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An Investigation of the Decision-Making Process for Prenatal Genetic Testing

Cécile Muller

Thesis submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy in Psychology,
The University of Auckland, 2011
ABSTRACT

With rapid advances in genomics and maternal care, health professionals will be increasingly required to assist prospective parents make decisions about prenatal testing. However, little is known about the way people make such choices. The present project aimed to fill in this research gap and consisted of three internet-based studies. Study One aimed: 1) to design a model of the process of prenatal genetic testing decision-making, accounting for the complex interactions between variables previously shown to influence testing intention; and 2) to create psychometrically sound measures of the constructs of interest. Data was collected using a scenario which asked 143 New Zealand adults to imagine expecting a child, mentioned a genetic mutation responsible for an unnamed fatal birth-onset condition and described prenatal testing. Results from principal components analyses confirmed the suitability of the new scales for subsequent studies. Study Two aimed to: 1) validate the hypothetical model proposed in Study One, and; 2) assess the role of condition characteristics and demographic characteristics on reproductive decisions. Over 565 men and women of different family statuses (childless, expecting or parents) were randomly assigned to one of four scenarios which described genetic conditions of varying onset ages (early or late) and degrees of severity (nonfatal or fatal). Data were collected using the measures developed in Study One. Path analysis validated the decision-making model. ANOVAs revealed that onset age and severity did not influence testing intention. However, willingness to terminate an affected pregnancy was greater for the fatal (than the not fatal) and the early-onset (than the late-onset) conditions. Childless men (relative to childless women) reported greater testing intention, abortion willingness and subjective norms of the partner. Study Three assessed the roles of perceived procedure-related miscarriage, information modality and trait anxiety in reproductive choices. One hundred and ninety three New Zealand adults were randomly allocated to a message presented in text, print or video. The scales validated in Study One and two new measures (perceived likelihood of miscarriage and trait anxiety) were used to collect data. As expected, miscarriage likelihood predicted testing intention and anxious individuals reported stronger emotional responses to the message delivered in a video. Clinical and educational implications are discussed.
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CHAPTER 1

Overall Introduction

With the completion of the Human Genome Project (International Human Genome Sequencing Consortium, 2001; Venter et al., 2001) and accelerating advances in genomics, assessing the genetic make-up of unborn children and, to some extent, predicting their risks of being affected by a genetic condition has been a clinical possibility in the Western World for a few decades (World Health Organization, 2009). The decision about whether or not to undergo prenatal genetic testing remains the responsibility of future parents. However, little is known about how couples make such reproductive choices. The aim of the present research project was to investigate the decision-making process for prenatal genetic testing.

This thesis is organised as follows. Chapter 2 describes the mode of inheritance, the penetrance and the molecular complexity of conditions with a genetic aetiology. The tests currently (and predicted to be) used to screen foetal genetic malformations linked to disabilities are also presented. These tests have become increasingly prevalent in maternal care in New Zealand (National Health Committee, 2003). Although no precise data seem to exist on the uptake rates, interest in such reproductive technologies is likely to fluctuate with the birth rates. Relevant statistics for the New Zealand population between 1996 and 2010 are provided in Chapter 2. These statistics show a steady rise in birth rates and indicate that prenatal testing has the potential to become increasingly relevant to the growing population of New Zealand.

Genetic testing has to some extent redefined health care. Whereas other medical practices have traditionally approached diseases from a curative or caring perspective, genetic testing relates to health threats from a preventive standpoint (Morren, Rijken, Baanders, & Bensing, 2007). This medical shift from disease management to risk prediction has simultaneously redefined the patient-practitioner relationship. Health professionals are ethically bound to provide informational and psychosocial support, whereas patients are expected to play an active role in health decision-making (Pelletier & Dorval, 2004). Understanding the process that parents go through to reach their decisions about whether or not to undergo prenatal testing is an important part of providing effective psychological support to prospective parents. However, the processes guiding prenatal genetic testing decisions remain under-
Chapter 1: Overall Introduction

researched. Study One (Chapters 3 to 7) aimed to address this research gap by proposing a theoretical model of prenatal genetic testing decision-making, which could have valuable clinical utility. Indeed, such models could enable clinicians to anticipate the relevant issues and concerns, and provide appropriate information and support. The introduction of Study One (Chapter 3) identifies the condition-related, ethics-related and test-related factors influencing one's decision to undergo prenatal testing and/or to terminate an affected pregnancy. Chapter 3 concludes with a proposed theoretical model of the influences of these variables on testing intention and abortion willingness. In order to test the model, a hypothetical scenario (Chapter 4) and scales measuring the constructs (for which no scales already existed) were created (Chapter 5). The hypothetical scenario asked participants to imagine expecting a child and provided them with general information about foetal disabilities and prenatal testing. Then participants were invited to rate a series of statements assessing the constructs of interest. Data gathered online using this method were subjected to principal components analyses, which supported the psychometric properties of the new and adapted scales (Chapter 6). It was concluded that these measures were appropriate measuring tools for assessing the model of prenatal testing decision-making (Chapter 7) and for the subsequent studies in the present research project.

With breakthroughs in molecular biological technologies, prenatal genetic testing can now be carried out to detect specific genetic anomalies associated with disabilities of various ages of onset and degrees of severity (Lau & Leung, 2005), for men and women with different experiences with pregnancies (Brisch, Munz, Kachele, Terinde, & Kreienberg, 2005; Etchegary et al., 2008). Despite the potential roles of conditions' and parents' characteristics in choices about family planning, the influence of these variables on prenatal testing decision-making remains largely under-researched. Addressing this research gap was the first aim of Study Two (Chapters 8 to 11). The second aim of Study Two was to test the model of prenatal testing decision-making proposed in Study One. Chapter 8 discusses the clinical, legal, ethical and psychosocial issues surrounding testing for various conditions, before proposing a series of hypotheses for the roles of condition onset (birth versus adult), condition severity (fatal versus nonfatal), gender and family status (childless versus expecting versus parents) on testing intention and selective abortion willingness. Chapter 9 presents the methodology used to recruit participants throughout New Zealand and to collect data. In particular, participants were randomly allocated to a hypothetical scenario describing one of
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Four conditions deliberately not named but described in terms of their onset (birth-onset versus adult-onset), severity (fatal versus nonfatal) and other characteristics such as their symptoms and treatment options. Participants were then invited to rate items measuring the constructs validated in Study One. Data were submitted to a series of ANOVAs, regression analyses and mediational analyses (Chapter 10). These calculations confirmed the model's adequacy in accounting for people's testing intention and abortion willingness and provided partial support to the hypotheses. Contrary to expectations, the condition severity and age of onset did not significantly influence testing intention. As predicted, however, abortion willingness was dependent on severity and onset age. Also in line with hypotheses were the findings that the combined roles of family status and gender did influence testing intention, abortion willingness and subjective norms of the partner. Chapter 11 provides interpretations of these results and outlines their clinical implications. Chapter 11 concludes by acknowledging that the studies did not provide opportunities to assess the roles of fears of incidental miscarriage or trait anxiety on testing intention.

Advances in genomics mean that potential users of prenatal testing will need to process an increasingly large amount of information about the tests and their consequences. People's ability to process and to adapt emotionally to possibly threatening health information is likely to depend on personality (Pelletier & Dorval, 2004) and on the way the information is presented (Mayer, 2008). Trait anxiety, defined as an enduring personality dimension (Eysenck, Derakshan, Santos, & Calvo, 2007) has been found to influence people's responses to health threat information (L. D. Cameron, 2003). It may also be a personality characteristic with a strong influence on prenatal genetic testing decisions. In terms of information presentation, messages are likely to be processed differently if they are presented written, verbally or in animated video-clips (Mayer, 2008). To date, the combined roles of trait anxiety and modality of information in prenatal testing choices remain unknown. Investigating their independent and interactive roles, as well as the influence of perceived likelihood of miscarriage on testing intention were the aims of Study Three (Chapters 12 to 15). Chapter 12 discusses the roles of modality (print versus audio versus video) and trait anxiety on condition-related variables (i.e., child-related worry, anticipated emotional distress, negative consequences and anticipated coping efficacy), perceived likelihood of miscarriage, benefits from negative results and testing intention. Chapter 12 ends by proposing a series of hypotheses. Chapter 13 details the techniques used to recruit
participants and to collect data. In particular, participants filled in Spielberger’s (1983) Trait Anxiety subscale before reading, listening to or watching a video health message of similar content. The remaining data were collected using the scales validated in Studies One and Two. Analyses presented in Chapter 14 confirmed that fear of iatrogenic miscarriage predicted lower testing intention. Also, and in line with expectations, participants with higher trait anxiety reported greater child-related worry, anticipated emotional distress and anticipated coping efficacy than less anxiety individuals. These differences were accentuated in the video group. Contrary to expectations, in the video group, anxious participants did not report significantly greater perceived likelihood of miscarriage, benefits from negative results or greater testing intention. Chapter 15 interprets these results and discusses clinical implications. Finally, Chapter 16 concludes the present research project. It summarises the implications and the limitations of the three studies, before discussing directions for possible future research.
CHAPTER 2

Background Information on Genetic Conditions, New Zealand
Demographic Data and Prenatal Genetic Testing

Chapter Overview

The science of genetics has evolved rapidly over the last few decades and has become increasingly prevalent in maternal care. It is now possible to test foetuses for genetic mutations that may develop into a disability after birth. However, the decision to undergo prenatal testing belongs to prospective parents rather than clinicians. Interest in such technologies is likely to be influenced by many factors, such as 1) understanding that even ‘healthy’ parents may carry a child with a genetic malformation, 2) the birth rates and population growth, and 3) the technologies available to detect such mutations, (Offit, Sagi, & Hurley, 2006; Reddy & Wapner, 2007). The present chapter addresses each of these issues in four sections. First, the historical progression of the sciences under consideration is summarised. The second section discusses the aetiology of genetic diseases. Third, data on New Zealand demographics and their implications for prenatal genetic testing decisions are provided. Finally, the different types of prenatal screening and diagnostic tests are reviewed.

From Laws of Inheritance to Genomics

The concept of heredity has been known for a long time (Kumar, 2007) but it was only in 1865 that Mendel, 'the father of modern genetics', revealed the laws of inheritance (Orel, 1994). Watson and Crick's (1953) discovery of deoxyribonucleic acid (DNA) in human cells was the next milestone in the field of genetics. This science includes the study of genes and disabilities caused by changes in single genes (e.g., Duchenne muscular dystrophy and Huntington’s disease) or by malformations in (parts of) chromosomes (e.g. trisomy 18, Down syndrome, etc.) (Anderson-Pompa, Foster, Parker, Wilks, & Cheek, 2008; Guttmacher & Collins, 2002; Kumar, 2007). Genetics was the sole science concerned with inheritance laws until the completion of the Human Genome Project. This 13-year international project,
completed in 2003, mapped out the complete human genome (i.e., 20,000-25,000 genes of human DNA). By doing so, the Human Genome Project provided valuable information about the genetic aetiology of many disorders and laid the foundation of a new science: genomics (Human Genome Management Information System, 2008; Human Genome Project Information, 2009; Lander et al., 2001; Venter et al., 2001).

Genomics is the study of the whole genome. It is concerned with the function of the entire DNA contained in an organism, and how this DNA may interact with the environment to exhibit or inhibit the organism's characteristics (Anderson-Pompa et al., 2008; Guttmacher & Collins, 2002). This science is still in its early stages but advances in human genomics are expected to broaden scientists' understanding of diseases' complex aetiologies. This knowledge will be valuable in detecting, preventing or managing genetic conditions as well as other widespread medical diseases with a genetic component, such as cardiovascular diseases and cancers (World Health Organization, 2002). Although genetics will continue to play an important role in human sciences, genomics has even greater potential for improving human health. It is therefore likely to become the leading field in medicine, including maternal care (Anderson-Pompa et al., 2008; Kumar, 2007).

One direct application of the development of human genomics in maternal care is the development of prenatal testing, which refers to "all of the technologies currently in use or under development to determine the physi(ologi)cal condition of a foetus before birth" (Lippman, 1994, p. 145). Prenatal genetic testing can provide parents-to-be with information about the genetic make-up of their unborn children. Test results may indicate the presence of genetic malformations which could develop into a genetic disease after birth (Genetic Alliance, 2007; Schmitz, Netzer, & Henn, 2009b). The term 'genetic disease' is often used broadly to refer to any disability with a genetic aetiology (Pelletier & Dorval, 2004). However, genetic disabilities may be inherited or may result from a genetic alteration during conception. The aetiologies of genetic diseases are discussed next.
Aetiology of Genetic Diseases

A person's likelihood of carrying a genetic mutation depends on that condition's mode of inheritance. Genetic disorders may be single-gene, chromosomal or multi-factorial.

**Single-gene (dominant or recessive) disorders**

Disorders caused by a single faulty gene are said to be dominant or recessive (Figure 2.1).

![Figure 2.1 Laws of inheritance of a dominant (left) and recessive (right) condition (Genetic Alliance, 2007, p. 8)](image)

A trait is dominant when the presence of only one allele (i.e. DNA sequence) is enough to produce the phenotype/ condition in the offspring (Figure 2.1, left). Examples of dominant conditions include Huntington's disease, Familial Hypercholesterolemia and Marfan syndrome. A trait is said to be recessive when both alleles are needed to express the phenotype/ disease. A person who inherits only one faulty recessive gene from their parents will not actually develop the disease. He/she will only be a 'carrier'. Two carriers of the same genetic condition have 1 in 4 chances of giving birth to a child with that condition (Figure 2.1, right). This accounts for some conditions 'skipping' generations (Yaron & Orr-Urtreger, 2002). Examples of recessive conditions include cystic fibrosis and congenital deafness (Genetic Alliance, 2007; Nolch, 2003). Not all genetic disorders, however, are inherited from
parents (Genetic Alliance, 2007). Chromosomal and multi-factorial disorders may appear in a family with no previous history of disabilities.

**Chromosomal disorders**

Most genetic disorders dealt with by health professionals have complex aetiology (Khoury & Romero, 2006). Unlike monogenic conditions, chromosomal disorders are not caused by single faulty genes but by a change in chromosomes (or parts of) during conception. These transformations may be numerical (due to extra or missing chromosomes) or structural (due to deletions, duplications, insertion, inversions, translocations of a chromosome segment) (Genetic Alliance, 2007). Given that these anomalies occur during conception, 'healthy' parents (i.e. not affected and not carriers) may carry a child with such mutations. Down syndrome is an example of a chromosomal disorder. It is caused by a duplication of chromosome 21 (Wald & Hackshaw, 2000). Although structural genetic abnormalities can be detected clinically with reasonable precision, the prognosis cannot be given as accurately. For instance, the third chromosome 21 can be reliably detected clinically. This abnormality has been associated with a wide spectrum of impairments and as yet, scientists are not able to predict the extent to which a person will be affected by the condition (Bijma et al., 2005). This means that the same genetic malformation may express differently across individuals.

**Multi-factorial disorders**

The most prevalent type of genetic disorders are 'multi-factorial' (Burgess, Laberge, & Knoppers, 1998). These are the result of the combination between a person's genetic susceptibility and his/her environment (National Health Committee, 2003; Pelletier & Dorval, 2004). Examples of such conditions include breast cancer (Armstrong, Eisen, & Weber, 2000), colorectal cancer (Lynch, 1999), Parkinson’s disease (Mouradian, 2002) and Alzheimer’s disease (St George-Hyslop, 2000). The role of the person's lifestyle in the development of such diseases means that the consequences (if any) of multi-factorial diseases on the patient's health cannot be predicted.

At the time of writing, the Human Gene Mutation Database (HGMD; Cooper et al., 2005) had identified 64,251 mutations in 2,362 human genes responsible for significant health impairments. Although individual mutations are rare, together, genetic abnormalities are not uncommon (Guttmacher & Collins, 2002; Leroi, 2006). In fact, all pregnancies have a 2 to 3% risk of being affected with birth defects, regardless of the parents' family history (Brent,
Couples planning a pregnancy and engaged in reproductive decision-making should be aware of the possibility that they, too, may carry a child affected with one of the genetic mutations described above. These concerns are likely to be of increasing relevance to the growing population of New Zealand.

**New Zealand Demographic Data**

Obtaining information about prenatal testing uptake rates in New Zealand is difficult. Reports on (diagnostic, predictive, susceptibility and carrier) genetic testing do exist but these do not include information about prenatal testing (National Health Committee, 2003). The difficulty in obtaining data on uptake rates rests in the fact that, in New Zealand, health professionals are not legally required to report these data. Practitioners who do so cover only 75-80% of all registered births (Hislop, 2008). In a recent media release, the New Zealand Ministry of Health estimated the yearly number of amniocentesis and CVS to detect Down syndrome at around 3,500 (Flyger, 2007). However, prenatal tests can be performed to detect other anomalies. Therefore, these figures are likely to under-represent the overall national uptake rate of all prenatal tests.

Some data on prenatal testing uptake rates has been published overseas. These figures are difficult to apply to New Zealand as they are likely to reflect sample variability and policy differences (e.g. Meiser et al., 2006, 2007). However, they are useful in showing that uptake rates have been increasing in most Western countries, including the United States (Baruch, 2007), Australia (Kasparian, Meiser, Butow, Soames Job, & Mann, 2007) and European countries (Andersen, Gianaroli, Nygren, & The European I.V.F. monitoring programme for the European Society of Human Reproduction Embryology, 2004; Andersen et al., 2008).

Despite the lack of official data on prenatal test uptakes in New Zealand, it could be argued that these would likely to concur with birth rates.

**New Zealand data sources**

Information about the New Zealand population is generally publicly available from two sources: New Zealand Health Information Service (NZHIS) and Statistics New Zealand. Information published by NZHIS is a combination of information sent by the National
Minimum Dataset (who collects medical information about patients in New Zealand hospitals) and the Maternity and New-born Information System (who collects maternal and new-born information from Lead Maternity Carers and hospital discharge). This collating process became systematic only in 1998. Therefore, data collected prior to that year may not be reliable.

Statistics New Zealand, on the other hand, has collected data since the 1970s. It is a government department and New Zealand's national statistical office. Data released by Statistics New Zealand concern births registered in New Zealand and do not include data about women who normally reside overseas. These are the data reported below. In addition, since 1996, New Zealanders can self-identify with more than one ethnicity in national censuses. For comparative purposes, only the data collected between 1996 and 2010 are reported below.

**New Zealand fertility rates (1996-2010)**

The fertility rates in New Zealand for the years 1996-2010 are illustrated below (Figure 2.2).

As illustrated in Figure 2.2, the average number of births per woman in New Zealand has been consistently increasing since 2002, when women gave birth to 1.89 children on average. The latest rate of 2.15 children/ woman was greater than the replacement rate of 2.10 children.
per women, which is the fertility rate at which the population is replaced. This trend has been reported over the last four years (Statistics New Zealand, 2010).

**Number of live births per mothers' age groups (1996-2010)**

Figure 2.3 shows the number of live births per mothers' age groups (1996-2010).

![Number of live births per mothers' age groups (1996-2010)](image)

*Figure 2.3 Number of live births per mothers' age groups (1996-2010)*

As can be seen above (Figure 2.3), the number of births per woman aged 35 and above has been steadily increasing over the past few years, from 7,825 in 1996 to 13,940 in 2010 (Statistics New Zealand, 2010). This is particularly noteworthy given that the risks of having a child with Down syndrome also increase with the mother’s age (Figure 2.4).
Figure 2.4 Risks (%) of having a child with Down syndrome by mothers' age (years)

The likelihood of carrying a foetus with Down syndrome rises steeply from the age of 35 (Flyger, 2007). However, more children with Down syndrome are born to younger women. This could be due to the fact that fertility rates are greater for younger women than for those aged 35 and over. It could also be due to prenatal testing being systematically offered to women aged 35 and over, most of whom choose to terminate the affected pregnancy (Hines, McCarthy Veach, & LeRoy, 2010). Prenatal testing is less frequently offered to younger women, mainly because the risks of procedure-related miscarriage are greater than their individual risks of giving birth to a child with Down syndrome (Flyger, 2007). Several prenatal tests may be carried out.

**Prenatal Screening and Diagnosis Tests**

The most common tests include, but are not limited to, prenatal screening tests and prenatal diagnosis tests.

**Prenatal screening tests**

Common screening tests include the maternal serum a-fetoprotein ("MSAFP"), "multiple-" or "triple-marker" screen, and ultra-sonography. The main advantages of these screening tests are that they are non-invasive and carry low medical risks. Neither the mother nor the unborn
child is put in danger (Chachkin, 2007). Their main limitation, however, is their typically low accuracy rates (Gene Tests, 2003). Test results do not provide definite diagnoses. They can only indicate whether the mother's likelihood of carrying a child with a genetic anomaly (often Down syndrome) is higher or lower than the one of other women of similar age (Chachkin, 2007; Flyger, 2007). When a genetic malformation is suspected, more accurate diagnostic tests are often recommended.

**Prenatal diagnosis tests**

Prenatal diagnostic tests may be recommended to clarify abnormal screening test results. Other indications for diagnostic testing include known family history (such as other children or relatives with a genetic condition), the mother's advanced age (i.e. over the age of 35 at the time of delivery) or belonging to an 'at risk' ethnic group (Jewish descendants are at risk of being affected by Tay-Sachs disease) (Cunniff & American Academy of Pediatrics Committee on, 2004; Genetic Alliance, 2007). The most common diagnostic tests are amniocentesis and chorionic villus sampling (CVS) (Chachkin, 2007; Lerman, Croyle, Tercyak, & Hamann, 2002). During amniocentesis, a clinician, guided by real-time ultrasound, inserts a needle through the mother's abdomen to collect a sample of the amniotic fluid surrounding the foetus and therefore containing foetal DNA. These samples are sent to laboratories and analysed for abnormalities. Early amniocentesis is conducted under week 15 of gestation, whereas late amniocentesis is conducted at up to week 20 (C. Cameron & Williamson, 2003; Chachkin, 2007; Genetic Alliance, 2007; Lerman et al., 2002; Nolch, 2003). Test results may be available in up to three weeks following the intervention (Nolch, 2003).

Chorionic Villus Sampling (CVS) is also an ultra-sound guided procedure. A catheter is inserted into the mother's uterus (either transcervically or through the abdominal wall) and a tissue sample is collected from the chorionic villi (part of the placenta). This area also surrounds the foetus. Living cells containing foetal DNA are examined for genetic abnormalities. The procedure may be carried out at approximately 10 to 14 weeks into pregnancy (C. Cameron & Williamson, 2003; Genetic Alliance, 2007).

Compared to screening tests, diagnostic tests achieve a much higher level of precision (i.e. 98 to 99% accurate). However, these procedures can still give 'false positive / negative': they can wrongly indicate the presence/ absence of a malformation (Burke, 2002; Schimpf & Domino,
2001). Also, the procedures are invasive. Although these bodily intrusions are usually safe, they may nonetheless increase the risks of miscarriage, membrane rupture and fluid leakage, bleeding, infections, or early initiation of labour (Chachkin, 2007; Genetic Alliance, 2007; Sangalli, Langdana, & Thurlow, 2004). Other (even less likely) complications include injuries to the umbilical cord (Deutchman & Sakornbut, 1995) or foetal brain damage (Squier et al., 2000). The advantages and risks of these technologies are of direct relevance to couples planning a pregnancy and considering prenatal testing.

**Newer technologies**

In addition to the tests outlined above, newer techniques are being developed to detect foetal abnormalities in the first trimester (Brice, 2009; Chachkin, 2007; Galbiati et al., 2008). They may be carried out *in vitro* (i.e., pre-implantation) or *in utero* (i.e., while the mother is carrying the child) (Boormans et al., 2010; Cirigliano et al., 2009; A. Hall, Bostanci, & Wright, 2010; Tong et al., 2010). With regards to *in vitro* prenatal testing, scientists have been trying to increase the efficiency and reduce the costs associated with current preimplantation genetic diagnosis by developing a test dubbed a 'ground breaking test' by The Telegraph (Knapton, 2008), a 'genetic MoT' by the Sunday Times (M. Henderson, 2008) or even a 'one-stop embryo test' by BBC (2008). The test referred to in this media hype is 'karyomapping'. It would consist of simple cheek swabs to obtain DNA samples of those genetically related to the embryo (e.g., parents, grand-parents and siblings) (M. Henderson, 2008). The genetic history of that family could then be mapped out and genetic regions linked to hereditary disorders determined. This genetic information would be compared to the embryo's whole DNA (approximately 300,000 genetic markers) in order to determine whether the child had inherited genetic defects. The main limitation is that karyomapping would be limited to predictions of inheritable conditions. It would not be able to prevent genetic mutations from occurring spontaneously during conception. Also, this potentially revolutionary test still needs to be developed further before it can be legally regulated and commercially available (Robey, 2008).

With regards to *in utero* procedures, advances have stemmed from the discovery of very small quantities of foetal cells (hence DNA) in the mother's blood. Though this newer technologies are still in their early stages, these non-invasive procedures remove the risks of procedure-related risks currently present with amniocentesis and CVS (Hahn & Chitty, 2008). A few years ago, Lo et al. (2007) reported having accurately detected trisomy 21 in a
foetus by simply analysing the mother's blood. More recently, Wright and Chitty (2009) predicted these non-invasive tests would be widely used in clinical settings in the next three to five years. Interest in further developing non-invasive prenatal testing is evident in Europe and in the United States. The European Commission has recently launched the SAFE (Special Non-invasive Advances in Foetal and Neonatal Evaluation Network) initiative, bringing together 50 partners/ institutions from 19 countries to develop safe non-invasive prenatal tests in Europe (Chitty, van der Schoot, Hahn, & Avent, 2008). In the United States, two large companies, Lenetix (Bennani, 2009) and Sequenom (Kuber, Kurian, & Kannan, 2009) have announced their intention to develop and launch non-invasive prenatal diagnosis into health care.

Altogether, these newer prenatal tests would have many advantages. They would be more time-efficient, performed earlier in pregnancy (between 6 to 10 weeks of gestation), less invasive, less risky (would remove all risks of iatrogenic miscarriage), more complete (could test any of the 15,000 known genetic conditions), more accurate, and less costly (Robey, 2008; Schmitz, Henn, & Netzer, 2009). Although these procedures require further development, these efforts are in line with the World Health Organisation's aim to prevent and manage birth defects (World Health Organization, 2010). Such advances would also have important clinical implications. Removing risks and increasing benefits could well raise couples' interest in prenatal genetic testing.

**Summary**

Every foetus has the potential to carry a genetic anomaly. This issue is likely to become increasingly relevant to the growing population of New Zealand. Several (current and newer) prenatal tests may be performed to assess the genetic make-up of the unborn child. Though newer technologies (under development) are expected to render prenatal testing more accurate and safer, current tests vary in their degree of accuracy, medical risks/benefits and technical difficulties. These aspects are amongst many that future parents need to consider when making informed choices about whether to undergo prenatal testing to find out about the health of their unborn child (Genetic Alliance, 2007; Schmitz et al., 2009b). Other social, emotional, ethical and cognitive variables are also likely to play a role in this decision-making process. They are discussed in the next chapter.
Study One
CHAPTER 3

Study 1 – Designing a Model of the Decision-Making Process for Prenatal Genetic Testing

Chapter Outline

Prenatal genetic testing refers to procedures which prospective parents can request to find out about the health of their unborn child. This technology has become an increasingly important part of prenatal care in most Western countries and we are being told to "get ready for the flood of foetal gene screening" (Greely, 2011, p. 289). Interest in prenatal testing has been gradually increasing and the number of couples making important reproductive decisions based on these technologies is predicted to keep rising. Choosing to undergo the procedure, receiving the test results and having to make an irreversible decision about the pregnancy outcome can be emotionally difficult for future parents (Kukulu et al., 2006). The psychological consequences of these experiences have been studied at length (Kukulu et al., 2006). These psychological impacts could be reduced considerably if the initial decision-making process was conducive to 'adaptive' decisions (i.e., based on knowledge and congruent with personal values). Health professionals can help patients reach such decisions. However, in order for them to do so, they must first understand how prospective parents reach their decisions.

The way couples make choices pertaining to reproduction and family planning remains under-researched. The aim of Study One was to address this research gap and to propose a theoretical model which could account for intention to undergo prenatal testing and willingness to terminate an affected pregnancy. The present chapter reviews the psychosocial constructs shown to influence such reproductive choices. It consists of four sections. The first section presents the most recent model of prenatal testing decision-making (van den Berg et al., 2008). It is argued that, although this model has been valuable in providing insights into screening for Down syndrome, it overlooks important variables shown by other studies to influence testing intention and willingness to undergo selective termination in the event of a positive diagnosis. Sections Two and Three identify these test-specific and abortion-specific variables, and theorise on their respective influence on testing intention and/or abortion
willingness. Finally, Section Four integrates these variables into a model of prenatal genetic testing decision-making, and presents a set of hypotheses for factors expected to impact on testing intention and abortion willingness.

**Current Model of Prenatal Testing Decision-Making**

![Diagram of model](image)

*Figure 3.1* van den Berg and colleagues' (2008, p. 436) final model of prenatal screening decision-making

The most recent model of prenatal testing decision-making was proposed by van den Berg and colleagues (2008) and is shown in Figure 3.1. This model, which was tested with 1,666 pregnant women in the context of prenatal screening for Down syndrome, identifies two key predictors of testing intention, namely subjective norms and attitudes towards undergoing prenatal screening. Evaluating the quality of this model requires consideration of not only the proposed model of conceptual relationships but also the measures used to test the model. Subjective norms (Ajzen, 1991) are assessed by combining scores on normative beliefs (*I think [referent] wants me to accept - decline the test*) with those on motivation to comply (*I find [referent]'s opinion about accepting or declining the prenatal test very important - very unimportant*) for three referents: the woman's partner, her midwife/obstetrician, and another significant referent (identified by the participants) (p. 432). The scale's internal consistency was limited; Cronbach's $\alpha = 0.59$. 
Child-related anxiety (Huizink, Mulder, Robles de Medina, Visser, & Buitelaar, 2004) is a reliable ($\alpha = 0.88$) 5-point scale (1 = low anxiety to 5 = high anxiety) assessing fears of bearing a physically or mentally handicapped child. Attitudes towards undergoing prenatal screening are assessed with four 5-point items: In my opinion, testing for congenital defects during my pregnancy, is... bad – good, frightening – not frightening, not reassuring – reassuring, not self evident – self evident (van den Berg et al., 2008). Scores on this scale (Cronbach’s $\alpha = .79$) are associated with attitudes towards termination and response efficacy. Attitude toward termination of pregnancy (Cronbach’s $\alpha = .78$) is measured using a similar scale with five items "In my opinion, the possibility of termination of pregnancy if the child appears to be severely handicapped, is... bad – good, frightening – not frightening, not reassuring – reassuring, not self evident – self evident". Low scores indicate negative attitudes. Response efficacy of the screening test is assessed with items focusing on perceived informativeness of the test result and perceived effort of undergoing the test.

The remaining variables in van den Berg et al.’s (2008) model are perceived risk and perceived severity of having a child with Down syndrome. Perceived risk is a single-item scale score ranging from 1 (very low) to 7 (very high). Perceived severity is measured using a 10-cm visual scale, where 0 = the best that can happen to me and 10 = the worst that can happen to me. Perceived risk and perceived severity are associated with testing intention only through their impact on child-related anxiety, which predict testing intention but only weakly ($\beta = .05$, $p < .05$). As pointed out by the authors, this finding is in contradiction with previous studies showing that attitudes towards the disability under consideration played an important role in decision-making (e.g., Green, Hewison, Bekker, Bryant, & Cuckle, 2004).

Van den Berg and colleagues' (2008) model has been valuable in guiding research that has shown that subjective norms played an important role in pregnant women's intention to undergo prenatal screening to find out about the presence of Down syndrome. Research guided by this model has also indicated that fears of bearing a child with a mental or physical handicap may only be a weak predictor of intention. This result is noteworthy in that it indicates that worries about the medical health of the unborn child may be less important in reproductive choices than intuitively expected. A few limitations, however, may be noted. First, the overall mean score on subjective norms, obtained by collapsing answers for all three referents, is likely to misrepresent the respective influence of medical professionals and
spouses on women's decision to undergo prenatal testing (Rini, Schetter, Hobel, Glynn, & Sandman, 2006). The low internal consistency further suggests that these norms are likely to be distinctive. Second, the scale measuring attitude towards termination does not discriminate between acceptance of selective abortion in principle and the participants' willingness to terminate their own pregnancy in the event of a positive diagnosis (Ekberg, 2007; García, Timmermans, & van Leeuwen, 2008a). Third, attitude towards abortion is regarded as a distal predictor of testing intention and yet many studies have shown that terminating an affected pregnancy is one of the main motivations for accepting the test (e.g., Dixon, 2008; Quadrelli et al., 2007). Fourth, this model was developed in the context of Down syndrome. It is unclear whether the findings could be generalised to other foetal abnormalities remain. Finally, the model does not account for emotions and ethical considerations. Risks (of procedure-related miscarriage, for instance) and uncertainty (created by the probabilistic nature of test results) are inherent to prenatal genetic testing (Marteau & Croyle, 1998). Health psychologists have argued that models about decisions involving an element of risk and uncertainty should include a combination of social, cognitive, emotional and ethical variables (Broadstock & Michie, 2000; Ubel & Loewenstein, 1997).

Given the limitations of the model developed Van den Berg and colleagues (2008), it was decided to design a new integrative model of prenatal testing decision-making. This consisted of 1) identifying the key predictors of prenatal testing intention, as indicated by the existing body of theory and research on health decision-making, and 2) hypothesising on their relationships with testing intention. To test these predictions, a hypothetical scenario was designed that provided a context for making a decision about whether or not to undergo prenatal genetic testing. The scenario asked participants to imagine that they were expecting a child. The information contained in the opening text included a statement about the foetus having 1 in 200 chances of being affected with a genetic abnormality. Information about prenatal testing was also included. (The full description of the scenario is provided in Chapter 4). The following sections will present theory and research for each component of the full model, which is presented in Figure 3.7. Each section will be illustrated with figures of the relevant section of the model.
Test-specific Variables

Studies on prenatal testing decision-making have revealed that, to reach their final decision about whether or not to undergo the procedure, prospective parents need to process a vast amount of information. First, they are likely to be provided with information on many different aspects of testing, such as the financial costs and the test's reliability. This information is likely to come from many different sources, such as medical experts and family members. Parents will need to re-organise these disjointed and often incomplete facts into a coherent and meaningful understanding of the situation. To do so, they may rely on their own intuition and beliefs about their likelihood of expecting a child with genetic mutations. This chapter will argue that these thoughts are interdependent and cannot be assessed in isolation.

Studies have shown that the social, cognitive, emotional and ethical variables influencing intentions to undergo genetic prenatal testing include: subjective norms (i.e., the motivation to comply with the perceived expectations of others), benefits from receiving test results, perceived vulnerability (of carrying a child with a genetic mutation), religiosity and abortion willingness. Their respective influences on testing intention are discussed in turn next.

Subjective norms

Subjective norms refer to the motivation to comply with others' perceived preference regarding a particular behaviour (Ajzen & Manstead, 2007). It is a key component of the Theory of Reasoned Action (Fishbein & Ajzen, 1975) and the Theory of Planned Behaviour.
According to these models, others' perceived expectations influence behavioural intentions. The role of subjective norms in intention to engage in a behaviour involving an element of risk has long been recognised (e.g., Short, 1984; Slovic, 1987). The relationship between subjective norms and behavioural intentions has also been reported in the context of genetic testing (Légaré et al., 2011). In fact, subjective norms were the most important predictors of testing intention in the model of prenatal testing decision-making proposed by van den Berg and colleagues (2008). This reflects the fact that attitudes about genetic testing occur in a socio-cultural context and decisions based on test results are expected to have far-reaching consequences for the prospective parents, other members of family and the wider community (B. J. Henderson, Maguire, Gray, & Morrison, 2006). Reproductive choices are often swayed by others important to the decision-maker and final decisions are likely to reflect these combined influences.

Investigating the role of subjective norms on decision-making without differentiating between referents is likely to give little insight into their respective roles. Referents often cited for swaying people's intentions regarding the procedure include their own partner/spouse, health professionals, family members and friends (Beeson, Golbus, Opitz, & Reynolds, 1985; Browner, Preloran, & Cox, 1999; Huber & Huber, 2008; Lerman et al., 2002; McCoyd, 2008; van den Berg et al., 2008).

**Partners / Spouses**

The literature shows that spouses exert the greatest influence on testing intention. Prospective parents usually consult each other to reach an agreement about prenatal genetic testing (Beeson et al., 1985; Browner et al., 1999; García, Timmermans, & van Leeuwen, 2008b; McCoyd, 2008). Most often, they agree on the course of actions (Genetic Alliance, 2007). When disagreements arise, couples tend to agree that it is more appropriate for the woman to make a decision that ultimately involves her body (Beeson et al., 1985; McCoyd, 2008). This consensus was also reported in 'machismo' communities, where men's authority tends to prevail (Browner et al., 1999). Hence, partners' / spouses' opinions are of the upmost importance in reproductive choices, and men's role is often regarded as secondary to the women's influence.
Health professionals

Health professionals (e.g. obstetrician-gynaecologists, family practitioners, midwives, perinatologists and genetic counsellors) also play a role in parents' reproductive choices. They are ethically bound to discuss the impact a child with disabilities might have on the family and to provide reliable up-to-date information about the procedures' risks and benefits (García et al., 2008b). They are expected to educate patients, to increase their understanding of the health threat and to ensure their consent is value congruent and knowledge-based (McCoyd, 2008; Thoolen, De Ridder, Bensing, Gorter, & Rutten, 2008). This informative role seems particularly important for less knowledgeable parents who tend to consult doctors more often than more knowledgeable parents during these times (Huber & Huber, 2008).

Health professionals cannot, however, deliberately direct their patients' decisions. This ethical requirement is partly to prevent overwhelmed parents from following their doctors' advice (whatever it may be), which some would be willing to do (Kukulu et al., 2006). Although non-directiveness may be misapprehended, most patients accept doctors' informative role. Although couples recognise professional expertise, fewer and fewer of them are willing to include them in their decision-making, which is often finalised outside the clinical setting (García et al., 2008b; S. D. Taylor, 2005).

Family and friends

Other parties reported to influence parents' reproductive choices are friends and family members, although findings are mixed with regards to the influence of relatives. Evidence suggests that pressure from mothers-in-law or other distant relatives has little bearing on such choices (McCoyd, 2008). Other findings, however, have revealed that parents and siblings do influence decisions about family planning (Browner et al., 1999; Bryant, Hewison, & Green, 2005). It has been suggested that the main reason for prospective parents to discuss these issues with family members is not to follow their advice but to ensure their approval. As for the role of friends in family planning, there seems to be no evidence indicating their influence in couples' decision-making. In summary, evidence suggests that subjective norms, especially with regards to partners / spouses and family members, are strong predictors of prenatal testing intentions. Therefore, in the present study, greater intention to comply with partners' perceived preference towards undergoing the procedure was expected to predict greater testing intention (Figure 3.2).
Perceived benefits from receiving test results

According to the utility theories (von Neumann & Morgenstern, 1947), Wroe et al's (1998) version of utility theory and the transtheoretical model of behaviour change (Prochaska & DiClemente, 1983) as applied to prenatal testing, the perceived benefits from receiving test results should influence parents' decision about undergoing the procedure (Prochaska & DiClemente, 1983; Wroe et al., 1998). Receiving (positive and negative) test results may be beneficial on several accounts.

For instance, prenatal genetic testing can provide parents-to-be with information about the genetic make-up of their unborn child. Positive (indicating the presence of a foetal abnormality) and negative results (indicating the absence of foetal abnormality) can bring relief from uncertainty (Kidd, Cook, & Marteau, 1993; Marteau, Plenicar, & Kidd, 1993; Santalahti, Latikka, Ryynänen, & Hemminki, 1996; Helen Statham & Green, 1993; H. West & Bramwell, 2006). For some parents, expecting a child but "not knowing [about the health of the foetus] is terrifying" (Browner et al., 1999, p. 1663). In their attempt to obtain an answer, parents may receive positive or negative test results.

Figure 3.3 Hypothesised relationships between benefits from receiving negative results, related variables and testing intention
Perceived benefits from receiving negative results and anticipated emotional distress

Receiving negative test results is expected to reduce uncertainty. It can also provide reassurance and relief from child-related anxiety (H. West & Bramwell, 2006). Most parents undergoing prenatal testing will receive 'good' news that their unborn child is most likely healthy (Borry, Goffin, Herman, & Dierickx, 2008; Pieters et al., 2011). After all, giving birth to a disease-free child is arguably every parent's wish (Dixon, 2008). Most parents hope to receive 'confirmation' that their unborn child is healthy so that they can enjoy the rest of their pregnancy. Couples generally undergo testing believing the results will be favourable to them (García et al., 2008b). Selective termination is therefore not an issue in early stages. Many couples happily postpone this thorny subject until they absolutely have to make this difficult decision (García et al., 2008b).

Some couples, however, also envisage the stressful possibility of having a child who is genetically affected. Negative test results can bring relief from that anticipated emotional distress (Borry et al., 2008; García et al., 2008b; Kalfoglou, Scott, & Hudson, 2005; Kidd et al., 1993; Marteau et al., 1993; Ramsoekh et al., 2007; Santalahti, Aro, Hemminke, Helenius, & Ryynänen, 1998; Santalahti et al., 1996; Helen Statham & Green, 1993; Thornton, Hewison, Lilford, & Vail, 1995; van den Berg et al., 2005; H. West & Bramwell, 2006). Hence, in the present study, it was hypothesised that perceiving negative test results as beneficial would predict greater intention to undergo prenatal testing. It was also predicted that anticipating a positive diagnosis as emotionally stressful would be associated with greater perceived benefits from receiving negative results (Figure 3.3).

Perceived benefits from receiving positive results

In some instances, the diagnosis will indicate the presence of foetal genetic abnormalities that are likely to develop into a disability after birth. The field of invasive foetal interventions is still in its early stages (Luks, 2011). Whilst it is increasingly attracting European attention (Oepkes et al., 2011), the clinical reality is that most conditions detected at prenatal stage are still not yet treatable. When a child is predicted to be born with a genetic condition, it is often a condition that cannot yet be treated prenatally. In addition, the prenatal tests currently available can only provide a structural assessment of a foetus' genetic make-up. They cannot predict the degree to which an individual will be affected. For instance, the presence of a third chromosome 21 indicates the presence of Down syndrome. However, it is not yet possible to
cure this disease nor to predict where, on the spectrum of Down syndrome, the individual will be (Borry et al., 2008).

These clinical limitations have brought many to question the benefits of receiving positive results, especially for parents against abortion (Pearson, 2008). Time and resources dealing with foetal genetic conditions can be spent either after birth (on managing the social, medical etc. 'consequences' of that disease) or before birth (in preventing the birth of that child). Parents against selective abortion but convinced the genetic condition under consideration will negatively impact the life of their child are likely to perceive positive results as somewhat beneficial. They can use the diagnostic to help them prepare for and to organise the arrival of a child with special needs. For conditions compatible with life, parents may wish to anticipate the child's medical needs, enquire about the support available to help families cope psychologically and financially, expand their knowledge on the treatment options, if/how to defer the condition and/or improve the prognosis (Genetic Alliance, 2007). For birth-onset conditions, preparations may involve finding facilities with professionals able to provide the appropriate medical support for the new-born (Howard, 2006). Anticipating the medical needs of a person born with an adult-onset condition may also be part of parents' concerns, although this might be more difficult because the individual will be healthy for several years, therefore not a patient in need of medical care (Borry et al., 2008). For life-threatening conditions, palliative care options may be considered (Howard, 2006).

In summary, obtaining positive test results may be beneficial for parents, including for those against selective abortion. However, no evidence exists to suggest that perceived benefits from positive results actually motivate couples to undergo prenatal testing. Hence, in the current study, no direct relationship was expected between perceived benefits from receiving positive results and testing intention. However, it was predicted that greater perceived negative consequences from living with a genetic disability would be associated with greater beliefs that receiving positive test results would be beneficial (Figure 3.3).

**Test response efficacy**

The concept of efficacy is also relevant to the hypothesised relationship between perceived benefits from negative results and testing intention. In the context of prenatal testing, test response efficacy refers to the test's perceived (in)ability to accurately detect a foetal genetic
mutation. According to research guided by the Protection Motivation Theory (Boer & Seydel, 1995) and the Extended Parallel Process Model (Witte, 1992, 1994), efficacy partly drives protective behaviour. Studies have confirmed that women are less likely to seek prenatal screening if they perceive the results as being "just a calculation of probability" or if "the test gives no certainty" (van den Berg et al., 2008, p. 431). The reality of genetic testing and laboratories is that users are not exempt from false positives (i.e., wrongly indicating the presence of a condition) or false negatives (i.e., failing to detect a genetic malformation). Misdiagnoses, though extremely rare, are a medical possibility (Hudson, 2006). As explained by Mark Hughes, founder and chief clinician at Genesis, US provider of assisted reproductive technologies, "there is going to be an error rate in any diagnostics [...] because genetic testing relies upon identifying a very short DNA sequence among a large volume of DNA that comprises the human genome" (Hudson, 2006, p. 14). Although the frequency of inaccurate results is currently very small, it remains that genetic test results cannot always be reliable. Prenatal testing's perceived accuracy may strengthen beliefs in the results' value. If parents believe that test results are trustworthy, then they are more likely to value their diagnostic abilities (McAllister, 2002; Michie et al., 2002). The role of test response efficacy in prenatal testing decision-making seems to have been largely overlooked. The present study aimed to address this research gap. It was predicted that greater test response efficacy would predict greater benefits from receiving negative results (Figure 3.3).

**Condition coherence**

Researchers have long recognised that the success of decision-making depends on one's ability to create a clear logical picture of the situation and of the ultimate goal(s) (Vlek, 1987). Bennett (1978, 1979) was one of the first scientists to argue that structuring disjointed information is a powerful form of psychological organisation. Pennington and Hastie further elaborated that "this mental activity occurs because comprehension is inherently a constructive process" (1991-1992, p. 131) and that this comprehension guides judgement and decision-making. Lipshitz (1993) also proposed that, when the information is incomplete or confusing, people use their 'schemata' (i.e. knowledge structures; Fiske & Taylor, 1991) to build a coherent unit. These schemata are based on past experiences, social norms, personal expectations, values, ethics, morals, etc. Schemata are thought to be individual-specific and easily accessible (Curley, Browne, Smith, & Benson, 1995). In summary, the decision-making process has long been thought to begin with complex, disjointed and interdependent
information and to end with a whole coherent combination of old and new information

This premise also holds true to health decision-making. Condition coherence (i.e., the extent
to which people make sense of a health threat) has been theorised to motivate behavioural
intention (Moss-Morris et al., 2002). The importance of internal logic is central to Wroe et
al.'s theory on decision-making in genetic testing according to which "internal idiosyncratic
subjective logic is different from objective logic" (1998, p. 601). From an illness
representation perspective, the cognitive interpretation of a health threat is theorised to
influence one's process of organising health information and subsequent intention to engage in
preventive behaviours (Leventhal, Brissette, & Leventhal, 2003; Michie et al., 2002).
Leventhal and colleagues' (2003) 'if-then' rule is particularly useful when trying to understand
patients' internal logics around health preventive behaviour. People are believed to have
representations of their coping strategies. The 'if-then' coherence rule assumes logical,
common-sense connections between their health threat representation and their coping
strategy representation. It assumes that patients' illness representations are logically linked to
the threat appraisals and the subsequent coping strategies (L. D. Cameron, Leventhal, &
Leventhal, 1995). If a patient's understanding of a health threat results in them believing that
their disease can be addressed with medicine, then they will find it more logical to follow a
treatment including drugs than to, for instance, changing their life styles. It is proposed that
patients are more likely to adhere to the health behaviour if it matches their own illness
representations.

Parents' decisions regarding foetal genetic abnormalities and prenatal genetic testing can be
regarded as a prototype of a situation where disjointed and complex health messages need to
be re-organised into a meaningful unit. Condition coherence should therefore play a role in
prenatal testing decision-making (Ekelin et al., 2009). In addition, such choices are likely to
be influenced by the 'if-then' rule (L. D. Cameron et al., 1995). If parents fail to understand
the genetic nature of the disease, then undergoing prenatal testing is likely to be perceived as
a pointless exercise. On the contrary, if they appreciate the genetic nature of the foetal
condition (i.e., report great condition coherence), then they are more likely to assess prenatal
 genetic testing as an appropriate way to detect that foetal genetic condition (i.e., report great
test response efficacy). Consequently, in the present study, greater condition coherence was expected to predict greater test response efficacy (Figure 3.3).

**Perceived vulnerability**

*Figure 3.4* Hypothesised relationships between perceived vulnerability and testing intention

Lay perceptions of risk are important motivators of preventive/protective health behaviour, such as interest and use of genetic testing, as shown by a vast amount of theoretical discussions (Ajzen & Manstead, 2007; Brewer, Cuite, Herrington, & Weinstein, 2004; Floyd, Prentice-Dunn, & Rogers, 2000; Leventhal et al., 2003; Loewenstein, Weber, Hsee, & Welch, 2001; Moss-Morris et al., 2002) and empirical evidence (L. D. Cameron, 2008; L. D. Cameron & Diefenbach, 2001; L. D. Cameron, Sherman, Marteau, & Brown, 2009; Croyle & Lerman, 1993; Dijk et al., 2003; Helmes, 2002; McCaul, Branstetter, Schroeder, & Glasgow, 1996; Miller, Roussi, et al., 2005; N. Peters et al., 2005; Wakefield et al., 2007; Weinstein et al., 2007). The consequentialist perspective and other expectancy-value theories, such as the Theory of Planned Behaviour (Ajzen, 1988, 1991), the Theory of Reasoned Action (Fishbein & Ajzen, 1975) and the Health Belief Model (Rosenstock, 1966), have long proposed that decision-making involving an element of risk and uncertainty is partly influenced by perceived vulnerability. This cognitive-affective variable may be defined as the "individual's belief about the likelihood of a health threat's occurrence" (Gerrard & Houlihan, 2007, p. 1). Hence, in theory, parents' perceived vulnerability of carrying a child with genetic abnormality should be positively related to their intention to undergo the procedure. In practice, however, the role of perceived vulnerability in testing intention seems unclear. For instance, in Green et al.’s (2004) review, perceived risk was an important determinant to undergoing prenatal screening. However, in van den Berg et al.’s (2008) model of prenatal testing decision-making, perceived risk (of having a child with Down's syndrome) did not predict intention
directly. Recent theories on health threat perception and behavioural intention may help account for this apparent disparity.

The common sense model of illness representation (Leventhal et al., 2003) and the cognitive-experiential self-theory (Epstein, 1985, 1994; Epstein, Lipson, Holstein, & Huh, 1992) postulate that a health threat is appraised through (at least) two pathways: an emotional/experiential pathway and a cognitive/rational conceptual pathway. It is proposed that these pathways guide people's coping strategies when dealing with health threats. They are believed to do so together as well as independently. The separate cognitive and emotional influences of risk perception on behavioural intention may be responsible for the mixed results reported in the literature. The role of cognition will be discussed later. The impact of emotions on judgement and decision-making behaviour is the focus of this section.

The emotion-based responses to health threats are thought to be fast, automatic and responsible for people's rapid assessment of the situation (Bower, 1981; Clore, 1992; Loewenstein et al., 2001; Moss-Morris et al., 2002; Schwarz & Clore, 1983; Zajonc, 1980). An increasing number of theories such as affect-as-information perspective (Schwarz & Clore, 1983), the affect heuristic (Slovic, Finucane, Peters, & MacGregor, 2004; Slovic, Peters, Finucane, & MacGregor, 2005) and the risk-as-feelings hypothesis (Loewenstein et al., 2001) give emotions a prominent role in decision-making. They posit that affective responses to risk often drive (risky and) precautionary behaviour, and that emotional appraisals of risk estimates directly impact on decision-making (Croyle & Lerman, 1993; Lerman et al., 1997; Schwarz & Clore, 1983; Slovic et al., 2004; Winkielman, Zajonc, & Schwarz, 1997).

One phenomenon known to trigger these direct affective responses to risk information is lay people's misunderstanding of probabilities (Finucane, Alhakami, Slovic, & Johnson, 2000; Loewenstein et al., 2001; Slovic, Flynn, & Layman, 1991). The principle of probability-(in)sensitivity in affectively-laden decisions has been the focus of several studies (L. D. Cameron et al., 2009; van den Berg et al., 2008). Findings have shown that people are relatively insensitive to probability differences, especially when estimates are low (Rottenstreich & Hsee, 2001; Slovic et al., 2005). People's difficulties in understanding statistics may lead them to under- or over-estimate risks (Gardner & et al., 1982; Johnson &
Tversky, 1983; Lindell & Earle, 1983; Renn & Swaton, 1984; Timmermans, 2005). Van den Berg and colleagues (2008) proposed that, when percentages are low, the mere possibility of an event happening (such as carrying a child affected by a genetic malformation) is enough to create a dichotomous reaction, and to lead people to wrongly equate "your child has a higher risk of Down syndrome" with "your child has Down syndrome" (Dixon, 2008, p. 35). In summary, probabilities about health threat are understood on a subjective/intuitive level which triggers emotional responses driving intentional behaviour. Hence, in the present study, greater perceived vulnerability of carrying a child with a genetic anomaly was hypothesised to be associated with greater intention to undergo prenatal testing (Figure 3.4).

Religiosity

In the context of family planning, religious and spiritual beliefs are also important to consider as they can strongly influence attitudes and uptake of prenatal testing (Alkuraya & Kilani, 2001; Bryant, Ahmed, Ahmed, Jafri, & Raashid, 2011; Hutchinson & Sharp, 2008; Ivry, Teman, & Frumkin, 2011; Korenromp, Page-Christiaens, van den Bout, Mulder, & Visser, 2007; Modell, 2007). Divergence of opinions have been noted amongst people affiliated with Buddhism (Harvey, 2008), Judaism (Rabbi Dr Romain, 2008), Islam (Raz, Atar, Rodnay, Shoham-Vardi, & Carmi, 2003; Sekaleshfar, 2008) and Christianity (Jones, 2008). In the latest New Zealand Census (2006a), most residents (approximately 1,3 million) reported being non-religious, Anglican (over 550,000) or Catholic (over 500,000). In the present study, the sample of participants was expected to be representative of the larger New Zealand population. They were therefore expected to report being affiliated with no religion or with a Christian religion. Hence, when considering the possible role of religiosity in prenatal testing intention, the Christian view of reproductive technologies was the most relevant when generating hypotheses.
In Christianity, several sets of beliefs exist. They range from strict anti-reproductive technologies and anti-abortion (approach represented by The Church) to less conservative / more flexible approaches (Jones, 2009). With regards to pregnancy-related issues, religiously committed individuals may consider prayers as more acceptable to ensure a healthy pregnancy than resorting to assisted reproductive technologies (Browner et al., 1999). Believers may prefer to put their trust and faith in 'the hands of God' rather than allowing medicine to interfere with a 'natural' event. They may view what "already happened when the egg and sperm first met" (Anderson, 1999, p. 132) as being outside of their control and under the one of a higher power. Therefore, greater religiosity was hypothesised to be linked with lower intention to undergo prenatal testing (Figure 3.5).

**Abortion willingness**

Another related objection to prenatal testing concerns views towards selective abortion. Most conditions detected during pregnancy cannot yet be treated prenatally. Hence, in most cases, the only intervention offered to prospective parents carrying an affected foetus is selective abortion. This option, however, is morally controversial for many parents, religiously committed or not.

In Western societies, parents are not only given the opportunity to abort an affected pregnancy, they are also implicitly expected to do so (Dixon, 2008). However, aborting a foetus because of a genetic condition may be perceived by prospective parents as an unacceptable 'choosy' and consumerist attitude towards reproduction (Wolfram, 2000). Studies have shown that people opposed to abortion for such moral reasons tend to decline prenatal testing (García et al., 2008b; van den Berg et al., 2005). However, some parents seeking prenatal testing do anticipate having to make a decision about selective abortion (Ekberg, 2007; Quadrelli et al., 2007). The widely reported relationship between abortion willingness and prenatal testing intention needs to be interpreted in light of the fact that most parents seeking prenatal testing are already prepared for the possibility of selective termination (van den Berg et al., 2005). As Ekberg argued, "accepting one usually implies accepting the other" (2007, p. 72). In the current study, it was therefore expected that greater willingness to opt for selective abortion would predict greater intention to undergo testing (Figure 3.5).
Opposition to selective abortion may also be driven by religious views. For instance, the Catholic Church strongly condemns the 'sinful' decision to terminate a pregnancy, even to prevent the birth of a child with a severe disorder (Kukulu et al., 2006). Some religiously committed individuals believe that the sanctity of life should prevail over the quality of life (Fukuyama, 2002a). Deeply religious people believe that diseases and illnesses happen for a reason, and that accepting suffering means respecting the divine gift of human life (Bell & Stoneman, 2000; Modell, 2007; Usta, Nassar, Abu-Musa, & Hannoun, 2010). They are generally against prenatal testing and would welcome a child with disabilities if this reflected God's will. Studies have repeatedly revealed a negative relationship between the intensity of religious beliefs and acceptance of selective abortion (e.g., Souka et al., 2010). Hence, in the present study, it was hypothesised that greater religiosity would predict lower willingness to undergo selective abortion (Figure 3.5).

**Abortion-specific Variables and Related Variables**

Even for parents generally in favour of selective abortion, choosing to terminate an affected pregnancy may be a difficult decision to make (Pieters et al., 2011). As pointed out by Fukuyama, with new reproductive technologies "the good and bad are intimately connected" (2002a, p. 182). Abortion willingness is likely to be driven by a series social, cognitive, emotional and ethical considerations. This section discusses the hypothesised relationships between abortion-specific variables (i.e. attitudes towards disabilities, anticipated emotional distress, anticipated coping efficacy and negative consequences), related variables (i.e. perceived vulnerability and child-related worry) and abortion willingness (Figure 3.6).
Indirect relationship between perceived vulnerability and testing intention

As previously mentioned, health threat risk perception is theorised to impact on behavioural intention directly (Figure 3.4) and indirectly through a reasoned pathway (Epstein, 1985, 1994; Epstein et al., 1992; Leventhal et al., 2003). The cognitive path is proposed to be slow, cognitively demanding and responsible for conscious appraisals of the situation. Its impact on behavioural intention may be biased by cognitive heuristics (e.g., the availability heuristic) and/or inter-related affective components (Loewenstein et al., 2001).

First, the availability heuristic has been shown to influence judgement of probabilities (Johnson & Tversky, 1983; Tversky & Kahneman, 1986). This cognitive bias refers to the
mechanism whereby the perceived likelihood of an event is biased by the rapidity with which it comes to mind. In health, the availability heuristic is best understood from an illness representation perspective (Leventhal et al., 2003). Messages about health threats are thought to trigger cognitive representation of that particular threat which, in turn, influence the way risk information is perceived. These cognitive representations are likely to be different for patients who know little about the disease than for patients with some experience with the disease because the consequences of the disease would be more readily available. Hence, the two types of individuals are likely to vary in their perceived vulnerability (Michie et al., 2002). Such biases may account for distorted assessment of probabilities in the context of prenatal testing. A person with a relative born with Down syndrome may evaluate his/her risk to carry a child with this condition differently from someone with less exposure, even though the risk for these two individuals is objectively similar (Bijma et al., 2005).

A second explanation for the indirect relationship between perceived vulnerability and testing intention is related to the role of risk-related states (Bechara, Damasio, Tranel, & Damasio, 1997; Damasio, 1994; Hay, McCaul, & Magnan, 2006; Loewenstein et al., 2001). Researchers have shown that, in decision-making involving an element of risk, risk-related responses may be mediated by anticipated states (i.e., post-event emotions imagined to be experienced as a result of the decision) (L. D. Cameron et al., 2009; Connolly & Zeelenberg, 2002; Loewenstein et al., 2001; Weinstein et al., 2007).

**Child-related worry**

A state believed to mediate the relationship between perceived vulnerability and testing intention is worry, which has been described as "a chain of thoughts and images, negatively affect-laden and relatively uncontrollable" (Borkovec, Robinson, Pruzinsky, & DePree, 1983, p. 10). In health, this construct is an important variable for its potential to 1) be a stronger predictor of intention than perceived risk, and; 2) be closely related to other risk-related affective responses, such as anticipated coping efficacy and anticipated emotional distress.

First, a growing body of research on genetic testing has shown that disease-related worry is associated with use and intention to engage in preventive behaviours (Esplen et al., 2001; Feeny et al., 2002; Glanz, Grove, Lerman, Gotay, & Marchand, 1999; Lerman et al., 2002; McAllister, 2002; McConkie-Rosell et al., 1999; Pilnick & Dingwall, 2001; Ritvo et al., 2000), and that worry is a stronger predictor of health behaviour than risk perception (L. D.
Cameron, 2008; L. D. Cameron & Diefenbach, 2001; L. D. Cameron & Reeve, 2006; Diefenbach, Miller, & Daly, 1999; Kaptein et al., 2007; Leventhal, Diefenbach, & Leventhal, 1992; Loewenstein et al., 2001). The relative importance of foetus-related worry over perceived risk on testing intention (Kleinveld et al., 2006) was further confirmed in the latest model of prenatal testing decision-making (van den Berg et al., 2008). Hence, in the present study, it was hypothesised that the greater perceived vulnerability of carrying a child with a disability would predict greater worry about the health of the foetus (Figure 3.6).

Although disease-related worry has been shown to be associated with testing intention, research has yielded mixed results with regards to the nature of this relationship. For instance, Marteau and colleagues (1989) found that women who underwent amniocentesis reported significantly greater child-related anxiety than those who did not. Likewise, Grant (2000) found that women who had undergone amniocentesis were significantly more anxious about the health of their unborn child than those who had not. However, van den Berg et al., (2008) found that child-related anxiety was a poor predictor of intention ($r = 0.05$). This mixed empirical evidence suggests that the relationship between child-related worry and testing intention is a complex one.

A theoretical account of the role of disease-related worry may help explain these apparent discrepancies. Worry is believed to enhance one's sensitivity to health threats, to motivate thorough information processing, and to channel the listener's cognitive attention into developing elaborated threat representations, which include ways to cognitively and emotionally overcome the threat (L. D. Cameron, 2003; Gleicher & Petty, 1992; Leventhal et al., 2003; Liberman & Chaiken, 1992; Ohman, Flykt, & Esteves, 2001; Raghunathan & Corfman, 2004). With regards to cognitive responses, worried individuals are likely to have greater needs to find ways to deal with the health threat (McCaul & Goetz, 2007). Empirical and theoretical evidence show that health messages that are worry-provoking but that also provide reliable and effective ways to cope with the threat are more likely to motivate worried people to engage in preventive behaviours, than messages that are purely worry-provoking (L. D. Cameron & Chan, 2008; Sanderson et al., 2008; Sanderson & Wardle, 2005). In theory, parents who perceive this information as threatening should worry about the health of their children (i.e., report greater disease-related worry), engage in deep thought processing, such as considering whether they would be able to cope with a child with special needs. They are
likely to be more motivated to seek ways to deal with this health threat and therefore report greater testing intention. The link between child-related worry and testing intention was not, however, expected to be direct.

As previously mentioned, disease-related worry may produce risk-related affective responses (Bijma et al., 2005; L. D. Cameron & Chan, 2008; Luu, Tucker, & Derryberry, 1998). The role of anticipated affective states in preparing individuals for the future has long been recognised. For instance, anticipated regret was given a prominent role in decision-making in the 'minimax principle of risky choice' (Savage, 1951), the Regret Theory (Bell, 1982; Loomes & Sugden, 1982, 1984) and in more recent research (Connolly & Zeelenberg, 2002; Elliott & Thomson, 2010; Weinstein et al., 2007; Ziarnowski, Brewer, & Weber, 2009).

Anticipated disappointment was central to the Disappointment Theory in decision-making (Bell, 1985; Loomes & Sugden, 1986, 1987), and discrepancy between anticipated pain and anticipated pleasure motivates choices, according to the Subjective Expected Pleasure Model (Mellers & Schwartz, 1999).

**Anticipated emotional distress**

The first anticipated emotion of interest for the present study is anticipated emotional distress. Studies in genetic testing have shown that the levels of worry experienced before testing is closely linked with the way individuals cope after testing with the results (Lodder et al., 2001; van Oostrom et al., 2003). Research also indicates that the prospect of receiving positive test results triggers anticipated emotional distress (L. D. Cameron et al., 2009). Furthermore, worry is theorised to "enhance emotional motivations to reduce the threat by detecting and treating it quickly" (L. D. Cameron & Diefenbach, 2001, p. 50). Together, this evidence suggests that, in the context of prenatal testing, people with elevated child-related worry are likely to anticipate receiving a positive diagnostic as more emotionally stressful than patients less worried about the health of the child. These worried individuals may, in turn, perceive prenatal genetic testing and selective abortion as a great way to detect foetal abnormalities and to reduce that health threat, respectively. Therefore, in the present study, greater worry about the health of the foetus was predicted to be associated with greater anticipated emotional distress from receiving a positive diagnosis. In addition, it was also hypothesised that greater anticipated emotional distress would predict greater willingness to opt for selective abortion, which in turn, would be associated with greater intention to undergo testing (Figure 3.6).
Anticipated coping efficacy

The second anticipated state closely linked to child-related worry was anticipated coping efficacy (or 'self-assessment'; McCoyd, 2008). This refers to one's perceived (in)abilities to mentally cope with raising a child with special needs. Studies have shown that only a minority of women felt psychologically ready to bring up a child with a disability. McCoyd (2008) and Korenromp and colleagues (2007) conducted studies in which they found that the majority of women reported that parenting such a child is "not something they could do" (McCoyd, 2008, p. 1495) and that they "considered the burden too heavy" for themselves (Korenromp et al., 2007, p. 149.e143). Women's low perceived abilities to cope with a child with special needs are often cited as a main reason for seeking prenatal testing and envisaging selective abortion (Lawson, 2006; Souka et al., 2010). In the present study, anticipating to not being able to cope with a child with special needs was hypothesised to be associated with greater willingness to undergo selective termination, which in turn, was hypothesised to predict greater intention to take the test (Figure 3.6).

Negative consequences

Though abortion intention driven by low sense of coping efficacy might be perceived as somewhat selfish and driven by self-interest (Korenromp et al., 2007), other non-egoistical reasons, such as the perceived negative consequences of the disease on the child's well-being and his/her quality of life have also been cited as reasons for considering prenatal testing and termination of an affected pregnancy (Borry et al., 2008; Devolder, 2005; García et al., 2008b; McCoyd, 2008, 2009; Pieters et al., 2011). Studies have shown that 'self-related reasons' (e.g., coping efficacy) and 'child-related motivations' (e.g., anticipated negative consequences of the disability on the child's life) are closely linked in prenatal testing decisions (Korenromp et al., 2007).

Most parents anticipate genetic disabilities to have negative consequences on their child's life for several reasons. First, on a societal ground, people tend to believe that individuals with disabilities are discriminated against. Couples may fear that if their children were born with special needs, they would be subjected to social stigma and rejected from others less understanding than themselves; that their children will be mistreated or taken advantage of (Goodley & Tregaskis, 2006). Second, on a more personal ground, parents-to-be have reported feeling powerless over a situation they perceive as overwhelming. Many feel unable to meet their child's needs or to protect them from social prejudice (Ekberg, 2007; Mahowald...
et al., 1996; McCoyd, 2008). Qualitative studies have revealed that perceived negative consequences are related to testing intention (McCoyd, 2008). Though quantitative studies have further confirmed this link, they have also indicated that this link may, in fact, be only small (van den Berg et al., 2008). This suggests that the relationship between negative consequences and testing intention may be indirect. Probable mediators include abortion willingness and anticipated emotional distress.

Studies have shown that parents believe genetic disabilities can have deleterious effects of human life and are incompatible with happiness. Their concerns about the consequences of a genetic disease on their child's quality of life, their wish to act in their child's best interest by preventing anticipated pain and suffering (through aborting an affected pregnancy) have often been reported to be the strong motivator behind prenatal testing (Dixon, 2008; García et al., 2008a, 2008b; Kalfoglou et al., 2005; van den Berg et al., 2008). Therefore, it was hypothesised that greater perceived negative consequences from living with a child with disability would predict greater intention to undergo testing, and that this relationship would be mediated by greater willingness to terminate an affected pregnancy (Figure 3.6).

Furthermore, according to the Common Sense model (Leventhal et al., 2003), the imagined negative consequences of the health threat are closely linked to emotional distress in influencing threat appraisal, and consequent health preventive decision-making (Loewenstein et al., 2001). Hence, in the context of prenatal screening, if prospective parents believe that the disability is likely to severely impact on their unborn child's life, then they should anticipate positive diagnostics to be stressful and perceive selective abortion as one means to prevent that foetal mutation. Therefore, in the present study, it was hypothesised that greater perceived negative consequences from living with a disability would predict greater anticipated emotional distress from receiving a positive diagnosis, which in turn would indirectly predict greater intention to take the test, through greater willingness to terminate the affected pregnancy.

**Attitudes towards disabilities**

The last aspect considered in the current study for its influence on testing intention is attitudes towards disabilities. Attitudes towards disabilities differ from negative consequences. The former refers to the overall perception and acceptance of disabilities as a natural part of life, whereas the latter refers to psychosocial consequences expected to impact on the patients’
well-being. According to the Theory of Planned Behaviour (Ajzen, 1988, 1991; Ajzen & Manstead, 2007) and the Theory of Reasoned Action (Fishbein & Ajzen, 1975), attitudes influence the way people behave and cope with their issues. Research has shown that attitudes towards disabilities, which vary widely between opponents and defenders of prenatal testing, predict interest and use of prenatal screening (Green et al., 2004).

Disability rights advocates and other opponents of prenatal genetic testing have argued that disabilities are in fact the society's failure to adapt to individuals with special needs (Roets & Goodley, 2008; Titchkosky, 2003). They believe that the number of conditions severe enough to make life not worth living is only very small and that the remaining disabilities, while not being treatable, can be reasonably well managed (World Health Organization, 2002). Therefore, to them, disabilities are not necessarily detrimental to happiness. Defenders of prenatal testing believe that, though disabilities may indeed be managed, "there will often be some residual disadvantage for people with serious conditions" (World Health Organization, 2002, p. 166). Such disadvantages include stigma, discrimination and costs for the individuals, their family and the society at large. Proponents of genetic testing also point out that the degree to which a person's quality of life will be affected after birth cannot be predicted prenatally. The unknown extent of the severity of these anticipated negative consequences may well account for parents' distress regarding the prospect of receiving positive test results (Dixon, 2008). Hence, in the present study, it was hypothesised that lower attitudes towards disabilities would predict greater perceived negative consequences from living with a disability and greater anticipated emotional distress from receiving a positive diagnosis (Figure 3.6).

Another point of contention between opponents and advocates of prenatal testing regards the termination of an affected pregnancy. Critics have argued that the unspoken aim of this technology is to prevent the existence of people with disabilities (Asch, 1999; McChesney, 2006; Nelson, 2007). They have condemned prenatal testing as being a form of eugenics. They have argued that the technology's aim is to "replace 'defective' by 'non-defective' individuals" (World Health Organization, 2002, p. 165). They have maintained that preventing the birth of children with special needs is morally reproachable and that when it comes to raising such children, human compassion should prevail (Dixon, 2008). These objections have also been counter-argued by scientists and other defenders of genetic testing
(American Academy of Paediatrics: Committee on Bioethics, 2001). First, supporters contend that these technologies target disabilities, not the individuals born with them. Second, the primary aim of prenatal testing is to facilitate informed reproductive decision-making. Wanting to know about the health of the foetus should not be viewed as a value judgement on people living with these disabilities. To supporters of prenatal testing, selective abortion is a reasonable means to achieve a legitimate goal (World Health Organization, 2002). Therefore, in the present study, lower attitudes towards disabilities were hypothesised to predict greater willingness to terminate an affected pregnancy (Figure 3.6).

In summary, this chapter has theorised that several constructs would influence intention to undergo prenatal testing and willingness to abort an affected pregnancy. Test-specific variables included subjective norms – partner, subjective norms – family, religiosity, abortion willingness, benefits from receiving negative results and perceived vulnerability. Abortion-specific variables included attitudes towards disabilities, anticipated emotional distress, anticipated coping efficacy and negative consequences. Other variables were also identified for their indirect influence on the testing intention and abortion willingness. These included child-related worry, benefits from receiving positive results, condition coherence and test response efficacy.

Rationale, Aim and Predictions

Rationale and Aim
This chapter has shown that prenatal genetic testing is a sensitive issue and that the decision whether to undergo the procedure is a complex one, influenced by a series of social, cognitive, emotional and ethical constructs. Given the potential ramifications such decisions may have on prospective parents, it is seems crucial to ensure couples receive adequate support in helping them make a ‘good’ decision, one that is knowledge-based and value congruent (Broadstock & Michie, 2000). A model representing the respective influences all of the test-specific and abortion-specific variables on testing intention would have theoretical (i.e. explanatory) and empirical (i.e. clinical) value (McAllister, 2002; Michie & Marteau, 1996; Rees, Fry, & Cull, 2001). However, no such model existed. Most health models were designed to promote healthy behaviours. Undergoing prenatal genetic testing is not a health-
promoting behaviour. In fact, the technology is best understood in the realm of health threat preventive measures (McAllister, 2002). The aim of the present study was to fill in this research gap and to develop a new and extensive prenatal testing decision-making model, which would account for the potential influence of all the constructs identified thus far. These hypothesised influences are illustrated in the all-encompassing model presented below (Figure 3.7).
Figure 3.7 Hypothesised model of prenatal genetic testing decision-making
One arguable drawback of including multiple variables in one model is the increased complexity of that model. However, decisions pertaining to prenatal genetic testing and family planning are complicated. Before forging an opinion and opting for a course of actions, future parents need to consider all the relevant (independent and interdependent) aspects of this decision. This multifaceted model was designed to represent such complexity.

This approach is also in line with Broadstock and Michie's (2000) views on models explaining complex 'real-life' decision-making. According to the authors, such models should be able to: 1) integrate the many different aspects relevant to the situation; 2) recognize the level of risk involved in the decision; 3) acknowledge the involvement of others; 4) consider the timeframe of the (instant or delayed) outcome(s) of the decision; 5) be sensitive to individual differences, such as people's past experiences, current knowledge, affective states, situation appraisal, coping strategies and ultimate goals. Overall, Broadstock and Michie argued that the usefulness of decision-making theories can be gauged by their "ability to deal with the complexity of all these factors [...] in understanding 'real life' patient decision making" (2000, p. 192).

These features are characteristic of naturalistic decision-making paradigms (Klein, Orasanu, Calderwood, & Zsambok, 1993; Zsambok & Klein, 1997). Examples of such theories include, but are not limited to, Rutter et al's (1993) Theoretical Model of psychosocial mediators and health outcomes, Epstein's (1985) Cognitive - Experiential Self-Theory, Leventhal et al.'s (1980) Common-Sense model and Loewenstein et al's (2001) Risk-as-feelings hypothesis. Naturalistic decision-making theories embrace complexities faced in real life by decision-makers, as opposed to trying to simplify them (Broadstock & Michie, 2000). They present the process of decision-making as one that is dynamic and context-specific (Bijma et al., 2005; Broadstock & Michie, 2000; B. J. Henderson et al., 2006; Klein et al., 1993; Lipshitz, 1993; Orasanu & Connolly, 1993; Zsambok & Klein, 1997).

Three common features of these naturalistic theories are of prime relevance to the present study: 1) decision-making is guided by construction of scenarios and use of schemata (i.e., knowledge structures) for the possible outcomes, each of them being considered one at a time, rather than a cognitive comparison of the pros and the cons of all the possible alternatives (Broadstock & Michie, 2000; Lipshitz, 1993); 2) cognitions and affect play an
important role in situation appraisal and decision-making, and; 3) complexity (of dynamic and interdependent variables) is accepted, rather than suppressed. Based on these premises, the model proposed in the Figure 3.7 was believed to be appropriate for the present study.

**Predictions**

The proposed model (Figure 3.7) was used to generate three sets of predictions. The first set of predictions involved factors expected to influence prenatal testing intention. Specifically, it was predicted that higher subjective norms – partners, higher subjective norms – family, greater perceived benefits from negative results and lower religiosity would be associated with greater testing intention. Abortion willingness and perceived vulnerability would also be directly associated with testing intention. The second set of predictions involved factors expected to be associated with abortion willingness. It was predicted that greater attitudes towards disabilities and greater anticipated coping efficacy would be associated with lower abortion willingness. In addition, lower religiosity, greater anticipated emotional distress and greater negative consequences would predict greater abortion willingness. The third set of predictions related to more distal predictors of testing intention and abortion willingness. It was predicted that less favourable attitudes towards disabilities would be associated with greater anticipated emotional distress (which, in turn, would predict greater perceived benefits from negative results) and greater negative consequences (which, in turn, would predict greater anticipated emotional distress but also greater benefits from receiving positive results). Greater perceived vulnerability was theorised to predict greater child-related worry, which would predict greater anticipated emotional distress. Finally, greater condition coherence was expected to be associated with greater test response efficacy which, in turn, was theorised to be associated with greater perceived benefits from negative results.

In order to test these hypotheses and predictions (Study Two), a series of psychometrically sound measures assessing the constructs of interest was needed. Given that this area of research was relatively new, established scales did not always exist. The primary aim of Study One was to develop psychometrically sound measures of the variables. The next chapter describes the rationale for the study design used in both Study One and Study Two.
CHAPTER 4

Study 1 – Study Design

An online survey was created to test the model of prenatal testing decision-making proposed in the previous chapter (Figure 3.7). The survey consisted of a hypothetical scenario introducing the topics of interest (Appendix A) and a series of items assessing the test-specific and abortion-specific variables hypothesised to influence testing intention and abortion willingness, respectively (Appendices B to D). This chapter discusses some of the methodological issues encountered when designing the online survey and contains six sections. The first section provides a rationale for choosing a hypothetical scenario over a 'real life' situation. The second section explains why a quantitative approach is appropriate to research prenatal testing decision-making. The third section discusses the importance of promoting informed consent, in real life situations as well as in research studies. The fourth and fifth sections explain how information about the foetal genetic condition and prenatal testing, respectively, was selected for inclusion in the online survey. Finally, possible limitations related to using web-based hypothetical scenarios were anticipated and addressed.

Hypothetical versus 'Real Life' Situations

Studies on prenatal testing decision-making tend to utilise hypothetical case scenarios (i.e. tests were not actually offered) or situations representing 'real life' experiences. Both approaches have their advantages and limitations. For instance, studies conducted on 'real life' situations allow researchers to gain some valuable insights into the experiences of individuals directly concerned by the issues under investigation. This type of inquiry provides opportunities to gather information that will be directly usable by clinicians during genetic counselling (Bijma et al., 2005). In addition, participants are more likely to understand the importance of such studies when the topic is of direct relevance to their current situation (Hegwer, Fairley, Charrow, & Ormond, 2006). However, questioning individuals on issues of a sensitive nature may further upset already distressed participants and deepen their negative emotional reactions.
One way to explore beliefs and expectations about delicate issues but from a less personal and less threatening perspective is through the use of hypothetical scenarios (Ulrich & Ratcliffe, 2007). This method has been criticised for not being representative of real life scenarios. It has been argued that ethical dilemmas emerging from hypothetical reflections bear little resemblance with those encountered during real life situations (e.g., Browner et al., 1999). However, van den Berg and colleagues (2008) found that hypothetical intentions to undergo prenatal screening correlated highly (Spearman’s correlation coefficient = 0.91) with test uptake, confirming that intentions were accurate representations of actual decisions.

Using hypothetical scenarios has many advantages. First, potential users are given the opportunity to think about what might happen if they were presented with the real situation and how their values might guide their decisions, without being overwhelmed by strong emotions that might interfere with their decision-making process. Participants can project themselves in a hypothetical scenario and start imagining what their lives would be like if this situation was real. Individuals can reflect on their values and beliefs, and realise what really matters to them, while considering their own strengths and weaknesses (Anderson, 2007).

The second advantage of using scenarios requiring hypothetical thinking is that the views of potential users of any new technology can be investigated before that technology becomes an important part of medicine. Understanding trends in health care needs is important as these trends may have a profound impact on the development of related services. Findings emerging from studies using hypothetical scenarios may help providers understand people's attitudes towards the issues at stake, identify and address misconceptions in order to better anticipate patients' needs and plan appropriate strategies to meet them. These arguments are also relevant to the fields of genetics and genomics. Prenatal genetic testing, in particular, is expected to grow rapidly and to keep raising psychological issues. Studies using hypothetical scenarios eliciting dilemmas about reproduction and family planning are valuable in making sure that the technologies are developing in a way that will meet the needs of future users (Guillemin & Gillam, 2006). Despite the importance of understanding such trends in genetics and prenatal medicine, people's expectations remain understudied (Wang & Watts, 2007).

The third advantage in using hypothetical scenarios concerns the opportunity to provide a venue for informed debates about sensitive topics. Genetic testing is a technology for which
rapid development has outpaced the understanding of its possible repercussions on future users. Without such studies, regulation agencies and other policy-makers may not be able to set timely and appropriate practices (Petersen, 1998). Research can help raise awareness and provide opponents and supporters with a chance to express their opinions and to voice their concerns in a collaborative enterprise (Dresser, 2009). It is believed that a 'healthy' development of a new technology is one that also takes objections into consideration and tries to address them. Before a "new genetic discovery is rushed into clinical practice" (Remennick, 2006, p. 22), discussions are needed to better understand the emerging ethical dilemmas, to offer a base for reflection and debates, which outcomes will be useful for informing policy makers and members of the public (Rabino, 2006).

A final reason why hypothetical scenarios were thought to be particularly suitable to the present study is that undergoing prenatal testing is sometimes viewed as a 'normal' part of maternal care, not a decision parents consciously make (van den Berg, Timmermans, ten Kate, van Vugt, & van der Wal, 2006). One study showed that people do not always perceive undergoing prenatal screening as being their decision but as something that is self-evident (Michie, Smith, & Marteau, 1999). Inviting participants to consider their options and whether or not they would undergo the procedure emphasised the fact that this decision has to be made by prospective parents, not by professionals on their behalf. In summary, using hypothetical scenarios seemed to be the appropriate methodology to explore prenatal genetic testing decision-making.

**Quantitative versus Qualitative Approaches**

Once the decision to use hypothetical scenarios was reached, the next methodological issue concerned the research design and whether it would be qualitative and/or quantitative. Qualitative approaches are useful for addressing a variety of research aims, such as when the focus of the research is on a limited number of individuals or on identifying new constructs or hypotheses about relationships between constructs. However, users of prenatal testing are not part of a restricted population but have been, and are predicted to be, numerous and highly diverse (Browner et al., 1999). Moreover, the wealth of existing theories and research on risk and decision-making within health context, as well as in the area of genetic testing, provided
sufficient foundations for generating a proposed model and associated hypotheses. Therefore, it was decided that a qualitative method was not appropriate for the present study. Instead, a quantitative approach was preferred as this method would address the limitation cited above. Indeed, the present study aimed to obtain data from a large sample of individuals and to yield results which would be generalisable to the wider population. Members of the public were chosen as participants because the ethical issues generated by the technology are of prime relevance to potential users. An additional strength of quantitative studies is that such approaches may uncover subtle yet psychologically important dynamics between variables.

Towards Informed Consent

The principle of informed and autonomous decision-making in health has long been recognised. It is now widely accepted that patients should voluntarily (i.e. free of external pressure) be involved in decisions regarding their health and that these decisions should be knowledge-based and in line with their personal beliefs (Broadstock & Michie, 2000; Harris, Winship, & Spriggs, 2005; Moulton & King, 2010; Pelletier & Dorval, 2004; Vadaparampil, Miree, Wilson, & Jacobsen, 2007).

Decisions about prenatal testing are no exception. Although recent studies have shown that some parents have little involvement with such decisions (Gagnon et al., 2010; Wynter, Rowe, Fisher, Lee, & Quinlivan, 2011), autonomous and informed reproductive choices are highly desirable on two accounts. First, freedom of choice is one of patients’ fundamental rights to reproductive independence (Robertson, 1996). Hence, encouraging autonomous decisions also means respecting this fundamental right. Second, couples’ choices can critically impact on their lives and on the one of other family members. Hence, parents must know and understand the possible repercussions of their choices (Potter et al., 2008; St-Jacques et al., 2008).

In theory, informed prenatal testing decision-making can only be achieved if patients receive comprehensive medical information about the condition(s) under investigation and the tests. With regards to the condition(s) for which the prenatal genetic test is designed to detect, it is believed that couples should be provided with, at least, the following: 1) the description of
the disease, such as its characteristics, its cause and its biological, cognitive and psychological daily impairments; 2) frequency rates of the condition in the population; 3) risks factors and genetic vulnerability; 4) likelihood of a future pregnancy to be affected by that disability; 5) literature about personal accounts from individuals and families living with the disability; 6) available social support, such as community, academic and financial support for the families and the patients; 7) treatment options, and; 8) financial costs of treatment and subsequent care (Asch, 1999; Bryant et al., 2001; Burgess et al., 1998; Chachkin, 2007; Croyle, Dutson, Tran, & Sun, 1995; Marteau, 1995; National Health Committee, 2003; Ormond, Gill, Semik, & Kirschner, 2003).

Likewise, with regards to prenatal testing, patients should theoretically receive comprehensive medical information about the test (Asch, 1999; Bryant et al., 2001; Chachkin, 2007; Marteau, 1995; Ormond et al., 2003). Cho, Arruda and Holtzman (1997) drew a list of 10 of the most important criteria from texts published by policy-making agencies. These criteria are: 1) intended purpose of the test (i.e. screening, diagnostic, carrier or predictive); 2) the test performance, including its sensitivity, predictive value and false positive/ negative rates; 3) the test's medical and social risks, limitations and benefits; 4) the patients' rights for confidentiality, informed consent and autonomy; 5) the candidates' suitability, based on their medical and/or family history; 6) the characteristics of the condition under investigation, such as its symptoms, incidence and inheritance patterns; 7) the availability of genetic counselling accompanying testing; 8) interpretation of test results; 9) treatment options, and; 10) costs to the patient. In addition, it has been argued that future parents should also be told about the uncertainty of outcomes, the (contentious) option of selective abortion, and the risks of psychological and social harm (Burgess et al., 1998; National Health Committee, 2003).

Although exploring all of these aspects with prospective parents may theoretically be ideal to ensure prenatal testing informed choices, in practice, it seems to be neither helpful for parents nor practical for professionals (Broadstock & Michie, 2000; Chilaka, Konje, Stewart, Narayan, & Taylor, 2001; Marteau, 1995; Seror, Costet, & Aymé, 2001). First, parents may not wish to be provided with such exhaustive information. Studies on predictive genetic testing have shown that users do not attend to every piece of information presented to them. For instance, patients may be disinterested in hearing about genetics. This aspect, however, is
typically covered in great detail during genetic counselling (B. J. Henderson et al., 2006). Patients may also become cognitively overloaded and fail to process all this complex data (Elias & Annas, 1994; Harris & Harris, 1995). Second, medical professionals may find it impractical to provide all the related facts to future parents. Indeed, with rapid advances in medical technologies, it is expected that single tests will be able to detect thousands of disabilities at once (e.g. Lau & Leung, 2005). Providing such information on each and every condition that could possibly be detected could a great medical challenge for professionals (Borry et al., 2008). The issue of informed decision-making was of direct relevance to the present study. When developing the hypothetical scenario, great care was taken to ensure that participants would not receive too much nor too little information, as ignorance may also lead to maladaptive decision-making (Müller, Bleker, Bonsel, & Bilardo, 2006; Ramsoekh et al., 2007; St-Jacques et al., 2008). The approaches used to select information (about the conditions and the tests) which would be included in the scenario are detailed next.

**Information about the Genetic Condition**

Leventhal and colleagues' (2003) Common-Sense Model (CSM) has been particularly useful in terms of delineating the key aspects of health threat information sought after and encoded by individuals as they develop representations of health threats such as genetic conditions. The CSM posits that people's cognitive representations of a health-threat typically include: 1) identity: the name or label of the threat; 2) cause: the threat's perceived causal mechanism (hereditary, external, internal); 3) timeline: the threat's perceived time trajectory (e.g. acute, chronic, cyclical…); 4) cure: whether something can be done to control the threat, and; 5) consequences: the expected impact of a threat on the patient's quality of life. Studies have confirmed patients' wishes to be informed about these five key domains (e.g., Ormond et al., 2003). The CSM was used in the current study to design the hypothetical scenario and ensure the selection of well-balanced information.

**Identity**

Most studies on prenatal testing decision-making have focused on specific birth defects, such as Down syndrome (e.g., Légaré et al., 2011; Wynter et al., 2011). The main limitation in using a particular condition when studying information processing is that responses may
reflect biases, especially from knowledgeable participants, rather than actual cognitive differences between individuals. An effective way to bypass the influence of preconceived ideas is to describe the disease without actually naming it (Hewison et al., 2007) or to assess cognitive processes on a new or unfamiliar disease (L. D. Cameron & Diefenbach, 2001). This latter approach was adopted in Study One, the aim of which was to investigate the influence of several social, emotional, ethical and cognitive constructs on prenatal testing intention, rather than specific responses to particular disorders. Hence, participants were told about a foetal "condition". This generic term was chosen because it had been rated by lay people as less offensive than 'abnormality' or 'birth defect' (Hodgson, Hughes, & Lambert, 2005).

**Cause**

This foetal condition was described as "...a disease caused by a genetic mutation". The reference to a single gene abnormality was meant to rule out ambiguities linked to multiple-gene conditions and/or interactions with the environment. With regards to expressing the likelihood of finding this mutation in the foetus, three issues needed to be addressed: 1) the terms used to introduce the notion of risk; 2) the 'framing' of outcomes (i.e. desired versus feared) and of probabilities (i.e., quantitative versus qualitative), and; 3) the actual occurrence.

First, the term 'risk' is negatively loaded and ambiguous (Hunt, Castañeda, & De Voogd, 2006; Linell, Adelsward, Sachs, Bredmar, & Lindstedt, 2002). It is often associated with potential losses, negative outcomes and feelings of dread (Hellesøy, Grønhaug, & Kvitastein, 1998; Slovic, 1987). Since giving birth to a child with a disability is not always perceived to be a negative event (Parker, Fortnum, Young, & Davis, 2000; S. J. Stern et al., 2002), great care was taken to avoid introducing this type of bias. According to a study on lay people's views of the appropriateness of medical terms, nouns such as 'chance', 'prospect', 'probability' and 'likelihood' do not carry negative (nor positive) connotation, while still being conceptually linked (Hodgson et al., 2005). Consequently, the word "chance" was used in the opening text.

A second aspect to consider when discussing probabilities is 'framing', as the way outcomes and probabilities are presented can affect risk perception and decision-making (Tversky & Kahneman, 1981). Possible outcomes that are framed positively (e.g. the foetus may be
disease-free) are more reassuring than those framed negatively (e.g. the foetus may not be disease-free) (Edwards, Elwyn, Covey, Matthews, & Pill, 2001; Jasper, Goel, Einarson, Gallo, & Koren, 2001; Marteau, 1989; Shiloh & Sagi, 1989; Tversky & Kahneman, 1981). The present study did not aim to reassure participants but to bring their attention to a possible health threat. Hence, people were told about their (hypothetical) chances "of having a child with this condition".

Furthermore, probabilities may be 'framed' qualitatively or quantitatively. Literature shows that qualitative terms such as 'probable', 'unlikely' and 'rare' are elastic and open to interpretation (Budescu, Weinberg, & Wallsten, 1988; Cohn, Schydowler, Foley, & Copeland, 1995). For instance, the term 'likely' can mean '1 in 10' for some patients, but '1 in 2' for others (Edwards, Elwyn, & Mulley, 2002). Presenting estimates in qualitative terms may create confusion amongst participants. Therefore, a quantitative notation was preferred.

Research on risk communication has repeatedly shown people's difficulties in understanding probabilistic data (Edwards et al., 2001; Edwards et al., 2002; Edwards et al., 2000; Schwartz, Woloshin, & Welch, 1999; St-Jacques et al., 2008). For instance, Abramsky and Fletcher (2002) studied the connotations of some of the words commonly used in genetic counselling. They asked 581 participants (372 health professionals and 209 non-health professionals) "which risk for a foetal abnormality sounds more worrying?". Significantly more participants (n = 384) reported that "1 in 5" was more worrying than "20%" (n = 173). Likewise, when asked about risks for foetal abnormality, significantly more participants found that "1 in 16" (n = 410) sounded higher than "7%" (n = 161). These results were consistent across age, gender and occupation. In the present study, biases due to estimates' 'framing' were minimised by presenting risk estimates in percentages and proportions. Participants were told that "on average, in the entire population, parents have 1 chance in 200 (0.5%) of having a child with this condition".

The estimate of 1 in 200 was chosen because it is similar to the risk of procedure-related miscarriage (Royal College of Obstetricians and Gynaecologists, 2006), an information that was also given in the opening scenario (see next section). Besides, when considering risky outcomes, once probabilities are greater than the 'zero threshold', even so slightly, a previously non-worrying issue becomes a source of concern (Prelec, 1998). The simple
thought of an unwanted event is enough to trigger emotional arousal and influence decision-making (Damasio, 1994).

Finally, modern health theories have posited that decision-making is guided by mental representations which include conceptual concepts emotional arousal and imagery contents (Leventhal et al., 2003). However, the vividness of responses to health threats is unlikely to increase when probabilities also increase. The mere possibility of an event happening seems more important in driving health behaviour than the actual probability, especially when estimates are less than 1 (Loewenstein et al., 2001; Rottenstreich & Hsee, 2001). Given the importance of vividness and mental imagery in decision making, the opening sentence of the hypothetical scenario was "vividly imagine…".

**Timeline**

Timeline information is also believed to be part of lay people's illness representations (Lau, Bernard, & Hartman, 1989; Leventhal et al., 2003). Within the context of prenatal testing, important aspects of timeline include age of onset. Consequently, participants read that "it is a progressive ADULT-onset condition: symptoms appear slowly between the ages of 30 and 50 years".

**Cure and consequences**

With regards to the condition's treatment options, information on Huntington's disease published by the Huntington's Disease Associations of New Zealand (2008) and the Australian Centre for Genetics Education (2008) was summarised and adapted for the purpose of the present study. These organisations were selected because they have been providing members of the public with professional and reliable information about Huntington's disease. The scenario stipulated that "...NO CURE is currently available. Individuals with this condition will live approximately 10 to 15 years after the onset of illness". Impairments were described as "involving a progressive deterioration in: Knowledge and understanding (cognitive deterioration); Movements, with occurrence of involuntary movements (neurological deterioration), and; Personality (deterioration of emotional systems)".
Information about Prenatal Testing

The opening text also contained practical information specific to invasive prenatal testing, such as the test’s purpose, performance and cost. Information about the time frames (regarding when the test could be taken and when the test results would be available), location where testing can be taken and risks related to the procedure were also included. These facts were selected to maximise participants’ opportunities to make an informed decision (Asch, 1999; Bryant et al., 2001; Chachkin, 2007; Cho et al., 1997; Marteau, 1995; Ormond et al., 2003). They had also been selected because previous studies had shown the importance of including information about these key issues in materials presented to patients trying to reach a decision about whether or not to take the test (C. Lewis, Mehta, Kent, Skirton, & Coviello, 2007; Ormond et al., 2007; Shepperd et al., 2006). Finally, visualising practical aspects of a procedure is believed to facilitate the process of decision-making (Lee, Cameron, Wünsche, & Stevens, 2011; Smith & Shaffer, 2000).

Test purpose and performance

The purpose and performance of the test were described as being:

...a pre-birth test that can detect with more accuracy than the scanner can whether the foetus is affected with a condition. The test consists of obtaining a small sample of placenta or amniotic fluid (these surround the foetus). Sometimes under local anaesthetic and with ultrasound guidance, a syringe is used to collect small samples of the required tissues.

Cost

Financial constraints have been reported to impede on testing intentions (Ramsoekh et al., 2007). To remove perceived financial obstacles, the following (generally true) statement was included: "In New Zealand and Australia, the test is usually free of charge".

Time-frames and location

The opening statement of the hypothetical scenario asked participants to “vividly imagine you and your partner are expecting a baby and are at the beginning (i.e. under 12 weeks) of the pregnancy”. The timeframe of 12 weeks was used to mirror the reality of maternal care but also because timing has been shown to be an important factor in reproductive decision-making (Green et al., 2004). In New Zealand, prenatal diagnosis may be carried out up to the
20th week of pregnancy, when selective termination is still legally allowed (New Zealand Ministry of Health, 1998). Hence, in the present study, the timeframe of 12 weeks was chosen to avoid the 'choice lost' situation (Sandelowski & Jones, 1996, p. 357) which refers to receiving a positive diagnosis at a time when selective abortion is no longer a legal option. Participants read that "The test is performed between 10 and 15 weeks of pregnancy, and up to 20 weeks. Results will be available 10-14 days following the procedure". Finally, the following practical details were mentioned: "This procedure is done as an outpatient procedure and partners (or a support person / Whānau / family support) can attend".

Risks

The main disadvantage of invasive prenatal tests concerns the increased risk of iatrogenic miscarriage. The following statement was therefore included:

*The probability of procedure-related miscarriage is between 0.5% and 1%. This means that between 1 in 100, and 1 in 200 women will miscarry as a result of the procedure. There is also a risk of natural miscarriage of 2% that is present in all pregnancies at 10 weeks gestation, whether or not the test is performed.*

In summary, the scenario constructed for the purpose of the current study included information about the condition (i.e. identity, cause, timeline, control and consequences) and about the prenatal testing (i.e. purpose, performance, cost, locations, time frames and risks). This scenario was designed to be part of a web-based survey. The next section discusses the possible limitations of delivering health information online and how these were addressed.

**Delivering Information Online – Addressing Possible Limitations**

The main limitation of delivering the opening text online concerns the fact that respondents may fail to carefully read the information. One clinical recommendation made over the years regards the need to repeat key information several times to ensure patients understand and retain it (Marteau & Dormandy, 2001). This cannot be done online. In fact, it is often not feasible within the context of a doctor's visit during which a prenatal genetic test is offered. To evaluate whether lack of careful reading may have undermined participants' understanding of the scenario and thus contributed to measurement error in their responses, participants’
comprehension and memory were tested with the following quiz, presented on the web page following the one containing the scenario:

The condition described previously is genetically determined and... (Please read and tick all the relevant statements)
☐ Detectable during pregnancy
☐ 0.5% likely to affect every pregnancy
☐ Develops between 30 and 50 years of age
☐ Fatal to the individual

(The survey would proceed to the next page only once the four options had been selected)

In summary, theoretical and empirical evidence guided the construction of a hypothetical scenario used to elicit views on genetic disabilities and prenatal testing. Information contained in this opening text included details about the condition under investigation and about prenatal testing. After reading the scenarios, participants were reminded of some key points before being invited to rate a series of statements. These statements assessed social, emotional, ethical and cognitive constructs hypothesised to influence prenatal genetic testing and willingness to undergo selective abortion in the case of a positive diagnosis. These measures, as well as the study methods for recruiting participants and collecting data, are detailed in the next chapter.
CHAPTER 5

Study 1 - Method

This chapter describes the method used to recruit participants and to collect data for testing the psychometric properties of the measures expected to predict testing intention and abortion willingness in response to a potential prenatal test for a genetic condition (Figure 3.7). It consists of three sections. The first section presents a summary of participants' demographic characteristics. The second section describes the measures used to assess the theoretical constructs hypothesised to influence prenatal testing decision-making. Finally, the procedure chosen to gather data is described.

Participants and Recruitment

A total of 143 participants (age $M = 28.66$ years; $SD = 9.00$ years, range = 18 – 57 years old) were recruited using flyers (Appendix F) posted on the University of Auckland message boards across campuses and uploaded on the university web-based information system for students (CECIL). In addition, study invitations were sent to staff members of most faculties of the University of Auckland. Anyone over the age of 18 was eligible to participate. The online questionnaire used to collect views on prenatal testing and related issues was reviewed and approved by The University of Auckland Human Participants Ethics Committee (reference number 2008/Q/023). Demographic characteristics of the sample are presented in Table 5.2. With regards to ethnicity, surveys used to collect data on New Zealanders since 1996 have been given people the option to self-identify with more than one ethnicity. The New Zealand Health Information Service has established a prioritisation of ethnicity system (Table 5.1) to rank people's ethnicity (Frazer, 2003, p. 84). This classification was also used in the present study when participants self-identified with two or more ethnicities.
Table 5.1

*Ethnicity Prioritisation Order*

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Order</th>
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<tbody>
<tr>
<td>New Zealand European</td>
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</tr>
<tr>
<td>Other European</td>
<td>14</td>
</tr>
<tr>
<td>Māori</td>
<td>1</td>
</tr>
<tr>
<td>Samoan</td>
<td>7</td>
</tr>
<tr>
<td>Cook Island Maori</td>
<td>6</td>
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<tr>
<td>Tongan</td>
<td>5</td>
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<tr>
<td>Niuean</td>
<td>4</td>
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<tr>
<td>Tokelauan</td>
<td>2</td>
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<tr>
<td>Fijian</td>
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<tr>
<td>Other Pacific</td>
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<td>Chinese</td>
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</tbody>
</table>
Table 5.2
*Gender, Relationship Status, Number of Children, Highest Completed Educational Level, Ethnicity and Religious Affiliation Reported by the Study Sample*

<table>
<thead>
<tr>
<th>Variables</th>
<th>n</th>
<th>Percentages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>117</td>
<td>81.8%</td>
</tr>
<tr>
<td>Men</td>
<td>26</td>
<td>18.2%</td>
</tr>
<tr>
<td>Relationship status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single, not in a serious relationship</td>
<td>45</td>
<td>31.7%</td>
</tr>
<tr>
<td>Single, in a serious relationship</td>
<td>36</td>
<td>25.4%</td>
</tr>
<tr>
<td>De facto / Married</td>
<td>59</td>
<td>41.5%</td>
</tr>
<tr>
<td>Separated / Divorced / Widowed</td>
<td>2</td>
<td>1.4%</td>
</tr>
<tr>
<td>Number of children</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>109</td>
<td>76.2%</td>
</tr>
<tr>
<td>1 or more</td>
<td>34</td>
<td>23.8%</td>
</tr>
<tr>
<td>Highest completed education level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High School</td>
<td>36</td>
<td>25.1%</td>
</tr>
<tr>
<td>Trade certificate</td>
<td>2</td>
<td>1.4%</td>
</tr>
<tr>
<td>Bachelor's degree</td>
<td>52</td>
<td>36.4%</td>
</tr>
<tr>
<td>Professional degree</td>
<td>11</td>
<td>7.7%</td>
</tr>
<tr>
<td>Master degree</td>
<td>27</td>
<td>18.9%</td>
</tr>
<tr>
<td>PhD / Doctorate</td>
<td>15</td>
<td>10.5%</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New Zealand European</td>
<td>87</td>
<td>60.8%</td>
</tr>
<tr>
<td>Other European</td>
<td>31</td>
<td>21.7%</td>
</tr>
<tr>
<td>Indian</td>
<td>6</td>
<td>4.2%</td>
</tr>
<tr>
<td>Other Asian</td>
<td>6</td>
<td>4.2%</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
<td>3.5%</td>
</tr>
<tr>
<td>Chinese</td>
<td>4</td>
<td>2.8%</td>
</tr>
<tr>
<td>Māori / Samoan / Tongan / South East Asian</td>
<td>4</td>
<td>2.8%</td>
</tr>
<tr>
<td>Religious affiliation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Christian</td>
<td>52</td>
<td>36.9%</td>
</tr>
<tr>
<td>None</td>
<td>46</td>
<td>32.3%</td>
</tr>
<tr>
<td>Agnostic</td>
<td>15</td>
<td>10.5%</td>
</tr>
<tr>
<td>Atheist</td>
<td>13</td>
<td>9.1%</td>
</tr>
<tr>
<td>Buddhist</td>
<td>3</td>
<td>2.1%</td>
</tr>
<tr>
<td>Hindu</td>
<td>3</td>
<td>2.1%</td>
</tr>
<tr>
<td>Catholic</td>
<td>2</td>
<td>1.4%</td>
</tr>
<tr>
<td>Muslim</td>
<td>2</td>
<td>1.4%</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>4.2%</td>
</tr>
</tbody>
</table>

N = 143

Most participants were women, in a relationship and childless. Also, the majority of participants had completed a university degree, were of European descent and reported not being affiliated with any particular religion, or being affiliated with a Christian religion.
Measures

The survey included measures of the social, emotional, ethical and cognitive constructs delineated in Figure 3.7. Some of these measures were adapted from existing and psychometrically sound scales. Most scales, however, were developed for the purpose of this research project. Measure items were constructed with careful attention to the selection of terms that would be inoffensive and easily understood. An Australian study (Hodgson et al., 2005) on the acceptability of medical terms, as judged by lay people, was particularly helpful in guiding the choice of words to use in the new items. For instance, words judged to be offensive (e.g. genetic disease) or directive (e.g. baby) were replaced by alternatives deemed more acceptable (e.g. genetic condition, unborn child, etc.). Face validity was tested by consultation with six other researchers involved in studies on people with disabilities and decision-making in health psychology. This team included one expert in Māori Studies, though it should be acknowledged that this expert's opinion may not be representative of Maori in general. With regards to the issue of reliability, single-item measures can be unreliable (Consedine, Magai, Krivoshekova, Ryzewicz, & Neugut, 2004). Therefore, it was decided to design brief scales containing a minimum of three items. Short scales were preferred to minimise participants' boredom and fatigue. Some scales were rated on a 5-point rating scale because they were derived from existing 5-point scales (Moss-Morris et al., 2002). New scales were measured on 7-point rating scales because reliability tends to increase slightly with more response categories (Weng, 2004). All the measures used in the present study are listed below. Negatively worded items were reverse-scored. Unless otherwise indicated, measure items were averaged to generate scores, with higher scores reflecting greater levels of the construct.

Testing intention

Intention to undergo prenatal testing was assessed with six newly-designed items (Appendix C). These items were rated on a scale from -3 (strongly disagree) to +3 (strongly agree). Two of the items (i.e. *It would be important to get the test* and *I would be likely to request the test*) had been adapted from Cameron and colleagues' (2001; 2006) scales on genetic testing interest.
Abortion willingness

Willingness to terminate an affected pregnancy was assessed with four items (e.g. *I would be opposed to giving birth to a child with THIS condition*) also scored from -3 (strongly disagree) to +3 (strongly agree) (Appendix C).

Social influence scales

*Subjective norms* are typically operationalised by multiplying ratings obtained on a normative beliefs scale (i.e. perceived expectations from others) by those obtained on a scale measuring motivation to comply (i.e. willingness to behave consistently with others' perceived expectations) for each referent (i.e. person or group of people important to the decision-maker) (Ajzen, 1991). In the present study, normative beliefs were assessed with asking participants "*How much would each of the following people want you to undergo prenatal testing?*" (Appendix N). Ratings ranged from 0 (not at all) to 6 (very much) and were averaged. The four referents were 1) your partner / spouse; 2) your doctor / Obstetrician / Midwife; 3) your family/ whānau; 4) your friends. Motivation to comply was measured by the item "*You would undergo prenatal testing if it was important to...*" followed by the same four referents (Appendix N). Responses were scored on a 7-point scale (-3 = strongly disagree to 3 = strongly agree). Mean scores were computed. The subjective norms scores for each referent were obtained by multiplying their respective means on normative beliefs by their mean on motivation to comply (e.g., Subjective norms – partner = normative beliefs – partner x motivation to comply – partner).

Condition-related measures

*Anticipated coping efficacy* was designed primarily with wordings and issues reported in McCoyd's (2008) study on prenatal decision-making. The five items included statements such as "*I would have the mental strength to cope with a child with this condition*" were scored on a 7-point scale ranging from -3 (strongly disagreed) to +3 (strongly agree) (Appendix B).

*Negative consequences* of the genetic condition of the child's quality of life were assessed using the subscale 'consequences' from the IPQ-R (Moss-Morris et al., 2002). This subscale has been found to demonstrate high internal consistency (α = .84). The six items used in the present study included statements such as "*This condition would have major consequences on my child's life*" and were also scored on a 5-point scale (-2: strongly disagree to +2 strongly agree) (Appendix B).
Anticipated emotional distress was assessed using some reworded items originally belonging to the emotional representation subscale of the IPQ-R (Moss-Morris et al., 2002). This subscale was internally consistent (α = .88). In addition, new items were also included (e.g. *The thought of having a child with this condition is distressing to me*). All five items were scored on a scale from -3 (strongly disagree) to +3 (strongly agree) (Appendix B).

Child-related worry consisted of four items (e.g. *I am concerned my child may be born with this condition*). The 7-point Likert scale ranged from -3: Not at all to +3: Extremely. Items from Cameron and Diefenbach's (2001) worry scale were used as the basis of this scale (Appendix B).

Perceived vulnerability (of carrying a child with a genetic disability) was assessed with three items (e.g. *I (we) would not be 'at-risk' of having a child with this condition*), scored from -3 (strongly disagree) to +3 (strongly agree) (Appendix B).

Ethics-related scales

Attitudes towards disabilities were assessed with four items (e.g. *People with disabilities add much to society*). Answers to these items were given on a scale ranging from -3 (strongly disagree) to +3 (strongly agree) (Appendix C).

Religiosity was measured with three items, such as "Every child is a gift from God / the Divine Force / the Holy Creator", scored from on a 7-point Likert scale (-3: strongly disagree to +3: strongly agree) (Appendix C).

Test-related measures

Condition coherence was evaluated using an adapted version of the illness coherence subscale from the Illness Perceptions Questionnaire-Revised (IPQ-R; Moss-Morris et al., 2002) which has demonstrated high internal consistency (Cronbach's α = .87). The five self-reported items included statements such as "I have a clear picture/understanding of this condition" These items were also scored from -2 (strongly disagree) to +2 (strongly agree) (Appendix D).

Perceived benefits from negative test results were measured with four newly created items (Appendix D). Statements such as "Knowing that my unborn child did not have the genetic
mutation...would help me feel less anxious about the pregnancy" were scored on a 5-point scale ranging from strongly disagree (-2) to strongly agree (+2), so that these ratings would be comparable to those used for the measure of perceived benefits from positive test results.

*Perceived benefits from positive test results* were measured with four items (Appendix D). One of them (i.e., *Knowing the test results would help us work to organise our lives*) had been adapted from Cameron and Diefenbach's (2001) testing benefits beliefs scale. All items were measured on a 5-point scale ranging from strongly disagree (-2) to strongly agree (+2).

*Test response efficacy* was assessed with four items (e.g. *undergoing prenatal testing would clearly indicate the presence of this condition*; Appendix D) scored on a 7-point Likert scale (-3: strongly disagree; +3: strongly agree).

**Demographic questions**

Data on participants' demographic characteristics were also covered (Appendix E). Individuals were invited to indicate their age (in years), gender, relationship status (1 = *single, not in a relationship* to 5 = *widowed*) and number of children (open-ended question). In addition, participants were asked to indicate their highest completed education levels (1 = *high school* to 7 = *PhD / Doctorate*), ethnicity (1 = *New Zealand European* to 15 = *other*; multiple answers accepted) and religious affiliation (1 = *Christian* to 8 = *other*).

**Procedure**

Individuals interested in obtaining more information about the study were invited to send a blank email to prenatal@auckland.ac.nz. This account had been set up to send an automatic reply (Appendix G) to the sender. This self-generated email explained the purpose of this study was to investigate men's and women's opinions regarding pre-birth testing for genetic risk for diseases and disabilities. The automatic reply also contained a hyperlink to the anonymous password-protected online survey, and two attachments: the Participant Information Sheet (Appendix H) and the Consent Form (Appendix I). This email emphasised that confidentiality and anonymity were guaranteed at all time. It also reminded participants of their right to withdraw from the study at any time, should they wish to do so. The measures used to collect participants' responses were presented in the following order: anticipated
emotional distress, child-related worry, condition coherence, test response efficacy, negative consequences, perceived benefits from positive results, positive benefits from negative results, perceived vulnerability, normative beliefs, motivation to comply, anticipated coping efficacy, testing intention, abortion willingness, attitudes towards disabilities and religiosity. Demographic characteristics were also covered. Completion time varied from 16 to 58 minutes ($M = 24.89$ minutes, $SD = 9.20$ minutes). Participants did not receive compensation (financial or otherwise) for their contribution but did receive a debriefing statement upon the completion of the survey (Appendix J).
CHAPTER 6

Study 1 - Results

Data were entered for analyses into the computerised Statistical Package for the Social Sciences (SPSS) version 17.0. The results are presented in three sections. The first section addresses the issues of missing data and data's suitability for principal component analyses (PCAs). The second section reports the findings from three successive PCAs conducted on cognitive, emotional and ethical and constructs, respectively. Finally, the descriptive statistics of these scales and the one measuring subjective norms are presented. Unless otherwise specified, results of inferential tests were considered statistically significant at $p < .05$.

Initial Screening and Missing data

Of the 154 submitted questionnaires, 11 had more than 25% missing data. These incomplete surveys were discarded (Coolican, 2005). The remaining 143 questionnaires had less than 3% missing data. Missing values analyses revealed no systematic differences between cases with missing values and cases without. It was concluded that missing values were missing completely at random (MCAR). Analyses were conducted by using the option cases pairwise deletion. Only specific values (not the entire case) were removed from the analyses (Byrne, 2001).

Principle Components Analyses

Findings from PCA are usually considered reliable when the number of participants is at least five times the number of items, with a preference of 10 participants per item (Grimm & Yarnold, 2004). In the current study, the sample size was 143 participants for 63 items, not 315 (i.e. $5 \times 63$). Given that the data could not be analysed in a single PCA, the dataset was divided into three subsets of theoretically linked items (e.g. E. A. Skinner, Chapman, & Baltes, 1988). Three PCAs were successively carried out on the variables related to the condition, ethics (with inclusion of testing intention items) and the test.
All three PCAs were carried out using a similar approach. First, SPSS was used to recode reverse-coded items. Then, Bartlett’s test of sphericity and Kaiser-Meyer-Olkin (KMO) were computed to assess the data's suitability for PCAs. Bartlett's test of sphericity tests the null hypothesis that there is no correlation amongst the variables. In the current study, Bartlett’s test of sphericity was significant for the first, second and third PCA; $\chi^2(231) = 1695.149, p < .001$, $\chi^2(276) = 2241.908, p < .001$ and $\chi^2(253) = 2076.325, p < .001$, respectively. The null hypothesis was rejected, leading to the conclusion that variables were significantly correlated.

KMO is a measure of sampling adequacy. Values greater than 0.6 suggest that a factor analysis of the variables is appropriate (Kaiser, 1974). In the current study, KMO was .75, .79 and .74 for the first, second and third PCAs, respectively, further confirming the data's suitability for PCA.

Next, the three PCAs were performed. Factor structures were considered satisfactory when simple structure was reached, i.e., when 1) each variable loaded significantly (i.e. greater than .30) onto only one factor; 2) each factor loaded significantly (i.e. greater than .30) onto only a few variables; and when 3) the identifiable factors could be interpreted meaningfully. However, none of the unrotated component matrices showed simple structure. As most correlation coefficients were less than 0.30, a direct oblimin rotation was undertaken for each PCA. This rotation was chosen on the premise that the factors were correlated. Items were carried forth if their factor loadings were greater than .30. They were otherwise removed from the analyses.

A first PCA was conducted on the 22 items (Appendix B) hypothesised to measure the following five condition-related constructs: anticipated coping efficacy, negative consequences, anticipated emotional distress, child-related worry and perceived vulnerability.
Table 6.1
Pattern Matrix for the 22 Items Subjected to the Principal Component Analyses on the Condition-related Variables

<table>
<thead>
<tr>
<th></th>
<th>Anticipated coping efficacy</th>
<th>Negative consequences</th>
<th>Anticipated emotional distress</th>
<th>Child-related worry</th>
<th>Perceived Vulnerability</th>
</tr>
</thead>
<tbody>
<tr>
<td>AntCopEff.BringUp</td>
<td>.86</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AntCopEff.PsychStrongREC</td>
<td>.88</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AntCopEff.ManageREC</td>
<td>.90</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AntCopEff.MentalStrengthREC</td>
<td>.82</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AntCopEff.TooMuchREC</td>
<td>.93</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NegCsqs.Serious</td>
<td>.61</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NegCsqs.MajorCnsqs</td>
<td>.80</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NegCsqs.NoEffectREC</td>
<td>.64</td>
<td>.30</td>
<td>-.42</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NegCsqs.StronglyAffect</td>
<td>.70</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NegCsqs.FinancCnsqs</td>
<td>.52</td>
<td>.43</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NegCsqs.ThosePartOf</td>
<td>.76</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AntEmoDiss.Depressed</td>
<td></td>
<td>.83</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AntEmoDiss.Upset</td>
<td></td>
<td></td>
<td>.72</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AntEmoDiss.Distressing</td>
<td></td>
<td></td>
<td>.78</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AntEmoDiss.AfraidREC</td>
<td></td>
<td></td>
<td>.73</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AntEmoDiss.SaddenREC</td>
<td></td>
<td></td>
<td>.57</td>
<td>.45</td>
<td></td>
</tr>
<tr>
<td>W.Worry</td>
<td></td>
<td></td>
<td>.75</td>
<td>.37</td>
<td></td>
</tr>
<tr>
<td>W.Concerned</td>
<td></td>
<td></td>
<td></td>
<td>.75</td>
<td>.34</td>
</tr>
<tr>
<td>W.Bother</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.78</td>
</tr>
<tr>
<td>PrCdVuln.LikelyHav</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.73</td>
</tr>
<tr>
<td>PrCdVuln.NotAtRiskREC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.78</td>
</tr>
<tr>
<td>PrCdVuln.UnlikelyBornREC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.82</td>
</tr>
</tbody>
</table>

Note. Factor loadings < .30 were suppressed for visual clarity.
Variables starting with 'AntCopeEff' represent items measuring anticipated coping efficacy.
Variables starting with 'NegaCsqs' represent items measuring negative consequences.
Variables starting with 'AntEmoDiss' represent items measuring anticipated emotional distress.
Variables starting with 'W' represent the items measuring child-related worry.
Variables starting with 'PrCdVuln' represent the items measuring perceived vulnerability.

The rotated matrix (Table 6.1) revealed several items loaded significantly onto more than one factor. For instance, the items 'NegaCsqs.NoEffectREC' (This condition would not have much effect on my child's life) and 'NegaCsqs.FinancCnsqs' (This condition would have serious financial consequences for us) cross-loaded significantly onto Factor 2, 3 and 4. After statistical revisions (i.e. higher loadings indicating best factor fit and item analyses higher 'Cronbach's α if item deleted'), it was decided to allocate them to Factor 2 measuring negative consequences (of the condition on the child's quality of life).
The item 'AntEmoDiss.Upset' (*Thinking about giving birth to a child with this condition makes me feel upset*) was originally designed to be part of the construct anticipated emotional distress (Factor 3). However, Table 6.1 reveals that this item's loading is higher on Factor 4, measuring child-related worry. Finally, Factors 1 and 5 measured anticipated coping efficacy and perceived vulnerability respectively. Final scales and their respective items are presented in Appendix K. The eigenvalues and amount of variance explained by all five factors are presented in Table 6.2.

### Table 6.2

*Eigenvalues and Percentage Variance Explained for the Principal Component Analyses on the Condition-related Variables*

<table>
<thead>
<tr>
<th>Components</th>
<th>Initial Eigenvalues</th>
<th>Rotations Sums of Squared Loadings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total (λ)</td>
<td>% of Variance</td>
<td>Cumulative %</td>
</tr>
<tr>
<td>1</td>
<td>5.05</td>
<td>22.96</td>
</tr>
<tr>
<td>2</td>
<td>4.01</td>
<td>18.22</td>
</tr>
<tr>
<td>3</td>
<td>2.60</td>
<td>11.81</td>
</tr>
<tr>
<td>4</td>
<td>1.84</td>
<td>8.36</td>
</tr>
<tr>
<td>5</td>
<td>1.60</td>
<td>7.27</td>
</tr>
<tr>
<td>6</td>
<td>.89</td>
<td>4.06</td>
</tr>
</tbody>
</table>

Table 6.2 showed that the first factor explained almost 23% of the variance. Over 68% of the cumulative variance in participants' responses was explained by five factors. This solution was appropriate, as indicated by Kaiser's criterion.

The second PCA was carried out on the items designed to measure the three following ethics-related variables: abortion willingness, attitudes towards disabilities and religiosity. The outcome variable of testing intention was also included in this PCA because, as indicated in the proposed model (Figure 3.7), two of these variables are likely to have strong, direct associations (Appendix C). The factor loadings of the 17 relevant items are presented below (Table 6.3).
Table 6.3
Pattern Matrix for all 17 Items Subjected to the Principal Component Analyses on the Ethics-related Variables

<table>
<thead>
<tr>
<th>Testing intention</th>
<th>Abortion willingness</th>
<th>Attitudes towards disabilities</th>
<th>Religiosity</th>
</tr>
</thead>
<tbody>
<tr>
<td>TestInt.TooDistressREC</td>
<td>.68</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TestInt.UnacceptREC</td>
<td>.85</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TestInt.UnnecessRiskREC</td>
<td>.88</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TestInt.NoBenefREC</td>
<td>.63</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TestInt.Important2Get</td>
<td>.73</td>
<td>-.36</td>
<td></td>
</tr>
<tr>
<td>TestInt.RequestTest</td>
<td>.72</td>
<td>-.47</td>
<td></td>
</tr>
<tr>
<td>AbortWill.DiminshREC</td>
<td>.65</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AbortWill.WouldRatherHav</td>
<td>.82</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AbortWill.OpposdREC</td>
<td>.87</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AbortWill.WantTerminREC</td>
<td>.81</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dis.ValuableMembers</td>
<td>.87</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dis.Add2Society</td>
<td>.89</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dis.Normal</td>
<td>.66</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dis.IrresponsREC</td>
<td>.53</td>
<td>.42</td>
<td></td>
</tr>
<tr>
<td>Rel.Prayers</td>
<td>-.32</td>
<td></td>
<td>.54</td>
</tr>
<tr>
<td>Rel.Gift</td>
<td>.83</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rel.GodDecide</td>
<td>.72</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. Factor loadings < .300 are suppressed for visual clarity

Variables starting with 'TestIntent' represent items measuring testing intention
Variables starting with 'AbortWill' represent items measuring the abortion willingness
Variables starting with 'Dis' represent the items measuring attitudes towards disabilities
Variables starting with 'Rel' represent the items measuring religiosity

The Oblimin Rotated Component Matrix (Table 6.3) indicated that several items loaded significantly onto two scales. Statistical revisions (i.e. higher loading indicating factor suitability) led to keep 'TestInt.Important2Get' (It would be important to get the test) and 'TestInt.RequestTest' (I would request the test) to Factor 1 measuring testing intention. Likewise, 'AbortWill.DiminshREC' (Someone with THIS condition would have a diminished quality of life) was kept in Factor 2 assessing abortion willingness. The item 'Dis.IrresponsREC' (It is irresponsible to impose a child with disabilities on society when it came be avoided) was originally designed to be part of the scale attitudes towards disabilities (Factor 4). However, as can be seen in the factor matrix (Table 6.3), this item belonged to Factor 2 (abortion willingness). Finally, the religiosity items all loaded together (Factor 5). The final scales and their respective items are presented in Appendix L. The total variance explained by the extracted components is displayed in Table 6.4.
Table 6.4
Eigenvalues and Percentage Variance Explained for the Principal Component Analyses on the Ethics-related Variables

<table>
<thead>
<tr>
<th>Components</th>
<th>Initial Eigenvalues</th>
<th>Rotations Sums of Squared Loadings</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total ($\lambda$)</td>
<td>% of Variance</td>
</tr>
<tr>
<td>1</td>
<td>5.51</td>
<td>32.42</td>
</tr>
<tr>
<td>2</td>
<td>2.94</td>
<td>17.28</td>
</tr>
<tr>
<td>3</td>
<td>2.31</td>
<td>13.57</td>
</tr>
<tr>
<td>4</td>
<td>1.37</td>
<td>8.06</td>
</tr>
<tr>
<td>5</td>
<td>.89</td>
<td>5.16</td>
</tr>
</tbody>
</table>

The first component explains over 32% of the total variability of 17. Progressive factors explain less and less. The eigenvalues being greater than 1 (Kaiser's criterion) confirmed the solution's adequacy. Together, these four factors explain 71.33% of the total available variance.

The third PCA was performed on the items hypothesised to measure the following four test-related variables: condition coherence, perceived benefits from negative test results, perceived benefits from positive test results and test response efficacy (Appendix D). Condition coherence was included in this PCA because, according to the model of prenatal testing decision-making (Figure 3.7), condition coherence was only hypothesised to be related to test response efficacy. On the first rotated matrix, the last factor consisted of a single item: 'RE.OnlyIdea.REC' (Undergoing this prenatal test would give me only an idea about the risks, not a definite answer). This item was removed from the dataset. The results from the third rotated component matrix (with oblimin rotation) are shown below (Table 6.5). The values below 0.30 have been suppressed to increase visual clarity.
Table 6.5
Pattern Matrix for all 16 Items Subjected to the Principal Component Analyses on the Test-related Variables, after Exclusion of 'RespEff.OnlyIdea.REC'.

<table>
<thead>
<tr>
<th>Condition coherence</th>
<th>Benefits from negative results</th>
<th>Benefits from positive results</th>
<th>Test response efficacy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coherence.PuzzlingREC</td>
<td>.82</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coherence.MysteryREC</td>
<td>.79</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coherence.UnderstandREC</td>
<td>.84</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coherence.NoSenseREC</td>
<td>.82</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coherence.ClearPic</td>
<td>.81</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benef.N.Uncertainty</td>
<td></td>
<td>.61</td>
<td></td>
</tr>
<tr>
<td>Benef.N.LssAnx</td>
<td></td>
<td>.90</td>
<td></td>
</tr>
<tr>
<td>Benef.N.Reassured</td>
<td></td>
<td>.92</td>
<td></td>
</tr>
<tr>
<td>Benef.N.Confidnt</td>
<td></td>
<td>.91</td>
<td></td>
</tr>
<tr>
<td>Benef.P.OrgLives</td>
<td></td>
<td>.63</td>
<td></td>
</tr>
<tr>
<td>Benef.P.PlanFuture</td>
<td></td>
<td>.90</td>
<td></td>
</tr>
<tr>
<td>Benef.P.PrepPsych</td>
<td></td>
<td>.87</td>
<td></td>
</tr>
<tr>
<td>Benef.P.NeedsMet</td>
<td></td>
<td>.90</td>
<td></td>
</tr>
<tr>
<td>RespEff.ClearlyIndic</td>
<td></td>
<td></td>
<td>.85</td>
</tr>
<tr>
<td>RespEff.NoConfidntREC</td>
<td></td>
<td></td>
<td>.77</td>
</tr>
<tr>
<td>RespEff.CouldIndic</td>
<td></td>
<td></td>
<td>.75</td>
</tr>
</tbody>
</table>

a: an alternative approach consisted of including the items hypothesised to measure condition coherence with the condition-related variables. Analyses yielded comparable patterns of findings.

Variables starting with 'Coherence' represent items measuring condition coherence.

Variables starting with 'Benef.N' represent items measuring perceived benefits from negative test results.

Variables starting with 'Benef.P' represent items measuring perceived benefits from positive test results.

Variables starting with 'RespEff' represent items measuring test response efficacy.

Table 6.5 shows the factor structure and loadings for the test-related variables. All items loaded significantly onto only one of the four factors. Factor 1 assessed condition coherence (e.g. 'Coherence.UnderstandREC': I don’t fully understand this condition). Perceived benefits from negative test results (e.g. 'Benef.N.Reassured': Knowing that my unborn child did not have the genetic mutation would make me feel reassured about the health of my unborn child) and perceived benefits from positive test results (e.g. 'Benef.P.PlanFuture': Knowing that my unborn child had this genetic condition would help me start planning our future with a child affected with the condition) were measured by Factors 2 and 3, respectively. Factor 4, which included items such as 'RespEff.ClearlyIndic' (Undergoing this prenatal test would clearly indicate the presence of this condition), measured test response efficacy. Final subscales and
their respective items are presented in Appendix M. The factors’ eigenvalues and variances are shown below (Table 6.6).

Table 6.6
Eigenvalues and Percentage Variance Explained for the Principal Component Analyses on the Test-related Variables

<table>
<thead>
<tr>
<th>Components</th>
<th>Initial Eigenvalues</th>
<th>Rotations Sums of Squared Loadings</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total (λ)</td>
<td>% of Variance</td>
</tr>
<tr>
<td>1</td>
<td>4.73</td>
<td>29.58</td>
</tr>
<tr>
<td>2</td>
<td>3.20</td>
<td>20.02</td>
</tr>
<tr>
<td>3</td>
<td>1.89</td>
<td>11.83</td>
</tr>
<tr>
<td>4</td>
<td>1.77</td>
<td>11.09</td>
</tr>
<tr>
<td>5</td>
<td>.86</td>
<td>5.36</td>
</tr>
</tbody>
</table>

The first component explains 29.587% of the total variability. Progressive factors explain less and less. The appropriateness of this 4-factor solution was confirmed by Kaiser’s criterion (i.e. eigenvalues greater than 1). Together, these five factors explained 72.51% of the total available variance.

Descriptive Statistics

In addition to the 13 scales discussed thus far, the scales measuring motivation to comply with perceived norms (Ajzen, 1991) and normative beliefs (Ajzen, 1991) were also expected to be used in the three studies of the present research project, as the scores on these two scales would be combined to produce subjective norms for four referents (partner/spouse, doctors, friends and family). A mean score was calculated for all 17 factors by taking the mean of the responses given to the items that loaded heavily onto their respective component. For example, a mean score on test response efficacy was obtained by averaging the responses to items 'RespEff.ClearlyIndic', 'RespEff.NoConfidntREC' and 'RespEff.CouldIndic'. The scales' mean scores (M), standard deviation (SD), Cronbach's alpha (α), skewness and correlation coefficients are provided below (Table 6.7).
Table 6.7
Mean Scores (M), Standard Deviations (SD), Cronbach’s Alpha (α), Skewness and Correlation Coefficients of all the Study Variables

<table>
<thead>
<tr>
<th>Variables</th>
<th>1</th>
<th>2</th>
<th>3a</th>
<th>4a</th>
<th>5a</th>
<th>6a</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
<th>13</th>
<th>14</th>
<th>15</th>
<th>16</th>
<th>17</th>
</tr>
</thead>
<tbody>
<tr>
<td>M</td>
<td>-.00</td>
<td>.22</td>
<td>5.70</td>
<td>5.10</td>
<td>2.41</td>
<td>-.85</td>
<td>1.22</td>
<td>.94</td>
<td>1.14</td>
<td>.00</td>
<td>-1.56</td>
<td>-1.15</td>
<td>1.45</td>
<td>.37</td>
<td>.60</td>
<td>.83</td>
<td>1.02</td>
</tr>
<tr>
<td>SD</td>
<td>1.42</td>
<td>1.44</td>
<td>6.21</td>
<td>6.48</td>
<td>5.60</td>
<td>5.41</td>
<td>1.47</td>
<td>.60</td>
<td>1.22</td>
<td>1.32</td>
<td>1.12</td>
<td>1.70</td>
<td>1.15</td>
<td>.91</td>
<td>.90</td>
<td>.82</td>
<td>1.10</td>
</tr>
<tr>
<td>α</td>
<td>.87</td>
<td>.87</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>.92</td>
<td>.78</td>
<td>.81</td>
<td>.86</td>
<td>.70</td>
<td>.84</td>
<td>.80</td>
<td>.88</td>
<td>.89</td>
<td>.87</td>
<td>.74</td>
</tr>
<tr>
<td>Skewness</td>
<td>-.11</td>
<td>-.13</td>
<td>.53</td>
<td>-.19</td>
<td>.54</td>
<td>.39</td>
<td>-.82</td>
<td>-.56</td>
<td>-.65</td>
<td>-.09</td>
<td>.72</td>
<td>.56</td>
<td>-.51</td>
<td>.21</td>
<td>-.37</td>
<td>-.98</td>
<td>-.41</td>
</tr>
</tbody>
</table>

1. Testing intention
2. Abortion willingness

**Social variables**
3. Subjective norms – partner     .51** | .38** | 1
4. Subjective norms – doctors     .46** | .42** | .37** | 1
5. Subjective norms – family      .42** | .25** | .48** | .48 | 1
6. Subjective norms – friends     .21** | .21** | .28** | .35** | .74** | 1

**Condition-related variables**
7. Anticipated coping efficacy     .01 | .00 | .06 | .06 | .03 | -.02 | 1
8. Negative consequences          .05 | .19 | .10 | .18 | .21 | .15 | -.21 | 1
9. Anticip. emotional distress    .37** | .35** | .31** | .25** | .36** | .25** | .03 | .29** | 1
10. Child-related worry           .40** | .47** | .37** | .44** | .40** | .33** | .01 | .15 | .55** | 1
11. Perceived vulnerability       .38** | .18 | .10 | .24** | .32** | .16 | -.04 | .06 | .21 | .28** | 1

**Ethics-related variables**
12. Religiosity                   -.17 | -.26 | -.21 | -.14 | -.06 | -.13 | .04 | -.06 | .15 | .19 | -.03 | 1
13. Attitudes twds disabilities   -.12 | -.50 | -.02 | -.30 | -.09 | -.11 | .16 | -.08 | -.06 | -.19 | -.12 | .13 | 1

**Test-related variables**
14. Condition coherence           .04 | -.07 | .11 | -.14 | .09 | .15 | .07 | .04 | -.01 | .25** | -.01 | -.11 | .18 | 1
15. Benefits negative results     .06 | -.01 | .11 | .07 | .17 | .05 | -.28 | .05 | -.03 | .08 | .00 | -.14 | .05 | -13 | 1
16. Benefits positive results     -.01 | -.07 | -.04 | -.08 | .11 | .05 | -.19 | .09 | -.19 | -.07 | -.09 | -.00 | -.05 | -.13 | .41** | 1
17. Test response efficacy        .28** | .09 | .09 | .12 | .08 | -.04 | -.10 | .28** | .16 | -.04 | .17* | -.09 | .05 | .18* | -.04 | -.09 | 1

**: p < 0.01; * p < 0.05
a: mean scores range from -18 (3 x -6) to 18 (3 x 6)
Table 6.7 shows the scales' internal consistency coefficients ranged from acceptable ($\alpha = .70$ for perceived vulnerability) to very satisfactory ($\alpha = .89$ for testing intention). Cronbach's alphas would have not increased by removing any items. Correlated item-total correlations further confirmed that the items measuring a same scale were conceptually related. Analyses of the scales' skewness revealed that all values were within an acceptable range (i.e. less than 1).

As indicated by the testing intention mean and standard deviation (Table 6.7) participants were mixed in their intention to undergo invasive prenatal testing to find out about the foetal abnormalities. Correlation coefficients indicated that being willing to comply with one's partner and family, as well as feeling 'at risk' of carrying a child with a genetic disability and being in favour of selective abortion were significantly associated with greater testing intention. However, being religiously committed was associated with lower testing intention.

As indicated by the abortion willingness mean and standard deviation (Table 6.7) participants tended to be in favour of selective abortion. Correlation coefficients suggested that participants who believed the condition could negatively impact on the child's quality of life and anticipated positive diagnosis to be emotionally stressful also reported greater willingness to undergo prenatal testing. However, those who reported great religious involvement and positive attitudes towards disabilities also reported lower abortion willingness.

Finally, correlation coefficients between the scales, age, gender and number of children were computed. Gender was positively correlated with benefits from receiving negative results ($r = .17, p < .05$) and attitudes towards disabilities ($r = .36, p < .001$). Women were more likely to perceive receiving a negative diagnosis as beneficial and to hold positive views towards people with disabilities. Number of children was positively correlated with age ($r = .67, p < .001$) but negatively correlated with anticipated emotional distress ($r = -.19, p < .05$) and testing intention ($r = -.26, p < .01$). Demographic group differences will be considered more extensively in Study Two of the present research project.
CHAPTER 7

Study 1 - Discussion

Prenatal genetic tests are procedures that may be performed to find out about whether an unborn child is affected by genetic abnormalities likely to develop into disabilities after birth. Prior to the present research, no model existed that fully accounted for the many factors believed to influence testing intention and abortion willingness, nor did quantitative survey measures exist for many of these constructs. Yet, such a model would have great scientific and clinical value in terms of supporting prospective parents in their decisions regarding whether or not to undergo prenatal testing. The aims of Study One were twofold: 1) to propose a model of prenatal testing decision-making; and 2) to create psychometrically robust scales for assessing the constructs of interest. The literature currently available on decisions pertaining to reproduction, family planning and health preventive behaviours was carefully evaluated. Pertinent empirical and theoretical evidence was selected and integrated into one all-encompassing model of prenatal testing decision-making (Chapter 3).

Chapter 4 presents the survey paradigm and the method used to recruit participants and to collect data. More specifically, an online survey was designed for the purpose of the present study. It consisted of two parts. The first part contained a hypothetical scenario, in which participants were invited to imagine they and their partner were expecting a child and were at the beginning (under 12 weeks) of their pregnancy. Participants were asked to imagine having heard about a foetal genetic mutation responsible for a birth-onset fatal condition, and a prenatal test which could detect such anomalies. Information about the genetic condition was selected using the Common Sense Model (Leventhal et al., 2003). Information about the test was selected following recommendations about key issues to include when developing new materials (C. Lewis et al., 2007; Shepperd et al., 2006). The second part of the online survey consisted of a series of items designed to measure the constructs hypothesised to influence testing intention and abortion willingness. The questionnaire items were either adapted from existing scales or newly created.

Data collected from 143 New Zealanders (Chapter 5) were analysed through successive principal component analyses (Chapter 6). These analyses led to removing several items from the whole data set and to allocate other items to different scales from those for which they
were originally associated with. Principal components analyses confirmed that, altogether, the items represented 17 clear scales. Two of them measured testing intention and abortion willingness. In addition, four assessed social variables (i.e. subjective norms – partner, subjective norms – doctors, subjective norms – family and subjective norms – friends). Five scales measured condition-related variables (i.e. anticipated coping efficacy, negative consequences, anticipated emotional distress, child-related worry and perceived vulnerability). Two scales assessed ethical variables (i.e. religiosity and attitudes towards disabilities). Finally, four scales measured test-related factors (i.e. condition coherence, benefits from negative results, benefits from positive results and test response efficacy). All of the factors had moderate to high internal consistency.

The present study confirmed that constructs assumed to be theoretically different were indeed different. For instance, it was confirmed that attitudes towards disabilities were conceptually different from negative consequences. The former measured general evaluation of disabilities on a social level, whereas the latter assessed the perceived negative consequences of the condition on the individual's quality of life. Data also provided support for the assumption that benefits from undergoing prenatal testing could derive from negative results or from positive results. This showed that receiving positive results may also be perceived as valuable by prospective parents. Also, conceptually linked variables were significantly correlated. For instance, child-related worry, anticipated coping efficacy and negative consequences were all significantly correlated.

A few methodological and theoretical limitations need to be acknowledged. First, the current sample was over-representative of New Zealand European women under 30 years old. It is therefore possible that the responses this sample may not be consistent across gender or generalisable to other ethnicities. Future research should aim to assess the properties of these scales across different ethnic groups. For instance, assessing the reliability of the scales on a sample of Maori or Asian participants would reveal whether or not the items are interpreted consistently between different ethnic groups living in New Zealand. Also, participants who accessed the survey online were self-selected. It is therefore difficult to ascertain whether the current patterns of responses were representative of current and future users of prenatal testing. The main theoretical limitation concerns the content of the hypothetical scenario. It described only one type of genetic conditions (i.e. one predicted to be present from birth and
incompatible with life). Future research should aim to test this model across several conditions.

Despite its limitations, the present study is one of the few to have developed a set of appropriate measurement tools for assessing psychosocial constructs believed to be important for future parents who are considering whether or not to undergo prenatal testing. Although the full psychometric properties of the scales (e.g., test-retest reliability) could not be tested, the present scales have promising characteristics for future research. In particular, these scales are likely to be applicable to other pre-birth tests, not just amniocentesis or CVS. Hence, the first strength of this study is that these reliable scales may be generalisable to other prenatal tests. The validation of these 17 scales represents an important scientific contribution to the fields of prenatal testing decision-making. A second strength is that the development of the model and of these scales makes it possible for researchers to study the intricate relationships that exist between the many dimensions involved in choices about prenatal testing. It is hoped that this study will motivate researchers to further investigate the process of prenatal testing decision-making. Such research would be invaluable in increasing practitioners' understanding of the psychological processes involved in parental decision-making and, in turn, assist their patients reach their final choice.
Study Two
CHAPTER 8

Study 2 – Introduction

Overview

Prenatal genetic tests may be carried out to detect the presence of foetal abnormalities. When scientists first introduced these tests into maternal care, they presented it as a valuable tool to facilitate informed family planning. Although this technology bears the unique advantage of enabling future parents to make informed reproductive choices, it is surrounded with a wide series of issues. Study One has theorised on the independent and inter-related roles of social, emotional, ethical and cognitive constructs on prenatal testing decision-making (Figure 3.7). The first aim of Study Two was to evaluate the model proposed in Study One. Validating it would be a valuable scientific advance in the field of genetic counselling, as no such model currently exists. The issues raised by decisions about prenatal testing can be further complicated by the characteristics of the conditions under investigation and personal differences. The second aim of Study Two was to investigate the roles of condition onset (early-onset versus late-onset), condition severity (fatal versus nonfatal), gender and experiences with pregnancies (i.e. childless versus expecting versus parents) on prenatal testing decision-making. Doing so would not only provide information about the role of these characteristics in choices about family planning. It would also test the extent to which the model could be generalised across conditions of various characteristics.

The present chapter discusses the role of condition age of onset, condition severity, gender and family status on prenatal decision-making, and contains five sections. The first three sections discuss issues related to prenatal testing from a health professional’s perspective. More specifically, Section One presents the clinical and legal realities of prenatal testing. Section Two summarises the ethical debates regarding the appropriateness of the different applications of prenatal testing. Section Three discusses the extent to which these ethical debates have informed regulation in some Western countries. The last two sections discuss prenatal testing decision-making from a user’s perspective. In particular, the fourth section discusses how parents’ reproductive choices can be driven by the conditions’ characteristics.
(e.g., severity and age of onset). Finally, Section Five shows that couples' decisions may be associated with demographic characteristics (e.g. gender and family status).

Clinical and legal realities of prenatal testing

Prenatal genetic testing was originally developed to detect genetic conditions caused by 'simple' mutations in single genes, associated with fully penetrant diseases present from birth. Since then, the field of genetics has progressed considerably. Nowadays, prenatal genetic testing can be carried out to detect complex genetic abnormalities that have been associated with diseases of various ages of onset and degrees of severity. It is now possible to determine whether the unborn child carries a genetic predisposition that will increase his/her risks of being affected by adult-onset cancers. For example, although the occurrences of most cancers are also linked to environmental factors (British Council of Disabled People, 2000), women who inherit the BRCA1 mutation are between 60-65% (SenGupta, Harper, Fordham, Serhal, & Delhanty, 2008) and 85% (Buxton, 2006) more likely to develop breast cancer by age 40 than are women without the genetic susceptibility. Breast cancer can, but not always, lead to death. In fact, this disease was the second cause of mortality amongst all New Zealand women in 2007, after lung cancer (New Zealand Ministry of Health, 2010). Another cancer known to have a significant genetic component is colorectal cancer. Individuals born with mutations on the APC gene are almost guaranteed (in absence of prophylactic surgery) to develop colorectal cancer in adulthood (Bionews, 2004; Buxton, 2006). Many patients survive this disease. However, colorectal cancer was the second cause of mortality in 2007 for New Zealand men and women together (New Zealand Ministry of Health, 2010).

Genetic susceptibilities to cancers are just a few examples of the genetic anomalies that can be tested for during pregnancy. It is also clinically possible to test for other foetal genetic predispositions for diseases of various degrees of severity and ages of onset, such as congenital fibrosis of extra-ocular muscles, familial hypercholesterolemia and early-onset Alzheimer's disease. Congenital fibrosis of extra-ocular muscles is an inheritable eye movement disorder. The eyesight of people born with the genetic susceptibility may be affected from birth by a squint, which severity varies between patients. While congenital fibrosis of extra-ocular muscles is not life-threatening, those affected by this birth-onset disease find it debilitating (Hamm, 2007). Familial hypercholesterolemia (FH) is a condition which increases risk of heart attacks, strokes and blood vessel failure of people born with the predisposition. Symptoms may appear at various times throughout people's lives and vary in
severity. Symptoms caused by the milder form of FH may be reduced through diet, physical activity and medication. The more severe form of FH, however, is less responsive to treatment and has been linked to dangerously high (sometimes fatal) levels of cholesterol in childhood (Buxton, 2007). Finally, susceptibility to early-onset Alzheimer's disease may also be inherited. Patients born with the mutation have an increased likelihood of being affected from the age of 35 years by memory loss and cognitive, neurological and behavioural impairments, such as confusion, language disturbance, hallucinations, seizures and incontinence (Sinclair, 2007; Thornhill, 2007).

The applications mentioned above are not only a clinically reality. They have been legally carried out, along with a small number of interventions aiming to detect predispositions for several genetic diseases. For instance, in Great Britain, the Human Fertilisation and Embryology Authority authorised the use of assisted reproductive technologies to detect and prevent several inherited cancer susceptibilities (Leather, 2006; Thornhill, 2005). In 2006, the University College Hospital in London helped conceive the first baby free from susceptibility to cancer of the retina caused by a faulty RB1 gene (Horsey, 2006). At the University College London, SenGupta and colleagues (2008) reported having successfully used prenatal testing to prevent inheritable susceptibility to several types of cancer. Reports of such interventions remain sparse. However, given that such applications are now clinically possible and legal in some Western countries, policy makers have the difficult task to reach an agreement about the future development of prenatal testing and to determine which abnormalities should be legally tested for during pregnancy (Boormans et al., 2010). Consensus on these topics is likely to involve consideration of ethical issues surrounding the conditions' characteristics. Indeed, with "the claim that the spectrum of conditions which could be screened for is enormous […] obviously, the ethical question is, if you can screen for anything, where do you draw the line?" (Dr Mark Hamilton, chairman of the British Fertility Society, cited by BBC, 2008).

**Ethical issues**

The introduction of prenatal testing into maternal care has sparked an ongoing ethical debate. Objections, often counter-argued by defenders of the technology, have concerned three main psychosocial areas: the possible ramifications of genetic testing on people with disabilities, the fact that important decisions regarding people's existence may be based on probabilities, and the reductionist biological approach to disabilities.
The first objection concerns the feared anticipated consequences on the lives of people with disabilities. Opponents of prenatal testing, such as organisations advocating for the rights of individuals with disabilities, have condemned the technology for being ethically unacceptable (Little, 2009). They have argued the real goal of prenatal testing is to search foetal genetic malformations in order to terminate affected pregnancies (Browner et al., 1999). They believe the underlying message in the development of prenatal testing is that lives with disabilities are not worth living. They fear that the ramification of this technology would be a negative impact on the quality of lives with people born with disabilities, through increased stigmatisation and discrimination.

The second objection regards the potential misallocation of scientific resources. According to critics of prenatal testing, scientists' contribution should be on encouraging the society to accept people with disabilities as equal citizens (Asch, 1999, 2000; Clapton, 2003; Munger, Gill, Ormond, & Kirschner, 2007) not on developing a science which could lead to a further discrimination of people with special needs. Opponents have compared prenatal testing to 'fortune telling' arguing that, with the current state of genetic knowledge, little more than predictions could be offered to couples expecting children carrying a genetic anomaly (Lock, 2005). Future parents are typically provided with estimates on their child's likelihood to develop disorders for which onset and severity are likely to depend on the patients' lifestyle and environment.

Third, some ethicists have criticised health professionals for their tendency to adopt a reductionist, disease-centred approach towards disabilities. For instance, Asch (1998) deplored the biological medical approach which consists of perceiving impairments as imperfections to be fixed, rather than integral part of a multi-facet individual. This stance is in line with the one adopted by the Catholic Church. The pope Benedict XVI has recently condemned 'the obsessive search for the perfect child' (Salamone, 2009). Disability rights advocates, also denouncing the systematic negative approach to disabilities, have used the life of Van Gogh as an illustration of their objections. Although the artist took his own life after 37 years of mental and physical suffering (due to a condition thought to have affected him most of his adult life), his existence was remarkable. Opponents of prenatal testing fear that a reductionist approach to genetic conditions combined with the current technologies would encourage parents to screen for foetuses carrying genetic predispositions to disabilities. Such
attitudes could prevent the birth of talented individuals and deprive the society from such artistic legacy.

Defenders of prenatal testing have conceded that the health benefits of prenatal testing may be limited and that (arguably desirable) disease prevention may indeed be a by-product of prenatal testing (C. F. Wright, Brice, Stewart, & Burton, 2010). They have, to a degree, agreed that the continued use of prenatal testing could result in a decrease of the number of people with genetic disabilities through selective abortion. However, to them, such arguments are not compelling enough to justify a ban on prenatal testing. They have stressed that the main purpose of this technology is to promote autonomous reproductive decision-making and that every couple should be able to take the test if this decision reflected their wishes and beliefs.

Advocates of prenatal testing have also pointed out the ethical obligations of medicine towards patients, once the test results are known. They note that knowing a person's health might be compromised at some point in life but not trying to minimise the severity of this possible outcome violates the ethos of medicine according to which prevention should prevail over cure (de Lacy-Brown, 2007; Ekberg, 2007). According to supporters of prenatal testing, prenatal genetic testing is best understood as a preventive measure as it can provide information about the health of individuals before they become patients (Borry et al., 2008). Defenders of the technology have argued that applications targeting the detection of genetic mutations is ethically justifiable, especially when these genetic anomalies could result in serious disabilities after birth (Fransen et al., 2010; Steinbock, 2007; A. Taylor, 2008).

The issue with the argument that reproductive technologies are ethically acceptable for serious disabilities resides in the fact that there seems to be no agreed-upon definitions for the words 'disabilities' and 'serious'. Both terms are open to interpretation and have been a source of disputes. With regards to 'disabilities', many would consider hearing impairment as being one. However, the Deaf Community perceive this characteristic as a sign of belonging to a linguistic minority (Gavaghan, 2008). Similarly, the severity of disabilities is also open to interpretation, as shown by the controversy surrounding prenatal genetic testing for early-onset Alzheimer's disease (Sinclair, 2007). Opponents of that application believe that prenatal testing should be reserved for conditions that are present early in life and fatal. Early-onset
Alzheimer's disease does not usually develop before the age of 35, which means that individuals born with the predisposition might enjoy almost four decades of disease-free existence (Thornhill, 2007). Although early-onset Alzheimer's disease is currently fatal, critics of prenatal testing for genetic susceptibility for this condition have pointed out that the possibility of a cure being one day discovered cannot be ruled out (Sinclair, 2007). Therefore, according to sceptics, early-onset Alzheimer's disease is not 'serious' enough to be screened by prenatal testing. A similar debate has been reported on the controversial (and still limited) use of genetic testing for hereditary cancer (Moutou, Gardes, Nicod, & Viville, 2007; Offit, Kohut, et al., 2006).

**Prenatal testing and policy-making**

The ethical debate presented above has somewhat informed regulation of assisted reproductive technologies in Western countries. It seems that policy-makers have taken into consideration the characteristics of the conditions when legalising applications of prenatal testing. In UK, for instance, the Human Fertilisation and Embryology Authority have been allowing prenatal testing for 'serious' conditions, an assessment made on careful consideration of several criteria which include physical pain and speed of degeneration (Dyer, 2006; Sinclair, 2007). Hence, the Human Fertilisation and Embryology Authority may allow prenatal testing for a late-onset and curable condition if they believe the patient will require substantial physical, emotional and financial support (Thornhill, 2007). In the US, the position of the Committee on Assessing Genetic Risks is slightly more restrictive. It recommends that testing for predispositions to late-onset diseases should only be considered for treatable or preventable conditions of relatively high frequency (Andrews, 1994). This stance underlines the view that genetic testing should be offered only if there is an anticipated medical benefit for the patient (A. Taylor, 2008).

The debates between clinicians, ethicists and policy-makers around the concepts of severity, disability and medical obligations have been valuable in clarifying some key dilemmas surrounding modern reproductive technologies. However, it is argued that such discussions tend to overlook one of the most fundamental principles in reproductive decision-making: parents' autonomy and freedom over their reproductive choices (Browner et al., 1999; Steinbock, 2007). People are not only the main decision-makers of if / when they wish to procreate but they are also ethically and legally expected to act in their children's best medical interests (Borry et al., 2008). Hence, although doctors might have their preferences regarding
the desirability of prenatal genetic testing and selective abortion (Ekberg, 2007), their role is to promote informed reproductive choices (A. Taylor, 2008). Lay people's views on genetic disabilities, prenatal testing and selective abortion are also likely to be influenced by the conditions' characteristics and the individuals' differences.

**Characteristics of the Condition**

The underlying factors driving the process of prenatal genetic testing decision-making remain unclear. Study One of the present research project included the development of a theoretical model delineating the relationships between, on one hand, several social, emotional, ethical and cognitive variables and, on the other hand, testing intention and abortion willingness (Figure 3.7). Although the model reflects relationships that are potentially consistent across context, contextual factors are likely to also influence these decision-making processes. Decisions about family planning may be further complicated by the fact that the mutations currently tested for during pregnancy have been associated with diseases of various ages of onset and treatability (Evans et al., 1996; Harman, 2003; Hewison et al., 2007; Mansfield, Hopfer, & Marteau, 1999; SenGupta et al., 2008; H. Statham, Solomou, & Chitty, 2000; Zlotogora, 2002). As the American Medical Association pointed out, when involved in reproduction decision-making, "a number of factors need to be considered: the severity of the disease, [...] the age at onset, and the time of gestation at which selection would occur" (The Council on Ethical Judicial Affairs American Medical Association, 1994, p. 639).

Studies of lay people and 'at-risk' families have reported varied interest and/or uptake of prenatal genetic testing for specific diseases, such as cystic fibrosis (Denayer, Evers-Kiebooms, De Boeck, & Van den Berghe, 1992; Henneman et al., 2001; Lafayette, Abuelo, Passero, & Tantravahi, 1999), Fragile X (D. Skinner, Sparkman, & Bailey, 2003), achondroplasia (Gollust, Thompson, Gooding, & Biesecker, 2003), adrenoleukodystrophy (Costakos, Abramson, Edwards, Rizzo, & Best, 1991) and Tay-Sachs disease (Kronn, Jansen, & Ostrer, 1998). In addition, anecdotal evidence suggests that, although the use of prenatal testing for inherited predispositions for conditions such as cancer remains rare, the demand for such applications to prevent passing on faulty genes has been increasing slowly (SenGupta et al., 2008). Altogether, these findings suggest that attitudes towards prenatal testing and selective abortion may vary according to the diseases' characteristics, such as their ages of onset and severity.
Onset age of condition

Studies on attitudes towards prenatal testing have revealed that the views of various types of participants (e.g. 'at risk' women, infertile couples and students) on the appropriateness of reproductive technologies depended on the characteristics of the conditions under considerations, including the conditions age of onset (Chamayou et al., 1998; Fernandez, De Vincentiis, Chillik, & Brugo-Olmedo, 2004; Green et al., 2004; Hui et al., 2002; Katz, Fitzgerald, Bankier, Savulescu, & Cram, 2002; Krones & Richter, 2004; Miedzybrodzka et al., 1993; Palomba et al., 1994; Pergament, 1991; Snowdon & Green, 1997). For instance, in a Canadian survey, most participants (93%) felt that using genetic testing to diagnose early-onset illnesses was 'somewhat' to 'very' acceptable (Martin, 2000). These results were later replicated in the United States where participants reported more favourable views towards the use of reproductive genetic testing to detect childhood diseases than to detect adult-onset conditions (Genetics and Public Policy Center, 2004).

Similar findings have been reported about the influence of the age of onset on abortion willingness. Rabino and colleagues (2006) conducted a survey on these issues in the USA and several European countries. They revealed that participants were more accepting of termination when the child's life was predicted to end at the age of 4 (i.e. 76% US and 74% European) than when it was predicted to end during adulthood (43% US and 41% European). These results indicate that the amount of time the child was predicted to live disease-free before the diseases onsets was associated with acceptability of selective abortion. Acceptance of selective termination decreased as the conditions' age of onset increased.

Severity of Condition

Studies have also revealed that the perceived severity of the condition may influence intentions to undergo prenatal testing and to terminate an affected pregnancy (Ahmed et al., 2008; Drugan et al., 1990; Hassed et al., 1993; Meiser, Mitchell, McGirr, Van Herten, & Schofield, 2005; Pryde, Drugan, Johnson, Isada, & Evans, 1993). A recent study conducted in New Zealand confirmed that attitudes towards assisted reproductive technologies varied with the perceived impact of the conditions on the patients' quality of life (Muller & Shepherd, 2009). These findings echoed those previously reported. For instance, a public consultation conducted in the United Kingdom by the Human Genetics Commission (2006) revealed that
most participants supported prenatal screening programmes for conditions that were 'serious' or 'severe'. Although the definition of 'serious' or 'severe' were not clearly stated, it remained that the severity of the condition was an important factor in deciding whether or not to undergo testing.

The severity of the conditions under investigation has been found to influence choices regarding the outcome of an affected pregnancy. Given legal access to professional services, most parents would choose to undergo prenatal testing to find out about a genetic mutation associated with a fatal condition or with a condition so debilitating that non-existing could potentially be viewed as being better than living with the disease (Drake, Reid, & Marteau, 1996; Gavaghan, 2008; Hewison et al., 2007; Leung et al., 2004; Meiser et al., 2005; Rabino, 2006; Schechtman, Gray, Baty, & Rothman, 2002; Souka et al., 2010). Such individuals generally undergo testing with the intention to terminate the affected pregnancy.

A condition does not necessarily need to be terminal to motivate testing intention and abortion willingness. Most disabilities qualified as 'severe' do not result in death or great suffering (Steinbock, 2007). Even anencephaly (a neural tube defect severely affecting the growth of the spinal cord and the brain) is unlikely to generate pain. Yet, most people would probably qualify this condition of 'severe'. Other nonfatal non-painful conditions may also be perceived as serious if their symptoms include severe cognitive or intellectual disabilities and challenging behaviour (de Lacy-Brown, 2007). The survey conducted by Rabino and colleagues (2006) in the US and part of Europe showed that the majority of participants (i.e. 81% of US and 78% of European) supported selective abortion to avoid giving birth to children with severe mental retardation.

Decisions to undergo prenatal testing and selective abortion seem even more difficult to reach when the severity of the diseases is less predictable. For instance, it is not yet clinically possible to predict the level of impairments in social communication, interactions and cognitive development of people affected with Down syndrome (Rabino, 2006). However, it has been argued that these conditions can reduce patients' potentials, engagement with their environment and their relationships with others (Savulescu, 1999). Some couples believe that a life with Down syndrome is worth living and that parenting a child with this disability would provide them with great happiness (Savulescu, 1999). Most parents, however, tend to
believe that Down syndrome warrants prenatal testing and selective abortion. Fears concern the child being bullied at school and later rejected by the wider society. These are prospects most parents would choose to prevent by undergoing prenatal testing and selective abortion (Aschcroft, 2009; Green et al., 2004).

Reproductive choices are perhaps the most ethically challenging for genetic susceptibilities to multi-factorial conditions, which may or may not develop during the person's life and for which severity is unpredictable. Very few parents have, so far, screened out embryos affected with the BRCA 1 mutation, known to increase one's risks of developing breast cancer. Those couples who have done so have pointed out that although some surveillance may be possible for cancers, none of these strategies currently guarantee timely detection and prevention (Garber & Offit, 2005; Offit, Sagi, et al., 2006). They have also argued that even if the condition never materialises, their children would live with "the sword of Damocles swinging above their head" (de Lacy-Brown, 2007; para. 3), a psychological stress they did not wish to impose on their children. In their views, susceptibility to breast cancer is a threat to their children's health, serious enough to justify prenatal testing and selective abortion (Fukuyama, 2002b). Most people, however, report little interest in using prenatal testing or selective abortion for conditions such as susceptibility to breast, ovarian and colon cancer (Garber & Offit, 2005), bipolar disorder (Meiser et al., 2005), depression and anticipated weight problems (Rabino, 2006).

In summary, the evidence presented above suggests that the onset age and the severity of the genetic conditions under consideration may further complicate decisions related to family planning. This is particularly relevant to the current medical practices where genetic testing offered to pregnant women can be carried out to detect foetal anomalies associated with conditions of various ages of onset and degrees of severity. However, the roles of condition onset age and severity in the process of prenatal testing decision-making seem to remain largely under-studied. The above discussion suggests that intention to undergo prenatal testing and to opt for selective abortion would be greater for early-onset and for fatal diseases.

**Socio-demographic characteristics**

Some socio-demographic variables can also play a role in testing intention and abortion willingness. The roles of gender and family status (not having any children versus currently expecting a child versus already being a parent) are discussed next.
Gender

Health psychologists have recommended investigating gender differences in reproductive decision-making, as tensions between prospective parents during pregnancy could lead to conflicts at a time when breakdown in communication would be less than desirable (Marteau, 1995). Most studies on prenatal testing, however, have focused solely on women’s views (St-Jacques et al., 2008). Therefore, evidence on gender differences in testing intention and abortion willingness is sparse.

Other studies on health and family planning have shown that, compared to men, women tend to be more interested in finding out about conditions running in their family and how these may affect their children (Catz et al., 2005). These preferences reflect two health-related, women-specific tendencies. First, compared to men, women tend to be more willing to discuss health issues and more inclined to make use of health-care services (Kaur, Stechuchak, Coffman, Allen, & Bastian, 2007; Shugarman, Bird, Schuster, & Lynn, 2007). Second, women tend to be more concerned about issues related to reproduction and to their children (Richards, 1996). Studies have shown that women do report greater worry about the health of their children than do men (Kowalcek et al., 2003; Marteau, 2002; Marteau, Kidd, et al., 1992; Roper et al., 1999; Tercyak, Johnson, Roberts, & Cruz, 2001). Together, this indicates that gender differences are likely to arise with regards to decisions about whether or not to undergo prenatal genetic testing. Generally speaking, women would be expected to report greater testing intention than men.

Gender is also likely to play a role in willingness to opt for selective termination. Studies investigating the role of gender in decisions about the outcome of an affected pregnancy have yielded inconsistent findings. These mixed results may be due to the fact that, compared to men, women tend to be more divided on the issue of selective abortion. It has been shown that men are generally accepting of termination for an affected pregnancy, whereas women vary widely in their attitudes about termination of an affected pregnancy (Catz et al., 2005). The mixed results about the role of gender in abortion willingness may also be accounted for by family status (i.e. childless, expecting or parents).
Family status

People's experiences with pregnancies have been shown to influence reproductive decision-making (Etchegary et al., 2008). It has been argued that parents may think very differently about these issues than those less experienced with pregnancy (Souka et al., 2010; Vergani et al., 2002). For instance, parents familiar with pregnancies may be less anxious about issues related to reproduction. They may be less worried about the health of their potential future children and less inclined to believe in the necessity of carrying tests assessing the health of the foetus. Studies conducted on pregnant women have revealed different trends (Fransen et al., 2010; Jaques et al., 2010; Seror & Ville, 2010). For instance, Souka and colleagues’ (2010) study of Greek pregnant women revealed that 86% of participants had requested the test with the intention to terminate their pregnancy if the test results revealed the presence of fatal foetal abnormalities. The high rate echoed those published in Australia (Jaques et al., 2010), France (Seror & Ville, 2010) and even in countries were termination is illegal, such as Argentina and Uruguay (Paolini et al., 2009). Finally, research conducted on childless individuals not expecting a child at the time of the study have reported great interest in prenatal genetic testing and intention to undergo selective abortion in the case of a positive diagnosis (Genetics and Public Policy Center, 2004; Hathaway, Burns, & Ostrer, 2009; Hewison et al., 2007). However, these responses were dependent on the other parents' perceived preferences, especially so for men. While men anticipated opting for the test and selective abortion, their answers were sometimes tainted by their anticipated inclinations to align with the preferences of their future children’s mother regarding these issues.

Altogether, the evidence discussed above suggests that gender and family status are likely to play an important role in family planning decision-making. More specifically, it could be expected that men without children would be more willing than childless women to terminate an affected pregnancy, but also more motivated to comply with their partners' perceived preferences regarding testing and less interested in prenatal testing.

Rationale, Aim and Predictions

With advances in maternal care, prenatal genetic testing is likely to occupy an increasingly important place in public health and to give parents the chance to find out about the presence
of up to thousands of genetic mutations, which could develop into conditions of various severity and ages of onset (Robey, 2008). Couples will continue to face ethical and psychological dilemmas (Erlen, 2006; Henn, 2000; Neumann et al., 2001). Health professionals can help patients reach decisions in line with their personal views. However, in order to do so, they need to understand the process of prenatal testing decision-making. Except for van den Berg et al.’s (2008) recent study on prenatal genetic testing decision-making, there seems to be little empirical evidence about the dynamics involved when such decisions are made. Study One of the present research project outlined some of the limitations of van den Berg et al’s model and proposed a theoretical model which could account for the role of several social, emotional, ethical and cognitive variables on prenatal testing decision-making. In addition, the present chapter has argued that the characteristics of the conditions and of the individuals may further impact on choices around family planning. However, the possible relationships between these attributes and testing intention or abortion willingness seem to be under-researched.

The aims of the present research project were twofold. The first aim was to test the prenatal testing decision-making model proposed in Study One (Figure 3.7). The second aim was to assess the role of condition and individual characteristics on testing intention and abortion willingness. The hypothetical scenario created for Study One was adapted to the present study and developed into four hypothetical scenarios. These scenarios described a foetal genetic mutation which could develop after birth into a condition that was early- or late-onset, and fatal or nonfatal. These conditions were chosen for the potential dilemmas they could represent for future parents. Men and women who were childless, expecting, or parents were randomly assigned to read and respond to one of the four scenarios. Two sets of predictions were proposed. The first set concerned the condition severity and age of onset. In particular, it was expected that testing intention and abortion willingness would be greater for the fatal condition than the nonfatal condition, and for the early-onset condition than the late-onset condition. The second set of predictions concerned the combined roles of gender group and family status. More specifically, childless men were hypothesised to report greater abortion willingness, but also greater subjective norms – partner and lower testing intention than childless women. The next chapter provides details on the methodology.
The present chapter describes the method used to test the model of prenatal testing proposed in Study One (Figure 3.7) and the predictions presented in Chapter 8. It consists of five sections. The first section describes the study design. The second section summarises the recruitment strategies and demographic characteristics of the participants. Section Three outlines the procedure. Section Four presents the measures used to collect data on the social, emotional, ethical and cognitive variables theorised to influence testing intention and abortion willingness. The fifth section provides the statistical strategy used to test the predictions.

Study Design

An online survey (Appendix O) was used to present the health message to participants and to collect data on the constructs of interest. This online survey consisted of five web-pages. The first web-page invited participants to indicate their day of birth (i.e. 1st to 7th, 8th to 15th, 16th to 23rd or 24th to 31st of the month). This manipulation was used to randomly direct participants to one of the four hypothetical scenarios, which started in the second web page. All four scenarios contained two parts. Part One provided a description of a foetal genetic condition which could be tested through prenatal genetic testing. This description had been designed by altering slightly the one used in Study One. The four conditions were identical in essence but their age of onset (at birth versus in adulthood) and the severity (fatal versus nonfatal) varied. These features had been manipulated because they were thought to involve different ethical and psychological dilemmas for prospective parents. So, for instance, participants born between 1st and the 7th of the month were allocated to the early-onset / fatal condition. Those born between the 8th and the 15th of the month were redirected to the early onset / nonfatal condition and so on. As per Study One, examples of such conditions were deliberately omitted in order to minimise preconceived ideas associated with any particular diseases (B. J. Henderson et al., 2006; Hewison et al., 2007; Sanderson & Michie, 2007; A. J. Wright, French, Weinman, & Marteau, 2006; A. J. Wright, Weinman, & Marteau, 2003). The study was concerned with the process of decision-making around prenatal testing and abortion willingness, not attitudes about specific disorders. Presenting participants with an
unfamiliar/unknown threat increases the likelihood of people relying on information provided in the scenario (B. J. Henderson et al., 2006). The second part of the four scenarios was the same as in Study One. It contained real information about prenatal tests currently available to New Zealanders.

The third web-page of the online survey contained a summary check. This was used to test participants’ recall and understanding. Participants were asked to tick all the correct statements. If one or more options had not been selected, the error message "Please read and tick all the relevant answers" appeared. Only when all four options were selected, would the next page of the online survey be displayed.

The fourth web-page invited participants to rate statements measuring the following scales: anticipated emotional distress, child-related worry, condition coherence, test response efficacy, negative consequences, perceived benefits from positive results, positive benefits from negative results, perceived vulnerability, normative beliefs, motivation to comply, anticipated coping efficacy, testing intention, abortion willingness, attitudes towards disabilities and religiosity. Demographic characteristics were also covered.

Given that this study used hypothetical scenarios, a careful debriefing section was included at the end of the online questionnaire, in the fifth and final web-page of the survey. Participants were provided with information about genetic testing and reliable web links to consult (i.e. Ministry of Health, Huntington’s disease Association of New Zealand and the Australian Centre for Genetics Education in Sydney).

**Recruitment and Participants**

A total of 566 participants (Age $M = 31.92$ years; $SD = 9.36$ years; ages ranged from 18 to 57 years old) were recruited from the whole of New Zealand using several techniques. First, the New Zealand Weekend Herald published a recruitment notice (Figure 9.1) on Saturday 17th and Sunday 25th of January 2009.
The New Zealand Weekend Herald was chosen over other New Zealand newspapers for its wide coverage. This best-selling newspaper is bought daily by over half a million New Zealand readers (The New Zealand Herald, 2008). The other appeal of this newspaper concerned the fact that all advertisements published in hard copies are automatically published online. This meant that the number of people reached by the newspaper could be much greater. Second, a similar recruitment notice was emailed to students and staff members of several faculties of the University of Auckland (i.e. the Business School, the Faculty of Education and the Faculty of Medical and Health Sciences) as well as the Liggins Research Institute. Third, the recruitment notice was posted on popular New Zealand chat forums, such as twinz.net.nz, treasures.co.nz, justfocus.org.nz and everybody.co.nz. Some organisations, including OhBaby.co.nz, littlies.co.nz and parentscentre.org.nz, offered to post the notice as a promotional insert on their home webpage. Fourth, many crèches, day-care centres and parents’ centres across New Zealand agreed to include the notice in their email newsletters. Fifth, several family centres agreed to display A3 posters in their waiting room and to keep flyers available for parents to take home. Finally, great care was taken to recruit men and (future) parents of multiple children. New Zealand websites targeted at male audiences, such as fatherandchild.org.nz, diyfather.com, Wellington Men Network, promisekeepers.org.nz and menshealth.co.nz, as well as multiple birth centres were
contacted. Most agreed to assist with the recruitment phase by circulating the recruitment notice amongst their members.

The recruitment notice invited anyone over the age of 18 years old and fluent in English to take part. Proficiency in English was necessary as language barriers may compromise the process of informed decision making (Fransen et al., 2009b). This recruitment method, as well as other documentation used in the present study, was reviewed and approved by The University of Auckland Human Participants Ethics Committee (reference number 2008/Q/023). Demographic characteristics of the sample are presented in Table 9.1. When participants self-identified with more than one ethnicity, the standard prioritisation of ethnicity established by Statistics New Zealand in 1996 (Frazer, 2003) was used to select the 'highest ranked' ethnicity.
Table 9.1
*Gender, Relationship Status, Number of Children, Pregnancy Status, Highest Completed Education Level, Ethnicities, and Religious Affiliations Reported by the Study Participants*

<table>
<thead>
<tr>
<th>Variables</th>
<th>n</th>
<th>Percentages</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>379</td>
<td>66.9%</td>
</tr>
<tr>
<td>Men</td>
<td>179</td>
<td>31.6%</td>
</tr>
<tr>
<td><strong>Relationship status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single, not in a serious relationship</td>
<td>84</td>
<td>15.3%</td>
</tr>
<tr>
<td>Single, in a serious relationship</td>
<td>77</td>
<td>14.0%</td>
</tr>
<tr>
<td>De facto / Married</td>
<td>380</td>
<td>69.2%</td>
</tr>
<tr>
<td>Separated / Divorced / Widowed</td>
<td>8</td>
<td>1.5%</td>
</tr>
<tr>
<td><strong>Number of children</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>255</td>
<td>45.1%</td>
</tr>
<tr>
<td>1 or more</td>
<td>311</td>
<td>54.9%</td>
</tr>
<tr>
<td><strong>Pregnancy status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not currently expecting</td>
<td>461</td>
<td>81.4%</td>
</tr>
<tr>
<td>Currently expecting</td>
<td>105</td>
<td>18.6%</td>
</tr>
<tr>
<td><strong>Highest completed university degree</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school</td>
<td>109</td>
<td>19.6%</td>
</tr>
<tr>
<td>Trade certificate</td>
<td>43</td>
<td>7.7%</td>
</tr>
<tr>
<td>Bachelor’s degree</td>
<td>204</td>
<td>36.7%</td>
</tr>
<tr>
<td>Professional degree</td>
<td>49</td>
<td>8.8%</td>
</tr>
<tr>
<td>Master’s degree</td>
<td>72</td>
<td>12.9%</td>
</tr>
<tr>
<td>PhD / doctorate</td>
<td>52</td>
<td>9.4%</td>
</tr>
<tr>
<td>Other</td>
<td>27</td>
<td>4.9%</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>New Zealand European</td>
<td>385</td>
<td>69.6%</td>
</tr>
<tr>
<td>Other European</td>
<td>65</td>
<td>11.8%</td>
</tr>
<tr>
<td>Other</td>
<td>32</td>
<td>5.8%</td>
</tr>
<tr>
<td>Maori</td>
<td>28</td>
<td>5.1%</td>
</tr>
<tr>
<td>Chinese</td>
<td>16</td>
<td>2.9%</td>
</tr>
<tr>
<td>Indian</td>
<td>8</td>
<td>1.4%</td>
</tr>
<tr>
<td>Other Asian</td>
<td>8</td>
<td>1.4%</td>
</tr>
<tr>
<td>Samoan / Other Pacific / Tongan</td>
<td>6</td>
<td>1.1%</td>
</tr>
<tr>
<td>South East Asian</td>
<td>5</td>
<td>.9%</td>
</tr>
<tr>
<td><strong>Religious affiliation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Christian</td>
<td>223</td>
<td>40.8%</td>
</tr>
<tr>
<td>None</td>
<td>208</td>
<td>38.0%</td>
</tr>
<tr>
<td>Atheist</td>
<td>42</td>
<td>7.7%</td>
</tr>
<tr>
<td>Agnostic</td>
<td>33</td>
<td>6.0%</td>
</tr>
<tr>
<td>Other</td>
<td>29</td>
<td>5.3%</td>
</tr>
<tr>
<td>Buddhist</td>
<td>8</td>
<td>1.5%</td>
</tr>
<tr>
<td>Jewish / Muslim</td>
<td>2</td>
<td>.4%</td>
</tr>
<tr>
<td>Muslim</td>
<td>2</td>
<td>.4%</td>
</tr>
</tbody>
</table>

*Note: N = 566*

1. missing values = 8; 2. missing values = 17; 3. missing values = 10; 4. missing values = 13; 5. missing values = 19
Most participants were women, in a committed romantic relationship, had at least one child and were not expecting a baby at the time of the study (Table 9.1). Most participants in the present study had completed a university degree; although this is not representative of the New Zealand population (Statistics New Zealand, 2006b), this bias may be due to participants having been recruited through The University of Auckland and proactive community groups. Finally, the majority of participants were of New Zealand European ethnicity and reported affiliation with Christianity or with no organised religion. These data are characteristic of the New Zealand population (Statistics New Zealand, 2006a).

**Procedure**

The email address prenatal@auckland.ac.nz had been set up to automatically send a message back to the recipients. The automatic reply (Appendix R) contained the same information as in Study One, namely a description of the study and two attachments: the Participant Information Sheet (Appendix H) and the Informed Consent (Appendix I). Special mentions were included about confidentiality and voluntary involvement. Potential participants were clearly informed that they would not be required to provide any information that could later be used to identify them. They were also informed of their right to withdraw at any stage from the study. The main difference between the automated reply used in Study One and the one used in the current study was the web link included in the email. It directed participants to another password-protected website. The completion time ranged from 11 to 67 minutes ($M = 22.06$ minutes, $SD = 10.2$ minutes). Each participant completed the study only once. No one received a financial compensation or other form of reward for their contribution.

**Measures**

The online questionnaire consisted of 60 items assessing the social, emotional, ethical and cognitive variables hypothesised to impact on intention to undergo prenatal testing to find out about the health of the unborn child and on willingness to terminate an affected pregnancy. The internal consistency of these scales was tested in Study One by subjecting data collected from 143 volunteers to a series of principal component analyses (Chapter 5). These measures are presented below. Mean scores were generated after having reverse-coded negatively
worded items. High scores represented greater levels of the constructs. Unless otherwise specified, the items were scored on a Likert-type scale ranging from strongly disagree (-3) to strongly agree (+3). The reported alphas were calculated using the present study data.

**Testing intention**

The intention to undergo invasive prenatal testing to find out about the presence of a genetic mutation was assessed with a series of six items (e.g. *I would request the test*; Appendix L). This scale had high internal consistency (Cronbach's $\alpha = .91$).

**Abortion willingness**

The willingness to undergo selective abortion was measured with six items (e.g. *I would be opposed to giving birth to a child with this condition*; Appendix L). The scale was internally reliable; $\alpha = .87$.

**Social variables**

*Subjective norms* were constructed by multiplying the mean of motivation to comply (Appendix N) with normative beliefs (Appendix N). *Motivation to comply* ($\alpha = .82$) was measured by the single item "*You would undergo this test if it was important to: ..."* followed by four referents: your partner / spouse, your doctor, your family / whānau and your friends. *Normative Beliefs* ($\alpha = .84$) also consisted of a single item: *How much would each of the following people want you to undergo prenatal testing?*. This question was followed by the same four referents. This scale was measured on a 7-point scale ranging from 0 (*would not want at all*) to 6 (*would want very much*). Means on the subjective norms scales could range from -18 (-3 x -6) to 18 (3 x 6).

**Condition-related variables**

*Anticipated coping efficacy* (Appendix K) contained five items (e.g. *I don’t think I could manage a child with this condition*). This scale had high internal consistency; $\alpha = .91$.

*Negative Consequences* (Appendix K) of the condition under consideration on the patient's well-being was made of six items (e.g. *This condition is serious*) scored ranged from -2 (strongly disagree) to +2 (strongly agree); $\alpha = .87$. 
Anticipated emotional distress (Appendix K) consisted of five items (e.g. I am not afraid to think about having a child with this condition); $\alpha = .84$.

Child-related worry (Appendix K) comprised four items (e.g. I am concerned my child may be born with this condition); $\alpha = .83$.

Perceived vulnerability (Appendix K) assessed participants' assessment of being 'at risk' of carrying a child with a genetic disability. The scale was made up of three items (e.g. I/we would not be 'at-risk' for having a child with this condition); $\alpha = .71$.

Ethics-related variables
Religiosity (Appendix L) comprised three items (e.g. Only God / the Divine Force / the Holy Creator should decide which child gets to live); $\alpha = .89$.

Attitudes towards disabilities (Appendix L) contained four statements (e.g. Disability is a normal part of life; $\alpha = .85$).

Test-related variables
Condition coherence (Appendix M) was assessed by five items (e.g. This condition is a mystery to me; $\alpha = .89$), rated on a 5-point Likert scale from -2 (strongly disagree) to +2 (strongly agree).

Perceived benefits from negative results (Appendix M) was made of four items (e.g. Knowing that my unborn child DID NOT have the genetic mutation would increase my confidence regarding the progress/ outcomes of the pregnancy). Items were scored on a Likert-type scale ranging from -2 (strongly disagree) to +2 (strongly agree); $\alpha = .85$

Perceived benefits from positive results (Appendix M) consisted of four items (e.g. Knowing that my unborn child HAD this genetic condition would help me work on making sure that my child's needs after birth would be met) also scored from -2 (strongly disagree) to +2 (strongly agree); $\alpha = .87$

Test response efficacy (Appendix M) was measured by three items, such as "Undergoing this prenatal test would clearly indicate the presence of this condition". High mean scores on this
reliable scale ($\alpha = .72$) indicated that prenatal testing was perceived as being an accurate and reliable way to find out about foetal genetic anomalies.

**Socio-demographic characteristics**

Participants were asked to self-report their age (in years), gender, relationship status (1 = *single, not in a relationship* to 5 = *widowed*), number of children (open-ended question) and whether they were currently expecting a child (0 = *no*, 1 = *yes*). In addition, participants were asked to indicate their highest completed education levels (1 = *high school* to 7 = *PhD / Doctorate*), ethnicity (1 = *New Zealand European* to 15 = *other*; multiple answers accepted) and religious affiliation (1 = *Christian* to 8 = *other*) (Appendix E).

**Summary check**

The summary check (Appendix O) contained four statements, namely that the condition 1) was detectable during pregnancy; 2) was 0.5% likely to affect every pregnancy; 3) would be present from birth (or develop between 30 and 50 years of age), and; 4) would be fatal (or nonfatal) to the individual born with the mutation. To ensure that participants attended to these statements, they had to read and check each statement before they could proceed with the questionnaire.

**Statistical Strategy**

A 2 (birth-onset versus adult-onset) × 2 (fatal versus nonfatal) × 2 (men versus women) × 3 (childless versus expecting versus parents) between subjects, quasi-experimental design was used as the analytical strategy to test the hypothesised role of onset age, severity, gender and family status on testing intention and abortion willingness (Chapter 8). Condition severity and age of onset were the two manipulated independent variables. Gender and family status were the group variables. The three 'family status' groups were created using data collected on pregnancy status and number of children. The frequencies in each group are presented next (Table 9.2).
Table 9.2
Number of Participants per Group

<table>
<thead>
<tr>
<th>Family status</th>
<th>Gender</th>
<th>NONFATAL Early-onset</th>
<th>NONFATAL Late-onset</th>
<th>FATAL Early-onset</th>
<th>FATAL Late-onset</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHILDERLESS</td>
<td>Men</td>
<td>18</td>
<td>21</td>
<td>16</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>Women</td>
<td>42</td>
<td>45</td>
<td>45</td>
<td>50</td>
</tr>
<tr>
<td>EXPECTING</td>
<td>Men</td>
<td>12</td>
<td>13</td>
<td>12</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>Women</td>
<td>15</td>
<td>14</td>
<td>14</td>
<td>12</td>
</tr>
<tr>
<td>PARENTS</td>
<td>Men</td>
<td>17</td>
<td>12</td>
<td>12</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>Women</td>
<td>37</td>
<td>33</td>
<td>38</td>
<td>34</td>
</tr>
</tbody>
</table>

1: missing values = 8

The 'childless' group was comprised of 255 participants. The 'expecting' group consisted of 105 participants and the 'parents' group was made up of 206 participants (Table 9.2). Data were entered into PASW Statistics v.17. When significant differences were found among family status, post-hoc comparisons using Tukey’s tests were carried out. This test is preferable when running pair-wise comparisons in terms of guarding against Type I errors (Coolican, 2005). During these post-hoc analyses, mean scores were considered significantly different if $p \leq .01$.

The model of prenatal testing decision-making (Figure 3.7) was tested using path analysis. Although this technique cannot establish cause-and-effect relationships, it can be used to determine the extent to which the hypothesised links are empirically supported (Sprinthall, 2007). Path analysis, as outlined in Cramer (2003) and Bryman and Cramer (2001), consists of a series of successive multiple regressions. The variable of interest (e.g., child-related worry) is momentarily treated as the dependent variable and is regressed onto all the hypothesised predictors (i.e. perceived vulnerability). That momentary dependent variable may later be treated as an independent variable if it had been hypothesised to predict other variables (i.e. anticipated emotional distress). The results of all the successive multiple regression analyses are combined to give an overall assessment of the proposed model.

To evaluate the hypothesised moderating relationships between the study variables, separate hierarchical regression analyses were conducted, as detailed by West, Aiken and Krull.
(1996). The theorised predictors of the momentary dependent variable were entered in step 2. Step 3 contained the study variables hypothesised to be more distal predictors of testing intention than the momentary dependent variable. When ANOVAs revealed group differences across gender (1 = male; 2 = female), family status (1 = childless; 2 = expecting; 3 = parents), severity (1 = nonfatal; 2 = fatal) and/or onset (1 = early; 2 = late), these group variables were treated as covariates. For the purpose of the analyses, two 'family status' dummy variables were created: DummyChildlessExpect (-1 = childless, 1 = expecting and 0 = parents) and DummyChildlessParents (-1 = childless, 0 = expecting and 1 = parents). These new variables were also used to compute interaction variables (e.g. gender x DummyChildlessExpect terms on abortion willingness). The level of significance was set at $p \leq .01$.

In summary, the procedure described in the present chapter was used to collect data in order to test the predictions made in Chapter Eight. The next chapter provides the results of these analyses.
CHAPTER 10

Study 2 – Results

Overview

The previous chapter detailed how 566 New Zealand men and women of varying family status (i.e. childless, expecting and parents) were recruited and randomly allocated to four groups with scenarios describing prenatal testing for a condition which varied in terms of two variables: severity (fatal or nonfatal) and age of onset (early or later in life). These participants were then invited to rate a series of items assessing the social, condition-related, ethical and test-related variables theorised to predict prenatal testing intention and/or willingness to undergo selective abortion influence (Chapter 3). Participants were also required to complete measures of testing intention and abortion willingness.

The present chapter provided testing of: 1) the model of prenatal testing decision-making proposed in Study One (Figure 3.7), and; 2) the hypotheses for differences associated with gender, family status, condition onset and condition severity in testing intention and abortion willingness (Chapter 8). Results are presented in six sections. The first section consists of results from preliminary analyses addressing the issue of missing values, statistical power and assumptions testing. The second section summarises descriptive statistics for the social (i.e., subjective norms for partner/spouse, doctors, family and friends), condition-related (i.e., anticipated coping efficacy, negative consequences, anticipated emotional distress, child-related worry and perceived vulnerability), ethical (i.e., religiosity and attitudes towards disabilities) and test-related variables (i.e., condition coherence, benefits negative results, benefits positive results and test response efficacy) variables hypothesised to influence prenatal testing intention and/or abortion willingness. The third section presents the findings from analyses of variance conducted on testing intention, abortion willingness, subjective norms – partner (and the remaining study variables), to test the hypotheses for the role of gender, family status, condition onset and condition severity in testing intention and abortion willingness (Chapter 8). In the fourth section, the prenatal testing decision-making model (Figure 3.7) is tested through a series of path analyses and mediational analyses. Section Five
presents the results from analyses conducted to assess the overall effects of variables shown to be directly and indirectly related to testing intention and abortion willingness. Section Six summarises the key findings. Unless otherwise specified, results of inferential tests were considered statistically significant at \( p < .01 \) (two-tailed).

**Preliminary Analyses**

Prior to running parametric analyses, missing values were dealt with, statistical power evaluated and assumptions for analyses of variance and path analyses tested.

**Missing values**

Not all respondents answered every question. Approximately 4% of the data were missing. In most cases, these missing values were dealt with using the 'mean imputation' method, which consists of replacing the missing values by the mean score of the particular scale (Byrne, 2001). When there were two or more missing values on items measuring the same construct, the whole case was deleted for the analyses.

**Statistical power for analyses of variance and path analysis**

Statistical power analyses were conducted for the analyses of variance (ANOVA) and the path analysis. The measure of effect size commonly used for ANOVAs is partial Eta Squared \( (\eta_p^2) \). General guidelines suggest that \( \eta_p^2 = .01 \) is a small effect, \( \eta_p^2 = .06 \) is a medium effect and \( \eta_p^2 = .14 \) is a large effect (Cohen, 1988). In the present study, a medium \( \eta_p^2 \) was considered acceptable as this would provide sufficient power to detect important effects. The general power analysis program G*Power 3.1.0 (Faul, Erdfelder, Buchner, & Lang, 2009) provided the following guidelines: For ANOVA (fixed effects, special, main effects and interactions), with \( \eta_p^2 = 0.06 \), \( \alpha = 0.01 \), total sample size \( N = 566 \), numerator \( df = 3 \), numbers of groups = 4, power was = 0.99 and effect size \( f = 0.25 \).

Adequate power for path analyses is one that can detect all significant paths in the model. Therefore, power analysis should be calculated for the regression equation that contains the most variables (Munro, 2005). In the present study, the regression equation that contained the most variables was the one for testing intention:
\[ TI = a + b \times SBP + c \times SBF + d \times Rel + e \times AW + f \times BNR + g \times PV \]

Where:
- \( TI \) = testing intention
- \( SBP \) = subjective norms – partner
- \( SBF \) = subjective norms – family
- \( Rel \) = religiosity
- \( AW \) = abortion willingness
- \( BNR \) = benefits negative results
- \( PV \) = perceived vulnerability

The general power analysis program G*Power 3.1.0 (Faul et al., 2009) provided the following guidelines: For linear multiple regression (Fixed model, \( R^2 \) increase) with \( \alpha = 0.01 \), total sample size \( N = 566 \), number of tested predictors = 6, total of predictors = 10 (i.e. including 4 covariates), power was = 0.99 and effect size \( f^2 = 0.15 \); critical \( F(6,545) = 2.83 \).

**Testing assumptions for ANOVAs and path analysis**

Assumptions were tested for ANOVAs and path analysis. In order to assess the suitability of the variables for parametric analyses, assumptions of homogeneity of variances and normality of distribution were tested. The assumptions were violated in places. Transformations were used to address the distributional issues in preliminary analyses. These yielded the same patterns of findings to those obtained using the untransformed values, so the latter were reported.

Path analysis is subject to statistical assumptions of two types: those relevant to general regression analyses and those specific to path analysis. Preliminary analyses revealed no violation of the assumptions of independence, normality, linearity and homoscedasticity. The path-specific assumptions of measurement level, low multicollinearity and recursivity were also met. In summary, it was concluded that the data was well suited for parametric statistical analyses.
Descriptive Statistics of the Study Variables

Group differences in personal characteristics as well as descriptive and inferential statistics for all of the study variables were examined. Analyses of variance were used for continuous variables (e.g., age) and Pearson \( \chi^2 \) analyses for nominal variables (e.g., gender).

Differences in personal characteristics

Analyses showed that participants from the four conditions (early-onset/ fatal, early-onset/ nonfatal, late-onset/ fatal and late-onset/ nonfatal) did not differ in age \( (F(3,531) = 2.52, \ ns) \), gender \( (\chi^2(3) = 5.46, \ ns) \), relationship status \( (\chi^2(12) = 12.08, \ ns) \), number of children \( (F(3,565) = 2.34, \ ns) \) or pregnancy status \( (\chi^2(15) = 14.87, \ ns) \). Participants from the four groups did not differ either on their highest completed university degree \( (\chi^2(18) = 22.04, \ ns) \), ethnicity \( (\chi^2(30) = 30.07, \ ns) \) or religious affiliation \( (\chi^2(21) = 29.50, \ ns) \). These analyses suggest that the randomisation process was successful.

Descriptive statistics of the study variables

The mean scores \( (M) \), standard deviations \( (SD) \) and correlation coefficients for all the study variables are presented next (Table 10.1).
Table 10.1

*Overall Mean Scores (M), Standard Deviations (SD) and Correlation Coefficients of the Study Variables*

<table>
<thead>
<tr>
<th>Variables</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
<th>13</th>
<th>14</th>
<th>15</th>
<th>16</th>
<th>17</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean (M)</td>
<td>0.00</td>
<td>-0.41</td>
<td>7.27</td>
<td>2.20</td>
<td>3.21</td>
<td>-1.25</td>
<td>0.95</td>
<td>0.87</td>
<td>0.88</td>
<td>0.12</td>
<td>-1.16</td>
<td>-1.08</td>
<td>1.37</td>
<td>-0.32</td>
<td>0.77</td>
<td>0.97</td>
<td>1.37</td>
</tr>
<tr>
<td>SD</td>
<td>1.55</td>
<td>1.59</td>
<td>7.29</td>
<td>6.68</td>
<td>7.77</td>
<td>5.84</td>
<td>1.45</td>
<td>0.85</td>
<td>1.45</td>
<td>1.39</td>
<td>1.15</td>
<td>1.93</td>
<td>1.25</td>
<td>0.96</td>
<td>0.88</td>
<td>0.81</td>
<td>1.20</td>
</tr>
</tbody>
</table>

1. Testing intention
2. Abortion willingness
3. Subjective norms – partner
4. Subjective norms – doctors
5. Subjective norms – family
6. Subjective norms – friends
7. Anticipated coping efficacy
8. Negative consequences
9. Anticip. emotional distress
10. Child-related worry
11. Perceived vulnerability
12. Religiosity
13. Attitudes twds disabilities
14. Condition coherence
15. Benefits negative results
16. Benefits positive results
17. Test response efficacy

**Note:** anticip = anticipated; twds = towards

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*a*: mean scores range from -18 (3 x -6) to 18 (3 x 6); **b**: single-item scales; ***: p < 0.01; *: p < 0.05
Mean scores indicated that, overall, participants were divided in their intention to undergo prenatal testing to find out about the presence of a foetal condition (Table 10.1). Over 48% of participants reported mild to strong opposition to prenatal testing, whereas 51.6% of them reported mild to strong interest in the procedure. With regards to the social, condition-related, ethical and test-related variables theorised to predict directly testing intention (i.e., abortion willingness, subjective norms – partners, subjective norms – family, perceived vulnerability, religiosity and benefits from negative results), on average, participants reported a slight opposition towards selective abortion, great willingness to comply with their partners'/spouses' and (to a lesser extent) with their family's perceived preference regarding the procedure. Participants also reported low beliefs of being 'at risk' of carrying a child with the disability described in the opening text, low religious commitment and beliefs that receiving negative test results would be somewhat beneficial.

Testing intention was significantly and positively correlated with abortion willingness, subjective norms – partner, subjective norms – family, perceived vulnerability and benefits from receiving negative results. Participants who were less willing to terminate an affected pregnancy or who thought they were at low risk of carrying a child with the disability under consideration reported lower intention to undergo prenatal testing. Participants who were willing to comply with the perceived preferences of their partners/spouses and family, or who viewed negative test results as somewhat beneficial, reported greater intention to take the test. Testing intention was also negatively correlated with religiosity. Participants with little religious affiliation reported greater intention to undergo prenatal testing.

With regards to variables theorised to predict abortion willingness (i.e., anticipated coping efficacy, negative consequences, anticipated emotional distress, religiosity and attitudes towards disabilities), Table 10.1 shows that, on average, participants perceived they would be somewhat able to cope with raising a child with the disability under investigation, believed that disability would have negative consequences on the child's quality of life, anticipated receiving positive test results would be moderately emotionally distressful and held positive attitudes towards people born with disabilities. Furthermore, abortion willingness was negatively correlated with anticipated coping efficacy, religiosity and attitudes towards disabilities. Participants who believed they would be able to cope with raising a child with special needs, who reported greater religious affiliation or who held more positive attitudes
towards people with disabilities reported lower willingness to undergo selective abortion. Abortion willingness was also significantly and positively correlated with negative consequences and anticipated emotional distress. Participants who believed the condition described in the opening text would not impact negatively on their child's life or who did not anticipate receiving positive diagnosis as being a distressful event reported lower willingness to terminate an affected pregnancy.

With regards to more distal variables expected to be associated with test intentions and abortion willingness (i.e., child-related worry, condition coherence, test benefits from positive results and test response efficacy), Table 10.1 shows that, on average, participants would worry slightly about the health of their unborn child, did not have a coherent understanding of the genetic condition described in the opening text, believed receiving positive test results would be mildly beneficial and perceived prenatal testing as a reliable way to detect foetal conditions. Furthermore, child-related worry was positively correlated with anticipated emotional distress and perceived vulnerability. That is, participants with lower levels of worry about the health of their unborn child had higher perceptions that receiving positive results would be emotionally distressful and believed they would be ‘at risk’ of carrying a child with the disability under consideration. Condition coherence and test response efficacy were negatively correlated, suggesting that lack of a coherent understanding of the condition was associated with higher beliefs that prenatal testing was an accurate way to detect foetal abnormalities. In addition, test response efficacy and benefits from negative results were positively correlated. Participants with higher beliefs that prenatal testing would accurately detect foetal anomalies had stronger perceptions that receiving negative test results would be beneficial. Finally, negative consequences were positively correlated with benefits from positive results. Higher beliefs that the condition would impact negatively on the child's quality of life were associated with higher beliefs that positive diagnoses as beneficial.

**Group Comparisons between Family Status, Gender and Condition Onset and Severity on Prenatal Testing Variables**

This section reports results from four-way (Severity x Onset Age x Gender x Family Status) ANOVAs for testing intention, abortion willingness, subjective norms – partners. Similar
analyses were conducted for the other test-specific variables, abortion-specific variables and more distal predictors of testing intention.

**ANOVA for testing intention**

ANOVA were conducted to assess differences in testing intention across Onset Age, Severity, Gender and Family Status. Mean scores (M) and standard deviation (SD) are reported below (Table 10.2).

<table>
<thead>
<tr>
<th>Family status</th>
<th>Gender</th>
<th>Severity</th>
<th>FATAL</th>
<th>NONFATAL</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Onset</td>
<td>Early</td>
<td>Late</td>
<td>Early</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Early</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Late</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CHILDLESS</td>
<td>Men</td>
<td>0.90 1.36</td>
<td>0.34 1.67</td>
<td>0.53 1.69</td>
<td>0.38 1.61</td>
</tr>
<tr>
<td></td>
<td>Women</td>
<td>-0.15 1.39</td>
<td>0.21 1.42</td>
<td>-0.16 1.50</td>
<td>0.13 1.43</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>0.11 1.44</td>
<td>0.24 1.48</td>
<td>0.11 1.60</td>
<td>0.23 1.50</td>
</tr>
<tr>
<td>EXPECTING</td>
<td>Men</td>
<td>0.42 1.49</td>
<td>0.83 1.39</td>
<td>0.31 1.04</td>
<td>0.87 1.73</td>
</tr>
<tr>
<td></td>
<td>Women</td>
<td>-0.46 1.45</td>
<td>0.09 1.65</td>
<td>-0.27 1.33</td>
<td>0.46 1.21</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>-0.25 1.48</td>
<td>0.06 1.62</td>
<td>-0.15 1.28</td>
<td>0.54 1.30</td>
</tr>
<tr>
<td>PARENTS</td>
<td>Men</td>
<td>-0.16 1.48</td>
<td>1.03 1.55</td>
<td>-0.56 1.50</td>
<td>0.32 1.39</td>
</tr>
<tr>
<td></td>
<td>Women</td>
<td>-0.16 1.75</td>
<td>0.24 1.61</td>
<td>1.05 1.58</td>
<td>0.38 1.67</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>-0.16 1.65</td>
<td>0.44 1.62</td>
<td>0.48 1.72</td>
<td>0.22 1.63</td>
</tr>
<tr>
<td>TOTAL</td>
<td>Men</td>
<td>0.35 1.48</td>
<td>0.20 1.72</td>
<td>0.08 1.59</td>
<td>0.22 1.58</td>
</tr>
<tr>
<td></td>
<td>Women</td>
<td>-0.21 1.53</td>
<td>0.00 1.54</td>
<td>0.23 1.59</td>
<td>0.19 1.50</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>-0.06 1.53</td>
<td>0.05 1.57</td>
<td>0.18 1.58</td>
<td>0.07 1.53</td>
</tr>
</tbody>
</table>

Contrary to hypotheses, Onset Age and Severity did not influence testing intention. However, a significant Gender × Family Status interaction effect was found; $F(2,531) = 4.68, p < .001$ (Figure 10.1).
Post-hoc comparisons revealed that, contrary to expectations, childless men ($M = .51$, $SD = 1.58$), not childless women ($M = .02$, $SD = 1.43$), reported greater testing intention. Post hoc analyses revealed similar trends in the expecting group: Men ($M = .05$, $SD = 1.42$) reported greater testing intention than did women ($M = -.30$, $SD = 1.42$). No other significant main or interaction effects were observed.

**ANOVAs for abortion willingness**

ANOVAs were carried out to determine whether abortion willingness varied according the condition's Onset Age, Severity, the participants' Gender or their Family Status. Mean scores ($M$) and standard deviation ($SD$) are reported below (Table 10.3).
Table 10.3
Means (M) and Standard Deviations (SD) for Abortion Willingness across Onset Age, Severity, Gender and Family Status

<table>
<thead>
<tr>
<th>Severity Onset</th>
<th>FATAL</th>
<th></th>
<th></th>
<th>NONFATAL</th>
<th></th>
<th></th>
<th>TOTAL</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Early</td>
<td>Late</td>
<td>Early</td>
<td>Late</td>
<td>Early</td>
<td>Late</td>
<td>Early</td>
<td>Late</td>
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</tr>
<tr>
<td>Family status</td>
<td>Gender</td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>CHILDLESS</td>
<td>Men</td>
<td>0.93</td>
<td>1.75</td>
<td>-0.32</td>
<td>1.65</td>
<td>-0.05</td>
<td>2.12</td>
<td>-0.12</td>
<td>1.66</td>
</tr>
<tr>
<td></td>
<td>Women</td>
<td>-0.14</td>
<td>1.50</td>
<td>-0.13</td>
<td>1.31</td>
<td>-0.92</td>
<td>1.37</td>
<td>-0.76</td>
<td>1.52</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>0.12</td>
<td>1.62</td>
<td>-0.18</td>
<td>1.39</td>
<td>-0.58</td>
<td>1.73</td>
<td>-0.50</td>
<td>1.59</td>
</tr>
<tr>
<td>EXPECTING</td>
<td>Men</td>
<td>0.70</td>
<td>0.62</td>
<td>0.60</td>
<td>0.59</td>
<td>-0.13</td>
<td>1.70</td>
<td>-1.52</td>
<td>0.66</td>
</tr>
<tr>
<td></td>
<td>Women</td>
<td>0.01</td>
<td>1.38</td>
<td>-0.48</td>
<td>1.60</td>
<td>-0.95</td>
<td>1.16</td>
<td>-0.61</td>
<td>1.21</td>
</tr>
<tr>
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<td>Total</td>
<td>0.18</td>
<td>1.26</td>
<td>-0.44</td>
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<td>-0.77</td>
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</tr>
<tr>
<td>PARENTS</td>
<td>Men</td>
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<td>-1.65</td>
<td>1.18</td>
<td>-0.39</td>
<td>1.91</td>
<td>-0.82</td>
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<tr>
<td></td>
<td>Women</td>
<td>0.03</td>
<td>1.55</td>
<td>-0.78</td>
<td>1.67</td>
<td>-0.26</td>
<td>1.64</td>
<td>-1.03</td>
<td>1.63</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>-0.03</td>
<td>1.58</td>
<td>-1.00</td>
<td>1.60</td>
<td>-0.31</td>
<td>1.72</td>
<td>-0.98</td>
<td>1.57</td>
</tr>
<tr>
<td>TOTAL</td>
<td>Men</td>
<td>0.42</td>
<td>1.64</td>
<td>-0.83</td>
<td>1.59</td>
<td>-0.19</td>
<td>1.95</td>
<td>-0.47</td>
<td>1.56</td>
</tr>
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<td>Women</td>
<td>-0.05</td>
<td>1.48</td>
<td>-0.42</td>
<td>1.52</td>
<td>-0.70</td>
<td>1.44</td>
<td>-0.84</td>
<td>1.50</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>0.08</td>
<td>1.54</td>
<td>-0.51</td>
<td>1.54</td>
<td>-0.53</td>
<td>1.64</td>
<td>-0.73</td>
<td>1.53</td>
</tr>
</tbody>
</table>

Analyses revealed a main effect of Onset Age for abortion willingness; $F(1,531) = 6.627, p < .01$ (Figure 10.2).

![Figure 10.2 Onset Age main effect on abortion willingness](image-url)
Although selective abortion was not a favoured option overall, participants were less opposed to terminating an affected pregnancy when the condition was early-onset ($M = -0.21, SD = 1.61$) than when it was late-onset ($M = -0.61, SD = 1.53$; Figure 10.2). ANOVAs also revealed a Severity main effect for abortion willingness; $F(1,531) = 6.924, p < .01$ (Figure 10.3).

![Severity main effect on abortion willingness](image)

*Figure 10.3 Severity main effect on abortion willingness*

As expected, willingness to opt for selective abortion was greater for the fatal genetic condition ($M = -0.22, SD = 1.56$) than for the nonfatal condition ($M = -0.63, SD = 1.58$; Figure 10.3).

Analyses also revealed a Gender $\times$ Family Status interaction effect on abortion willingness; $F(2,531) = 3.363, p < .001$ (Figure 10.4).
Consistent with predictions, childless men ($M = .05, SD = 1.82$) reported greater willingness to undergo selective abortion than did childless women ($M = -.42, SD = 1.45$; Figure 10.4). No other main or interaction effect was observed.

**ANOVAs for subjective norms – partner**

Results from the ANOVAs one willingness to comply with partners' perceived preferences regarding prenatal testing are reported below (Table 10.4).
Table 10.4
*Means (M) and Standard Deviations (SD) for Subjective Norms – Partner across Family Status, Gender, and the Condition's Severity and Onset*

<table>
<thead>
<tr>
<th>Severity Onset</th>
<th>Family Status</th>
<th>Gender</th>
<th>M</th>
<th>SD</th>
<th>M</th>
<th>SD</th>
<th>M</th>
<th>SD</th>
<th>M</th>
<th>SD</th>
<th>M</th>
<th>SD</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Early</td>
<td></td>
<td>Late</td>
<td></td>
<td>Early</td>
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<td></td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>FATAL</td>
<td>CHILDLESS</td>
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<td>7.74</td>
<td>6.30</td>
<td>9.75</td>
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<td>5.74</td>
<td>10.60</td>
<td>6.22</td>
<td>7.74</td>
<td>5.91</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Women</td>
<td>6.37</td>
<td>8.08</td>
<td>7.93</td>
<td>7.35</td>
<td>6.44</td>
<td>7.01</td>
<td>6.95</td>
<td>8.06</td>
<td>6.40</td>
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<td>7.88</td>
<td>7.06</td>
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<td>6.74</td>
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<td></td>
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</tr>
<tr>
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<td>Men</td>
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<tr>
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<td>7.80</td>
<td>6.76</td>
<td>6.09</td>
<td>6.83</td>
<td>7.94</td>
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<tr>
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<td>6.30</td>
<td>8.02</td>
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<td>6.32</td>
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<td>7.10</td>
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<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
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<td>Men</td>
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<td>6.19</td>
<td>3.15</td>
<td>6.26</td>
<td>5.31</td>
<td>7.19</td>
<td>7.64</td>
<td>5.33</td>
<td>5.39</td>
<td>6.59</td>
<td>5.21</td>
<td>6.16</td>
</tr>
<tr>
<td></td>
<td>Women</td>
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<td>7.45</td>
<td>8.08</td>
<td>10.79</td>
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<td>6.03</td>
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<td>9.09</td>
<td>7.62</td>
<td>6.73</td>
<td>8.25</td>
</tr>
<tr>
<td></td>
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<td>7.68</td>
<td>6.35</td>
<td>7.83</td>
<td>8.84</td>
<td>7.16</td>
<td>6.38</td>
<td>7.85</td>
<td>7.87</td>
<td>7.47</td>
<td>6.37</td>
<td>7.80</td>
</tr>
<tr>
<td></td>
<td>TOTAL</td>
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<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
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<td>Men</td>
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<td>7.04</td>
<td>5.76</td>
<td>6.49</td>
<td>7.76</td>
<td>6.54</td>
<td>7.03</td>
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<td>6.48</td>
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<td></td>
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<td>7.43</td>
<td>7.73</td>
<td>8.04</td>
<td>6.93</td>
<td>6.67</td>
<td>8.10</td>
<td>7.45</td>
<td>7.37</td>
<td>7.09</td>
<td>7.89</td>
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<tr>
<td></td>
<td>TOTAL</td>
<td></td>
<td>7.38</td>
<td>7.54</td>
<td>7.07</td>
<td>7.49</td>
<td>7.94</td>
<td>6.78</td>
<td>6.78</td>
<td>7.44</td>
<td>7.64</td>
<td>7.19</td>
<td>6.93</td>
<td>7.45</td>
</tr>
</tbody>
</table>

A Family Status × Gender interaction effect was found on subjective norms – partner; $F(2,531) = 5.31, p < .001$ (Figure 10.5).
Although it seemed important to all participants to comply with the other parent’s perceived preferences regarding prenatal testing, post hoc comparisons revealed that, as expected, childless men reported greater subjective norms – partner ($M = 9.01, SD = 6.17$) than did childless women ($M = 7.00, SD = 7.62$). In addition, mothers reported greater subjective norms – partner ($M = 7.83, SD = 8.02$) than did fathers ($M = 5.32, SD = 6.36$).

**ANOVAs for test-specific variables**

Similar analyses were carried out on subjective norms – family, religiosity, perceived benefits from negative results perceived vulnerability and abortion willingness.

**Subjective norms – family**

Results from the ANOVA on subjective norms – family are displayed below (Table 10.5).

| Family status | Gender | Severity | Onset | FATAL | | NONFATAL | | TOTAL | | |
| | | | Early | Late | | Early | Late | Early | Late |
| | | | M | SD | M | SD | M | SD | M | SD |
| CHILDLESS | Men | 4.67 | 7.46 | 3.34 | 6.89 | 1.80 | 6.88 | 3.66 | 6.25 | 3.03 | 7.17 | 3.53 | 6.44 |
| | Women | 2.00 | 6.87 | 4.27 | 6.42 | 2.76 | 7.10 | 2.85 | 7.08 | 2.31 | 6.93 | 3.67 | 6.71 |
| | Total | 2.66 | 7.05 | 4.04 | 6.51 | 2.39 | 6.96 | 3.18 | 6.72 | 2.53 | 6.98 | 3.63 | 6.60 |
| EXPECTING | Men | 1.17 | 8.11 | 4.00 | 7.01 | 1.17 | 3.97 | 2.20 | 5.50 | 0.00 | 6.21 | 2.50 | 4.97 |
| | Women | 1.85 | 4.86 | 2.82 | 7.37 | 0.00 | 4.22 | 1.95 | 7.14 | 0.86 | 4.57 | 2.44 | 7.20 |
| | Total | 1.13 | 5.76 | 2.87 | 7.23 | 0.25 | 4.12 | 2.00 | 6.74 | 0.66 | 4.93 | 2.45 | 6.94 |
| PARENTS | Men | 0.94 | 4.13 | 1.00 | 3.92 | 1.95 | 5.37 | 0.64 | 7.02 | 0.46 | 4.92 | -0.25 | 5.49 |
| | Women | 2.08 | 7.92 | 2.87 | 7.15 | 0.87 | 8.83 | 1.72 | 6.12 | 1.56 | 8.28 | 2.29 | 6.63 |
| | Total | 1.15 | 7.07 | 1.88 | 6.66 | 1.25 | 7.73 | 1.48 | 6.27 | 1.19 | 7.33 | 1.68 | 6.44 |
| TOTAL | Men | 1.24 | 6.72 | 1.60 | 6.06 | 1.77 | 5.87 | 2.70 | 6.36 | 1.52 | 6.26 | 2.22 | 6.22 |
| | Women | 2.00 | 6.91 | 3.49 | 6.86 | 1.37 | 7.18 | 2.22 | 6.68 | 1.72 | 7.02 | 2.91 | 6.79 |
| | Total | 1.80 | 6.84 | 3.09 | 6.72 | 1.50 | 6.75 | 2.36 | 6.56 | 1.66 | 6.79 | 2.73 | 6.64 |

A Family Status main effect was found on subjective norms – family; $F(2,531) = 4.73, p < .001$ (Figure 10.6).
As can be seen in Figure 10.6, complying with the family perceived expectations regarding undergoing prenatal testing was not important to participants, but it was even less so for the 'expecting' ($M = 1.54, SD = 6.05$) and the 'parents' participants ($M = 1.44, SD = 6.89$) than for the 'childless' group ($M = 3.13, SD = 6.78$).

**Religiosity**

Results from the ANOVA revealed no group differences on religiosity. Overall, participants reported low religious commitment ($M = -1.08, SD = 1.93$).

**Perceived benefits from negative test results**

Results from the ANOVA on perceived benefits from negative test results are reported below (Table 10.6).
Table 10.6
Means (M) and Standard Deviations (SD) for Perceived Benefits from Negative Test Results across Family Status, Gender and the Condition's Severity and Onset

<table>
<thead>
<tr>
<th>Family status</th>
<th>Gender</th>
<th>Severity</th>
<th>Onset</th>
<th>M</th>
<th>SD</th>
<th>M</th>
<th>SD</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>FATAL</td>
<td>Early</td>
<td>0.75</td>
<td>0.89</td>
<td>0.60</td>
<td>1.00</td>
<td>0.66</td>
<td>0.95</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Late</td>
<td>0.44</td>
<td>0.87</td>
<td>0.29</td>
<td>0.95</td>
<td>0.35</td>
<td>0.91</td>
</tr>
<tr>
<td></td>
<td></td>
<td>NONFATAL</td>
<td>Early</td>
<td>0.89</td>
<td>0.85</td>
<td>0.37</td>
<td>0.87</td>
<td>0.68</td>
<td>0.89</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Late</td>
<td>1.00</td>
<td>0.71</td>
<td>0.91</td>
<td>0.91</td>
<td>0.96</td>
<td>0.80</td>
</tr>
<tr>
<td></td>
<td></td>
<td>TOTAL</td>
<td>Early</td>
<td>0.86</td>
<td>0.85</td>
<td>0.46</td>
<td>0.92</td>
<td>0.67</td>
<td>0.90</td>
</tr>
<tr>
<td></td>
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<td></td>
<td>Late</td>
<td>0.86</td>
<td>0.79</td>
<td>0.66</td>
<td>0.97</td>
<td>0.76</td>
<td>0.88</td>
</tr>
</tbody>
</table>

Analyses revealed a significant Family Status × Gender × Onset interaction effect on perceived benefits from negative test results; $F(2,531) = 3.81, p < .001$ (Figure 10.7).
As can be seen in Figure 10.7, for the late-onset condition, childless women perceived receiving negative test results as more beneficial ($M = .96, SD = .80$) than the childless men did ($M = .35, SD = .91$), whereas there were no gender differences elsewhere.

**Perceived vulnerability**

ANOVA on perceived vulnerability showed no group differences. Overall, participants did not perceive being 'at risk' of carrying a child with a genetic mutation ($M = -1.17, SD = 1.15$).

In summary, analyses conducted on the test-specific variables revealed that family status only influenced subjective norms – partners: childless participants reported greater motivation to comply with their partners' perceived preferences than the other two groups. A Family $\times$ Gender $\times$ Onset Age interaction was found on benefits negative results. Childless women in the late-onset condition believed receiving negative results was more beneficial than childless men. No other main or interactive effects were found. In particular, the severity did not influence any measure scores.

**ANOVAs for abortion-specific variables**

Similar analyses were conducted on attitudes towards disabilities, anticipated emotional distress, anticipated coping efficacy and negative consequences.

**Attitudes towards disabilities**

Results from the ANOVA on attitudes towards disabilities are presented below (Table 10.7).
A Gender main effect was found on attitudes towards disabilities; $F(1,531) = 6.50, p < .01$ (Figure 10.8).

Figure 10.8 Gender main effect on attitudes towards disabilities
Women had more positive attitudes towards disabilities \((M = 1.48, SD = 1.18)\) than men did \((M = 1.07, SD = 1.39; \text{Figure 10.8})\). ANOVAs also revealed a Family Status main effect on attitudes towards disabilities; \(F(2,531) = 4.24, p < .01\) (Figure 10.9).

![Figure 10.9](image)

*Figure 10.9 Family Status main effect on attitudes towards disabilities*

Post hoc comparisons revealed that attitudes towards disabilities were greater the expecting \((M = 1.47, SD = 0.97)\) and the parents \((M = 1.54, SD = 1.15)\) than for the 'childless' group \((M = 1.19, SD = 1.42; \text{Figure 10.9})\)

*Anticipated emotional distress*

Results from the ANOVA on anticipated emotional distress are shown below (Table 10.8).
### Table 10.8
*Means (M) and Standard Deviations (SD) for Anticipated Emotional Distress across Family Status, Gender and the Condition's Severity and Onset*

<table>
<thead>
<tr>
<th>Severity</th>
<th>FATAL</th>
<th>NONFATAL</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Onset</td>
<td>Early</td>
<td>Late</td>
<td>Early</td>
</tr>
<tr>
<td>Family status</td>
<td>Gender</td>
<td>$M$</td>
<td>SD</td>
</tr>
<tr>
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<td>1.39</td>
</tr>
<tr>
<td></td>
<td>Women</td>
<td>1.43</td>
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<td>1.33</td>
</tr>
<tr>
<td>EXPECTING</td>
<td>Men</td>
<td>1.92</td>
<td>0.72</td>
</tr>
<tr>
<td></td>
<td>Women</td>
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<td>1.40</td>
</tr>
<tr>
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<tr>
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<td>1.31</td>
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</tbody>
</table>

ANOVA revealed a Severity main effect on anticipated emotional distress; $F(1,531) = 11.120, p < .001$ (Figure 10.10).

![](image.png)

*Figure 10.10* Severity main effect on anticipated emotional distress
As can be seen in Figure 10.10, participants reported greater anticipated emotional distress when the condition was fatal ($M = 1.14$, $SD = 1.38$), than when it was nonfatal ($M = .60$, $SD = 1.45$).

**Anticipated coping efficacy**
No significant group differences were found for anticipated coping efficacy. Overall, participants slightly agreed they would be able to cope raising a child with a disability ($M = 0.95$, $SD = 1.45$).

**Negative consequences**
Results from the ANOVA on negative consequences are summarised below (Table 10.9).

Table 10.9
*Means (M) and Standard Deviations (SD) for Negative Consequences across Family Status, Gender and the Condition’s Onset and Severity*

<table>
<thead>
<tr>
<th>Family Status</th>
<th>Severity</th>
<th>Onset</th>
<th>FATAL</th>
<th></th>
<th></th>
<th>NONFATAL</th>
<th></th>
<th></th>
<th>TOTAL</th>
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<td>SD</td>
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<td>M</td>
<td>SD</td>
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</tr>
<tr>
<td>CHILDLNESS</td>
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<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Men</td>
<td>1.57</td>
<td>0.36</td>
<td>0.76</td>
<td>0.73</td>
<td>0.96</td>
<td>0.76</td>
<td>0.55</td>
<td>0.86</td>
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</tr>
<tr>
<td></td>
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<td>Women</td>
<td>1.48</td>
<td>0.45</td>
<td>1.07</td>
<td>0.62</td>
<td>0.64</td>
<td>0.82</td>
<td>0.62</td>
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<tr>
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<td>0.66</td>
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<td>0.80</td>
<td>0.59</td>
<td>0.91</td>
<td>1.16</td>
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<td>0.89</td>
<td>-0.17</td>
<td>0.57</td>
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</tr>
<tr>
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<td>0.47</td>
<td>0.74</td>
<td>0.74</td>
<td>0.70</td>
<td>0.93</td>
<td>0.59</td>
<td>0.81</td>
<td>1.03</td>
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<tr>
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<td>Total</td>
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<td>0.45</td>
<td>0.74</td>
<td>0.73</td>
<td>0.67</td>
<td>0.91</td>
<td>0.44</td>
<td>0.81</td>
<td>1.06</td>
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<tr>
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</tr>
<tr>
<td></td>
<td></td>
<td>Men</td>
<td>1.41</td>
<td>0.48</td>
<td>0.65</td>
<td>0.72</td>
<td>0.97</td>
<td>0.68</td>
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<td>0.88</td>
<td>0.92</td>
<td>0.94</td>
<td>0.12</td>
<td>0.92</td>
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<td>0.71</td>
<td>0.91</td>
<td>0.74</td>
<td>0.41</td>
<td>0.89</td>
<td>1.20</td>
</tr>
<tr>
<td></td>
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<td>1.46</td>
<td>0.48</td>
<td>0.83</td>
<td>0.77</td>
<td>0.75</td>
<td>0.89</td>
<td>0.41</td>
<td>0.94</td>
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<td>Total</td>
<td>1.48</td>
<td>0.46</td>
<td>0.81</td>
<td>0.75</td>
<td>0.80</td>
<td>0.84</td>
<td>0.41</td>
<td>0.92</td>
<td>1.16</td>
</tr>
</tbody>
</table>

A significant Onset Age main effect was found on negative consequence; $F(1,531) = 39.062$, $p < .001$ (Figure 10.11).
Participants reported significantly greater perceived negative consequences when the condition was early-onset ($M = 1.16, SD = .75$) than late-onset ($M = .61, SD = .86$; Figure 10.11). ANOVAs also revealed severity main effect on negative consequence; $F(1,531) = 32.615, p < .001$ (Figure 10.12).

Negative consequences were perceived as greater when the condition was fatal ($M = 1.13, SD = .71$) than when it was nonfatal ($M = .60, SD = .90; p < .001$; Figure 10.12).

In summary, analyses conducted on abortion-specific variables revealed that gender and family status only influenced scores on attitudes towards disabilities. Men and childless
participants tended to report more negative views about disabilities. Onset impacted solely on negative consequences. Living with a condition predicted to be present from birth was perceived to have more negative consequences on the quality of life of person living with the disease. Severity influenced mean scores in negative consequences and anticipated emotional distress. When the condition was fatal, participants perceived that a positive diagnosis would be more stressful, and that the condition would impact more negatively on the child's quality of life, than when the condition was nonfatal. No other significant differences were found.

ANOVAs for distal predictors of testing intention

The final set of analyses was conducted on child-related worry, condition coherence, test response efficacy and perceived benefits from positive test results.

Child-related worry

Results from the ANOVA on child-related worry are summarised below (Table 10.10).

<table>
<thead>
<tr>
<th>Family Status</th>
<th>Severity Onset</th>
<th>Gender</th>
<th>FATAL</th>
<th></th>
<th>NONFATAL</th>
<th></th>
<th>TOTAL</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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<td>Late</td>
<td>Early</td>
<td>Late</td>
<td>Early</td>
<td>Late</td>
</tr>
<tr>
<td>CHILDLESS</td>
<td></td>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Men</td>
<td></td>
<td>0.77</td>
<td>1.10</td>
<td>-0.19</td>
<td>1.46</td>
<td>0.36</td>
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<tr>
<td>Women</td>
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<td>1.40</td>
<td>0.54</td>
<td>1.14</td>
<td>0.28</td>
<td>1.43</td>
</tr>
<tr>
<td>Total</td>
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<td>0.33</td>
<td>1.44</td>
<td>0.19</td>
<td>1.38</td>
<td>0.10</td>
<td>1.35</td>
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<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Men</td>
<td>1.54</td>
<td>1.22</td>
<td>0.00</td>
<td>1.42</td>
<td>0.04</td>
<td>1.51</td>
<td>0.16</td>
<td>1.27</td>
</tr>
<tr>
<td>Women</td>
<td>0.03</td>
<td>0.90</td>
<td>0.21</td>
<td>1.32</td>
<td>0.01</td>
<td>1.48</td>
<td>0.05</td>
<td>1.23</td>
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<tr>
<td>Total</td>
<td>0.39</td>
<td>1.17</td>
<td>0.20</td>
<td>1.29</td>
<td>0.00</td>
<td>1.46</td>
<td>0.18</td>
<td>1.33</td>
</tr>
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<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Men</td>
<td>0.07</td>
<td>1.32</td>
<td>-0.63</td>
<td>1.46</td>
<td>0.03</td>
<td>1.40</td>
<td>0.05</td>
<td>1.34</td>
</tr>
<tr>
<td>Women</td>
<td>0.34</td>
<td>1.43</td>
<td>-0.03</td>
<td>1.43</td>
<td>0.63</td>
<td>0.98</td>
<td>0.47</td>
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</tr>
<tr>
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<td>1.45</td>
<td>0.42</td>
<td>1.17</td>
<td>0.33</td>
<td>1.29</td>
</tr>
<tr>
<td>TOTAL</td>
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<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Men</td>
<td>0.58</td>
<td>1.30</td>
<td>-0.37</td>
<td>1.43</td>
<td>0.19</td>
<td>1.47</td>
<td>0.38</td>
<td>1.40</td>
</tr>
<tr>
<td>Women</td>
<td>0.30</td>
<td>1.27</td>
<td>0.26</td>
<td>1.40</td>
<td>0.01</td>
<td>1.28</td>
<td>0.17</td>
<td>1.28</td>
</tr>
<tr>
<td>Total</td>
<td>0.37</td>
<td>1.28</td>
<td>0.13</td>
<td>1.43</td>
<td>0.07</td>
<td>1.34</td>
<td>0.23</td>
<td>1.32</td>
</tr>
</tbody>
</table>
A Severity main effect was found on child-related worry; $F(1,564) = 6.00, p < .001$ (Figure 10.13).

![Figure 10.13 Severity main effect on child-related worry](image)

As Figure 10.13 shows, participants reported greater child-related worry when the condition was fatal ($M = .25, SD = 1.36$) than when it was nonfatal ($M = -.02, SD = 1.41$). A Family Status × Gender interaction effect was also found on child-related worry; $F(2,549) = 3.36, p < .01$ (Figure 10.14).

![Figure 10.14 Family Status × Gender interaction effect on child-related worry](image)

In the parents group, women reported significant greater worry about the health of the unborn ($M = .21, SD = 1.44$) than men ($M = -.18, SD = 1.30$; Figure 10.14).
**Condition coherence**

ANOVA revealed no significant group differences for condition coherence. Overall, participants reported low condition coherence ($M = -.32, SD = .95$).

**Test response efficacy**

No significant group differences were found for test response efficacy. Participants believed that prenatal testing was a reliable way to detect foetal mutations ($M = 1.37, SD = 1.20$).

**Perceived benefits from positive test results**

Results from the ANOVA on perceived benefits from positive results are reported below (Table 10.11).

<table>
<thead>
<tr>
<th>Severity Onset</th>
<th>Family status</th>
<th>Gender</th>
<th>FATAL</th>
<th>NONFATAL</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Early</td>
<td>Late</td>
<td>Early</td>
<td>Late</td>
<td>Early</td>
</tr>
<tr>
<td><strong>CHILDLESS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>1.33</td>
<td>0.64</td>
<td>0.63</td>
<td>1.06</td>
<td>0.94</td>
</tr>
<tr>
<td>Women</td>
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<td>0.80</td>
<td>1.00</td>
<td>0.60</td>
<td>1.17</td>
</tr>
<tr>
<td>Total</td>
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<td>0.91</td>
<td>0.75</td>
<td>1.08</td>
</tr>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>1.29</td>
<td>0.71</td>
<td>1.00</td>
<td>0.68</td>
<td>1.04</td>
</tr>
<tr>
<td>Women</td>
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<td>0.91</td>
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<tr>
<td>Total</td>
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<td>0.83</td>
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<td>1.13</td>
</tr>
<tr>
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</tr>
<tr>
<td>Men</td>
<td>0.96</td>
<td>0.66</td>
<td>0.56</td>
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<td>0.94</td>
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<tr>
<td>Women</td>
<td>1.11</td>
<td>0.89</td>
<td>0.84</td>
<td>0.91</td>
<td>1.44</td>
</tr>
<tr>
<td>Total</td>
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<td>0.82</td>
<td>0.77</td>
<td>0.89</td>
<td>1.26</td>
</tr>
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<td><strong>TOTAL</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>1.16</td>
<td>0.67</td>
<td>0.61</td>
<td>0.94</td>
<td>0.95</td>
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<tr>
<td>Women</td>
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</tr>
<tr>
<td>Total</td>
<td>1.10</td>
<td>0.75</td>
<td>0.85</td>
<td>0.82</td>
<td>1.16</td>
</tr>
</tbody>
</table>
An Onset main effect was found on perceived benefits from positive test results; $F(1,531) = 10.173, p < .01$ (Figure 10.15).

![Benefits Positive Results](image)

*Figure 10.15 Onset main effect on perceived benefits from positive test results*

Receiving positive was perceived as more beneficial when the condition was early-onset ($M = 1.12, SD = .72$) than when it was late-onset ($M = .83, SD = .86$; Figure 10.15).

In summary, analyses conducted on distal predictors of testing intention revealed a main effect for Severity and a Gender x Family Status interaction on child-related worry. Participants reported greater worry about the health of their unborn children when the condition was described as fatal, than when it was described as nonfatal. In addition, mothers tended to report greater child-related worry than fathers. No other main or interactive effects were revealed. In particular, Onset Age did not impact on any mean scores of distal predictors of testing intention.

**Model Testing**

The aim of this section was to test the model of prenatal testing decision-making (Figure 3.7) using path analysis. Results from regression analyses conducted on the study variables. The group variables shown by ANOVAs to have a significant effect on the momentary dependent variable were treated as covariates (Table 10.12).
Table 10.12
Final Models from the Hierarchical Multiple Regression Assessing the Predictive Value of the Model of Prenatal Testing Decision-Making (Figure 10.16)

<table>
<thead>
<tr>
<th>Variables</th>
<th>B</th>
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<th>β</th>
<th>t</th>
<th>F</th>
<th>R²</th>
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<td>10.83***</td>
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<td>0.02</td>
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</tr>
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<td>-0.28</td>
<td>ns</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender x DummyChildlessParents</td>
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<td>0.14</td>
<td>0.26</td>
<td>ns</td>
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<td></td>
</tr>
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<td>0.28</td>
<td>6.59***</td>
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<td></td>
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</tr>
<tr>
<td>Negative consequences</td>
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<td>0.04</td>
<td>0.28</td>
<td>6.69***</td>
<td></td>
<td></td>
</tr>
<tr>
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<td></td>
<td></td>
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<td>0.07</td>
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<td>-0.26</td>
<td>-6.38***</td>
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</tr>
<tr>
<td><strong>Negative consequences</strong>²</td>
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<td></td>
<td></td>
<td>55.33***</td>
<td>0.23</td>
</tr>
<tr>
<td>Onset</td>
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<td>0.06</td>
<td>-0.32</td>
<td>-8.54***</td>
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<tr>
<td>Severity</td>
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<td>0.06</td>
<td>0.32</td>
<td>8.69***</td>
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<td></td>
</tr>
<tr>
<td>Attitudes towards disabilities</td>
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<td>-4.19***</td>
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</tr>
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<td>0.06</td>
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<td></td>
</tr>
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<td>0.03</td>
<td>0.54</td>
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<td>0.27</td>
<td>7.98***</td>
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<tr>
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<td>0.02</td>
<td>0.37</td>
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<tr>
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<td>-0.02</td>
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<td>0.09</td>
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<td>Gender</td>
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</tr>
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<td>Gender x DummyChildlessParents</td>
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<td>-0.33</td>
<td>-10.71***</td>
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<tr>
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<td>0.02</td>
<td>-0.32</td>
<td>-11.93***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Negative consequences</td>
<td>0.40</td>
<td>0.06</td>
<td>0.22</td>
<td>6.34***</td>
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<td></td>
</tr>
<tr>
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<td>0.04</td>
<td>-0.18</td>
<td>-6.43***</td>
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<tr>
<td>Anticipated emotional distress</td>
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<td>0.16</td>
<td>4.88***</td>
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Table 10.12 (Continued)

<table>
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<th>Variables</th>
<th>B</th>
<th>SE B</th>
<th>β</th>
<th>t</th>
<th>F</th>
<th>R²</th>
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<td>Testing intention¹</td>
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</tr>
<tr>
<td>Gender</td>
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<td>0.11</td>
<td>-0.06</td>
<td>ns</td>
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<td></td>
</tr>
<tr>
<td>DummyChildlessExpecting</td>
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<td>0.24</td>
<td>0.02</td>
<td>ns</td>
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<td></td>
</tr>
<tr>
<td>Gender x DummyChildlessExpecting</td>
<td>-0.11</td>
<td>0.14</td>
<td>-0.09</td>
<td>ns</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subjective norms – partner</td>
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<td>0.01</td>
<td>0.38</td>
<td>10.64***</td>
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<td></td>
</tr>
<tr>
<td>Religiosity</td>
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<td>0.02</td>
<td>-0.18</td>
<td>-5.84***</td>
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<td></td>
</tr>
<tr>
<td>Abortion willingness</td>
<td>0.18</td>
<td>0.03</td>
<td>0.18</td>
<td>5.26***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benefits from negative results</td>
<td>0.29</td>
<td>0.06</td>
<td>0.16</td>
<td>5.25***</td>
<td></td>
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</tr>
<tr>
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<td>0.04</td>
<td>0.12</td>
<td>4.38***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subjective norms – family</td>
<td>0.03</td>
<td>0.01</td>
<td>0.11</td>
<td>3.55***</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: *** = p < .001; ** = p < .01; ¹: N = 555; ²: N = 566

Table 10.12 shows that the hypothesised relationships were empirically supported. The relationship between variables may be illustrated on a path diagram by either single-headed arrows (showing the direction of the hypothesised relationships between the predictor(s) and the criterion; e.g., between child-related worry and anticipated emotional distress). The path coefficients are the standardised partial regression coefficients β (Table 10.12). The path diagram and the path coefficients are displayed below (Figure 10.16).
Figure 10.16 Final model of prenatal genetic testing decision-making

$p < .01.$
Together, Table 10.12 and Figure 10.16 show that higher scores on perceived vulnerability were associated with higher scores on child-related worry. Negative views towards disabilities in general predicted greater beliefs that the condition described in the opening text would negatively impact on the child's quality of life. Greater worry about the health of the unborn, greater beliefs that the condition would impact negatively on the child's quality of life and negative views towards disabilities predicted greater beliefs that receiving positive test results would be emotionally stressful. Participants who believed that the genetic condition would impact negatively on the child's quality of life also believed that receiving positive test results would be beneficial. Lower scores on condition coherence were associated with greater beliefs that prenatal testing could accurately detect foetal abnormalities. Participants who reported stronger beliefs that receiving positive results would be emotionally stressful and that prenatal testing can accurately detect foetal abnormalities, also reported stronger beliefs that receiving negative test results would be beneficial. Lower levels of anticipated coping efficacy, lower religiosity scores, greater beliefs that the condition would have negative consequences on the child's quality of life, less positive views towards disabilities and greater anticipation that receiving positive test results would be emotionally stressful were all significant independent predictors of abortion willingness. Finally, greater motivation to comply with one's partner's/spouse's (and to a lesser extent one's family's) perceived preferences about undergoing the procedure, greater willingness to terminate an affected pregnancy, lower level of religiosity, greater perceived benefits from receiving negative results and greater perceived vulnerability of carrying a genetically malformed foetus were all predictors on greater testing intention.

Further mediational analyses were conducted on the variables shown to be directly and indirectly related to testing intention (i.e. religiosity and perceived vulnerability) and abortion willingness (i.e. attitudes towards disabilities and negative consequences) (Figure 10.16).

**Mediational analyses between religiosity and testing intention**

Hierarchical regression analyses were carried out to assess the mediational effects of abortion willingness on the relationship between religiosity and testing intention (Table 10.13).
Mediational analyses between perceived vulnerability and testing intention

The second series of hierarchical regression analyses performed to assess the mediational effects of child-related worry, anticipated emotional distress, abortion willingness and benefits from negative results on the relationship between perceived vulnerability and testing intention (Table 10.14).
Table 10.14

Hierarchical Regression Analyses between Perceived Vulnerability and Testing Intention

<table>
<thead>
<tr>
<th>Model 1</th>
<th>B</th>
<th>SE B</th>
<th>β</th>
<th>t</th>
<th>F</th>
<th>R²</th>
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<tbody>
<tr>
<td>Constant</td>
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<tr>
<td>Perceived</td>
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<td>0.06</td>
<td>0.20</td>
<td>4.65</td>
<td>***</td>
<td>.06</td>
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<tr>
<td><strong>Model 2</strong></td>
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<tr>
<td>Constant</td>
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<td>0.40</td>
<td></td>
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<td>ns</td>
</tr>
<tr>
<td>Perceived</td>
<td>0.12</td>
<td>0.05</td>
<td>0.09</td>
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<td></td>
<td>ns</td>
</tr>
<tr>
<td>Child-related</td>
<td>0.47</td>
<td>0.05</td>
<td>0.42</td>
<td>10.46</td>
<td>***</td>
<td>.22</td>
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<tr>
<td>Constant</td>
<td>0.04</td>
<td>0.38</td>
<td></td>
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<td>ns</td>
</tr>
<tr>
<td>Perceived</td>
<td>0.13</td>
<td>0.05</td>
<td>0.10</td>
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<td></td>
<td>ns</td>
</tr>
<tr>
<td>Child-related</td>
<td>0.30</td>
<td>0.06</td>
<td>0.27</td>
<td>5.15</td>
<td>***</td>
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<td>Anticipated</td>
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<td>0.06</td>
<td>0.02</td>
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<td>Constant</td>
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<td>ns</td>
</tr>
<tr>
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<td>0.14</td>
<td>3.99</td>
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<td>0.05</td>
<td>-0.13</td>
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<td>0.04</td>
<td>0.43</td>
<td>10.40</td>
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<tr>
<td>Willingness</td>
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<td>0.07</td>
<td>0.26</td>
<td>6.93</td>
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<td></td>
</tr>
</tbody>
</table>

*** = p < .001; ** = p < .01

* Abortion willingness and benefits from negative results were brought in together in model 4

Alone, perceived vulnerability accounted for approximately 6% of the variability in testing intention (Table 10.14). When child-related worry, anticipated emotional distress, abortion willingness and benefits from negative results are entered in the model, the prediction of testing intention improves to 44%. However, only perceived vulnerability, benefits from negative results and abortion willingness remained significant predictors. The Sobel test (1982) was used to assess the mediating role of benefits from negative results and abortion willingness on the relationship between perceived vulnerability and testing intention.

Perceived vulnerability was not a significant predictor of benefits from negative results or of abortion willingness (p > .01). These results confirmed that child-related worry, anticipated emotional distress, abortion willingness and benefits from negative results did not have a significant influence on the relationship between perceived vulnerability and testing intention.

**Mediational analyses between negative consequences and abortion willingness**

Similar analyses were carried out to determine the mediating role of anticipated emotional distress in the relationship between negative consequences and abortion willingness (Table 10.15).
Table 10.15
Hierarchical Regression Analyses between Negative Consequences and Abortion Willingness

<table>
<thead>
<tr>
<th>Model 1</th>
<th>B</th>
<th>SE B</th>
<th>β</th>
<th>t</th>
<th>F</th>
<th>R²</th>
</tr>
</thead>
<tbody>
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<td></td>
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<td>0.07</td>
<td>0.53</td>
<td>13.00</td>
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<td>.27</td>
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<table>
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<th>β</th>
<th>t</th>
<th>F</th>
<th>R²</th>
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<tr>
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<td>0.33</td>
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</tr>
<tr>
<td>Negative consequences</td>
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<td>0.08</td>
<td>0.31</td>
<td>6.95</td>
<td>***</td>
<td>.37</td>
</tr>
<tr>
<td>Anticip. emotional distress</td>
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<td>0.04</td>
<td>0.38</td>
<td>9.15</td>
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</table>

*** = p < .001; ** = p < .01

Alone, negative consequences account for 27% of the variability in abortion willingness. When anticipated emotional distress is entered in the model, together, they account for 34% of the variance (Table 10.15). Sobel test (Sobel, 1982) was used to assess the role of anticipated emotional distress in the relationship between negative consequences and abortion willingness. Negative consequences significantly predicted anticipated emotional distress ($B = 0.98$, $SE B = 0.07$, $p < .001$). In turn, anticipated emotional distress significantly predicted abortion willingness ($B = 0.58$, $SE B = 0.04$, $p < .001$). Sobel Test revealed that anticipated emotional distress had a significant influence on the relationship between negative consequences and abortion willingness ($z = 10.07$, $p < .001$).

**Mediational analyses between attitudes towards disabilities and abortion willingness**

The last series of hierarchical analyses were performed to determine the mediating role of negative consequences and anticipated emotional distress in the relationship between attitudes towards disabilities and abortion willingness (Table 10.16).
Table 10.16
Hierarchical Regression Analyses between Attitudes towards Disabilities and Abortion Willingness

<table>
<thead>
<tr>
<th>Model</th>
<th>$B$</th>
<th>$SE$</th>
<th>$\beta$</th>
<th>$t$</th>
<th>$F$</th>
<th>$R^2$</th>
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</tr>
<tr>
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<td></td>
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<td>.25</td>
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<tr>
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<td>0.05</td>
<td>-0.46</td>
<td>-12.25***</td>
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<td>.41</td>
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<td>-11.59***</td>
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<td>0.07</td>
<td>0.46</td>
<td>12.37***</td>
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</tr>
<tr>
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<td>0.31</td>
<td></td>
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<td>67.62***</td>
<td>.46</td>
</tr>
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<td>-9.84***</td>
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<td>0.08</td>
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<td>7.45***</td>
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<tr>
<td>Anticipated emotional distress</td>
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<td>0.04</td>
<td>0.28</td>
<td>7.00***</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*** = $p < .001$; ** = $p < .01$

Alone, attitudes towards disabilities explain 25% of the variance in abortion willingness. When negative consequences and anticipated emotional distress are added to the model, together, they account for 46% of the variability in abortion willingness. Attitudes towards disabilities significantly predicted negative consequences ($B = -0.10$, $SE = 0.03$, $p < .001$) which was also a significant predictor of abortion willingness ($B = 0.98$, $SE = 0.07$, $p < .001$). Sobel test (Sobel, 1982) indicated that negative consequences did not have a significant influence on the relationship between attitudes towards disabilities and abortion willingness ($z = -0.33$, $p > .05$). Negative consequences was a significant predictor of anticipated emotional distress ($B = 0.98$, $SE = 0.07$, $p < .001$) which also predicted abortion willingness ($B = 0.58$, $SE = 0.04$, $p < .001$). The Sobel test revealed that anticipated emotional distress had a significant influence on the relationship between negative consequences and abortion willingness ($z = 10.07$, $p < .001$).

**Overall Impact Analyses**

The aim of this section is to report the overall impact of the study variables identified above as having a direct and indirect impact on testing intention and abortion willingness. The overall influence of an independent variable on a dependent variable can be calculated by adding up the direct with the indirect impact. The value of the former is equal to the standardised regression coefficient, whereas the value of the latter can be calculated by
multiplying all the indirect coefficients between them (Cramer, 2003). The only two variables having a direct and indirect impact on testing intention were perceived vulnerability and religiosity (Figure 10.16). The overall impact of religiosity on testing intention was -0.23 (direct = -0.17 + indirect = -0.32×0.20) and the overall impact of perceived vulnerability was 0.13 (direct = 0.12 + indirect = 0.27×0.52×0.16×0.20 + 0.27×0.52×0.37×0.16). These calculations showed that the direct impact of perceived vulnerability and religiosity on testing intention accounted for most of their overall influence on the outcome variable.

The only two variables having a direct and indirect impact on abortion willingness were attitudes towards disabilities and negative consequences (Figure 10.16). The overall impact of attitudes towards disabilities was -0.22 (direct = -0.18 + indirect = -0.16×0.22 - 0.16×0.27×0.16) and the overall impact of negative consequences on abortion willingness was 0.26 (direct = 0.22 + indirect = 0.27×0.16). These calculations indicated that the overall impact of attitudes towards disabilities and negative consequences were greater than their direct effect.

**Summary of Findings**

The present chapter presented results from analyses carried out to fulfil two aims. The first aim of Study Two was to validate the model on prenatal testing decision-making proposed in Study One (Figure 3.7). Overall, participants were divided in their intention to undergo prenatal testing, slightly against selective abortion and motivated to comply with their partners' perceived preferences. All the hypothesised test-specific variables (i.e. subjective norms – partner, religiosity, abortion willingness, benefits from negative results, perceived vulnerability and subjective norms – family) were indeed predictors of testing intention. Greater motivation to comply with the perceived preference of one's partner (and to a lesser extent one's family) regarding prenatal testing, lower religious commitment, greater willingness to terminate an affected pregnancy, greater beliefs that negative results would be beneficial and greater perceived vulnerability of carrying a child with a genetic anomaly all predicted greater intention to undergo prenatal testing. All the hypothesised abortion-specific variables (i.e. anticipated coping efficacy, religiosity, negative consequences, attitudes towards disabilities and anticipated emotional distress) were predictors of abortion willingness. Anticipating not being able to cope with a child with special needs, having low
religious commitment, believing that the condition would have negative consequences on the child's quality of life, holding negative views of disabilities and anticipating that a positive diagnosis would be emotionally stressful all predicted greater willingness to terminate an affected pregnancy. As for the more distal predictors of testing intention, the expectation that child-related worry, benefits from positive results, condition coherence and test response efficacy would not be significantly related to testing intention was supported.

The second aim of Study Two was to test two sets of predictions for the role of condition onset, condition severity, gender and family status on testing intention, abortion willingness and subjective norms – partner. Results provided partial support for the first set of hypotheses on condition onset and severity. Contrary to expectations, testing intention was not greater for the early-onset (than the late-onset) and for the fatal (than the nonfatal) conditions. The condition's onset or severity had no impact on testing intention. As expected, abortion willingness was greater for the fatal and for the early-onset conditions. The second set of hypotheses for the combined roles of gender and family status also received partial support. Contrary to expectations, childless men reported greater, not lower, testing intention compared to childless women. In line with the predictions, childless men reported greater abortion willingness and greater subjective norms – partner than childless women.

The analyses presented in the present chapter also showed that onset and severity had only a limited role in prenatal testing decision-making. Of the 15 variables presented in the model (Figure 10.16), onset influenced only one test-related variable (i.e. benefits from negative results, and only for the childless group) and one abortion-specific variable (i.e. negative consequences). Severity impacted only on two abortion-specific variables (i.e. anticipated emotional distress and negative consequences) and on one distal predictor (i.e. child-related worry). All the results reported thus far are interpreted in the next chapter.
CHAPTER 11

Study 2 – Discussion

The idea that some important aspects of our health are "laid down before birth" (Davison, Macintyre, & Smith, 1994, p. 344) has been an important drive behind the development of prenatal genetic testing. This technology refers to the invasive procedures carried out during pregnancy to find out about the presence of foetal genetic mutation(s) which could materialise into a disability after birth. When prenatal testing was first introduced into maternal care, applications were limited to detecting single-gene diseases. With advances in the medical field, the mutations screened for during pregnancy now also include genetic predispositions to more complex diseases of various ages of onset and degrees of severity.

Study One proposed a model accounting for the social, emotional, ethical and cognitive constructs that might influence parents’ intention to undergo testing and willingness to terminate an affected pregnancy (Figure 3.7). Study Two aimed to validate this model and to assess whether reproductive decisions may be swayed by the characteristics of the individuals (e.g. family status and gender) and/or of the conditions (e.g. onset age and severity). Data were collected on a wide sample of men and women throughout New Zealand using an online survey which consisted of four hypothetical scenarios and a series of items measuring the constructs of interest. Each of the scenarios described a condition of different degrees of severity and ages of onset (Chapter 9). Data were analysed (Chapter 10). The present chapter interprets these findings reported and contains four sections. Section One discusses the results of the descriptive analyses on the outcome variable: testing intention. Section Two interprets the findings relating to the hypotheses on the role of the condition characteristics and individual differences on testing intention, abortion willingness and subjective norms – partner. Section Three focuses on the findings from analyses carried out to test the whole model of prenatal testing decision-making. Finally, Section Four acknowledges some of the limitations of the present study.
Testing Intention

Descriptive analyses revealed that participants were divided on whether they would undergo invasive prenatal testing to find out about the mutation described in the hypothetical opening scenario, if they were expecting a child. This wide spread of opinions amongst lay people echoed others previously reported (Fransen et al., 2010; Garcia et al., 2008b; Genetic Alliance, 2007). In the present study, just under half of the participants reported being opposed to the test. Participants who reported a mild to strong opposition to prenatal testing might have exercised their procreative 'right not to know' (Chadwick, 1997; Lau et al., 1989; Robertson, 1996; Rose, Peters, Shea, & Armstrong, 2005). This right has been recognised by The European Convention on Human Rights and Biomedicine who stipulated that "the wishes of individuals not to be informed shall be observed" [no date, article 10, §2]. Likewise, the Universal Declaration on the Human Genome and Human Rights adopted by the United Nations Educational Scientific and Cultural Organization also stated that "the right of every individual to decide whether or not to be informed of the results of genetic examination and the resulting consequences should be respected" (UNESCO; 1997; article 5c).

The right not to know seems to have stemmed from two principles: 1) the recognition that the test may be perceived as having little, if any, medical value; and 2) the potential psychological damage that could result from patients' inability to 'undo' the knowledge (Borry et al., 2008). First, in the medical arena, knowledge is generally assumed to be synonymous of empowerment, and that knowing about a health threat means being able to treat or prevent it (Caulfield & Wertz, 2001). Often, this assumption does not apply in prenatal testing. In most cases, the information acquired through this technology can only be used to identify an abnormality, not to cure it. Indeed, most malformations currently tested for during pregnancy cannot be treated prenatally. Instead, test results may mostly be used to decide about the pregnancy outcome. Hence, the information provided by prenatal testing may be perceived as worthless, especially by parents opposed to selective abortion.

Second, knowing about a foetal genetic malformation but not being able to treat it may leave parents in a stressful position (Levitt, 2001). The inability to cure the disease combined with the inability to 'undo the knowledge' has been shown to lead to the "burden of certainty" (Borry et al., 2008, p. 290) and the "unbearable certainty of knowing" (Rhodes, 2006, p. 610).
This, in turn, can result in "pointless anxiety" and "unnecessary worry" (Rose et al., 2005, p. 148). Altogether, people may fear the consequences of this arguably worthless and anxiety-provoking technology (García, Timmermans, & van Leeuwen, 2009). Such views may have led some participants of the present study to believe that 'ignorance is bliss' and that they would not to seek prenatal testing, if they were expecting a child.

A small majority of participants reported mild to strong intention to undergo prenatal testing. These individuals may have wished to exercise their procreative 'right to know' (Hunt et al., 2006). Research has suggested that not knowing about the health of the unborn child may be more stressful than receiving a diagnosis, even one indicating the presence of a genetic mutation (Benkendorf et al., 1997; Campbell & Ross, 2005; Hamann et al., 2000). Studies have shown that prospective parents seek prenatal testing not just because they wish to acquire information about the genetic make-up of the foetus but also because they hope the diagnosis will be negative (Ekelin, Crang-Svalenius, & Dykes, 2004; García et al., 2008b; Rose et al., 2005).

**Roles of Severity, Age of Onset, Gender and Family Status on Testing Intention, Abortion Willingness and Subjective Norms – Partner**

ANOVA:s were carried out to test the predictions for the roles of the condition's characteristics (i.e. severity and age of onset) and the individuals' differences (i.e. gender and family status) on testing intention, abortion willingness and subjective norms – partner. Results are summarised and discussed based on their relevance to the hypotheses stated in Chapter 8.

**Testing intention**

The first series of ANOVA:s revealed that, contrary to expectations, testing intention was not significantly greater for the fatal (than for the nonfatal) or for the early-onset (than the late-onset) conditions. The manipulation on the condition age of onset and severity did not influence intention to undergo prenatal testing. This lack of discrimination between the conditions may be methodologically or theoretically accounted for.
First, with regards to methodological considerations, the scenarios used to elicit attitudes about prenatal testing had been designed specifically for this present study. They described the genetic conditions in terms of causes, consequences, timeframe and treatment, but did not actually name the diseases. The deliberate omission of labels may have confused participants, compromised their overall understanding of the conditions and decreased the salience of the characteristics manipulated (i.e. onset and severity). This supposition is supported by the fact that condition coherence was uniformly low across all groups. According to the Common Sense Model (Leventhal et al., 2003), condition coherence is a key predictor of health threat appraisal and health preventive behaviour. Labelling health threats is believed to allow people to take control and ownership of their health. It is possible that the study design chosen to assess people's cognitive processes during decision-making had resulted in people distancing themselves from the issues under investigation, and had impeded on their abilities to discriminate between features believed to be important in decisions about family planning.

A second explanation for the lack of group differences across onset and severity may have been that intentions regarding prenatal testing were simply not influenced by the conditions' characteristics. It could be that participants' decisions were driven by a motivation not to find the presence of a mutation but one to not find any mutation, regardless of its predicted severity or onset age. This 'approach versus avoidance' perspective is characteristic of differences of expectations between medical professionals and users. Physicians perceive prenatal testing as a way to detect (and possibly eliminate) a genetic abnormality, whereas patients undergo prenatal testing hoping to not find any. Hunt and colleagues presented these differences of perspectives in terms of clinicians' "disvalue of the anomaly" versus the patients' "value of the pregnancy" (2006, p. 206).

The second series of ANOVAs were carried out to test the hypothesised interaction between gender and family status on testing intention. Contrary to expectations, childless men reported greater, not lower, testing intention than childless women. Empirical evidence on gender differences in the context of prenatal testing is sparse, as most studies have been conducted on women only (for a review, see St-Jacques et al., 2008). In addition, research on the role of men in issues related to family have focused primarily on their experiences of birth and fatherhood, not on their views regarding prenatal testing (Green et al., 2004). Evidence in other health areas, such as the use of health care for chronic pain (Kaur et al., 2007) and
colorectal cancer (Shugarman et al., 2007) has shown that women tend to be greater users of medical resources than men. It was therefore expected that female participants would report greater intention to use prenatal testing than men. The unexpected opposite trend in the present study could perhaps be due to women being aversive to the invasiveness of the procedures. Indeed, amniocentesis and chorionic villus sampling consist of inserting a needle through the woman's womb, or a catheter through the woman's uterus. Further research would need to verify this assumption. Regardless, the present results indicated that men may be more involved with the issues surrounding pregnancy than generally assumed. With regards to reproductive decision-making, they may wish to be "more than just bystanders" (Locock & Alexander, 2006, p. 1349).

**Abortion willingness**

Abortion willingness was a measure of people's motivation to undergo selective termination in the event of positive test results. Descriptive analyses indicated that, overall, participants did not favour termination of an affected pregnancy. This finding was somewhat unexpected as previous studies have shown that expectant couples tend to opt against giving birth to children with disabilities (McCoyd, 2008; Shaffer, Caughey, & Norton, 2006). However, this result may have reflected participants' willingness to exercise their "moral and legal right to choose whether or not to reproduce" (Robertson, 1996, p. 426). Also, the fact that the majority of participants were in favour of testing but opposed to selective abortion should not be perceived as contradictory. Prenatal testing is often presented by medical professionals in conjunction with selective abortion. However, most parents do not necessarily associate the two. In fact, studies show that couples do not wish to think about the pregnancy outcome until they absolutely have to (Ahmed et al., 2008; García et al., 2008a).

Low abortion willingness rates may reflect broad societal factors, such as national religious bans, education levels and/or educational backgrounds. First, opposition to abortion is characteristic of countries, such as Israel and Pakistan, where real or perceived religious bans of termination have resulted in prenatal testing to be largely dismissed (Ahmed et al., 2008; Alsulaiman, Al-Odaib, Rijjal, & Hewison, 2010; Raz et al., 2003). In such countries, couples tend to believe that prenatal testing would be useful only if abortion was legal. Given that the latter is reprehensible by law (or perceived to be), the former is often perceived as meaningless. No such religious ban exists in New Zealand. In fact, termination of pregnancy was made legal by the Contraception, Sterilisation and Abortion Act 1977 "for women of any
age, if two certifying consultants agree that the pregnancy will seriously harm a woman's physical or mental health” (Abortion Services in New Zealand, Last updated: 26 July 2010). Participants of the present study may have had their own religious reasons for opposing abortion (the role of religiosity in prenatal testing decision-making will be discussed in Section Three). However, the argument regarding the repercussions of a national religious prohibition of abortion on testing intention could not have accounted for the low abortion rates in the present study.

Low abortion willingness in Western countries may also be characteristic of highly educated participants (Beeson et al., 1985) and/or maternal occupational background (Khoshnood, de Vigan, Vodovar, Bréart, & et al., 2006). For instance, Schechtman and colleagues (2002) found that abortion rates were inversely related to individuals' educational level. Patients who had not completed high school reported greater abortion intention rates than college graduates. Similarly, Khoshnood and colleagues (2006) found that women of less advanced occupational categories (i.e., administrative, public service and no occupation) were more likely to terminate an pregnancy affected with Down's syndrome than women with more advanced professional careers. In the present study, most participants had completed an (undergraduate or postgraduate) university degree. It is therefore possible that this educational bias skewed the overall patterns of response and led to a general opposition to selective abortion.

The next series of analyses consisted of ANOVAs to test the hypothesised roles of condition severity and condition age of onset on abortion willingness. As predicted, selective abortion was less opposed to when the condition was fatal or early-onset, than when it was nonfatal or late-onset, respectively. These findings mirrored others also showing that the characteristics of the genetic conditions under investigation may sway parents into believing that the procedure may, sometimes, be ethically permissible. For instance, Schechtman and colleagues (2002) analysed the outcome of 53,630 pregnancies in the United States in the case of varying foetal anomalies. They found that the severity of the foetal condition acted as an important determinant of selective abortion. Likewise, Hewison and colleagues (2007) reported that women theoretically opposed to termination of pregnancy would make an exception for Anencephaly, trisomy 13 or 18, quadriplegia and Duchenne muscular dystrophy. Similarly, in García and colleagues' (2008a) study, participants opposed to abortion in principle could
ethically justify this option if the disease was predicted to severely diminish their child's quality of life or to be incompatible with life. More recently, Souka and colleagues' (2010) study on pregnant women showed that abortion willingness ranged from 45% for physical disfigurement to 86% for lethal anomalies. Altogether, this empirical evidence indicates that the condition's characteristics can affect people's attitudes towards selective abortion.

The last hypotheses on abortion willingness concerned the combined roles of gender and family status. ANOVAs showed that, as predicted, childless men reported significantly greater abortion willingness than childless women, and this across all conditions. This was particularly noteworthy given the previous results showing that men reported greater intention to undergo testing. This view amongst men with no prior experience with pregnancy may reflect a discretionary attitude towards reproductive technologies and expectations towards future healthy pregnancies. Research does show that less than a year separates most selective abortions from the next pregnancy (Cameron & Williamson, 2003). For women, deciding about the pregnancy outcome is typically more difficult (Ahmed et al., 2008; McCoyd, 2007). Women seem to be more sensitive to the fact that either choice will result in an undesirable outcome. Carrying an affected pregnancy to term would mean giving birth to a child with special needs (which is often a feared outcome), whereas terminating that pregnancy would mean losing a wanted child and experiencing great bodily intrusion (Robertson, 1996). When having to decide about the pregnancy outcome, may women tend to believe that "abortion is painful but a sick child is much worse" (Remennick, 2006, p. 36) and that they would "rather be safe than sorry" (Remennick, 2006, p. 34).

**Subjective norms (-partner and -family)**

Subjective norms referred to one's motivation to comply with the referent's perceived preference regarding undergoing prenatal testing. Descriptive analyses showed that, overall, participants reported an strong desire to comply with their partner's/spouse's expected preference. Four-way ANOVAs were conducted to assess the hypothesised combined roles of gender and family status on subjective norms – partner. As predicted, childless men reported greater willingness to comply with the perceived preferences of the other parent, than childless women, regardless of the characteristics of the genetic condition under investigation. This need for partnership between men and women in the context of family planning has been widely recognised (Durand, Stiel, Boivin, & Elwyn, 2010; García et al., 2008b; Rini et al., 2006; Tsianakas & Liamputtong Rice, 2002).
In the childless group, men's greater willingness to comply with the perceived preference of the future mother of their children could be interpreted as a sign of indifference or, on the contrary, as a sign of support. The former interpretation was discarded as it would have conflicted with the results previously reported indicating men's desires to be involved in the decision-making process. The second explanation was therefore favoured, as it could be empirically and theoretically justified. The childless group consisted of individuals with no first-hand experience with pregnancies. Hence, people's responses reflected their expectations about a possible future, including expectations about their partner's needs for support. Generally speaking, pregnancy is a time when women need and seek social support (Alteneder et al., 1998; Kukulu et al., 2006; Rini et al., 2006). Three types of social support have been identified: emotional support (e.g., empathetic listening and display of genuine concern and affection), informational support (e.g., provision of facts, advice, knowledge, etc.) and task support (e.g., help with household duties, chores, etc.) (Rini & Dunkel Schetter, 2010). Pregnancy occurs in a social context (Rowe, Fisher, & Quinlivan, 2009) and research shows that, in their decision-making process, women seek different providers for their different types of needs (Carroll, Brown, Reid, & Pugh, 2000).

Pregnant women seem to turn to the future father of their children for emotional support (Humphreys, Cappelli, Hunter, Allanson, & Zimak, 2003). Women's need for this type of help is greater for those anxious about the health of the foetus (Rini & Dunkel Schetter, 2010) and having difficulties reaching a decision (Carroll et al., 2000). In the present study, childless participants reported both. They were worried about the health of their children and they also varied widely about the decision whether or not they would undergo prenatal testing. It is therefore likely that childless women anticipated turning to the future father of their children for assistance in dealing with their worry and in reaching a decision (Humphreys et al., 2003). This assumption would be consistent with studies showing that the most support pregnant women receive during pregnancy does indeed come from the future father (Kukulu et al., 2006). It is further possible that, in the present studies, childless men anticipated their partners' need for empathetic listening and were willing to provide them with this type of emotional support. Hence, childless men's higher scores on subjective norms – partner should not be viewed as indifference or disinterest. On the contrary, these scores should be interpreted as men's willingness to meet their partner's perceived needs for emotional support.
and their desire to provide the future mother of their children with this type of psychological assistance.

For the second type of social support, namely informational support (Rini et al., 2006), pregnant women seem to turn to medical professionals, as men are often perceived to lack knowledge about issues related to pregnancy (Tsianakas & Liamputtong Rice, 2002). For task support, women are more likely to approach friends/family (Browner et al., 1999; Humphreys et al., 2003; Kenen, Smith, Watkins, & Zuber-Pittore, 2000). The involvement of family in reproductive decisions is particularly relevant to the present study. Analyses on subjective norms – family showed that participants were willing to comply with their families' perceived expectations, but only to a certain extent. These results were in line with previous studies showing that relatives played only a small role on parental decisions (García et al., 2008b).

There could have been, at least, two explanations for these findings. First, anticipating others to be judgmental towards one's behaviour has been described as "a spontaneous human response that happens in all human relationships" (Anderson, 2007). In addition, "expectations of accountability are an implicit or explicit constraint on virtually everything people do" (Tetlock, 1992, p. 337). It is possible that participants with no personal experience with pregnancy might have felt particularly vulnerable to their family criticisms. They may have, to some extent, contemplated conforming to their relatives' preferences as a way to lessen these criticisms. Due to the lack of empirical evidence on this topic, this interpretation is only speculative.

The second explanation for the group differences in family status with regards to subjective norms – family refers directly to parents' needs for task and information support (Rini & Dunkel Schetter, 2010). Childless participants may have anticipated a need to involve their family in their decision-making and to build (or strengthen) an alliance with some relatives who might later be able to provide them with practical support. Childless participants may have wished to rely on their family to help them reach a decision about an area they had little experience with.
Model of Prenatal Testing Decision-making

This section reports and interprets findings of analyses carried out to test the whole model of prenatal testing decision-making (Figure 3.7 and Figure 10.16). The following discussion focuses first on the test-specific predictors, then on the abortion-specific variables.

Test-specific predictors

Mediational analyses confirmed that subjective norms – partner, abortion willingness, benefits from negative results, perceived vulnerability and religiosity were all predictors of testing intention. Their respective influences on testing intention are discussed in turn.

Subjective norms – partner

Path analysis showed that subjective norms – partner was the strongest predictor of testing intention. The influence of spouse/partner on testing intention has been widely reported (Anderson, 2007; Browner et al., 1999; García et al., 2008b; Humphreys et al., 2003; Julian-Reynier et al., 1994; Kukulu et al., 2006; Marteau & Croyle, 1998; Potter et al., 2008; Rini et al., 2006; van den Berg et al., 2008). In fact, subjective norms were also of prime importance in the latest model of prenatal testing decision-making proposed by van den Berg and colleagues (2008). This is perhaps not surprising given that the romantic relationship is one of the most important relationships in adults' life (Alea & Vick, 2010; Beach, Fincham, Katz, & Bradbury, 1996) and that the quality of such relationships is directly related to prenatal depression and prenatal adjustment (Pajulo, Savonlahti, Sourander, Helenius, & Piha, 2001).

When discussing prenatal testing options, men and women may sometimes disagree on what they consider to be the best course of action (Durand et al., 2010). In these instances, there seems to be a tendency for some future mothers to become the main decision-maker and to choose what will inevitably involve her body. More often, however, parents seem to agree on decisions concerning the future of their family, including choices regarding prenatal testing. For instance, in Tsianakas and Liamputtong Rice's (2002) study, most women reported having made a joint decision to take the test. These future mothers also explained they would have willingly refused the procedure, had the father of their children been opposed to it. The participants' desires to side with their husbands were not based on the perceived expertise of the men, who were in fact believed to be less medically knowledgeable. The women valued
the supportive and counselling role played by their husbands, and wanted to align with an opinion they respected.

For childless individuals, as was the case for most participants in the present study, the sought involvement of partners in reproductive decision-making could be expected for at least two reasons. First, romantic relationships can foster psychological well-being for both men and women by providing valuable feedback when one member of the couple needs help to adjust to stressful times. In particular, relationships can provide much needed support during challenging life events and can help facilitate transitional periods (Figueiredo et al., 2008). The months of pregnancy can be stressful and transitional to parenthood. Pregnancy can be perceived as the prelude to important psychological and social changes in the couple's life (Teixeira, Figueiredo, Conde, Pacheco, & Costa, 2009). In this context, relying on one's romantic relationship can be part of a coping strategy during emotionally difficult times.

Second, prenatal testing decision-making can have far-reaching consequences on the future of the family. Individuals may want to ensure the other parent is actively involved in such important choices. It was therefore not surprising that testing intention reported by participants in the present study was strongly predicted by their willingness to comply with their partner's / spouse's perceived preference regarding the procedure. Relationships are not, however, without their difficulties. They can be a source of disagreement, conflict and stress, which can have deleterious effects on individuals' psychological health and adjustment to their new family life (Figueiredo et al., 2008).

The findings about the importance of subjective norms – partner in prenatal testing decision-making have scientific and clinical implications. The present results are helpful in reminding us that issues related to pregnancy may have important ramifications on the lives of prospective parents (Humphreys et al., 2003). In addition, expectations about social support in decisions regarding prenatal testing seem to be gender specific. It appears that women are in greater need of and search for emotional support, whereas men are expected and seemingly willing to meet these needs. However, the success of this 'provider – receiver' dynamic is likely to depend on the quality of the romantic relationship (Rini et al., 2006). Indeed, couples may have diverging views on the test, selective abortion or raising children with special
needs. When prospective parents disagree in their expectations regarding reproduction and the future of their family, couples should be encouraged to discuss and address these issues.

Health professionals can help achieve this goal. First, genetic counsellors could encourage couples to attend medical appointments together and try to foster an environment conducive to high-quality communications (Humphreys et al., 2003; Kukulu et al., 2006). Studies have shown that parents are not always present together at medical appointments (Humphreys et al., 2003). Hence, doctors could invite future fathers to meetings and integrate them in the consultations, by allocating a part of the meeting to discussing couples' issues (Humphreys, Cappelli, Aronovitch, Allanson, & Hunter, 2008). Physicians could also discuss the possible negative consequences of conflicts around prenatal testing and refer to studies showing that conflicts during pregnancy lead to greater distress in women (Humphreys et al., 2008) at a time where they are already emotionally vulnerable. While acknowledging that relationships may have their difficulties, genetic counsellors could point out that relationships can also be a great source of support and that parents who make joint decisions report greater confidence in their choices and in their abilities to cope with possible adverse consequences (Humphreys et al., 2008).

Second, medical professionals could mediate communications between conflicting parents in order to bring about reconciliation. They could help couples prepare for the transitional nature of pregnancy and the stresses often encountered by future parents (Durand et al., 2010), such as the emotional stress from adverse diagnoses (Leithner et al., 2004) or the psychological difficulties associated with terminating a wanted but affected pregnancy (Salvesen, Øyen, Schmidt, Malt, & Eik-Nes, 1997). Physicians could foster environments in which points of disagreement could be raised openly and invite patients to express their expectations and concerns about the pregnancy outcome. Parents could identify their own strengths and weaknesses, and recognise the timing and nature of support needed by the other member of the couple (Humphreys et al., 2003). Together, prospective parents could explore avenues on how to best remedy potential stresses. Such consultations could help restore the buffering function of romantic relationships.
Benefits from negative results

Another key construct in the present study was perceived benefits from receiving negative results. Overall, such diagnoses were perceived as having some benefit. Results from mediational analyses revealed that benefits from negative results positively predicted testing intention. Participants who perceived negative results as valuable were more likely to report greater intention to undergo prenatal testing. This relationship is best interpreted in relation to other findings indicating positive relationships between child-related worry, anticipated emotional distress and benefits from negative results. It seemed that the value attributed to negative results was linked to their perceived ability to provide relief about the health of the foetus and to reduce emotional distress linked to potentially receiving positive diagnosis.

For some couples, the simple fact of being offered prenatal testing by doctors is enough to create a state of anxiety about their unborn child and about the possibility they may receive positive results (Caulfield & Wertz, 2001). This worry may bring about a desire for answers which would reduce their state of uncertainty (B. J. Henderson et al., 2006). Receiving negative test results can provide cognitive closure and reassurance (García et al., 2009). In fact, undergoing prenatal testing to get relief about the health of the unborn has been reported as one of the main reasons for seeking the procedure (García et al., 2008a; Kobelka, Mattman, & Langlois, 2009).

However, parents may receive 'false reassurance' if they wrongly believe that negative test results guarantee the child will be born disease-free (Marteau & Slack, 1992) or if they mistakenly assume the test's infallibility (H. West & Bramwell, 2006). To truly appreciate the meaning of diagnoses, couples need to understand the probabilistic nature of test results and the fact that such results may be subject to human errors. First, test results provide an estimate of the likelihood of a genetic mutation being present. Therefore, they cannot be used to guarantee the child will definitely be born disease free. Second, the reality of genetic testing and laboratories is that patients are not exempt from false positives (i.e. results wrongly indicating the presence of a condition) or false negatives (i.e. failure to detect a genetic malformation). Although extremely rare, misdiagnoses are a medical possibility (Hutson, 2006). As explained by Mark Hughes, founder and chief clinician at Genesis, "there is going to be an error rate in any diagnostics […] because genetic testing relies upon identifying a
very short DNA sequence among the large volume of DNA that comprises the human genome” (Hutson, 2006, p. 14).

Hence, the values of negative test results depend also on the tests' perceived ability to accurately detect foetal abnormalities. This link between the test perceived reliability and the assessment of test results was also apparent in the present study. First, descriptive analyses showed that, overall, participants rated test response efficacy highly. Second, path analysis revealed a positive relationship between test response efficacy and benefits from negative results. Participants who believed in the test's ability to accurately detect foetal genetic anomalies also believed in the value of negative test results.

The main clinical implication from these findings concerns the context in which test results may be perceived as beneficial and in turn, drive patients' motivation to undergo prenatal testing. Health professionals are ethically required to provide patients with information necessary to promote informed consent (Marteau, 1995; Marteau, Dormandy, & Michie, 2001). However, the sole delivery of that information may generate anxiety about the health of the unborn child or that something may be wrong with the pregnancy. These patient-practitioner communications may inadvertently create a context in which prenatal testing may be part of the solution (in reducing parental concern about the health of their unborn children) but also part of the problem (in increasing awareness about possible health problems). Hence, couples' perceptions on the tests' benefits in reducing anxiety may need to be assessed in consideration of the fact that their worries might have been accidentally increased by doctors. Health professionals should try to monitor this possible escalation of negative feelings during their interactions with prospective parents.

Perceived vulnerability
Perceived vulnerability referred to "the subjective estimation of the likelihood of an event" (Gana et al., 2010, p. 142). Descriptive statistics indicated that, in the present study, scores on perceived vulnerability were low. Overall, participants did not believe they would be at high risk of carrying a child with any genetic condition, should they be expecting a child. These results mirrored research showing that minimisation is a frequent response to health risk, especially when this risk is not familiar (Croyle & Ditto, 1990; Croyle & Lerman, 1995). People tend to underestimate their likelihood of being affected by health threats (Lloyd, 2001;
Thoolen et al., 2008). It is possible that participants in the present study also underestimated the likelihood their future children would be affected by a hypothetical genetic condition.

Another explanation for the overall low scores on perceived vulnerability pertained to condition coherence. The Common Sense Model (Leventhal et al., 2003) posits that a disease is unlikely to be perceived as serious if it is not meaningful to the patient. In the present study, participants tended to report low condition coherence. It is therefore possible that a limited understanding of the conditions described in the opening text of the online questionnaire had resulted in participants downplaying their risk estimates.

A third explanation for the overall low scores on perceived vulnerability concerns the possible effect of numeracy on risk perception. Numeracy refers to "the ability to process basic probability and numerical concepts" (E. Peters et al., 2006, p. 407). The complex interactions between risk statistics, risk perception and health behaviour have been widely studied (Bijma et al., 2005; Croyle & Jemmott III, 1996; Hunt et al., 2006; Kelly et al., 2005; Linell et al., 2002; Maule & Svenson, 1993; Michie, Lester, Pinto, & Marteau, 2005; Nagle, Hodges, Wolfe, & Wallace, 2009; Pelletier & Dorval, 2004; Sarangi, Bennert, Howell, & Clarke, 2003; Schapira, Nattinger, & McAuliffe, 2006; A. J. Wright, Whitwell, Takeichi, Hankins, & Marteau, 2009). These studies have shown that lay people's understanding of statistics tends to be limited. For instance, presenting the same risk estimates but in different formats (i.e. percentages versus proportions) is enough to alter people's risk perception. Given that risk estimates motivate interest to undergo prenatal testing (Kobelka et al., 2009), it seemed important to ensure that participants' scores on testing intention were not merely influenced by a misinterpretation of the probabilities. Therefore, in the present study, the risks of carrying a child with a disability were given both in proportion (i.e. '1 chance in 200') and in percentages (i.e. '0.5%'). This clarification was thought to minimise the potential impact of poor numeracy on risk appraisal. However, there is no guarantee that this manipulation alone successfully addressed the issue of numeracy.

Path analysis supported the predictions that greater perceived vulnerability would have a dual (i.e. direct and indirect) influence on testing intention. The direct link accounted for most of the impact of perceived vulnerability on testing intention. Participants who believed they were at low risk of expecting a genetically affected child reported low intention to undergo prenatal
testing. These findings were in line with those reported previously (Fransen et al., 2009; García et al., 2008a; Kobelka et al., 2009; Marteau & Croyle, 1998). One explanation for this dual influence resides in the argument that risk contains a cognitive and an emotional component. The cognitive dimension contains the element of unknown and refers to the objective evaluation of the risk's likelihood. The emotional element, on the other hand, involves the element of dread and refers to the subjective response to risk, and includes the fear of the unknown as well as a perceived lack of control over the threat (Slovic et al., 1991). The cognitive and emotional components of risk have been theorised to be appraised on two parallel levels. The overall appraisal is believed to motivate preventive health behaviour (Croyle & Jemmott III, 1996; Croyle & Lerman, 1995; Linell et al., 2002; E. Peters & Slovic, 1996; Slovic et al., 2005).

The theoretical discussion on the dual influence of risk perception on health behaviour is directly relevant to studies on genetic testing, as DNA technologies tend to be assessed on an emotional and an cognitive level (E. Peters & Slovic, 1996). In the present study, the direct relationship of perceived vulnerability on prenatal testing intention was interpreted as reflecting an emotional response to the health message. The indirect influence seemed to represent a more reasoned evaluation of the positive relationship between perceived vulnerability and testing intention. Results from the path analysis suggested that participants who rated their likelihood of carrying a child with a disability as low were not worried about the health of their children. In turn, these participants anticipated only mild emotional distress from receiving positive diagnosis, were not willing to terminate an affected pregnancy and reported low intention to undergo prenatal testing. This was consistent with studies showing that people do not feel the need to undergo prenatal testing to be reassured about a foetal condition they see as personally irrelevant (Kobelka et al., 2009).

The findings reported above have clear clinical relevance in that they provide additional evidence that the perception of being vulnerable to carrying a child with a disability is a significant predictor of prenatal testing decision-making. Moreover, the results are consistent with previous findings suggesting that the subjective response of risk perception (i.e. feelings of risk and vulnerability) may well account for most of the overall impact of perceived vulnerability on testing intention (Caughey, Washington, & Kuppermann, 2008; Tapon, 2010). Genetic counsellors should be aware that patients' responses to risk estimates may not
necessarily be the result of careful considerations of all the facts presented to them. Finally, the present results about the relationship between perceived vulnerability and testing intention were irrespective of the conditions' characteristics. This is particularly relevant to the anticipated growth of prenatal testing. Scientists have predicted that an increasing number of foetal genetic mutations could be screened for in the near future (e.g., Chiu et al., 2011). Therefore, the issues of risk perception presently discussed are likely to be generalisable to many other conditions.

Religiosity
Another important contributor to testing intention in the present study was religiosity (i.e., the extent of one's religious dedication). Results from descriptive statistics showed that, although most participants reported being affiliated with a Christian religion, they showed low levels of religious commitment (as indicated by participants' low religiosity mean scores). This finding was useful in exemplifying the disparity that might exist between simple religious affiliation and actual religious commitment, and in bringing into question the predictive power of these two measures.

The low levels of religious commitment amongst participants were representative of New Zealand (Statistics New Zealand, 2006a). They may also have been a result of the recruitment method. Participants were self-selected from an advertisement labelled "attitudes towards genetic testing on unborn children". It may be that the semantics used in this title acted as a deterrent for individuals opposed to such application for religious reasons. It is therefore possible that more religiously committed individuals decided against taking part in this study out of principle. Hence, the recruitment strategy might have resulted in biased responses on religiosity.

Results from mediational analyses revealed that religiosity was directly and indirectly (through abortion willingness) negatively linked to testing intention. Low religiosity scores were predictive of greater prenatal testing intention. The importance of religion in family planning has been well documented (Alsulaiman et al., 2010; Alsulaiman & Hewison, 2006; Browner et al., 1999; Fransen et al., 2009; García et al., 2008a; G. Jones, 2009; Kendall, Kendall, Catts, Radford, & Dasch, 2007; Kobelka et al., 2009; Remennick, 2006; Rev Dr O’Brien, 2009; Souka et al., 2010). In the present study, given that most participants who were
religiously committed reported being affiliated with Christianity, the results are best interpreted in light of Christian beliefs towards reproduction.

Christian attitudes towards reproductive technologies are not unanimous. The more traditional view argues that life is a divine creation and that humans should not interfere with reproduction. However, in the Western world, a whole range of reproductive technologies (e.g., in vitro fertilisation, PGD and embryonic stem cell research) have been developed. It could therefore be argued that, to some degree, human beings have become creatures of scientists (G. Jones, 2009). This growing medical control over human reproduction is often perceived by traditional Christians as an intolerable intrusion into the Holy territory. In addition, many strong believers consider the use of technologies, that may result in discarding human embryos, as an unacceptable attack to God's will (e.g., Teo & Calbreath, 2006). It is therefore not surprising that prenatal testing and selective abortion pose theological challenges for some Christians (G. Jones, 2009).

However, the view that reproductive technologies should be objected to on religious grounds is not anonymously adopted by all Christians. First, not all believers are against treatment involving embryonic stem cell. Boomsma, for instance, presented such technologies as having been "developed in response to God’s desire that humans work with him as he develops and redeems his creation and in response to his call to stewardship" (2004, p. 46). Second, there seems to be a lack consensus on the beginning of life amongst Christians. This was acknowledged in The Church of Scotland report 'Embryo Research, Human stem cells and cloned embryos' released in 2006 (G. Jones, 2009). For instance, Shannon and Walter (2003), two Roman Catholic bioethicists, redefined the status of an embryo. They declared that during the three weeks after conception, the embryo has a genetic value (i.e. its genetic uniqueness) but cannot yet be considered as a physical individual. This may help explain why a minority of church bodies have started considering the use of young embryos for research as be acceptable (G. Jones, 2009) and why some Christians are less opposed to prenatal testing or selective abortion than others.

In summary, there does not seem to be one Christian position on the issues of reproductive technologies. This "theological murkiness" (G. Jones, 2009, p. 23) amongst Christians has at least two implications for research on reproductive technologies and for the patient-
practitioner relationship. First, when conducting studies on issues about human reproduction, scientists should avoid grouping participants according to their religious affiliation as this may hinder differences of opinions and therefore produce results of questionable validity. Second, in clinical settings, health professionals should try to respect their patients' religious objections to prenatal testing, but not stereotype couples based on their religious backgrounds. Although secular individuals are unlikely to report religious objections to prenatal testing and/or selective abortion, religiously committed patients may not necessarily object to reproductive technologies on spiritual grounds.

Abortion willingness
Path analysis revealed that abortion willingness was the second strongest predictor of testing intention. Low scores on abortion willingness were associated with low testing intention. The widely reported association between selective termination and prenatal testing (García et al., 2008a; Kobelka et al., 2009; Tapon, 2010; van den Berg et al., 2005) is somewhat related to the technology's aim to allow parents to make informed reproductive decision (Tapon, 2010). Studies have indicated that selective abortion is the preferred course of action for most parents at risk of giving birth to a child with disabilities (Boyd et al., 2008; Caughey et al., 2008; Khoshnood et al., 2006; Kobelka et al., 2009; Souka et al., 2010; Tercyak et al., 2001). These preferences have also been reported in countries such as Argentina and Uruguay where abortion for congenital malformations is prohibited. Yet, studies have shown that parents would choose an unsafe and illegal abortion over the birth of a severely disabled child (Gadow et al., 2006; Paolini et al., 2009; Quadrelli et al., 2007).

Not all positive diagnoses, however, are followed by selective abortion. Some couples will undergo testing and still carry the affected pregnancy to term (García et al., 2008a, 2008b; Khoshnood et al., 2006; Kobelka et al., 2009; Tymstra, Bosboom, & Bouman, 2004). This is in line with some disability support groups who encourage the use of prenatal testing and termination of affected pregnancies (as a way to prevent suffering) but also advocate in favour of social integration of people with disabilities once they are born. For instance, according to The Israeli Organization for Rare Disorders, it is "Important to Know, Important to Test, Important to Support" (Raz, 2004, p. 1861). This brief discussion has shown a wide spectrum of opinions regarding the perceived appropriateness of selective termination and the
relationship between abortion willingness and testing intention. Results from the path analysis have shed some light on the motivation behind these differences of abortion willingness.

**Abortion-specific predictors**

Mediational analyses also supported the hypotheses that abortion willingness would be predicted by attitudes towards disabilities, anticipated coping efficacy, negative consequences and anticipated emotional distress (and religiosity as discussed previously).

**Attitudes towards disabilities and anticipated coping efficacy**

Descriptive analyses showed that, overall, people held positive views towards disabilities and believed they would be able to cope moderately well with a child born with special needs. ANOVAs indicated that men reported significantly more negative views towards disabilities than women. It was also shown that childless participants thought more negatively about disabilities than the participants in the 'expecting' and 'parents' groups.

Path analysis confirmed that, as predicted, higher scores on attitudes towards disabilities and on anticipated coping efficacy predicted lower abortion willingness, which in turn, was associated with lower testing intention. Participants who held positive views about disabilities or believed they would be able to cope with a child with special needs found it less permissible to terminate an affected pregnancy and were also less interested in undergoing prenatal testing. The role of perceived coping ability in prenatal testing intention has been reported before (Carroll et al., 2000). Typically, women who believe that looking after a child with special needs was beyond their physical and mental abilities opted in favour of termination.

**Negative consequences and anticipated emotional distress**

Descriptive statistics and ANOVAs showed that participants tended to believe that the conditions described in the opening scenario could have negative consequences on their future child's quality of life. This was particularly the case for the early-onset and the fatal conditions. Results also revealed that participants expected to feel mildly emotionally distressed if they received a positive diagnostic. This was even more so when the condition was fatal.
Mediational analyses indicated that higher scores on anticipated emotional distress and negative consequences predicted greater abortion willingness. Participants were more likely to consider selective abortion if they perceived receiving a positive diagnosis as a stressful event and if they believed the condition would impact negatively on their child's quality of life. The role of anticipated emotions in decision-making has long been recognised (McCoyd, 2008). The children's imagined quality of life, their welfare and overall happiness have also shown to influence family planning. If parents believe that a genetic condition would impact negatively on the well-being of their future children, then they are more likely to decide against the birth of such children (Blyth & Cameron, 1998; Boivin & Pennings, 2005; García et al., 2008a; García et al., 2009; Murray & Kaebnick, 2003; Parker, 2007; Pennings, 1999; Raz, 2005; Savulescu, 2002).

The influence of negative consequences on abortion willingness may be related to the moral dilemma parents face when making reproductive decisions. The lack of therapy or treatment for most of the conditions currently screened for during pregnancy may lead parents to an inevitable conflict of interests. Upon receiving positive diagnoses, parents need to choose between their duty to respect life and their responsibility to alleviate suffering (Brookes, 2001; Getz & Kirkengen, 2003). These highly desirable principles are linked to two mutually exclusive options: respecting life by carrying the pregnancy to term means bringing about less-than-optimal life conditions, whereas alleviating suffering by terminating the pregnancy means disrespecting an unborn child's right to life (Bryant et al., 2005; Clancy, 2010; Lassetter, Mandleco, & Roper, 2007; McCoyd, 2008; Sawyer et al., 2006). Studies have suggested that when such ethical dilemmas arise, parents justify their decision to undergo selective abortion by their desire to act in their children's best interests, acknowledging that their decisions to prevent suffering may violate the principle of parental unconditional love for their children (García et al., 2009).

The findings reported above have direct ethical and clinical implications. First, they inform the ethical debate surrounding prenatal testing, disabilities and selective abortion. Some disabilities right activists have opposed prenatal testing on ethical grounds. According to them, this technology is being morally objectionable because it inevitably links disabilities to abortion and indirectly undermines the social status of people with disabilities (Parens, 2009; Parens & Asch, 1999, 2003; Parens & Knowles, 2003). They believe prenatal testing is "the
Chapter 2: Discussion

The greatest insult" as it implies that "some of us are 'too flawed' in our very DNA to exist; we are unworthy of being born" (Saxton, 1997, p. 308).

Results from the present study did not support this argument known as the "disability critique" (Raz, 2004, p. 1858). Participants in general did not report low attitudes towards disabilities and their abortion willingness did not appear to be motivated by their overall judgement on people with disabilities, but by specific concerns about their child's quality of life and happiness. It has been argued that ethical issues with little personal relevance (such as social views on the conditions of people with disabilities) are unlikely to influence people's decisions about deeply personal issues (Caulfield & Wertz, 2001). The other aspect worth considering is that having a child with disabilities is not necessarily seen as a negative outcome. Such events can actually have positive ramifications on the family (García et al., 2009). Hence, people's decision to terminate an affected pregnancy is more likely to reflect concerns about their own children than their overall views on people with special needs (World Health Organization, 2002).

This ethical discussion has a major implication for health professionals. Couples may opt for abortion either because they do not want to parent 'any' children or because they do not want to parent a 'particular' child (e.g., one born with an undesirable characteristic). Genetic counsellors should be aware of this 'any/particular' distinction (A. Taylor, 2008) as their description of the condition being tested for may influence reproductive choices of parents still undecided about the pregnancy outcome. However, the same description might be less relevant to couples opposed to giving birth to any genetically malformed child. These couples are more likely to be interested in technical information about termination of pregnancy than in information about a life with a child born with the disability under investigation. Health professionals should try to remain sensitive to their patients' reproductive wishes.

Limitations

The results reported thus far need to be interpreted in light of the study's methodological and theoretical limitations. The first limitation pertains to the sample not being fully representative of the general population. In particular, the educational backgrounds of the
participants were higher than the national average. It is possible that responses obtained in the present study (e.g. on abortion willingness) were influenced by these characteristics. However, the role of education on issues related to reproductive technologies was not assessed. It is therefore not possible to ascertain the role of education on participants' responses. Second, some participants were recruited online. This recruitment mode may have created a self-selection bias. For instance, it is possible that this study appealed more to women, which could have explained the gender imbalance, despite active efforts to invite men. However, it should be noted that gender imbalances have been commonly reported in studies on reproductive choices (e.g., Frost, Myers, & Newman, 2001; Lawson, 2006). Although the recruitment strategy used in the present study might have resulted in an under-representation of male participants, it nonetheless had the great potential of reaching a wide range of people throughout the whole of New Zealand.

Two theoretical limitations also need to be acknowledged. First, the role of dispositional affects, such as trait anxiety, was not accounted for. Affective states have shown to have informative and directive influences on judgement and decision-making (Schwarz & Clore, 1983; W. F. Wright & Bower, 1992). In the context of health protective behaviour in general (Cameron & Chan, 2008) and in prenatal testing (Brisch et al., 2005; Lobel, Dias, & Meyer, 2005), evidence suggests that anxiety plays an important role in decision-making. However, the role of such personality trait was not accounted for. This limitation will tentatively be addressed in Study Three of the present research project.

The second theoretical limitation concerned the unexplored role of the perceived likelihood of incidental miscarriage (which is a known complication of invasive procedures) on testing intention. Studies have shown that when deciding whether to undergo these invasive procedures, prospective parents weigh the risks of giving birth to a child with disability with the risks of miscarrying it (French, Kurczynski, Weaver, & Pituch, 1992; Halliday, Lumley, & Watson, 1995; Halliday et al., 2001; Hunt et al., 2006; Jaques et al., 2010; Kobelka et al., 2009; S. M. Lewis, Cullinane, Carlin, & Halliday, 2006). Despite the importance of iatrogenic miscarriage in reproduction choices, this construct was not included in the present study or in the latest model of prenatal testing decision-making (van den Berg et al., 2008). Study Three will provide an opportunity to explore attitudes towards procedure-related miscarriage in prenatal testing decision-making.
Conclusion

Several findings emerging from Study Two were particularly noteworthy. The most striking result was that intention to undergo prenatal testing did not depend on the conditions' characteristics or the participants' personal differences. Participants were divided about whether to under the procedure, but this range of opinions was not due to the conditions' severity, age of onset, the participants' gender or family status. Instead, testing intention was influenced by a series of social, emotional, cognitive and ethical constructs. In particular, individuals reported lower testing intention if 1) they perceived their vulnerability to carry an affected foetus was lower, and/or 2) they were (mildly to strongly) opposed to selective abortion. This reluctance towards termination of pregnancy was driven by greater attitudes towards disabilities and greater anticipated coping efficacy. On the contrary, individuals who reported greater testing intention reported 1) greater willingness to comply with their partner's, and to a lesser degree, their family's perceived preference towards the procedure; 2) lower religious commitment, and; 3) greater beliefs that receiving negative test results was beneficial in relieving anticipated emotional stress from receiving a positive diagnostic (given the test results would be reliable and accurate). Together, these results suggested that declining prenatal testing may be driven by personal assessments of vulnerability to genetic mutations and of perceived coping abilities, whereas social expectations, search for reassurance and cognitive assessment of the test may drive testing intention.

Choices about family planning can have a profound impact on people's lives. It is therefore crucial that patients receive appropriate support during these decision-making times. In order for medical professionals to be able to provide this type of assistance, they must first understand processes underlying such decisions. This conceptual framework illustrates multiple ways a decision about prenatal testing may be reached. Provided it is verified through further research, this model represents a scientific development for at least three reasons. First, it expands on previous models of prenatal testing decision-making. Second, this model held across the condition severity and onset age. Third, it reveals that prenatal testing decision-making is not influenced merely by cognitive evaluation of the procedure but by a complex interaction of perceived social expectations, emotional concerns, ethical values and cognitive assessment of the test results.
The main implication of this model is in showing that future parents are likely to have predetermined values about family planning before entering a clinical setting. Their most salient concerns may not be medical facts and population risk estimates. Hence, to promote informed decision (i.e., one that is knowledge-based and value congruent), medical professionals should refrain from adopting a purely biological approach to prenatal testing. While covering medical information about the procedure and the condition(s) under investigation is an important part of genetic counselling, broader issues about reproductive options should also be addressed. Clinicians should aim to foster an environment in which patients could explore all the relevant dimensions of such decisions. Prenatal testing decision-making is a relatively new area of research. The Human Genome Project is expected to keep providing knowledge of direct relevance to reproductive choices. The amount of information available to future parents is therefore expected to keep increasing and to keep on presenting dilemmas for future parents. Given the sensitive nature of this ever-increasing knowledge, future research should aim to determine how individuals' affective traits (such as anxiety) and information modality may impact on prenatal testing decision-making. These aspects are examined in the next study.
Study Three
CHAPTER 12

Study 3 – Introduction

Study One of the present research project proposed a model of the process of prenatal testing decision-making (Figure 3.7). This model theorised that testing intention was influenced by a series of social factors (e.g., subjective norms – partner), emotional responses (e.g. anticipated emotional distress), ethical dilemmas (e.g., abortion willingness) and cognitive evaluation (e.g., perceived benefits from receiving negative results). Study Two validated these theoretical assumptions. Study Two also showed that personal characteristics (such as gender and family status) and condition characteristics (i.e. severity and age of onset) could further complicate reproductive decisions. Thus far, this research project did not provide opportunities to explore the influence of perceived risk of procedure-related miscarriage on testing intention, nor to relate the process of decision-making to enduring personality traits or to the way health messages are delivered.

Extensive information about the risks and benefits of prenatal testing is usually provided to couples considering whether or not to undergo the procedure. It has been shown that being mentally prepared for possible future outcomes facilitates long-term psychological adjustment (Marteau, 1995; Marteau, Johnston, et al., 1992; Thornton et al., 1995). Health information may be delivered in writing, discussed verbally during consultations and/or watched on audio-visual clips (Marteau, 1995). This abundance of resources is particularly helpful given that patients vary in the nature and amount of information they need to reach a decision (Ende, Kazis, Ash, & Moskowitz, 1989). However, with increased awareness about the risks related to prenatal testing, such as those pertaining to iatrogenic miscarriage and to possible health threats to the foetus, come risk-related negative affect. These emotional responses are likely to be exacerbated by personal characteristics, such as trait anxiety. However, little is known about the roles of 1) the mode of information delivery; 2) the perceived likelihood of procedure-related miscarriage; 3) trait anxiety, and; 4) the interaction between modality and trait anxiety, on people’s cognitive engagement, emotional responses and willingness to engage in prenatal genetic testing.
In an attempt to extend scientific knowledge of choices pertaining to family planning, Study Three extended the focus of the previous two studies of the present research project by including different aspects of information about prenatal testing and about the risks of procedure-related miscarriage. The present study had four aims. They consisted of 1) testing the roles of information modality; 2) quantitatively evaluating the influence of perceived likelihood of miscarriage on testing intention, and; 3) of trait anxiety in emotional responses to issues surrounding prenatal testing and intention to undergo prenatal testing. The fourth aim was to assess the combined effects of trait anxiety and modality on these responses.

The present chapter contains five sections. The first section presents the different modes of information used to educate prospective parents about prenatal testing and discusses their influence on learning. The second section discusses the relationship between attitudes towards incidental miscarriage and intention to undergo prenatal testing. Section Three describes the role of trait anxiety in the condition-related variables (i.e. anticipated emotional distress, child-related worry, anticipated coping efficacy and negative consequences), perceived likelihood of miscarriage, perceived benefits from negative results and testing intention. The fourth section considers the combined influences of trait anxiety and information modality on these same variables, given that trait anxiety and modality co-occur in the decision-making context. The final section expands on the rationale and summarises the hypotheses for the role of perceived likelihood of iatrogenic miscarriage, trait anxiety and modality of information on reproductive decision-making.

**Modality of Information and Prenatal Genetic Testing Decision-making**

Genetic counsellors have the ethical obligation to promote independent and informed health decision-making (Marteau, 1995; Summers, Langlois, Wyatt, & Wilson, 2007; Weil, 2003). This imperative usually results in providing prospective parents with extensive non-biased and non-directive information about the procedure and the condition(s) tested for (Bryant et al., 2001; Marteau, 1995; Summers et al., 2007; Weil, 2003). Health information may be presented in at least one of the following three formats: verbal, written and audio-visual (C. Stern & Lockwood, 2005). Verbal communication, while easily forgotten (Kessels, 2003), is
an important part of client-practitioner consultations. Face-to-face consultations are the designated venues through which clinicians fulfil their informative role (Marteau, 1995).

Written information is provided through many different sources such as leaflets, commercially produced book/booklets, standard and personal letters written by clinicians (C. Lewis et al., 2007; Shepperd et al., 2006). A meta-analysis (C. Stern & Lockwood, 2005) revealed that pamphlets/booklets were the most commonly used form of patient education within clinical settings. Similar findings have since been reported in screening programs (Fox, 2006) and prenatal screening (Dahl, Kesmodel, Hvidman, & Olesen, 2006). Printed instructions of medical facts can have numerous advantages for the practitioners and patients alike. For instance, clinicians can personalise written information and provide selected facts to specific clients. Pamphlets are also a cost-effective way to educate potential users (Dixon-Woods, 2001). In addition, patients can store printed information and refer to it at any stage throughout the decision-making process. Studies have shown that written documents can improve patients' comprehension and recall of important information (e.g., C. Bennett, 2007).

The third modality of information is audio-visual clips or presentations. Graphic pictures have been increasingly used in health awareness campaigns on the damaging effects of alcohol and tobacco in several Western countries (Dadich, 2009; Fathelrahman et al., 2009; Stanbrook & Hebert, 2010; Wilkinson & Room, 2009), including New Zealand (Parackal, Parackal, & Harraway, 2010). A meta-analysis (C. Stern & Lockwood, 2005) indicated that the effectiveness of audio-visual supports in preparing patients for medical interventions remains to be determined. However, the evidence currently available suggests that explicit animated images are useful in clarifying complex technical information. Instructional videos have a clear potential to improve patients' understanding of medical interventions, and even more so for individuals with limited medical knowledge (Best, Rowe, Ozuru, & McNamara, 2005). Audio-visual materials differ from written and audio messages in that they expose people to spoken words and explicit images.

Mayer (2008) provided a useful explanation on how multimedia instructional messages may be designed to foster learning. The author reviewed theoretical and empirical evidence on psychology and learning, and showed that research-based theories of learning can be effectively applied to developing educational materials. The Cognitive Theory of Multimedia
Learning (Mayer, 2008) is based on at least two assumptions of learning. First, only a small amount of visual and audio information can be processed by the human brain at one time. Second, these two types of information are processed separately along two separate pathways (Mayer, Heiser, & Lonn, 2001). It has been further theorised that, if these two premises are respected when designing instructional multimedia materials, then such supports can maximise learning.

The assumption regarding the brain's limited ability to process vast amounts of data at once implies that too much information can lead to cognitive overload, which can, in turn, impede learning (Mayer, 2008). Hence, for educational multimedia messages to be informative, cognitive energy should not be 'wasted' on superfluous information and cognitive overload should be avoided. At least four strategies exist to limit the amount of non-relevant information presented to learners. First, the content of narrated animations should avoid including pieces of information that are not central to the key message. It has been shown that concise information helps people remain mentally focused on the facts to be learnt (Mayer et al., 2001; Mayer & Jackson, 2005). Second, the layout of multimedia instructional materials should not require people to attend to several parts of large visual spaces, but should present visual information in selected spaces. This should help people remain visually focused on the key aspects of the material (Mayer, Steinhoff, Bower, & Mars, 1995; Moreno & Mayer, 1999). Third, whenever verbal and visual instructions are used to explain a same point, they should not be presented successively, but at the same time. Simultaneous presentation of words and images can help learners connect the information more easily (Mayer, Moreno, Boire, & Vagge, 1999). Fourth, in the absence of pictures, spoken instructions are easier learnt when they are accompanied by written words on the screen, than when they are presented alone (Mautone & Mayer, 2001; Stull & Mayer, 2007). Altogether, the content, the layout, the combination of two and written emphases of spoken words can be used effectively in animated instructional videos to by-pass humans' natural limited cognitive abilities and promote learning.

With regards to information being processed along two pathways, at least two strategies exist to ensure that information, even if complex, is channelled all the way into working memory, where learning takes place (Mayer, 2008). First, long explanations should not be presented continuously. Instead, they should be broken into short and well-paced segments. Pausing
between important pieces of information provides learners with opportunities to assimilate each part of the material before being exposed to the next one (Mayer & Chandler, 2001; Mayer, Dow, & Mayer, 2003). Second, graphics and printed words should not be used concurrently to present the same fact, as too much visual information can lead to visual overload. Information is better assimilated when it is processed by the auditory sensory memory and by the visual sensory memory simultaneously. Studies have shown that combining pictures with verbal information facilitates understanding, even when messages are complex (Harskamp, Mayer, & Suhre, 2007; Moreno & Mayer, 2000). Altogether, evidence suggests that segmenting messages and using multimedia can help information being brought into working memory, which should foster learning.

In summary, a theoretical understanding of how people process information can be valuable in designing instructional materials aimed to maximise understanding and learning. In particular, the use of selected spoken words together with clear and well-paced animated images should be more effective in increasing people's knowledge and understanding, than the use of (spoken or written) words alone. Applied to the context of prenatal testing, this summary implies that audio-visual information about the tests would be more likely to foster learning, than the same information presented verbally or in print only. Videos freely available on the internet typically explain and show that an ultrasound is used to locate the foetus, to ensure that the needle used during amniocentesis is inserted into a safe location into the woman's uterus. The first hypothesis was that individuals watching such videos would perceive the procedure as less likely to result in miscarriage, than would people reading or hearing the same explanation.

Perceived Likelihood of Iatrogenic Miscarriage and Testing Intention

One type of information regularly provided to prospective parents concerns the risks of prenatal testing. Two types of risks exist: 1) risks related to the probabilities of finding out genetic anomalies in the foetus, and; 2) risks related to the possibility of losing the pregnancy as a result of the invasive procedure (American College of Obstetricians and Gynecologists, 2007).
The main aim of prenatal testing is to provide prospective parents with information about the health of the foetus. For parents, not knowing about the genetic make-up of their unborn child may be worrying. The prospect of giving birth to a child with special needs can be even more concerning (Chan et al., 2006; Chan, Sahota, Chan, Leung, & Lau, 2009). It has been hypothesised that uncertainty is aversive and that not knowing about a feared outcome can trigger negative affect, such as fear, worry and distress (Baum, Friedman, & Zakowski, 1997). It has also been argued that uncertainty about a health threat can be an important determinant of health behaviours. The need to reduce aversive uncertainty-related emotions can drive intentions to engage in uncertainty-reducing behaviours (Baum et al., 1997). Consequently, parents may perceive prenatal testing as a way to obtain an answer to their troubling questions about the health of their unborn children.

However, intention to undergo prenatal testing may be hampered by the possibility that such behaviour could paradoxically lead to greater, not lesser, stress. Indeed, parents who choose to take the test in a bid to gain cognitive closure about the health of the foetus may receive positive test results indicating the presence of a genetic condition. Such diagnoses can be stressful as most mutations currently screened for during pregnancy cannot yet be cured. These parents also run the risk of losing the pregnancy, as invasive prenatal tests carry a small risk (between 0.5% to 1%) of iatrogenic miscarriage (American College of Obstetricians and Gynecologists, 2007).

Studies have shown that incidental miscarriage is a common source of concern for parents considering invasive procedures (e.g., Tsianakas & Liamputtong Rice, 2002). Such prospects seem to be particularly stressful when taking the test is associated with anticipated guilt of losing a possibly healthy child (García et al., 2008b). Anxiety related to undergoing the procedure has been shown to act as a deterrent against taking the test, but not always. It seems that procedure-related anxiety can be overridden if parents anticipate the test results will bring relief about the health of the unborn child (Brisch et al., 2005; Ferber, Onyeije, Zelop, O'Reilly-Green, & Divon, 2002; Kukulu et al., 2006; Tercyak et al., 2001).

In summary, the paradoxical 'benefits versus new risks' scenario discussed above is likely to influence parents’ decision to undergo prenatal testing. In particular, people are likely to decline prenatal testing if they believe the procedure is more risky than beneficial. This line
of reasoning gave rise to the second hypothesis for the present study. More specifically, it was expected that people who believed that losing a child as a result of the invasive procedure was likely, would report lower intention to undergo prenatal testing.

**Trait Anxiety and Reproductive Choices**

The hypothesised relationship between perceived likelihood of incidental miscarriage and testing intention are likely to be moderated by intrapersonal characteristics that shape responses to threat (Baum et al., 1997; Shoda et al., 1998), such as trait anxiety. Trait anxiety has been defined as a dispositional proneness to experience anxiety-related thoughts, emotions, and somatic sensations in response to cues of threat, risk, or uncertain outcomes (Eysenck et al., 2007). Some people generally report higher levels of anxiety, regardless of the situation (Brisch et al., 2005; Pacheco-Unguetti, Acosta, Callejas, & Lupianez, 2010). This personality dimension is particularly relevant to risk perception and decision-making in the context of genetic testing. The moderating role of trait anxiety on health-related behaviours (through its on attention processing, affective responses and cognitive evaluation of health threat information) has been theoretically recognised (Baum et al., 1997; L. D. Cameron, Young, & Wiebe, 2007; Eysenck et al., 2007; Mathews & MacLeod, 2005; Pacheco-Unguetti et al., 2010; Shoda et al., 1998). While studies have provided empirical support for the existence of a relationship between anxiety and behaviour, they have, however, yielded mixed results on how trait anxiety motivates health behaviour (Barnett & Breakwell, 2001; Bouyer, Bagdassarian, Chaabanne, & Mullet, 2001; Hellesøy et al., 1998; Kallmen, 2000). A theoretical account of the role of anxiety on attention may help explain these empirical differences.

Attention is best understood, not as a unique system, but as a complex entity made up of several networks (Corbetta, Patel, & Shulman, 2008). Posner and Petersen (1990) have proposed the existence of three attentional networks, each activating separate areas in the brain and each having different function. The first subsystem is associated with the conscious processing of information. The second attentional division is responsible for maintaining a state of alertness and sensitivity, whereas the third network is responsible for selecting information. The last two functions of attention (i.e., alertness and selection) are particularly
relevant to the theoretical discussion about the role of anxiety on cognitive process, emotional responses and behavioural intention.

Individuals with higher trait anxiety are prone to exhibiting a consistent state of high alertness and to directing their cognitive resources to selecting cues about risk (Derakshan & Eysenck, 1997; Shoda et al., 1998; Vasey, El-Hag, & Daleiden, 1996). In the context of health, anxious individuals are thought to be cognitively biased to pay more attention to messages containing a health threat. People with greater trait anxiety have been theorised to be hyper-vigilant to health messages containing threatening information, to scan for stressful medical information and to actively search for distressing facts (Miller, 1995). Anxious individuals have the tendency to attend preferentially to worry-provoking health information and to be more active in their search for related information (L. D. Cameron, 2003; Öhman, Flykt, & Esteves, 2001; Raghunathan & Corfman, 2004). Instead of distracting themselves from potentially health-threatening information, they cognitively rehearse the aversiveness and severity of medical facts (Wells & Matthews, 1996). Applied to studies on prenatal testing, individuals with higher trait anxiety would be expected to attend more intensively to information about risks related to pregnancies, than people with lower trait anxiety.

The attentional biases mentioned previously have been hypothesised to be linked to emotional biases, such as the experience of negative emotional responses through distortion of beliefs and expectations (Shoda et al., 1998). Anxious individuals tend to anticipate the future through pessimistic lenses and to attribute ambiguous cues (e.g., symptoms) to threatening causes (e.g. illnesses or harmful conditions) (L. D. Cameron, Leventhal, & Love, 1998). Compared to people with lower trait anxiety, anxious individuals are likely to expect worse outcomes, to have little hope for their future, and to have more negative views of their own abilities to cope with feared outcomes (Kallmen, 2000). All these cognitive appraisals produce fear-related emotional responses, such as distress and anxiety. In the context of health, anxious patients are therefore more likely to exaggerate the severity of a health threat and to experience greater anticipated distress (Lerman, Daly, Masny, & Balshem, 1994; Miller, Fleisher, et al., 2005; Miller, Roussi, et al., 2005; Wakefield et al., 2007).

The above discussion on the role of trait anxiety on emotional responses to health threat information can be applied to studies of prenatal testing decision-making. Compared to
individuals with low anxiety levels, anxious people should develop more detailed mental representations of foetal abnormalities, of undergoing the procedure, of the moment they could receive the test results and of their future lives with a child with special needs. These assumptions gave rise to the third set of hypotheses. Compared to individuals with lower trait anxiety scores, anxious people would be expected to: 1) worry more about the health of the unborn child; 2) perceive genetic disabilities would impact more negatively on the child's quality of life; 3) believe they would be more likely to miscarry as a result of undergoing the procedure; 4) anticipate receiving positive diagnoses as more emotionally stressful; 5) value negative test results as beneficial, and; 6) anticipate being less able to cope raising a child with disabilities.

Thus far, this section has addressed how that trait anxiety can distort emotional and cognitive appraisals of potential health threats. These emotional and cognitive biases have, in turn, been theorised to influence health decision-making and health behaviours. According to the Common-Sense Model (Leventhal et al., 2003), both emotional responses and cognitive assessment of health threats motivate health behaviour in parallel and partially independent ways. The Common Sense Model has been successfully used as a theoretical framework to explain people's responses and adjustment to a broad range of health-related threats (Fischer et al., 2010; Hamilton-West, Milne, Chenery, & Tilbrook, 2010; Kaptein et al., 2010; Nouwen, Urquhart Law, Hussain, McGovern, & Napier, 2009; Quiles & Terol, 2011), including decisions relating to genetic testing (e.g., L. D. Cameron et al., 2009).

It could be argued that, if trait anxiety can impact on cognitive and emotional responses and that if, in turn, these responses can influence health behavioural intention, then trait anxiety should impact indirectly on intention to engage in health behaviours. It has increasingly been argued that anxiety plays a moderating role in regulating illnesses and health behavioural intention (L. D. Cameron, 2003; L. D. Cameron et al., 2007; Conrada & Coups, 2003), by influencing efforts to control fear and danger, and preparing people for action (L. D. Cameron & Chan, 2008). Anxious individuals should therefore be more psychologically prepared for preventive or protective action than less anxious patients (L. D. Cameron & Chan, 2008). They should report greater intention to engage in health threat preventive behaviour and not, as this could intuitively seem to be the case, display 'fatalism' or avoidance behaviour towards the health threat, (L. D. Cameron & Diefenbach, 2001; Das, de
Wit, & Stroebe, 2003). To date, there seems to be no clear evidence that individuals with greater levels of trait anxiety do indeed engage more in health preventive or protective behaviours. In the context of reproductive decision-making, it could be hypothesised that anxious participants would report significantly greater testing intention than less anxious participants.

**Combined Roles of Modality of Information and Trait Anxiety on Prenatal Testing Choices**

The theoretical assumption presented above about the link between trait anxiety and genetic testing intention did not account for the role of modality of information. While it has been shown that modality of information and trait anxiety can, independently, have an impact on prenatal testing choices, in reality, these two variables are likely to interact with each other and to further complicate reproductive decision-making. However, the extent to which trait anxiety and information modality can, together, generate emotional responses and motivate preventive health behaviour remains unclear.

**Moderating roles of anxiety and modality on condition-related variables and perceived likelihood of miscarriage**

The present chapter has, thus far, presented a few key points of great relevance to the present study. In the context of prenatal testing and reproductive decision-making, information presented to prospective parents is likely to address a range of possible stressful events. Such potentially distressing events may include the prospects of miscarrying as a result of the procedure, of receiving a positive diagnosis, and of living with a child with special needs. All of these eventualities can trigger emotional responses. These negative affective reactions are likely to be exacerbated in anxious individuals, and even more so if the health message is presented in audio-visual format. Trait anxiety has been associated with greater demands of information but also with greater attention, encoding, and cognitive processing of that information. Hence, multimedia instructional materials, which are rich in audio and visual content, should meet the needs for information of anxious people better than messages delivered in written or verbal formats only. Once in possession of this information, anxious people (who tend to have pessimistic views of about the future and their own coping abilities;
Kallmen, 2000) are likely to be more affected than less anxious people are, even though both groups had watched the same health message.

This discussion gave rise to the following hypotheses. It was predicted that the differences in responses to condition-related variables associated with trait anxiety would be exacerbated if the information is presented through multimedia educational materials. In particular, amongst individuals being informed about prenatal testing through video-clips, those with higher trait anxiety would be expected to report 1) greater worry about the health of the foetus; 2) greater anticipated emotional distress from positive test results; 3) greater negative consequences of living with a genetic condition; 4) lower anticipated ability to cope with a child with special needs, and: 5) greater perceived likelihood of incidental miscarriage.

**Moderating roles of anxiety and modality on testing intention and perceived benefits from negative results**

Anxious individuals are likely to find themselves in a partially self-generated, anxiety-provoking cycle. Indeed, their tendencies to direct their attention to threatening information make them more prone to react with emotional distress. Upset, they may look for reassuring information. This could help explain why anxious individuals are more demanding of medical professionals (Miller, 1995) and show greater interest in messages about health threat than less anxious individuals do (L. D. Cameron & Diefenbach, 2001; Das et al., 2003).

Being exposed to comprehensive information about the different options and possible outcomes can help patients validate their fears, attach a meaning to their experiences and allow them to emotionally rehearse potential outcomes. In essence, this can help individuals be prepared for their options. Equipped with answers to their many questions and instructions about their options, anxious patients may be motivated to play an active part in their medical future (Miller, 1995). Hence, a seemingly contrary pattern of thoughts and beliefs could arise whereby negative beliefs about a condition could actually be associated with positive attitudes towards a preventive health behaviour. Studies on genetic testing have shown a positive relationship between high anxiety and interest in screening (e.g., Michie et al., 2002). For instance, it has been shown that people high in cancer worry were more interested in genetic tests and more prone to view these tests as having beneficial consequences than less worried individuals (L. D. Cameron & Diefenbach, 2001). Using genetic testing may be
viewed as a way to cope with specific-distress by increasing control over the health threat (Lerman et al., 2002).

Applied to the context of prenatal testing, it is suggested that audio-visual materials are likely to increase the salience of the issues related to reproduction in anxious individuals. These people would be more likely to report stronger beliefs in testing benefits and greater intentions to seek prenatal testing. Hence, it was hypothesised that, when presented with multimedia messages about prenatal testing, individuals high in trait anxiety would report 1) greater benefits from negative results, and; 2) greater testing intention, than those less anxious.

**Rationale, Aim and Predictions**

Decisions about prenatal testing may be influenced by attitudes towards procedure-related miscarriage and a series of cognitive and emotional factors. These relationships are likely to be moderated by trait anxiety and the format in which information is delivered. It is important to understand the role of trait anxiety in decisions regarding family planning, as trait anxiety is one of the primary personality characteristics unlikely to be amenable to change. Trait anxiety is therefore likely to systematically influence reactions to prenatal genetic testing. By understanding the combined roles of trait anxiety and information modality, health professionals and educational organisations could tailor instructional materials in such a way as to address and support the needs of high-anxious individuals.

It is also important to understand the role of modality on decision-making as it has been predicted that the ever-growing field of reproductive technologies will soon offer prospective parents the ability to test for hundreds of genetic mutations at one time, in a much faster and cost-effective way (Chiu et al., 2011; C. F. Wright, Quake, Bianchi, & Wald, 2011). With these growing clinical opportunities come the growing requirements to inform users about their possible options. The need to establish the role of modality in choices pertaining to reproduction is therefore becoming increasingly pressing.

Prenatal testing decision-making has been researched in a few Western countries such as England, the United States of America and Australia (Dixon-Woods, 2001). However, such
studies remain sparse in New Zealand. In fact, the interactions between provision of information and personality in determining prenatal genetic decision-making seem to have been largely ignored worldwide. Such studies would have great clinical utility for health professionals and patients. They could help increase practitioners' knowledge of the way anxious people react to potentially anxiety-provoking information. An increased understanding of psychological responses from anxious individuals should lead to health professionals being better able to ensure patients' choices do not result in adverse psychosocial consequences, but instead, reflect their needs and preferences.

The present study had four aims. The first aim was to assess the relationship between perceived likelihood of procedure-related miscarriage and testing intention. The second and third aim were to investigate the independent roles of information modality and trait anxiety on cognitive and emotional responses to issues related to prenatal testing and intention to undergo the procedure, respectively. The fourth aim was to assess the combined roles of trait anxiety and modality of information on these same variables. To achieve these aims, participants' levels of trait anxiety were assessed. Then, volunteers were randomly presented a health message in one of three possible modalities: text, audio or video. Finally, participants rated a series of items measuring the constructs of interest.

Several predictions were proposed. First, it was expected that greater perceived likelihood of iatrogenic miscarriage would predict lower testing intention, regardless of modality. Second, individuals in the video group were predicted to report lower perceived risk of miscarriage than participants in the audio or text groups. Third, participants with higher scores on trait anxiety were expected to report greater child-related worry, greater anticipated emotional distress, greater negative consequences, lower anticipated coping efficacy, greater perceived likelihood of miscarriage, greater benefits from negative results and greater testing intention, than participants with lower anxiety scores. Fourth, Trait Anxiety x Modality interaction effects were expected for the same condition-related and test-related variables. In particular, the associations between trait anxiety and the variables of child-related worry, anticipated emotional distress, negative consequences, anticipated coping efficacy, perceived likelihood of miscarriage, benefits from negative results and testing intention were predicted to be greater for those in the video group than for participants in the text and audio groups. The next chapter describes the method followed to collect data needed to test these hypotheses.
CHAPTER 13

Study 3 – Method

The present chapter describes the methodology used to collect data for testing the predictions proposed in Chapter 12 and consists of five sections. The first section presents the study design. The second section describes the three information modalities used to present the health message to participants, demographic data of whom are summarised in Section Three. The fourth section details the measures used to collect views about prenatal testing and related issues. Finally, Section Five outlines the procedures chosen to recruit and collect data.

Study Design

The present study utilised a between-subjects quasi-experimental design with Information Modality (text versus audio versus video) as the manipulated independent variable and trait anxiety as a moderating personality variable. People's day of birth was used to randomly allocate participants to one of the three modality conditions. The seven dependent variables were: child-related worry, anticipated emotional distress, negative consequences, anticipated coping efficacy, perceived likelihood of miscarriage, benefits from negative results and testing intention.

Information Modality

Text

The 'text' modality (Appendix T) contained a similar health message to the one used in Study Two of the present research project. The main difference was that prenatal testing was introduced as a way to detect genetic mutations of various ages of onset and severity. Participants allocated to the text group read that "[...] some of these disabilities can be present from birth and be fatal (such as Cystic Fibrosis) or nonfatal (such as Down's syndrome). They may also develop later in life, and again, they may be fatal (such as breast cancer) or not (such as bipolar disorder)". No pictures, diagrams or other visual illustrations were presented with the printed message.
Audio

The 'audio' message contained a recorded version of the text message used in the 'text' group. It lasted three minutes.

Video

The 'video' message was a combination of animated images (illustrating a pregnant woman undergoing CVS and amniocentesis) with the recorded message used in the audio group. It lasted three minutes. This short narrated animation was one of many educational clips freely accessible online from the Blausen Medical website (http://blausen.com/home). Approval to use this copyrighted video-clip was sought and obtained. This video was selected for its theoretical relevance to the present study. In particular, it was consistent with the assumptions of the Cognitive Theory of Multimedia Learning regarding humans' limited cognitive capacity and channelling of information (Mayer, 2008). The short animated movie described only important information, so that people's limited cognitive abilities were used to process only relevant material. The clip had a good 'central' layout (so images were easy to follow) and presented words and images simultaneously (to facilitate connections between the two types of information). For instance, it was explained and shown that "an ultrasound is used to locate the foetus and the placenta [pause.] Once the foetus is located, a long thin needle is inserted into a safe location into the uterus". Furthermore, important information was divided in well-paced segments (to allow for comprehension) and presented visually as well as verbally (so as not to over-use or under-use the visual or the verbal channels). For example, the statement "these tests carry a risk of miscarriage which ranges from 0.5% to 1%" appeared on the screen at the same time as it was verbally stated on the audio file. A few key video shots are included in Appendix U.

Participants

Announcements (Appendix Q) were used to recruit 193 participants (age $M = 32.66$ years; $SD = 11.70$ years; range = 18 to 50 years) through discussion forums on community websites (e.g., TradeMe) and university email lists. Men or women fluent in English and over the age of 18 were eligible to take part. Ethics approval was sought and approved by The University of Auckland Research Ethics Committee (reference number 2010/063) for this experimental
study on prenatal testing and related issues. The demographic characteristics of the sample are summarised below (Table 14.1).

Table 14.1
*Gender, Relationship Status, Number of Children, Highest Completed Educational Level, Ethnicity and Religious Affiliation Reported by the Study Sample*

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>Percentages</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>153</td>
<td>79.69%</td>
</tr>
<tr>
<td>Men</td>
<td>39</td>
<td>20.31%</td>
</tr>
<tr>
<td><strong>Relationship status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>de Facto / Married</td>
<td>77</td>
<td>42.1%</td>
</tr>
<tr>
<td>Single, in a serious relationship</td>
<td>52</td>
<td>28.0%</td>
</tr>
<tr>
<td>Single, not in a serious relationship</td>
<td>45</td>
<td>24.4%</td>
</tr>
<tr>
<td>Separated / Divorced</td>
<td>10</td>
<td>5.5%</td>
</tr>
<tr>
<td><strong>Number of children</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>113</td>
<td>65.4%</td>
</tr>
<tr>
<td>1 or more</td>
<td>65</td>
<td>34.6%</td>
</tr>
<tr>
<td><strong>Highest completed education level</strong></td>
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<td></td>
</tr>
<tr>
<td>Bachelor's degree</td>
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<td>40.9%</td>
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<tr>
<td>Master’s degree</td>
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</tr>
<tr>
<td>High School</td>
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<td>10.4%</td>
</tr>
<tr>
<td>PhD / Doctorate</td>
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<td>8.3%</td>
</tr>
<tr>
<td>Professional degree</td>
<td>11</td>
<td>5.7%</td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
<td>3.6%</td>
</tr>
<tr>
<td>Trade certificate</td>
<td>5</td>
<td>2.6%</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>New Zealand European</td>
<td>94</td>
<td>48.7%</td>
</tr>
<tr>
<td>Other European</td>
<td>48</td>
<td>24.9%</td>
</tr>
<tr>
<td>Maori</td>
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<td>8.8%</td>
</tr>
<tr>
<td>Chinese</td>
<td>10</td>
<td>6.3%</td>
</tr>
<tr>
<td>Samoan / Fijian / South East Asian</td>
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<td>6.3%</td>
</tr>
<tr>
<td>Other</td>
<td>10</td>
<td>6.3%</td>
</tr>
<tr>
<td><strong>Religious affiliation</strong></td>
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</tr>
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<td>None</td>
<td>81</td>
<td>44.2%</td>
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<tr>
<td>Christian</td>
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<td>28.2%</td>
</tr>
<tr>
<td>Atheist</td>
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<td>11.0%</td>
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<tr>
<td>Agnostic</td>
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<td>8.6%</td>
</tr>
<tr>
<td>Other</td>
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<td>4.9%</td>
</tr>
<tr>
<td>Muslim / Buddhist / Jewish</td>
<td>5</td>
<td>3.0%</td>
</tr>
</tbody>
</table>

*N = 193*

:a: missing value = 1; b: missing value = 9; c: missing value = 15; d: missing value = 17; e: missing value = 7; f: missing value = 10.

: when several ethnicities were selected, the standard prioritisation order of ethnicity established by The New Zealand Health Information Service (Frazer, 2003) was used to select the 'highest ranked' ethnicity.
Of the 193 individuals who took part in this study, most participants were women in child-bearing age, in a committed romantic relationship and without children. This meant that the issues of prenatal testing were particularly relevant to this sample. In addition, the majority of participants had completed an (undergraduate or postgraduate) university degree, were of European descent and were not affiliated with any religion (Table 14.1).

**Measures**

The online questionnaire consisted of eight scales (not including the demographic scales). The measures used to assess child-related worry, anticipated emotional distress, negative consequences, anticipated coping efficacy, benefits from negative results, testing intention and the demographic scales had been validated in Study One and Study Two of the present research project (c.f. Chapter 9 and Appendices K to N). The only new items used in the present study assessed trait anxiety and perceived likelihood of iatrogenic miscarriage.

**Trait anxiety**

The trait anxiety subscale of the Spielberger’s (1983) state-trait anxiety inventory was chosen to assess participants’ level of trait anxiety (Appendix P). It contains 20 items asking people how they usually / generally feel on a four-point Likert scale ranging from 0 (*not at all*) to 3 (*very much*). The norms of this widely used self-administered instrument have been well established in the general population (Spielberger, 1983). Its internal consistency is high, ranging from $\alpha = 0.94$ to 0.96 (Dinc & Terzioglu, 2006). In the present study $\alpha = .91$ (Table 15.1). Mean scores were generated after having reverse-coded negatively worded items. Higher scores indicated greater levels of trait anxiety.

**Perceived likelihood of iatrogenic miscarriage**

Perceived likelihood of incidental miscarriage following prenatal testing was assessed with the single item scale "*if I/we underwent prenatal testing, I/we would be likely to lose the baby as a result of the procedure*". Participants were invited to indicate the extent to which they agree with this statement on a scale from -3 (*totally disagree*) to +3 (*totally agree*). Although single-item scales may be criticised for their limited abilities to measure complex theoretical constructs (Loo, 2002), studies have also shown that such measures may contain more face validity and are less time consuming than multiple-item scales (Chafouleas et al., 2010;
Nagy, 2002; Woods & Hampson, 2005). This was particularly appealing in the present study given that participants were already required to watch, read or listen to the health message. A single-item approach was therefore considered to be a reasonable alternative to multiple-item scales to maximise brevity and to keep potential boredom to a minimum.

**Procedure**

The flyer (Appendix Q) used to recruit participants briefly described the study and invited potential participants to send a blank email to prenataltesting@auckland.ac.nz. This email address had been set up to automatically send back a message (Appendix S) containing two attachments, namely the Participation Information Sheet (Appendix H) and the Consent Form (Appendix I). The automated reply also provided detailed information about the study and the link to the password-protected anonymous online survey. This online survey consisted of three sections. First, participants were asked to complete the trait anxiety subscale of Spielberger’s (1983) State and Trait Anxiety Index. Trait anxiety was assessed before the start of the experiment to ensure anxiety mean scores were not affected by the health messages (L.D. Cameron & Diefenbach, 2001). Then, participants were invited to indicate their day of birth (i.e., 1st to 10th, 11th to 20th or 21st to 31st of the month). This manipulation was used to randomly allocate volunteers to one of the three groups: text, video and audio, respectively. Finally, participants rated a series of statements used to elicit views on issues related to prenatal testing. The scales were presented in the following order: anticipated emotional distress, child-related worry, perceived likelihood of iatrogenic miscarriage, negative consequences, anticipated coping efficacy, benefits from negative results and testing intention. Demographic characteristics were also covered. Each participant completed the questionnaire only once, which took on average $M = 10.58$ minutes ($SD = 3.15$ minutes). Participants did not receive a reward (financial compensation or otherwise) for their contribution but did receive a short debriefing statement at the end of the questionnaire (Appendix J). Data collected through this procedure were analysed.
CHAPTER 14

Study 3 – Results

Chapter Overview

This chapter presents the results of the analyses conducted on the data collected using the method described previously. It consists of six main sections. The first section presents the analytical strategy. Second Two summarises preliminary analyses assessing the data's suitability for parametric analyses. The third section provides the descriptive statistics for all of the study scales. Section Four summarises results from analyses carried out to test the role of Modality on perceived risk of procedure-related miscarriage. Section Five presents the findings from analyses conducted to assess the influence of Trait Anxiety on testing intention, benefits from negative results, perceived likelihood of miscarriage and the condition-related variables (i.e. child-related worry, anticipated emotional distress, negative consequences and anticipated coping efficacy). Finally, the sixth section investigates the Modality x Trait Anxiety interacting effects on the same study variables.

Analytical Strategy

The data were analysed using the analytical software PASW Statistics 17.0. Correlation analyses were chosen to assess relationships between the study variables, including the relationship between perceived likelihood of miscarriage and testing intention. Correlation coefficients were also used to assess the relationships between trait anxiety and testing intention, benefits from negative results, perceived likelihood of miscarriage and the condition-related variables. Analyses of variance (ANOVAs) and post-hoc Tukey tests were used to investigate differences between the three modality groups (i.e. text, audio and video) on perceived likelihood of miscarriage. Finally, regression analyses were used to assess the moderating effect of trait anxiety on the study variables, using the techniques described by West and colleagues (1996). Results of inferential tests were considered statistically significant at $p < .05$ (two-tailed).
Preliminary Analyses

Initial analyses consisted of determining the sample size, addressing the issue of missing values, testing assumptions for parametric analyses and assessing a priori group differences with regards to participants' demographic characteristics.

Sample size

The minimum number of participants needed to detect Modality group differences can be calculated using partial Eta Squared. In this study, a medium Eta Squared (i.e. $\eta^2_{\text{partial}} = .06$) was considered acceptable to detect significant effects (Cohen, 1988). The program G*power (Faul et al., 2009) indicated that each group should have at least 34 participants (given $\eta^2_{\text{partial}} = 0.06$, $\alpha = .05$, power $=.95$, numerator $df = 2$, numbers of groups $= 3$) to detect the main effects of modality on the dependent measures. In the current study, groups contained between 60 (in the audio group) and 72 (in the video group) participants.

The minimum sample size needed to detect significant Modality x Trait anxiety effects was also calculated. Analyses indicated that at least 85 participants would be needed to ensure sufficient power to detect medium sized associations (effect size 0.50). A total of 193 volunteers took part in the present study. It was therefore concluded that the sample size was adequate to test hypothesised main and interactional effects of trait anxiety and information modality.

Missing values

Missing values (3%) were dealt with the 'mean imputation' method. The missing values were replaced by the mean score of the scale the item belonged to (Byrne, 2001).

Testing assumptions

Assumptions (of normality, linearity and homogeneity of variance) for ANOVAS and (of homoscedasticity and multicollinearity) for regression analyses were tested to assess data's suitability for parametric analyses. First, the assumption of normality was tested using the QQ probability plots and the scales' skewness coefficients. Visual inspections of QQ plots (Tukey's method) revealed that the scales' distributions were approximately normally distributed. The skewness coefficients were all between -1 and +1, except for two scales:
benefits from positive results (skewness = -1.31) and benefits from negative results (skewness = -1.120).

Second, the Levene's test for equality of variance revealed that the assumption of homogeneity of variance was violated only for benefit from positive results ($F(2,5190) = 1.65, p < .01$). However, analyses of variance are also robust to violations of the assumption of normality and homogeneity, especially when the sample sizes are approximately similar in all groups (Howell, 2007). This was further confirmed with analyses performed on logarithmic transformations of the benefits from positive results and the benefits from negative results measures (after having added a fixed value of 4 to individual mean scores theoretically ranging from -3 to +3). These logarithmic analyses revealed equivalent patterns of findings to analyses conducted on the untransformed data.

Third, the overall square shape of the bivariate residuals scatterplots indicated that, for all variables, the assumption of linearity was met. Fourth, the standardised residual plots showed that the data were approximately equally spread on either side of the zero line, indicating that the assumption of homoscedasticity had been met. Finally, the correlation matrix (Table 15.2) shows the assumption of lack of multicollinearity was also met as the highest correlation coefficient was $r = -.62$ (between anticipated coping efficacy and abortion willingness). It was concluded that the data was fit for parametric statistical analyses.

**A priori group differences**

Demographic differences across the three experimental groups (text, audio and video) were investigated through ANOVAs for continuous variables (e.g., age) and Pearson Chi-square analyses for nominal variables (e.g., gender). Before running analyses on education levels, the groups 'other' and 'trade certificate' were collapsed into one due to their low frequencies. No group differences were revealed in age ($F(2,166) = 4.60, ns$), gender ($\chi^2(3) = 1.69, ns$), relationship status ($\chi^2(6) = 11.09, ns$), number of children ($\chi^2(14) = 13.22, ns$), education levels ($\chi^2(12) = 24.41, ns$), ethnicity ($\chi^2(18) = 28.97, ns$), religious affiliation ($\chi^2(14) = 19.52, ns$) or trait anxiety ($F(2,190) = 1.25, ns$).
Descriptive Statistics

The mean scores, standard deviations, possible ranges of mean scores and reliability coefficients for all of the study variables are presented below (Table 15.1).

Table 15.1
Means (M), Standard Deviations (SD), Possible Ranges of Mean Scores and Cronbach’s Alpha (α) for all the Study Variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>M</th>
<th>SD</th>
<th>Possible ranges of mean scores</th>
<th>α</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Trait anxiety</td>
<td>0.94</td>
<td>0.51</td>
<td>0 to +3</td>
<td>.91</td>
</tr>
<tr>
<td>2. Testing intention</td>
<td>0.67</td>
<td>1.40</td>
<td>-3 to +3</td>
<td>.90</td>
</tr>
<tr>
<td>3. Benefits from negative results</td>
<td>1.61</td>
<td>0.84</td>
<td>-3 to +3</td>
<td>.82</td>
</tr>
<tr>
<td>4. Miscarriage likelihood</td>
<td>-1.77</td>
<td>1.28</td>
<td>-3 to +3</td>
<td>n/a</td>
</tr>
<tr>
<td>5. Child-related worry</td>
<td>0.67</td>
<td>1.29</td>
<td>-3 to +3</td>
<td>.81</td>
</tr>
<tr>
<td>6. Anticipated emotional distress</td>
<td>0.88</td>
<td>1.22</td>
<td>-3 to +3</td>
<td>.75</td>
</tr>
<tr>
<td>7. Negative consequences</td>
<td>0.65</td>
<td>1.24</td>
<td>-2 to +2</td>
<td>.85</td>
</tr>
<tr>
<td>8. Anticipated coping efficacy</td>
<td>0.63</td>
<td>1.53</td>
<td>-3 to +3</td>
<td>.92</td>
</tr>
</tbody>
</table>

N = 193

Overall, participants tended to score low in trait anxiety and to have a slight intention to undergo prenatal testing (Table 15.1). In addition, participants tended to perceive negative results as beneficial and iatrogenic miscarriage unlikely. They reported moderate worry about the health of the unborn child and anticipated receiving positive diagnosis would be moderately stressful. Also, participants tended to believe that being born with a genetic condition would have negative consequences of the person's quality of life and anticipated being able to cope moderately well with raising a child with special needs. Table 15.1 also shows that the scales had a moderate (anticipated emotional distress α = .75) to high internal consistency (e.g. anticipated coping efficacy α = .92). Correlation coefficients between these variables were also computed. Results are displayed below (Table 15.2).
As hypothesised, lower perceived likelihood of miscarriage was associated with greater testing intention (Table 15.2). In addition, higher levels of trait anxiety were related to greater perceived likelihood of miscarriage, greater child-related worry, greater anticipated emotional distress and lower anticipated coping efficacy. Greater testing intention was associated with greater benefits from negative results, greater child-related worry, greater anticipated emotional distress, greater negative consequences and lower anticipated coping efficacy. Finally, a strong positive correlation coefficient was found between benefits from negative test results, child-related worry and anticipated emotional distress. Perceiving negative diagnoses as valuable was associated with worrying about the health of the unborn child and anticipating that receiving positive test results would be stressful.

### Role of Modality on Perceived Risk of Miscarriage

A one-way ANOVA was performed to test the hypothesis for the Modality effect on perceived risk of miscarriage. Contrary to expectations, participants in the video group did not perceive that miscarriage would be less likely ($M = -1.79$, $SD = 1.30$) than did individuals in the audio group ($M = -1.51$, $SD = 1.36$) and in the text group ($M = -2.00$, $SD = 1.12$); $F(2, 190) = 2.35, p > .05$. 

---

Table 15.2  
**Correlation Coefficients for all of the Study Variables**

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Trait anxiety</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Testing intention</td>
<td>-0.06</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Benefits from negative results</td>
<td>0.01</td>
<td>0.31**</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Miscarriage likelihood</td>
<td>0.19**</td>
<td>-0.32**</td>
<td>-0.10</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Child-related worry</td>
<td>0.17**</td>
<td>0.43**</td>
<td>0.41**</td>
<td>-0.06</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Anticipated emotional distress</td>
<td>0.21***</td>
<td>0.31**</td>
<td>0.37**</td>
<td>-0.02</td>
<td>0.66**</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>7. Negative consequences</td>
<td>0.09</td>
<td>0.11*</td>
<td>0.12**</td>
<td>0.12*</td>
<td>0.21*</td>
<td>0.35**</td>
<td>1</td>
</tr>
<tr>
<td>8. Anticipated coping efficacy</td>
<td>-0.18**</td>
<td>-0.30**</td>
<td>-0.27**</td>
<td>-0.11</td>
<td>-0.46**</td>
<td>-0.53**</td>
<td>-0.39*</td>
</tr>
</tbody>
</table>

**:** $p < .01$; *: $p < .05$
Role of Trait Anxiety on Testing Intention, Benefits from Negative Results,
Perceived Likelihood of Miscarriage and the Condition-related Variables

Table 15.2 shows that, contrary to expectations, trait anxiety did not influence testing intention or benefits from negative results. The hypothesis that trait anxiety would play a role in perceived likelihood of miscarriage was supported. Anxious participants believed incidental miscarriage would be more likely than did less anxious individuals. In addition, as expected, trait anxiety significantly predicted child-related worry, anticipated emotional distress and anticipated coping efficacy. Participants with higher trait anxiety reported significantly greater worry about the health of the unborn child, anticipated positive diagnoses would be more emotionally stressful and had lower faith in their abilities to deal with a child with special, than did less anxiety participants. Finally, the prediction that negative consequences would increase with trait anxiety was not supported.

Interactive Effects of Modality and Trait Anxiety on Testing Intention, Benefits from Negative Results, Perceived Likelihood of Miscarriage and the Condition-related Variables

The last series of analyses were conducted to test the hypothesised roles of trait anxiety and modality of information on the same seven variables: testing intention, benefits from negative results, perceived likelihood of miscarriage and the condition-related variables (i.e. child-related worry, anticipated emotional distress, negative consequences and anticipated coping efficacy). Several variables were created: Trait anxiety centred (AnxietyC = individual trait anxiety score - 0.94), DummyTextVideo (text = -1, video = 1, audio = 0) and DummyAudioVideo (text = 0, video = 1, audio = -1). Two interaction terms were also computed: AnxietyC × DummyTextVideo and AnxietyC × DummyAudioVideo. Regression analyses were conducted with the newly created variables (i.e. Trait anxiety centre, DummyTextVideo, DummyAudioVideo, AnxietyC × DummyTextVideo and AnxietyC × DummyAudioVideo) as independent variables and the variables of interest (e.g. testing intention) as the dependent variable. The results are displayed in Table 15.3. and the
interaction effects are graphed (Figures 15.1 to 15.3) using estimated values of the dependent measures for values that are 1 standard deviation above and below the trait anxiety mean (S. G. West et al., 1996).
### Table 15.3
**Regression Analyses Assessing Moderating Effects of Trait Anxiety and Modality on the Study Variables**

<table>
<thead>
<tr>
<th>Variables</th>
<th>$B$</th>
<th>SE $B$</th>
<th>$\beta$</th>
<th>$t$</th>
<th>$F$</th>
<th>$R^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Testing intention</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trait anxiety centred</td>
<td>-0.14</td>
<td>0.20</td>
<td>-0.05</td>
<td>-0.67</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DummyTextVideo</td>
<td>0.07</td>
<td>0.15</td>
<td>0.04</td>
<td>0.51</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DummyAudioVideo</td>
<td>0.10</td>
<td>0.15</td>
<td>0.06</td>
<td>0.72</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AnxietyC $\times$ DummyTextVideo</td>
<td>-0.43</td>
<td>0.28</td>
<td>-0.13</td>
<td>-1.54</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AnxietyC $\times$ DummyAudioVideo</td>
<td>0.32</td>
<td>0.28</td>
<td>0.09</td>
<td>1.15</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Benefits negative results</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trait anxiety centred</td>
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<td>0.12</td>
<td>0.03</td>
<td>0.43</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DummyTextVideo</td>
<td>0.12</td>
<td>0.09</td>
<td>0.12</td>
<td>1.38</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DummyAudioVideo</td>
<td>0.03</td>
<td>0.09</td>
<td>0.03</td>
<td>0.33</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AnxietyC $\times$ DummyTextVideo</td>
<td>0.07</td>
<td>0.17</td>
<td>0.04</td>
<td>0.44</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AnxietyC $\times$ DummyAudioVideo</td>
<td>0.04</td>
<td>0.17</td>
<td>0.02</td>
<td>0.23</td>
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<td></td>
</tr>
<tr>
<td><strong>Miscarriage likelihood</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trait anxiety centred</td>
<td>0.29</td>
<td>0.20</td>
<td>0.11</td>
<td>1.63</td>
<td></td>
<td></td>
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<tr>
<td>DummyTextVideo</td>
<td>0.30</td>
<td>0.16</td>
<td>0.16</td>
<td>1.88</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DummyAudioVideo</td>
<td>0.05</td>
<td>0.16</td>
<td>0.03</td>
<td>0.34</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AnxietyC $\times$ DummyTextVideo</td>
<td>-0.27</td>
<td>0.30</td>
<td>-0.07</td>
<td>-0.91</td>
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<td></td>
</tr>
<tr>
<td>AnxietyC $\times$ DummyAudioVideo</td>
<td>0.45</td>
<td>0.30</td>
<td>0.12</td>
<td>1.50</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Child-related worry</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trait anxiety centred</td>
<td>0.46</td>
<td>0.18</td>
<td>0.18</td>
<td>2.54*</td>
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<td></td>
</tr>
<tr>
<td>DummyTextVideo</td>
<td>-0.07</td>
<td>0.13</td>
<td>-0.04</td>
<td>-0.50</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DummyAudioVideo</td>
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<td>0.13</td>
<td>0.08</td>
<td>0.91</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AnxietyC $\times$ DummyTextVideo</td>
<td>-0.24</td>
<td>0.25</td>
<td>-0.08</td>
<td>-0.96</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AnxietyC $\times$ DummyAudioVideo</td>
<td>0.61</td>
<td>0.25</td>
<td>0.19</td>
<td>2.41**</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Anticipated emotional distress</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trait anxiety centred</td>
<td>0.31</td>
<td>0.17</td>
<td>0.13</td>
<td>1.84</td>
<td></td>
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</tr>
<tr>
<td>DummyTextVideo</td>
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<td>0.12</td>
<td>0.02</td>
<td>0.18</td>
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</tr>
<tr>
<td>DummyAudioVideo</td>
<td>0.15</td>
<td>0.12</td>
<td>0.10</td>
<td>1.24</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AnxietyC $\times$ DummyTextVideo</td>
<td>-0.28</td>
<td>0.14</td>
<td>-0.11</td>
<td>-1.45</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AnxietyC $\times$ DummyAudioVideo</td>
<td>0.76</td>
<td>0.24</td>
<td>0.26</td>
<td>3.23**</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Negative consequences</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trait anxiety centred</td>
<td>0.13</td>
<td>0.22</td>
<td>0.04</td>
<td>0.62</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DummyTextVideo</td>
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<td>0.16</td>
<td>0.16</td>
<td>1.88</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DummyAudioVideo</td>
<td>0.05</td>
<td>0.16</td>
<td>0.03</td>
<td>0.34</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AnxietyC $\times$ DummyTextVideo</td>
<td>-0.27</td>
<td>0.30</td>
<td>-0.07</td>
<td>-0.91</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AnxietyC $\times$ DummyAudioVideo</td>
<td>0.45</td>
<td>0.30</td>
<td>0.12</td>
<td>1.50</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Anticipated coping efficacy</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trait anxiety centred</td>
<td>-0.33</td>
<td>0.16</td>
<td>-0.18</td>
<td>-2.13*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DummyTextVideo</td>
<td>-0.36</td>
<td>0.21</td>
<td>-0.12</td>
<td>-1.66</td>
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<td></td>
</tr>
<tr>
<td>DummyAudioVideo</td>
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<td>0.16</td>
<td>0.09</td>
<td>1.10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AnxietyC $\times$ DummyTextVideo</td>
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<td>0.30</td>
<td>0.13</td>
<td>1.61</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AnxietyC $\times$ DummyAudioVideo</td>
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<td>0.30</td>
<td>-0.20</td>
<td>-2.47*</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*: $p < 0.05$; **: $p < 0.01$
Contrary to expectations, no significant interaction effects were found for testing intention, benefits from negative results, perceived likelihood of miscarriage or negative consequences. However, as predicted, a significant Trait Anxiety x Modality interaction effect was found on child-related worry (Figure 15.1).

![Figure 15.1 Trait Anxiety x Modality interaction effects on child-related worry](image)

As expected, individuals with higher trait anxiety in the video group reported significantly greater child-related worry than all other participants (Figure 15.1). A second significant Trait Anxiety x Modality interaction effect was found on anticipated emotional distress (Figure 15.2).
Figure 15.2 Trait Anxiety x Modality interaction effects on anticipated emotional distress

As hypothesised, in the video group, participants with higher trait anxiety reported significantly greater anticipated emotional distress than all other individuals (Figure 15.2). Finally, a third significant Trait Anxiety x Modality interaction effect was found on anticipated coping efficacy (Figure 15.3).

Figure 15.3 Trait Anxiety x Modality interaction effects on anticipated coping efficacy
As hypothesised, in the video group, individuals with higher trait anxiety reported significantly lower anticipated coping efficacy than those with lower scores on trait anxiety (Figure 15.3).

In summary, the results reported above far have provided partial support for the four sets of hypotheses proposed in Chapter 12. First, as expected, greater perceived likelihood of incidental miscarriage was associated with lower testing intention for all participants. Second, contrary to expectations, participants in the video group did not report lower perceived risk of miscarriage scores than did participants in the audio or text groups. Third, the predictions for the role of trait anxiety received only partial support. Compared to participants with lower trait anxiety, anxious individuals reported significantly greater child-related worry, greater anticipated emotional distress, lower anticipated coping efficacy and greater perceived likelihood of miscarriage. However, contrary to expectations, no group differences were found for negative consequences, benefits from negative results and testing intention. The main effects on Trait Anxiety were superseded by the interaction effects, as shown by the results of analyses carried out to test the fourth set of hypotheses. In the video group, individuals with higher trait anxiety scores reported significantly greater child-related worry, greater anticipated emotional distress and lower anticipated coping efficacy than less anxiety individuals. No interaction effects were found for negative consequences, perceived likelihood of miscarriage, benefits from negative results or testing intention.
CHAPTER 15

Study 3 – Discussion

Genetic discoveries have paved the way for the development of prenatal genetic testing. Procedures such as amniocentesis and chorionic villus sampling are now an established part of maternal care despite ethical and procedural issues (Humphreys et al., 2008). The field of prenatal testing is predicted to keep on developing (C. F. Wright et al., 2011) and therefore to keep on presenting challenges for medical professionals and prospective parents (Marteau, 1995). Despite the growing prevalence of prenatal testing in maternal care, research on the process of prenatal testing decision-making remains limited. The present study aimed to: 1) test the relationship between perceived likelihood of iatrogenic miscarriage and testing intention, 2) assess the roles of modality of information and 3) trait anxiety on issues related to prenatal testing. The fourth and final aim was to evaluate the combined roles of information modality and trait anxiety on the condition-related variables (i.e. child-related worry, anticipated emotional distress, negative consequences and anticipated coping efficacy), perceived likelihood of miscarriage, benefits from negative results and testing intention. This chapter interprets the findings presented in Chapter 14.

Relationship between Perceived Likelihood of Miscarriage on Testing Intention

Descriptive statistics showed that participants reported a wide range of opinions regarding intention to undergo prenatal testing, were they to be expecting a child. These findings are in line with previous research showing that people do vary widely in their attitudes towards prenatal testing (e.g., Humphreys et al., 2008). Overall, the majority of volunteers in the present study reported a slight preference towards taking the test. This tendency was observed across all three Information Modality groups (i.e., text, audio and video). Descriptive statistics also revealed that participants did not believe that losing the pregnancy would be a likely outcome of undergoing prenatal testing. The hypothesised relationship between perceived likelihood of miscarriage and testing intention was tested through correlation analyses. As expected, participants who believed that the procedure would result in miscarriage reported lower intention to take the test.
The relationship between testing intention and perceived likelihood of miscarriage needs to be interpreted in light of the methodology used in the present study, and also in light of the findings on perceived benefits from negative test results and child-related worry. First, perceived likelihood of iatrogenic miscarriage was measured with one item. Before the present study, it appeared that no scale existed in the literature to measure incidental perceived likelihood of miscarriage. Consequently, a new measure had to be designed. Using a single-item scale was considered to be an appropriate measuring technique in the current study, as such scales have been shown to have good face validity and to be less time consuming than multiple-item scales (Chafouleas et al., 2010; Nagy, 2002; Woods & Hampson, 2005). However, single-item scales have also been criticised for their limited psychometric properties (Loo, 2002). This possible methodological consideration indicates that the present results may need to be interpreted with care. However, there is no clear evidence that the use of a single-item scale compromised the current findings. In fact, the relationship between attitudes towards incidental miscarriage and testing intention reflected existing findings suggesting that the prospect of losing a pregnancy was a real concern for parents considering prenatal testing (Chan et al., 2006; Kuppermann et al., 2000).

Second, results from descriptive statistics and correlation analyses on benefits from negative results and child-related worry may shed some light on the relationship between perceived likelihood of miscarriage and testing intention. Descriptive statistics revealed that, overall, participants tended to view negative test results as beneficial. This echoed findings from previous studies showing that negative test results are generally highly valued by prospective parents (Mooney & Lange, 1993; Ryan, Miedzybrodzka, Fraser, & Hall, 2003; Stone & Stewart, 1996). It seems that the main benefit of negative diagnoses resides in the results' abilities to reduce parents' concerns about the health of the foetus (Durand et al., 2010; J. Hall, Fiebig, King, Hossain, & Louviere, 2006; Leithner et al., 2004). In the present study, correlation analyses did indicate that perceived benefits from negative results were associated with greater child-related worry and greater anticipated emotional distress from receiving positive test results.

If scores on perceived benefits from negative results did reflect worry about the health of the unborn child then the present results indicated that similar risk estimates (i.e. 1 in 200 / 2 in 200) raised more concerns about the genetic make-up of the foetus than about the safety of
the procedure. Indeed, the hypothetical scenario used to introduce the issues of prenatal testing to participants mentioned that 1 in every 200 pregnancies could be affected by a genetic mutation. The same scenario also stated that the risks of pregnancy loss associated with invasive procedures could range between 1 in 200 (0.5%) and 2 in 200 (1%). These probabilities were purposely chosen to be comparable, as presenting similar risk estimates was believed to increase the salience of the ethical dilemmas pertaining to respective options. If the estimates of 1 in 200 to 2 in 200 had been assessed purely cognitively, then participants would have reported similar levels of concern about the procedure and about the health of the unborn child. In fact, the safety of prenatal testing should have been perceived as slightly more worrying as incidental miscarriage was presented as being up to twice as likely as an affected pregnancy. Yet, participants seemed to believe that negative test results were more beneficial than miscarriage was likely.

The present results indicated that probabilities alone were not entirely responsible for participants' patterns of answers. Reasons for this discrepancy in subjective interpretation of risks pertaining to pregnancy and prenatal testing are not clear but it has been argued that estimates of 1 in 100 or less may play only a small role in risky decision-making (Seror, 2008). It has also been theorised that decisions involving small probabilities may be driven by "principles choices" (Seror, 2008, p. 571), ones that are based on values about the issue, rather than careful consideration of the possible outcomes and their respective likelihood. In the current study, it is possible that participants paid little attention to the actual risk estimates and that their assessments of the hypothetical scenario were biased by external factors. For instance, experiential knowledge (i.e. objective and subjective personal assessment) of topics related to reproduction has been shown to play an important role in prenatal decision-making (d’Agincourt-Canning, 2005; Etchegary et al., 2008). Such knowledge may include stories from / about other couples having taking the test and for whom the procedure had been safe. In the present study, it appeared that personal histories with reproduction were more conducive to lead participants to think that taking the test would be a safe procedure and would bring about some reassurance about the health of the foetus. Prenatal testing was perceived as a gain-seeking behaviour rather than an act associated with losses (Seror, 2008).

If the present results were rightly interpreted as indicating the importance of external/individual factors in prenatal testing decision-making, then these findings have clear
implications for medical professionals. Patients enter medical consultations with their preconceived ideas about the issues at stake (Lerman et al., 2002; Ormond et al., 2009). This means that prenatal testing decision-making will likely be influenced by a range of factors acquired through personal life, and not just by the probabilities discussed in clinical settings. Personal convictions about reproductive technologies and intuitive assessment of the potential risks are likely to be part of the many factors influencing decision-making (Cederholm, Sjödén, & Axelsson, 2001). Hence, when discussing risks with their patients, medical professionals should expect personal values to play a bigger role in prenatal decision-making than the statistics.

Roles of Modality and Trait Anxiety on Perceived Likelihood of Miscarriage, Benefits from Negative Results and Testing Intention

In order to achieve informed decision-making, users must receive adequate information (Shepperd et al., 2006). However, specialised medical facts are typically difficult to understand and are often misinterpreted by lay people (Durand et al., 2010; Jaques, Halliday, & Bell, 2004; Ormond et al., 2009). With predicted advances in genetics and maternal care, issues surrounding comprehension of complex information will become increasingly relevant to couples. This information will likely come from many services (Godard et al., 2003) and be provided in many different formats, including print, audio and video. The presentation of information about genetic disabilities and prenatal testing is likely to play an important role in reproductive decision-making (Shepperd et al., 2006).

The present study aimed to test the influence of Modality in perception of procedure-related miscarriage. Modality was hypothesised to influence perceived likelihood of incidental miscarriage. However, results from a one-way ANOVA revealed that, contrary to predictions, participants in the video group did not believe that miscarriage would be less likely to occur than did participants in the audio or text groups. As it has already been discussed, overall, participants did not seem particularly concerned about the procedure-related risks of miscarriage. Hence the video-clip may have not been very useful in further reassuring participants about a procedure they already perceived as being safe. These results deserve consideration for their clinical implications. It is possible that some people may not perceive
prenatal testing as a risky procedure. It may be that, when making decisions about issues related to reproduction and congenital conditions, individuals pay less attention to the medical aspect of prenatal testing and more attention to psychosocial prospects, such as the possibility that a genetic mutation may impact on their pregnancy, the life of their future children and their own lives.

Another aim of the present study was to investigate the combined roles of trait anxiety and modality on perceived likelihood of miscarriage, benefits from negative test results and testing intention. Results from regression analyses revealed that, contrary to expectations, trait anxiety did not moderate participants' answers in the video group. In the video group, participants with higher trait anxiety seemed to be equally likely to perceive the benefits of test, were not more prone to anticipate a miscarriage, and were equally likely to want to get the test, compared to less anxious individuals. These findings conflicted with previous studies suggesting that anxious individuals tend to overestimate negative health outcomes and that, despite their pessimistic tendencies, they are still interested in engaging in health protective behaviours (L. D. Cameron & Chan, 2008; L. D. Cameron et al., 1998).

Lack of empirical support for the hypothesised moderating role of trait anxiety in the video group on miscarriage perceived likelihood, benefits from negative results and testing intention may be methodologically accounted for. The Trait Anxiety subscale of the State and Trait Anxiety Index (Spielberger, 1983) was used to assess participants' anxiety levels. It is possible that this scale was too general for the present study and did not capture anxiety specific to genetic testing (Lerman et al., 2002). Trait anxiety may not be the personality characteristic that influences these variables, but more specific anxiety-related attributes such as anxiety about genetic testing or pregnancy anxiety may be (Dunkel Schetter & Glynn, 2011). Researchers have argued that anxiety related to pregnancy is a relatively complex multidimensional construct, somewhat distinct from general anxiety. It has been argued that assessing general anxiety in pregnant women might lead to overlooking the impact anxiety specific to issues about pregnancy might have on issues related to prenatal testing. In fact, studies have shown that general anxiety only account for small variance of pregnancy-specific anxiety (Huizink et al., 2004; Saisto, Salmela-Aro, Nurmi, & Halmesmäki, 2001; Van den Bergh, 1990). The present findings indicate when conducting studies on risk
perception in expectant women, there may be a need to distinguish between general anxiety and pregnancy-specific anxiety.

**Roles of Modality and Trait Anxiety on the Condition-related Variables**

The last series of hypotheses regarded the combined influences of trait anxiety and modality on the condition-related variables (i.e. negative consequences, child-related worry, anticipated emotional distress, and anticipated coping efficacy). Contrary to hypotheses, regressions analyses revealed no Modality x Trait Anxiety interaction effect on perceived negative consequences of living with a genetic disability. One tentative explanation may be put forward to account for this unexpected result. Negative consequences was a measure of the perceived impact of a genetic disability on the child's quality of life. It could be argued that this construct was conceptually slightly different from the other condition-related variables on at least two accounts. First, negative consequences referred to an individual different from the person taking part in the study. It is possible that anxious individuals are comparable to non-anxious people in their perceptions others would be better able than themselves to live with a genetic condition. Second, negative consequences referred to a future situation likely to involve other people. It may be that anxious participants are comparable to non-anxious participants in envisaging a future in which the other parent, for instance, would play an important caring role. With little empirical evidence to rely on, this interpretation remains speculative. However, if this explanation was correct, then anxious participants might have not perceived the future of their unborn child more negatively than did participants with lower trait anxiety. Such interpretation could explain why anxious participants did not differ from less anxious individuals in their scores on negative consequences.

Regression analyses were also performed to test the hypothesised combined roles of trait anxiety and modality on child-related worry, anticipated emotional distress, and anticipated coping efficacy. As expected, participants with higher trait anxiety in the video group reported 1) greater worry about the health of the unborn child, 2) greater anticipated emotional distress (from receiving a positive diagnosis), and 3) lower anticipated coping efficacy (of raising a child with special needs) than all other participants. To better
understand the combined roles of trait anxiety and modality on these results, it is useful to first consider how trait anxiety might, alone, play a role in the present findings.

Three characteristics of people with higher trait anxiety are particularly relevant to the present discussion. First, anxious individuals have the tendency to anticipate life events more negatively than less anxious people and to seek anxiety-provoking information (L. D. Cameron & Chan, 2008). One study has shown that patients with high trait anxiety had more negative emotional responses to ultrasound scanning than less anxious users did (Leithner et al., 2004). Anxious people believe they were at greater risks of being the receiver of bad news. Another study on genetic testing has shown that trait anxiety was associated with increased worry about the health threat (L. D. Cameron et al., 1998). In the present study, it is possible that anxious participants believed their unborn children would be more likely to be affected by a genetic mutation than less anxious individuals. This interpretation could account for the finding that, compared to less anxious individuals, participants with higher trait anxiety scores reported greater worry about the health of the foetus, and this, regardless of modality.

Second, evidence suggests that anxious individuals are not only hyper-sensitive to threats, but they also have a tendency to be fearful (Ulleberg & Rundmo, 2003) and to have an external locus of control (Kallmen, 2000). This means that anxious people generally anticipate being unable to control feared and unwanted situations. In the context of prenatal testing, simply receiving information about the availability of prenatal testing has been shown to increase the salience of possible issues with pregnancy (Lobel et al., 2005). Also, prospective parents have very little, if any, control the test results. In the present study, it is possible that this lack of control over the procedure and over the test results had been perceived as especially stressful by anxious people. Combined with their pessimistic tendencies, anxious participants could have been particularly sensitive not only to the fact that the outcome of the test was out of their control, but also that this uncontrollable situation could result in the announcement of a positive diagnosis. This imagined prospect could have led to increased concern about the test results. If such interpretation was correct, then it could explain why participants with higher scores on trait anxiety anticipated greater emotional distress from receiving positive results, compared to less anxious individuals, in all three modality groups.
Third, individuals with higher trait anxiety are characterised by their low degree of self-efficacy (Kallmen, 2000). Anxious individuals do not believe in their abilities to cope well with adverse situations. Raising children with special needs can be perceived as physically and mentally challenging. Indeed, bringing up children with disabilities is known to require intense care-giving (Greco, Sloper, Webb, & Beecham, 2007; King, Teplicky, King, & Rosenbaum, 2004; Lowe, Bravery, & Gibson, 2008). Studies have shown that, when thinking about raising a child with special needs, prospective parents picture how their lives would be like (Etchegary et al., 2008). They may anticipate having to arrange their house so that it was safe for the child, to provide on-going medical support, to witness their child suffering from the condition and to deal with the related strains on their relationships with the other parent. Such prospects may be particularly overwhelming for anxious individuals. If this interpretation was correct, then it may account for the finding that anxious participants reported lower anticipated coping efficacy than less anxious individuals, in all three groups (audio, text and video).

Thus far, this theoretical discussion has been useful in explaining the role of anxiety alone on condition-related variables. However, results from regression analyses confirmed the hypotheses that the differences in scores on child-related worry, anticipated emotional distress and anticipated coping efficacy between anxious participants and those with lower trait anxiety would be also present in the video group. A fourth characteristic of anxious individuals is relevant to these findings not found in the other modality groups. People with higher trait anxiety tend to want more medical information than less anxious people do (L. D. Cameron & Chan, 2008). These informational needs are better met when the health message is delivered by multimedia instructional materials, as such supports provide information visually and orally (Mayer, 2008). While audio-visual educational clips are likely to fulfil the needs of anxious individuals for information, such supports are also likely to increase the salience of fear-provoking information and stressful events. Together, this theoretical discussion on the role of trait anxiety and multimedia can explain why fears related to prenatal genetic testing were heightened in the video group, for participants with higher scores on trait anxiety.
Limitations

Two limitations need to be acknowledged. The first limitation relates to the sample. Most participants in the present study were women and had no children. With regards to the gender imbalance, such biases are often reported in studies on reproduction decision-making (e.g., Frost et al., 2001; Lawson, 2006). Nevertheless, the present results may not sufficiently represent men's views on the issues related to prenatal testing. Further research is needed better evaluate men's views on issues related to prenatal testing and family planning. Furthermore, the fact that over 65% of the participants did not have children suggests these people were unlikely to have first-hand experiences with pregnancy. A lack of personal relevance with reproductive issues might have influenced the present results. Past histories with the prenatal testing, test results (e.g., wrong diagnoses) and/or pregnancies (e.g. miscarriage, selective terminations and stillbirths) can increase maternal anxiety and impact on decisions about later pregnancies (Brisch et al., 2005; Etchegary et al., 2008; Gaudet, Séjourné, Camborieux, Rogers, & Chabrol, 2010; Spencer, 2002; Tercyak et al., 2001). If issues related to previous pregnancies had not been dealt with successfully, then a new pregnancy can re-activate these negative emotional reactions and result in increased distress in prospective parents (Hughes, Turton, Hopper, & Evans, 2002). It is therefore possible that the present results were not representative of all prospective parents. Future studies could assess more systematically the role of previous pregnancy histories in perceptions of issues related to reproduction and family planning.

The second potential limitation concerns the mode of delivery of information to participants. For the purpose of the present study, the health messages were presented in a text, audio or video format. While participants could listen, read or watch the health messages as many times as they wanted, they could not ask any questions. Geller and colleagues (1997) have warned that providing information does not necessarily equate with increasing understanding. People vary greatly with regards to their medical literacy, the nature and amount of information needed to comprehend the issues at stake and to make a decision (Durand et al., 2010; Ormond et al., 2009; Ormond et al., 2007). In real clinical settings, patients are often given some opportunities to raise their concerns and to ask questions. However, such settings are not always conducive to asking questions because of time constraints or patients' own inhibitions. In addition, reproductive decisions happen mostly outside the consultation room.
Prospective parents are likely to seek and receive information about prenatal testing via the Internet. In fact, the video used in the present study was one of the many freely available online. The Internet is an increasingly important venue for receiving medical information without the ability to ask questions. Given that couples are more likely to search and access medical information on their own, future research could try to discover the degree of technicality, the amount and the content of information people generally wish to learn about. Such studies would be valuable in ensuring that instructional materials meet the informational needs of possible users.

**Implications**

The results discussed above have clear educational and clinical implications. First, most decisions about genetic testing are made outside the consultation room (Lerman et al., 2002). This means that users obtain the majority of their information from sources other than medical professionals, such as the Internet, which often presents information graphically. Previous research has shown that visual representations can reduce anxiety through increasing understanding of complex medical information. For instance, it has been shown that illustrating probabilities with graphs or charts, or showing a video of the steps involved in an amniocentesis, can help clarify information (Durand et al., 2010), which in turn, can increase understanding and reduce procedure-related anxiety (Zlotogorski, Tadmor, Duniec, Rabinowitz, & Diaman, 1995). The present study has added to the existing literature on the role of educational materials in the decision-making process for undergoing amniocentesis. It showed that multimedia instructional materials can also increase emotional responses and reduce perceived coping efficacy in people with high trait anxiety. Hence, organisations designing educational materials should be aware that the format in which they present health messages may influence information processing and emotional responses to potentially anxiety-provoking.

One potential strategy for providing anxiety-reducing information without provoking distress is to use narratives that provide first-hand accounts of people's experiences of the situation under consideration. Anecdotal narrative that contain concrete context-specific examples and emotionally evocative information is proposed to be more convincing in conveying personal
health risks (de Wit, Das, & Vet, 2008). Strengths of narratives include their ability to present
different interpretations of a same issue. For instance, parents raising children with
disabilities could be invited to provide an account of their hardship but also of the rewards
they get from bringing up their children. Such stories may help meet the informational needs
of anxious individuals, without increasing their anxiety levels. Further research is needed to
explore the role of narratives on reproductive choices of anxious individuals.

Second, the results from the present study also have clinical applications. While people may
seek information outside clinical settings, face-to-face interactions with genetic counsellors
are likely to remain an important part of genetic testing decision-making (Durand et al., 2010;
Hoskovec et al., 2008; Lerman et al., 2002; Lobel et al., 2005). Such medical encounters are
likely to be influenced by people's personal expectations. Indeed, the findings of the present
study echoed others previously published indicating that users' final choices may reflect their
own beliefs and views, as much as (if not more than) the information provided in health
messages (Etchegary et al., 2008). Factors including past reproductive histories, personal
experiences with pregnancy and knowledge about prenatal testing may all influence the way
patients process information and reach a decision (Etchegary et al., 2008; Geller et al., 1997).
Hence, medical professionals could explore couples' views about psychosocial issues
surrounding reproduction and disabilities, such as previous pregnancies, care-giving
experiences with people with disabilities (d’Agincourt-Canning, 2005) or even their
intuitions about the unborn child (Suter, 2002). By recognising the personal nature of prenatal
testing decision-making and by tailoring their consultations to patients' own values, genetic
counsellors could not only address people's concerns, but also uncover and possibly rectify
misperceptions prenatal testing.

The third implication concerns the role of trait anxiety in decisions about family planning
(Ulleberg & Rundmo, 2003). The present results indicate that emotional reactions triggered
by messages about potential health threats may reflect enduring aspects of people's
personality (Bouyer et al., 2001). It has been suggested that, with regards to family issues,
trait anxiety may exacerbate parental emotional involvement and affective responses to risk
information (L. D. Cameron et al., 2007). Anxious parents may not only demand more
medical explanations but may also require greater emotional support than perhaps less
anxiety patients would, to adjust to this self-generated negative emotional states (Miller,
The present study was the first one to provide evidence that anxious individuals are more likely to have lower coping efficacy and stronger emotional distress responses to information about prenatal testing, when these health messages are presented in a multi-media format. Professionals should recognise the possibility for an unfortunate conundrum whereby their ethical obligations to promote informed decision-making and to reduce uncertainty-related anxiety by providing medical data (Hoskovec et al., 2008), may simultaneously increase health-related anxiety. Medical professionals should recognise the possibility that patients' emotional reactions to health communications may be influenced by their personality characteristics as much as by the actual content of the information discussed during consultations. Therefore, genetic counsellors could tailor consultations according to these individual dimensions (Ulleberg & Rundmo, 2003) by ensuring, for instance, that informative support is closely followed by emotional support.

Conclusion

The present study added to the available literature showing that concerns about the safety of prenatal testing may be an important deterrent to undergoing the procedure. This is of prime relevance to the ever-growing field of genomics and reproductive technologies. Scientists have claimed that new non-invasive tests would soon be available to expectant parents (Chiu et al., 2011; C. F. Wright et al., 2011). If these predictions are revealed to be true, then the issues of iatrogenic miscarriage would become irrelevant to the process of prenatal testing decision-making. With the disappearance of such risks, the uptake rate could rise considerably. This implies that health professionals could be involved in an increasing number of discussions pertaining to reproduction and genetic disabilities (Offit, Sagi, et al., 2006). Advances in safe prenatal tests would also impact on the content of health messages presented to potential users. Issues surrounding the risks of prenatal testing would no longer be covered. Instead, instructional materials would likely focus on the impact of positive diagnoses and to raising children with special needs.

Furthermore, it was shown that information-seeking coping styles of anxious patients may result in greater anxiety about issues that are already potentially anxiety-provoking, especially if the information is provided through multimedia instructional material. This
finding implies that doctors' attempts to educate couples may result in increasing patients' anxiety levels, if these couples are naturally anxious and if the information is presented visually. Genetic counsellors should be aware that the information delivered to facilitate decision-making may inadvertently result in greater anxiety levels (Green et al., 2004). In particular, anxious parents may become overwhelmed by the prospects of raising a child with special needs and by the fears of failing motherhood (Remennick, 2006). Therefore, health professionals may need to consider affective personality traits in reproductive decision-making (Pacheco-Unguetti et al., 2010). They could aim to tailor their consultations to their patients' personality characteristics.

Although the results of the present study were based on a sample of predominantly young and educated female participants, the strengths of the present study need to be acknowledged. It was the first study to quantitatively assess the role of perceived likelihood of miscarriage, as well as the moderating roles of trait anxiety and information modality on anxiety-related variables in the context of prenatal testing. This assessment used a hypothesis-driven study design, which incorporated psychometrically robust measuring tools. These results were also the first to provide some insight into how future patients in Western countries may react to anxiety-provoking information delivered visually. It is hoped that future research will replicate these findings on a more diverse sample of individuals. Such studies would be valuable in helping genetic counsellors anticipate and respond to their patients' informational needs, while minimising aversive affective responses to health threat information. Such studies could also help guide the development of educational materials for potential users.
CHAPTER 16

Overall Conclusion

The present research project aimed to investigate the process of prenatal testing decision-making. It consisted of three studies. Study One proposed a model accounting for the independent and interrelated roles of social, ethical, emotional and cognitive variables previously shown to impact on reproductive choices. This model was valuable in showing that the biological aspect of genetic conditions is only one of many components involved in decisions about family planning. The first study also created reliable measuring tools for the psychosocial constructs involved in the process of prenatal testing decision-making. The main scientific advance of Study One was in presenting a psychometric paradigm which could be used to theoretically guide future studies on the process of prenatal testing decision-making.

Study Two advanced the understanding of the process of prenatal testing decision-making by testing the model proposed in Study One. As predicted, subjective norms – partner (and to a lesser extent subjective norms – family), religiosity, abortion willingness, benefits from negative results and perceived vulnerability were all found to influence testing intention. It was also confirmed that religiosity, attitudes towards disabilities, anticipated emotional distress, anticipated coping efficacy and negative consequences influenced abortion willingness. These results validated expectations that social, moral, emotional and cognitive considerations impacted on choices pertaining to family planning. The main clinical implication emerging from these findings was that, when discussing reproduction options with their patients, genetic counsellors should explore people's concerns about issues other than those simply pertaining to the medical aspects of the procedure.

Study Two also provided a novel contribution to the field of decision-making about pre-birth testing by exploring the role of some aspects of the genetic conditions and of people's demographic characteristics on choices pertaining to family planning. The influences of condition severity (nonfatal versus fatal), condition age of onset (early versus late), gender and family status (childless versus expecting versus parents) on intention to undergo prenatal testing and on willingness to terminate an affected pregnancy were investigated. One key finding was that the condition's characteristics may be of little relevance to parents' intention to undergo testing. The condition's characteristic may, however, be of prime importance when
deciding about the outcome of an affected pregnancy. It was therefore recommended that genetic counsellors be aware that their description of foetal conditions and possible long-term consequences on the family may result in irrevocable decisions regarding the future of pregnancy.

Study Three added to the body of research by evaluating the role of perceived likelihood of miscarriage, trait anxiety and information modality on prenatal testing decision-making. It was found that fears about incidental miscarriage could act as a deterrent to undergoing invasive procedure. Study Three also showed that trait anxiety could exacerbate emotional responses to sensitive issues related to reproduction. It appeared that one's abilities to cope emotionally with information about foetal health threats and a possible future of raising a child with special needs, depended on enduring personal traits. This pattern of responses was exaggerated when the health message was delivered through multimedia instructional materials. Hence, while audio-video instructional supports may increase knowledge and understanding, they may simultaneously increase negative affective responses to complex and emotional issues. Trait anxiety did not, however, seem to influence testing intention or evaluation of possible risks and benefits which could result from undergoing the procedure. These results were interpreted as possibly indicating greater cognitive dissonance amongst anxious individuals.

Study Three had clear clinical and education implications. If, as predicted, safer prenatal tests were to become available to expectant parents in the near future, then uptake rates could increase. This means that health professionals could be involved in an increasing number of discussions about reproductive technologies. It is therefore crucial that physicians be prepared for such conversations about prenatal testing. In particular, health professionals would need to recognise that reproductive choices are emotionally laden and that enduring personality traits may aggravate affective responses to anxiety-provoking information. Hence, great care should be taken when delivering information of a sensitive nature to naturally anxious patients. The role of multimedia educational materials in responses to anxiety-provoking issues in people with higher trait anxiety was also discussed. Health professionals should be aware of the possible dilemma residing in recommending anxious patients to watch health messages.
Finally, avenues for further research were proposed. It was recommended that future investigations in the process of prenatal testing decision-making include participants of different cultural backgrounds (e.g., Māori) so that under-represented voices could be heard. It was also suggested that attitudes of men should be explored as their views may differ from those of female participants. Gaining a thorough understanding of people's beliefs about reproductive technologies could have great implications for health care. Indeed, by being able to anticipate people's expectations and responses to issues raised by prenatal testing, health professionals may be able to manage emotional responses and foster adaptive responses. Such understanding of the process of prenatal testing decision-making could increase the quality of patient-practitioner interactions and communications about the gender-specific / cultural-specific issues. Genetic counsellors would be better able to provide future patients with appropriate medical and psychological support. This means that members of the public could more fully benefit from the fast growing fields of genomics.
Appendices and References
Appendix A – Hypothetical scenario used in Study One

Vividly imagine you are expecting a baby and are at the beginning (under 12 weeks) of the pregnancy. You hear about a pre-birth test that can detect with more accuracy than an ultrasound can whether the foetus is affected with a condition.

Now imagine that this condition is a disease caused by a genetic mutation. The condition involves a progressive deterioration in:
- Knowledge and understanding (cognitive deterioration)
- Movements, with occurrence of involuntary movements (neurological deterioration), and
- Personality (deterioration of emotional systems)

The condition is a progressive 'ADULT-onset' condition: symptoms appear slowly between the ages of 30 and 50 years. On average, in the entire population, parents have 1 chance in 200 (0.5%) of having a child with this condition. NO CURE is currently available. Individuals with this condition will live approximately 10 to 15 years after the onset of illness.

The test consists of obtaining a small sample of placenta or amniotic fluid (these surround the foetus). Sometimes under local anaesthetic and with ultrasound guidance, a syringe is used to collect small samples of the required tissues.

This procedure may be mildly uncomfortable for the mother, as some angling to get good views of the baby may be required. There may also be discomfort due to bruising and some cramps may be experienced. However, these usually resolve within 24 hours.

The risk of procedure-related miscarriage is between 0.5% and 1%. This means that between 1 in 200 and 2 in 200 women will miscarry as a result of the procedure. There is also a risk of natural miscarriage of 2% that is present in all pregnancies at 10 weeks gestation, whether or not the test is performed.

This procedure is done as an outpatient procedure and partners (or a support person / Whānau / family support) can attend. The test is performed between 10 and 15 weeks of pregnancy (depending of the sample required). Results will be available 10-14 days following the procedure. In New Zealand and Australia, the test is usually free of charge.

The second webpage displays the following summary check:

The condition described is genetically determined and... (Please read and tick all the relevant statements)

- [ ] Detectable during pregnancy
- [ ] 0.5% likely to affect every pregnancy
- [ ] Develops between 30 and 50 years of age
- [ ] Fatal to the individual

The next webpage would follow only if all four options had been ticked
Appendix B – Items designed to measure condition-related variables, subjected to the first principal component analyses in Study One

Table B
Hypothesised Constructs, Code Names and Items Designed to Measure the Condition-related Variables, Subjected to the First Principal Component Analyses in Study One

<table>
<thead>
<tr>
<th>Hypothesised constructs</th>
<th>Items</th>
<th>Items’ code names</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Anticipated coping efficacy</strong></td>
<td>I feel I could bring up a child with this condition</td>
<td>AntCopEff.BringUp</td>
</tr>
<tr>
<td></td>
<td>I would not be psychologically strong enough to look after a child with this condition</td>
<td>AntCopEff.PsychStrongREC</td>
</tr>
<tr>
<td></td>
<td>I don’t think I could manage a child with this condition</td>
<td>AntCopEff.ManageREC</td>
</tr>
<tr>
<td></td>
<td>I would have the mental strength to cope with a child with this condition</td>
<td>AntCopEff.MentalStrengthREC</td>
</tr>
<tr>
<td></td>
<td>Looking after a child with this condition would be too much for me</td>
<td>AntCopEff.TooMuchREC</td>
</tr>
<tr>
<td><strong>Negative consequences</strong></td>
<td>This condition is serious</td>
<td>NegaCsqs.Serious</td>
</tr>
<tr>
<td></td>
<td>This condition would have major consequences on my child's life</td>
<td>NegaCsqs.MajorCnsqs</td>
</tr>
<tr>
<td></td>
<td>This condition would not have much effect on my child's life</td>
<td>NegaCsqs.NoEffectREC</td>
</tr>
<tr>
<td></td>
<td>This condition would strongly affect the way others would see my child</td>
<td>NegaCsqs.StronglyAffect</td>
</tr>
<tr>
<td></td>
<td>This condition would have serious financial consequences for us</td>
<td>NegaCsqs.FinancCsqs</td>
</tr>
<tr>
<td></td>
<td>This condition would cause difficulties for those who will be part of my child's life</td>
<td>NegaCsqs.ThosePartOf</td>
</tr>
<tr>
<td><strong>Anticipated emotional distress</strong></td>
<td>I feel depressed when I think that a child of mine could be affected with this condition</td>
<td>AntEmoDiss.Depressed</td>
</tr>
<tr>
<td></td>
<td>Thinking about giving birth to a child with this condition makes me feel upset</td>
<td>AntEmoDiss.Upset</td>
</tr>
<tr>
<td></td>
<td>The thought of having a child with this condition is distressing to me</td>
<td>AntEmoDiss.Distressing</td>
</tr>
<tr>
<td></td>
<td>I am not afraid to think about having a child with this condition</td>
<td>AntEmoDiss.AfraidREC</td>
</tr>
<tr>
<td></td>
<td>Thinking about how my life would be with a child with this condition does not sadden me</td>
<td>AntEmoDiss.SaddenREC</td>
</tr>
<tr>
<td><strong>Child-related worry</strong></td>
<td>If I (we) were expecting a child, I would worry about it being affected with this condition</td>
<td>W.Worry</td>
</tr>
<tr>
<td></td>
<td>I am concerned my child may be born with this condition</td>
<td>W.Concerned</td>
</tr>
<tr>
<td></td>
<td>The thought of giving birth to a child with this condition bothers me</td>
<td>W.Bother</td>
</tr>
<tr>
<td><strong>Perceived vulnerability</strong></td>
<td>If I (we) were expecting a child, I feel it would be likely that my child would have this condition</td>
<td>PrcdVuln.LikelyHav</td>
</tr>
<tr>
<td></td>
<td>I (we) would not be ‘at-risk’ of having a child with this condition</td>
<td>PrcdVuln.NotAtRiskREC</td>
</tr>
<tr>
<td></td>
<td>It is very unlikely that my child would be born with this condition</td>
<td>PrcdVuln.UnlikelyBornREC</td>
</tr>
</tbody>
</table>
Appendix C – Items designed to measure testing intention and ethics-related variables, subjected to the second principal component analyses in Study One

Table C
Hypothesised Constructs, Code Names and Items Designed to Measure the Ethics-related Variables, Subjected to the Second Principal Component Analyses in Study One

<table>
<thead>
<tr>
<th>Hypothesised constructs</th>
<th>Items’ code names</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Testing intention</strong></td>
<td></td>
</tr>
<tr>
<td><em>Undergoing this prenatal test would be too distressing for me</em></td>
<td>TestInt.TooDistrssREC</td>
</tr>
<tr>
<td><em>For me, even a slight increase in the chance of miscarriage would be unacceptable</em></td>
<td>TestInt.UnacceptREC</td>
</tr>
<tr>
<td><em>This prenatal test would expose my unborn child to unnecessary risks</em></td>
<td>TestInt.UnncessRiskREC</td>
</tr>
<tr>
<td><em>Prenatal testing would be of no benefit to myself or my family</em></td>
<td>TestInt.NoBenefREC</td>
</tr>
<tr>
<td><em>It would be important to get the test</em></td>
<td>TestInt.Important2Get</td>
</tr>
<tr>
<td><em>I would request the test</em></td>
<td>TestInt.RequestTest</td>
</tr>
<tr>
<td><strong>Abortion willingness</strong></td>
<td></td>
</tr>
<tr>
<td><em>Someone with this condition would have a diminished quality of life</em></td>
<td>AbortInt.DiminshREC</td>
</tr>
<tr>
<td><em>I would rather have a child with this condition than no child</em></td>
<td>AbortInt.WouldRatherHave</td>
</tr>
<tr>
<td><em>I would be opposed to giving birth to a child with this condition</em></td>
<td>AbortInt.OpposdREC</td>
</tr>
<tr>
<td><em>If the test showed the presence of this condition, I would want to terminate the pregnancy</em></td>
<td>AbortInt.WantTerminREC</td>
</tr>
<tr>
<td><strong>Attitudes towards disabilities</strong></td>
<td></td>
</tr>
<tr>
<td><em>People with disabilities are valuable members of society</em></td>
<td>Dis.ValuableMembers</td>
</tr>
<tr>
<td><em>People with disabilities add much to society</em></td>
<td>Dis.Add2Society</td>
</tr>
<tr>
<td><em>Disability is a normal part of life</em></td>
<td>Dis.Normal</td>
</tr>
<tr>
<td><em>It is irresponsible to impose a child with disabilities on society when it came be avoided</em></td>
<td>Dis.IrresponsREC</td>
</tr>
<tr>
<td><strong>Religiosity</strong></td>
<td></td>
</tr>
<tr>
<td><em>I would rather rely on prayers than on testing to ensure the unborn child was healthy</em></td>
<td>Rel.Prayers</td>
</tr>
<tr>
<td><em>Every child is a gift from God / the Divine Force / the Holy Creator</em></td>
<td>Rel.Gift</td>
</tr>
<tr>
<td><em>Only God / the Divine Force / the Holy Creator should decide which child gets to live</em></td>
<td>Rel.GodDecide</td>
</tr>
</tbody>
</table>
Appendix D – Items designed to measure subjected to the PCA on the test-related variables, subjected to the third principal component analyses in Study One

<table>
<thead>
<tr>
<th>Hypothesised constructs</th>
<th>Items’ code names</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Condition coherence</strong></td>
<td></td>
</tr>
<tr>
<td><em>The symptoms of this condition are puzzling to me</em></td>
<td>Coherence.PuzzlingREC</td>
</tr>
<tr>
<td><em>This condition is a mystery to me</em></td>
<td>Coherence.MysteryREC</td>
</tr>
<tr>
<td><em>I don't fully understand this condition</em></td>
<td>Coherence.UnderstandREC</td>
</tr>
<tr>
<td><em>This condition does not make any sense to me</em></td>
<td>Coherence.NoSenseREC</td>
</tr>
<tr>
<td><em>I have a clear picture / understanding of this condition</em></td>
<td>Coherence.ClearPic</td>
</tr>
<tr>
<td><strong>Perceived benefits from negative test results</strong></td>
<td></td>
</tr>
<tr>
<td><em>The test results would resolve the uncertainty about whether or not my unborn child has this condition</em></td>
<td>Benef.N.Uncertainty</td>
</tr>
<tr>
<td><em>Knowing that my unborn child did not have the genetic mutation...</em></td>
<td></td>
</tr>
<tr>
<td>... <em>would help me feel less anxious about the pregnancy</em></td>
<td>Benef.N.LssAnx</td>
</tr>
<tr>
<td>... <em>would make me feel reassured about the health of my unborn child</em></td>
<td>Benef.N.Reassured</td>
</tr>
<tr>
<td>... <em>would increase my confidence regarding the progress/outcomes of the pregnancy</em></td>
<td>Benef.N.Condfnt</td>
</tr>
<tr>
<td><strong>Perceived benefits from positive test results</strong></td>
<td></td>
</tr>
<tr>
<td><em>Knowing the test results would help us work to organise our lives</em></td>
<td>Benef.P.OrgLives</td>
</tr>
<tr>
<td><em>Knowing that my unborn child had this genetic condition...</em></td>
<td></td>
</tr>
<tr>
<td>... <em>would help me start planning our future with a child affected with the condition</em></td>
<td>Benef.P.PlanFuture</td>
</tr>
<tr>
<td>... <em>would help me prepare myself psychologically for a life with this child</em></td>
<td>Benef.P.PrepPsych</td>
</tr>
<tr>
<td>... <em>would help me work on making sure that my child's needs after birth would be met</em></td>
<td>Benef.P.NeedsMet</td>
</tr>
<tr>
<td><strong>Test response efficacy</strong></td>
<td></td>
</tr>
<tr>
<td><em>Undergoing this prenatal test would give me only an idea about the risks, not a definite answer</em></td>
<td>RespEff.OnlyIdeaREC</td>
</tr>
<tr>
<td><em>Undergoing this prenatal test would clearly indicate the presence of this condition.</em></td>
<td>RespEff.ClearlyIndic</td>
</tr>
<tr>
<td><em>I do not feel confident that this prenatal test would give accurate information about whether or not my unborn child would have the condition.</em></td>
<td>RespEff.NoConfidntREC</td>
</tr>
<tr>
<td><em>This prenatal test could indicate whether or not something is wrong</em></td>
<td>RespEff.CouldIndic</td>
</tr>
</tbody>
</table>
Appendix E – Demographic questions used in all three studies

Finally, please answer a few questions about yourself

Age: 

Gender: 
- Male
- Female

Are you currently: 
- Single, not in a serious relationship
- Single, in a serious relationship
- De facto / Married
- Separated / Divorced
- Widowed

Are you currently expecting a child? 
- No
- Yes

How many children do you have? 

Education level (please indicate the highest education level that has been completed): 
- High School
- Bachelor's degree
- Master degree
- Professional degree
- PhD / Doctorate
- Trade certificate
- Other (Please specify)
Ethnicity:
- New Zealand European
- Other European
- Māori
- Samoan
- Cook Island Māori
- Tongan
- Niuean
- Tokelauan
- Fijian
- Other Pacific
- South East Asian
- Indian
- Chinese
- Other Asian
- Other – please specify

What religion are you affiliated to?
- Christian
- Jewish
- Muslim
- Buddhist
- Agnostic
- Atheist
- None
- Other (Please specify)
Appendix F – Recruitment flyer used in Study One and Study Two

Research participants needed for study on:

**Attitudes towards genetic testing for unborn children**

We are looking for participants to take part in a study about men's and women's opinions on pre-birth testing for disease and disability risk.

To learn more, please send a *blank* email to

prenatal@auckland.ac.nz
Appendix G – Automatic reply email used in Study One

Thank you very much for showing interest in our study on attitudes towards prenatal testing

This research aims to investigate men's and women's opinions regarding pre-birth testing for genetic risk for diseases and disabilities. Complete information regarding the study and your rights as a participant is provided in the Information Sheet (IS) and the Consent Form (CF) attached.

If you agree to participate, you will be presented with a hypothetical scenario about a genetic condition and pre-birth testing. You will then be asked to complete an online questionnaire. Your responses will be treated as anonymous and confidential. Please be assured that your anonymity will be completely assured at all times throughout the project.

Your participation is completely voluntary; by clicking here (or by copy-pasting the link https://www.surveymonkey.com/s.aspx?sm=cjKePsOw9D2a7BBOqmYZZzw3d_3d in your browser) you are expressing your consent to take part in this study. Altogether this questionnaire should take 15-20 minutes to complete.

There is a small risk you might feel distressed by the scenario presented next. Please remember it is hypothetical. However, if you do have any concern, we would suggest you talk to your GP. Also, please contact us if you have any questions or concerns about the survey, if the study raises any questions or concerns about disease or disability risk and pre-birth testing, or if you would like more information about the survey.

Taking part in this study will take some of your time to consider how you feel about the questions asked to you. So thank you very much in advance for your help… and your patience!
Your help will be hugely appreciated,

Cecile Muller

Department of Psychology
Building 721, Room 340
Tamaki Campus

The University of Auckland
Private Bag 92019
Auckland Mail Centre, Auckland.
Phone: +64 (0)9 373 7599 ext. 85224
Fax: +64 (0)9 373 7043
Appendix H – Participant Information Sheet used in all three studies

Dear Participant,

My name is Cecile Muller. I am a PhD student in the department of Psychology, Faculty of Science, The University of Auckland. I would like to invite you to take part in my research which aims to investigate men's and women's opinions regarding pre-birth testing for genetic risk for diseases and disabilities. The participants in this study are aged 18 years or older.

Participants will be randomly allocated to 1 of 4 hypothetical scenarios about pregnancy and pre-birth testing. Participants will then be asked to complete an online questionnaire exploring a number of themes, including their current thoughts about the availability, and the benefits and costs of prenatal testing. It is hoped that these answers will contribute to our understanding of how men and women make judgements and decisions about issues relating to pregnancies.

Taking part in this study will take some of your time to consider how you feel about the questions asked to you. Altogether this questionnaire should take about 25 minutes to complete. Your responses will be included in a password-protected database on a password-protected computer in a locked office at the University of Auckland. The dataset will be deleted 6 years after the publication of the survey findings.

If you agree to take part in this study, your responses will be treated as anonymous and confidential. The dataset will not include any information that could be used to identify you as the source of your responses. Reports of the data will only include summaries of general patterns of responses, such as group means (averages) and proportions (percentages). Your anonymity is therefore completely assured at all times throughout the project.

Please note that, because your responses are anonymous, they cannot be withdrawn from the study once they have been submitted. There are no direct benefits or risks to you as a participant, and there is no payment for your participation. If you are a university student, your decision to participate or to not participate in the survey will not affect your grades or your academic relationships with the department or members of the academic staff.
Your participation in this study is completely voluntary. Submission of the questionnaire serves as consent to participate in this study. You do not have to answer any question you don’t want to answer. You are free to withdraw at any stage during completion of the questionnaire.

This participation sheet will remain available on this website until the end of the study, on 01/07/2010. You are welcome to print out this page for your own records. There is a small risk you might feel distressed by the scenario. If you have any concern, we would suggest you talk to your GP, midwife or Lead Maternity Carer. Also, please contact us if you have any questions or concerns about the survey, if the study raises any questions or concerns about disease or disability risk and pre-birth testing, or if you would like more information about the survey.

Researcher: Cecile Muller, Department of Psychology, The University of Auckland (Tamaki Campus), Private Bag 92019, Auckland. (09) 373 7599 ext. 85224; c.muller@auckland.ac.nz

Supervisor: Associate Professor Linda Cameron, Department of Psychology, The University of Auckland (Tamaki Campus), Private Bag 92019, Auckland. (09) 373 7599 ext. 86869; l.cameron@auckland.ac.nz

Head of Department: Associate Professor Fred Seymour, Department of Psychology, The University of Auckland, Private Bag 92019, Auckland. Telephone 373 7599 ext. 88516; f.seymour@auckland.ac.nz

For any queries regarding ethical concerns you may contact the Chair, The University of Auckland Human Participants Ethics Committee, The University of Auckland, Office of the Vice Chancellor, Private Bag 92019, Auckland 1142. Telephone 09 373-7599 ext. 87830.

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE
for 3 years on 12th June 2008, Reference Number 2008/ Q / 023
Appendix I – Consent form used in all three studies

Consent Form
This form will be kept for ten years

Researcher: Cecile Muller
Title: Pre-birth testing and decision-making

I have read the Participant information sheet. I have understood the nature of the research. By clicking on the link included in the email, I am expressing my consent to participate in this study. I understand that:

- I am under no obligation to take part in this study as my participation is completely voluntary
- I have the right to withdraw my participation at any time during the study
- The data provided thereafter may be used for publication
- My answers may be stored for ten years, before being completely destroyed
- Completion of the following questionnaire may require up to 20 minutes
- I can contact the researcher, supervisor, (etc.) if any questions or concerns about the survey, if the study raises any questions or concerns about disease or disability risk and pre-birth testing, or if I would like more information about the survey.

I agree to take part in this research.

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE
for 3 years on 12th June 2008, Reference Number 2008/ Q / 023
Appendix J – Debriefing statement

Thank you for completing this survey

* People vary in their beliefs about prenatal testing and pregnancy decisions. These are personal views that are very much respected, and all views will be treated in a non-judgemental manner.

* Please note that we do not advocate or condemn abortion or the use of these types of genetic tests. We are merely interested in understanding the diversity of opinions about what people may do and feel in regards to their reproductive decisions.

* We wish to emphasise that the aim of this study is NOT to influence parents one way or the other in regards to any aspect of prenatal testing. Rather, we feel it is essential to understand people’s views so that we can identify ways for providing support for parents, regardless of their decisions, during these potentially difficult times.

The scenario about the genetic condition contained HYPOTHETICAL information about the onset age, the severity of the condition and the general population risk for Huntington’s disease. Here is what is currently known about Huntington's disease:

Huntington's disease (HD) is a very rare condition and affects only about 1 in 10,000 people in Western countries (0.01% of Westerners).

HD is a genetic condition that can only be passed on from parents to children. This means that if the parents are not carriers of the faulty gene, children will not be affected either. For those who do get born with the faulty gene, symptoms will not appear for many years, most often not until 30-50 years later.

Research suggests that the information in other genes appears to modify the age of onset, although exactly which genes are important and how they influence this is still under investigation.

Substances that have been shown to delay the onset of symptoms in mice are being tested in humans. It is anticipated that research will lead to new treatments.

Most importantly, since HD is passed on from parents, children who have not inherited it from their parents are not at risk of developing HD. Also, they cannot pass the faulty gene copy on to their children.

Several screening and diagnostic testing for HD are available during pregnancy to help couples assess their likelihood of carrying a child with that condition. These tests are not compulsory and they are generally free of charge for most patients.

More information about prenatal genetic testing and Huntington's disease can be found on the Huntington's disease Associations of New Zealand http://www.huntingtons.org.nz or on the Australian Centre for Genetics Education in Sydney website: http://www.genetics.com.au
Appendix K – Final scales measuring condition-related, used in Study Two and Study Three

Anticipated coping efficacy

*How much do you agree/ disagree with the following statements?*

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel I could bring up a child with this condition</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
</tr>
<tr>
<td>I would not be psychologically strong enough to look after a child with this condition*</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
</tr>
<tr>
<td>I don’t think I could manage a child with this condition*</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
</tr>
<tr>
<td>I would have the mental strength to cope with a child with this condition*</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
</tr>
<tr>
<td>Looking after a child with this condition would be too much for me*</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
</tr>
</tbody>
</table>

* indicates items needing reverse-coded before analyses

Negative consequences

*How much do you agree / disagree with the following statements?*

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>This condition is serious</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
</tr>
<tr>
<td>This condition would have major consequences on my child's life</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
</tr>
<tr>
<td>This condition would not have much effect on my child's life*</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
</tr>
<tr>
<td>This condition would strongly affect the way others would see my child</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
</tr>
<tr>
<td>This condition would have serious financial consequences for us</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
</tr>
<tr>
<td>This condition would cause difficulties for those who will be part of my child's life</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
</tr>
</tbody>
</table>

* indicates items needing reverse-coded before analyses
## Anticipated emotional distress

*Please read the statements below and click on the options that best describe your views*

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel depressed when I think that a child of mine could be affected with this condition</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
</tr>
<tr>
<td>The thought of having a child with this condition is distressing to me</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
</tr>
<tr>
<td>I am not afraid to think about having a child with this condition*</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
</tr>
<tr>
<td>Thinking about how my life would be with a child with this condition does not sadden me*</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
</tr>
</tbody>
</table>

* indicates items needing reverse-coded before analyses

## Child-related worry

*Please click on the options that best describe your views*

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not at all</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thinking about giving birth to a child with this condition makes me feel upset</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
</tr>
<tr>
<td>If I (we) were expecting a child, I would worry about it being affected with this condition</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
</tr>
<tr>
<td>I am concerned my child may be born with this condition</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
</tr>
<tr>
<td>The thought of giving birth to a child with this condition bothers me</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
</tr>
</tbody>
</table>

* indicates items needing reverse-coded before analyses

## Perceived vulnerability

*Please click on the options that best suit your views*

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>If I (we) were expecting a child, I feel it would be likely that my child would have this condition</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
</tr>
<tr>
<td>I (we) would not be 'at-risk' for having a child with this condition*</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
</tr>
<tr>
<td>It is very unlikely that my child would be born with this condition*</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
</tr>
</tbody>
</table>

* indicates items needing reverse-coded before analyses
Appendix L – Final scales measuring testing intention and the ethics-related variables, used in Study Two and Study Three

### Testing intention

*If you were offered this prenatal test to find out whether your unborn child was affected with this condition, to what extent would the following apply to you?*

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Undergoing this prenatal test would be too distressing for me*</td>
<td>○ ○ ○ ○ ○ ○ ○</td>
</tr>
<tr>
<td>For me, even a slight increase in the chance of miscarriage would be unacceptable*</td>
<td>○ ○ ○ ○ ○ ○ ○</td>
</tr>
<tr>
<td>This prenatal test would expose my unborn child to unnecessary risks*</td>
<td>○ ○ ○ ○ ○ ○ ○</td>
</tr>
<tr>
<td>Prenatal testing would be of no benefit to myself or my family*</td>
<td>○ ○ ○ ○ ○ ○ ○</td>
</tr>
<tr>
<td>It would be important to get the test</td>
<td>○ ○ ○ ○ ○ ○ ○</td>
</tr>
<tr>
<td>I would request the test*</td>
<td>○ ○ ○ ○ ○ ○ ○</td>
</tr>
</tbody>
</table>

*indicates items needing reverse-coded before analyses

### Abortion willingness

*How much do you agree/disagree with the following statements?*

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Someone with THIS condition would have a diminished quality of life*</td>
<td>○ ○ ○ ○ ○ ○ ○</td>
</tr>
<tr>
<td>I would rather have a child with THIS condition than no child</td>
<td>○ ○ ○ ○ ○ ○ ○</td>
</tr>
<tr>
<td>I would be opposed to giving birth to a child with THIS condition*</td>
<td>○ ○ ○ ○ ○ ○ ○</td>
</tr>
<tr>
<td>If the test showed the presence of THIS condition, I would want to terminate the pregnancy*</td>
<td>○ ○ ○ ○ ○ ○ ○</td>
</tr>
<tr>
<td>It is irresponsible to impose a child with disabilities on society when it came be avoided*</td>
<td>○ ○ ○ ○ ○ ○ ○</td>
</tr>
</tbody>
</table>

*indicates items needing reverse-coded before analyses
### Attitudes towards disabilities

*How much do you agree/disagree with the following statements?*

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>People with disabilities are valuable members of society</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
</tr>
<tr>
<td>People with disabilities add much to society</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
</tr>
<tr>
<td>Disability is a normal part of life</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
</tr>
</tbody>
</table>

### Religiosity

*How much do you agree/disagree with the following statements?*

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I would rather rely on prayers than on prenatal testing to ensure the unborn child was healthy</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
</tr>
<tr>
<td>Every child is a gift from God / the Divine Force / the Holy Creator</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
</tr>
<tr>
<td>Only God / the Divine Force / the Holy Creator should decide which child gets to live</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
</tr>
</tbody>
</table>
Appendix M – Final scales measuring the test-related variables, used in Study Two and Study Three

### Conditions coherence

*How much do you agree / disagree with the following?*

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>The symptoms of this condition are puzzling to me*</td>
<td>○ ○ ○ ○ ○ ○ ○</td>
</tr>
<tr>
<td>This condition is a mystery to me*</td>
<td>○ ○ ○ ○ ○ ○ ○</td>
</tr>
<tr>
<td>I don't fully understand this condition*</td>
<td>○ ○ ○ ○ ○ ○ ○</td>
</tr>
<tr>
<td>This condition does not make any sense to me*</td>
<td>○ ○ ○ ○ ○ ○ ○</td>
</tr>
<tr>
<td>I have a clear picture / understanding of this condition</td>
<td>○ ○ ○ ○ ○ ○ ○</td>
</tr>
</tbody>
</table>

* indicates items needing reverse-coded before analyses

### Perceived benefits from negative test results

*How much do you agree/ disagree with the following statements?*

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>The test results would resolve the uncertainty about whether or not my unborn child has this condition</td>
<td>○ ○ ○ ○ ○</td>
</tr>
</tbody>
</table>

Knowing that my unborn child did not have the genetic mutation…

… would help me feel less anxious about the pregnancy | ○ ○ ○ ○ ○ |

… would make me feel reassured about the health of my unborn child | ○ ○ ○ ○ ○ |

… would increase my confidence regarding the progress/ outcomes of the pregnancy | ○ ○ ○ ○ ○ |
## Perceived benefits from positive test results

*How much do you agree/ disagree with the following statements?*

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowing the test results would help us work to organise our lives</td>
<td>○ ○ ○ ○ ○ ○</td>
</tr>
<tr>
<td>Knowing that my unborn child had this genetic condition…</td>
<td></td>
</tr>
<tr>
<td>… would help me start planning our future with a child affected with the condition</td>
<td>○ ○ ○ ○ ○ ○</td>
</tr>
<tr>
<td>… would help me prepare myself psychologically for a life with this child</td>
<td>○ ○ ○ ○ ○ ○</td>
</tr>
<tr>
<td>… would help me work on making sure that my child's needs after birth would be met</td>
<td>○ ○ ○ ○ ○ ○</td>
</tr>
</tbody>
</table>

## Test response efficacy

*How much do you agree/ disagree with the following statements?*

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Undergoing this prenatal test would clearly indicate the presence of this condition.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
</tr>
<tr>
<td>I do not feel confident that this prenatal test would give accurate information about whether or not my unborn child would have the condition. *</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
</tr>
<tr>
<td>This prenatal test could indicate whether or not something is wrong</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
</tr>
</tbody>
</table>

*indicates items needing reverse-coded before analyses
Appendix N – Scales measuring normative beliefs and motivation to comply, used in all three studies

**Normative Beliefs**

*How much would each of the following people want you to take this prenatal test?*

<table>
<thead>
<tr>
<th></th>
<th>Would not want at all</th>
<th>Would want very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>- your partner / husband / wife</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
</tr>
<tr>
<td>- your family / Whānau</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
</tr>
<tr>
<td>- your doctor / obstetrician / midwife</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
</tr>
<tr>
<td>- your friends</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
</tr>
</tbody>
</table>

**Motivation to comply**

*You would undergo prenatal testing if it was important to:*

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>- my partner / husband / wife</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
</tr>
<tr>
<td>- my family / Whānau</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
</tr>
<tr>
<td>- my doctor / obstetrician / midwife</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
</tr>
<tr>
<td>- my friends</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
</tr>
</tbody>
</table>
Appendix O – Online survey used in Study Two

**Web page 1**

**PRE-BIRTH TESTING AND DECISION-MAKING**

Thank you very much for agreeing to take part in this study.

Please indicate the day you were born:

- **the 1\textsuperscript{st} and the 7\textsuperscript{th} of the month** → sends participants to page 2: scenario describes an adult-onset/fatal condition
- **the 8\textsuperscript{th} and the 15\textsuperscript{th} of the month** → sends participants to page 4: scenario describes birth-onset/fatal condition
- **the 16\textsuperscript{th} and the 23\textsuperscript{rd} of the month** → sends participants to page 6: scenario 3 describes adult-onset/nonfatal condition
- **the 24\textsuperscript{th} and the 31\textsuperscript{st} of the month** → sends participants to page 8: scenario 4 describes birth-onset/nonfatal condition
Vividly imagine you are expecting a baby and are at the beginning (under 12 weeks) of the pregnancy. You hear about a pre-birth test that can detect with more accuracy than an ultrasound can whether the foetus is affected with a condition.

Now imagine that this condition is a disease caused by a genetic mutation. The condition involves a progressive deterioration in:
- Knowledge and understanding (cognitive deterioration)
- Movements, with occurrence of involuntary movements (neurological deterioration), and
- Personality (deterioration of emotional systems)

The condition is a progressive 'ADULT-onset' condition: symptoms appear slowly between the ages of 30 and 50 years. On average, in the entire population, parents have 1 chance in 200 (0.5%) of having a child with this condition. NO CURE is currently available. Individuals with this condition will live approximately 10 to 15 years after the onset of illness.

The test consists of obtaining a small sample of placenta or amniotic fluid (these surround the foetus). Sometimes under local anaesthetic and with ultrasound guidance, a syringe is used to collect small samples of the required tissues.

This procedure may be mildly uncomfortable for the mother, as some angling to get good views of the baby may be required. There may also be discomfort due to bruising and some cramps may be experienced. However, these usually resolve within 24 hours.

The risk of procedure-related miscarriage is between 0.5% and 1%. This means that between 1 in 200 and 2 in 200 women will miscarry as a result of the procedure. There is also a risk of natural miscarriage of 2% that is present in all pregnancies at 10 weeks gestation, whether or not the test is performed.

This procedure is done as an outpatient procedure and partners (or a support person / Whānau / family support) can attend. The test is performed between 10 and 15 weeks of pregnancy (depending of the sample required). Results will be available 10-14 days following the procedure. In New Zealand and Australia, the test is usually free of charge.

Web page 3

The condition described is genetically determined and... (Please read and tick all the relevant statements)

- Detectable during pregnancy
- 0.5% likely to affect every pregnancy
- Develops between 30 and 50 years of age
- Fatal to the individual

The next webpage would follow only if all four options had been ticked
Web page 4 - for participants born between the 8th and the 15th of the month; describes the birth-onset / fatal condition

Vividly imagine you are expecting a baby and are at the beginning (under 12 weeks) of the pregnancy. You hear about a pre-birth test that can detect with more accuracy than an ultrasound can whether the foetus is affected with a condition.

Now imagine that this condition is a disease caused by a genetic mutation. The condition involves a progressive deterioration in:
- Knowledge and understanding (cognitive deterioration)
- Movements, with occurrence of involuntary movements (neurological deterioration), and
- Personality (deterioration of emotional systems)

The condition is a progressive 'BIRTH-onset' condition: symptoms are present from birth. On average, in the entire population, parents have 1 chance in 200 (0.5%) of having a child with this condition. NO CURE is currently available. Individuals with this condition will live approximately 10 to 15 years after the onset of illness.

The test consists of obtaining a small sample of placenta or amniotic fluid (these surround the foetus). Sometimes under local anaesthetic and with ultrasound guidance, a syringe is used to collect small samples of the required tissues.

This procedure may be mildly uncomfortable for the mother, as some angling to get good views of the baby may be required. There may also be discomfort due to bruising and some cramps may be experienced. However, these usually resolve within 24 hours.

The risk of procedure-related miscarriage is between 0.5% and 1%. This means that between 1 in 200 and 2 in 200 women will miscarry as a result of the procedure. There is also a risk of natural miscarriage of 2% that is present in all pregnancies at 10 weeks gestation, whether or not the test is performed.

This procedure is done as an outpatient procedure and partners (or a support person / Whānau / family support) can attend. The test is performed between 10 and 15 weeks of pregnancy (depending of the sample required). Results will be available 10-14 days following the procedure. In New Zealand and Australia, the test is usually free of charge.

Web page 5

The condition described is genetically determined and... (Please read and tick all the relevant statements)

- Detectable during pregnancy
- 0.5% likely to affect every pregnancy
- Present from birth
- Fatal to the individual

The next webpage would follow only if all four options had been ticked
Web page 6 for participants born between the 16th and the 23rd of the month; describes the adult-onset / nonfatal condition

Vividly imagine you are expecting a baby and are at the beginning (under 12 weeks) of the pregnancy. You hear about a pre-birth test that can detect with more accuracy than an ultrasound can whether the foetus is affected with a condition.

Now imagine that this condition is a disease caused by a genetic mutation. The condition involves a progressive deterioration in:
- Knowledge and understanding (cognitive deterioration)
- Movements, with occurrence of involuntary movements (neurological deterioration), and
- Personality (deterioration of emotional systems)

The condition is a progressive 'ADULT-onset' condition: symptoms appear slowly between the ages of 30 and 50 years. On average, in the entire population, parents have 1 chance in 200 (0.5%) of having a child with this condition. A cure IS currently available. Individuals with this condition who receive the treatment will live after the onset of illness and with minimal effects of the condition.

The test consists of obtaining a small sample of placenta or amniotic fluid (these surround the foetus). Sometimes under local anaesthetic and with ultrasound guidance, a syringe is used to collect small samples of the required tissues.

This procedure may be mildly uncomfortable for the mother, as some angling to get good views of the baby may be required. There may also be discomfort due to bruising and some cramps may be experienced. However, these usually resolve within 24 hours.

The risk of procedure-related miscarriage is between 0.5% and 1%. This means that between 1 in 200 and 2 in 200 women will miscarry as a result of the procedure. There is also a risk of natural miscarriage of 2% that is present in all pregnancies at 10 weeks gestation, whether or not the test is performed.

This procedure is done as an outpatient procedure and partners (or a support person / Whānau / family support) can attend. The test is performed between 10 and 15 weeks of pregnancy (depending of the sample required). Results will be available 10-14 days following the procedure. In New Zealand and Australia, the test is usually free of charge.

Web page 7

The condition described is genetically determined and... (Please read and tick all the relevant statements)

- Detectable during pregnancy
- 0.5% likely to affect every pregnancy
- Develops between 30 and 50 years of age
- Nonfatal to the individual

The next webpage would follow only if all four options had been ticked
Vividly imagine you are expecting a baby and are at the beginning (under 12 weeks) of the pregnancy. You hear about a pre-birth test that can detect with more accuracy than an ultrasound can whether the foetus is affected with a condition.

Now imagine that this condition is a disease caused by a genetic mutation. The condition involves a progressive deterioration in:
- Knowledge and understanding (cognitive deterioration)
- Movements, with occurrence of involuntary movements (neurological deterioration), and
- Personality (deterioration of emotional systems)

The condition is a progressive 'BIRTH-onset' condition: symptoms are present from birth. On average, in the entire population, parents have 1 chance in 200 (0.5%) of having a child with this condition. A cure is currently available. Individuals with this condition who receive the treatment will live after the onset of illness and with minimal effects of the condition.

The test consists of obtaining a small sample of placenta or amniotic fluid (these surround the foetus). Sometimes under local anaesthetic and with ultrasound guidance, a syringe is used to collect small samples of the required tissues.

This procedure may be mildly uncomfortable for the mother, as some angling to get good views of the baby may be required. There may also be discomfort due to bruising and some cramps may be experienced. However, these usually resolve within 24 hours.

The risk of procedure-related miscarriage is between 0.5% and 1%. This means that between 1 in 200 and 2 in 200 women will miscarry as a result of the procedure. There is also a risk of natural miscarriage of 2% that is present in all pregnancies at 10 weeks gestation, whether or not the test is performed.

This procedure is done as an outpatient procedure and partners (or a support person / Whānau / family support) can attend. The test is performed between 10 and 15 weeks of pregnancy (depending of the sample required). Results will be available 10-14 days following the procedure. In New Zealand and Australia, the test is usually free of charge.

**Web page 9**

The condition described is genetically determined and... (Please read and tick all the relevant statements)

- [ ] Detectable during pregnancy
- [ ] 0.5% likely to affect every pregnancy
- [ ] Present from birth
- [ ] Nonfatal to the individual

The next webpage would follow only if all four options had been ticked
Appendix P – Trait version of the State-Trait Anxiety Inventory (Spielberg, 1983)

A number of statements which people have used to describe themselves are given below. Read each statement and, using the scale below, write the appropriate number in the space to the right of the statement to indicate **how you generally feel**. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe **how you generally feel**.

<table>
<thead>
<tr>
<th>Statement</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel pleasant</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I tire quickly</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel like crying</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I wish I could be as happy as others seem to be</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am losing out on things because I can't make up my mind soon enough</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel rested</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am &quot;calm, cool, and collected&quot;</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel that difficulties are piling up so that I cannot overcome them</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I worry too much over something that doesn't really matter</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am happy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am inclined to take things hard</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I lack self-confidence</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel secure</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I try to avoid facing a crisis or difficulty</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel blue</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am content</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some unimportant thought runs through my mind and bothers me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I take disappointments so keenly that I can't put them out of my mind</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am a steady person</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I get in a state of tension or turmoil as I think over my recent concerns and interests</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix Q – Recruitment flyer used in Study Three

Research participants needed for study on:

Attitudes towards genetic testing for unborn children

We are looking for participants to take part in a study about men's and women's opinions on pre-birth testing for disease and disability risk.

To learn more, please send a blank email to

prenataltesting@auckland.ac.nz
Appendix R – Automatic reply email used in Study Two

Thank you very much for showing interest in our study on 
attitudes towards prenatal testing

This research aims to investigate men's and women's opinions regarding pre-birth testing for genetic risk for diseases and disabilities.
Complete information regarding the study and your rights as a participant is provided in the Information Sheet (IS) and the Consent Form (CF) attached.

If you agree to participate, you will be presented with a hypothetical scenario about a genetic condition and pre-birth testing. You will then be asked to complete an online questionnaire. Your responses will be treated as anonymous and confidential. Please be assured that your anonymity will be completely assured at all times throughout the project.

Your participation is completely voluntary; by clicking here (or by copy-pasting the link https://www.surveymonkey.com/s.aspx?sm=A\[Fi\sl\f\pe46afp_54sca] in your browser) you are expressing your consent to take part in this study. Altogether this questionnaire should take 15-20 minutes to complete.

There is a small risk you might feel distressed by the scenario presented next. Please remember it is hypothetical. However, if you do have any concern, we would suggest you talk to your GP. Also, please contact us if you have any questions or concerns about the survey, if the study raises any questions or concerns about disease or disability risk and pre-birth testing, or if you would like more information about the survey.

Taking part in this study will take some of your time to consider how you feel about the questions asked to you.
So thank you very much in advance for your help… and your patience!
Your help will be hugely appreciated,

Cecile Muller
Department of Psychology
Building 721, Room 340
Tamaki Campus
The University of Auckland
Private Bag 92019
Auckland Mail Centre, Auckland.
Phone: +64 (0)9 373 7599 ext. 85224
Fax: +64 (0)9 373 7043
Appendix S – Automatic reply email used in Study Three

Testing Unborn Children for Genetic Conditions

Thank you for showing an interest in our study.

This research aims to investigate people’s opinions about prenatal testing for genetic disabilities. Complete information regarding your rights as a participant is provided in the Information Sheet attached.

If you agree to participate, you will be presented with information about prenatal testing. You will then be asked to complete an online questionnaire. Your responses will be anonymous. Your anonymity will be completely assured at all times throughout the project. It is hoped that these answers will contribute to our understanding of how men and women make judgements and decisions about issues relating to pregnancy.

Your participation is completely voluntary; by clicking on the link http://flexiblelearning.auckland.ac.nz/testing_unborn_children_for_genetic_conditions/ (or by copying-pasting it in your browser) you are consenting to take part in this study. Altogether this questionnaire should take 15-20 minutes to complete.

There is a small risk you might feel distressed by the scenario presented next. If you do have any concerns, we suggest you talk to your GP. Additional information about prenatal testing will be provided at the end of the session. Also, please feel free to contact us if you have any questions about the survey.

Participating in this study will take some of your time as you consider how you feel about the questions asked of you. Thank you very much in advance for your help… and your patience. This is much appreciated.

Cecile Muller

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Tamaki Campus

The University of Auckland
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Auckland Mail Centre, Auckland.
Phone: +64 (0)9 373 7599 ext. 85224
Fax: +64 (0)9 373 7043
Appendix T – Health message used in the 'text' group, Study Three

Vividly imagine you and your partner are expecting a baby and are at the beginning (under 12 weeks) of the pregnancy. You hear about a prenatal test that can detect with more accuracy than the ultrasound can whether the foetus is affected with a genetic disability. Some of these disabilities can be present from birth and be fatal (such as Cystic Fibrosis) or nonfatal (such as Down's syndrome). They may also develop later in life, and again, may be fatal (such as breast cancer) or not (such as bipolar disorder).

The test consists of obtaining a small sample of placenta OR a small amount of amniotic fluid surrounding the foetus. Both tissues have the same genetic makeup as the growing foetus.

The placenta can be in several different locations within the uterus. Therefore, an ultrasound is performed to locate the foetus and the placenta. A catheter is then guided through the vagina and cervix, into the placenta. With suction from the catheter, a small piece of placenta is gently removed.

An ultrasound is also used to collect small samples of amniotic fluid. This fluid surrounds the foetus within the uterus and is produced primarily by the foetal urination. Once the foetus is located, a long thin needle is inserted through the skin of the abdomen into a safe location into the uterus. This is sometimes done under local anaesthetic. About 30milligrams of amniotic fluid is withdrawn. The amniotic fluid will be naturally replaced in about 3 to 4 hours.

The samples are sent to the laboratory for examination and tested for abnormalities such as genetic malformations.

This procedure may be mildly uncomfortable for the mother, as some angling to get good views of the baby may be required. There may also be discomfort due to bruising and some cramps may be experienced. However, these usually resolve within 24 hours.

These tests carry a risk of miscarriage which range from 0.5% to 1%. This means that between 1 in 200 and 2 in 200 women will miscarry as a result of the procedure. However, there is always a small risk of natural miscarriage of 2% that is present in all pregnancies at 10 weeks gestation. This means that 4 in 200 women will lose their children during pregnancy, whether or not these tests are performed.

These tests are done as outpatient procedures; Partners, Whānau or a support person can attend. They are performed between 10 and 15 weeks of pregnancy. Results are usually available 1 to 3 weeks after the procedure. In New Zealand, this is usually free.
Appendix U – key shots of the video used in Study Three

These tests carry a risk of miscarriage which ranges from 0.5% to 1%

This means that between 1 in 200 and 2 in 200 women will miscarry as a result of the procedure.
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