35, indicating that the two factors were partially measuring the same construct.

Reliability alphas were computed. For the pre-intervention factor I had an alpha of 0.61, factor II had an alpha of 0.79, whilst factor III had an alpha of 0.65. The alpha for factor I and III were considered unacceptably low. Moreover the factors were closely linked, deeming the differentiation of different factors questionable. On closer examination of the scale the researchers decided only items in factor II (item no. 1, 8 and 10) were measuring self-efficacy over genetic testing decisions. The questions in factor II are directly concerned with personal control over the decision to undergo testing. The other two factors (difficulty in making the decision to undergo testing and outside influences...
controlling the decision to undergo testing) were considered to be tapping into other constructs and were deleted from further data analysis.

The specific efficacy scale now had one factor. In the pre-intervention the single factor accounted for 69.10% of the variance, in the post-intervention the single factor accounted for 72% of variance (for eigen values over 1). The associated importance scale mirrors the specific efficacy scale, so the scale needed to be shortened in a likewise fashion - to include only questions 1, 8 and 10. The importance scale had one factor with the pre-intervention data accounting for 69.25% of the variance and the post-intervention data accounting for 74.84% of variance (for eigenvalues over 1). To determine the internal consistency of the scales a reliability analysis was conducted (using SPSS) and Cronbach’s Alpha coefficients were computed. The shorter specific efficacy scale now had an alpha of 0.77, with the associated importance scale having an alpha of 0.77. The General Efficacy Scale had an alpha of 0.79. The scale measuring the importance of general efficacy had an alpha of 0.92.

5.5.2 Main data analysis
Before testing our main hypothesis we needed to ascertain whether people’s perceived self-efficacy over the decision to undergo genetic testing (specific self-efficacy) could be experimentally manipulated – via an alleged media statement. In order to achieve this independent samples t-tests were computed for each of the three questions used to directly access the impact of the media reports. See table 3 below-
Table 3. Independent samples t-test – media report questions

<table>
<thead>
<tr>
<th>Question</th>
<th>Perceived threat</th>
<th>Threatening condition</th>
<th>Enhancement condition</th>
<th>Mean</th>
<th>t</th>
<th>Sig.2 tailed P &lt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Question 1</td>
<td>Perceived threat</td>
<td>Threatening condition</td>
<td>1.97</td>
<td>-11.03</td>
<td>.000</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Enhancement condition</td>
<td>3.32</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Question 2</td>
<td>Perceived efficacy</td>
<td>Threatening condition</td>
<td>2.25</td>
<td>4.338</td>
<td>.000</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Enhancement condition</td>
<td>1.71</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Question 3</td>
<td>Strength of feeling</td>
<td>Threatening condition</td>
<td>3.00</td>
<td>2.772</td>
<td>.009</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Enhancement condition</td>
<td>2.60</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: Response range 1- 4. Question 1. 1 = no control, 4 = control. Question 2. 1 = active, 4 = not active. Question 3. 1 = no effect, 4 = effect.

As shown, the two experimental conditions were highly effective in producing significantly different responses to the media reports.

We then tested the main hypothesis using repeated measures, mixed ANOVAs. Before the computation of these tests both of the associated importance measures (total scores for the pre and post-questionnaires) were transformed into four low and high dichotomous variables. New variables were also computed to transform General Efficacy (total scores for pre and post-questionnaires) into two low and high dichotomous variables. The new variables were divided around the median, with 1 assigned for a low score and 2 for a high score.

To test the first hypothesis - when specific efficacy (over testing decisions) was important a threat to this control (via the experimental manipulation) would
1) Significantly lower self-efficacy and similarly and
2) An enhancement to this control would significantly increase efficacy - a 2 x 3 x 2 ANOVA was performed.
The within subjects factors (DVs) were specific efficacy at time 1 and 2. The between subjects factors (IVs) were the three experimental conditions, and low or high levels of associated importance.

A significant interaction was produced for specific efficacy (before versus after the intervention), and the experimental condition, \( (F(2, 294) = 11.86, p \sim .0) \), with a medium effect size produced \( (\eta^2 = .08) \), (see Cohen, 1988). The threatening intervention resulted in a significant decrease in specific efficacy, likewise the enhancement intervention resulted in a significant increase in efficacy \( (t(98) = 2.87, p < .005 \) and \( t(99) = -2.62, p < .01 \), respectively, using a Bonferroni adjusted alpha of .02). See Table 4 for means and standard deviations.

Table 4. Means and standard deviations – Specific-efficacy scores

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Time 1 (pre)</th>
<th>Time 2 (post)</th>
<th>t</th>
<th>df</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>Threat</td>
<td>13.42</td>
<td>1.57</td>
<td>13.02</td>
<td>1.40</td>
</tr>
<tr>
<td>Control group</td>
<td>13.31</td>
<td>1.65</td>
<td>13.16</td>
<td>1.73</td>
</tr>
</tbody>
</table>

*** \( p < .005 \)  ** \( p < .01 \)

No significant interaction was produced for time (before versus after the intervention), the experimental conditions, and the importance of specific efficacy \( (F(2, 294) = 2.91, \) n.s). We further analysed participants’ responses to the interventions. Only participants who felt specific efficacy was highly important, and who had received the threatening intervention, had a significant change in efficacy score \( (t(36) = 3.98, p \sim .0, \) with a Bonferroni adjusted alpha of .008), see figure 7.
Figure 7. Specific-efficacy - scores of participants who felt efficacy in this domain was of either high or low importance.

In line with our prediction those participants who felt specific efficacy was of low importance did not experience a significant change in efficacy (see figure 7). See Table 5, for means and standard deviations.
Table 5 Means and standard deviations – Specific efficacy scores - divided by whether participants felt efficacy in this domain was of low or high importance

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Time 1 (pre)</th>
<th>Time 2 (post)</th>
<th>t</th>
<th>df</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>Threat</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low importance</td>
<td>12.98</td>
<td>1.54</td>
<td>12.84</td>
<td>1.39</td>
</tr>
<tr>
<td>High importance</td>
<td>14.16</td>
<td>1.32</td>
<td>13.32</td>
<td>1.38</td>
</tr>
<tr>
<td>Enhancement</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low importance</td>
<td>12.98</td>
<td>1.28</td>
<td>13.40</td>
<td>1.49</td>
</tr>
<tr>
<td>High importance</td>
<td>13.95</td>
<td>1.28</td>
<td>14.28</td>
<td>1.09</td>
</tr>
<tr>
<td>Control group</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low importance</td>
<td>12.52</td>
<td>1.52</td>
<td>12.31</td>
<td>1.57</td>
</tr>
<tr>
<td>High importance</td>
<td>14.37</td>
<td>1.16</td>
<td>14.30</td>
<td>1.21</td>
</tr>
</tbody>
</table>

* p ~ .0

The results indicate that the level of importance placed on efficacy did determine the impact of the experimental manipulation, with this impact being greater when specific efficacy was threatened rather than enhanced.

To test the second hypothesis - general efficacy would only be lowered (by the threatening experimental manipulation) if
1) existing levels of general efficacy were low and
2) if general efficacy was important
- a 2 x 3 x 2 x 2 ANOVA was performed. The within subjects factors (DVs) were general efficacy time 1 and 2. The between subjects (IVs) factors were the three experimental conditions and low or high levels of importance of general self-efficacy and low or high levels of general self-efficacy. A significant interaction was produced for general efficacy (time 1 and 2) by the experimental conditions, \( F (2, 8.79) = 4.08, p ~ .0 \) with a medium effect size \( \eta^2 = .06 \). As expected both the threat and the enhancement interventions
resulted in significant decreases and increases in perceptions of general self-efficacy, ($t$ (98) = 3.56, $p < .001$ and $t$ (99) = -3.99, $p ~ .0$ respectively, using an adjusted alpha of .02), with the control group having no significant differences in mean score across time, see Figure 8, and Table 6, for means and standard deviations.

![Figure 8. General Efficacy Scores](image)

**Table 6. Means and standard deviations - General Efficacy Scores**

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Time 1 (pre)</th>
<th>Time 2 (post)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>Threat</td>
<td>29.69</td>
<td>5.22</td>
</tr>
<tr>
<td>Enhancement</td>
<td>29.97</td>
<td>5.21</td>
</tr>
<tr>
<td>Control group</td>
<td>31.09</td>
<td>5.12</td>
</tr>
</tbody>
</table>

**$** p ~ .0 $ * p < .001
In further support of the second hypothesis a significant interaction was produced for general efficacy (time 1 and 2) by the experimental conditions ($F (2, 276) = 4.08, p < .01$), with a small effect size produced ($\eta^2 = .03$). For participants receiving the threatening intervention efficacy was significantly reduced but only in those participants with initially low levels of general efficacy ($t (50) = 2.90, p < .006$). Somewhat surprisingly participants given the enhancement condition and those in the control group with initially low levels of general efficacy, also experienced increased general efficacy at time 2 ($t (51) = -3.25, p < .002$ and $t (48) = -2.76, p < .008$, respectively, using an alpha level of .008). Notably no interaction was found for levels of general efficacy (time 1 and 2), by the experimental conditions and the importance of general self-efficacy. See table 7 for means and standard deviations.

Table 7. Means and standard deviations - General Efficacy - divided by whether participants had initially low or high levels of general efficacy

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Time 1 (pre)</th>
<th>Time 2 (post)</th>
<th>t</th>
<th>df</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>Threat</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low efficacy</td>
<td>25.76</td>
<td>3.99</td>
<td>24.76</td>
<td>5.18</td>
</tr>
<tr>
<td>High efficacy</td>
<td>33.85</td>
<td>2.33</td>
<td>33.27</td>
<td>2.57</td>
</tr>
<tr>
<td>Enhancement</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low efficacy</td>
<td>26.17</td>
<td>3.93</td>
<td>27.48</td>
<td>4.06</td>
</tr>
<tr>
<td>High efficacy</td>
<td>34.08</td>
<td>2.70</td>
<td>34.73</td>
<td>3.09</td>
</tr>
<tr>
<td>Control group</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low efficacy</td>
<td>27.78</td>
<td>2.80</td>
<td>28.41</td>
<td>3.32</td>
</tr>
<tr>
<td>High efficacy</td>
<td>34.21</td>
<td>4.85</td>
<td>33.04</td>
<td>2.71</td>
</tr>
</tbody>
</table>

*** $p < .002$  ** $p < .006$  * $p < .008$
Earlier t-tests conducted on the participants' direct response to the media reports (see table 3) demonstrated that the experimental interventions were effective in manipulating perceptions of control. To determine whether the responses to the media reports were greater when efficacy over testing was highly important, univariate ANOVA's were computed. The between-subjects factors were the experimental conditions and low or high levels of importance of testing-efficacy by the question number.

The results showed that the third hypothesis - if the manipulations were successful they would have most impact when specific efficacy was important - was not supported (Question 1. perceived threat F (1, 195) = .00, n.s; Question 2. perceived efficacy F (1, 195) = .23, n.s; Question 3. strength of feeling F (1, 195) = 1.64, n.s). The participant responses were significantly different across the experimental conditions regardless of the importance of self-efficacy. In addition we predicted that the threatening manipulation would have less impact when levels of general efficacy were high - because of the buffer effect discussed earlier. Univariate ANOVA's were again computed, the between factors being low or high levels of general efficacy by the question number. Again the results did not support our prediction (Question 1. perceived threat F (1, 197) = .3.07, n.s; Question 2. perceived efficacy F (1, 197) = .39, n.s; Question 3. strength of feeling F (1, 197) = .01, n.s). Levels of general efficacy did not affect responses to the media reports as measured by the intervention questionnaire.

5.5.3 Comments recorded from Message Questionnaire

To gain a detailed picture of how participants felt about the media report we invited written comments. Overall responses to the threatening report suggested the participants felt angry and worried. Responses to the efficacy enhancing report were less concerned and less frequent; suggesting the participants felt the choice offered was more reasonable – for some examples see below -
Examples of participant responses to the media report threatening efficacy

1. I feel that as it could save the NHS millions of pounds that they don’t have, genetic testing is very important for those with a history of heart disease.

2. Reading the statement made me realise two things – firstly by not being tested, this could lead to my future life being affected and I could even be left with a shorter time on this planet. Secondly if I don’t get tested on advice of my doctor, this could stop doctors from finding cures for new diseases etc. Scary!!!

3. Mixed feelings, it’s good, but out of my control.

4. Makes me realise the pressures to have the testing - may be taken out of our hands one day – and made compulsory. Deeper issues than I first realised were involved.

5. I think the statement was fair. If there is a way of testing which could save time, money and lives then it should be compulsory as those refusing to take it are not only affecting themselves.

6. I wonder about the practicalities of an aging population, that in the normal way things (as now) would die of these diseases.

7. I wondered exactly how the reduction in heart disease was expected to come about? Was it to be because of preventative treatment for those at risk? Or could it be taken one step further to prevent those at risk having children who could inherit the condition? I would strongly object to people being forced to have sterilization or abortion because of their own medical history.

8. The statement made me angry. There should be no compulsion to undergo testing. To suggest that treatment might be withheld from people who have not been tested is tantamount to blackmail.
9. I can see the importance of the test but, at the end, me and my family is my concern, and I like to have control over my own situation. Just like everything else, this is about saving money. His last comment, say no!

10. I think it is good to offer the testing but I totally disagree with the idea of making it compulsory.

11. In the event that genetic testing is made compulsory, what will stop government from taking it further to genetically modifying babies. This can be seen in the film Gattaca, as to how far genetic testing can go. I personally feel that one should not be forced to be genetically tested as it could keep them from jobs and healthcare. It could also reach a point where the society may consider certain diseased people as outcasts, i.e. Lepers.

12. Whilst I can see the benefits of tackling the causes of heart disease – I am concerned about other illnesses – Downs Syndrome for example and wonder where this is leading....

Examples of participant responses to the media report enhancing efficacy

1. It isn’t the fact that genetic information could be used for medical information, but for classification and other forms of social control.

2. I feel that the article is neutral and does not contain information that can cause moral panic – as many articles do.

3. Very interesting that a beautiful discovery has been made. Lots of research has gone into the project and it is good that a result has been produced. Good progress for families who suffer from diseases such as cystic fibrosis, to know that there medical care for them to lengthen their lives. Good to know that a new branch of medical care is available which is optional. Underline participants own
4. It makes genetic testing sound like a desirable thing to do.

5. The statement seemed fair and no extreme pressure was placed to have the testing.

6. The statement has confirmed my opinion that the choice of undergoing genetic testing is mine. But also I think it is commendable that this is made public.

7. It made me think that maybe people should be expected to get genetically tested for the greater good of humanity, but I believe at the end of the day it is very much an individual’s choice, which the statement reflects.

5.6 Discussion

The study set out to determine the extent to which perceived efficacy over genetic testing decision-making could be manipulated via different presentations of information. The research then examined whether a lack of efficacy in this domain would generalise to other areas of personal control, as measured by a decrease in general self-efficacy. The relationship between specific and general efficacy was examined with potential factors - the importance of efficacy and levels of general efficacy - influential in the process of generalisation explored.

The results showed that perceived efficacy over testing decision-making could be successfully manipulated with the use of alleged media reports. The results then indicated that changes to specific-efficacy did impact on levels of general self-efficacy. Participants had significantly lower general efficacy after reading the threatening report, and significantly higher general efficacy after reading the enhancing report, with no significant differences reported for the control group. The research hypothesised that the importance of efficacy was influential in the process of efficacy generalisation, as were initial levels of general efficacy. The study predicted that the threatening media interventions would impact of efficacy when levels of general efficacy were low and also
when general efficacy was highly important. If, as discussed, general efficacy gives the individual a strong sense of overall competence, then the threat would be controlled, if levels of efficacy were high. Results were mixed. Significantly both the threat and enhancement had more impact when levels of general efficacy were low, but this change occurred regardless of the importance of general efficacy, although the importance of efficacy did appear relevant at a domain specific level. Participants who felt efficacy over testing decisions was highly important had significantly lower specific-efficacy after reading the threatening media report.

In addition to the main hypotheses, the researchers administered a questionnaire, to gauge participant’s direct responses to the intervention. As already discussed the media reports significantly increased or decreased perceived self-efficacy, but this change occurred regardless of levels of importance, or levels of general efficacy. Due to the time-consuming nature of participation, the intervention questionnaire was kept short. The level of measurement used may not have been sensitive enough to compare perceived threat with perceived importance. Equally we asked the participants how they ‘felt’ reading the media report but this may not relate to importance. The participants may have felt the report was taking away their self-efficacy, even if efficacy was unimportant to them. The written comments participants made about the media reports also suggest that the two media messages may not have been perceived in qualitatively different ways. For example the responses to the efficacy-threatening media are more clearly concerned with a lack of perceived control over genetic testing decision-making. In contrast responses to the efficacy-enhancing report are favourable but do not indicate that that the media message was perceived as increasing perceived control over this area of decision-making (even if this was the end result).

Overall the results show mixed support for the concept of importance, as a factor in efficacy generalisation. Levels of importance did appear to determine the level of perceived threat to testing efficacy, but not the level of enhancement. This difference may be due to the threatening report having more impact than the enhancement, resulting in a stronger response yet this seems unlikely, because the enhancement did significantly
heighten specific-efficacy, just not in regard to importance. More likely perhaps is the suggestion that two different processes are involved. The importance or value of control may be relevant when a specific domain is threatened, not enhanced, then the question of whether an efficacy domain is of major or minor value may not matter. Moreover, efficacy over the decision to undergo genetic testing appeared important to most of our participants (when directly questioned), but in actuality this domain is a small part of most people’s lives (1.3% percent of our sample had undergone this procedure). If as shown, a small domain of efficacy can impact on feelings of general competence, the question raised is whether a domain that encompasses a broader area of life would have a larger effect, and vice versa. To fully answer this question research needs to measure the generalisation between specific and general efficacy, when the specific value of a domain varies more widely. The results also suggest that a measure of importance may be more useful for explaining changes in domain specific efficacy rather than general efficacy. As Bandura points out (1997, p.51) specific efficacy beliefs vary greatly in importance – with some areas personal efficacy more vital to one’s life than others. Our results suggest the same variation may not be present with general efficacy. The negatively skewed and peaky distribution of the general efficacy scores suggests that perceptions of general efficacy are universally important.

Bandura, (1997, p. 51) proposes that changes in specific efficacy generalise to other specific areas of efficacy, when there is shared or similar qualitative features. For example, mastery of a high-risk physical activity will generalise to types of physical stressors but not to mental tasks. Our findings suggest that these changes can have a wider impact, generalising beyond specific domains to affect the individuals overall sense of competence, although the psychological process by which this generalisation occurs is unclear and warrants further investigation. The methodology used obviously permits certain conclusions, but leaves other questions unanswered. A question that needs clarification is the role of high general efficacy. We hypothesised that an overall sense of competence would control the impact of any potential threat posed by genetic testing. The results found that both the threat and enhancement had more impact when levels of
general efficacy were low, suggesting high general efficacy acts as buffer, diluting the impact of any potential change.

5.6.1 **Conclusions and future directions**

Our results suggest that both the negative and positive effects of having to decide whether to take a genetic test are complex, with perceived efficacy having a central role in the decision-making process. The findings revealed that a lack of perceived efficacy over the decision to undertake testing can have wider implications for the health and well-being of society, in serving to lower general self-efficacy, and perhaps lower intention to undertake testing. The next stage of investigation will expand our understanding of efficacy processes, and directly test whether and how changes in both specific and general efficacy alter people’s intention to undergo testing.
Chapter Six

The intention to undertake genetic testing: The relationship between perceived risk, disease controllability and self-efficacy

6.1 Research Aims

The aim of this study was to investigate the second major theme to emerge from the earlier focus group study – people’s perceptions of genetic risk and their control over this risk. The data emerging from the initial study suggest these constructs have a pivotal role in shaping genetic-testing decision-making, although how these factors interact to influence genetic-testing intentions was unclear. This study set out to answer this question by determining how perceptions of disease risk and self-efficacy interact, and whether and how these constructs affect people’s intentions towards undertaking predictive genetic testing. The study also aimed to clarify issues raised in the last study by further investigating the relationship between health-specific and general self-efficacy.

Psychological research suggests that increased perceptions of risk can both increase and decrease testing intentions and screening behaviour (Cappelli et al. 1999; Lerman, Daly, Masny and Balshem 1994; Clavel-Chapelon, Joseph and Goulard 1999; Cappelli et al. 2001; Macrae et al. 1984; Lipkus, Biradavolu, Fenn, Keller and Rimer 2001). Research has also shown that high levels of self-efficacy can determine whether risk is translated into actual health behaviours (Rimal 2001), and that for individuals at high-risk of a disease control-related reasons can be associated with interest in genetic testing (Shiloh, Petel, Papa, and Goldman 1998). However the question of whether and how self-efficacy interacts with perceptions of risk, to change personal feelings of vulnerability and intentions towards genetic testing, has not been directly researched.

The current study examined this question by manipulating perceived control (the management of disease symptoms and genetic risk) over a common disease - arthritis. The study then investigated whether participants at high perceived risk of arthritis had
decreased self-efficacy after reading information stating that arthritis was uncontrollable and genetically inherited. Studies by Senior, Marteau and Peters (1999) and Senior, Marteau and Weinman (2000) have examined the impact of different types of information on perceived control over the symptoms of disease. When risk is attributed to genetic rather than lifestyle causes, the condition is seen as less preventable and threatening. Data from our earlier focus study further supports this view. When a disease was conceptualised by our participants as ‘genetic’, perceptions of self-efficacy appeared to decrease, alongside the intention to undergo testing. The conception of a disease as genetic appeared to engender a sense of helplessness and fatalism, “...because it’s no good telling a person that they have something in their gene and this and that, if you can’t do something after that to help them.”

Studies also suggest that being ‘genetically’ susceptible to a disease is a factor that contributes to the development of generalised beliefs about control and subsequent behaviour. Surprisingly research has shown that the perception of increased risk is often not associated with increased surveillance behaviours, or lifestyle changes aimed at lowering risk (Becker and Levine 1987; Clavel-Chapelon, Joseph and Goulard 1999), suggesting that people respond to high risk with a lack of self-efficacy. People may feel that if their DNA can’t be changed then they are powerless to help themselves, rendering genetic testing and other behavioural or medical interventions useless (Holtzman and Marteau 2000). Obviously these conclusions are tentative; it may not be a perception of high risk, but people’s beliefs about particular diseases that predispose them to fatalistic thinking. The study examined this question, by asking participants to think about their family history of arthritis, and evaluate their perceived risk, both before and after administration of experimental manipulations, aimed at altering the perceived controllability of arthritis (specific-efficacy) and perceived genetic risk. Arthritis was chosen because it is a common complaint, for which genetic testing is feasible yet, unlike genetic testing for breast cancer, has received little media coverage, hopefully resulting in less crystallised attributions regarding causality and cure. Equally, research suggests the onset of arthritis is less attributed to behavioural lifestyle factors than other health problems, such as heart disease or lung cancer (Strain 1996), which may create less of
threat to self-identity, allowing the perceived outcome of the information to drive the participants' responses.

Investigating whether it is possible to decrease specific self-efficacy in people at high risk of a disease, although interesting, was unlikely to produce startling findings. A more interesting question is the degree of generality of any change in specific self-efficacy. Our previous study demonstrated that changes in domain-specific efficacy could generalise beyond similar domains, as measured by a change in general self-efficacy. The current study aimed to replicate this finding by again demonstrating that a decrease in specific efficacy (the ability to prevent the symptoms of arthritis) could transfer to produce a significant decrease in general self-efficacy. In addition we aimed to clarify the role of importance. In our previous study the importance of self-efficacy appeared to impact on changes to domain-specific rather than general self-efficacy. It seems probable that the impact of a lack of perceived control (over the symptoms and development of a disease) is largely dependent on whether the individual believes they are at risk of the disease in question. If the perception of disease risk is high, then the importance of maintaining efficacy is also likely to be high, with information aimed at lowering this efficacy having a greater impact.

Another question the research addresses is whether a change in specific self-efficacy or self-general efficacy, impact on intentions to undergo genetic testing. Research has shown that perceived self-efficacy is a powerful independent predictor of health intentions, and is crucial for volitional processes that transform intentions into corresponding actions (Armitage and Conner, 1999; Povey, Conner, Sparks, James and Shepherd, 2000). It seems highly probable that a decrease in general self-efficacy (low levels of global competence) would have more power to affect genetic testing intentions than a decrease in health-specific self-efficacy.
6.2 Research hypotheses

The study design included three experimental manipulations. All the manipulations stated that arthritis was genetically determined. In addition, one manipulation gave information that aimed to enhance self-efficacy (over managing the symptoms of arthritis), another gave information that threatened self-efficacy. A fourth group acted as a control, with participants given general information about arthritis, but no information about genetic determination or disease management. The aim was to investigate whether the enhancement and threat impacted on perceptions of self-efficacy and genetic-testing intentions. Additionally, we wanted to investigate whether just being informed that arthritis was genetically inherited had any impact on intentions. This last part of the research was exploratory, with psychological theory or supporting evidence not available to make predictions. However, for participants at high-risk of arthritis, and for whom efficacy over this disease was highly important, we predicted that the threatening information would produce a significant decrease in specific-efficacy (the ability to prevent the symptoms of arthritis). We also predicted that this decrease would generalise to produce a significant decrease in general self-efficacy. Finally we predicted that low levels of general efficacy would result in low intention to undergoing genetic testing. In concordance, we predicted that for participants at low risk of arthritis, or for whom efficacy over arthritis was not important, the threatening information would have no impact on levels of specific-efficacy, and produce no generalisation effect.

In summary when the perceived risk of arthritis was high and when specific efficacy was important -

- A threat would produce significant decreases in specific efficacy, and would generalise to produce
- A significant decrease in general efficacy leading to
- Low intention to undergo testing
When the perceived risk of arthritis was low and when specific efficacy was unimportant

- *A threat would have no impact on levels of specific efficacy*

### 6.3 Method - Pilot study

#### 6.3.1 Aims
In order to generate valid and reliable scales for use in the main study, the measures detailed below were piloted.

#### 6.3.2 Sample
The pilot study sample consisted of one hundred members of the public shopping in the Bentall Centre in Kingston (with kind permission of the centre management). Participants were randomly selected, to represent a wide distribution of ages (approximately 20 participants representing each ascending decade) and occupations. Forty-four participants were women and 56 were men, with the mean age 44 and with ages ranging from 20-76 years.

#### 6.3.3 Procedure
The researcher randomly approached people walking through the shopping centre concourse. The aim of the study was briefly explained, then shoppers agreeing to partake completed the pilot questionnaire (see Appendix XX).

#### 6.3.4 Measures
In order to test the research hypotheses scales were needed to measure:

- The perceived risk of arthritis
- Arthritis (specific) self-efficacy
- The importance of arthritis (specific) self-efficacy and
- General self-efficacy
The Risk of Arthritis Index was based on a scale developed by Becker and Levine (1987) (measuring the perceived risk of heart disease), and aimed to measure the participant’s perceived risk of arthritis. The index comprised of five items. The first item asks the participants to indicate (1) whether anyone in the family suffers from arthritis. This question is not part of the scored index but is intended to encourage the participant to think about their genetic risk of arthritis, in terms of having a family history of the disease. The other four questions form part of the scored index and address (2) the frequency of concern over developing arthritis, (3) an estimate of the likelihood of developing arthritis over the next five years, (4) an estimated lifetime risk and (5) an estimated risk compared to other people of the same age and sex. The Specific-efficacy Scale aimed to measure the perceived ability to control the symptoms of arthritis. The index comprised of 8 items concerned with whether the participants believed they could control the symptoms of the disease. The Importance of Specific-efficacy Scale consisted of two items and measured the perceived importance of being efficacious in regard to controlling the symptoms of arthritis. The scales were constructed by reviewing existing literature and research to obtain an initial pool of items. The three measures were pre-piloted (n=25) to ascertain the ease with which questions could be answered, overall comprehension and rudimentary score distribution. Feedback from the pre-pilot data was used to modify the content and direction of the pilot study. The General Efficacy Scale by Schwarzer and Jerusalem, (1995) was used to measure general self-efficacy. All the measures had a Likert style response format.

6.3.5 Analysis

Histograms were computed for all four scales with normal distribution curves superimposed. The graphs indicated normal distribution. Skewness and kurtosis measures were calculated (using SPSS frequencies), with figures not exceeding + or -1 (which strongly indicates normal distribution). Frequencies were also calculated for each of the risk of arthritis questions, as an equal number of low and high risk participants were required for the main study. Table 8 below indicates that more people felt at low than high risk of arthritis, although the researcher felt this distribution was not sufficiently skewed to warrant concern regarding data collection for the main study.
Table 8. Frequency of response (percent) - Risk of Arthritis Index.

<table>
<thead>
<tr>
<th>Question</th>
<th>Response 1</th>
<th>Response 2</th>
<th>Response 3</th>
<th>Response 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Question 1</td>
<td>42</td>
<td>44</td>
<td>12</td>
<td>2</td>
</tr>
<tr>
<td>Question 2</td>
<td>12</td>
<td>52</td>
<td>26</td>
<td>10</td>
</tr>
<tr>
<td>Question 3</td>
<td>4</td>
<td>41</td>
<td>39</td>
<td>16</td>
</tr>
<tr>
<td>Question 4</td>
<td>15</td>
<td>64</td>
<td>15</td>
<td>6</td>
</tr>
</tbody>
</table>

* Response 1 indicates low risk, 4 indicates high risk

**Factor analysis**

A principal components factor analysis with non-orthogonal oblique rotation was performed and scree plots produced (see figure 9 and 10), to examine the factor structure of the risk of arthritis index, and the specific self-efficacy Scale. The importance of specific efficacy scale only consisted of two items, so factor analysis was deemed unnecessary.

Figure 9. Scree plot - Risk of Arthritis Index.
The factor analysis of the risk of arthritis index showed that a single component accounted for 63.34% of the variance (for eigen values over 1). Initial factor analysis of the specific-efficacy scale revealed a two-factor solution with the first component explaining 44.08% of the variance and the second explaining 13.46% of the variance (57.55% variance in total for eigen values over 1), see table 9 below.

Table 9. Pattern matrix of structural coefficients - Two-factor solution specific-efficacy scale

<table>
<thead>
<tr>
<th>Factor</th>
<th>I</th>
<th>II</th>
</tr>
</thead>
<tbody>
<tr>
<td>Question 1</td>
<td>-.874</td>
<td></td>
</tr>
<tr>
<td>Question 2</td>
<td>-.722</td>
<td></td>
</tr>
<tr>
<td>Question 3</td>
<td>.540</td>
<td></td>
</tr>
<tr>
<td>Question 4</td>
<td></td>
<td>-.876</td>
</tr>
<tr>
<td>Question 5</td>
<td>.830</td>
<td></td>
</tr>
<tr>
<td>Question 6</td>
<td>.634</td>
<td></td>
</tr>
<tr>
<td>Question 7</td>
<td>.767</td>
<td></td>
</tr>
<tr>
<td>Question 8</td>
<td>.703</td>
<td></td>
</tr>
</tbody>
</table>

*A lack of simple structure is indicated.
On further examination it was discovered that the two constructs correlated by .43, suggesting that each factor was not sufficiently distinct to be considered separate, and that the scale is uni-dimensional. Examination of the questions also suggested variation within the single construct of specific efficacy, however question 3 appeared problematic in not loading highly on either factor. On examination, question 3 appeared to measure the belief in the efficacy of medical interventions, rather than self-efficacy over the symptoms of arthritis (I could help control the symptoms of arthritis with the use of medical treatment). Reliability analysis confirmed that the question was not measuring the appropriate construct (see below), and the item was deleted. The authors of the General Self-efficacy Scale (Schwarzer and Jerusalem, 1995) state that the measure is uni-dimensional.

Reliability analysis was computed for each scale. The risk of arthritis index had an Alpha of .81, which could not be improved with item deletion, indicating good reliability. The specific-efficacy Scale had an Alpha of .81. The importance of specific-efficacy had a correlation coefficient $r = .094$. Reliability analysis of the General Self-efficacy scale resulted in an alpha of .88.

6.4 Method - Main study

6.4.1 Design
The study was a repeated measures 4 x 2 mixed design. All participants were randomly assigned to one of four conditions. The risk index and self-efficacy scales were then administered (in the form of a single questionnaire) at two separate time intervals - before and after administration of the experimental interventions.

6.4.2 Sample
Prior to sampling, power analysis was conducted. The optimal number of participants required for the main study with 95% power, small effect sizes (0.2) and a 5% Alpha, was 327. Three hundred and thirty participants were eventually recruited for the main study, with 301 responses used in the final analysis. On examination, 29 responses were
spoiled because of partial non-completion. With 301 participants power is reduced to 93%, an acceptable and realistic figure. All the participants were an opportunity sample recruited from the local community and included –

- staff from a pharmacy, a shop, a health centre, a children’s nursery, two factories, two business premises and a dental practice
- governors and parents at primary school
- a drama group and a poetry study group
- students from Surrey University and
- parishioners at a local church.

Older people (particularly women) were not targeted in the sampling, as arthritis rates in this group are high. Individuals suffering from any form of the disease were screened out during the study’s initial stage (see Arthritis Questionnaire Appendix XXI). Participants were recruited through direct contact by the researcher with local community groups and employers.

Of the 301 responses used 130 were from men and 171 from women. The mean age was 35; the median age was 26, with ages ranging from 18 to 80. Forty eight percent of the participants had been to University, with only 22% having no education after age 16. Twenty two percent of participants were in full time education with 17% classified as associated professionals and 12% classified as professionals, all other occupations made up the remaining 51% percent of sample. Of the 301 participants used in the data analysis, 46% were married, 41% single, 10% divorced, and 3% were classified as otherwise.

6.4.3 Procedure
A repeated measures design was used. The study was personally explained to each participant then each person was given a study information form (see Appendix XXII). Participants agreeing to take part in the study were then asked to sign a consent form (see Appendix XXIII). After consent was obtained, the questionnaire was administered by the
researcher (see Appendix XXI). The participants were then randomly allocated to one of four experimental conditions (see Appendix XXIV):

Condition 1. Gave general information about arthritis (the control group).
   2. Gave information stating that arthritis is a genetically determined disease, largely without the possibility of disease prevention or cure.
   3. Gave information stating that arthritis is a genetically determined disease but emphasising medical and lifestyle interventions that are available to help prevent disease onset and manage symptoms.
   4. Gave information stating that arthritis is a genetically determined disease with no information regarding controllability.

Following the intervention information a short (five minute) distraction task (see Appendix XVI) was administered to each participant before the measures were re-administered. Participants were then asked to complete a form stating whether they would have genetic testing to determine their risk of arthritis (see Appendix XXV). Lastly all participants were personally debriefed by the researcher and given a debriefing letter to take away (see Appendix XXVI). Participation took approximately twenty minutes.

6.4.4 Ethical considerations
The study was submitted to the University’s Advisory Committee in Ethics. Ethical approval was subsequently granted on 9th September 2001, reference ACE/2001/53/Psych. Ethical issues were particularly relevant for those participants in experimental group 2, who considered themselves to be at high risk of arthritis and were told the disease was largely uncontrollable. However, although the information was emotive, it was obtained from organisations concerned with giving the public information regarding the disease, with a different emphasis picked out for each condition regarding possible disease management.
All participants were given an information sheet prior to participation and asked to sign a consent form. To avoid any undue distress all participants were personally debriefed immediately following participation. Each participant was additionally given a debriefing letter reiterating the information given by the researcher - that the information given was not taken entirely from the Arthritis Research Campaign, as stated (although a large part of the text was from this source). It was also explained that the information may be misleading and should not be considered definitive, that the disease does not necessarily result in the joints being destroyed and that arthritis can be a minor condition that is successfully managed.

6.4.5 Measures
After the initial data analysis scales were computed (see below). The risk index and the General Self-efficacy Scale are uni-dimensional with good reliability, so remained unaltered. The Specific-efficacy Scale was reduced to 6 questions, with item 7 deleted (I believe there is nothing I could do to control the symptoms of arthritis) to improve reliability. The importance of specific-efficacy scale mirrors the specific self-efficacy scale so likewise the scale was reduced to 6 questions, with item 7 deleted. This scale was increased from two to seven questions for the main study, because on reflection it was felt continuity between the two scales would help with drawing final conclusions from the data analysis. New alpha coefficients were computed. The Specific-efficacy Scale now had an alpha of .82 and the Importance of Specific-efficacy Scale had an alpha of .94. As in the pilot study, Schwarzer and Jerusalem’s (1995) General Self-efficacy Scale was used to measure general efficacy (see Appendix XXI).

6.5. Results

6.5.1 Initial data analysis
Analysis of frequencies was carried out on the data set, to check for imputing errors, odd numbers and ceiling effects. SPSS explore was then used to test for univariate normality. For each of the four measures (and the intention question) 5% trimmed means, Kolmogorov-Smirnov statistic, normal Q-Q plots, detrended normal Q-Q plots, boxplots,
histograms and skew and kurtosis were computed to check the distribution of scores. From the data output the scales appeared approximately normally distributed.

The intention to undergo testing question was positively skewed (skewness divided by standard error = 2.34) and very flat (kurtosis divided by standard error = -3.52), so a large number of scores were low indicating that the intention to undergo testing within our sample was high (62% of participants would ‘definitely take the test’ or were ‘inclined to have the test’). The risk index was positively skewed (skewness divided by standard error = 2.97) and only slightly flat (kurtosis divided by standard error = -1.14), so again scores were low indicating that perceived risk of arthritis within our sample was low. The Specific-efficacy Scale was negatively skewed (skewness divided by standard error = -2.86) and slightly peaky (kurtosis divided by standard error = 1.10), so scores were high indicating that our sample felt highly efficacious regarding arthritis. The Importance of Specific-efficacy Scale was negatively skewed (skewness divided by standard error = -3.36) and slightly peaky (kurtosis divided by standard error = 1.34), so scores were high again indicating that our sample felt control over arthritis was important. The General Self-efficacy Scale was positively skewed (skewness divided by standard error = 2.18), and kurtosis was normal (kurtosis divided by standard error = .88), so scores were low. Due to the size of the sample (over 200), the risk in underestimation of the variance because of these deviations in normality is lessened. On inspecting the shape of the scale distributions, it was felt that none of the scales were sufficiently skewed or flat to warrant transformation, also because the scales were meaningful, and data analysis involved high and low scores on the scales, transformation would have made interpretation of the results difficult – with reported means representing transformed means rather than actual means.

Mahalanobis distance was then computed to check for multivariate outliers and scatterplots were computed to check for linearity. Five extreme scores were identified but it was decided to leave these in as there was no adequate reason for deleting them, they were correctly scored and part of the data population sampled.
Factor analysis - principal components analysis with Oblimin rotation - was computed, for each of the new scales, with scree plots produced. The scales were uni-dimensional. The risk index had one factor which accounted for 69.68% of the variance, the specific-efficacy scale had one factor which accounted for 49.66% of the variance, and the importance of specific-efficacy scale likewise had one factor accounting for 75.45% of the variance. Reliability analysis, with Cronbach's alpha, was then computed. The risk index has an alpha of .85 (with no possible improvement), the Specific-efficacy Scale has an alpha of .64 (improved to .82 if item 7 is deleted), the Importance of Specific-efficacy Scale had an Alpha of .95 (with no possible improvement) and the General Self-efficacy Scale had an Alpha of .88 (with no possible improvement).

6.5.2 Main data analysis
The hypotheses were tested using repeated measures, mixed ANOVAs. Before the computation of these tests, the importance measure was recomputed into a dichotomous variable, divided by the median - low and high importance - with 1 assigned for a low score, and 2 for a high score. The Risk of Arthritis Index was similarly recomputed and divided by the median into low and high scores, to examine whether perceived high risk affected responses to the experimental interventions. The intention to undergo testing question was recoded so 1 equalled low intention and 4 equalled high intention to undergo genetic testing.

To test parts 1 and 2 of the hypothesis - for participants at perceived high risk of arthritis, and when arthritis specific-efficacy is highly important, the threatening information given in condition two (arthritis as genetically determined and largely uncontrollable) would produce -

1) a significant decrease in specific-efficacy, and generalise to produce
2) a significant decrease in general efficacy

and to test the null hypothesis - for participants at low perceived risk of arthritis, or whom specific efficacy was unimportant the threatening information given in condition two would produce –

1) no change in levels of specific or general efficacy
a repeated measures 2 x 2 x 2 x 2 x 4 ANOVA was performed. The within subjects factors (DVs) were specific efficacy (time 1 and time 2) and general efficacy (time 1 and time 2). The between subjects factors (IVs) were low and high importance of specific efficacy, low and high risk, and the four experimental condition. See tables 10 and 11 for results.

Table 10. ANOVA Significant Results – Multivariate within-subjects effects

<table>
<thead>
<tr>
<th></th>
<th>df</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time</td>
<td>2</td>
<td>3.53</td>
<td>.031</td>
<td>.024</td>
</tr>
<tr>
<td>Time*condition</td>
<td>6</td>
<td>15.66</td>
<td>.000</td>
<td>.142</td>
</tr>
<tr>
<td>Time<em>condition</em>risk</td>
<td>6</td>
<td>2.53</td>
<td>.020</td>
<td>.026</td>
</tr>
</tbody>
</table>

Table 11. ANOVA Significant Results – Multivariate between-subjects effects

<table>
<thead>
<tr>
<th></th>
<th>df</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Condition</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Specific efficacy</td>
<td>3</td>
<td>6.89</td>
<td>.000</td>
<td>.068</td>
</tr>
<tr>
<td>General efficacy</td>
<td>3</td>
<td>.50</td>
<td>NS</td>
<td>.068</td>
</tr>
<tr>
<td>Risk</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Specific efficacy</td>
<td>1</td>
<td>.702</td>
<td>NS</td>
<td>.026</td>
</tr>
<tr>
<td>General efficacy</td>
<td>1</td>
<td>7.48</td>
<td>.007</td>
<td>.026</td>
</tr>
<tr>
<td>Imp. of efficacy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Specific efficacy</td>
<td>1</td>
<td>69.11</td>
<td>.000</td>
<td>.195</td>
</tr>
<tr>
<td>General efficacy</td>
<td>1</td>
<td>15.05</td>
<td>.000</td>
<td>.195</td>
</tr>
<tr>
<td>Condition*Imp. of efficacy</td>
<td>3</td>
<td>.46</td>
<td>NS</td>
<td>.036</td>
</tr>
</tbody>
</table>

The results show that the experimental manipulation did significantly alter specific-efficacy, but that this change occurred regardless of the level of risk or the importance of self-efficacy. The effect of the IVs and the manipulation on general efficacy was less clear. Line graphs for each IV and DV were computed to obtain a visual picture of how
the means of each were variable changed after the intervention (time 2). See graphs below.

Figure 11. Means - Importance of specific-efficacy
Figure 12. Means – Specific efficacy

Figure 13. Means - General efficacy
The graph in figure 11 shows that the importance of specific-efficacy is severely decreased after condition 2 (arthritis as uncontrollable and genetically inherited). In figure 12 specific-efficacy is again decreased after condition 2 and increased after condition 3 (arthritis as controllable and genetically inherited) with no change for the control group or condition 4 (the disease as genetic with no information about control). Figure 13 demonstrates that general efficacy scores were affected by the experimental conditions with general efficacy scores behaving in the expected way - efficacy decreasing after condition 2 and increasing after condition 3. Figure 13 additionally demonstrates that general efficacy scores at time 1 were extremely variable. This variability of scores accounts for the multivariate within groups result being significant, but the between groups calculation showing a non-significant finding. Figure 14 demonstrates that the experimental manipulation increased perceived risk in all the experimental conditions including the control group, suggesting that just reading about arthritis, or completing the arthritis questionnaire, increased perceptions of risk. Figure 14
additionally demonstrates that risk was particularly increased after condition 2 (arthritis as uncontrollable and genetically inherited).

The variability in general efficacy (at time 1) was investigated with regard to possible demographic differences between the participants across our four experimental conditions. Chi-squared analysis (each condition by each set of demographic data) revealed no significant differences in the four groups in terms of age, education, and occupation. Groups 2 and 3 had significantly more women than groups 1 and 4. Groups 3 and 4 had more married participants than groups 1 and 2. Subsequently the high general self-efficacy recorded in group 4 (at time 1) may be due to the group having significantly more married men, or an anomaly of our particular sample.

Paired t-tests were computed to determine whether specific-efficacy scores significantly differed after the participants were exposed to the four experimental conditions. The results revealed that specific efficacy scores significantly decreased after the efficacy threatening condition (2) and significantly increased after the efficacy enhancing condition (3), with no significant difference found in conditions 1 and 4, see table 12.

Table 12. T-tests Specific Self-Efficacy Scores - time 1 and time 2.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Mean time 1</th>
<th>Mean time 2</th>
<th>t</th>
<th>Df</th>
<th>Sig. P&lt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Condition 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean time 1</td>
<td>15.60</td>
<td>16.31</td>
<td>-2.59</td>
<td>76</td>
<td>*NS</td>
</tr>
<tr>
<td>Mean time 2</td>
<td>16.31</td>
<td>3.40</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Condition 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean time 1</td>
<td>16.00</td>
<td>14.12</td>
<td>4.58</td>
<td>75</td>
<td>.000</td>
</tr>
<tr>
<td>Mean time 2</td>
<td>14.12</td>
<td>3.56</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Condition 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean time 1</td>
<td>15.57</td>
<td>17.85</td>
<td>-6.17</td>
<td>74</td>
<td>.000</td>
</tr>
<tr>
<td>Mean time 2</td>
<td>17.85</td>
<td>3.22</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Condition 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean time 1</td>
<td>16.11</td>
<td>16.01</td>
<td>.29</td>
<td>72</td>
<td>*NS</td>
</tr>
<tr>
<td>Mean time 2</td>
<td>16.01</td>
<td>3.90</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Bonferroni adjusted alpha of .004
Paired t-tests were also computed, to determine whether general efficacy scores significantly differed after participants were exposed to the experimental interventions. The results show that general efficacy was significantly reduced after the threatening condition (2) and also after the condition stating arthritis was genetic (4). See table 13 for results.

Table 13. T-tests General Efficacy Scores at time 1 and time 2.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Mean time 1</th>
<th>Mean time 2</th>
<th>t</th>
<th>df</th>
<th>Sig. P&lt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Condition 1</td>
<td>30.81</td>
<td>30.86</td>
<td>-3.23</td>
<td>76</td>
<td>*NS</td>
</tr>
<tr>
<td>Condition 2</td>
<td>31.51</td>
<td>30.84</td>
<td>2.95</td>
<td>75</td>
<td>.004</td>
</tr>
<tr>
<td>Condition 3</td>
<td>30.92</td>
<td>31.40</td>
<td>-2.31</td>
<td>75</td>
<td>*NS</td>
</tr>
<tr>
<td>Condition 4</td>
<td>32.05</td>
<td>31.26</td>
<td>3.57</td>
<td>72</td>
<td>.001</td>
</tr>
</tbody>
</table>

* Bonferroni adjusted alpha of .004

Paired t-tests for the importance of specific-efficacy show that scores were significantly reduced after the threatening condition (2), see table 14 for results.
Table 14. t-tests Imp. of Specific Efficacy Scores - time 1 and time 2.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Mean time 1</th>
<th>Mean time 2</th>
<th>T</th>
<th>df</th>
<th>Sig. P&lt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Condition 1</td>
<td>19.78</td>
<td>19.14</td>
<td>1.379</td>
<td>76</td>
<td>*NS</td>
</tr>
<tr>
<td>Condition 2</td>
<td>20.75</td>
<td>18.53</td>
<td>3.694</td>
<td>75</td>
<td>.000</td>
</tr>
<tr>
<td>Condition 3</td>
<td>19.55</td>
<td>19.69</td>
<td>-0.226</td>
<td>74</td>
<td>*NS</td>
</tr>
<tr>
<td>Condition 4</td>
<td>20.77</td>
<td>20.08</td>
<td>1.293</td>
<td>72</td>
<td>*NS</td>
</tr>
</tbody>
</table>

* Bonferroni adjusted alpha of .004

A 4 x 1 repeated measures ANOVA was then computed, to ascertain whether the four experimental conditions significantly affected the participants’ intention to undertake genetic testing for arthritis. As shown in table 15, the experimental conditions did significantly predict intention.

Scheffe’s test showed that the mean difference in intention between groups 1 and 2 was significant (mean difference .81, std. error .16, p ~ 0). The mean difference in intention was also significantly different between groups 1 and 4 (mean difference -.54, std. error .16, p ~ 0).

Table 15. ANOVA – Experimental condition x intention to undergo testing

<table>
<thead>
<tr>
<th>Condition</th>
<th>Mean</th>
<th>Std.d</th>
<th>N</th>
<th>Df</th>
<th>F</th>
<th>Sig. P&lt;</th>
<th>eta²</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. No manipulation</td>
<td>3.22</td>
<td>.79</td>
<td>77</td>
<td>3</td>
<td>9.481</td>
<td>.000</td>
<td>.09</td>
</tr>
<tr>
<td>2. Gen. uncontrollable</td>
<td>2.41</td>
<td>1.13</td>
<td>76</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Gen. controllable</td>
<td>2.84</td>
<td>.92</td>
<td>75</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Genetic</td>
<td>2.68</td>
<td>.98</td>
<td>73</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Intention was highest for those participants in the control group who were given no genetic information about arthritis. Participants given information that arthritis had a genetic component but was controllable had the second highest level of intention - with participants in this group having an increase in specific-efficacy after reading the experimental intervention. Participants told that arthritis was genetic and uncontrollable had the lowest levels of intention - with participants in this group having a decrease in specific-efficacy after reading the experimental intervention. Participants, who were told that arthritis was genetic, with no information about controllability, had the second lowest levels of intention.

The results indicate that the changes in specific efficacy did significantly alter the participants’ intentions. The higher levels of intention reported in the control group (compared to the other three experimental groups) additionally suggest that just reading information about arthritis - in terms of the disease being genetic - reduced the participants’ intention to undergo genetic testing.

In order to test the third part of the hypothesis - that low levels of general efficacy would results in low intention to undergoing genetic testing - one-way ANOVA’s were computed, to determine the impact of each of our variables on intention (see table 16).

Table 16. One way ANOVA – Intention to undergo testing

<table>
<thead>
<tr>
<th>Between factors</th>
<th>df</th>
<th>F</th>
<th>Sig. P&lt;</th>
<th>eta²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Risk (time 2)</td>
<td>12</td>
<td>2.397</td>
<td>.006</td>
<td>.091</td>
</tr>
<tr>
<td>General eff. (time 2)</td>
<td>22</td>
<td>.570</td>
<td>NS</td>
<td>.043</td>
</tr>
<tr>
<td>Specific eff. (time 2)</td>
<td>18</td>
<td>3.163</td>
<td>.000</td>
<td>.168</td>
</tr>
<tr>
<td>Imp. of eff.(time 2)</td>
<td>24</td>
<td>2.498</td>
<td>.000</td>
<td>.178</td>
</tr>
</tbody>
</table>

The results of the ANOVA show that risk, specific efficacy and the importance of specific-efficacy, affect intention to undergo genetic testing. Bivariate correlations were
then computed to explore the strength of the relationship between the variables and intention (see table 17 below).

Table 17. Bivariate correlations – efficacy and risk factors with intention

<table>
<thead>
<tr>
<th></th>
<th>Intention</th>
<th>Pearson’s r</th>
<th>Sig. P&lt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Risk (time 2)</td>
<td>-.02</td>
<td>NS</td>
<td></td>
</tr>
<tr>
<td>General eff. (time 2)</td>
<td>.07</td>
<td>NS</td>
<td></td>
</tr>
<tr>
<td>Specific eff. (time 2)</td>
<td>.25</td>
<td>.000</td>
<td></td>
</tr>
<tr>
<td>Imp. of eff. (time 2)</td>
<td>.23</td>
<td>.000</td>
<td></td>
</tr>
</tbody>
</table>

The results of the analysis show that levels of general self-efficacy and perceived risk do not correlate with intention. Specific efficacy is significantly positively correlated with intention to undergo testing (Pearson correlation .25, p ~ .0) - the higher the specific efficacy the higher the inclination towards testing. The importance of specific efficacy significantly positively correlates with intention to undergo testing (Pearson correlation .23, p ~ .0 respectively) - the more important the specific efficacy the higher the inclination towards genetic testing.

Line graphs were then produced to explore the relationship between our variables and intention more closely (see figures 15, 16, and 17).
Figure 15. The relationship between intention to undergo testing and perceived risk.

**Total arthritis efficacy scores (time 2) and intention**

Figure 16. The relationship between intention to undergo testing and specific efficacy.
Total importance of arthritis efficacy scores (time 2) and intention

Figure 17. The relationship between intention to undergo testing and the importance of specific efficacy.

Figure 15 suggests that the relationship between perceived risk and intention is non-linear. It was decided to re-examine this relationship with risk divided - into high and low perceptions of risk of arthritis and intention (see figure 18).
Figure 18. The relationship between intention to undergo testing and risk
Figure 18 demonstrates that the relationship between low risk and intention is positive (Pearson's correlation $r = .195$, $p < .013$) - the lower the risk the lower the intention. However, the second graph clearly demonstrates that for participants at high risk, the relationship between risk and intention is negative (Pearson's correlation $r = -.21$, $p < .012$), - the higher the perceived risk the lower the intention to undergo testing.

Having ascertained which variables influence intention, multiple regression analysis was computed. Because low and high risk have different relationships with intention, separate regression analyses were computed for participants with perceived low risk (risk scores $< 10$), and high risk (risk scores $> 9$), specific-efficacy and the importance of efficacy, see tables 18 and 19.

Table 18. Multiple regression - participants with perceived low risk

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Std. Error</th>
<th>Std. Beta</th>
<th>T</th>
<th>Sig. P&lt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low risk (time 2)</td>
<td>163</td>
<td>.061</td>
<td>.190</td>
<td>2.381</td>
<td>.018</td>
</tr>
<tr>
<td>Specific eff. (time 2)</td>
<td>163</td>
<td>.021</td>
<td>.101</td>
<td>1.240</td>
<td>NS</td>
</tr>
<tr>
<td>Imp. Eff (time 2)</td>
<td>163</td>
<td>.014</td>
<td>.101</td>
<td>1.240</td>
<td>NS</td>
</tr>
<tr>
<td>$R^2$</td>
<td>.064</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$R^2$ adjusted</td>
<td>.046</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Df</td>
<td>3,159</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F</td>
<td>3.629</td>
<td></td>
<td></td>
<td></td>
<td>.014</td>
</tr>
</tbody>
</table>
Table 19. Multiple regression - participants with perceived high risk

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Std. Error</th>
<th>Std. Beta</th>
<th>T</th>
<th>Sig. P&lt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>High risk (time 2)</td>
<td>138</td>
<td>.044</td>
<td>-.258</td>
<td>-3.388</td>
<td>.001</td>
</tr>
<tr>
<td>Specific eff. (time 2)</td>
<td>138</td>
<td>.023</td>
<td>.310</td>
<td>3.748</td>
<td>.000</td>
</tr>
<tr>
<td>Imp. eff (time 2)</td>
<td>138</td>
<td>.018</td>
<td>.216</td>
<td>2.583</td>
<td>.011</td>
</tr>
<tr>
<td>R^2</td>
<td></td>
<td>.241</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>R^2 adjusted</td>
<td></td>
<td>.224</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Df</td>
<td></td>
<td>3,134</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F</td>
<td></td>
<td>14.16</td>
<td></td>
<td></td>
<td>.000</td>
</tr>
</tbody>
</table>

Table 18, demonstrates that, for participants at perceived low risk of arthritis our variables predict only 4% of variance in intention. Table 19, demonstrates that for participants at perceived high risk, the prediction is much larger with 22% of variance in intention.

The risk factor was then deleted from the regression analysis to determine how much variance was explained by specific-efficacy and the importance of efficacy. In this analysis the two variables alone only predict 8% of variance in intention (see table 20).

Table 20. Multiple regression – specific efficacy and the importance of efficacy

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Std. Error</th>
<th>Std. Beta</th>
<th>t</th>
<th>Sig. P&lt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specific eff. (time 2)</td>
<td>301</td>
<td>.016</td>
<td>.200</td>
<td>3.423</td>
<td>.001</td>
</tr>
<tr>
<td>Imp. eff (time 2)</td>
<td>301</td>
<td>.011</td>
<td>.163</td>
<td>2.777</td>
<td>.006</td>
</tr>
<tr>
<td>R^2</td>
<td></td>
<td>.088</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>R^2 adjusted</td>
<td></td>
<td>.082</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Df</td>
<td></td>
<td>2,298</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F</td>
<td></td>
<td>14.37</td>
<td></td>
<td></td>
<td>.000</td>
</tr>
</tbody>
</table>

The regression results from tables 18, 19 and 20 clearly indicate that the perception of high rather than low risk needs to be taken into account when considering the impact of...
self-efficacy, and the importance of self-efficacy on people’s intention to undergo genetic testing. Table 19 additionally demonstrates that the relationship between high risk, specific efficacy and the importance of efficacy is complex. It appears that intention to undergo testing is predicted by high risk, but that this relationship is negative - so participants classified as high risk, who feel efficacious about this risk and for whom efficacy over disease is important, genetic testing is unattractive.

6.6 Discussion

The study set out to determine how perceptions of disease risk and self-efficacy interact, and whether and how these constructs affect people’s intention towards undertaking predictive genetic testing. The study also aimed to clarify issues raised in the previous study, by further investigating the relationship between specific and general self-efficacy. Specifically the current study aimed to replicate findings from the previous study, by again demonstrating that a decrease in health specific efficacy (the ability to prevent the symptoms of arthritis) would transfer to produce a significant decrease in general self-efficacy. In addition, we aimed to clarify the role of importance in determining changes to specific self-efficacy, and investigate whether changes in specific efficacy or general efficacy would impact on intentions to undergo genetic testing.

The results showed that the disease information successfully manipulated both perceived specific efficacy and disease risk. After the experimental condition, aimed at threatening control specific-efficacy scores significantly decreased. Likewise after the experimental condition aimed at enhancing increasing control, specific-efficacy scores significantly increased, with no significant differences found in the conditions that did not aim to manipulate self-efficacy (conditions 1 and 4). These changes occurred regardless of the importance of efficacy in this domain, or the level of disease risk. Although importance did not appear to influence changes in specific-efficacy, the results showed that importance of specific-efficacy was affected by the experimental interventions, in being significantly lower after the intervention threatening control (condition 2). The results additionally showed that, after exposure to all four experimental conditions, perceptions
of risk were increased, with this increase most pronounced after the intervention threatening control (condition 2). These results suggest that just reading about a disease increases perceptions of risk, but that perceptions of risk became particularly salient when a disease is labelled as both genetic and uncontrollable.

In line with the findings from our previous study, the results found that changes to specific-efficacy appeared to affect levels of general self-efficacy, with general efficacy significantly reduced after the condition threatening control (2), and also significantly reduced after the condition stating that arthritis was genetically determined (4). Likewise, general efficacy was significantly increased after the condition aimed at enhancing control (3). However decreased levels of general efficacy did not affect the participant’s intention to undergo genetic testing. The analysis revealed that intention to undergo genetic testing was affected by perceptions of high risk, specific efficacy and the importance of specific efficacy.

The finding, that neither risk nor the importance of control over the symptoms of arthritis mediated the impact of the experimental manipulation, has several explanations. Firstly, the distribution of importance scores was bunched and negatively skewed, with efficacy in this domain moderately or very important to most of the participants. Few of our participants felt efficacy in this domain was of total importance or not important. This lack of variability suggests that the importance of control may be universal - that people feel being efficacious is of value in every area of life. If this is the case, a threat or enhancement to any area of control may be considered relevant, regardless of the specific value or specific level of risk. Equally, our research required that none of the participants actually had arthritis so the importance of efficacy over the symptoms of this disease was largely theoretical. The importance of specific efficacy may have more impact if a threat to control over health is a current issue in the individual’s life.

As discussed, the importance of specific-efficacy did not influence changes in specific-efficacy, however the level of importance was affected by the threatening intervention. After the threatening condition (2) importance scores were significantly decreased. This
finding mirrors results from our earlier study - which found that the importance of efficacy (over genetic testing decision-making) was decreased after a threat to this domain. Identity process theory by Breakwell (1989) explains this change as a useful strategy, a defensive reaction that allows for self-protection. The individual no longer feels threatened because the area of self under attack is no longer important, consequently the negative effects of the threat to self-efficacy are minimised and self-esteem is maintained. Our results add further weight to Breakwell’s theory and give further support to the concept of importance, when considering how threats to specific efficacy are coped with.

In Self-efficacy Theory, Bandura, (1997, p.51) states that changes in specific efficacy generalise to other domains of self-efficacy, when there are shared or similar qualitative features. For example mastery of a high-risk physical activity will generalise to other types of physical stressors, but not to mental tasks. The results of both this and our previous study suggest that changes to specific efficacy can also have a wider impact, generalising beyond specific domains to affect the individuals overall sense of competence. The psychological process by which this change in general self-efficacy occurs is currently unclear, but our results suggest that changes in specific efficacy directly transfer to impact on levels of general efficacy. The results of our latest study also showed that general efficacy scores were extremely variable. This level of variability led to a significant multivariate within groups result, but a non-significant between-groups finding. This variability in general efficacy scores may be an anomaly of our sample. Analysis of demographic differences between the four groups revealed that group 4 had significantly more married men than the three other groups, although whether this difference accounted for the groups overall higher general efficacy scores is arguable; there may just be wide variability in general efficacy within the normal population. What is most relevant is that after administration of the experimental interventions general scores changed in accordance with the direction predicted by our hypotheses.

Our results revealed that, although general efficacy scores were affected by the experimental manipulations, levels of general efficacy did not appear to relate to people’s
intention to undergo testing. Theoretically, this finding is difficult to explain. Perhaps levels of general efficacy are too global when considering factors related to people's intentions to undergo a diagnostic health procedure. If this is the case a general measure of health efficacy (see Becker, 1993) may be more useful. In our study, the intention to undergo testing was related to perceptions of risk, specific self-efficacy and the importance of specific-efficacy. Data analysis of risk and intention showed that high-risk correlated more strongly with intention than low-risk. Interestingly low-risk was related to high intention and high-risk with low intention. Multiple regression analysis went on to reveal that, when combined with specific-efficacy and the importance of efficacy, low-risk served to decrease the predictive value of efficacy, whereas high-risk greatly increased the amount of variance.

This result clearly demonstrates that in order to predict genetic testing intentions interactions between perceptions of high rather than low risk, plus self-efficacy and the importance of self-efficacy are relevant. These findings support the work of Shiloh, Petel, Papa and Goldman (1998) discussed earlier. In the study, women attending an outpatient breast-care centre in Israel were asked to explore their motives behind the decision to undertake genetic testing for breast cancer susceptibility (Shiloh, Petel, Papa and Goldman 1998). Interestingly, the researchers found testing was more strongly rejected amongst women at high-risk. In giving a reason for intending to undertake testing, only women at high risk mentioned 'control-related' reasons, whilst women at average risk often had "no concern and interest" in testing.

In the case of our participants with low perceived risk, the question of whether they would consider undergoing genetic testing may be less salient because testing is considered favourable, and attractive because of the small possibility of a negative result, alternatively because this small probability may deem testing unnecessary. Likewise, the reality of undergoing genetic testing may seem distant, rendering the participant's responses less reliable. Research by Wroe, Salkovskis, and Rimes (1998) examined the reasons given for people's decision making when contemplating genetic testing. In the study they found the perception of low risk was given as a reason both for and against
undertaking genetic testing. For participants with perceived high-risk of arthritis our results revealed a different relationship; the higher the risk - hence the greater the possibility of a positive result - the lower the intention to undergo testing. This finding supports the work of Shiloh, Petel, Papa and Goldman (1998), and the behavioural research reviewed earlier (Becker and Levine 1987; Clavel-Chapelon, Joseph and Goulard 1999; Lerman et al., 2000; Audrain et al., 1999 and Bratt et al., 2000), which found that increased risk of disease was not associated with increased surveillance behaviours attached to that disease.

Overall our finding suggest that feeling efficacious over one's health, and the value of this control deems genetic testing unattractive, if a positive test result (carrying the gene) is highly probable. As with those individuals at low risk, the perception of extremely high risk may again deem testing irrelevant, this time because participants feel they will certainly develop the disease, so testing to confirm this belief is unnecessary. A considerable amount of psychological research suggests most people tend to exhibit unrealistic optimism when assessing risk in relation to their own health (see Petrie and Weinman, 1997) although, as discussed earlier, this bias is less clear in participants involved in genetic testing protocols (see Lipkus et al., 2001). Within these groups there is a tendency to overestimate, not underestimate, one's personal risk of cancer (Bratt et al., 2000; Lerman, Croyke, Tercyak and Hamann 2002). Shiloh, Petel, Papa and Goldman (1998) reported that women at average risk displayed 'unrealistic optimism' regarding their cancer risk, whilst women at high-risk were pessimistic by comparison.

An alternative explanation is that participants at extreme high risk may feel that maintaining a level of uncertainty about their genetic risk - however small - is desirable. For participants who feel efficacious and particularly value this control, the threat offered by a positive test result may be too great. It may be easier to cope with perceived risk, and feel more efficacious about the management of this risk, than live with the possible knowledge of a genetic predisposition to disease. Equally, the anxiety caused by the high possibility of positive result may be a strong deterrent against undertaking testing. A study by Kash et al (1992) examined perceived risk, psychological adjustment and
participation in breast screening behaviours. They found that general anxiety was an important predictor of poor surveillance behaviour alongside the perception of high risk.

6.6.1 Conclusions and future directions

Work by Marteau and Lerman (2001) has suggested that the perception of a disease as genetic, and the availability of genetic testing, may lead to fatalistic thinking and behaviour, with people feeling that a genetic test or risk assessment deems them powerless to control their health. The higher levels of intention we found in the control group (compared to the other three experimental groups) certainly support this proposition. For our participants, just reading information about arthritis - in terms of the disease being genetic - appeared to reduce their intention to undergo genetic testing suggesting that as a disease become ‘geneticized’ both control over that disease and general control may become eroded.

Our findings additionally suggest that for people at extremely high risk of disease, who feel both in control of any potential symptoms and value this control, genetic testing is unattractive. This disinclination may arise from the increased likelihood of a positive test result deeming testing unnecessary, or alternatively from the perception that a genetic diagnosis will erode current levels of control. Our research findings demonstrate that perceived loss of control over the symptoms and development of a disease can have wide reaching consequences, in appearing to negatively impact on perceived control over life in general, although how this transfer occurs is currently unknown. Obviously, the conclusions are tentative. Our next study will aim to solidify these conclusions by addressing some of the theoretical questions raised in more detail. Specifically in the next study we will further investigate the perceived consequences attached to being diagnosed with a genetic predisposition, and the subsequent intentions towards genetic testing for individuals, both at low and high perceived risk of disease. In addition we aim to further examine how people construct self-efficacy in the context of genetic testing decision-making. The re-examination of factors influential in the perception of testing will enable us to identify which areas of efficacy have most impact on decision-making and intentions.
Chapter Seven

The prospect of predictive genetic testing for participants at low and high perceived risk: analysis of intentions

7.1 Research Aims

The aim of this fourth and final study is to further investigate the perceived consequences attached to being diagnosed with a genetic predisposition, and the subsequent intention towards genetic testing for individuals, both at low and high perceived risk of disease. The findings from the previous study showed that participants with high perceived risk of disease, who felt in control of this disease and valued this level of control, had little intention to undergo genetic testing. In contrast participants at low risk of disease had high intentions to undergo genetic testing. These results suggest that maintaining perceived control over disease is a motivating factor for individuals at high risk of disease but is not as influential for individuals at low risk. This indicates that the motivational processes underlying intention to be tested is different across these two groups. Furthermore, pictorial examination of the relationship between participants with low and with high risk of disease, and the intention to undergo genetic testing revealed a lack of symmetry, suggesting that perceptions were quantitatively and qualitatively different.

For individuals at low-risk, having no family history of disease may result in the consequences of testing being viewed superficially, with the reality of living with the knowledge of developing a serious health condition largely unconsidered. Equally, for individuals at low-risk, testing may be viewed as a health screening opportunity that should not be turned down; a chance to gain beneficial and reassuring knowledge with little chance of negative outcome. As mentioned earlier, the perceptions of low risk and the small probability of a negative result may deem testing unnecessary. However, the diagnostic opportunities offered by genetic testing, or any form of health screening, may differ once the anticipated outcome and the attached personal consequences of the procedure are considered more thoroughly. Psychological research suggests that people
often appear keen to have the opportunity to undergo predictive genetic testing, but on further reflection this initial enthusiasm wears off (see Salkovskis and Rimes 1997). For participants at high perceived risk having a family history of disease may result in risk being deeply anchored in personal consequences. Reflection of these consequences may bring a vivid perception what it means to live with the certainty of developing ill-health (see Parsons and Atkinson, 1993). Perhaps for these individuals maintaining a level of doubt about the future is desirable, in allowing room for hope. It may be easier to cope with the uncertainty of risk than live with the more concrete knowledge of future illness (see Marteau and Richards 1986). More concrete knowledge may be perceived as overwhelming in not allowing for perceived self-efficacy over one's future life.

Results from our previous two studies suggest that genetic testing decisions can impact on the individual's overall sense of control over their life although, interestingly, levels of general self-efficacy were not found to influence people's intention to undergo predictive genetic testing. People's intentions towards testing appeared determined by specific self-efficacy (and importance of this efficacy) regarding the disease in question. Theoretically, this finding is difficult to explain, one would expect a more reciprocal relationship - with general self-efficacy both being affected by genetic testing decisions, and by levels of perceived self-efficacy having some impact on intentions. Perhaps the specific domain of efficacy we manipulated in the last study determined both the depth and breadth of any generalisation effect and subsequent impact. For example, areas of self-efficacy particularly concerned with the ability to make future decisions - such as control over the decision to undergo genetic testing - may have a qualitatively different effect on general efficacy and intentions than efficacy over disease symptoms. Alternatively, the measure used may not have been sensitive enough to measure the impact of general self-efficacy levels on testing intentions. Whatever the explanation, findings from both psychological research (Kash et al. 1992) and this thesis suggest that perceived self-efficacy, in the context of genetic testing decision-making, is multidimensional and complex. Hence the second aim of the study is to further unravel this complexity. Using semi-structured interview data from adults with low and high perceived risk of heart disease and cancer (who were asked to contemplate the possibility
of undergoing predictive genetic testing for these conditions) the study set out to further examine how people construct self-efficacy in this context. The study specifically aimed to examine factors that determine whether predictive genetic testing is perceived as decreasing or enhancing control over one’s health and life in general, and further identify areas of self-efficacy which have most impact on genetic testing decision-making and intentions.

7.2 Method - Pilot study

7.2.1 Aims
Before commencing the main study two semi-structured pilot interviews were conducted. The interviews were conducted to ensure that the proposed structure of interview schedule (for use in the main study) was appropriate. The aim was also to identify any other useful areas of questioning and include these in the interview schedule used in the main study. The pilot interviews additionally ensured that any questions posed were relevant and easy to understand, and that the interviews were directed with the correct amount of researcher intervention. The data from each of the pilot interviews was analysed before actively choosing the next participant and commencing the next interview.

7.2.2 Sample
The initial interview structure was piloted on two participants who agreed to take part in the initial stage of the study. Both participants were personally approached by the researcher (through acquaintances) and chosen with the aim of generating contrasting data. With this in mind the first interviewee was a woman at high perceived risk of both heart disease and breast cancer. The second interviewee was a man with no family history of disease. After the second interview it was felt that enough data had been generated to design the interview schedule for use in the main study.

189
7.2.3 Procedure

Prior to the commencement of the pilot interviews the study was presented to each participant both verbally (see Appendix XXVII) and through an information sheet (see XXVIII). In the verbal presentation, the researcher explained current advances in genetic testing, how testing is conducted and the current availability of testing for diseases such as breast cancer and heart disease. Both interviewees were then asked to sign a consent form (see Appendix XXIX). After a short period for questions the interviews began. Topics covered in the interviews concerned the participant’s beliefs and concerns regarding genetic testing, whether they would consider undertaking a genetic test and their reasoning behind this answer. The researcher used a number of questions to shape or redirect the discussion as necessary (see Appendix XXX), although the structure of the interviews was left as open as possible. The duration of the pilot interviews was twenty-five to thirty-five minutes. The interviews were conducted at offices supplied by the University of Surrey. The conversations were audio-taped but not transcribed. On completion of the interview an informal debriefing period was held to answer any further questions and to thank the participants (see main study below).

7.3 Method - Main study

7.3.1 Design

This is a qualitative descriptive study of adults, at both low and high perceived risk of heart disease and cancer, who were asked to contemplate the possibility of undergoing predictive genetic testing for these conditions.

7.3.2 Sample

Participants from a random section of people within the community were asked if they wished to participate. Participants were identified and recruited through snowballing, via the researcher’s personal contacts and through links with local community groups. Participants were selected on the grounds of whether they considered themselves to be at high or low risk of heart disease or any form of cancer. Participants were recruited until it was felt that theoretical saturation was reached, with no significantly new material
coming to light (see Strauss and Corbin 1990). For the main study, twenty two interviews were conducted in total, over a period of eight weeks. Eight participants perceived themselves to be at low risk of developing both heart disease and cancer, 5 participants felt themselves to be at high risk of developing heart disease (but at low risk of developing cancer), 5 participants felt themselves to be at high risk of developing cancer (but at low risk of developing heart disease), and 2 participants felt at high risk of developing both heart disease and cancer. Two people approached declined to be interviewed and two people (one with low perceived risk of disease and one with high perceived risk of heart disease) participated in the pilot interviews.

In order to gather a cross section of responses, participants represented a random range of ages, occupations, educational levels and familial viewpoints. The participants’ ages ranged from 23 to 65. Thirteen of the participants had children. Thirteen participants were women and 7 were men. Elderly persons over age 70 and persons under age 18 were excluded from the study, as it was felt that predictive genetic testing may not be as relevant for these groups. Participants diagnosed with, or currently undergoing treatment for heart disease or any form of cancer were excluded from the project, with this issue raised and explained by the researcher when giving out the initial information form.

7.3.3 The interviews

The data gathered from the pilot interviews allowed the researcher to identify and further generate useful areas of questioning for use in the main interviews, and ensure any questions posed were relevant and easy to understand, and that the interview was directed with the correct amount of researcher intervention. The questions developed from the pilot interviews were largely open-ended, to encourage the interviewees to freely explore their thinking and feelings surrounding this topic (see Appendix XXXI). In the methodology used - grounded theory - overly directing the conversation by cutting off interesting theoretical leads is be avoided. Material within the conversation should be left to emerge naturally and not be overly driven by the researcher’s prior assumptions about what is theoretically relevant (see Pigeon and Henwood 1996).
After reviewing the pilot interviews, it was felt that focusing the main interview into five main topics would be useful. These topics aimed to cover –

- How the participants viewed their own health
- How at risk they felt of developing heart disease and cancer, and how this risk was conceptualised
- How they viewed general health screening
- How they viewed predictive genetic testing
- Their intentions towards genetic testing

Although the interview schedule was semi-structured, the researcher aimed to cover all the topic areas outlined above, with the interview schedule used to direct the conversation if and when necessary (see Appendix XXXI). The interview focused on the participant’s perceived risk of heart disease and cancer, because genetic testing is currently available and viable for these conditions and both the diseases are common within the population. The aim was to assess how the participant understood their risk of disease, to ascertain their attitudes towards their health and to explore factors influential in the acceptance or rejection of predictive genetic testing.

7.3.4 Procedure

Respondents interested in participating in the study were given an information sheet, outlining the study aims and detailing what participation involved (see Appendix XXXII). Interviews were then arranged and conducted at the participant’s home. At the time of the interview the researcher again explained the aim of the interview and the nature of participation. Respondents choosing to participate signed a consent form (see Appendix XXXIII). Prior to the interview the researcher explained verbally current advances in genetic testing, how testing is conducted and the current availability of testing for diseases such as breast cancer and heart disease (Appendix XXVII). The interviews typically took fifty minutes to one hour to conduct. The interviews were tape-recorded and transcribed. Both the tapes and transcripts were kept in a locked cabinet and the tapes were destroyed after transcription. Personal names or identifying facts were deleted or replaced with fictitious ones wherever possible. On completion of the
interview an informal debriefing period was held to answer any further questions and to thank the participants.

7.3.5 Ethical considerations
The study was submitted to and approved by the University's Advisory Committee on Ethics on 29th May 2002, reference number: ACE/2002/19/Psych. Although the subject matter discussed was emotive and topical, the researcher did not feel the questions posed caused distress or were overly intrusive or invasive. Many of the health issues and questions raised are of wider public concern and as such are commonly discussed and debated. Additionally, the researcher made it clear throughout the interview that participants could freely refuse to answer any questions and could terminate the interview at any time. At stated, on completion of the interview an informal debriefing period was held to answer any further questions and to thank the participants. At this point participants were advised to contact their own physician if they felt anxious about their risk of disease, or if they wished to know more about the prevention or management of the health conditions discussed, with the name, address and web site of the British Heart Foundation, and CancerBACUP made available.

7.3.6 Method of analysis
The 22 transcribed interviews were analysed using grounded theory procedures and techniques as laid down by Glaser and Strauss (1967) and Strauss and Corbin (1990). See the earlier chapter on epistemological and methodological issues for a detailed explanation of the research process and a description of the research strategy.

7.4 Results

7.4.1 Initial data analysis
The aim of the first stage of the analysis was to break down the data into conceptual labels and then categorise the data into groupings that appeared to belong together. This involved an intense line by line analysis of the texts. At this stage the analytical process was both broad and minute. General reflections and thoughts were recorded in a memo
diary, with idiosyncratic conceptions and images drawn and debated. Additionally, each piece of text was studied intensely with words, phrases and sentences picked out then sorted and grouped together to form conceptual descriptive labels. The labels were clustered and further developed into analytical categories with shared properties, attributes, and dimensions. Theoretical sensitivity was enhanced by constantly comparing and verifying the categories to the actual text and with the use of constant questioning. The researcher additionally used diagrams to map patterns of interactions and conceptual relationships and to look for the meaning of inconsistencies within the data. Through a detailed analysis of words, sentences and phrases and by making different level comparisons, broader themes emerged from within the categories to aid the next stage of analysis. Part of this process is illustrated below using excerpts of text taken from the first stage of interviewing. For brevity only a small selection of the texts and work undertaken is shown although an overall summary of the work done within this stage is provided. For ease of illustration, the words highlighted form part of the label shown. Other phrases and words included in the excerpt are not redundant but may form parts of other labels not shown (see Appendix XXXIV and Appendix XXXV for two complete examples of the transcribed interviews).

The participants were asked to consider what they thought caused their risk of disease. A sample of answers are recorded below -

T.1. 33-38. *I've got mixed genes, my mum and my dad, and the cancer side I think I've probably escaped. I don't, don't know why I just think I probably have, but I feel the blood pressure side of things I haven't escaped, my father's side of things. I feel I'm at risk of a heart attack through it. So I think it depends what, how you're inherited what from each side of the family really, so.*

T.3.53-57. *Yes, well, yeah, I am just conscious of the fact that my Nan died of it, and my dad has had two heart attacks, and I'd say that my dad is quite a healthy person, so I think it's a hereditary thing like. I do feel that health wise I probably take after my dad, more than my mum, so I think it's probably in me to some extent, that problem.*
These responses were categorised and named ‘the cause of disease risk’ and were labelled as shown below:-

Family history of disease

- hereditary – the genes you inherit from close family members
- the family member you most resemble (either mother or father)

The participants were asked to explore how it felt to be at low or high perceived risk of disease. Excerpts of some replies from those at low perceived risk are recorded below -

T.2.11-17. I don’t have many worries or concerns. I feel quite fortunate that I don’t really. My health does not worry or preoccupy me like it does a lot of other people. My dad had angina at age sixty nine so occasionally it crosses my mind, but not often really. ...I feel very healthy at the moment. So I feel very lucky.

T.5.42-46. I suppose it’s a security (being at low risk), a kind of security within the knowledge that you think you are low risk, so you don’t worry about it. It feels good, obviously to say this. I don’t think about it much, but saying it, it feels good, nice, like a warm feeling, no real worries. So I guess I feel quite lucky when I think about, but as I’ve said I really don’t think about it very much.

T.9.35-40. Oh, I’m pleased about it, as I don’t have to worry about going in hospital or being ill, um... in the future, and hopefully it will mean I will live longer. So yes it’s good to say I’m low risk of these things. You don’t have to think about your health all the time, and you’re just less worried about getting ill, so yeah you have that confidence.

These responses were named and included in the category ‘concept of disease risk’ and were labelled as shown below -

Low risk means

- freedom from worrying about your health
• feeling happy about life/health
• living longer
• a sense of security, confidence about the future
• feels good, nice, warm, lucky

Some participants discussed how genetic testing could be socially controlled. A sample of these conversations are shown below -

T.1.205-209. *I think there has to be strong guidelines because I think not everyone is, if you like, stable enough to accept the information, and then there are other people who will be able to take it on board and will flourish from that day forward, so really I think people have got to be chosen, or looked at in a very careful manner, when comes to genetic testing, because the information is greater.*

T.5.207-209. *But for the general run of the mill day to day appointment at the doctors, 'right we are going to do genetic testing,' no I don't think so. I don’t think it should be across the board.*  T.5.232-234. *There are lots of people out there who shouldn’t get there hands on this sort of information, because I think depending on their frame of mind it could take a really, really bad turn and be a very negative thing.*

The responses were named and included in the category ‘strategies for maintaining control over genetic testing decision-making’ and were labelled as shown -

By having a restricted choice
• access to testing and results should be governed – it is the job of those in authority to help protect, manage and control these decisions, to protect people from the negative consequences of this knowledge (we are vulnerable)

The next excerpts concern the participant’s discussion of the perceived consequences of genetic testing.
It’s the sort of news I can do without, the worry would probably kill me before the actual thing itself... I think we all sort of live life and feel we are going to be immortal, I think that’s quite a nice feeling for many of us for many years. And I think if you had a test like that you just wouldn’t feel the same. I don’t know if you could feel so happy, about your life...I would feel that someone had put a damper on how emotionally I felt.

I think it (news of testing result) could worry you sick...it’s just worry, worry and illness for the future and I can’t see the point of that. I think the knowledge, let alone the actual disease could make you ill, you could worry yourself into being ill. You have that cloud hanging over your head all the time. Just that cloud, that maybe one day in the future....

The excerpts were named and form part of the category ‘specific determinants of genetic testing decision-making’ and were labelled –

The perceived consequences of a negative outcome (having a genetic predisposition to disease)

- Becoming excessively worried and becoming sick, or dying because of this worry
- Loss of sense of immortality
- Loss of happiness about life
- An emotional blight on life

A summary of the overall findings from this stage of the analysis were developed and are shown below. At this initial stage the categories are represented as separate concepts. In the next stage links between the categories and labels are shown more clearly. It should be acknowledged that this division is partly artificial. In actuality some of the connections mentioned in the main analysis were recognised and recorded at the earlier stage of analysis and vice versa. The aim is not to mislead the reader but to improve clarity by give a sense of process rather than a strict account of every emerging thought.
The first main category to emerge from the initial data analysis represents the participant’s conversations regarding the perceived cause of disease. Interestingly, the cause of disease appeared to be primarily discussed in one of two ways. The participants primarily discussed disease being caused by genes or current health problems. Disease cause was also discussed in term of fate or luck, with the overall suggestion that anyone could get ill at any time for any or no reason. In this latter case, the uncertainty and unfairness attached to the randomness of disease was discussed, and appeared to represent a strong source of anxiety for many participants, a theme which is further represented in category 2 below.

1. Cause of disease risk

Family/own history of disease

• hereditary - genes you inherit from close family members
• family member you are most like regarding your health (either mother or father)
• how well I am, and how well I’ve have been in the past very strong cause of anxiety

Due to Luck – to fate (random and uncontrollable)

• being lucky/unlucky – inheriting the right/wrong genes
• nothing you can really do to prevent ill health (death and illness can happen to anyone, anytime, down to fate)

Participants were asked what it felt like to be at low or high risk of disease. Words describing high risk appeared to represent highly salient, graphic and fearful concepts. High risk was described as ‘blight’ or ‘curse’ or as ‘wrecking your life’. High risk was also conceptualised as ‘shadow’, a ‘sword’ or a ‘black cloud, hanging over you’. In contrast low perceived risk was described as providing freedom from worry and a sense of security, see below -

2. The concept of disease risk

Low risk means

• freedom from worrying about your health – poor health is less salient
• feeling happy about life/health
• living longer
• a sense of security, confidence about the future
• feels good, nice, warm, lucky

*High risk (emotionally stronger fear based descriptions) means*

• living closer to death and living with worry and anxiety - poor health is more salient
• losing a sense of immortality
• you are helpless against your genes
• living in fear of the future
• feels scary, fearful, emotional, uncontrollable, overwhelming and random

Talking about both the cause of disease and the concept of disease-risk appeared to be a source of anxiety for many of the participants interviewed. The next category represents the reasons the participants gave for having either low or high anxiety about their risk of disease. The reasons appeared divided into two main areas. Firstly, risk anxiety appeared associated with how close the person perceived themselves to be to the risk. For example if they felt they were close to the age when people develop cancer, or if they felt at higher risk because of their lifestyle. If a person ate well and exercised regularly this was seen as partly lessening their risk, and also as lessening their anxiety about this risk (see category 4). Another representation that appeared linked to anxiety, although not directly discussed by the participants, concerned ‘the salience of risk’. This category represents, the centrality of risk to the participant, for example if the participant had been recently ill, had a history of illness, or had a family member who was ill, risk appeared to be salient and disease-risk anxiety high, see below -

3. Determinates of risk anxiety

*Proximity of risk*

• in relation to my lifestyle - as compared to other people
• my age, in terms of the perceived end of my lifespan and my likelihood of contracting a major illness associated with aging—such as Alzheimer’s disease, a stroke, or breast cancer
• result - my level of disease anxiety

Salience of risk

• perceived state of my own health – physical and mental (see cause of risk)
• the health of significant others close to me (friends and family)
• my biographical experience of disease (the consequences of ill health)
• result - my level of disease anxiety

A continuation of this category was a discussion of the personal strategies the individual could use to lessen the anxiety caused by their risk of disease. Most interesting is the large number of different strategies discussed, and how often this issue was at the forefront of the conversation. People discussed attempting to live a more healthy life, exercising and eating well. People also discussed psychological methods, such as attempting to reduce disease-risk anxiety, by actively trying to ignore it and denying it through not speaking of it. Another strategy was to ‘live for the day’ - to pack as much into life as possible - just in case. The consequences of not being able to reduce the anxiety were also discussed with some dramatic results - some participants felt that worrying about your risk of disease could make you seriously ill or even kill you. See below -

4. Strategies for maintaining personal control over risk

Engage in practical lifestyle behaviours

• give up smoking, eat a good diet, exercise, lose weight, take vitamin supplements and manage stress levels (efficacy beliefs regarding prevention were not strong and often engaged in without strong levels of commitment, see cause of risk)
• engage in health screening behaviours – with early detection comes a higher chance of cure or treatment (again the efficacy of this behaviour was highly variable)

Keep risk in the background - strategies attached to salience

200
don’t dwell on, obsess or worry about risk
keep busy – so you have too many other things to worry about
don’t seek out risk information, or look too far ahead (seek and you will find – close your eyes and it’s not there)
don’t talk about risk (talking makes risk more real)
keep thoughts of risk private – to oneself
tell yourself you don’t care about your risk, or your death

Minimise (or deny) level of risk
• even if you have a strong family history, are on medication, or are told of your risk by a doctor - believe risk does not apply to me - I am immortal

Generalise risk and embrace randomness
• we all have to die anyway, sometime, somehow ‘you could get run over by a bus’
• is the same for everyone, we all have something we are at risk of
• it is fifty, fifty - I am either dead or alive, well or ill

Distance yourself from risk – attached to proximity
• risk does not apply to me because I am different from other people (the availability of this strategy appears to depends on the level, proximity or salience of risk)

Live for today
• get the most out of life, enjoy life, live life to the full (serves two functions - too busy getting on with life to think about death, and as insurance - in case death is imminent)

The consequences of not doing these things
• risk is made a reality – by talking or thinking about risk
• fear of risk overtakes your life, blights your life
• worrying about risk stops you getting on with life and the worry may kill you

Leading from strategies concerned with controlling disease-risk anxiety were strategies for controlling genetic-testing decision making. These strategies primarily concerned how the public could be protected from making the wrong decisions. Many of the participants also talked about people being given the right amount of choice and were unsure about
balance between this choice and being protected. Many participants felt that it was the job of the government and those in ‘authority’ to deal with this problem and protect them, although there appeared to be some scepticism about whether and how this could be achieved. See below -

5. Specific strategies for maintaining control over genetic testing decision-making

Medical intervention
- being told what to do to minimise your risk by someone in authority (a doctor)
- being offered counselling and psychological support – being protected from making decisions too rashly and supported afterwards (living with the consequences of genetic testing is a big decision - a huge burden)

Informed consent
- being given information about testing – understanding how testing works and the consequences of this choice
- by having a choice - not being forced to undergo testing

By having a restricted choice
- access to testing and testing results are governed – the job of those in authority to help protect, manage and control these decisions and protect people from the negative consequences of this knowledge (we are vulnerable)

The next category concerns the reasons given for pursuing testing. These were varied and appeared divided into personal reasons and wider societal reasons. Two personal reasons for undertaking testing that featured strongly were putting an end to uncertainty and worry, and the ability to seek medical interventions – if the disease could be cured or controlled. The ability to change future outcomes, and the risk to one’s children, also featured heavily in the conversations. See below -

6. Reasons for pursuing genetic testing

Knowledge of your future risk
- allows for stringent screening practices and early detection - a higher chance of cure of treatment
• allows you to plan and prepare for your family’s future (at least you know what’s coming)
• allows you make informed family planning decisions
• alleviates curiosity – the need for self-knowledge
• quells worry and ends uncertainty - particularly if risk is blighting your life, then testing can offer peace of mind (if distancing or other strategies for managing risk are not available to the person)

_Pерceived ability to cope with risk information_
• I have the inner strength to overcome difficulties and make changes
• I don’t think I could cope with the result (intention strongly linked to perceived ability to cope)

_Pерceived controllability of a particular disease_
• can the medical profession prevent, treat or cure the disease (perceptions were extremely variable, some people felt heart disease was curable others felt nothing could be done to prevent this)
• does the disease affect my mental or physical capacity (mental ailments were seen as being worse)
• can I pass it on to my children
• can I do to something to change my future (extreme variability, perceived change of outcome strongly linked to intention)

The participants talked about genetic testing affecting the future of society. Generally people appeared divided on whether they thought future changes would result in more harm or more good. People were concerned about issues such as confidentiality, cloning and the creation of a super-race. People also felt that genetic technology would bring many benefits and improve the health of future generations. Many people expressed feeling that, regardless of the impact, the continued introduction of this technology was inevitable. See below for summary -
7. Genetic testing and the future of society

Genetic testing is

- a crystal ball into the future (the end of uncertainty, which is ‘very scary’ – a strong dialogue)
- mainly for younger/older people
- very powerful – in terms of the knowledge it brings
- for helping with current health problems, not for creating new things

Imperative nature of science and technology

- the social desirability of progress (it’s difficult to say scientific progress is a bad thing)
- the inevitability of progress - ‘can’t put genie back in the bottle’
- our overwhelming need for knowledge - regardless of the consequences

The positive power of technology and genetic testing

- helps solve health problems
- provides better health care for the next generation

The negative power of technology and genetic testing

- a dangerous, uncontrollable, unknown entity
- involves messing with, and abusing nature - cloning and creating a super-race
- results in discrimination and creates financial hardship - the future effect on insurance, jobs and mortgages

Perceived ability to control access to risk information

- confidentiality of the test results - from family, insurance companies and employer (intention linked to perceived ability to control dissemination of information)

The final category to emerge from this stage of the analysis is rather messy. The idea behind this category is that it represents specific issues and consequences attached to genetic testing decision-making that are not included elsewhere. These ideas include the participant’s perceived consequences of having genetic-testing knowledge, perceived reactions to this knowledge and a growing awareness of these issues when discussing this topic.
8. Specific determinants of genetic testing decision-making

General perceived consequences of genetic risk knowledge

- a more certain view of the future (universal definition)
  (living with more certain knowledge of risk, of your death = very scary)
- the end of peace and happiness, forever worrying about the onset - versus
- being given peace of mind (at least you know where you are)
- better family planning
- the loss of procreation (if you were found to be a carrier you shouldn’t have children)
- the negative impact on other family members

Perceived reaction and consequences of a positive outcome

- euphoria
- relief
- freedom from anxiety and worry
- new impetus to make lifestyle changes (a great escape and new start)
- engage in more risky health behaviour (no longer bother to take care of your health)
- enjoy life more (with no health worries)
- carry on as normal

Perceived consequences of a negative outcome (having a predisposition to disease)

- new impetus to make lifestyle changes
- learn to live for today
- prepare for the future
- plan for death
- prevent progression of the disease
- do financial planning (after your death) - also
- shock, disbelief and distress
- becoming depressed (and unable to do anything to help yourself)
- becoming excessively worried and becoming sick, or dying because of this worry
- becoming inactive regarding looking after your health (being fatalistic)
• feeling helpless
• losing sense of immortality (huge loss – linked to low intent)
• loss of happiness about life
• an emotional blight on life, ‘a curse, death sentence, terrible burden’ (strongly linked to no intent)
• a re-evaluation of life

Contemplation of genetic testing
• a growing awareness of the difficulties and consequences (initial desire to say testing is a good thing, perhaps due to the imperative nature of progress/self-knowledge changes)
• a growing awareness that ‘more is at stake’, a potentially bigger psychological impact (leads to less intention)

7.4.2 Main data analysis
In the next level of analysis the researcher’s aim was to allow the relationships, between and within, the concepts and their categories to be further developed and viewed from a number of different perspectives. Specifically the aim was to identify and verify relationships and larger stories that were strongly presented and widely repeated within the data, and to find and examine incidences of variation and examine these. To achieve this, data from the transcripts was again unpacked and put back together, a process characterised by comparing and contrasting categories and making associations. The results were recorded in a memo file, with flow charts and diagrams used to provide a concise illustration of the function of different relational concepts. The focus was on considering the conditions that gave rise to a category, and on making coherent links. As relationships between the categories developed, larger more coherent themes emerged. The emerging themes were continuously validated against the previous set of texts and compared to the next set of texts drawn from another 8 interviews (see Glaser 1992).

On further examining the participant’s attitudes and intentions towards genetic testing, perceptions of self-efficacy did appear pivotal. The participants appeared divided on whether they thought genetic testing would give them more or less self-efficacy over
their future life and health. Some participants expressed believing that the knowledge gained from testing would give them more control. The overall feeling was that, no matter how difficult, problems were best out in the open and tackled ‘head on’ - and they expressed feeling confident enough to do this. However, if nothing could be done to prevent ill health or death the knowledge gained from genetic testing still offered these participants a clearer sense of control over future. Whatever the outcome of testing, these participants felt it was better to know their disease risk and ‘deal with it’, so making the best of the rest of their lives. See below -

T.15.103-105 Yes I would (have genetic testing), because a lot of people say ignorance is bliss, but a lot of the time when your faced with you know, the worst, perhaps you can deal with it. Perhaps you know, you get this inner strength to say, well this is what I’m faced with, I can do two things, you know, or you can ignore it, but well it’s not going to go away, so you can decide to be pro-active and take this problem head on.

T.10.151-154. If I’d have been thirty I wouldn’t want to know it, but there’s a difference in the age. But now I could probably cope with it, I’d think if is there anything I could do now to make my life, my life more liveable, more comfortable etc, then I’d do it, I’d cope.

T.6.106-115. I think it’s always better to know what you can about your health, to be prepared, then you can act. You can make clear decisions for the future... It’s better to know, even with something like Alzheimer’s disease that you can’t cure, it’s better to know, then you can plan ahead...

For these participants the consequences of genetic testing appeared to be viewed rationally in terms of taking practical action and forward planning. Testing was described as offering the chance to control future outcomes such as making financial provision for the family after death. Within these conversations, the emotional consequences of living with the knowledge of your risk appeared less important, and the anxiety associated with testing was often described as a problem that needed managing. Intentions towards undertaking genetic testing were often high. See below -
Beyond any shadow of doubt I think genetic testing is a very good thing, yes. As I've said knowledge is power. The point is if um... if medicine has solutions to prevent problems, to lead to the prevention of problems then it just makes sense to have tests which enable those solutions to be accessed, earlier rather than later. Just common sense to me.

I still would have the test; most definitely I think I would. I would be able to plan out how best to spend the time I had left and I would feel better knowing that. So yes, even if it couldn't be cured I could take action to plan for the future and I rather know what lay ahead of me.

Other participants expressed that genetic testing was only useful if it offered the possibility of controlling specific diseases. For these participants the perceived ability to make lifestyle adjustments, or access some form of medical intervention to prevent the onset or progression of the disease, was key to their intentions. If medical interventions were unavailable, or lifestyle changes not possible, then genetic testing was perceived as offering no control over the future, only the creation of worry.

...for me personally it would be very important that I could do something... for me personally I need to feel that I could do something, either diet, or lifestyle or the job I lead, whatever. If I could do things to minimise the risk, then I'd like to know more, but if not, then I wouldn't want to know. I wouldn't want to know I was going to get Alzheimer's. I don't feel there's anything they can do for that.... no there's not an awful lot... then no I wouldn't want to know.

I need to know I could do something about it, that in some way I had some control over it's development, otherwise I just can't see anything positive in having that knowledge, it would just give you worry, and you'd just be waiting for it to happen, feeling helpless really, just feeling helpless and worried and what good would that do, none that I can see, none at all.
T.17.106-109. I think it could be beneficial if there are measures that you can take. Um...like changing your diet and things, but if there isn't measures that you could take then I don't think it would beneficial to know.

Another group of the participants described the development of disease as inevitable, and appeared to express little or no perceived self-efficacy regarding their ability to prevent the onset of a disease perceived as genetic. See below -

T.3.132-134. No I think you are better off not knowing (your genetic risk). You can't prevent these things from happening, really, otherwise it wouldn't be genetic, it wouldn't be a gene, and so that's it, no point.

T.18.194-197. People should just get on with living. If you can't change it why worry about it, what will be will be, if it's in your genes then, that's it really, nothing you can do about that, can't change that, change your genes, so, best to just get on with things.

Many participants viewed genetic testing negatively. The consequences of undergoing genetic testing were often addressed in terms of being told 'you are a diseased person', not about the possibility of receiving good news (a negative test result). For many participants, the consequences of the procedure did not appear to be viewed practically or rationally but emotionally, with the perceived results of genetic testing often described in 'catastrophic' terms. Genetic testing would mean the 'loss of immortality' and serve to put 'an emotional blight on life'. For participants who expressed no intention to undertake this procedure an overall a sense of helplessness, fear and loss was often present in the conversation. See below -

T.8.121-130. It makes it's more certain, more set, you have no control over that, and I wouldn't want it. It turns your destiny into something solid, and I think you'd feel that your whole future was in some way taken out of your hands, out of your control. I think that idea is quite fright..., quite scary in a way. ...I feel it would be like living with a death sentence, with a curse hanging over you, you'd feel like a person with a disease.
bomb inside you ticking away. It would change everything and I don't think it would be a good change, a good thing...

T.2.30-33. *Even if it was something I could prevent that would take ten, twenty years off my life, you know I cannot live my life with that envelope or waiting for results. I would be obsessed by it, I would be obsessed by the result, if it was bad. And I would be obsessed waiting for the result, it would ruin my life, the whole process would.*

Interestingly, it was not the practical consequences of being at risk of disease or of being ill that were discussed, but the emotional consequences of coping with the worry associated with the genetic testing information. Current strategies used for coping with risk, such as ignorance, were perceived as being removed by the process of genetic testing along with control over the management of disease-risk anxiety. Many participants felt they would be unable to cope with this outcome. See below -

T.11.92-96. *I ... I wouldn't want to know I was going to get an illness that was terminal or life threatening...not really. I really don't think so. I think it would cause me great anxiety, it could be quite bad in the way it could affect you... and I don't know how I'd cope with that, I think it could be quite bad really, you know mentally hard to cope with, yes I think so, it would be. I don't think I would cope.*

T.18.180-184. *(How would she cope with the test result) Oh God, I don't even want to go down that road. Oh God that would be terrible wouldn't it, to be told you were going to get something, oh it would be so awful I can't imagine it, too awful to contemplate. It's like having a sword of Damocles hanging over you wouldn't it. Really too awful to think about.*

The anxiety created by this perceived lack of control over disease, and ultimately over death, appeared huge for some of the participants -
...but yeah, sometimes when I sit down and think too hard it's difficult. Sometimes it's a terrible weight on my shoulders, sometimes I feel like...it's almost like a loss, like I've lost something good, the feeling of good health I guess. It sounds stupid but sometimes I just feel like it's like living under a black cloud.

Um... I suppose sometimes I feel anxious when I... if I'm feeling low, something like that. I might feel... you know there have been a few things happen in my life, from a mental point of view, from a psychological point of view, and I do worry about it then... I try not to dwell, try not to be anxious... but sometimes the thought of getting ill, of illness is on my mind, but it's so scary, it really frightens me to death, so I try to ignore it, really.

Thinking about it (my risk of disease) makes me quite emotional because I do worry quite a lot about my health, when I think about it I feel quite panicky, quite scared really. It's stupid I know, but the thought of getting seriously ill scares me, the fear of being dependent, of being a burden, that sort of thing (starts to look tearful).

Specific beliefs regarding the ability to protecting oneself from the onset of disease also appeared strongly influential in shaping attitudes. Some participants sought to be efficacious regarding their health and were active in finding ways of trying to minimise their risk of disease and consequently reduce their anxiety. This group of participants describe actively taking care of their health by choosing to engage in healthy lifestyle behaviours such as exercising and healthy eating.

I try to exercise, I go to the gym three times a week, I've stopped smoking, and I try to eat healthy, but that's all I can do really. Going to the gym and stuff does make me feel like I'm doing something about the situation, I do feel like I'm taking control of the problem, it does make me feel better about things, doing something.

I try to exercise, not as much as I should, but... I try to eat healthy, I try to have um... fruit and veg every day and drink quite a lot of water and cut down on things that... diary products and things like that. So yes I do quite a lot to look after myself. It
makes you feel more pro-active, you want to do something about it, and it makes you feel in some ways that you are doing something about it, which is quite good, that you are aware of the dangers.

Leading a ‘healthy’ life was seen as a means of decreasing risk and coping with the anxiety associated with ill health. See below -

T.2.86-90. I’m a lot more optimistic about it now (my disease risk), I feel a lot more in control of my own health, than I probably did. If you would have interviewed me ten years ago I probably would have been alive with different anxieties, about which disease could lead to my imminent death. So at the moment I’m much more relaxed about things. If I lead a healthy lifestyle then I feel OK, so I’ve calmed right down about all these things.

T.3.70-73. At the moment it doesn’t bother me (my risk of disease), because I feel I look after my health so it’s a risk that won’t affect me. I look after myself and so it doesn’t affect me now. So no, it’s not a problem, I am healthy and I have other more pressing concerns that take up my time at the moment, in the future that may change, but right now I don’t worry about it.

Engaging in health screening was perceived as another way of actively protecting yourself, of taking control and of minimising your chances of falling ill. Screening was thought to help increase survival in being able to detect health problems in the early stages. Participants who were more active in looking after their health and favoured health screening appeared to express more positive attitudes towards undertaking genetic testing.

T.15.44-48. I think they are very valuable (health screening tests). Obviously, I’ve been for... I have had mammograms in the past and they have proved to be very helpful, so I would encourage people to go along for mammograms, if they can...I think it’s a good idea. It’s better to know about these things as soon as possible because that way you have
more chance of doing something about them, so yes I think they are a very good idea. I'd have all the tests that were offered to me.

However, not all the participants shared this view. Some participants felt that nothing much could be done to prevent disease so ‘you were better off living in ignorance’. Some participants expressed the idea that screening gave you health problems, or could make you ill with unnecessary worry. See below -

T.3.71-90. I can’t say really that I very keen on them at all, no (health screening tests). I’d probably say that I’m really quite anti them. ...I think to have them when you haven’t got a problem can cause an awful lot of anxiety and you could go for an ECG and they could tell you that you have a heart problem and you could spend the next ten years worrying about that, that you’re going to die of a heart attack, then you could get run over in a years time. Probably that why I’m against them, really. I think with breast cancer, I think, you know... people lead quite healthy lives, and they’re quite old and all of a sudden they go for breast screening, and all of a sudden there’s a lump there, and they spend the next twenty years in misery really, when they would have spent twenty years, exactly the same time, without the misery.

Similarly, not all the participants shared the view that taking active measures to look after your health minimised your risk of disease. A large number of the participants felt taking direct action to reduce your risk, with activities such as exercising and attending screening, had a limited value or was of no value. For these participants predictive genetic testing was seen as pointless and as a means of increasing worry about their future well-being.

T.20.10-15 I do a physical job, but other than that, no I don’t do anything health wise. ...No, not really, I smoke, and drink, probably a bit too much, so I’m not active. I’m not a health conscious person; I’m not actively interested in looking after my health. ...Don’t think it makes any difference, doesn’t stop you getting sick, and anyway I can’t be bothered. No point, what will be, will be. That’s it.
Many participants expressed that ill health was a gamble, a ‘game of chance’. You could try to increase your odds of survival (gambling analogies were used) by living a ‘more healthy’ life, but there was no guarantee of success in terms of avoiding premature death.

T.8.15-16. *I think your future health is a bit like Russian roulette, you can be the fittest person in the world and still develop a cancer that kills you...*

T.20.39-42. *...people get these illnesses regardless of how they live their life, they can be extremely fit, and still have a heart attack and die. So, there’s not way of knowing, for everyone it’s a fifty-fifty gamble, people from all walks of life, no matter how healthy they are, can suffer from a serious illness.*

As discussed, a number of participants considered lifestyle behaviours ineffective. For these participants, managing disease-risk anxiety did not involve actively caring for their health but instead involved ignoring this risk. Disease anxiety was dealt with by not discussing it and trying not to think about it. These participants appeared to use solely this strategy to minimise their anxiety, however all the participants - including those who felt leading a healthy life might help protect them - expressed that disease risk was something you should avoid dwelling on. See below -

T.1.83-84. *When you talk about it (anxiety over risk of disease) somehow it’s more in your face, more real, and also it gets kind of scary.*

T.7.74-77. *... talking about it (risk of disease) makes it more worrying in some ways, more real, don’t know...maybe I feel no-one would be that interested. Don’t know, I think I just try to keep it to a level, you know to something in the background.*

T.11.37-40. *If I think too much about myself and the future, well it ties up you in knots, just makes you feel down, and worried, stops you getting on with living life, worrying about what might happen, so I try to just get by, keep it in the background (risk of disease), and live day to day.*
The dialogues outlined represent basic themes that emerged from the data, and serve to highlight differences in perceptions. It is also important to note the similarities that were present. Throughout the twenty interviews there appeared to be a strong belief that worrying about becoming ill could make you ill. Many participants also felt gaining future knowledge of their disease risk would render them powerless and that testing could only bring fear and worry - you could quite literally worry yourself ill or dead. See below.

T.5.167-171. .....but you'd probably live in the fear of symptoms, and they wouldn't be there, wouldn't be signs and symptoms, but you'd be 'Yes', constantly thinking about it. So you might actually make things happen, make things progress quicker than perhaps they would. It could make you ill, thinking, thinking about it all the time. A self-fulfilling prophecy.

T.3.110-114. No, I feel I might have a heart problem because it's hereditary, but I'm not going to worry about it. I might pack up smoking, and hopefully eat a sensible diet, but I certainly wouldn't want someone to confirm this, and spend the rest of my life worrying about it, something that may never happen. I think you can die from worry or make yourself ill from worry.

T.18.83-85. It's not healthy in itself to keep dwelling on these things, it's best to just get on with living and deal with any trouble when it comes, otherwise you can worry your life away, worry problems into coming.

The second concurrent theme was that risk of disease was primarily due to a person's family history - the genes you were lucky or unlucky enough to inherit from close family members, especially the parent you felt most similar too. Some participants did mention lifestyle factors as increasing their risk of disease, although the frequency of this dialogue was less evident. It is acknowledged that the concept of disease as genetic may be partly influenced by the nature of the research study. The participants were aware that the focus
of the interview concerned genetic testing, so it is not surprising that the influence of genes in causing disease were foremost in the conversations – see below.

T.6.25-30. *I know that my cholesterol problem is inherited, um... and if I didn’t know before - it was confirmed, because my identical twin brother and I both have exactly the same thing. Um... and, and therefore I do believe there are some causes of heart disease which are genetic, therefore I believe I’ve inherited this and do have a predisposition to heart disease, therefore I have a greater risk than people who don’t have that.*

T.16.21-26. *I’d probably say high risk. ...basically my family history. My mother has high blood pressure, her mother had a heart attack, well more than one heart attack, um...and had cancer. And my father - his brother had cancer and a heart attack, a triple by pass. So both sides of the family have both cancer and heart disease.*

In assessing the cause of disease, and assessing their perceived risk the participant’s family experiences were widely discussed. For some participants dwelling on their risk was a positive experience, particularly if they perceived themselves to be at low risk – see below.

T.4.15-19. *I would say I’m low risk, going on my family history...Obviously as you get older you start to think about these things more, and I think well, I feel healthy, and luckily for me my family haven’t got a high incidence of cancer or heart disease, so I count myself lucky, I’m not going to have it...*

However for the participant below discussing her risk of disease was traumatic. Although she considered herself to be at low risk (of cancer and heart disease) she had a family member who was currently ill. This appeared to make the reality of ill health and the possibility of disease more salient -

T.13.13-26. *I don’t think of it toward me (risk of disease), but I am very aware of the diseases...Well, I constantly worry myself about getting ill, with my brother and
everything. I know first hand how illness can totally devastate your life. I worry about being around, being alive and well for my children growing up, all that sort of thing... It's very important in my life. My health and the health of my family are probably the most important things in my life because I know what the loss of that means. I see my brother and I am very aware how the loss of that is. So it's very important to me yes... because I see my brother, with a degenerative disease, every day, so you can't help but worry about your own health. It's a big issue in my life.

Another concurrent theme was the role of genetic testing for individuals who were already excessively worried about their future. Many participants felt that if an individual was already experiencing excessive anxiety then genetic testing could only be of benefit. The worry attached to receiving a genetic test result could not ‘blight’ the person’s life as this was already the case. In these circumstances genetic testing was perceived as offering relief from uncertainty.

T.15.140-145. If I had a general worry about any particular health issue, if it really, really concerned me, if I thought I was at risk you know at some point in my life of having some sort of terrible disease, then if they offered me a test I would definitely, you know, if it really, really worried me, and if I was having trouble sleeping, stuff like that then I would think, you know, just for peace of mind I would take the test.

T.19.25-27 I think if a person is worried about cancer, say because their parents had it, or a heart attack or something, then if they have the test and it allays them fears, or confirms things for them, then I think it's a good thing...

There also appeared to be universal agreement about the use of genetic testing for reproduction - in terms of preventing serious childhood diseases such as cystic fibrosis - and universal disapproval about genetic advances such as cloning. People expressed being concerned about genetic technology ‘going to far’.
T.13.202-206. I think like I said if they can cure people of some of these terrible diseases that can only be for the good, but there again, I am worried about it too, you know cloning and messing around with the sex of babies, and stuff like that. I feel quite scared with I think about the future in some ways, because it all seems so alien and new, and I don't think people really know enough about what going on, so I don't know.

T.5.222-227. ...the experiments going on with the genetic testing, and the fact that you can chose certain factors within the gene pool, and I think that's ethically wrong. Um...I do feel that's wrong. But I don't think people should have the choice, I don't know if I'm going off the rail, but choosing eye colour etc. Um...I think the human race, has to be the human race. Um... if you start mixing with technology then things can get dangerous later on. Get out of hand.

There was another dialogue running through out the texts concerning our human desire for self-knowledge and the imperative nature and power of technology.

T.9.126. I'm generally keen on all forms of technology and information, so I think the more the better, really. I'd be keen to know more about myself.

T. 5.157-159. ...there is this facility available, so now people want to know. You can't take away that knowledge once it there can you, can't put the genie back into the bottle.

All the participants, even those with no intention to undertake the procedure, felt the development of this technology offered some positive possibilities -

T.13.177-176....if you can, through genetic testing, save people from being born with cystic fibrosis and all these illnesses that could be prevented then that's a huge thing, and obviously I agree with that.
When people are planning a family it might be good, if there is some sort of genetic history of something, then I think it would be useful to know, so you could plan whether you wanted a child with this or not.

Equally the majority of the participants were worried about the societal control of genetic technology, and felt that access to genetic testing and test results should be governed by those in authority. For sample texts see category label – ‘determinants of genetic testing decision-making’ in results stage 1.

Finally within this stage of the analysis the complexity of the issues raised must be acknowledged. Within the interviews participants expressed many contradictory viewpoints and had many changes of opinion. Inconsistencies within the dialogues were not uncommon and serve to demonstrate that people’s decision-making and attitudes regarding genetic testing are both problematical and manifold.

Yeah I would have genetic testing, I would for arthritis, because it would be useful to know if I was going to get that... (later on) I think genetic testing is a bad thing. Because it totally changes the way people think, and live their lives, and they must become obsessed about their health and I don’t think that’s a good thing, no....

...this thing I'm going for the heart foundation, I think it's a DNA test, yes it is, and I've agreed to do that, to take part in a research project. ... (much later) In my job I'm involved in chemical warfare and it's because people have messed around with viruses and things that can kill people, that chemical warfare has become an issue. Sort of sixty years ago, there was no known chemicals that would wipe out whole nations if you like, now there are, and this is due to research. This is the irresponsibility of research... So I don't think genetic testing is, on the whole, a good thing.

The decision-making itself (regarding undertaking testing) was relatively straightforward for only a small number of the participants, however it is noteworthy that such strong and unequivocal viewpoints did exist. For these participants coherent explanations were given
to support the decision-making, and there appeared to be little debate or ambivalence regarding this decision. The intention towards undertaking genetic testing were clearly stated ‘yes’ or ‘no’ and not wavered from. However for many other participants the decision of whether or not they would have genetic testing was characterised by indecision. Participants often appeared to be quite keen on the idea of this procedure at the beginning of the interview but on further reflection of the issues the attraction of genetic testing appeared to wane.

T.12.131-156. It sounds like I’m contradicting myself now, but part of me would want to live with the uncertainty, but then...Because there is always that chance that you wouldn’t get it, and if you’re told that you will get it, then you know there’s not much hope is there, for that. ...it’s complicated, it gets more complicated the more you think about it really, because part of me thinks no I wouldn’t, part of me things yes, but I don’t know. It’s so difficult, I think when it came to it, I would have to give it a lot of thought.

T.5.242-244. I think from the beginning of the tape my feeling was that it was very important to test, but now I’ve got near to the end of the interview um... I don’t know, I’m not so sure, I think I’ve changed my mind on that.

Below is a summary of the core themes that emerged from the data set as a whole –

Attitudes and intentions towards predictive genetic testing were determined by whether this procedure was perceived as increasing or decreasing control over one’s life and future health. Perceptions of control were determined by -

- Levels of general self-efficacy – an overall belief in the ability to tackle difficult problems.
- Levels of health specific self-efficacy – a belief in the ability to minimise disease risk and to cope with future anxiety associated with this risk.
- Levels of perceived anxiety associated with ill health

Attitudes and intentions towards predictive genetic testing were also determined by

- The extent to which the factors above were reflected upon.
7.5 Discussion

The study aimed to investigate the perceived consequences of undertaking predictive genetic testing for individuals at low and high perceived risk of disease. The study additionally aimed to further examine the role of self-efficacy in genetic-testing decision-making. Specifically, the study set out to examine factors that determined whether predictive genetic testing was perceived as decreasing or enhancing control over health and life in general. We also set out to identify which areas of self-efficacy had most impact on genetic-testing intentions.

Analysis of the data revealed that some participants' attitudes and intentions towards genetic testing appeared to be influenced by perceived levels of general efficacy - the overall belief in their ability to tackle difficult problems. For some participants the overall feeling was that, no matter how difficult, problems were best tackled, and they expressed feeling confident enough to do this (regardless of their level of perceived risk of disease). However other participants felt less confident in their ability to cope with a negative result. The ability to plan ahead was not enough - if medical interventions were unavailable than genetic testing offered no positive outcome, only the creation of worry and a lack of control over the future. For a third groups of participants there was little debate about whether the disease being tested for might be curable, with the development of disease described as inevitable. A sense of helplessness dominated these participant's conversations and they appeared to want to deal with this lack of self-efficacy by ignoring or denying their risk (see below) rather than taking active measures to protect their health. This group of participants most strongly expressed the intention not to undertake this procedure.

Results from the previous two studies suggest that genetic testing decisions can impact on the individual's overall sense of control over life although, interestingly, levels of general self-efficacy were not found to influence people's intention to undergo predictive genetic testing. People's intentions towards testing appeared determined by specific self-efficacy (and importance of this efficacy). Theoretically this finding was difficult to explain, one
would expect a reciprocal relationship - with general self-efficacy both being affected by genetic-testing decisions and levels of perceived self-efficacy having some impact on intentions. The findings from this study offer an explanation by suggesting that levels of general self-efficacy may be only relevant to decision-making when the individual’s confidence is extremely high, in that the person feels confident to cope with the test result, regardless of any possibility or cure or prevention. For people with less general efficacy the ability to action health specific outcomes may be more important, or alternatively the ability to ignore their risk.

Self-efficacy is a cognitive process and interestingly those participants who expressed feeling efficacious about their ability to cope with problems, or who felt they might be able to prevent the disease, appeared to view the advantages of testing in more practical terms, such as being able to action future plans. This perception was in contrast to those participants who expressed less self-efficacy about their ability to cope with a negative test result. For these participants it was not the practical consequences of being at risk of disease or of being ill that were discussed, but the emotional consequences of coping with the worry associated with receiving genetic-testing information. Current strategies used for coping with their risk such as ignorance were perceived as being removed by testing, along with any control over the management of disease-risk anxiety. Many participants expressed feeling fearful that they would unable to cope with this outcome. Research into risk-taking and decision making has found that people do produce different kinds of consequences when declining an action than when considering taking it, with the risks incurred by taking action not mirroring the risks avoided through declining (see Fischhoff, Downs and Bruine de Bruin 1998).

Both intentions and attitudes towards genetic testing appeared linked to levels of health specific self-efficacy - how the participants perceived dealing with their risk of disease and coping with the associated anxiety. Generally those participants who dealt with their risk by being efficacious and taking active measures to control their health risk - such as attending screening and eating well expressed more positive comments regarding genetic testing. As discussed, for other participants managing their disease-risk did not involve
actively caring for their health but instead involved avoidance strategies. It was notable that throughout the interviews, the ability to keep disease risk in the background, and prevent risk from becoming too salient, was perceived as vital to a person’s psychological well being and ability to enjoy life. Different strategies for achieving this were talked about at length, you could either tackle risk ‘head on’ by leading a healthy lifestyle, or you could try your best not to dwell on your health and just get on with living. Overall the anxiety caused by disease risk was something not to be discussed or talked about (even by those who engaged in active measures to control their health) as this made things ‘more real’ and ‘frightening’. The extensive use of these different strategies suggests that this task was not perceived as easy, but as imperative. Equally the language used to describe disease risk was powerful and destructive. Risk was like “a bomb, ticking away inside you”, or a game of “Russian Roulette”. It is also noteworthy that the participants universally agreed that the certainty offered by genetic testing was of benefit for someone excessively worried about their disease risk. This dialogue suggests that living with excessive levels of disease anxiety is perceived as a strong deterrent to leading a ‘happy’ life.

For some participants, their level of perceived anxiety over their disease-risk was huge, with high levels of anxiety appearing related to high perceived risk, although this was not always the case. The risk of disease was expressed as being due to a person’s family history, with anxiety about this risk appearing dependent on aspects of the participant’s biographical history and how this affected the perceived proximity and salience of risk (see analysis stage 1). For example an individual could feel at low risk of a disease yet the possibility of ill health could be salient, and occupy a central position in their lives because a close family member was currently unwell. Alternatively a young and fit individual could have a strong family history of heart disease so state they were at high risk but feel that this risk was a long way away, so the risk was not salient and their anxiety was low. One of the participants expressed very clearly feeling at low risk of both cancer and heart disease but because she had a brother with a degenerative neurological disease her own anxiety about her risk was high.
For many participants, with high levels of disease-risk, anxiety facing up the reality of their risk seemed impossible. It was expressed that facing up the reality of disease risk might quite literally worry the person to death. This dialogue helps to support and explain the results from our previous study; when we found that participants with a high perceived risk of disease had little intention to undergo genetic testing, particularly when they felt in control of their health and valued this level of control. It may not have just been the level of their perceived risk that was pivotal, but the level of anxiety attached to this risk. This rationale also helps to explain the study by Kash et al., (1992) mentioned earlier. The study researched the impact of having a heightened risk of breast cancer on surveillance behaviours using the health belief model (HBM). The study found that contrary to the HBM, increased anxiety led to decreased preventative health care behaviours. In the study, increased perceived susceptibility and increased personal efficacy also predicted less health care behaviours; again results opposite to predictions made by the HBM. The data from our study suggests that the high probability of being diagnosed with breast cancer, rendered breast self-examination and clinical screening too anxiety provoking, in that risk could no longer be avoided or denied. In another study by Lerman, (1993) into mammography adherence it was also found that amongst women with a family history of breast cancer (in at least one first degree relative) excessive breast cancer worries were associated with reduced screening.

Throughout the conversations, the decision-making process (regarding undertaking testing) was characterised by ambivalent and contradictory statements, although as mentioned a few participants did state their intentions with an unequivocal 'yes' or 'no'. However, many participants were unsure about whether they wanted testing and about their ability to cope with the end result. Ambivalence in the decision-making process appeared to arise from the desire for certainty offered by genetic testing. Testing appeared to offer a tantalising glimpse into the future, with the possibility of freedom from disease worry and a means of taking more control over one's health. There was a desire for increased knowledge of the future and a new level of control particularly for participants who felt at high risk because testing could offer freedom from anxiety. But equally, for participants with high risk, the flip side of this equation was the probability
of a negative result, and the dilemma of not knowing the outcome of the test until after
the event. The psychological impact of ambivalence in regard to genetic testing decision-
making, intentions and behaviours has not been studied, although research has indicated
that conflict is particularly common regarding health-related behaviours (Conner and
Sparks, 2002). Research on the impact of ambivalent attitudes and the intention to engage
in sex found that ambivalence significantly moderated the impact of affective attitudes,
but did not moderate cognitive attitudes regarding intentions (Conner and Sparks, 2002).

The researcher also noted that participants often appeared to be quite keen on the idea of
undertaking predictive genetic testing at the beginning of the interview, but on reflection
the attraction of genetic testing often appeared to wane, perhaps as the incumbent
psychological burden attached to living with a negative test result was considered more
deply. Initially, genetic testing tended to be viewed favourably in offering a useful
medical diagnostic opportunity, with the human desire for self-knowledge, and the
imperative nature and power of technology expressed. All the participants even those
with no intention felt that the scientific development of this technology offered positive
new possibilities to some people. Research by Tymstra (1989) suggests that medical-
technical possibilities are often experienced as strongly compelling, with use of health
screening viewed favourably by society and attendance easily becoming automatic.
Within our study this compelling desire to take up and develop new therapeutic
diagnostic opportunities appeared to coexist with, on further reflection, concerns about
where these developments would lead, and how the results of technology would be
controlled both personally and at a societal level.

7.5.1 Conclusions and future directions
The findings from the study suggest that levels of general self-efficacy may affect
intentions to undertake genetic testing, but only when levels are high enough to allow the
individual to feel confident about coping with the test result, regardless of any possible
outcomes. The findings from this study also suggest that levels of health specific self-
efficacy (the ability to reduce risk and cope with the worry associated with risk)
determine genetic testing decision-making and intentions, with those individuals active in
protecting their health, and coping with their risk, expressing more positive attitudes about the possibility of testing. However, attitudes and intentions towards genetic testing also appear to be strongly determined by levels of disease-risk anxiety. For many individuals with high anxiety the reality of facing their risk appeared impossible, with the perceived emotional consequences overwhelming more cognitive and rationale decision-making. Similarly the attraction of testing appeared to wane when the consequences of genetic testing were ruminated upon. Again any practical advantages of testing may be eclipsed when the psychological consequences of living with a negative test result are considered more deeply. Obviously these conclusions are tentative. Exactly how levels of disease-anxiety, risk and self-efficacy interact with each other to determine intentions still needs clarification. The concepts and themes generated by the study provide a starting point for psychological research, psychology needs to examine further the relative impact of each of the specific factors identified, and further investigate how they might interact to shape decision-making.
Chapter Eight

Overall discussion
The current research set out to contribute to, and extend, psychological understanding of the public’s decision-making when contemplating undertaking predictive genetic testing. The following sections identify how the research achieves this aim.

8.1 Brief overview
The qualitative and quantitative methods employed address several important theoretical and ethical questions. Firstly, the research provides a detailed picture of how more general groups of people perceive predictive genetic testing; the issues that they perceive as salient to undertaking this new health choice; the perceived costs, consequences and concerns. The research gives new insights into the impact of decision-making in this area. The findings show that a lack of perceived control, over predictive genetic testing, has wide reaching consequences, in serving to decrease global perceptions of competence, and decrease the value of control in this domain. Additionally, the results show that intentions towards testing are different in people with low or high perceived risk of disease. Interestingly, participants with high risk, who felt in control of this disease, and valued this control, had little intention to undergo testing. Results, from the final study, suggest this lack of intention stems from the belief that ‘genetic-disease’ is largely immutable. Hence, the knowledge gained from testing creates excessive anxiety, with many participants expressing that genetic testing might quite literally worry them to death. There was also a strong belief that the knowledge gained from testing could be self-fulfilling, that the worry created by this knowledge could bring on ill-health. Although many of these conclusions are tentative, the findings presented do raise ethical questions that need to be asked and answered, before the wider use of predictive genetic testing can be advocated with confidence.
8.2 Summary of the findings

Due to a lack of previous research, the first study uses an exploratory focus group methodology, to explore how general groups of people perceive predictive genetic testing. The aim was to elicit factors that influence how people respond to the possibility of undertaking testing. From the analysis two main topic areas emerge. Firstly, people appeared concerned with their risk of genetic diseases, and their perceived control over possible outcomes. Overall, the participants perceived genetic diseases as largely immutable - if you had the genes you were at high risk and were going to get ill. However, differences in opinion were divided, regarding what action could be taken to control this risk. Those participants more in favour of testing appeared more optimistic and efficacious, about their ability to control the future, after genetic testing. Individuals high in self-efficacy may perceive genetic testing as a positive way of accessing new outcome options, and taking more control over their health and future. Individuals low in self-efficacy may find genetic testing detrimental, with the lack of perceived ability to action outcomes, resulting in feelings of powerlessness and fatalism. Research has shown that high levels of self-efficacy can determine whether risk is translated into actual health behaviours (Rimal 2000). However, the question of whether self-efficacy interacts with perceptions of risk, to change personal feelings of vulnerability and intentions towards genetic testing, had not been researched.

The second main topic discussed, in the focus groups, concerned perceived control over genetic-testing decision-making, and the dissemination of information resulting from this procedure. Many participants felt that predictive genetic testing would become compulsory, with some participants expressing that freedom in this matter was already illusionary. In our sample, intentions towards testing appeared strongly influenced by this issue. If the respondent felt that genetic testing would be a matter of individual choice and allow for personal autonomy, then the procedure was seen as a more viable. This perception of control may again be linked to individual differences in perceived self-efficacy - but at a more general level. A high level of self-belief may allow the individual to believe they have the personal resources to exert control over any threat, posed by the introduction of this new technology. Similarly, a high sense of general self-efficacy may
allow the individual to feel in control of any situation. If genetic testing confirms a high risk of a disease, then the individual will perceive being able to tackle this.

The second study investigates the impact of specific and general self-efficacy, on genetic-testing decision-making, and examines the relationship between self-efficacy at a specific and general level. Investigating whether and how testing decisions impact on perceptions of control increases understanding of the impact of these health decisions, and provides a useful starting point in unravelling why some people may decide not to utilise testing in the future. The study firstly determined the extent to which perceived efficacy over genetic testing decision-making could be manipulated, by examining the effect of being given or denied the choice of undertaking a predictive genetic test, for a common illness. The research then examined whether a lack of efficacy in this domain could generalise, to other areas of personal control, as measured by a decrease in general self-efficacy. The relationship between specific and general efficacy was examined with potential factors, the importance of self-efficacy and levels of general efficacy, influential in the process of generalisation, explored.

The results showed that perceived self-efficacy, over decision-making, could be successfully manipulated. The results then indicated that changes to specific-efficacy did impact on levels of general self-efficacy. Significantly, both the threat and enhancement to specific-efficacy had more impact when levels of general efficacy were low. This suggests that high general-efficacy acts as buffer, diluting the impact of any potential threat or change. This change in general self-efficacy occurred regardless of the importance of this construct, although the importance of efficacy did appear relevant at a domain-specific level. Participants who felt self-efficacy over testing decisions was highly important had significantly lower efficacy after reading the threatening media report.

The third study investigates the second major theme to emerge from the earlier focus groups - people’s perceptions of genetic risk, and their control over this risk. The aim was to determine how perceptions of disease-risk and self-efficacy interact. The study also
aimed to expand understanding of the role of self-efficacy, by examining whether changes in specific or general efficacy alter people's intention to undergo testing. In addition, the study aimed to replicate the previous findings, by again demonstrating that changes to specific efficacy could produce changes in general self-efficacy. The research also aimed to clarify whether the importance of efficacy played a part in any generalisation process.

The results showed that the experimental intervention (disease information about arthritis) successfully manipulated both specific-efficacy and perceptions of risk. After the intervention aimed at threatening control, specific-efficacy scores significantly decreased. Likewise after the intervention aimed at enhancing control specific-efficacy scores significantly increased. No significant differences were found in the experimental conditions that did not aim to manipulate self-efficacy. These changes occurred regardless of the importance of self-efficacy, or the level of risk. Although importance did not effect changes in specific-efficacy, the results showed that levels of importance were significantly lower after the threat. The results additionally showed that, after exposure to the four experimental conditions, perceptions of disease risk increased, with this increase most pronounced after the intervention threatening control. This suggests that just reading about a disease, increases perceptions of risk, with risk becoming particularly salient, when a disease is labelled both genetic and uncontrollable. In line with the findings from the second study, the results from the third study also found that changes to specific-efficacy appeared to affect levels of general efficacy. General efficacy was significantly reduced after the condition threatening control. However, decreased levels of general efficacy did not affect the participant’s intention to undergo testing. Theoretically, this finding was difficult to explain. One would expect a reciprocal relationship, with general self-efficacy both affected by genetic-testing decisions and having some impact on intentions.

The analysis revealed that intention to take testing was affected by perceptions of high risk, specific-efficacy (over the symptoms of arthritis) and the importance of this specific-efficacy. Participants with high risk of disease (arthritis), who felt in control of
this disease, and valued this control, had little intention to undergo genetic testing. In contrast participants with moderate to low levels of risk intended to have testing. These results suggest, the motivational processes underlying intention to be tested are different, across the two risk groups. Furthermore, pictorial examination of the relationship, between participants with low and high risk of disease and intention, revealed a lack of symmetry. This suggests that perceptions, in the two groups, were quantitatively and qualitatively different.

Hence, the aim of the fourth and final study was to investigate the perceived consequences, of being diagnosed with a genetic predisposition, and subsequent intentions towards testing, for individuals at low and high perceived risk of disease. The fourth study additionally aimed to examine factors that determined whether predictive genetic testing was perceived as decreasing or enhancing control. We also hoped to identify other areas of self-efficacy that might impact on genetic-testing intentions. The analysis revealed that general self-efficacy appeared relevant to decision-making, when levels were extremely high. In this instance the participant appeared confident to cope with the test result, regardless of any possibility or cure or prevention. For individuals with less general efficacy, the ability to action health specific outcomes, or alternatively ignore their risk, appeared more important. Both intentions and attitudes towards testing appeared linked to levels of health-specific efficacy; to how the participants perceived they could deal with this risk. Generally, those participants who dealt with their risk by being efficacious, and taking active measures to control their health, were more positive about undertaking testing. Other participants appeared to manage their risk by using avoidance strategies.

Attitudes and intentions towards genetic testing were strongly determined by levels of anxiety. Many participants with high levels of risk, stated that facing up the reality of this risk was too anxiety provoking. It was expressed that facing up to one’s risk might quite literally worry the person to death. This dialogue helps to support and explain the results from our previous study. Many participants with high perceived risk had little intention to undergo genetic testing, particularly when they felt in control of their health, and
valued this level of control. However, it may not be just the level of perceived risk that is pivotal, but the level of anxiety attached to this risk. For many participants, genetic testing was conceptualised in terms of the negative emotional consequences attached to this procedure, with cognitive and rational decision-making less evident. Equally, the attraction of testing appeared to wane, when the consequences of genetic testing were reflected upon. The practical advantages of being tested appeared diminished, when the psychological consequences of living with a negative test result, were considered more deeply.

8.3 Wider implications

In considering the implications attached to these findings, several important issues are raised. Predictive genetic testing was, presumably, developed to improve the health and well-being of the nation, so people could know with some certainty their future risk of disease, and take action accordingly. However, that people want to have this knowledge, and perceive it as allowing them to take control, live longer and better plan their lives, cannot be assumed. Within all the main models of health behaviour discussed, there is an assumption that people act rationally, and in ways that enable them to be pro-active, and take control to improve their health, once obstacles such as a lack of knowledge have been removed. Our research suggests, with predictive genetic testing this is not always the case. For many of our participants genetic testing did not represent an opportunity to gain knowledge about their health, or be more pro-active in protecting themselves from disease. Generally, perceived control, over the development of diseases labelled as ‘genetic’ was low. Even if the disease being tested for could be actively controlled, many participants expressed that they simply didn’t want to know. Many, but not all, of the participants expressed that disease-risk was something best dealt with by using avoidance strategies. It was better to just get on with life, and not think about one’s chance of illness. If, as research suggests (Senior, Marteau and Peters 1999), people are more pessimistic about the control of ‘genetic diseases’, in believing that prevention is not possible, then predictive testing appears to offer little. Even more worrying, is the suggestion that information resulting from testing may be detrimental.
Research into behaviour change, following testing, suggests that people don’t always take action to reduce their risk. A study by Audrain et al. (1999) examined the behaviour of smokers, given genetic-susceptibility testing. Smokers who were given feedback, about their increased susceptibility to lung cancer, were initially more likely to attempt to quit smoking. However, 12 months on, they were no more likely to have actually quit than participants who received minimal counselling. Other researchers suggest that genetic information may have an opposite effect, to the one desired, in creating a sense of fatalism and inevitability about the onset of disease (Marteau and Lerman 2002). The results, from the third study, support this rationale, with individuals with high risk, who felt in control of the disease, and valued this control not intending to take testing. Dialogue, from study four, suggests this lack of interest stems from the belief that genetic disease is largely immutable. Hence the knowledge gained from testing creates excessive anxiety and lack of perceived control over the future. Certainly, there appears little benefit in informing people that their smoking behaviour is likely to lead to nicotine related illnesses and earlier death (as in the Audrain et al, 1999, study cited earlier), if they are unable, or unwilling to change their lifestyle.

However, as mentioned, not all our participants felt that predictive genetic testing would rob them of a ‘sense of control over the future’. Opinions, regarding what predictive genetic testing could offer the individual were divided, with the key to this division appearing to be determined by perceived self-efficacy. In the first study, those participants who stated they are more in favour of testing, appeared more optimistic and efficacious, about their ability to control the future after a genetic-test result. However, data from the third study did not support this suggestion. Those participants high in health-specific self-efficacy, and with high risk, did not intend to undergo testing. Additionally, levels of general self-efficacy did not appear to influence testing intentions. Data, from the fourth study, offers some explanation for this contradiction, in suggesting that levels of general self-efficacy may be only relevant to decision-making when the individual’s confidence is extremely high. For those high in general self-efficacy, there appeared to be an ability to cope with the test result, regardless of any cure or prevention.
For people with less general efficacy, the ability to action health-specific outcomes, or alternatively ignore their risk was more important.

Obviously, these conclusions need further investigation, but overall the findings do suggest that the relationship between self-efficacy and genetic testing decision-making is complex. The findings also suggest that this complex relationship may have wider implications, for the population’s health and well-being, than has previously been recognised. In the first study, many of the participants felt that, the decision to undertake genetic testing was something they would have no personal control over, because control over their health was something they were already denied. Interestingly, findings from the second study, found that a lack of perceived control, over the decision to undergo genetic testing, impacted on people’s sense of general self-efficacy, and the importance of maintaining control in this domain. If, as seems likely, predictive genetic testing does become more mainstream, real-life testing decisions will have to be made. The results presented suggest the impact of not having perceived control over these decisions will be significant - in eroding peoples’ global perceptions of control, and the desire to maintain this control.

The results also have important implications for Bandura’s self-efficacy theory (1997). The theory states that changes in specific efficacy will generalise, to other specific areas of efficacy, when there is shared or similar qualitative features. For example, mastery of a high-risk physical activity will generalise to types of physical stressors, but not to mental tasks. The findings suggest that the process of generalisation is wider and more complex. Changes to a specific domain of efficacy, can transfer to impact on global perceptions of competence. Additionally, the results suggest that, changes in an area of self-efficacy that encompass a relatively small part of peoples’ lives - few of our participants had actually undergone genetic testing - can have a significant impact on a general efficacy.

The research set out to investigate the process by which efficacy transfer might occur. Bandura has suggested that the perceived importance of a self-efficacy domain may be influential (Bandura 1995), but no research had been conducted to confirm or refute this
theory. The research set out to determine the answer to this question, in two different ways. Firstly, the study investigated whether the perceived importance of specific-efficacy affects the impact of a perceived threat. Secondly, the study examined whether the perceived importance of general efficacy itself, acted to moderate the process of transfer. Overall, the thesis produced mixed support for the concept of importance, as a factor in generalisation. Levels of importance appeared more influential to changes in specific rather than general efficacy. In regard to general efficacy, the results were again mixed. In the second study, both the threat and enhancement, had more impact when levels of general efficacy were low, suggesting high general efficacy may dilute the impact of any potential change - both positive and negative. This outcome was further supported in study four, with participants who appeared to have high levels of general confidence, appearing less concerned about coping with the consequences of testing. However, these conclusions are speculative. To fully answer these questions more research, focused on measuring base levels of general self-efficacy, and any perceived change, across a number of different threatening and empowering situations, is needed. Similarly, if, as shown, a small domain of efficacy can impact on feelings of general competence, the question raised is whether a domain that encompasses a larger area of life, would produce a larger effect, and vice versa.

8.4 Limitations of the research and methodological issues

One limitation of the research, is the perceived importance of the specific domains of efficacy measured (genetic-testing decisions or the symptoms of arthritis). In the second and third studies, an analysis of the importance of these domains, revealed that the majority of participants felt having control in these areas was important to them. Yet, for practical and ethical purposes, few of our participants had ever made genetic-testing decisions. None of our participants sampled were currently affected by arthritis. Conducting research that encompasses a more immediate area of living would be useful, such as measuring the impact of a threat to mobility, for both disabled and able-bodied individuals. Such research would enable us to determine, whether change to an area of efficacy that varied more widely in importance, similarly impacted on levels of specific and general efficacy.
Similarly, although the researcher made great efforts to gather a wide range of participants, the demographic and socio-economic location, of both the researcher, and the University where the research was undertaken, was a limiting factor. Individuals with higher education, or professional or semi-professional occupations, were over represented. The negatively skewed and peaky distribution of the importance of general efficacy scores also suggests that perceptions of general efficacy were universally important in our sample - another factor which may have lessened the impact of our findings. The sampling and methodology used obviously permits certain conclusions, but leaves other questions unanswered.

The multi-method approach adopted enabled us to develop our theory more widely, and with greater complexity, than a single methodology might afford. The qualitative research enabled us to identify salient areas of concern, when investigating the public’s contemplation of predictive genetic testing. The methodology allowed the researcher to obtain a detailed understanding of how these identified concerns, particularly self-efficacy and disease-risk, were constructed. The qualitative analysis added a richness of meaning, complexity and depth to the constructs, not easily determined using psychometric scales. From this level of analysis, the researcher was able to develop new theories, regarding how these concepts might relate to, and impact on, each another. The quantitative research then allowed the content of this initial theory building to be tested further. The repeated measures experiments were robust means of further examining the role of self-efficacy and disease risk, on decision-making and intentions, enabling an unravelling of the relationships between this constructs.

Having used a multi-method approach, to establish that a lack of perceived control over testing-decisions and risk, can influence global perceptions of competence, and intentions, an important next question is the enduring nature of this change. Currently, no longitudinal research has been conducted that addresses this issue. Yet, the longer-term implications of a lack of efficacy, over decision to undertake genetic-testing, resulting in low general efficacy, are weighty. The findings also suggest that, for many of our
participants, decision-making in this area was complex, ambivalent and anxiety
provoking. Again, the wider and longer term impact of this ambivalence and anxiety is
unknown, with wide-scale predictive genetic testing yet not available. Obviously this lack
of availability means it is difficult to conduct longitudinal studies, which judge the impact
of factors such as perceived self-efficacy, on the actual uptake of testing. It is accepted
that factors which may influence peoples' initial intentions, may not be relevant to the
action of taking testing – and that this question currently remains largely unanswered.
However, it seems sensible to start by considering factors that might influence a person's
decision to become informed about testing. Equally, it is not just those individuals in a
clinical situation that need to be considered. It is important to explore the early decision-
making, and motivations, of the vast majority of individuals who may decide not to
approach their doctor about genetic testing, so will never present themselves as part of
the clinical population.

8.5 Conclusions
Advances in human genetics have been based on enormous financial and technological
efforts, however there is little sign of any comparable intensity in our efforts to
understand and deal with the impact of this new health choice. If genetic services are to
be targeted, and successfully utilised, by those most at risk, ensuring that this new
technology really does serve to improve the nation's health, such questions will need to
be asked. Failure to understand the range of psychological responses attached to this
choice, will at best, result in the potential offered by this technology not being realised,
and the needs of the public not being met. At worst, it may lead to the view that
psychological casualties are an acceptable aspect of this area of health care. Psychology
needs to enable people to make the best genetic-testing decisions possible, and provide
people with the best tools to use this information constructively. By uncovering people's
anxieties, and addressing them, psychology will enable clients to make informed and safe
choices, maximising the benefits and minimising the negative consequences attached to
testing. We need to ensure that the decision to undergo genetic testing serves as a catalyst
for empowerment and positive change, and does not become a fatalistic and negative
prophecy.
Bibliography


genetic testing for breast cancer in high-risk women. Psychology, Health and Medicine, 6 (3) 321-333.


Decruyenaere, M., Ever-Kiebooms, G., Boogaerts, A., Cloostermans, T., Cassiman, J.,
for Huntington’s disease: Individual decision-making, personality and avoidant


Dinoff, B. L., & Kowalski, R. M. (1999). Reducing aids risk behaviour: The combined
efficacy of protection motivation theory and the elaboration likelihood model. Journal of
Social and Clinical Psychology, 18 (2), 223-239.

and perceptions of genetic testing in a sociodemographically diverse sample. Journal of
Behavioural Medicine, 23 (1), 15-36.

Dudok de Wit, A. C., Tibet, A., Duivenoorden, H. J., Niermeijer, M. F., & Passchier, J.
(1998). Predicting adaptation to presymptomatic DNA testing for late onset disorders:
who will experience distress. Journal of Medical Genetics, 35, 745-754.


college students: The problem of motivating change. Health Education Research, 3 (1),
59-65.


Hutton, D. (2002). Health, inside information. With our knowledge of genetics, we will soon be able to predict the diseases we are likely to suffer from and take preventative steps. It's a big idea, but one we need to get to grips with, says Deborah Hutton. *Vogue*, Conte Naste Publications, May edition, 2002, 147-150.


Appendix I - study 1

Verbal information given preceding participation

Thank you for agreeing to take part in this research. As I have previously mentioned I would like us to talk about some of the health issues that we all have to deal with as a consequence of developments in medical science. In particular I would like us to talk about health tests that enable a healthy person to find out about the likelihood of them developing a particular disease in the future. As you may know these tests are called genetic tests. For example, currently a person can request to have a genetic test for breast cancer. This service is currently available to people at very high risk of this disease.

Genetic testing involves attending a genetics clinic and having a blood test, the blood is then genetically analysed. The person being tested will then be told whether they carry a gene - predisposing them to developing breast cancer. If the person does carry the gene, they will be told what the estimated likelihood is - of them developing breast cancer in their lifetime – compared to a person within the normal population without the gene. This type of testing has also been developed for diseases such as heart disease, Alzheimer’s disease, diabetes, colon cancer and many others. Although genetic testing for these conditions is still quite rare, it is widely thought that genetic testing for these conditions will be more widely available in the near future.

Before we begin would you like to ask me any questions about the information I have just given you?
Appendix II - study 1

Information form - version 1 - pilot study
One copy to client, one to be retained

Date

Dear

Postgraduate Research - Lay Beliefs, Attitudes and Intentions towards Genetic Testing: A focus group study.

I am a postgraduate research student working at the University of Surrey. I have been sponsored by the European Social Research Council to research how people feel about genetic testing, the reasons why they would or would not have a genetic test. To carry out this work I need volunteers. Volunteers don’t need to be particularly knowledgeable about this subject; in fact it’s probably better if they are not.

Gathering the opinions of people like you is vital. The final published research will ensure the views of ordinary people are known, and help inform policy makers and shape new developments in this area. Participation involves talking about your opinions, how you feel about genetic testing, with me, the researcher for approximately half an hour.

The interview will be audio-taped so it can be remembered accurately later on, but at no time will you be asked to give your name, and you will not be personally identified. Your views will not be used for any purposes other than the research. You are free to withdraw from the project at any time, talk freely about what ever you wish, with no set or right answers expected. If you feel you would like to take part, please indicate below.

If you have further enquires please contact myself (Tel: 0181 399 9536), or Dr. Lyons who is supervising this project, at the School of Human Sciences, University of Surrey (Tel: 01483 876902). I hope taldng part is a positive experience and thank you for your time and assistance.

Yours sincerely

Jane Hendy. (BSc. MSc.)
(Postgraduate Ph.D. Student University of Surrey)

( ) I confirm I would like to participate in the above study
( ) I would not like to participate in the above study

265
Appendix III - study 1

Dear

Postgraduate Research - Lay Beliefs, Attitudes and Intentions towards Genetic Testing: A focus group study.

This form is to ensure you fully understand what participation in the above study involves, and that you wish to take part.

As discussed, participation involves talking to the researcher about your opinions regarding predictive genetic testing for approximately half an hour. The interview will be audio-taped and transcribed so it can be remembered accurately later on, but at no time will you be asked to give your name and you will not be personally identified. Your views will not be used for any purposes other than the research stated.

You are free to withdraw from the project at any time, talk freely about what ever you wish, with no set or right answers expected at any time. If you fully understand what is involved and have no further questions please sign the consent form attached.

Please feel free to contact me if you do have any further enquires or alternatively you can contact Dr. Lyons who is supervising this project, at the School of Human Sciences, University of Surrey (Tel: 01483 876902). I hope taking part is a positive experience and thank you for your time and assistance.

Yours sincerely

Jane Hendy. (BSc. MSc.)
(Postgraduate Ph.D. Student University of Surrey)

I confirm my full understanding of, and agreement to participate in the above study

Signed: - Date:-

--------------------------- ---------------------------

266
1. Genetics tests are becoming increasingly available. These tests predict the possibility of a person developing certain genetically influenced diseases or conditions, such as different cancers, heart disease, Alzheimer's disease, alcoholism, and some forms of mental disorders like manic depression. Would you have such a test?

2. What are your reasons for or against having testing?

3. What do you think should be the most important thing in making that decision?

4. What comes to mind when I say the words genetic testing?

5. Would you have a test to tell you the likelihood of any children you might have inheriting a serious medical disorder?

6. Under what circumstances do you think unborn children should be genetically tested?

7. Do you think people carrying a serious genetic disorder should have children?

8. Would having a known family history of a disease be a relevant factor in deciding whether or not to have genetic testing?

9. Have you got any concerns about the future of genetic testing - in terms of your own life, the life any possible children or grandchildren you might have, or just general concerns?

10. Do you generally feel the development of this technology is a good thing or bad thing?
Information form - version 2 - main study
One copy to client, one to be retained

Dear

Postgraduate Research - Lay Beliefs, Attitudes and Intentions towards Genetic Testing: A focus group study.

I am a postgraduate research student working at the University of Surrey. I have been sponsored by the European Social Research Council to research how people feel about genetic testing, the reasons why they would or would not have a genetic test. To carry out this work I need volunteers. Volunteers don't need to be particularly knowledgeable about this subject; in fact it's probably better if they are not.

Gathering the opinions of people like you is vital. The final published research will ensure the views of ordinary people are known, and help inform policy makers and shape new developments in this area. Participation involves talking about your opinions, with other people in a group for approximately one hour.

I will be present during the group discussion, asking the group some questions. The discussion will be audio-taped and transcribed so it can be remembered accurately later on, but at no time will you be asked to give your name, and you will not be personally identified. Your views will not be used for any purposes other than the research. You are free to withdraw from the project at any time, talk freely about whatever you wish, with no set or right answers expected. If you feel you would like to take part, please indicate below.

If you have further enquires please contact me (Tel: 0181 399 9536), or Dr. Lyons who is supervising this project at the School of Human Sciences, University of Surrey (Tel: 01483 876902). I hope taking part is a positive experience and thank you for your time and assistance.

Yours sincerely

Jane Hendy. (BSc. MSc.)
(Postgraduate Ph.D. Student University of Surrey)

( ) I confirm I would like to participate in the above study
( ) I would not like to participate in the above study

268
Dear

Postgraduate Research - Lay Beliefs, Attitudes and Intentions towards Genetic Testing: A focus group study.

This form is to ensure you fully understand what participation in the above study involves, and that you wish to take part.

As discussed, participation involves talking in a group about your opinions regarding predictive genetic testing, for approximately one hour. I will be present during the group discussion, asking questions and taking notes. The discussion will be audio-taped and transcribed so it can be remembered accurately later on, but at no time will you be asked to give your name and you will not be personally identified. Your views will not be used for any purposes other than the research stated.

You are free to withdraw from the project at any time, talk freely about whatever you wish, with no set or right answers expected at any time. If you fully understand what is involved and have no further questions please sign the consent form attached.

Please feel free to contact me if you do have any further enquires or alternatively you can contact Dr. Lyons who is supervising this project, at the School of Human Sciences, University of Surrey (Tel: 01483 876902). I hope taking part is a positive experience and thank you for your time and assistance.

Yours sincerely

Jane Hendy. (BSc. MSc.)
(Postgraduate Ph.D. Student University of Surrey)

I confirm my full understanding of, and agreement to participate in the above study

Signed: - Date:-
Appendix VII - study 1

Examples of possible prompts used by the researcher to direct the focus group discussion

Genetics tests are becoming increasingly available. These tests predict the possibility of a person developing certain genetically influenced diseases or conditions, such as different cancers, heart disease, Alzheimer’s disease, alcoholism, and some forms of mental disorders like manic depression.

1. Would you have such a test?
2. Can you tell me about your thinking in deciding that?
3. What are your reasons for or against genetic testing?
4. What do you think should be the most important issue in making that decision?
5. What comes to mind when I say the words genetic testing?
6. Would you have a test to tell you the likelihood of any children you might have inheriting a serious medical disorder?
7. Under what circumstances do you think unborn children should be genetically tested?
8. Do you think people carrying a serious genetic disorder should have children?
9. Do you think the decision to have genetic testing should be entirely personal?
10. Do you think other people - for example doctors or other family members - should have a say in this decision?
11. Would having a known family history of a disease be a relevant factor in deciding whether or not to have genetic testing?
12. Would the nature of the disease be important, for example how preventable a disease was?
13. If you underwent a genetic test to determine your susceptibility to a certain disease, say cancer, and they said - yes, you have an 80% chance of developing cancer in your lifetime - how do you think the information would affect your life?
14. What would you do?
15. How would knowing this risk make you feel?
16. Have any of you got any concerns about the future of genetic testing - in terms of your own life, the life any possible children or grandchildren you might have, or just general concerns?

17. Do people generally feel the development of this technology is a good thing or bad thing?
Appendix VIII - study 1

Example transcript

Focus group no. 2. - Retail Workers in clothes shop.
I = Interviewer   R = Respondent

Interview preamble then –

I: Do you think any of you would ever consider having a genetic test?

R: I would.

R: I wouldn’t, not as from now, because there wouldn’t be any point really. Cause O.K they might tell you you’ve got a gene that predisposes you to breast cancer, but if you’re the age that I am you look for lumps, for breast cancer anyway.

R: But if you had a family?

R: Yes, then I would, but I haven’t got a family history of anything like that, so no.

R: But in my case I got a daughter who might have children, so therefore yes, that might be quite important.

R: It depends on your circumstances.

R: Yes, because you’re on your own, and if you had someone else you’d think ahead.

R: I don’t know cause I’ve got a daughter, and I feel the same as L.

R: If someone asked me tomorrow do I want to go and have a test for breast cancer my answer would be no, I don’t want to know...what’s the point of knowing something there’s no cure for. It’s just your own abuse and I wouldn’t want the worry... I think you only want to know if there was a cure. I mean I only want to
know if they cure me. If they said I'll give you a test for breast cancer, but they can
cure you if you've got the gene, I'd be first in the queue. If they couldn't 100% cure
me then afraid not.

R: But you might find out.

R: But you could know what's in store for the future, they might be able to eradicate
this in the future.

R: What the point in worrying about it now cause they can't eradicate it now. If you
went for a test to find out if you were predisposed to breast cancer and they said yes,
'you are, you've got the gene', you'd spend the next ten years worrying you're going
to get breast cancer.

R: Yes, there is that too.

R: I don't think you'd have a test unless you had a family history. Unless there was
some sort of reason.

R: Yes, and it would be important to anyone that was adopted who didn't know their
family history.

R: Yes that's true.

R: I hadn't thought of that, that's a different angle.

R: I know my friend J, who is adopted and when she was trying for a child she had no
idea whether her parents were of white origin, or anything, cause she was never able
to trace her parents at all. I know when she was pregnant it was quite an issue to her.
Cause she said to me you know your parents and grandparents, you know your kid
could look like me or your other half, but I haven't got a clue.

R: It probably would be a good idea cause they can test for so many different things
now.
I: Do you think how preventable it was, do you think that would be an issue? Make a difference?

R: It's got to be an added bonus, cause I've got arthritis and maybe if I known earlier I could have stopped it. But if A (daughter) has got it, and she was tested there is probably something that would help it, that would stop that. I'd do anything to stop her having that.

R: This is the difference I think when you have children.

R: Yes this is the difference, yeah, because you're thinking ahead all the time.

R: Yes and it's not just the child, it's grandchildren as well.

R: And the advances by then will be so good that they will be able to stop all sorts of things.

R: Is it hereditary then, your arthritis?

R: I don't know.

R: There must be a particular gene that predisposes you to it.

I: Can I put a scenario to you, if you decided to have a test for say breast cancer and they said yes, you have an 80% change of developing the disease, how do think that would affect your life?

R: I had read in magazines of women who have had both breasts removed because they were told that, they had both breast removed now. So they won't get it, because they're already had it done, and they're much happier, cause both parents or the grandparents had died at thirty-five.

R: Wouldn't you feel great if they said you're not susceptible to anything you're one hundred percent healthy, you feel wonderful wouldn't you, but then you get run over by a bus. (Laughter)
R: You can worry about it, worry about it to death. You can go on holiday tomorrow and your plane drops out of the sky.

R: What’s the point of doing something to make you feel stressed about if there isn’t anything you can do about it.

I: Would you have a test?

R: Well yeah, if there was some reason, then I would have it. But I’m not sure, um, that if I had predisposition to breast cancer or something, then it would worry me. But I’m not sure if I would go to the extreme of having both breasts removed, to prevent it. I would probably pester the hospital and doctors to death to make sure they did everything to prevent it, if it did occur. That they acted very quickly. But yes there’s for and against. I wouldn’t want to know I don’t think, unless there was some reason to think something might go wrong.

R: I think if you had a grandparent or parent die earlier, then I think you would.

R: But you wouldn’t have you breasts taken off just in case you might die.

R: They wouldn’t give you the test unless you had a family history.

R: You could have a check up every three months, couldn’t you?

R: You could pay for any tests that you want to have done, so that’s irrelevant really, so you could have the tests done.

I: Are you worried about who might gain access to your genetic information? Say prospective employers, or insurance companies?

R: That’s the most worrying the thing I think.

R: Yeah.
R: You can be prejudiced against before you even walk into the room for an interview.

R: J is. He can’t get life insurance.

R: I think they are going to want to know things like that.

R: It can stop you getting health insurance and things like that, if you’ve got a gene that predisposes you to something.

R: The thing is, it predisposes you, it doesn’t mean you’re going to get, that you’re going to die, so really they shouldn’t be able to do that.

R: But they do it now, J can’t get life insurance, cause he’s got things wrong with him, they won’t insure him now, so...

R: You’ve only got to be smoking, not to be insured. That’s the first question they ask you, and if you say yes, the premium goes way up.

R: So this testing thing, this is going to have even more of an effect. And the drugs as well, because certain types of drugs they will think you are unsuitable for because, if you have a certain gene.

R: It would just stress you out, so much pressure.

R: And the drugs as well, because certain types of drugs they will think you are unsuitable for because, if you have a certain gene, so you won’t be able to get them so easy.

R: I’m like anyone, when someone comes for a job you analyse them to see if they’re had a lot of time off sick, and then I’m wondering what sort of genes have they got? Well you would wouldn’t you. You could employ someone and then they’d be off sick for the next two years, prime example.

R: So you would have no private things at all.
R: I think the information should be between you and your doctor.

R: But it never is. It’s not now. There are always people who will find out that information.

R: You’ve got to have strict guidelines of who needs to know.

R: Yes, very strict.

R: It’s like credit card information, I work full time and I’m for ever being offered these things. My mother who doesn’t work, said to me the other day ‘nobody ever offers me credit cards’.

I: So do you think your genetic information would get out, or do you think it would stay confidential?

R: No (all round).

R: Nothing is confidential.

R: When it’s computerised, nothing is confidential.

I: So is that a concern? The lack of confidentiality.

R: Yeah, Yes (all round).

R: Who has access to your information, that’s the concern?

R: I think it depends on what it was for.

R: It’s only as confidential as the person putting it in, isn’t it. If you got Aids or something and someone knows someone, who’s coming to work for me, they’re going to say to you, ‘oh did you know so and so they’ve got Aids’. And you’d be like, ‘Oh!’... You’ve never going to keep that secret.
R: You’d get things, like when I worked in the Post Office with the Official Secrets Act. I had to sign, but that doesn’t mean to say its secret, just cause you signed it...

R: I mean like the Prime Minister's life, nothing is private, so what chance have we got?

R: A couple of years ago a kid hacked into the Pentagon, so even that sort of information is not secure.

I: Another issue I like to put to you is the sponsorship of this research by pharmaceutical companies, and the attempt to patent genes.

R: I don’t think any company should own a gene.

R: It’s wrong.

R: But it could take years and years to pinpoint a gene, and cost a lot of money.

R: I think it’s really sad, because if you’re really rich you could be cured of it, and if you poor you haven’t got access to that patent, so you wouldn’t be cured.

R: It’s the same as it is basically now, in a lot of ways. If you can’t afford to pay you go on the waiting list.

I: So the cost is an issue?

R: I don’t see that they should be able to make money out of people’s illnesses...

R: But if it’s going to be helpful.

R: But they’ve been doing research for years without there being patent on genes.

R: But there is more illness now, people are living longer, so we need to know more.
R: We do need to know more, I'm not saying that you don't, but I'm not at all sure I'm in favour of them owning genes just to make money.

R: But as M says nobody's going to do all this research if they are not going to make some money at the end of it.

R: You don't want to go to work for nothing.

R: I think the products should be available to everyone.

R: It's like MS if you've got the right Doctor, or the money you can have the drugs, if not you can't. That is happening now.

I: Is whether you have to pay for these tests an issue then?

R: You're going to have to pay for it. In years to come who knows? If there is an outcry?

R: It's like it is now, you can go private. I can't pay and I have to wait. That's the way it is now.

I: I'd like to ask you now - whether you would consider having a genetic test to tell you whether your children would have cancer?

R: It's all very extreme, they're trying to breed a perfectly healthy nation, and that's going to alter the course of the whole world isn't it.

R: I heard years ago about whether you could pick your baby, blue eyed blonde haired girl.

R: And that's going to be possible isn't it?

R: It shouldn't be possible though.
R: L could go out tomorrow and decide - I want a baby - and if she’s got enough money she can decide what type of hair.

R: Yes, and what type of person that baby is going to be. So I could choose.

R: That’s terrible.

R: But as I’m the only one here without children, if I was going to get pregnant I would opt for the test where I was going to be tested first - before I got pregnant - so I would know the genes before I had the child. Just in case.

R: Yes rather than waiting until you were pregnant, and then having it done.

R: That’s dangerous anyway, isn’t it?

R: If was available and I had the choice of doing it anyway, I’d have it done before.

R: When I was pregnant with F I was offered the test. And after getting pregnant all I wanted was this child, and the Doctor said did I want to tested for Down’s – blah, blah, blah. And my personal view was that no matter what difficulties my child had, I still wanted it, and I said to my doctor I really don’t care. I just wanted my daughter. But I must admit it was difficult cause they put the question to me, just the question to you, the choice is like, ‘oh my God’.

R: But if genetic tests were available to have before you had the baby would you have had them?

R: I suppose yes, if the tests were available before you had the baby then yes, but once you’re got them it’s really difficult, you’re deciding whether you want to kill that baby or not.

R: I agree the same, but some things don’t work before you’ve had the baby, things like Downs. But I don’t think I would want to know, not unless there was something very serious in the family, I wouldn’t want to know.
I: Do people generally feel the development of the technology is a good thing or bad thing?

R: I feel it's a good thing as long as it's kept in check as long as there are guidelines that have to be followed.

R: Have they checked this on animals?

I: Yes, I think it's gone beyond animals now, it's already available for certain types of cancers, and lots of known genetic disorders.

R: It has been in the paper this - last week about it.

R: I think some testing, depending on what the disease was, might be advisable. So it depends on the testing, what you're testing for, or what you think you might be carrying. Because some children just don't have lives with a genetic disorder.

R: I must admit when I had my scan... It's the same thing really they're checking you.

I: There is a disease called Huntington's disease, it's fatal and you can be tested to know if you have it, 100%. It's just an example, but if you knew you were at risk of a potentially fatal disease do you think the opinions of other people would affect you decision?

R: I think you'd try and find out as much knowledge as you could before you listened to other people's views. You'd listen to other people but at the end of day it's your decision, you'd do what you wanted.

R: I think some people would disapprove, 'how could you do this if you knew'. I should think it would be quite an issue, especially from family. When I was pregnant with my daughter, anything like that I knew, I don't think I could have gone ahead, to be quite honest. Cause I'd be going ahead for reasons of my own, not for her... I think we are all influenced by what other people think all our lives aren't we, even to the most unimportant issue like you hair. So the opinions of others, regarding your child
it's the ultimate isn't it. With my daughter, everyone wants people to say isn’t she lovely, not isn’t she ugly.

R: They’re things people would look at. If it was heart or if it was blood disease, you know that. Perhaps you carry that and give it to your baby, and go ahead and have a baby. ‘Oh I’m pregnant’. Can you imagine what your mother would say, or what your sisters would say, you know. ‘How could you do this.’ And your baby might be, you know...might be badly disfigured or something.

R: I watched it on children’s hospital, where one child is badly disfigured and needs mega medical treatment and the parents have gone on to have another child who needed exactly the same, and I must admit, in that case I have thought ‘oh why have they had another kid’. I have put my opinion forward, and maybe that is wrong.

R: But not all ailments you can see, you can’t see if you’ve got cancer, or heart disease, or a blood disease. If you’re deformed you can see that can’t you? But with this genetic testing you would not be able to tell.

R: For deformities and mental problems yes. But there’s got to be other illness, or what going to happen, there’s going to be too many people in the world. We can’t have perfect babies all the time, and there’s no room for everybody in the world is there.

R: Do we want perfect babies all the time? Do we want a perfect nation? Are we going to become a society where we’re not going to allow imperfection?

R: Everybody loves the idea of a perfect world, but there’s no such thing as a perfect world, just like there’s no such thing as a perfect person.

R: Everyone’s got something wrong with them.

R: We are all so different, we all want different things, our morals are so different. So you know -
R: Because someone hasn't got no legs we treat them so awful, yet they may have more to offer than someone so perfect – like that scientist man on the tele – you know.

R: I think genetic testing will lead to that, (to abortions and designer babies discussed all at once in background). Would you really want a dear little baby and know right from the word go that it's going to have something wrong with it.

R: People have got to have this, and got to have that, and they're going to want the perfect family. I think that's the danger, people are going to want to choose to have perfect children, and your going to lose...

R: When you say perfect, you mean healthy, just healthy.

R: But how many people are healthy?

R: But D that snowballs into people choosing exactly what type of children they want.

R: What about people having genetic tests before they marry like AIDS tests?

R: Well it might be useful, so they can prevent a genetic disorder.

R: But I think it should be that person's choice.

R: But then you get one healthy child and one abnormal child.

R: But that's still their choice.

R: But I think there's a danger that it will not be a person's choice. You can choose what you want to do, you can chose to have these tests, you can choose not to have them, but there's a danger years down the line that you don't have a choice.

R: If you're going to get married there's a law that you're going to have to have this genetic testing. If you're going to have children you got to have them perfect. And that will be a curse, like Hitler again, perfect families, perfect people.
R: Do you think we will all want these perfect people?

R: A brave new world, and the expense - that they are going to cost. Right from the start it’s going to cost a lot of money.

R: But I still think if there were certain illnesses that could be cured, that you could be tested for.

R: But I still think it should be the choice of that individual. I don’t think that ‘they’ should make it. The problem is it’s becoming so much, that if you’re going to take out health insurance or mortgages or whatever, you are asked these questions, and they want to know exactly what you might or might not get. And I think it should be a person’s individual choice whether they disclose that information.

R: I think L is right I don’t think we’ll have the choice. Even now without us realising it you don’t have the choice. When you’re pregnant you automatically have these scans. You don’t have the choice. You don’t ask for them, you don’t request them. And if you say you don’t want them they think you’re like the pits, so already you don’t have the choice, they’ve already put medical issues upon you...yon don’t have a choice in this. You’re just unaware of it.

R: You don’t abort unless it not right.

R: When you’re pregnant you don’t have a choice, you have to go for that scan. They don’t want you have your baby at home, when you have the baby in the hospital the first thing they do is take it away from you, and do lots of things to it, you don’t have a choice in this.

R: There’s a strong danger that this is going to get more and more, in all aspects of your life that you are not going to have a choice. That’s the thing that is, the most worrying thing. You won’t have a choice and people won’t notice it because it is going to happen so gradually. Like you said, you look back ten years ago we didn’t all have scans, you had the baby naturally.
R: But N got a brother who is brain damaged. All through her pregnancy we were worried, in case our children had brain damage, but with these tests you can actually know. It's your choice.

R: And then when you have the scan, if you don't want the baby it's up to you, so you have a choice then.

R: They shouldn't say to you, 'we don't think you should have that baby'. You do have a choice, but that's the danger, that you won't have a choice, you'll be told.

R: 'We think it's better for you to have this'. Someone in authority.

I: Another issue I want to put to you is the moral or spiritual issue. Are we tampering with nature, with natural law? Does anyone have any thoughts on this?

R: It goes back to everybody's individual opinion, you have got the choice, and you and your partner make that choice, it not something anybody can really dictate. You can't have the head of the church saying 'oh, you've got to go and do that'.

R: You might have in Ireland though.

R: Jehovah's witnesses.

R: If you've got nothing in your family, if nothing ever goes wrong you'd think no I would never have it done. But if you had a problem you can't say what you'd do, if you were given the choice or opportunity. It only when it comes very close to home that's it's a different outlook.

R: It's very easy to say, 'oh no I wouldn't have this done'.

R: Two perfect people can make a wrong.

R: I've heard people say to me 'oh, no I never want a pigs heart', but if it's your child you'd do anything.
R: Of course you would.

I: Does anyone feel it’s morally wrong.

R: They need rules on it.

R: They’re got to have very strict guidelines.

R: I don’t believe in God, I don’t think God would make these poor little dreadful children.

R: Yes, it not to do with God, it’s all wrong, like with the Jehovah’s witnesses.

I: So you all think it’s morally and ethically O.K?

R: Yes (all round).

R: I think we can go to extremes, there has got to be limits on it.

I: What are the limits on this?

R: Cloning... We all disagree with cloning (Lots of agreement).

R: They shouldn’t do testing without you knowing.

I: What about abortions, that was raised?

R: I think it’s your choice.

R: It’s your conscience - you have to live with it.

R: Absolutely.

R: Up to the individual person.
R: I think, my own personal view, which I feel very strongly, once the baby is a certain age, I don’t agree with aborting it, cause it’s a human being.

I: If I was sitting here legislating for you people what would you want me to do?

R: We all disagree with cloning.

R: The information, clear information, strict guidelines, and security.

R: I think the security part for individuals, is most important. That information is not passed on to anyone else without your permission. We should be more aware of this information. We can’t do testing without the general public being aware. Got to be public knowledge, got to make sure it’s right.

R: I mean if your taking about the Hitler thing, everybody’s idea of perfection is different, so I don’t think everybody will be blue eyed blonde and five foot tall, if you like. So I don’t think that is very serious. I mean you have the choice now, you can have the child or abort it. You didn’t have that choice even a few years back, that choice wasn’t available.

R: It’s all happening so quickly and people will just accept it because it becomes the norm.

R: A lot of the illnesses are being bred out because of this.

R: It will be interesting to see how far it will go, be allowed to go, I should say.

R: If you think of how many people nowadays have Down’s syndrome children.

R: Or spastics.

R: In my aunt’s generation it was quite a few. If I think of how many people I know now with Down’s syndrome children, I could say none. They’ve wiped it out really.

R: It not cause you have less older mothers, it’s because of the testing.
R: Giving people the choice.

I: Getting back to your own selves, if you could have a test for your own selves, say heart disease, indigestion, a whole range of things. Just go down the clinic and have a blood test, to tell you your predisposition to a whole range of stuff, how do each of you feel about that?

R: I wouldn’t go for it, it would just give me blood pressure and I’d die anyway.

R: I’d only have it if it was curable.

R: I’ve have it, cause you could tailor your lifestyle then, you diet, and if things were going really bad for you, you could prolong your life, a better quality of your life.

R: Say they came back to you and said ‘yes’, you had a predisposition to all these things. How would that make you feel, you think, ‘Oh my God’.

R: Your only predisposed, your not necessarily going to get it.

R: But you’ve still got that worry, at the back of your mind haven’t you. You’d still think about it.

R: You’d worry yourself sick.

R: Not necessarily it depends on your state of mind. In ten years time I might start thinking about it.

R: You think - when you go for your scan, that fortnight of waiting for the answer is the longest fortnight of your life. If they said yes, you’ve got this - blah, blah, blah, you spend the next five years waiting for it to happen.

R: Every twinge you’d start to think I’m going to get this, I’m waiting to get that.

R: I don’t know - it depends on your mental outlook.
R: The only way I’d have that was if I was going to have children, and I thought there was might be a problem in my family.

R: I think the problem is when someone says to you do you want these tests, and you automatically have it done, and you automatically think you’re going to be Ok. I think the problem is, if you came back and they said, ‘sorry Mrs. M but in two years time your going to be dead’, life would be awful wouldn’t it.

R: Would you have it done?

R: Yes, but only if it was recommended for a particular reason, if I’d gone to the doctor with something, and he said, ‘well we don’t know but we think you should have this done’.

I: In what ways do you think it might be good?

R: Well as I says you could then tailor your lifestyle, your diet, whatever, to what reasons there were for having it. If you were predisposed to a stroke or something.

R: But there are things you can’t do anything about.

R: That’s true but...

R: If I went for a test to find out - my mothers got Alzheimer’s - if I went for a test to find out. It’s not hereditary that sort of thing, not hers. If I went for a test to see if I was going to get that, I wouldn’t want to know. Every time you forgot something, you dropped a cup you’d be, ‘oh my God’.

R: There isn’t something you could do now, but there might be a cure in five years time.

R: But I still don’t want to know, unless in five years time they say ‘yes you’ve got that, and I can cure it’.
R: If you knew you could be cured you'd have the test?

R: Not helped, but cured, yes.

I: You said you would have test?

R: Yes, I've got the same problem as L. My mothers got the start of Alzheimer's, and yes I can't cure it, but I might be able to do something to stop it getting any worse, so yes, I'd want to know. I want to know if I have some ghastly illness.

R: I don't know, I'd do it on a need to know basis, myself.

R: They thought I had a brain tumour a few years ago, and they were talking about the scan results, but I lived though that. But I wanted to know, so I could plan my life, so I knew what I wanted to do. Um, certain things in my life I'd love to do, and if I had a limited time I'd go and do them. You'd do it if you have something coming. A little bit of preparation can go an awful long way, mentally and physically.

R: But that depends on your outlook on life.

R: That's right. I suppose in some ways I'm a pessimist. I always do look on the bright side.

R: That's not a pessimist. (Laughter).

R: Is it Alzheimer's we're talking about? (More laughter).

R: I'm sure we give her fizzy water.

R: It just depends on the individual doesn't it?

I: We getting to the end now, so I just wondered if there were any important issues any of you would like to raise.
R: Now they've got the knowledge it isn't going to go away, so you can't go back can you. It's there, so hopefully they'll find some way to make it work. So like you say it's going to happen anyway, so if they can just make sure it's for everyone's benefit, and it's regulated probably then I think it's OK.

R: I just think it's worrying, with the people who do this research, they have such enthusiasm, they will go to any lengths to get this research, and that's what really worrying. There is probably no guidelines already, on how far they go, and what I would like to see is definite guidelines on how far they go. Are we trying these new drugs in third world countries, how far will we go? Are we cloning people? It's really very worrying.

R: How much money do they spend on this research, millions and millions. So that could perhaps be spent better.

R: I think there's good things and bad things. Good if it's regulated if people are protected, but I wouldn't have it otherwise.

R: Sometimes the fear of something is in the not knowing, rather than the knowing.

R: I just think when you go to doctors they automatically take your blood pressure, they don't ask you. I just think if we not careful in ten years time you will go to doctor, and they will tell you whether you're going to die of this disease, that disease. Without even being asked, cause are we not asked now? We're not.

R: Just thinking about that, now you can only get some drugs in some areas, and other areas you can't. So if you've got something serious, is your doctor going to say, 'no I don't want you on my list cause your going to cost a lot of money'.

R: That happens now, funded practices.

I: Any last comments?
R: It's just information in advance, preventative medicine isn't it. Which is what it boils down to, in my mind, and whether you want to take the risk and have the test done, it's up to you. I think I'd do it.

I: So lastly can I ask each of you in turn, do you think on the whole it's a good idea?

R: Yes (all round), with guidelines.

R: It would be interesting to know what the very young think about it.

R: I think it's a bad thing – we won't be protected.

R: I think a good thing with the right guidelines.

R: You can't stop it. Whatever anyone says it going to go on.

R: We will be like Hitler, only the perfect child lives.

R: It happens already, so many older people. Average age is eighty.

R: How much nature do we want to interfere with?

R: Good thing, but with very strong reservations.

End of tape.
Appendix IX - study 1

Example transcript

Focus group no. 3. - Support workers in a medical centre.
I = Interviewer   R = Respondent

Interview preamble then –

I: Would any of you consider having such a test?

R: I would. I would certainly consider it because I have a very strong family history of heart disease. My Mum died at 48; my sister had two lots of open-heart surgery at under fifty and a stroke, so therefore I would be very happy to take part in the test.

I: What do you think the test would give you?

R: Hopefully it would give me an idea of things I could do to help myself.

R: I mean you can’t cure it, if it’s hereditary, you can’t cure it...

R: It might give you an idea of things you could do.

R: Isn’t genetic testing though only for if you want offspring? That’s the only reason I’d ever have a genetic test, because your genes are being passed on to your child, and then you’ve got to come to the idea of what your going to do if you’ve got this.

R: Logic tells me that if it’s going to do this sort of survey, and offering B the opportunity to, for them to say you’ve got a heart problem, and its genetic then we should be offering a genetic solution to it. So I see the two linking hand in hand, because there would be no point doing it and testing somebody without giving them a cure. So we’ve got to, got to put that part with a cure.
R: What would be the point in telling B cause she’s already had offspring, surely it got to be - surely somebody who’s going to have offspring.

R: I think it would be quite useful, for example if my daughter knew she was predisposed to this - again - what can I do to help myself. I may not necessarily be able to cure it, but there may be things I can do to improve my lifestyle and that may help.

R: Not just die.

R: Yes, yes.

R: And if you found out would you have children?

R: It would depend what it was I was being tested for, if it was something like heart disease then probably yes, but certainly if it was other things - mental illness, I certainly wouldn’t.

R: No cause we’ve got to think about that.

R: Yes.

I: Would how preventable a disease was, would that be an issue?

R: Might do, because I think it would be very foolish to test everybody just because they want to test people, without being able to offer them some sort of cure.

I: They offer breast cancer genetic testing at the moment with no actual cure.

R: So presumably if you had a female embryo you’re going to have that aborted, you can take it to the extremes can’t you.

R: Um, it’s a brave new world, all going too far.

R: I think they are farther down the road in America - where they are…
R: But that’s always been available for things like haemophilia, you can test if you’ve got a male or a female. If you’ve got a male you abort it, if you’ve got a female you can have it. To me we seem to have accepted that but were not accepting this new stuff. Are we?

R: But I think there’s a danger of taking it too far, we’re going to start altering the human race.

R: Um, Um.

R: I think we are naturally curious, aren’t we, as human beings, so it’s got to go far. But how we deal with the information is another matter.

R: But would you have a child if you thought it was going to be manic-depressive later on?

R: But is Alzheimer’s minor stuff?

R: I think Alzheimer’s must be absolutely horrendous to live with, especially when you see a loved one who has been an able bodied fit person.

R: My dad.

R: Yes you’re dad is a classic example, but they don’t know if it’s a family thing.

R: How long ago did your dad die?

R: About eighteen month’s two years ago. He was eighty-five.

R: Say he had the choice of genetic testing to see if he would get Alzheimer’s?

R: Knowing that he would get Alzheimer’s at eighty-five?

R: Yes that he would get it, so you abort him, but he had eighty-five good years.
R: But more to the point are your daughters going to genetically tested because they’re grandfather had Alzheimer’s at eight-five?

R: What a thing to think of, would you put your daughter through it, I wouldn’t.

R: Would you like to know whether you’re going to get Alzheimer’s or not.

R: No, no you can’t get me at the doctors I won’t go.

R: But you have that thing about Doctor’s don’t you C? So that puts you in an almost different category to most people, who at the slightest thing think, ‘Oh, I must go to the doctors’, cause that’s your natural reaction.

R: There are some things like your heart thing, that you’d like to know, that it would be handy and there are some things like Alzheimer’s that none of us would really want to know. I think that’s right.

R: You could also take this to another extreme if you were genetically counselled prior to marriage, you might have your husband to be genetically counselled, now if he had the same defunct gene, it could all get...

R: It could all get out of hand.

R: It would be like a prenuptial agreement.

R: There was a wonderful T.V program the other day, it was about a couple who had a genetically tested child, and the next child was a love child, and the child that was a love child was really looked down on, and got menial jobs because of it. So I almost see this scenario happening...

R: Isn’t it a bit science-fiction though, because you have your partner and yourself genetically done, and you love them and you find out you could have all these genetic problems, what do you do? Have a prenuptial agreement - and right - I’m off if you get anything.
R: Don’t you think this is always going to be the thing - where some couples think no matter what I can cope with it, and then there’s other people say - there’s no way - I don’t want to know. So it’s always going to be very very personal. You to your partner, to your family. Some families can cope with incredible things and other families would go under.

R: I think we’re missing the point, I don’t think we’re looking at genetic counselling for ourselves, were surely looking at it for the next generation. We’re not looking at it to say whether our partner will get a disease were looking at it....

R: No I’m looking at the future.

R: If I want to be genetically counselled, I mean tested, no I wouldn’t, definitely.

R: But what if something develops when they’re twenty, twenty-five and had you already known about it, you could have done something about it.

R: Not if there is no cure. If you can be genetically counselled and there is a cure I might, but not to be genetically counselled and there is no cure.

R: Say a heart defect something like that - that showed up. ‘Yes you’re got it, so therefore if we start your son on this sort of treatment now he will live a near normal life’.

R: No I wouldn’t cause I wouldn’t want to put that limitation on his life really. I rather that he had a short but enjoyable life, rather than drugged up worried life.

I: What about for yourself? Would you be genetically tested?

R: No, I don’t think so. I just don’t particularly want to do it. I’m all for living for the moment I don’t particularly want to grow old. I certainly don’t want to end up in a nursing home; I’d just would rather live a short but happy life.

R: I don’t want to end up like my father.
R: Exactly - and that’s what you’d worry about.

R: I think though, at the age that you are you can say that, but as you get older you’re clinging on. You’ve only got a few more years left so your attitude is...

R: Also socially we cannot, we can’t sustain people living for ever, because we don’t have enough working people to look after elderly people. But then I take that back because if they are fit elderly people that’s all right. It’s if we are supporting ill elderly people - that rather throws my argument.

R: I think it’s a moral argument eventually, because what we’re doing with medicine is sustaining life, if they couldn’t feed themselves, and everything else, boom. It’s only because we’re keeping them alive, and we’ve been told it’s the Hippocratic oath and everything, and we are indoctrinated to accept that life is paramount, and we must keep it at all costs.

R: Which is a great pity because if it doesn’t add quality to your life you’re not living, you’re just existing.

R: It doesn’t just apply to the old, saying that.

R: If your saying at 75 possibly, because that’s what happened to your parents - you’ve got Alzheimer’s - could you actually do something about your own life at 75? You could will something - that if I get Alzheimer’s then I want no medication, I want Nothing! I don’t want to become an Alzheimer’s person.

R: I’m a practising Christian and I don’t believe in ending your life in any way so that’s a very difficult thing for me to make that decision, I couldn’t do it. I wouldn’t want to end up like that but as a practising Christian I couldn’t do it.

I: As a Christian do you think that this technology is in any way going against God, against nature?
R: To some extent yes, but if it is improving life then I’m very much in favour of it but as a practising Christian there’s no way...

R: It has the possibility of destroying life.

R: But as a practising Christian I couldn’t put my hand on my heart and say I don’t want any treatment and things like that. What my family decide to do afterwards if I got Alzheimer's, and it was not in control, that’s a different matter all together. But the Christian in me could not make that decision, could not say that.

R: But in the end are they’re not just trying to, not in ten years time - but eventually, trying to end up with a super race.

R: And the other question is what colour would we be, would we be blue eyed and blonde, or black?

R: No cancer cells, and no manic-depressives and no... Everybody would be perfect.

I: Do people think this super-race thing is an issue?

R: I think it would be a great pity if it became that, yes.

R: I think it’s heading that way eventually.

R: Eventually it will happen, but we can’t not be curious, we’ve got to keep looking haven’t we.

R: I don’t think so now, up to about a hundred years ago.

R: If you talk about genetic testing, to be honest there are other factors like organ donation and things like that. People are waiting for organs, lungs and hearts from other people that might die. Now if genetic testing was done on a road accident victim, and they know - if the genetic details of that person was on a computer, they would know if it’s ok to put that heart of that person there. Because I don’t know, you can tell if the heart from the road accident victim - if the, the heart is any good. If they
put that on a computer they will be able to tell instantly, don’t bother doing a five-hour operation.

R: What are you saying everybody should be genetically tested?

R: I’m just wondering if maybe that isn’t a good idea, put it all on computer, that would make it just then an ordinary mundane thing.

I: Is the computer issue, that your information could be made available via computer to all sorts of people, your employer, health insurance people, does that concern you?

R: It’s a minefield.

R: Well seeing as they only need your postcode to find out about you, everything about you now, will it make a difference?

R: Will we all be breeding a race of sheep?

R: It gets back to the super-race again.

R: Big brother watching you.

R: Because they might say now they’re not going to use it, but ten years down the line.

R: And then it will affect our children, not necessarily us, we’re older. So it doesn’t affect us, does it, but it will affect our children.

R: It’s all stored on computer. They’ll have everything they want, it’s big brother. Big brother watching you. Which is more or less what it is now. The more information they’ve got on you, the more they’re going to use, they’ve got you.

R: And is this a personal choice, are people concerned about personal choice?

R: Definitely.
R: I think for most people personal choice had already been taken away. So much, what have we got left really?

R: Yes, even your testing we do at work I find it slightly - I find it - where you’re looking at people for heart problems and things like that.

R: So do I. Yeah we’re beginning to do it here, and I find it quite disturbing. I find it disturbing from their point of view. You know if they’ve got a heart problem you’re sort of bringing it to the forefront of their brain - therefore they are then dwelling - instead of getting on with their lives they’re focused on this heart.

I: So do you think genetic testing will be a choice?

R: Probably at first, but it won’t be. But in the future there won’t be no choice. No choice. (Everyone Agrees). Not in the future. Instead of the K injection of whatever they put in there with babies, it will be the genetic test. I think it is the way it’s going.

R: Saying that....

R: They’re invited.

R: Yes I know they’re invited, but they come to that desk and I’ve not seen one unworried looking man.

R: You will have a superior race, it may be even come to people who are not genetically up to scratch... Being knocked off.

R: Eventually.

R: Oh yeah.

R: What going to happen to the educationally subnormal? You get your genes tested as you say, it’s like you’re going to have a genetically abnormal child of some form, or get aborted, so you are streamlining the human race.
R: People are doing that already.

R: You can do it, but this is going to be become a matter of course as opposed to...

R: It is happening. People do have their child aborted if they decide they can't cope with a Down's syndrome child.

R: But what a lot of people will think now B, is yes, we will cope rather than get rid of them. But if it gets to the stage where so many people say no, we will abort, and it will be only the very, very minority of children, they're not going to want them. Just for the fact that they'll be so very different from the rest of the human race. Even though they want it, they're going to be scared to go ahead and have it.

R: I think people will always choose cause people have very strong feeling about their babies and it is extremely personal and people - it's amazing - people you think wouldn't want to keep a child keep it. And people who you'd think could cope say - no I can't, no way. I think it is so personal that.

R: Can I just say, why if it's going ahead that way, it's only applicable to educated countries, what about the third world and that, are you going to try it there?

R: It's a financial issue.

R: What the point of being genetically tested here when you've got India, Africa and all that. What's the point of doing one country if you're not doing the whole world.

R: Perhaps the educated countries want to make sure they stay that way.

R: Super-race.

I: What about the cost, it's expensive to be genetically tested?

R: Well I wouldn't pay for it.
R: It must available for all, you cannot have the few privileged do it. It’s just got be very carefully controlled. I mean I’m all for genetic counselling for cystic fibrosis. But genetic counselling to see of I’m going to die at eighty or seventy, you’ve got to be very careful. Genetic counselling if I’m going to have black hair or blonde hair?

R: No I agree with B, with that. Only for diseases that have a cure.

R: That’s no point without a cure.

I: But genetic testing is available to Huntington’s and most people would accept being tested for that, and having an abortion. Is testing for Alzheimer’s, which may affect you that bit older so very different?

R: It’s a thin wedge. What I would rather see is the right to euthanasia. With all the charities about, if there were euthanasia one I would subscribe to that. We’ve got to such an extent - we can control human life to such an extent that there’s no quality of life.

R: Well if I was tested and I had genetic leaning towards Alzheimer’s like my father then I could write something to say, I would have it.

R: Would you have the test? If it showed that it was, then you could organise your life.

R: That’s right. On the - that particular point I would have the test, not anything else. As long as I could be put down if I was that way inclined. If you’ve had somebody with it, it’s hell, absolute hell.

R: It also seems though we’re scared of the testing we haven’t yet gone into, yet we accept the ones like Huntington’s and Down’s because we’ve already done that anyway, so it is cause it’s new.

R: But yeah, it covers so many more things. Your going to get cancer, there’s not really a cure, what are you going to be doing? Looking for lumps all the time. If you’re got it that way inclined. What do you do if you find it?
I: Where do people think the line is between testing children for predisposition to cancers and say testing for Down's?

R: I think with Down's you're talking about something totally different. Down's Syndrome child, its life expectancy is so much greater and thirty years ago you would not have outlived your child. Your child would not have outlived you. It's a concern of the parents. You want to look after that child, and you know because of the dependency of Down's you've going to die before them, and it's just human nature isn't it.

R: You also have a very poor quality of life with cystic fibrosis, but with breast cancer you've got a good life, for thirty five years you've got good years.

R: But you've not, if you know you're going to get breast cancer at thirty-five years, you spend thirty-five years worrying yourself sick.

R: Not necessarily. But when you get to thirty or thirty-two...

R: It's something you know about that the child you might or might not have, so you might decide not to have that child, and then if somebody dies, you tell that child.

R: But when people desperately want to have child, if as women you are told yes, it's a girl, and it has a predisposition to breast cancer, and she's then got to decide to abort it...

R: It's a dreadful decision to take. So ignorance is bliss.

R: But then you can have that child and know by the time that your twenty-five, perhaps you know by the time that child's twenty-five there'll be a cure.

R: But it's science fiction at the moment, it's not going to happen at the moment.

R: But this technology is rapidly accelerating so it not really science fiction.
R: But I mean it's not really common place now.

R: No, because in America there actually talking about whether it's blonde or blue eyed.

R: In theory eventually you will be able to test for everything? In time?

R: But surely with type of information were getting, we'll be getting gene therapy to counteract these illness. Because it's got to walk on - we can't say, well yes, we can - but we're not going to do it anymore, because people don't accept it. I don't think that will ever happen. We've still got to keep walking down that path, we're just so inquisitive aren't we? And things will develop from it. We can see minuses in it, we don't know. It is a roll of the dice.

R: I'd like to come back and be a fly on the wall, but I won't like to live, and see it.

R: If we didn't change we'd all still be in caves, we'd all still be having skins around our nether regions.

R: But it's gone too far now.

R: It's gone too far.

R: Everything going faster and faster.

R: Twenty years ago, no fifty years there was three computers in the world, now everyone has got one. It's got to move on because we want it too, we want to embrace it.

I: Do you think there might become a sort of social pressure, say if you found out you carried a genetic disease and decided not to be tested, to have children anyway, do you think you might feel social pressure?

R: I'm sure they might blame you, you knew this might happen.
R: I think it's an individual decision.

R: I don't think we can judge, because it's always going to be personal to you.

R: I agree.

R: You might have an ordinary abortion cause you can't cope, got a bad marriage, social reasons, and I think it's so personal, I really do.

R: I mean your gut reaction is, if we didn't accept it, and somebody had made that choice, you might think bloody hell what an idiot. But that's their individual choice, but still I think we'd accept people.

R: I've seen a classic case, I was just talking to C coming in the car. My daughter's friend had three children and had a Down's baby last year. H is a devout Christian and there's no way she would have aborted the baby or anything, but little girl has changed the life of that family. Has brought joy to them, but also brought a tie in other ways, because they are nearly forty, and elderly parents. With the life expectancy of those children nowadays, one of those siblings is going to have to have her at some stage.

R: I've got a cousin with Down's and it hasn't brought joy.

R: This child has brought joy.

R: Tell me again when she's thirty of forty.

R: Yes this is it you see.

R: Working with mentally ill in Norfolk we actually took a man in his fifties, Down's syndrome, so the life expectancy is the same.

R: Yes, one of those siblings is going to have to be responsible at some stage.
R: I mean to ask you this, how accurate is genetic testing, how accurately can you see?

I: It depends in the disease, with Huntingdon’s it’s just about 100% accurate, with Breast Cancer a positive result means you have an about an 80% lifetime chance of developing it, but they can’t say when you going to develop it.

R: What do they do to test you?

I: A blood test.

R: They’re going to have the whole genetic chromosome thing aren’t they, all mapped by the end of the decade.

R: One blood test and there going to tell you all that you’re going to have.

R: I volunteered at the Marsden to have it done.

R: Is that right?

R: Can they test foetuses?

I: Yes they have the technology.

R: The scenario I can see is that eventually we’ll start testing babies from birth, the child will have the test then, and then eventually the parents will be tested. I can see that scenario.

R: Maybe it will be on your medical files, and the doctors will be the only ones to know.

R: I don’t think so. Not when it boils down to money.

R: Insurance companies and everything.
R: Let me look at your genetic tests results before I marry you.

R: Exactly.

R: And you’re not going to work for me cause you might get breast cancer, Ha, Ha, (laughter from group).

R: I’m having a hard enough job as it is! (More laughter).

R: Perhaps you should get tested - then you can say look I’m all right.

R: I might have a heart attack in five years so I don’t think I’ll bother.

R: Weird scenario.

I: We’re reaching the end now. I’d like to finish by asking you each in turn; if I said to you do you think genetic testing is a good or bad idea what would you say? And would you have it?

R: I think it’s horrendous. The implications I think are horrendous. No so I wouldn’t.

R: I’m open-minded on it. I think it will happen, and I don’t think it will be my choice necessarily, and I might not necessarily want to be tested, but I think it will have to happen.

R: I’ll think it will happen and in lots of ways be a good idea, but we will have to control it very carefully – we need proper regulations and all that.

R: I’m fairly open-minded but probably vying on the side of no, but I would be genetically counselled, if I knew there was a cure for the disease, otherwise no.

R: I think it’s definitely going to happen, and I have very mixed feelings about it but that’s because of my beliefs.
R: I think it’s already happening, so therefore we just don’t accept the ones we don’t know, but we already accept the ones we do, like cystic fibrosis. But a good thing. I’d be tested for everything me. Bring it on.

End of tape.
Information Form - version 1 - pilot study

Dear Participant

Postgraduate Research – Genetic testing and self-efficacy.

I am a postgraduate research student working at the University of Surrey. I have been sponsored by the Economic and Social Research Council to conduct a three-year research project into public attitudes to genetic testing. The following questionnaire is a part of this study. The aim of the questionnaire is to discover how you feel about issues attached to genetic testing, and the types of issues that are important to you. The questionnaire talks about genetic testing. In this instance it refers to any form of genetic testing you might undertake to see whether you or your children were likely to develop a serious health condition.

Genetic testing is currently available (both in this country and in other countries) to predict genetic disorders such as cystic fibrosis and muscular dystrophy. Genetic testing is also now becoming available (to limited numbers of high risk individuals) to predict the likelihood of developing diseases such as breast cancer, Alzheimer’s disease, colon cancer, some forms of heart disease, alcoholism and depression. Gathering the opinions of people like you is vital. The final published research will ensure the views of ordinary people are known, and help inform policy makers and shape new developments in this area. Participation takes approximately ten minutes.

Please think about the questions and try to answer them as honestly and carefully as you can. Your answers are anonymous.

If you have further enquiries please contact me (Tel: 0208 399 9536), or Dr. Lyons, who is supervising this project at the School of Human Sciences, University of Surrey (Tel: 01483 876902).

Thank you for your time.

Yours sincerely

Jane Hendy

Jane Hendy. (BSc. MSc.)
(Postgraduate Ph.D. research student at the University of Surrey)
Appendix XI - study 2

Genetic testing Questionnaire - Pilot study

Full name: ....................................................................................................................

Age: ...... yrs

Gender: (please tick) Male Female

Education: (please tick) High School Sixth form college (to age 16) (to age 18)

College University (over age 18)

Occupation: ....................................................................................................................

Marital status: (please tick) Single Married Divorced Other

Have you ever undergone any form of genetic testing? (Please tick)

No Yes - do you know what this test was for?

No Yes - please state below.

......................................................................................................................
......................................................................................................................
......................................................................................................................

Please complete the enclosed questionnaire.

Please read the questions carefully, and tick the answer that most applies. Please try to be as honest with yourself as possible.

Please answer all the questions in sequence, please do not go back and change any of your answers once completed.

Thank you for your time and assistance.
1. I have complete control over the decision to undergo genetic testing.

<table>
<thead>
<tr>
<th>completely</th>
<th>partly</th>
<th>neither agree</th>
<th>partly</th>
<th>completely</th>
</tr>
</thead>
<tbody>
<tr>
<td>disagree</td>
<td>disagree</td>
<td>nor disagree</td>
<td>agree</td>
<td>agree</td>
</tr>
</tbody>
</table>

2. I feel my doctor has control over any decision I make regarding undertaking genetic testing.

<table>
<thead>
<tr>
<th>completely</th>
<th>partly</th>
<th>neither agree</th>
<th>partly</th>
<th>completely</th>
</tr>
</thead>
<tbody>
<tr>
<td>disagree</td>
<td>disagree</td>
<td>nor disagree</td>
<td>agree</td>
<td>agree</td>
</tr>
</tbody>
</table>

3. I think that society has control over my decision to undertake genetic testing.

<table>
<thead>
<tr>
<th>completely</th>
<th>partly</th>
<th>neither agree</th>
<th>partly</th>
<th>completely</th>
</tr>
</thead>
<tbody>
<tr>
<td>disagree</td>
<td>disagree</td>
<td>nor disagree</td>
<td>agree</td>
<td>agree</td>
</tr>
</tbody>
</table>

4. I might not be able to make the decision whether or not to undergo genetic testing.

<table>
<thead>
<tr>
<th>completely</th>
<th>partly</th>
<th>neither agree</th>
<th>partly</th>
<th>completely</th>
</tr>
</thead>
<tbody>
<tr>
<td>disagree</td>
<td>disagree</td>
<td>nor disagree</td>
<td>agree</td>
<td>agree</td>
</tr>
</tbody>
</table>

5. It might be difficult for me to exercise my rights in deciding whether or not to undertake testing, due to family pressures.

<table>
<thead>
<tr>
<th>completely</th>
<th>partly</th>
<th>neither agree</th>
<th>partly</th>
<th>completely</th>
</tr>
</thead>
<tbody>
<tr>
<td>disagree</td>
<td>disagree</td>
<td>nor disagree</td>
<td>agree</td>
<td>agree</td>
</tr>
</tbody>
</table>

6. It might be difficult for me to be in control of the decision to undertake testing, due to a lack of understanding of genetic issues.

<table>
<thead>
<tr>
<th>completely</th>
<th>partly</th>
<th>neither agree</th>
<th>partly</th>
<th>completely</th>
</tr>
</thead>
<tbody>
<tr>
<td>disagree</td>
<td>disagree</td>
<td>nor disagree</td>
<td>agree</td>
<td>agree</td>
</tr>
</tbody>
</table>

7. Other people have control over my decision to undertake genetic testing.

<table>
<thead>
<tr>
<th>completely</th>
<th>partly</th>
<th>neither agree</th>
<th>partly</th>
<th>completely</th>
</tr>
</thead>
<tbody>
<tr>
<td>disagree</td>
<td>disagree</td>
<td>nor disagree</td>
<td>agree</td>
<td>agree</td>
</tr>
</tbody>
</table>

8. It is my choice whether or not I receive genetic testing.

<table>
<thead>
<tr>
<th>completely</th>
<th>partly</th>
<th>neither agree</th>
<th>partly</th>
<th>completely</th>
</tr>
</thead>
<tbody>
<tr>
<td>disagree</td>
<td>disagree</td>
<td>nor disagree</td>
<td>agree</td>
<td>agree</td>
</tr>
</tbody>
</table>

9. If I was confronted with the problem of having to decide whether or not to undertake genetic testing I would find it difficult.

<table>
<thead>
<tr>
<th>completely</th>
<th>partly</th>
<th>neither agree</th>
<th>partly</th>
<th>completely</th>
</tr>
</thead>
<tbody>
<tr>
<td>disagree</td>
<td>disagree</td>
<td>nor disagree</td>
<td>agree</td>
<td>agree</td>
</tr>
</tbody>
</table>
10. It is entirely my decision whether or not to undertake genetic testing.

completely partly neither agree partly completely
disagree disagree nor disagree agree agree

Please indicate how important the following statements are to the way you think about yourself, and the way you wish to live your life. Please tick the answer that most applies.

It is IMPORTANT to think of myself as ...

1. ... a person who has complete control over the decision to undergo genetic testing.

   Of total Very Moderately Barely Not at all
   Importance Important Important Important Important

It is IMPORTANT to think of myself as ...

2. ... a person who would not allow my doctor to control any decision I make regarding undertaking genetic testing.

   Of total Very Moderately Barely Not at all
   Importance Important Important Important Important

It is IMPORTANT to think of myself as ...

3. ... a person who would not allow society to have control over my decision to undertake genetic testing.

   Of total Very Moderately Barely Not at all
   Importance Important Important Important Important

It is IMPORTANT to think of myself as ...

4. ... a person who could make the decision whether or not to undergo genetic testing.

   Of total Very Moderately Barely Not at all
   Importance Important Important Important Important

It is IMPORTANT to think of myself as ...

5. ... a person who could exercise their rights in deciding whether or not to undertake testing, regardless of family pressures.

   Of total Very Moderately Barely Not at all
   Importance Important Important Important Important
It is IMPORTANT to think of myself as …

6. ...a person who could be in control of the decision to undertake testing, due to a good understanding of genetic issues.

<table>
<thead>
<tr>
<th>Of total</th>
<th>Very Important</th>
<th>Moderately Important</th>
<th>Barely Important</th>
<th>Not at all Important</th>
</tr>
</thead>
</table>

It is IMPORTANT to think of myself as …

7. ...a person who would not let other people have control over the decision to undertake genetic testing.

<table>
<thead>
<tr>
<th>Of total</th>
<th>Very Important</th>
<th>Moderately Important</th>
<th>Barely Important</th>
<th>Not at all Important</th>
</tr>
</thead>
</table>

It is IMPORTANT to think of myself as …

8. ...a person who can choose whether or not to receive genetic testing.

<table>
<thead>
<tr>
<th>Of total</th>
<th>Very Important</th>
<th>Moderately Important</th>
<th>Barely Important</th>
<th>Not at all Important</th>
</tr>
</thead>
</table>

It is IMPORTANT to think of myself as …

9. ...a person who would not find it difficult, when confronted with the problem of having to decide whether or not to undertake genetic testing.

<table>
<thead>
<tr>
<th>Of total</th>
<th>Very Important</th>
<th>Moderately Important</th>
<th>Barely Important</th>
<th>Not at all Important</th>
</tr>
</thead>
</table>

It is IMPORTANT to think of myself as …

10 ...a person who decides entirely for themselves whether or not to undertake genetic testing.

<table>
<thead>
<tr>
<th>Of total</th>
<th>Very Important</th>
<th>Moderately Important</th>
<th>Barely Important</th>
<th>Not at all Important</th>
</tr>
</thead>
</table>

Please read the question carefully and tick the answer that most applies.

1. I can always manage to solve difficult problems if I try hard enough.

   (1) not at all true   (2) barely true   (3) moderately true   (4) exactly true

2. If someone opposes me, I can find the ways and means to get what I want.

   (1) not at all true   (2) barely true   (3) moderately true   (4) exactly true
3. It is easy for me to stick to my aims and accomplish my goals.

(1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

4. I am confident that I could deal efficiently with unexpected events.

(1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

5. Thanks to my resourcefulness, I know how to handle unforeseen situations.

(1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

6. I can solve most problems if I invest the necessary effort.

(1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

7. I can remain calm when facing difficulties because I can rely on my coping abilities.

(1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

8. When confronted with a problem, I can usually find several solutions.

(1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

9. If I am in trouble, I can usually think of a solution.

(1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

10. I can usually handle whatever comes my way.

(1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

(Schwarzer & Jerusalem 1995)

Please indicate how important the following statements are to the way you think about yourself, and the way you wish to live your life.

Please read the question carefully and tick the answer that most applies.

It is IMPORTANT to think of myself as ...

1. ...a person who can always manage to solve difficult problems if they try hard enough.

<table>
<thead>
<tr>
<th>Of total Importance</th>
<th>Very</th>
<th>Moderately</th>
<th>Barely</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>Importance</td>
<td>Important</td>
<td>Important</td>
<td>Important</td>
<td>Important</td>
</tr>
</tbody>
</table>
It is IMPORTANT to think of myself as ...

2. ...a person who if opposed by someone, is able to find the ways and means to get what I want.

   Of total Importance
   Very Important
   Moderately Important
   Barely Important
   Not at all Important

It is IMPORTANT to think of myself as ...

3. ...a person who finds it easy to stick to my aims and accomplish my goals.

   Of total Importance
   Very Important
   Moderately Important
   Barely Important
   Not at all Important

It is IMPORTANT to think of myself as ...

4. ...a person who could confidently deal efficiently with unexpected events.

   Of total Importance
   Very Important
   Moderately Important
   Barely Important
   Not at all Important

It is IMPORTANT to think of myself as ...

5. ... a person who thanks to personal resourcefulness, knows how to handle unforeseen situations.

   Of total Importance
   Very Important
   Moderately Important
   Barely Important
   Not at all Important

It is IMPORTANT to think of myself as ...

6. ...a person who can solve most problems if I invest the necessary effort.

   Of total Importance
   Very Important
   Moderately Important
   Barely Important
   Not at all Important

It is IMPORTANT to think of myself as ...

7. ...a person who can remain calm when facing difficulties, because I can rely on my coping abilities.

   Of total Importance
   Very Important
   Moderately Important
   Barely Important
   Not at all Important

It is IMPORTANT to think of myself as ...

8. ...a person who when confronted with a problem, can usually find several solutions.

   Of total Importance
   Very Important
   Moderately Important
   Barely Important
   Not at all Important

316
It is IMPORTANT to think of myself as ...

9. ... a person who when in trouble, can usually think of a solution.

<table>
<thead>
<tr>
<th>Importance</th>
<th>Very Important</th>
<th>Moderately Important</th>
<th>Barely Important</th>
<th>Not at all Important</th>
</tr>
</thead>
</table>

It is IMPORTANT to think of myself as ...

10. ... a person who can usually handle whatever comes my way.

<table>
<thead>
<tr>
<th>Importance</th>
<th>Very Important</th>
<th>Moderately Important</th>
<th>Barely Important</th>
<th>Not at all Important</th>
</tr>
</thead>
</table>

Thank you

Please return to:

Jane Hendy (research student) Department of Psychology, University of Surrey, Guildford, Surrey, GU2 5XH.
Appendix XII - study 2

Efficacy threatening media statement

*Please read the following statement, made to the British press by Professor Colin Radcliffe – Chairman of the British Human Genetics commission, on Monday October 25th 2000.*

Genetic testing has become available for individuals with a family history of heart disease. The British Medical Association (BMA) has asked General Practitioners to their check medical records in order to identify patients at risk. Those individuals deemed eligible for genetic screening will be refereed to specialist regional genetic centres. Trained physicians will carry out the procedure. The BMA acknowledges that people may not want to undergo this procedure, but stresses that implementation of this testing program will lead to those most at risk being targeted for preventive health care. Heart disease is costly and difficult to treat, and attending testing is strongly advocated. Once uptake of the procedure reaches optimal levels the NHS will save in the region of 120 million pounds a year, from not having to perform heart transplants and treat heart disease patients. The move has been strongly supported by the British Association of Insurers. Whilst they reiterate that testing is not at present compulsory, they stress that those individuals who ignore this advice are denying themselves and their children access to a healthier life, and the possibility of cheaper insurance premiums.
Appendix XIII - study 2

Efficacy enhancing media statement

Please read the following statement, made to the British press by Professor Colin Radcliffe – Chairman of the British Human Genetics commission, on Monday October 25th 2000.

Genetic testing has become available for individuals with a family history of heart disease. The British Medical Association (BMA) has advised that anyone who thinks themselves at risk of heart disease can approach their General Practitioner for advice. Genetic testing is currently on offer to any individual who requests it, through specialist regional genetics centres. The BMA acknowledges that many people may decide not to undergo this procedure, and stresses that the decision to undergo genetic screening is solely the patients, and should be reached only after careful consideration of all the facts. Genetic testing results are completely confidential, and are only forwarded to General Practitioners on the patient’s request. Trained physicians and counsellors are on hand to give help and advice. The availability of genetic testing is an active step forward, allowing people to preserve their own health and make more informed health decisions. This technology will enable people to become more aware of how they can actively help themselves to live longer.
Dear Participant

Postgraduate Research - Genetic testing and self-efficacy

I am a postgraduate research student working at the University of Surrey. I have been sponsored by the Economic and Social Research Council to conduct a three-year research project into public concerns regarding genetic testing. The following questionnaire is part of this study. The aim of the questionnaire is to discover how you feel about issues attached to genetic testing, and the types of issues that are important to you. The questionnaire talks about genetic testing. In this instance it refers to any form of genetic testing you might undertake to see whether you or your children were likely to develop a serious health condition.

Genetic testing is currently available (both in this country and in other countries) to predict genetic disorders such as cystic fibrosis and muscular dystrophy. Genetic testing is also now becoming available (to limited numbers of high risk individuals) to predict the likelihood of developing diseases such as breast cancer, Alzheimer's disease, colon cancer, some forms of heart disease, alcoholism and depression.

Gathering the opinions of people like you is vital. The final published research will ensure the views of ordinary people are known, and help inform policy makers and shape new developments in this area. Participation takes approximately fifteen minutes.

Please think about the questions and try to answer them as **honestly** and **carefully** as you can. Please answer the questionnaires in sequence, and do not go back and change any of answers once completed. If you have further enquiries please contact me (Tel: 0208 399 9536), or Dr. Lyons, who is supervising this project at the School of Human Sciences, University of Surrey (Tel: 01483 876902).

Thank you for you time.

Yours sincerely

Jane Hendy

Jane Hendy. *(BSc. MSc)*
*(Postgraduate Ph.D. research student at the University of Surrey)*

Date
Appendix XV - study 2

Genetic testing Questionnaire - Main study

Full name: .........................................................................................................................

Age: ...... yrs

Gender: (please tick) Male Female

Education: (please tick) High School Sixth form college
(to age 16) (to age 18)

College University (over age 18)

Occupation: .....................................................................................................................

Marital status: (please tick) Single Married Divorced Other

Have you ever undergone any form of genetic testing? (Please tick)

No if Yes - do you know what this test was for?

No if Yes - please state below.

...........................................................................................................................................

...........................................................................................................................................

Please complete the enclosed questionnaire.

Please read the questions carefully, and tick the answer that most applies. Please try to be as honest with yourself as possible.

Please answer all the questions in sequence. Please do not go back and change any of your answers once completed.

Thank you for your time and assistance.

Please read each question carefully and tick the answer that most applies. Please try to be as honest with yourself as possible.
1. I have complete control over the decision to undergo genetic testing.

   completely  partly  neither agree  partly  completely
   disagree    disagree nor disagree agree agree

2. I feel my doctor has control over any decision I make regarding undertaking genetic testing.

   completely  partly  neither agree  partly  completely
   disagree    disagree nor disagree agree agree

3. I think that society has control over my decision to undertake genetic testing.

   completely  partly  neither agree  partly  completely
   disagree    disagree nor disagree agree agree

4. I might not be able to make the decision whether or not to undergo genetic testing.

   completely  partly  neither agree  partly  completely
   disagree    disagree nor disagree agree agree

5. It might be difficult for me to exercise my rights in deciding whether or not to undertake testing, due to family pressures.

   completely  partly  neither agree  partly  completely
   disagree    disagree nor disagree agree agree

6. It might be difficult for me to be in control of the decision to undertake testing, due to a lack of understanding of genetic issues.

   completely  partly  neither agree  partly  completely
   disagree    disagree nor disagree agree agree

7. Other people have control over my decision to undertake genetic testing.

   completely  partly  neither agree  partly  completely
   disagree    disagree nor disagree agree agree

8. It is my choice whether or not I receive genetic testing.

   completely  partly  neither agree  partly  completely
   disagree    disagree nor disagree agree agree

9. If I was confronted with the problem of having to decide whether or not to undertake genetic testing I would find it difficult.

   completely  partly  neither agree  partly  completely
   disagree    disagree nor disagree agree agree

322
10. It is entirely my decision whether or not to undertake genetic testing.

| completely disagree | partly disagree | neither agree nor disagree | partly agree | completely agree |

Please indicate how important the following statements are to the way you think about yourself, and the way you wish to live your life. Please tick the answer that most applies.

It is IMPORTANT to think of myself as ...

1. ... a person who has complete control over the decision to undergo genetic testing.

| Of total | Very Important | Moderately Important | Barely Important | Not at all Important |

It is IMPORTANT to think of myself as ...

2. ... a person who would not allow my doctor to control any decision I make regarding undertaking genetic testing.

| Of total | Very Important | Moderately Important | Barely Important | Not at all Important |

It is IMPORTANT to think of myself as ...

3. ... a person who would not allow society to have control over my decision to undertake genetic testing.

| Of total | Very Important | Moderately Important | Barely Important | Not at all Important |

It is IMPORTANT to think of myself as ...

4. ... a person who could make the decision whether or not to undergo genetic testing.

| Of total | Very Important | Moderately Important | Barely Important | Not at all Important |

It is IMPORTANT to think of myself as ...

5. ... a person who could exercise my rights in deciding whether or not to undertake testing, regardless of family pressures.

| Of total | Very Important | Moderately Important | Barely Important | Not at all Important |
It is IMPORTANT to think of myself as ...

6. ...a person who could be in control of the decision to undertake testing, due to a good understanding of genetic issues.

<table>
<thead>
<tr>
<th>Of total Importance</th>
<th>Very Important</th>
<th>Moderately Important</th>
<th>Barely Important</th>
<th>Not at all Important</th>
</tr>
</thead>
</table>

It is IMPORTANT to think of myself as ...

7. ...a person who would not let other people have control over the decision to undertake genetic testing.

<table>
<thead>
<tr>
<th>Of total Importance</th>
<th>Very Important</th>
<th>Moderately Important</th>
<th>Barely Important</th>
<th>Not at all Important</th>
</tr>
</thead>
</table>

It is IMPORTANT to think of myself as ...

8. ...a person who can choose whether or not to receive genetic testing.

<table>
<thead>
<tr>
<th>Of total Importance</th>
<th>Very Important</th>
<th>Moderately Important</th>
<th>Barely Important</th>
<th>Not at all Important</th>
</tr>
</thead>
</table>

It is IMPORTANT to think of myself as ...

9. ...a person who would not find it difficult, when confronted with the problem of having to decide whether or not to undertake genetic testing.

<table>
<thead>
<tr>
<th>Of total Importance</th>
<th>Very Important</th>
<th>Moderately Important</th>
<th>Barely Important</th>
<th>Not at all Important</th>
</tr>
</thead>
</table>

It is IMPORTANT to think of myself as ...

10 ...a person who decides entirely for themselves whether or not to undertake genetic testing.

<table>
<thead>
<tr>
<th>Of total Importance</th>
<th>Very Important</th>
<th>Moderately Important</th>
<th>Barely Important</th>
<th>Not at all Important</th>
</tr>
</thead>
</table>

-----------------------------

324
Please read the question carefully and tick the answer that most applies.

1. I can always manage to solve difficult problems if I try hard enough.
   (1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

2. If someone opposes me, I can find the ways and means to get what I want.
   (1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

3. It is easy for me to stick to my aims and accomplish my goals.
   (1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

4. I am confident that I could deal efficiently with unexpected events.
   (1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

5. Thanks to my resourcefulness, I know how to handle unforeseen situations.
   (1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

6. I can solve most problems if I invest the necessary effort.
   (1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

7. I can remain calm when facing difficulties because I can rely on my coping abilities.
   (1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

8. When confronted with a problem, I can usually find several solutions.
   (1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

9. If I am in trouble, I can usually think of a solution.
   (1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

10. I can usually handle whatever comes my way.
    (1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

(Schwarzer & Jerusalem 1995)
Please indicate how important the following statements are to the way you think about yourself, and the way you wish to live your life.

Please read the question carefully and tick the answer that most applies.

It is IMPORTANT to think of myself as ...

1. ...a person who can always manage to solve difficult problems if I try hard enough.

<table>
<thead>
<tr>
<th>Importance</th>
<th>Very Important</th>
<th>Moderately Important</th>
<th>Barely Important</th>
<th>Not at all Important</th>
</tr>
</thead>
</table>

It is IMPORTANT to think of myself as ...

2. ...a person who if opposed by someone, is able to find the ways and means to get what I want.

<table>
<thead>
<tr>
<th>Importance</th>
<th>Very Important</th>
<th>Moderately Important</th>
<th>Barely Important</th>
<th>Not at all Important</th>
</tr>
</thead>
</table>

It is IMPORTANT to think of myself as ...

3. ...a person who finds it easy to stick to my aims and accomplish my goals.

<table>
<thead>
<tr>
<th>Importance</th>
<th>Very Important</th>
<th>Moderately Important</th>
<th>Barely Important</th>
<th>Not at all Important</th>
</tr>
</thead>
</table>

It is IMPORTANT to think of myself as ...

4. ...a person who can confidently deal efficiently with unexpected events.

<table>
<thead>
<tr>
<th>Importance</th>
<th>Very Important</th>
<th>Moderately Important</th>
<th>Barely Important</th>
<th>Not at all Important</th>
</tr>
</thead>
</table>

It is IMPORTANT to think of myself as ...

5. ... a person who thanks to personal resourcefulness, knows how to handle unforeseen situations.

<table>
<thead>
<tr>
<th>Importance</th>
<th>Very Important</th>
<th>Moderately Important</th>
<th>Barely Important</th>
<th>Not at all Important</th>
</tr>
</thead>
</table>

It is IMPORTANT to think of myself as ...

6. ...a person who can solve most problems if I invest the necessary effort.

<table>
<thead>
<tr>
<th>Importance</th>
<th>Very Important</th>
<th>Moderately Important</th>
<th>Barely Important</th>
<th>Not at all Important</th>
</tr>
</thead>
</table>

326
It is IMPORTANT to think of myself as ...

7. ...a person who can remain calm when facing difficulties, because I can rely on my coping abilities.

<table>
<thead>
<tr>
<th>Importance</th>
<th>Very Important</th>
<th>Moderately Important</th>
<th>Barely Important</th>
<th>Not at all Important</th>
</tr>
</thead>
</table>

It is IMPORTANT to think of myself as ...

8. ...a person who when confronted with a problem, can usually find several solutions.

<table>
<thead>
<tr>
<th>Importance</th>
<th>Very Important</th>
<th>Moderately Important</th>
<th>Barely Important</th>
<th>Not at all Important</th>
</tr>
</thead>
</table>

It is IMPORTANT to think of myself as ...

9. ...a person who when in trouble, can usually think of a solution.

<table>
<thead>
<tr>
<th>Importance</th>
<th>Very Important</th>
<th>Moderately Important</th>
<th>Barely Important</th>
<th>Not at all Important</th>
</tr>
</thead>
</table>

It is IMPORTANT to think of myself as ...

10. ...a person who can usually handle whatever comes my way.

<table>
<thead>
<tr>
<th>Importance</th>
<th>Very Important</th>
<th>Moderately Important</th>
<th>Barely Important</th>
<th>Not at all Important</th>
</tr>
</thead>
</table>

Thank you

Please return to:-
Jane Hendy (research student) Department of Psychology, University of Surrey, Guildford, Surrey, GU2 5XH.
Appendix XVI - study 2 & 3

Distraction task

Please complete the tasks below

Task 1

Please count then record the number of Z in both lists. You have three minutes.

A) IVWIMEYZWVKYITVXIYT
   KYIVMXWEMIVYZVIX
   YVTKMIZXTYFIIMYX
   VYTIMWIVMXWIVW
   VIWXIYZIWMWIEZYVIX
   KIWIVMYIXZWITIVMKIXIIWXM
   Total no:-

B) ODUGZOPDROUGOBDOQ
   GODCBOURQBOUBDB
   UOBGZOURQBCOURBUG
   DDOCUOGBAQUOBUOCZIBICO
   OGODUPCAUBOPUQOOUUC
   OUBOCUZCDBOUBAQODZOUQUOB
   Total no:-

Task two

Please count and record the number of f’s in the following text. You have two minutes.

The science of manufacturing textiles is very complex and is of a highly sophisticated nature. The introduction of new first class technologies has resulted in a fifty four percent increase of stock turnover and a twenty five percent decrease in manufacturing error.

Total no:-

Over the page are the correct answers.
Correct Answers

Task one - A) = 6 Z’s   B) = 5 Z’s
Task two - 11 f's
Appendix XVII - study 2

Media statement questionnaire

Please indicate below how reading the above statement made by Professor Radcliffe made you feel. Please tick the answer that most applies.

The statement made me feel that decisions regarding my health were being taken out of my control.

(1) completely agree  (2) partly agree  (3) partly disagree  (4) completely disagree

The statement made me feel that I could do something active to improve my health

(1) completely agree  (2) partly agree  (3) partly disagree  (4) completely disagree

The statement did not affect how I feel about genetic testing.

(1) completely agree  (2) partly agree  (3) partly disagree  (4) completely disagree

If none of the above statements apply, or you wish to add further comments, please indicate how you felt reading the statement, in the space provided below.
Debriefing statement 1.

Date

Dear Participant,

The statement you have just read, made by Professor Colin Radcliffe is fictitious, no such person exists. The information contained within the statement is not entirely fictitious. The genetic advances described have been made, and some of the testing procedures described are available, although these are limited to a very small numbers of ‘at risk’ people, attending specialist regional genetic centres. The claims made by the BMA are entirely fictional. General Practitioners have not been asked to identify individuals at risk of heart disease, nor is genetic testing for heart disease widely available. You were asked to read the statement in order to ascertain your response to such a development in the future.

If you have any further questions regarding this information please contact the researcher.

Please do not go back and change any of your answers.

Thank you again for your time and assistance.
Debriefing statement 2.

Dear Participant,

The statement you have just read, made by Professor Colin Radcliffe is fictitious, no such person exists. The information contained within the statement is not entirely fictitious. The genetic advances described have been made, and some of the testing procedures described are available, although these are limited to a very small numbers of at risk people, attending specialist regional genetic centres. The claims made by the BMA are entirely fictional. People at risk of heart disease are not being advised to approach their General Practitioners, nor is genetic testing for heart disease widely available. You were asked to read the statement in order to ascertain your response to such a development in the future.

If you have any further questions regarding this information please contact the researcher.

Please do not go back and change any of your answers.

Thank you again for your time and assistance.
Appendix XX - study 3

Pilot study - Arthritis Questionnaire

Age: ...... yrs

Gender: (please tick) Male Female

Education: (please tick all which apply)

School (to age 16) College (to age 18)

Higher education (over age 18) University

Occupation: ..............................................................

Marital status: (please tick) Single Married Divorced Other

Have you ever been diagnosed with any form of arthritis?

If the answer is YES - please do not complete the questionnaire.

If the answer is NO - please complete the enclosed questionnaire.

Please answer all the questions in sequence. Please do not go back and change any of your answers once completed.

Read each question carefully and the answer that most applies. Try to be as honest with yourself as possible.

The following questions are concerned with your opinion, whether you perceive yourself to be at risk of arthritis.

Please take a few moments to think about this before answering the following questions.

Please tick the answer that most applies.

333
1. Please indicate whether anyone in your family suffers from arthritis.

   (1) No-one    (2) Distant relative    (3) Close relative    (4) A parent

2. Please indicate how often you worry about developing arthritis.

   (1) Never    (2) Occasionally    (3) Often    (4) All the time

3. Please estimate your chances of developing arthritis in the next five years.

   (1) No possibility    (2) Unlikely    (3) Likely    (4) Highly likely

4. Please estimate your lifetime risk of developing arthritis.

   (1) No risk    (2) Low risk    (3) Medium risk    (4) High risk

5. Please estimate your lifetime risk of developing arthritis - compared to other people your own age and sex.

   (1) Less    (2) About the same    (3) More    (4) Much More

The following questions are concerned with how much control you perceive yourself to have over the symptoms of arthritis. Please take a few moments to think about this before answering the following questions.

1. I could control the symptoms of arthritis, by making positive changes to my lifestyle.

   (1) not at all true    (2) barely true    (3) moderately true    (4) exactly true

2. I could control the symptoms of arthritis, by adopting a positive attitude and outlook on life.

   (1) not at all true    (2) barely true    (3) moderately true    (4) exactly true

3. I could control the symptoms of arthritis, with the use of medical treatments.

   (1) not at all true    (2) barely true    (3) moderately true    (4) exactly true

4. I could control the symptoms of arthritis, by living a healthier life.

   (1) not at all true    (2) barely true    (3) moderately true    (4) exactly true
5. The symptoms of arthritis are something I believe I could control.
   (1) not at all true   (2) barely true   (3) moderately true   (4) exactly true

6. I could be in control of arthritis, by determining how the disease affected my life.
   (1) not at all true   (2) barely true   (3) moderately true   (4) exactly true

7. I could manage the symptoms of arthritis.
   (1) not at all true   (2) barely true   (3) moderately true   (4) exactly true

8. I believe there is *nothing* I could do to control the symptoms of arthritis.
   (1) not at all true   (2) barely true   (3) moderately true   (4) exactly true

The following questions are concerned with having control over the symptoms of arthritis, and whether this is *important* to you.

Again please tick

1. It is **IMPORTANT** to think of myself as ...
   ...a person who could control the symptoms of arthritis.

   Of total Importance       Very Important       Moderately Important       Barely Important       Not Important

2. It is **IMPORTANT** to think of myself as ...
   ...a person who would be able to control the symptoms of arthritis by making positive changes to my lifestyle.

   Of total Importance       Very Important       Moderately Important       Barely Important       Not Important

*Please continue*
The following questions are concerned with life in general. Again please tick the answer that most applies.

1. I can always manage to solve difficult problems if I try hard enough.
   (1) not at all true   (2) barely true   (3) moderately true   (4) exactly true

2. If someone opposes me, I can find the ways and means to get what I want.
   (1) not at all true   (2) barely true   (3) moderately true   (4) exactly true

3. It is easy for me to stick to my aims and accomplish my goals.
   (1) not at all true   (2) barely true   (3) moderately true   (4) exactly true

4. I am confident that I could deal efficiently with unexpected events.
   (1) not at all true   (2) barely true   (3) moderately true   (4) exactly true

5. Thanks to my resourcefulness, I know how to handle unforeseen situations.
   (1) not at all true   (2) barely true   (3) moderately true   (4) exactly true

6. I can solve most problems if I invest the necessary effort.
   (1) not at all true   (2) barely true   (3) moderately true   (4) exactly true

7. I can remain calm when facing difficulties because I can rely on my coping abilities.
   (1) not at all true   (2) barely true   (3) moderately true   (4) exactly true

8. When confronted with a problem, I can usually find several solutions.
   (1) not at all true   (2) barely true   (3) moderately true   (4) exactly true

9. If I am in trouble, I can usually think of a solution.
   (1) not at all true   (2) barely true   (3) moderately true   (4) exactly true

10. I can usually handle whatever comes my way.
    (1) not at all true   (2) barely true   (3) moderately true   (4) exactly true

(Schwarzer & Jerusalem 1995)

Thank you.

Please return to:-
Jane Hendy (research student) Department of Psychology, University of Surrey, Guildford, Surrey, GU2 7XH.

336
Appendix XXI - study 3

Main study - Arthritis Questionnaire

Age: ...... yrs

Gender: (please tick) Male Female

Education: (please tick all which apply)

School (to age 16)
College (to age 18)

Higher education (over age 18)
University

Occupation: ............................................................................................................................

Marital status: (please tick) Single Married Divorced Other

Have you ever been diagnosed with any form of arthritis?

If the answer is YES - please do not complete the questionnaire.

If the answer is NO - please complete the enclosed questionnaire.

Please answer all the questions in sequence. Please do not go back and change any of your answers once completed.

Read each question carefully and the answer that most applies. Try to be as honest with yourself as possible.

The following questions are concerned with your opinion, whether you perceive yourself to be at risk of arthritis.

Please take a few moments to think about this before answering the following questions.
Please tick the answer that most applies.
1. Please indicate whether anyone in your family suffers from arthritis.

   (1) No-one  (2) Distant relative  (3) Close relative  (4) A parent

2. Please indicate how often you worry about developing arthritis.

   (1) Never  (2) Occasionally  (3) Often  (4) All the time

3. Please estimate your chances of developing arthritis in the next five years.

   (1) No possibility  (2) Unlikely  (3) Likely  (4) Highly likely

4. Please estimate your lifetime risk of developing arthritis.

   (1) No risk  (2) Low risk  (3) Medium risk  (4) High risk

5. Please estimate your lifetime risk of developing arthritis - compared to other people your own age and sex.

   (1) Less  (2) About the same  (3) More  (4) Much More

The following questions are concerned with how much control you perceive yourself to have over the symptoms of arthritis. Please take a few moments to think about this before answering the following questions.

1. I could control the symptoms of arthritis, by making positive changes to my lifestyle.

   (1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

2. I could control the symptoms of arthritis, by adopting a positive attitude and outlook on life.

   (1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

3. I could control the symptoms of arthritis, by living a healthier life.

   (1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

4. The symptoms of arthritis are something I believe I could control.

   (1) not at all true  (2) barely true  (3) moderately true  (4) exactly true
5. I could be in control of arthritis, by determining how the disease affected my life.
   (1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

6. I could manage the symptoms of arthritis.
   (1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

7. I believe there is nothing I could do to control the symptoms of arthritis.
   (1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

The following questions are concerned with having control over the symptoms of arthritis, and whether this is important to you.

Again please tick.

1. It is IMPORTANT to think of myself as...

   ...a person who could control the symptoms of arthritis, by making positive changes to my lifestyle.

   Of total Very Moderately Barely Not
   Importance Important Important Important Important

2. It is IMPORTANT to think of myself as...

   ...a person who could control the symptoms of arthritis, by adopting a positive attitude and outlook on life.

   Of total Very Moderately Barely Not
   Importance Important Important Important Important

3. It is IMPORTANT to think of myself as...

   ...a person who could control the symptoms of arthritis, by living a healthier life.

   Of total Very Moderately Barely Not
   Importance Important Important Important Important
4. It is IMPORTANT to think of myself as…

...a person who could control the symptoms of arthritis.

<table>
<thead>
<tr>
<th>Of total Importance</th>
<th>Very Important</th>
<th>Moderately Important</th>
<th>Barely Important</th>
<th>Not Important</th>
</tr>
</thead>
</table>

5. It is IMPORTANT to think of myself as...

...a person who could control the symptoms of arthritis, by determining how the disease affects my life.

<table>
<thead>
<tr>
<th>Of total Importance</th>
<th>Very Important</th>
<th>Moderately Important</th>
<th>Barely Important</th>
<th>Not Important</th>
</tr>
</thead>
</table>

6. It is IMPORTANT to think of myself as...

...a person who could manage the symptoms of arthritis.

<table>
<thead>
<tr>
<th>Of total Importance</th>
<th>Very Important</th>
<th>Moderately Important</th>
<th>Barely Important</th>
<th>Not Important</th>
</tr>
</thead>
</table>

7. It is important NOT to think of myself as...

...a person who is powerless to control the symptoms of arthritis.

<table>
<thead>
<tr>
<th>Of total Importance</th>
<th>Very Important</th>
<th>Moderately Important</th>
<th>Barely Important</th>
<th>Not Important</th>
</tr>
</thead>
</table>

Please continue
The following questions are concerned with life in general. Again please tick the answer that most applies.

1. I can always manage to solve difficult problems if I try hard enough.
   (1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

2. If someone opposes me, I can find the ways and means to get what I want.
   (1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

3. It is easy for me to stick to my aims and accomplish my goals.
   (1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

4. I am confident that I could deal efficiently with unexpected events.
   (1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

5. Thanks to my resourcefulness, I know how to handle unforeseen situations.
   (1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

6. I can solve most problems if I invest the necessary effort.
   (1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

7. I can remain calm when facing difficulties because I can rely on my coping abilities.
   (1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

8. When confronted with a problem, I can usually find several solutions.
   (1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

9. If I am in trouble, I can usually think of a solution.
   (1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

10. I can usually handle whatever comes my way.
   (1) not at all true  (2) barely true  (3) moderately true  (4) exactly true

   (Schwarzer & Jerusalem 1995)

Thank you.

Please return to:--
Jane Hendy (research student) Department of Psychology, University of Surrey, Guildford, Surrey, GU2 7XH.

341
Appendix XXII - study 3

Jane Hendy
BSc (Hons) MSc
University of Surrey
Guildford
Surrey GU2 5XH UK
Tel: +44 (0)1483 876861
Fax: +44 (0)1483 259553
Email: j.hendy@surrey.ac.uk

Department of Psychology

Information Form

Date

Dear Participant

Postgraduate Research – The impact of disease information on perceptions of control.

I am a postgraduate research student working at the University of Surrey. I have been sponsored by the Economic and Social Research Council to conduct a research project into attitudes towards arthritis. I am looking for volunteers to take part.

If you decide to participate, you will be asked to complete an arthritis questionnaire, which involves giving an estimate of your risk of developing arthritis, and answering general questions about control in your life, and control over the symptoms of arthritis. You will then be given information about the disease, and be asked your opinion about a current issue related to arthritis, before being asked to complete the questionnaire again. Filling in the questionnaire is straightforward and involves ticking the box that most applies to you. Participation should take about 15 minutes.

You do not need to know anything about arthritis, or have any prior experience of this condition, in order to take part. You will not be asked to give your name, and your answers will not be used for any purposes other than the research stated. The information you give will be anonymous, and treated as confidential. You will not be personally identified during completion of the study, or named in any subsequent publications.

Gathering the views of people like you is vital. The final published research will ensure the views of ordinary people are known, and help inform policy makers and shape new developments in this area. If you would like to take part in the research, please see the researcher, who will explain the project to you in more detail, and ask you to sign a consent form. The decision to take part is entirely yours. If at any point you decide you no longer wish to participate, this is fine. All I would ask is that you see the researcher before you leave.

If you have further enquiries please contact me (Tel: 01483 876946), or Dr. Lyons who is supervising this project, at the School of Human Sciences, University of Surrey (Tel: 01483 876902). Both of us will be happy to answer any questions you may have. Thank you for your time.

Yours sincerely

Jane Hendy

Jane Hendy. (B.Sc. M.Sc.)
(Postgraduate Ph.D. research student at the University of Surrey)
Appendix XXIII - study 3

Jane Hendy
BSc (Hons) MSc

University of Surrey
Guildford
Surrey GU2 5XH UK
Tel: +44 (0)1483 876861
Fax: +44 (0)1483 259553
Email: j.hendy@surrey.ac.uk

Department of Psychology

Consent form
One copy to client, one to be retained

Dear Participant

Postgraduate Research – The impact of disease information on perceptions of control.

If you have read the enclosed information sheet, and would like to participate in the above study, please sign the consent form below. Please ensure the researcher has answered any questions you might have, before you sign.

Thank-you

Jane Hendy

Jane Hendy. (B.Sc. M.Sc.)
(Postgraduate research student at the University of Surrey)

I have read and understood the information sheet enclosed. I have been given the opportunity to ask questions, and I have understood the answers given by the researcher.

I consent to take part in the study.

Signed __________________________ Date __________

I understand I am free to change my mind at any time, and that my answers will not be used for any purposes other than the research stated.
Appendix XXIV - study 3

Experimental conditions (1 to 4)

1.

Please read the following factual information.

Osteoarthritis is a common joint disorder that usually occurs at the knee, hip, spine, and in the hands, especially at the base of the thumb and in the fingers. Osteoarthritis is not really a disease or even a single condition; rather it is the end result of a number of different episodes of damage to the joint over a period of time. These changes initially result in a joint that looks different to normal but which nevertheless functions well and without pain. Eventually the joint may become very painful with a variable degree of disability. Doctors usually make a diagnosis by examining the joints and looking at X-rays.
Osteoarthritis is a common joint disorder that usually occurs at the knee, hip, spine, and in the hands, especially at the base of the thumb and in the fingers. Osteoarthritis is not really a disease or even a single condition; rather it is the end result of a number of different episodes of damage to the joint over a period of time. These changes initially result in a joint that looks different to normal but which nonetheless functions well and without pain. Eventually the joint may become very painful with a variable degree of disability. Doctors usually make a diagnosis by examining the joints and looking at X-rays. The most unavoidable risk factor is genetic inheritance. If other family members, such as a sister (or brother), parents or grandparents, have had osteoarthritis, your risk of developing the disease is five times higher than the general population. Currently, in spite of all the recent advances made in Rheumatology, modern medicine has no effective way of slowing down or reversing the damage caused by osteoarthritis. Unfortunately the cartilage (the part of the body that allows joints to move smoothly) is quite unique, in that it doesn’t have a blood supply. Normally it is the blood that provides repair to damaged tissue. Hence the process of deterioration caused by the arthritis is difficult to stop, and over a period of time the joints may become totally destroyed.
Osteoarthritis is a common joint disorder that usually occurs at the knee, hip, spine, and in the hands, especially at the base of the thumb and in the fingers. Osteoarthritis is not really a disease or even a single condition; rather it is the end result of a number of different episodes of damage to the joint over a period of time. These changes initially result in a joint that looks different to normal but which nevertheless functions well and without pain. Eventually the joint may become very painful with a variable degree of disability. Doctors usually make a diagnosis by examining the joints and looking at X-rays. The most unavoidable risk factor is genetic inheritance. If other family members, such as a sister (or brother), parents or grandparents, have had osteoarthritis, your risk of developing the disease is five times higher than the general population. Exercise and weight are important components in the management and onset of osteoarthritis. Aerobic exercise has a definite benefit, and helps with weight control. It can also increase general well-being. Local strengthening exercises are also particularly useful in reducing any pain and improving balance and stability. Being overweight is a risk factor that worsens the condition, so a slow steady weight loss can reap great benefits. Other effective management options include dietary supplements and drug therapies.
Osteoarthritis is a common joint disorder that usually occurs at the knee, hip, spine, and in the hands, especially at the base of the thumb and in the fingers. Osteoarthritis is not really a disease or even a single condition; rather it is the end result of a number of different episodes of damage to the joint over a period of time. These changes initially result in a joint that looks different to normal but which nevertheless functions well and without pain. Eventually the joint may become very painful with a variable degree of disability. Doctors usually make a diagnosis by examining the joints and looking at X-rays. The most unavoidable risk factor is genetic inheritance. If other family members, such as a sister (or brother), parents or grandparents, have had osteoarthritis, your risk of developing the disease is five times higher than the general population.
Appendix XXV - study 3

Intention to undertake genetic testing question

Please indicate whether you would have a genetic test to discover the likelihood of your developing arthritis in the future.

Please tick the answer that most applies.

If my G.P offered me the chance to have a genetic test to determine my lifetime risk of developing arthritis I would -

a) Definitely take the test

b) Be inclined to have the test

c) Be unlikely to have the test

d) Definitely decline the test
Dear Participant

Postgraduate Research – The impact of disease information on perceptions of control.

The management and treatment of arthritis is complex, and varied according to each individual’s medical diagnosis and personal needs. Although some of the information you have just read is based on fact, other parts of the information may not be accurate. The information was put together by the researcher, for the purposes of the research project, and should not be considered definitive.

If you wish to know more about the successful management of arthritis please contact: - Arthritis Care, 18 Stephenson Way, London, NW1 2HD. Tel: 020 73806562. If you wish to know more about the risk factors attached to arthritis, and the treatment of this disease please contact: - The Arthritis Research Campaign, St. Mary’s Court, St. Mary’s Gate, Chesterfield, Derbyshire. S41 7D. Tel: 01246 558033 - http://www.arc.org.uk

If you have questions about the information you have read please contact myself (Tel: 01483 876946), or Dr. Lyons, who is supervising this project at the School of Human Sciences, University of Surrey (Tel: 01483 876902). Both of us will be happy to answer any of your questions. Thank you for your time.

Yours sincerely

Jane Hendy

Jane Hendy. (B.Sc. M.Sc.)

(Postgraduate Ph.D. research student at the University of Surrey)
Appendix XXVII - study 4

Verbal information given preceding participation

Thank you for agreeing to take part in this research. As I have previously mentioned I would like us to talk about some of the health issues that we all have to deal with as a consequence of developments in medical science. In particular I would like us to talk about health tests that enable a healthy person to find out about the likelihood of them developing a particular disease in the future. As you may know these tests are called genetic tests. For example, currently a person can request to have a genetic test for breast cancer. This service is currently available to people at very high risk of this disease.

Genetic testing involves attending a genetics clinic and having a blood test, the blood is then genetically analysed. The person being tested will then be told whether they carry a gene - predisposing them to developing breast cancer. If the person does carry the gene, they will be told what the estimated likelihood is - of them developing breast cancer in their lifetime - compared to a person within the normal population without the gene. This type of testing has also been developed for diseases such as heart disease, Alzheimer’s disease, diabetes, colon cancer and many others. Although genetic testing for these conditions is still quite rare, it is widely thought that genetic testing for these conditions will be more widely available in the near future. I would like to hear about what you think about these tests – whether you would consider having one.

Before we begin would you like to ask me any questions about the information I have just given you?
Dear Participant

Postgraduate Research - The prospect of predictive genetic testing: analysis of intentions

I am a postgraduate research student working at the University of Surrey. I have been sponsored by the Economic and Social Research Council to conduct a Ph.D. research project into people's attitudes towards predictive genetic testing. I am looking for volunteers to take part.

Participation involves being interviewed by myself for a period of about half an hour. The interview will be concerned with your views on recent developments in medical science, particularly genetic testing. I will ask general questions about your health, then I will ask how you feel about genetic testing - a health test which informs people about the likelihood of them developing a particular disease in the future. You do not need to know anything about genetic testing in order to take part, as you will be given information about this procedure prior to the interview. The interview will be conducted wherever and whenever is most convenient for you.

The interview will be tape recorded, to make it easier for the researcher to remember what was said, but you will not be asked to give your name, and your answers will not be used for any purposes other than the research stated. The information you give will be anonymous, and treated as confidential, in accordance with the Data Protection Act 1998. You will not be personally identified during completion of the study, or named in any subsequent publications. If you would like to take part in the research, or have further enquiries please contact me (Tel: 01483 876946), or Dr. Lyons who is supervising this project at the School of Human Sciences, University of Surrey (Tel: 01483 876902). Both of us will be happy to answer any questions you may have.

Thank you for your time.

Yours sincerely

Jane Hendy. (B.Sc. M.Sc.)
(Postgraduate Ph.D. research student at the University of Surrey)
Appendix XXIX - study 4

Jane Hendy
BSc (Hons) MSc

University of Surrey
Guildford
Surrey GU2 5XH UK
Tel: +44 (0)1483 876861
Fax: +44 (0)1483 259553
Email: j.hendy@surrey.ac.uk

Consent form - version 1 - Pilot study
One copy to client, one to be retained

Dear

Postgraduate Research - Lay Beliefs, Attitudes and Intentions towards Genetic Testing: A focus group study.

This form is to ensure you fully understand what participation in the above study involves, and that you wish to take part.

As discussed, participation involves talking to the researcher about your opinions regarding predictive genetic testing for approximately half an hour. The interview will be audio-taped so it can be remembered accurately later on, but at no time will you be asked to give your name and you will not be personally identified. Your views will not be used for any purposes other than the research stated.

You are free to withdraw from the project at any time, talk freely about whatever you wish, with no set or right answers expected at any time. If you fully understand what is involved and have no further questions please sign the consent form attached.

Please feel free to contact me if you do have any further enquires or, alternatively you can contact Dr. Lyons who is supervising this project at the School of Human Sciences, University of Surrey (Tel: 01483 876902). I hope taking part is a positive experience and thank-you for your time and assistance.

Yours sincerely
Jane Hendy. (BSc. MSc.)
(Postgraduate Ph.D. Student University of Surrey)

I confirm my full understanding of, and agreement to participate in the above study

Signed: - Date:-

~~~~~~~~~~~~~~~~~~~~  ~~~~~~~~~~~~~~~~~~
Appendix XXX - study 4

Pilot interviews – useful questions to ask interviewees

This interview is particularly concerned with how you feel about genetic testing for heart disease and some forms of cancer, can I ask

1. Whether you feel you are particularly susceptible to developing these either of these conditions?
2. Compared to other people would you say you are at low, average or high risk of either heart disease or cancer?
3. Can I ask why you feel you are *not* vulnerable to developing this particular condition/disease?
4. Can you think of any particular times when you most think about your health?
5. Do you feel being at low risk of … disease affects how you live your life?
6. How central is the risk of … disease to your life?

I would now like you to consider whether - if you were offered a genetic test - this week - to determine your lifetime risk of developing heart disease or any type of cancer

7. Would you take it?
8. If I said I could offer you a genetic test for any health condition, say something you would most like to know (you don’t need to tell me what this is) would you have genetic test to find out your chances of developing this condition?
9. Can you talk me through the reasons for your decision?
10. Can you think of anything that would help you make your decision?
11. If you did have the results of a genetic test, how do you think that information would affect or change your life - if the results were negative or positive?
12. Can you think of any circumstance, in which you would be more likely to *undergo/reject* genetic testing?
13. Can you explain why?
14. Is there any type of situation where you think that genetic testing is *more/less* acceptable to you?
15. Or to society as a whole?
16. Can you explain your answer?
Before we start I would like you to confirm that you have never been diagnosed with heart disease or any form of cancer.

I’d also like to remind you that you are free to end the interview at any time, and if you don’t want to answer any questions this is fine. I’d also like to say that there are no right or wrong answers to any of the issues we are going to talk about, I am only interested in what you think - in your opinions.

Part 1 - How they view their health
If you are ready I like to start off by asking you -
1. How often do you think about your health?
2. What do you think about when you consider your health?
3. What sort of measures if any do you take to look after your health?
4. How active do you feel you are in looking after your health?
5. How central would you say your health is in your life?
6. Do you ever have any concerns or worries about your health - both now and in the future?
7. Can I ask you whether you feel you are susceptible to developing any particular health problem?

Part 2 - How at risk they feel of developing heart disease and cancer and how is this risk conceptualised
This interview is particularly concerned with how you feel about genetic testing for heart disease and some forms of cancer. Can I ask -
8. Whether you feel you are particularly susceptible to developing these either of these conditions?
9. Compared to other people would you say you are at low, average or high risk of either heart disease or cancer?
10. Can I ask why you feel you are *not* vulnerable to developing this particular condition/disease?
11. Can you explain for me what being at ‘low risk’ means - for example - can you explain the difference between you and a person with a high risk of developing this disease?

12. Can you tell me how talking about your health and your risk of disease feels - what thoughts go through your mind when you say - “I’m at low risk of ... disease”?

13. Do you ever think about your risk of ... disease?

14. Can you think of any particular times when you most think about your health?

15. Do you ever discuss your health with other people?

16. Do you feel being at low risk of ... disease affects how you live your life?

Part 3 - How do they view general health screening

I would now like to ask you some general questions about health tests.

17. How do you feel about health screening for diseases such as breast cancer and heart disease - for example undergoing a mammogram to see if you have a breast lump, or an E.C.G to see how your heart is working?

18. Do you think these types of health tests are good or bad thing? Can you explain your answer?

Part 4 - How they view predictive genetic testing

19. What do you think about predictive genetic testing for heart disease or breast cancer? - having a test to tell you whether you are likely to develop this disease in the future.

20. In what ways do you think having a genetic test for the breast cancer gene is different from undergoing a mammogram to see if you have a breast lump?

21. Do you feel this form of health testing - identifying whether a person has a ‘disease’ gene – is a good or bad thing? Call you talk me through the reasons for your answer?

Part 5 - Their intentions towards genetic testing

22. Have you ever considered having a genetic test?

23. Do you know of anyone who has ever considered having a genetic test?

24. If yes - can you tell me about the sorts of things that were considered important to them or you – when thinking about this decision?
25. I would now like you to consider whether if you were offered a genetic test this week, to determine your lifetime risk of developing heart disease or any type of cancer, would you take it?

26. If I said I could offer you a genetic test for any health condition, say something you would most like to know (you don’t need to tell me what this is), would you have genetic test to find out your chances of developing this condition?

27. Can you talk me through the reasons for your decision?

28. Can you think of anything that would help you make your decision? For example what sort of information, services or reassurances would you want, and how would these help you?

29. If you did have the results of a genetic test, how do you think that information would affect or change your life - if the results were negative or positive?

30. Can you think of any circumstance, in which you would be more likely to *undergo/reject* genetic testing? Can you explain why?

31. Is there any type of situation where you think that genetic testing is *more/less acceptable to you? Or to society as a whole? Can you explain your answer?

I think we are getting the end of the specific questions I wanted to cover with you, can you think of anything else you’d feel you’d like to add, that we haven’t talked about?

And finally before I turn off the tape can I ask whether you feel happy with the tape, with how your views are represented?

* low will be deleted to say high risk as appropriate
* undergo will be deleted to say reject as appropriate
* more will be deleted to say less acceptable as appropriate
Dear Participant

Postgraduate Research - The prospect of predictive genetic testing: analysis of intentions

I am a postgraduate research student working at the University of Surrey. I have been sponsored by the Economic and Social Research Council to conduct a Ph.D. research project into people's attitudes towards predictive genetic testing. I am looking for volunteers to take part.

Participation involves being interviewed by myself for a period of about forty minutes to one hour. The interview will be concerned with your views on recent developments in medical science, particularly genetic testing. I will ask general questions about your health, then I will ask how you feel about genetic testing - a health test which informs people about the likelihood of them developing a particular disease in the future. You do not need to know anything about genetic testing in order to take part, as you will be given information about this procedure prior to the interview. The interview will be conducted wherever and whenever is most convenient for you.

The interview will be tape recorded, to make it easier for the researcher to remember what was said, but you will not be asked to give your name, and your answers will not be used for any purposes other than the research stated. The information you give will be anonymous, and treated as confidential, in accordance with the Data Protection Act 1998. You will not be personally identified during completion of the study, or named in any subsequent publications. If you would like to take part in the research, or have further enquiries please contact me (Tel: 01483 876946), or Dr. Lyons who is supervising this project at the School of Human Sciences, University of Surrey (Tel: 01483 876902). Both of us will be happy to answer any questions you may have.

Thank you for you time.

Yours sincerely

Jane Hendy

Jane Hendy. (B.Sc. M.Sc.) (Postgraduate Ph.D. research student at the University of Surrey)
Dear [Client]

Postgraduate Research - Lay Beliefs, Attitudes and Intentions towards Genetic Testing: A focus group study.

This form is to ensure you fully understand what participation in the above study involves, and that you wish to take part.

As discussed, participation involves talking to the researcher about your opinions regarding predictive genetic testing for approximately forty minutes to one hour. The interview will be taped and transcribed so it can be remembered accurately later on, but at no time will you be asked to give your name and you will not be personally identified. Your views will not be used for any purposes other than the research stated.

You are free to withdraw from the project at any time, talk freely about whatever you wish, with no set or right answers expected at any time. If you fully understand what is involved and have no further questions please sign the consent form attached.

Please feel free to contact me if you do have any further enquires or alternatively you can contact Dr. Lyons who is supervising this project at the School of Human Sciences, University of Surrey (Tel: 01483 876902). I hope taking part is a positive experience and thank you for your time and assistance.

Yours sincerely

Jane Hendy. (BSc. MSc.)
(Postgraduate Ph.D. Student University of Surrey)

I confirm my full understanding of, and agreement to participate in the above study

Signed: - Date:-

358
Appendix XXXIV - study 4

Example transcript

**Interview number 5 - Respondent at low risk of disease**

I = Interviewer   R = Respondent

*Interview preamble then –*

I: ...OK I’d like to start off by asking you how often you think about your health?

R: Quite a bit, maybe once a week, I’m not really sure, but I do think about staying healthy quite a bit, yeah.

I: And what sort of things do you think about?

R: Just staying healthy, keeping slim, I think about that a lot. I’ve just had a young baby so I think about eating properly and getting back in shape. I want to be healthy for the baby, and for myself. So yes, I do think about my health quite a lot.

I: And do you ever worry about your health, or have any particular health concerns?

R: I’d don’t have any concerns about my health, but I do realise that I could have a healthier lifestyle, as far as physical fitness and eating habits as well, so that is on my mind quite a bit.

I: Do you every worry about your health in the future? Think about your future health?

R: I do, I think that if I don’t do something about it now I might regret it later in life. Especially when it’s your eating habits or something, it’s something you need to change now rather than later.

I: So your health is quite important to you, it’s something you think about?
R: Yes, yes it is. Like I said I’ve got a young child now, so I need to look after myself, not just me, but for her. I also feel I need to keep well to keep up with her. She can be quite a lot of work really, pretty exhausting at times.

I: And can I ask you whether you have any focus for concern, whether feel particularly vulnerable of developing any particular diseases in the future?

R: No, no I don’t because they isn’t anything in the family. So no, I haven’t thought about, I feel very healthy overall.

I: And today, in this particular interview I am especially interested in what you might think about genetic testing for forms of cancer and heart disease, can I ask whether you feel at any risk of these conditions?

R: Again I’m not one hundred percent sure that cancer is genetic but um...again there is nothing in the family so, it’s something I haven’t really considered. I haven’t really thought about it if I’m honest.

I: Great. So if you had to say whether you were say low or high or average risk of these conditions what would you say?

R: I’d say low risk, definitely low risk, because like I’ve said there isn’t anything like that in my family, no history of cancer or heart disease or anything of that sort in my family, and although I don’t do all the things I could, I do feel I live a reasonable-healthy lifestyle. I’ve never been seriously ill, or had any major health problems, not ever, not really.

I: And when you say that, how does that feel, do you have any thoughts on this?

R: I suppose it’s a security, a kind of security within the knowledge that you think you are low risk you don’t worry about it. It feels good obviously to say this. I don’t think about it much, but saying it, it feels good, nice like a warm feeling, no real worries. So I guess I feel quite lucky when I think about. But as I’ve said I really don’t think about it very much.
I: And does this sense of security affect how you live your life in any way?

R: Well I don’t worry about it. It’s not something that ever crosses my mind it really, is it. I just live my life and feel quite happy about my health, about life in general really. I don’t worry much, haven’t got the time. So it’s good I … I guess I’m quite lucky really.

I: Great thank you. Now I’d like to ask you some general questions about how you feel about health tests. I like to ask you how you feel about health screening tests like mammograms for breast cancer, cervical smears and ECG’s for heart problems. What do you feel about these sorts of tests?

R: I think it’s very important that if someone does have that concern the technology is there, to give them the answers that they will probably want, and need as well.

I: Do you think these tests are a good thing or?

R: Yes, yes I do, I think they are a very good thing, yes, especially with the likes of Alzheimer’s etc. People want to know what’s going to be happening in their future and if there is something that they may have to come up against, at some point in their live. So yes I think all sorts of health tests are a good thing.

I: And would you go for these sorts of test if offered?

R: Yes I would, because prevention is better than cure, and hopefully you could take some kind of medication to sort you out.

I: And what do you think about predictive genetic testing for things like breast cancer and heart disease, what do you think about these new developments?

R: I probably don’t know enough about it to make any useful comments on it.

I: They basically tell a person the likelihood of them getting a disease in the future.
R: So it's not a definite answer, it's a likelihood.

I: Usually it is likelihood, for most things, yes. They give a risk percentage, rather than a definite answer, say 80% risk for people identified with the breast cancer gene.

R: That's quite high isn't it, well then I think definitely it's something that's very important to the individual who want to find out this information so yes, very good. I would agree with it. Yes, most definitely. I would have that if I felt it was necessary.

I: Can you talk me through some of the reasons why you think it's a good thing?

R: Why? Um... I actually saw a program and it was a young family and his mum was suffering from Alzheimer's disease and his brother had had the testing done and he was positive that Alzheimer's was going to be something that would come to him, and he wanted to know so he could prepare his family for it etc. So I think for that, you do need... I do understand it can also have an effect on insurance policies etc. But I think to be prepared for what lay ahead, it's important, it allows you to take control, to feel you have some control over the future, and I would want to know.

I: You would?

R: Yeah.

I: So if I offered you a genetic test for anything you might want to know, this week what would your reply be?

R: If it was a concern, say there was, there was an individual in the family with it, already suffering, I probably would be tested, especially if I had another child, so I would definitely get testing done, if it was a concern. I would want to know before I had another child so I could be prepared for that. So in terms of planning my family I think it would give me a lot to think about.

I: And if it wasn't in the family?
R: If it wasn't in the family, I probably wouldn't. No. But if there was anything I would, definitely, but right now I wouldn't because there isn't anything in the family that I'm worried about. So I don't really feel that this sort of testing would affect me too much, I think it's more for people with a strong family history of a genetic disease in their family.

I: So you haven't ever considered having any sort of genetic test?

R: No, no it's never crossed my mind really.

I: Do you know of anyone who has every considered this?

R: No.

I: If you were deciding, say someone put that proposition to you, what sorts of things would be important to you, to help you make that decision?

R: Well whether it was controllable or not, that would make a difference to me. Something like Alzheimer's then no, because they can't do anything about it, but something I could manage, that would be different, and so I would have to consider that. And also whether it was mental or physical, I think a physical illness you could probably cope with more, so that would make a difference. And with some forms of cancer I don't know, because I don't know if you can prevent it. But I guess even with this you could look for signs and try to catch it in the early stages.

I: There is a difference there, what you feel you could do to prevent it?

R: Yes I think so.

I: And how you could cope with it?

R: Definitely, yes.

I: And are there any other factors you can think of?
R: Well I would definitely have to consider the need to know, and how much that would change my life, because obviously the answer to that test would be, could be quite devastating to my lifestyle at the moment, and change how I see the future. So I would have to think, think very hard about taking some form of testing...whether it would be something that would be beneficial right now, or whether it would be something to leave for a later date. I think you have to consider your children. When you are considering having a child, that’s when you have to sit down and think. But to be honest when you sit down and think about it, it’s a bit scary really, isn’t it.

I: What scares you?

R: Well you might be living your life thinking everything is fine, then bang they tell you that have this horrible disease coming, you have the genes for it.

I: What do you think you’d feel if you had a test and it was positive? And how do you think you’d react to that news?

R: I would probably go into some kind of state of shock, and I would then, as an individual try and deal with it, and um... I suppose there would be disbelief as well. Um... you may need some kind of counselling, for you to come to terms with it, never mind having to discuss it with the family, and see the way forward with it. But I think it would probably be a very difficult time in my life, if that was the case. So it would be a very difficult thing, something not to be taken lightly.

I: So you have feelings are mixed on this?

R: I think it would probably be a very negative thing to know to start with, very negative, but it would also be important for making other decisions, for your future etc, as far as having other children, because you need to consider whether you would pass the same things on to your child and it’s going to perpetuate down the line.

I: Generally do you think the availability of such information is a good or bad thing?

R: We didn’t need it years ago, people just lived their lives but the technology’s there now, it’s there and people want to know, but I think if the technology hadn’t
developed the way it has then probably people would live as they always had, and just go on with their lives, and it was for the best, people lived their lives and didn’t live in fear. Yeah, they just got on with it, and just lived day to day instead of trying to look into the future, but there is this facility available, so now people want to know. You can’t take away that knowledge once it there can you, can’t put the genie back into the bottle.

I: So do you think genetic testing is a bit like living in fear of things, having that test?

R: I think it’s probably finding out something years before perhaps anything would develop, those years would probably change considerably if you had the knowledge, whereas if you didn’t you probably wouldn’t worry about it.

I: So a negative change?

R: Negative yes, definitely, because you’d probably continue to have children, and just continue live your life on a day to day basis... but you’d probably live in the fear of symptoms, and they wouldn’t be there, wouldn’t be signs and symptoms, but you’d be ‘Yes’, constantly thinking about it. So you might actually make things happen, make things progress quicker than perhaps they would. It could make you ill, thinking, thinking about it all the time. A self-fulfilling prophecy.

I: Yes.

R: Yes. Making the worst happen.

I: And if you were having to make that decision, considering taking a genetic test, can you think of any information, services or reassurances you’d want to help you in that?

R: I think you’d definitely have to have some kind of counselling, on the positive and the negative of having this testing. Um... I suppose you’d have to have reading on it, in terms that perhaps I would understand. You know you have your technical terms, but I would need information that I could understand, in layman’s terms. Um... probably the ins and outs of how it would affect my future having the results and policies, life endowments, all these different areas would have to be looked at because
if you got a negative result then um... Obviously it would affect your life and your families life, so whether you’d want to do that I’m not so sure.

I: Can you think of any sort of circumstance where you think genetic testing is more of less acceptable, to either you personally or society as a whole?

R: I think genetic testing has to be an individual decision, especially if there are fears within your family circle, if there was breast cancer etc, then I think it should be made available, but I don’t think it should be used as a general testing, if your understand? Do you understand?

I: Yes.

R: I think it’s a personal choice, some people want to know, other people don’t, it’s a personal thing. But I think it should be available to the people who feel they require it but I don’t think it should be across the board just to say, you know, to double check that there isn’t something there. I think if there is breast cancer in a family then yes I can understand, but I don’t really understand just anybody who doesn’t really have it in their family; I don’t think they should have all this testing.

I: You’re not for wide screen testing for everybody?

R: No I don’t think it should be wide screen. It should be for the individual.

I: Can you tell why you feel uncomfortable with wider testing?

R: I think is just not on, because your make up is your make up, you shouldn’t feel you have to go and have testing to find um... if there isn’t a fear of it already there. You are putting fear there when there isn’t fear there already. Yes, there would probably be a need for it if, in my family there was a family history, if there was cancer etc, then I would consider it. But for the general run of the mill day to day appointment at the doctors, right we are going to do genetic testing, no I don’t think so. I don’t think it should be across the board.
I: So if you were offered a genetic test this week, for anything, for a condition you'd most want to know about developing in the future, what would you say to me?

R: I wouldn't want a test, basically no I wouldn't.

I: And why would that be?

R: I don't have any fears right now, so testing would only be telling me something I perhaps wouldn't know for many, many years down the line and it would waste, it would spoil the years leading up to that. I rather not know and just get on with things, definitely.

I: And can I ask how you feel about the development of genetic testing in the future?

R: I think with all the experiments, and I'm not completely knowledgeable on these things, but the experiments going on with the genetic testing, and the fact that you can chose certain factors within the gene pool, and I think that's ethically wrong. Um...I do feel that's wrong. But I don't think people should have the choice, I don't know if I'm going off the rail, but choosing eye colour etc. Um...I think the human race, has to be the human race. Um... if you start mixing with technology then things can get dangerous later on. Get out of hand.

I: Yes.

R: Yes, you could be producing blonde blue eyed children because that is your choice instead of letting nature take it's course... I believe nature still very much has its place. Um...I am concerned for the future I am concerned that it will get into the wrong hands. There are lots of people out there who shouldn't get there hands on this sort of information, because I think depending on their frame of mind it could take a really really bad turn and be a very negative thing.

I: So you do have fears about this for the future?
R: I do, perhaps not in my lifetime, but in my daughter’s lifetime. I think the technologies going to go maybe one step to far, and we are going to be messing up nature, and that sort of thing.

I: I think we are getting the end of the specific questions I wanted to cover with you, is there anything else you’d feel you’d like to add that we haven’t covered yet?

R: I think from the beginning of the tape my feeling was that it was very important to test, but now I’ve got near to the end of the interview um... I don’t know, I’m not so sure, I think I’ve changed my mind on that. I don’t believe that genetic testing should be across the board, it has to be for individual families, that perhaps have that medical need, that are medically affected by it. But in general I feel there is no point finding out about things you don’t already know about, it will still come to you, in time anyway, and you might just spoil the time you have worrying about the future. When you think about it more deeply it’s kind of scary really, so I’m not sure at all. That’s it really, that’s all I have to say.

I: Ok. And do you feel happy with the tape, with how your views are represented?

R: Yes.

I: Great. I’ll turn off now.
Appendix XXXV - study 4

Example transcript

Interview number 10 - Respondent at high risk of cancer
I = Interviewer  R = Respondent

Interview preamble then –

I: ...OK I’d like to start off by asking you how often you think about your health?

R: Oh yes! Every day, several times a day probably, my health does preoccupy me quite a bit a would say.

I: And what sort of things do you think about?

R: Whether I am developing this or that disease, my hip, my eyesight, my back you know all those things that start to seize up, if I will remain healthy I guess, those types of things mostly.

I: And do you ever worry about your health, or have any particular health concerns?

R: Yes I do quite a lot. Yes my health is of great concern to me generally.

I: And can you tell me a bit more about these concerns?

R: Well obviously I worry whether I will stay healthy, I don’t want to be a burden on anyone, I want to remain active and fit, but you know you get up in the morning and everything is getting a little bit stiffer and you feel older. It’s quite frightening when you dwell on it.

I: So you think about how your health will be in the future?
R: Yes, I do worry about my health a great deal. Mainly, probably... because I am at the age I am, dementia and things like this, having to rely on other people to look after me and things like this, that sort of thing really bothers me. So yes I do worry a real lot about my health, and my independence in the future.

I: So your concerns over your health, how large a place, do you feel these have in your life?

R: Fairly large now, much larger than they ever used to have. I think that’s probably something to do with age, must be something to do with age, because, when I was younger I was more worried about other people, you know my children, taking the children to the doctors, my mother, my father and all that, etc. But now I worry more about me, much more than I ever did, yeah.

I: And you feel fairly anxious about this?

R: In actual fact yes I do, I do. Thinking about it makes me quite emotional because I do worry quite a lot about my health, when I think about it I feel quite panicky, quite scared really. It’s stupid I know, but the thought of getting seriously ill scares me, the fear of being dependent, of being a burden, that sort of thing (starts to look tearful).

I: OK... so it’s quite an emotional thing.

R: Yeah it is, especially when you live on your own, you worry about trying to keep yourself going I suppose, I can’t thing of another word for it I suppose. So you are healthy and will not be a burden on other people.

I: And do you take any measures to look after your health?

R: Well I try to keep well, and keep my weight down, but not hard enough (laughs). I certainly could be slimmer and exercise more, but I do walk the dog a lot and stuff like that. I try to keep as active as I can. But no I could probably do more. You know what it’s like... I’ll start that diet on Monday morning and Monday comes and oh well. So I try to make inroads but if I’m honest I am aware that I could do more, but well, life is for living, if you never did anything you enjoyed well, it would be pretty
boring, so...as well I think it is a balance. You can get these things out of proportion can’t you?

I: Yeah, you can....That great, that’s given me an idea about how you view your own health. And also, in this interview I am specifically interested in your views on genetic testing for heart disease and cancer. Do you feel particularly susceptible to either of those two conditions?

R: Yes, I do feel I am susceptible to cancer, very much I feel I probably am....um...No I don’t feel I am susceptible to heart disease. There is no heart disease in my family, and I’ve had my heart and cholesterol checked and the doctor said I was as strong as an ox, had the heart of young girl, shame not the body to go with it (laughs).

I: And in thinking about your susceptibility to cancer would you say you are low risk, or average risk or high risk?

R: Well I always thought I was probably a high risk, simply because my mother died of breast cancer and my father died of colon cancer, and four of my mothers’ sisters have had breast cancer.

I: So cancer is in the family, and is this why you see yourself at risk?

R: Yes, I try to put, I always try to put it at the back of my mind that. And that used to bother me more a while ago than it does now. Age has taken that worry....ten years ago I was much more worried about getting breast cancer than I am now, because I’ve become sixty years of age and I’m now more worried about other illnesses.

I: OK, so this central this risk has become less central in your life?

R: Yes it has.

I: And is there any particular circumstance when your health risks are more to the fore in your life, when you think about them more?
R: Um... I don’t know, when I think about them more. I guess a lot of it is emotional, if you get friends that die, or are ill. You see people that you knew that have dementia, or you see people who are younger than me, say, dying of breast cancer, or colon cancer, or any sort of cancer, and you... You realise that they are maybe five, ten years younger than I am, then it comes to the fore and you think about it for a while.

I: And your worries about your health, do you chat about them with anybody?

R: No, no.

I: You keep them to yourself?

R: Mostly I think. I do sometimes joke about them with people, people I work with, and they joke with me, oh one day you’ll be like that .... But I suppose everybody’s skirt ing round it peripherally. But no I don’t do my basic anxieties with anyone.

I: And why is that?

R: Well again I suppose I don’t want to worry anyone, at the end of the day there’s not much you can do about these things, so there is no point talking about them is there. It’s just something I keep at the back of my mind, not something I would want to concern other people about.

I: Great, that gives me a general picture of how you view your health. Now I’d like to ask you some general questions about health tests. How do you feel about health tests for heart disease and cancer, say an ECG or mammogram – do you feel these types of tests are a good or bad thing?

R: I think they are a very good thing, because I wouldn’t like... some of these things are preventable, and if they are preventable you should take the chance, the opportunity not the chance, you should take the opportunity of grabbing it.

I: So if you were offered these types of tests would you make use of them?
R: Yes I would, yes. Yes I think because if they are caught within...an early stage of anything, colon cancer, breast cancer, heart disease, you have a greater chance of looking after yourself and coping with it.

I: And now I’d like to ask you what you think about predictive genetic testing. Do you have any feelings about predictive genetic testing; you know having a test to tell you whether you are likely to develop a disease such as breast cancer in the future?

R: I’m not sure.

I: Do you think these tests are different in any way to the other test we’ve talked about?

R: Yes, I think they are. I think if you could be tested to be an alcoholic, I think that would probably be a good thing to know, but whether it would control your life or not, I don’t know. If you ... I think if you had a test and you knew you were going to become an alcoholic, you could control your life much better, you would perhaps stop at a fourth drink, or perhaps never drink, I don’t know if you would not ever drink but if I knew that I would become an alcoholic, because I drank wine, but I would make sure that it was controlled. Whether that’s possible or not I don’t know, whether you can control alcoholism but saying say I’ll always have six glasses and never have another one. Um...but breast cancer of course if you knew you were going to have it, I don’t think I’d like to have that information, because there is nothing you can do about it anyway, except go for regular mammograms.

I: So you think some of these tests are OK, but it depends on what you can do with that information.

R: Yes, yes. I mean the fact that you could have a test for heart disease and know that if you ate a good fairly healthy diet, and led a healthy lifestyle that would be fine, but if you had a test and somebody sort of explained it to you that no matter what...we’ve tested you for heart disease and even though you might eat a healthy diet, and whatever, and you will still get heart disease, I wouldn’t want to know that. No.

I: So it’s a question of what you can do with that information.
R: Yes, yes it would be.

I: And generally this form of health testing, looking for genes if you like, do you think it is a good or bad thing?

R: Um... (Long pause). I think it's a good thing for the individual, whether it's a good thing for the world, world wide, I'm not sure on that really. Um...it's probably a good thing if they are the things you want to know, as an individual, if you want to know them, then it's good. I don't think that everybody should be all and sundry tested, or given this knowledge. And I'm not sure...because the world is so over-populated anyway, that keeping everybody alive come what may is a good thing.

I: So you've got mixed feeling about it?

R: Yeah I have, yeah.

I: And can I ask you have you ever considered having a genetic test yourself, or do you know of anyone who had considered this?

R: No. Well I've never been offered one, so I suppose I've never considered it, I suppose I would have considered having um... a test, probably I would have done, had a test for breast cancer, if I was given the opportunity.

I: You said if you were offered a test, you'd probably have one, what sorts of things would be important to you when making this decision?

R: Um...I think probably just to be able to see your future. Although I've stated other things, probably contrary to that, if someone actually said to me, if we test you today and we can tell you if likely to get colon cancer, because I'm older I wouldn't mind knowing that now. If I'd have been thirty I wouldn't want to know it, but there's a difference in the age. But now I could probably cope with it, I'd think is there anything I could do now to make my life, my life more liveable more comfortable etc. And if that was possible, if somebody said to be me oh, we can test you and you can do something positive about it, by eating roughage, cause it decreases colon cancer
and things, then I would want to know, now. But at thirty I probably wouldn’t have wanted to know.

I: So you think you’re age has a lot to do with it?

R: I think probably it has.

I: And why is that do you think?

R: I don’t feel more in control of my health, but I wouldn’t a life sentence hanging over me, my life at thirty, but at sixty you know there is only twenty years left, at the most probably, as I can make things better perhaps by living my life more sensibly, but not to be worried about it from thirty.

I: And do you feel you’d be able to make those changes if you needed to?

R: Yes, I think I could, although I don’t diet, I ought to diet; I ought to be slimmer and not eat some of the things I eat. But if somebody said to be me you are actually going to have colon cancer if you don’t eat, I don’t know, fibre twice a day, or a glass of orange juice, or if you cut out chocolate you’ll never get colon cancer, I would cut out chocolate. It depends what it was, but because of my age I would do most things that I would have to do. I might sometimes slip up, but overall I would adhere to it.

I: And if you did slip up?

R: I would get just back on track, I wouldn’t beat myself up about it, because with twenty years left, it’s not worth it. So I wouldn’t beat myself up about it.

I: Now I’d like you to imagine I was going to offer you a genetic test this week, for anything you most want to know, any health problem, you don’t have to tell me which one, what would you say? Would you take it?

R: Yes. I would.

I: And what would that knowledge, either good or bad, give you?
R: Control of my life, and again it's to do with my age. I know I keep going back to this, but because of my age, it would be important to me. So if I could have a genetic test telling me I was going to have Alzheimer's I would have it. I would plan my life, the rest of my life.

I: And that would be a good thing?

R: Yes, very good.

I: And can you see any negative things about getting that information?

R: Only that I would suffer the shock of it at the time and I would... the shock of it would take me three or four days to settle down from the news. Um... but then if I had the test and the news was that I wasn't going to get Alzheimer's, I'd have four days of euphoria, so I would have the test.

I: And um... in making that decision, or for others needing to make that decision, what sort of services, information or reassurances would you want to be supplied with.

R: Well confidentiality would be the first thing... because it all depends what the test was about, but it would be confidentiality, although I don't put much store of it, confidentiality is not as good as they often tell you it is. And just for you, I think it should be just for you, especially if it's anything to do with your health, it should not be for your family or anybody else, it should be just for you.

I: So confidentiality would be your main concern?

R: Yes, it's very important, it would be very important to me. I wouldn't want my children to know, if I had that test, and it was a really serious test, and whatever, and if I fell down, and went to the hospital and one of the people would say, of course you know your mother is going to get... that I wouldn't want, so yes confidentiality is very important to me.
I: Is there any sort of information you would want, before or after the test?

R: No, I’d find out all I could before. I hope they would explain to me, before I had the test, when they were offering me the test, and then afterwards I would do my own... If it was a bad result then I would do my own investigation. Or perhaps I would decide not to do any more investigating, just plan my life accordingly.

I: We are getting towards the end now, but I’d just like to ask you, can you think of any situation, either personally or for society in general, where you think that genetic testing is unacceptable?

R: Well genetic testing is for the person themselves really, some people would want to be genetically tested, they might want to see if they were going to have a cystic fibrosis child or a Down’s syndrome child, some people wouldn’t want to be tested for that and they would be quite happy if their child was perhaps born with Down’s syndrome, because it’s the only child they are going to have, so it is a personal choice. Genetic testing shouldn’t be enforced on anybody. I think that if you want a genetic test on something... and then if it’s available, have it, but be forewarned about the results... because you may be very shocked once you’re got the results, and that’s a big dilemma. Somebody’s medical history, um... ought to perhaps, although I’m talking about confidentiality, although I’m talking about testing, um... people should study you and your medical history before deciding to give you the test, if it’s a really serious thing that they are testing you for.

I: OK. That’s great, and the last thing I’d like to ask you is, can you think of any circumstance where you would be less likely to have genetic testing, for yourself?

R: Now, I think I would go in for some genetic testing. Thirty years ago some I would and some of it I wouldn’t and now some I would and some I wouldn’t, so it’s just difficult to say really. But I’d like the opportunity to be there if I choose to do so. I’d like to be given the choice, to decide, to make up my own mind about these things.

I: And generally do you think genetic testing; is a good or bad development for the future of society?

377
R: Well I think as I’ve said before we are all living too long, so I’m not sure about genetic testing, but it’s great for the individual, so a two edged sword really. Um...people that are coming on it’s a good thing. And of course it will be generally accepted, just like MMR vaccine, so eventually it will just be done and we will all accept it. And I think that’s a positive thing, because we will just accept it and there will be nothing to it really.

I: OK, so I think we’re getting to the end of the questions I’d like to ask you. I’d like to ask if there is anything you’d like to add to the tape? Any other comments you’d like to make other than we have discussed.

R: I think genetic testing is a good thing. I don’t know whether they can have a genetic test on dementia yet, or not, because that’s something else that would bother me, and I think that’s lots of people would like to know, when they get older, what’s going to happen to them. It’s like looking into a crystal ball, no-body can tell. But most people when they get to my age, I know they would love to look in that crystal ball, so they can decide what’s happening for the rest of their lives, so in that way, genetic testing would be a good thing for people of my age. That’s it really - I haven’t got anything more to say.

I: Ok, that’s great, thank you. So finally can I ask whether you are happy with this tape, your representation on this tape?

R: Yes very happy. Yes quite happy thank you.