

The Weight of History: Does Family History Influence Men's Perceptions of Risk and Prostate Cancer Screening Decisions

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The Weight of History: Does Family History Influence Men's Perceptions of Risk and
Prostate Cancer Screening Decisions?

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Abstract

The benefits of early detection screening for prostate cancer are still unclear and current screening guidelines recommend that men make an informed, personal decision based on an understanding of the risks, benefits, and uncertainties associated with screening. Men with a first-degree family history of prostate cancer are at more than double the risk of being diagnosed with prostate cancer than are men without a family history. However, contrary to predictions put forward in previous research, although men with a family history of prostate cancer report greater risk perceptions and prostate cancer screening behaviour, increased risk perceptions do not predict screening. Previous research on how men with a family history of prostate cancer integrate heightened familial risk information into what is already a complex health decision has neglected to examine how men understand, combine, and weigh information about prostate cancer risk and the uncertainties of early detection screening to reach their decisions. The aim of the current thesis was to address these issues by applying three major theoretical models of judgement and decision-making to examine prostate cancer screening decisions for men with a family history and comparing their decisional process with that of men without a family history.

A description of the complex decision environment faced by men in relation to prostate cancer screening was described in Chapter 2 including a discussion of the uncertainties associated with prostate cancer screening, current knowledge about risk factors, and results from previous research on first-degree relatives of men with prostate cancer. Chapter 3 discussed current conceptualisations of rational choice and introduced Subjective Expected Utility theory (SEU theory), the Heuristic-Systematic Processing Model (HSM), and Social Judgement Theory (SJT) as theoretical models for

understanding how people make decisions. Two heuristic decision strategies described in Chapter 3 and relevant to the HSM, the availability and representativeness heuristics, were applied in Chapter 4 and were found to contribute to the prediction of the relationships between family history, risk perceptions and prostate cancer screening behaviours. The results from the application of SEU theory in Chapter 5 suggested that men did not consider many reasons for or against participating in prostate cancer screening when making their decisions. Rather, men could be categorised into four distinct classes of reasons suggesting different underlying motivations may guide screening decisions and not all men with a family history consider having a family member with prostate cancer to be a salient or important reason for screening.

Consistent with these findings, the application of SJT theory in Chapter 6 found that although all men weighted having a family history of prostate cancer as the most important cue for determining a man's risk of being diagnosed with prostate cancer, men with a family history weighted specific relationship cues (e.g., men who had a brother or a father with prostate cancer) less than did men without a family history. Finally, in accordance with the HSM, a qualitative methodology known as Verbal Protocol Analysis was applied in Chapter 7 to categorise heuristic and systematic reasoning strategies used by men when considering their risk of prostate cancer and when considering prostate cancer screening. Results from Chapter 7 suggested that although men with a family history were more likely to make use of positive availability heuristics in relation to risk and screening judgements, all men used a variety of reasoning strategies to process information about prostate cancer and frequently relied on heuristic reasoning strategies. Implications of these findings for the application of theoretical models to real world decisions and for informing IDM approaches to screening decisions are discussed in Chapter 8.

Declaration of Originality for the thesis entitled

The weight of history: Does family history influence men's perceptions of risk and prostate cancer screening decisions?

This work has not previously been submitted for a degree or diploma in any university.

To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.

Michelle Elizabeth McDowell

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CHAPTER 1

Aims and Overview of the Thesis

The decision about whether men should participate in early detection screening for prostate cancer is complex. Medical and statutory bodies do not endorse population-based screening for prostate cancer owing to a lack of evidence that early detection screening reduces mortality and that the benefits of screening outweigh the harms (Andrology Australia, 2009; Cancer Council Australia, 2008; Lim, Sherin, & ACPM Prevention Practice Committee, 2008; Peters, Jovell, Garcia-Altes, & Serra-Prat, 2001; Royal Australian College of General Practitioners, 2006; Smith, et al., 2001; U. S. Preventive Services Task Force, 2008; Urological Society of Australia & New Zealand, 2009; Wolf, et al., 2010). On this basis, current prostate cancer screening guidelines recommend that all men be informed about a range of risks, benefits, and uncertainties associated with early detection screening and weigh the information to reach an informed personal decision. Men with a first-degree family history of prostate cancer are at more than double the risk of being diagnosed with prostate cancer (Bruner, Moore, Parlanti, Dorgan, & Engstrom, 2003; Johns & Houlston, 2003; Zeegers, Jellema, & Ostrer, 2003). However, these men are not presented with alternative or heightened screening recommendations. Rather, they are similarly advised to make an informed decision that includes integrating information about their increased risk.

In this connection, informed decision-making (IDM) approaches are considered best practice for facilitating medical decision-making, particularly when medical decisions involve uncertainty within the medical community as to the optimal decision and where patients must consider their personal values in reaching a decision (Bowen, et al., 2006). However, IDM approaches are based largely on normative theories of

decision-making that assume people are capable of considering and integrating complex information to make decisions and neglect to consider how decisions are made within a broader social context. Having a family member with prostate cancer changes the decision context for men with a family history such that they are able to draw on additional information about prostate cancer from the experiences of their affected relatives. People are known to incorporate personal experience and prior knowledge into their judgements (Goldberg, 2006; Shafir, Simonson, & Tversky, 1993; Ubel, 2010; Weinstein, 1989). For instance, people with a family history of cancer have been shown to interpret high familial risk information with respect to how alike they perceive themselves to be to their relative with prostate cancer (Sanders, Campbell, Sharp, & Donovan, 2003). The aim of the current thesis was to explore how having a family history of prostate cancer impacts on the decision to participate in prostate cancer screening and on the construction of risk perceptions in relation to these decisions.

In order to explore the impact of family history on prostate cancer risk perceptions and screening behaviours, the current study employed multiple theoretical and methodological approaches to address the research questions from multiple angles. Specifically, three major theoretical approaches to understanding judgement and decision-making were applied across four studies, utilising both quantitative and qualitative methodologies, to examine the different ways in which family history could influence judgements. Subjective Expected Utility theory (SEU theory; Savage, 1954) was applied in Chapter 5 to examine the information men consider when making decisions about prostate cancer screening and to explore whether the process by which men integrate information to reach a decision differs for men with a family history. The Heuristic Systematic Processing Model (HSM; Chaiken, 1980) was applied in Chapters 4 and 7 to examine how men with a family history used information available from their

experiences with prostate cancer to guide heuristic and systematic processing, using both quantitative and qualitative methods. Social Judgement Theory (SJT; Hammond, Stewart, Brehmer, & Steinmann, 1975) informed the design of the study presented in Chapter 6 and explored the process men used to make judgements based on available cues in their environment. Further, the implementation of these different theoretical models to prostate cancer screening decisions provided unique yet complementary results across studies and also extended the application of these models beyond laboratory-based or experimental studies to understanding how people actually make decisions about real world issues.

CHAPTER 2

Prostate Cancer, Family History and Early Detection Screening

In 2008, there were an estimated 899,000 new diagnoses of prostate cancer worldwide making prostate cancer the second most common cancer in men (Ferlay, et al., 2008; Parkin, Bray, Ferlay, & Pisani, 2005). Men with a first-degree family history of prostate cancer are at more than double the risk of being diagnosed than men without a family history (Bruner, et al., 2003; Johns & Houlston, 2003; Zeegers, et al., 2003). However, current prostate cancer screening guidelines do not endorse population-based screening for any asymptomatic men owing to a lack of evidence that early detection screening reduces mortality and that the benefits of screening outweigh the harms (Andrology Australia, 2009; Cancer Council Australia, 2008; Lim, et al., 2008; Peters, et al., 2001; Royal Australian College of General Practitioners, 2006; Smith, et al., 2001; U. S. Preventive Services Task Force, 2008; Urological Society of Australia & New Zealand, 2009; Wolf, et al., 2010). Consequently, men are faced with a complex decision where guidelines recommend that they be informed about the risks, benefits, and uncertainties of early detection screening and weigh up the information to make personal screening decisions. Despite an increased risk of prostate cancer, men with a family history are similarly advised to make an informed and considered decision that will necessarily include reconciling and integrating information about their increased risk.

To date, there has been no research examining how men weigh up the information about screening efficacy and how men with a family history use their heightened risk of prostate cancer to guide their personal screening decisions. Research has focused almost exclusively on the role of risk perceptions as a determinant of

screening behaviour and proposes that risk perceptions mediate the relationship between family history and prostate cancer screening uptake (Jacobsen, et al., 2004). However, risk perceptions are not consistent predictors of prostate cancer screening in first-degree relatives (McDowell, Occhipinti, Gardiner, Baade, & Chambers, 2009) and, contrary to normative models of decision-making (Savage, 1954; von Neumann & Morgenstern, 1947), men appear to draw on the nature of their relatives' cancer experiences to make judgements about their personal cancer risk (Beebe-Dimmer, et al., 2004; Bratt, et al., 2000; Sanders, et al., 2003). The current chapter argues that prior research on first-degree relatives has neglected to consider how family members' diagnoses of prostate cancer alter the decision for unaffected male relatives and as such overlooked the fact that these men have additional information available to them about prostate cancer through their interpretations of and personal experiences with their affected relatives.

The current chapter describes the incidence, prevalence, and mortality associated with prostate cancer along with details of early detection screening efficacy issues, treatment burdens, and current prostate cancer screening guidelines. The known risk factors for developing prostate cancer are presented in Section 2.2. Sections 2.1 and 2.2 provide an overview of the information men, and specifically men with a first-degree family history of prostate cancer, are faced with when deciding whether to be screened for prostate cancer. Section 2.3 considers the effect a family member's diagnosis of prostate cancer can have on the decision for unaffected male relatives, particularly with regard to the potential for their knowledge, attitudes, beliefs, and emotions to be influenced by the circumstances of their relative's cancer. These experiences have implications for decision-making, as first-degree relatives may base their judgements about personal cancer risk and the benefits of early detection screening on interpretations of and beliefs about their relatives' experiences. Next, Section 2.4

reviews previous research on first-degree relatives of men with prostate cancer including screening prevalence, risk perceptions, and prostate cancer knowledge. The results from this review suggest that men draw on the nature of their family history to make judgements about their risk and to inform their screening decisions. Finally, Section 2.5 summarises these findings and discusses the implications for understanding prostate cancer screening decision-making within a family history context.

2.1 Prostate Cancer Epidemiology: Incidence, Prevalence and Mortality

Prostate cancer is the second most common cancer in men worldwide, accounting for an estimated 13.6% of all new cancer diagnoses in men in 2008 (Ferlay, et al., 2008). In Australia, prostate cancer is the most frequently diagnosed cancer in men representing around 23% of all new cancer diagnoses (McDermid, 2005). In 2008, an estimated 105 out of every 100,000 Australian men were diagnosed with prostate cancer (Ferlay, et al., 2008), and one in seven men are estimated to be diagnosed with prostate cancer by the time they reach 75 years of age (Australian Institute of Health and Welfare, 2010). The widespread availability of early detection testing has contributed to the marked increase in the incidence of prostate cancer, influenced by the detection of latent cancers through screening and as a result of more men being able to participate in screening (Baade, Youlden, & Krnjacki, 2009; Jacobsen, et al., 1995; Parkin, et al., 2005). Further, owing to an aging population in most of the western world (Australian Institute of Health and Welfare, 2007) and to the long natural history of prostate cancer, prevalence is increasing (Parkin, 2001; Parkin, Bray, & Devesa, 2001).

Prostate cancer is a less prominent cause of death in men, accounting for 7% of all cancer deaths in men worldwide (Baade, et al., 2009; Parkin, et al., 2005; Parkin, et al., 2001). Prostate cancer is commonly a slow-growing cancer with a long latency and a long natural history, and can be asymptomatic during its early stages (Crawford, 2009). When symptoms do appear they can include: urinary problems, erection difficulties, and pain in the lower back and upper thigh areas. These symptoms are not specific to prostate cancer and can be caused by other conditions, including benign prostate hyperplasia, benign prostate enlargement, or prostatitis. Early detection screening can help to identify tumours when asymptomatic or in their early stages and facilitate the commencement of treatment while the cancer is still confined to the prostate gland (Postma & Schroder, 2005). However, whereas the early detection of prostate cancers has increased substantially following the availability of screening using the PSA test, prostate cancer mortality has decreased only slightly during this time (Baade, Coory, & Aitken, 2004; Baade, et al., 2009; Etzioni, et al., 1999; Parkin, et al., 2005; Parkin, et al., 2001).

At present, there is no clear randomised control trial (RCT) evidence that early detection screening reduces mortality and that the benefits of screening outweigh the harms. Preliminary results from two ongoing longitudinal RCTs suggest that there may be a small reduction in mortality as a result of early detection testing but that this is associated with a risk of overdiagnosis (Andriole, et al., 2009; Schroder, et al., 2009). The Prostate, Lung, Colorectal, and Ovarian (PLCO) Cancer Screening Trial, a longitudinal RCT randomising 76,693 US men to receive either annual screening or usual care, reported no significant overall mortality reduction as a result of early detection screening (Andriole, et al., 2009). The European Randomized Study of Screening for Prostate Cancer (ERSPC), a longitudinal RCT randomising 162,243

European men to receive screening a minimum of once every 4 years or to usual care, found a 20% reduction in mortality but at a high cost: for every prostate cancer death prevented, 1,410 men would need to be screened and an additional 48 cases of prostate cancer would need to be treated (Schroder, et al., 2009). Although there are differences in the design of the two RCTs, in the degree of contamination in the control group from men participating in screening, and in the need for reports of longer follow-up data, these two studies are the largest RCTs to date and results are anticipated to provide some clarity about the benefits of early detection screening and the efficacy of the screening tests.

There are currently two early detection screening tests for prostate cancer. One, a digital rectal examination (DRE) involves a physician inserting a gloved finger into the rectum of a patient to feel for any physical abnormalities in the prostate and two, the prostate specific antigen (PSA) blood test measures the serum PSA levels in the blood, with higher levels presumed to indicate a likelihood of prostate cancer. The DRE alone is not as accurate as the PSA test at detecting prostate cancers but can enhance the detection of tumours when used in combination with the PSA test (Catalona, et al., 1994). Since its introduction in the USA in 1986, the PSA blood test has been the most widely used early detection screening test for prostate cancer. However, the PSA blood test cannot differentiate between clinically significant and indolent cancers (Brawley, Ankerst, & Thompson, 2009). As well, the PSA test lacks specificity and sensitivity as high elevations in serum PSA levels can be the result of conditions other than prostate cancer (e.g., benign prostatitis) leading to a high incidence of false-positive as well as some false-negative PSA tests (Gambert, 2001; Postma & Schroder, 2005; Wolf, et al., 2010). There is also considerable debate regarding the normal range of serum PSA

levels and the appropriate cut-off for serum PSA levels to indicate a positive PSA test result and a referral for biopsy (Brawley, et al., 2009; Postma & Schroder, 2005).

To confirm a diagnosis of prostate cancer, men who have a positive PSA test are required to undergo a transrectal ultrasound biopsy (TRUS) where an ultrasound probe is inserted into the rectum to visualise the prostate and 12 or more biopsy slivers of tissue are taken. This procedure can be quite painful for patients and the wait for biopsy results can lead to the experience of anxiety and worry (Cohen, et al., 2003; Dale, Bilir, Han, & Meltzer, 2005). Such distress may be unnecessary for most men considering that two out of every three positive PSA tests turn out to be false-positives. Results of biopsies follow a grading system (the most widely used grading system is the Gleason score) and biopsy results are used to confirm a diagnosis, predict the behaviour of the cancer, and provide information for determining prognosis and cancer staging or likelihood of metastasis. However, even the PSA test and biopsy results in combination cannot accurately distinguish between clinically significant and non-lifethreatening prostate cancers (Postma & Schroder, 2005). Consequently, the overdiagnosis rate for prostate cancer has been estimated to be as high as 50% leading to the overtreatment of screen-detected cancers that would have been unlikely to cause problems for men had they remained undetected (Gambert, 2001; Postma & Schroder, 2005; Wolf, et al., 2010).

The overtreatment of screen-detected cancers is particularly problematic considering that there are harms as well as benefits associated with current prostate cancer treatment options. Treatment choice is another uncertain decision for patients where chances of treatment success must be weighed against post-treatment side-effects. For localised tumours, treatment can potentially cure prostate cancer, and for advanced cancers and cancers that have metastasised, treatment may prolong survival

(Gomella, Johannes, & Trabulsi, 2009). However, a significant proportion of prostate cancers are not life-threatening (age-adjusted five-year survival is approximately 76% in developed countries; Baade, et al., 2009) and treatments have a high degree of morbidity and are associated with enduring iatrogenic side-effects (see Table 2.1 Gomella, et al., 2009; Gore, Kwan, Lee, Reiter, & Litwin, 2009). Side-effects include: impotence, erectile and bowel dysfunction, urinary incontinence, hot flushes, cognitive impairment, loss of muscle mass and bone substance, and induced metabolic syndrome (Harris & Lohr, 2002; Loblaw, et al., 2007; Neal, Leung, Powell, Hamdy, & Donovan, 2000). In addition, the experience of physical treatment-related side-effects can affect other quality-of-life domains owing to the experience of psychosocial distress, depression, and relationship and spousal distress (Sestini & Pakenham, 2000). Thus, treatment can lead to substantial negative quality-of-life outcomes (Andriole, et al., 2009; Gore, et al., 2009; Schroder, et al., 2009).

Table 2.1

Prostate Cancer Treatments and Associated Side-Effects

Treatment	Side-effects
Brachytherapy ^a	Bleeding at the invasive site, blood in urine, scrotal burning, incontinence, impotence
Chemotherapy ^b	Nausea, hair loss, vomiting, mouth sores
Cryosurgery & cryotherapy ^{a,b}	Pelvic pain, blood in urine, scrotal swelling, mild urinary urgency, impotence
Hormone therapy ^a	Impotence, weight gain, hot flashes, fatigue, loss of muscle mass
Radiation therapy ^a	Tiredness, diarrhoea, skin irritation, upset stomach, frequent or burning urination, proctitis
Prostatectomy ^a	Surgical complications, impotence, incontinence
Robotic prostatectomy ^a	Impotence, incontinence, blood loss, other surgical complications
Watchful waiting ^{a,b}	Cancer may grow between monitoring visits and spread to other parts of the body
Complementary & alternative medicine	Lack of clinical evidence and potential for harmful treatment interactions

Note. Adapted from (Renowned Doctors, 2010). ^a generally recommended for localised disease. ^b generally recommended for advanced disease or as a salvage therapy.

2.1.1 Screening Guidelines for the Early Detection of Prostate Cancer

In order to address the concerns of medical professionals and patients with respect to the overdiagnosis and overtreatment of prostate cancer, various medical and statutory bodies have sought to develop evidence-based screening guidelines. Since the introduction of the PSA blood test there have been more than 20 papers or policy documents that review the emerging evidence for and against early detection screening

for prostate cancer. The recommendations deriving from each review state that there is insufficient evidence to conclude that the benefits of prostate cancer screening outweigh the costs or that population-based screening should be endorsed (Wolf, et al., 2010). Accordingly, many professional and statutory bodies do not endorse population-based screening for prostate cancer in asymptomatic men (see Table 2.2).

Table 2.2

Prostate Cancer Screening Guidelines and Position Statements

Organisation	Recommended Guidelines	Specific Guidelines for High-Risk Men
American College of Preventive Medicine (ACPM)(2008)	<p>There is currently insufficient evidence to recommend routine population screening with DRE or PSA.</p> <p>Men should be given information about the potential benefits and harms of screening and limits of current evidence in order to make an informed decision about screening.</p>	<p>Those men who are at high risk may benefit from earlier screening beginning at age 45, while higher-risk men (those with two or more first-degree relatives with prostate cancer before age 65) be screened at age 40.</p> <p>There is still no evidence establishing effectiveness of screening in high-risk men.</p>
American Cancer Society (ACS) (2010)	<p>Asymptomatic men who have at least a 10-year life expectancy should have an opportunity to make an informed decision with their health care provider about whether to be screened for prostate cancer, after receiving information about the uncertainties, risks, and potential benefits associated with prostate cancer screening.</p> <p>Prostate cancer screening should not occur without an informed decision-making process. Men at average risk should receive this information beginning at age 50 years.</p>	<p>Men at higher risk, including African American men and men who have a first-degree relative (father or brother) diagnosed with prostate cancer before age 65 years, should receive this information beginning at age 45 years.</p> <p>Men at appreciably higher risk (multiple family members diagnosed with prostate cancer before age 65 years) should receive this information beginning at age 40 years.</p>

Organisation	Recommended Guidelines	Specific Guidelines for High-Risk Men
Andrology Australia (2009)	<p>Population-wide screening for prostate cancer using the current assessment tools of prostate specific antigen (PSA) testing and/or digital rectal examination (DRE) cannot be recommended until the results of randomised controlled trials are complete.</p> <p>It is imperative that men requesting prostate cancer testing are appropriately counselled about their prostate cancer risk and the potential benefits, limitations and implications of PSA testing prior to being tested; and in doing so are supported by their practitioner to make an informed decision consistent with their values and personal preferences.</p>	<p>Men with an affected father or brother are twice as likely to develop prostate cancer as men with no affected relatives and should consider being tested after the age of 40 years. However, they should be given verbal and written information about what a positive test result means and the benefits and risks of treatment, to help inform their decision.</p>
Cancer Council Australia (CCA) (2008)	<p>Does not support population-based screening of asymptomatic men for prostate cancer. In the absence of direct evidence showing a clear benefit of population based screening for prostate cancer, a patient centred approach for individual decisions about testing is recommended. Ideally this takes the form of an informed, shared, decision-making process between the doctor and man, discussing the benefits, risks and uncertainties of testing, and discussion about treatment options and side effects.</p>	<p>Men at above-average risk of prostate cancer should discuss the risks and benefits of prostate cancer screening with their doctor, taking age and other individual risk factors into account. They also should be given adequate objective information about the potential benefits and harms of screening, diagnostic procedures and treatment for prostate cancer to allow them to make a fully informed decision on whether to be tested or not.</p>
Royal Australian College of General Practitioners (RACGP) (2006)	<p>Men aged 50–79 years should be informed of risks and benefits of screening. Routine screening for prostate cancer with DRE, the PSA or transabdominal ultrasound is not recommended. Patients should make their own decision after being fully informed of the potential benefits, risks and uncertainties of prostate cancer testing.</p>	<p>Recommendations do not differ for men at high-risk.</p>

Organisation	Recommended Guidelines	Specific Guidelines for High-Risk Men
UK National Screening Committee (UKNSC) (2010)	The harms from prostate cancer screening using PSA are currently likely to outweigh the benefits. In this circumstance screening for prostate cancer cannot be justified on the current evidence.	No specific recommendations for men at high-risk.
Urological Society of Australia and New Zealand (USANZ) (2009)	The Urological Society of Australia and New Zealand (USANZ) currently does not recommend the use of mass population-based Prostate Specific Antigen (PSA) screening as public health policy, as published studies to date have not taken into account the cost effectiveness of screening, nor the full extent of over-detection and over-treatment. PSA based testing, together with digital rectal examination (DRE), should be offered to men in the 55-69 year age group, after providing information about the risks and benefits of such testing.	Defines high-risk as those men who have a PSA value above age-specific median PSA values. Those men with PSA levels above age-specific median levels should be carefully monitored and considered for biopsy. Other factors including family history, ethnicity, digital rectal examination findings, PSA velocity and PSA derivatives such as the free/total ratio should also be considered. Men with levels below age-specific median can be reassured that they are at lower risk and monitored less frequently.
U.S Preventive Services Task Force (USPSTF) (2008)	The current evidence is insufficient to assess the balance of benefits and harms of prostate cancer screening in men younger than age 75 years. Recommends against screening for prostate cancer in men age 75 years or older.	No specific recommendations for men at high-risk.

Rather, health professionals are advised to inform their patients of the uncertainties associated with early detection screening and encourage them to consider the risks and potential benefits so as to make informed personal decisions (Andrology Australia, 2009; Cancer Council Australia, 2008; Lim, et al., 2008; Peters, et al., 2001; Royal Australian College of General Practitioners, 2006; Smith, et al., 2001; U. S. Preventive Services Task Force, 2008; Urological Society of Australia & New Zealand, 2009; Wolf, et al., 2010). Specifically, asymptomatic men who have a minimum of 10 years life expectancy should be offered the opportunity to be informed about prostate cancer screening on average from age 50 years, or at an earlier age in accordance with any risk factors (risk factors are discussed in Section 2.2). Screening is not recommended for men who are aged 70 years or greater, who are in poor health, or who have an average life expectancy of less than 10 years. At a minimum, the American Cancer Society recommends that patients be informed of the information presented in Figure 2.1 (Wolf, et al., 2010). For men who are at higher risk of developing prostate cancer, these same guidelines apply with the additional stipulation that these men think about their heightened risk when considering the risks and benefits of screening. The implications of risk status on screening decision-making will be discussed further in subsequent sections.

Core elements of the information to be provided to men to assist with their decision include the following (taken from the American Cancer Society Guideline for the Early Detection of Prostate Cancer):

- Prostate cancer is an important health concern for men.
- Screening with the PSA blood test alone or with both PSA and digital rectal examination (DRE) detects cancer at an earlier stage than if no screening is performed.
- Prostate cancer screening may be associated with a reduction in the risk of dying from prostate cancer; however, evidence is conflicting and experts disagree about the value of screening.
- For men whose prostate cancer is detected by screening, it is not currently possible to predict which men are likely to benefit from treatment; some men who are treated may avoid death and disability from prostate cancer, whereas others who are treated would have died from unrelated causes before their cancer became serious enough to affect their health or shorten their lives.
- Depending on the treatment selected, treatment for prostate cancer can lead to urinary, bowel, sexual, and other health problems. These problems may be significant or minimal, permanent or temporary.
- The PSA and DRE may produce false-positive or false-negative results, meaning that men without cancer may have abnormal results and get unnecessary additional testing, and clinically significant cancers may be missed. False-positive results can lead to sustained anxiety about prostate cancer risk.
- Abnormal results from screening with the PSA or DRE require prostate biopsies to determine whether or not the abnormal findings are cancer. Biopsies can be painful, may lead to complications like infection or bleeding, and can miss clinically significant cancer.
- Not all men whose prostate cancer is detected through screening require immediate treatment, but they may require periodic blood tests and prostate biopsies to determine the need for future treatment.

Figure 2.1 An example of the information to be provided to patients to assist with their decisions about early detection screening (Wolf, et al., 2010).

2.2 Prostate Cancer Risk Factors

Prostate cancer is a disease of older men and risk of being diagnosed with and dying from prostate cancer increases exponentially after the age of 50 (Parkin, et al., 2005). In Australia, 84% of prostate cancer diagnoses recorded in 2003 occurred in men aged over 60 years old as well as 84% of all prostate cancer deaths (Australian Institute of Health and Welfare, 2007). Prostate cancer incidence varies across developed and developing nations and trends appear to be consistent with an increase in incidence rates when early detection screening has been put into practice in developed countries such as the United States (the nation with the highest recorded incidence rates), Canada, and Australia (Baade, et al., 2009). As well, results from epidemiological analyses adjusting for a range of known confounds demonstrate racial variations in prostate cancer risk with African American men having 60% higher incidence, more than double the mortality rate of European-American men, and being diagnosed at an earlier age and with more aggressive cancers (Crawford, 2003; Powell, 2007; Williams & Powell, 2009). By contrast, there is lower incidence of prostate cancer in Asian populations compared to Anglo populations and populations of developing nations (Baade, et al., 2009; Parkin, et al., 2005).

Apart from age and racial variations in prostate cancer risk, family history is one of the few established risk factors for prostate cancer. Three systematic and meta-analytic reviews have examined the relative risk of prostate cancer in men who have a family history. Men with a first-degree family history (FDR; i.e., brother, father, or son diagnosed with prostate cancer) have more than double the risk of being diagnosed with prostate cancer (Relative Risk 2.22-2.53) with brothers being at greater risk (RR 2.87-3.5) than fathers or sons (RR 2.12-2.50) (Bruner, et al., 2003; Johns & Houlston, 2003;

Zeegers, et al., 2003). Family history risk increases further when there are multiple affected relatives (RR 3.50-5.08) and when the relative is diagnosed prior to the age of 65 (no RR available; Johns & Houlston, 2003; Zeegers, et al., 2003). Accordingly, the role of heredity in prostate cancer is thought to be greater than in any other cancer (Lichtenstein, et al., 2000). However, recent advances in the identification of susceptibility genes have not yet led to the discovery of a clearly identifiable gene for prostate cancer (Pomerantz, Freedman, & Kantoff, 2007; Zheng, et al., 2008). Thus, currently genetic testing is not a practical option for determining prostate cancer susceptibility (Gronberg, 2003; Langeberg, Isaacs, & Stanford, 2007; Schaid, 2004).

A range of additional risk factors for prostate cancer have been explored including the contributions of hormones, vitamins, diet and lifestyle, and occupational factors. To date, there is some evidence for a relationship between the consumption of red meat or dietary fat and increased prostate cancer risk, which may help to explain the higher incidence of prostate cancer in Western countries; however the evidence for this linkage is mixed (Boyle, Severi, & Giles, 2003; Fleshner & Zlotta, 2007). Also, although these results require confirmation, the consumption of tomatoes and tomato concentrated products may act as a protective factor against the development of prostate cancer (Boyle, et al., 2003) and there are promising results from studies examining Vitamins E and D as preventive factors (Fleshner & Zlotta, 2007). By contrast, Watters et al (2009) found that current and former smokers have a reduced risk of diagnosis of non-advanced prostate cancer but current smokers have an increased risk of mortality from prostate cancer. These findings also need to be confirmed.

To summarise the conclusions of five recent epidemiological reviews of current research into prostate cancer risk and protective factors, there is no evidence that any of the following factors contribute to the risk of developing prostate cancer: environmental

or lifestyle factors (e.g., smoking status, alcohol consumption), occupation, physical or sexual activity, medical procedures such as vasectomies, exposure to environmental hazards (e.g., pesticides), BMI or obesity, or diet (Boyle, et al., 2003; Crawford, 2003; Fleshner & Zlotta, 2007; Gronberg, 2003; Hsing & Chokkalingam, 2006). Although research into risk and protective factors for prostate cancer has returned some promising results, the only established risk factors are increasing age, being African American, and having a family history.

2.3 Implications of Familial Risk on Screening Decision-Making

To make an informed and considered decision about screening for prostate cancer, men must weigh up a large quantity of uncertain information about the benefits and harms associated with early detection testing, including the implications of a possible diagnosis on treatment decisions and quality-of-life outcomes. However, despite the complexity of the decision for all men, informed decision-making approaches, such as that recommended in current prostate cancer screening guidelines, assume that men are capable of integrating complex information and are proficient at making quality health decisions. Unlike lab-based decisional scenarios, decisions about real issues such as prostate cancer screening necessarily occur within the context of an individual's environment; people draw on their surroundings, pre-existing knowledge structures, attitudes, and beliefs to guide their decision-making (Kahneman & Frederick, 2002; Tversky & Kahneman, 1974; Verplanken & Holland, 2002; Weber & Johnson, 2009). It is for these reasons that early normative decision theories (e.g., Expected Utility Theory, von Neumann & Morgenstern, 1947) that proposed that people carefully weigh information according to decision-relevant risks, benefits, and outcome

probabilities were heavily criticised for their neglect of subjectivity (Kahneman & Tversky, 1979; Keys & Schwartz, 2007; Shafir & LeBoeuf, 2002). Rather, people make use of their personal experience and prior knowledge as an information source for judgements, and we need to consider the implications this can have on decision quality, particularly when personal experiences do not provide an adequate or accurate representation of information (Kahneman & Tversky, 1973).

For men with a family history of prostate cancer, judgements about screening occur in an unquestionably more complex decision environment that unavoidably involves their experiences with a relative with prostate cancer. Current prostate cancer screening guidelines recommend that men with a first-degree family history of prostate cancer consider their heightened risk of being diagnosed with prostate cancer when weighing information about the risks and benefits associated with early detection screening (see Table 2.2). By implication, this requires men with a family history to acknowledge their heightened risk, to reconcile the risk information, and to integrate it into their judgements about screening. However, people have difficulty interpreting risk information owing to a poor understanding of statistical probabilities and numerical information (Rothman & Kiviniemi, 1999). Accordingly, the relationship between actual risk and perceived risk is low and people use their personal beliefs and experiences to interpret risk information (Leventhal, Kelly, & Leventhal, 1999). In particular, family members of people with cancer are known to make judgements about their personal vulnerability to cancer based on their subjective experiences with affected relatives (Kenen, Ardern-Jones, & Eeles, 2003; Sanders, Campbell, Donovan, & Sharp, 2007; Sanders, et al., 2003; Walter & Emery, 2006; Walter, Emery, Braithwaite, & Marteau, 2004). For example, in a qualitative study on the construction of risk perceptions for people with a family history, Sanders et al. (2003) reported that

concerns about family members' perceptions of their risk of cancer were found to be related to the affected relative's disease status (i.e., less concerned if their relative was stable). These results suggest that an affected family member's experience with prostate cancer is being used as a basis for making judgements about personal prostate cancer risk.

Consequently, for reasons beyond having knowledge or an awareness of familial risk, the decision faced by first-degree relatives is different to that faced by men from the general population. First-degree relatives (FDRs) have access to a multitude of additional information about prostate cancer owing to their affected relatives' experiences. First-degree relatives process information about prostate cancer, risk, and screening in a context influenced by their personal experiences with a close family member with prostate cancer. For example, their perceptions of a relative's cancer may guide judgements about being at increased or decreased risk in comparison to the relative; the severity of the cancer, treatment outcomes, and quality-of-life may provide information about the benefits or risks of detecting prostate cancer during its early stages; and knowledge of prostate cancer, coping strategies, information-seeking behaviours and the experience of family pressures to be screened may also affect the FDRs' screening decisions. Thus, first-degree relatives have access to and may focus on different information about prostate cancer to inform their judgements of the benefits of early detection screening.

To date, there have been no studies examining the process by which men make personal decisions about screening, how men weigh risk and benefit information, or how men with a family history of prostate cancer use their personal experiences with an affected relative to guide their judgements. The following review of prior research on first-degree relatives highlights those findings that support the argument that men make

decisions in consideration of their family cancer experiences. These findings will demonstrate the need for judgement and decision-making theories to be applied to better understand the implications of familial risk on information processing and to guide future research into decision-making processes.

2.4 Review of Research on Prostate Cancer, Family History, and Screening Decision-Making

Most studies conducted on samples of men with a first-degree family history of prostate cancer explore the implications of having a heightened familial risk of being diagnosed with prostate cancer on risk perceptions and subsequently, screening behaviours. A literature review of CINAHL, Medline and PsycINFO databases was conducted for the period 1990 to January 2011. The search used keywords relating to: (a) prostate cancer; (b) having a first-degree family history of prostate cancer (first-degree relative; family history; high-risk; son, father, brother, or sibling); (c) prostate cancer screening (prostate specific antigen; early detection; preventive health); and (d) risk perceptions (perceived risk, susceptibility, or vulnerability). Ancestry searches of reference lists and Web of Science cited reference searches identified any additional studies examining men with a family history of prostate cancer, and citation alerts were set up for all included papers to notify of any subsequent papers that were published that met inclusion criteria. Studies that specifically examined a sample of first-degree relatives of men with prostate cancer, were published in peer-reviewed journals in the English language, and did not examine primarily biomedical aspects of prostate cancer screening (e.g., examining PSA serum levels) or prostate cancer diagnoses were included. At the time of this review, approximately 23 studies had been published

examining screening behaviours, risk perceptions, prostate cancer knowledge, and psychosocial concerns of first-degree relatives of men with prostate cancer (see Table 2.3), and two systematic reviews summarise the findings from the majority of these papers (see Appendix A: McDowell, et al., 2009; and Wakefield, et al., 2008).

Table 2.3

Review of Articles Examining First-Degree Relatives of Men with Prostate Cancer

Study	Country	Study Design	Sample	PSA Screening Prevalence			Main Findings
Arar et al. (2000)	USA	Qualitative	3 unaffected FDR ^a , 12 affected patients, 1 affected son, 4 wives recruited through contact with affected relative				Aware of prostate cancer risk in families but this did not encourage unaffected male relatives to seek testing Lifestyle factors viewed important risks factors and not necessarily family history, ethnicity or socio-demographic
Beebe-Dimmer et al. (2004)	USA	Cross-sectional	111 FDR ^a brothers recruited through contact with affected sibling				Majority perceived risk to be $\geq 50\%$ Younger brothers had higher risk estimates than brothers who were older than their affected sibling Long-term risk greater than short-term risk estimates
Bock et al. (2003)	USA	Cross-sectional	64 FDRs ^a of families participating in Prostate Cancer Genetics Project (PCGP) who had an affected father and an affected brother	FDR ^a	95%	ever	Majority of unaffected men had prior PSA test Half of first-degree relatives received first PSA test prior to the age of 50 years
Bratt et al. (1997)	Sweden	Cross-sectional	100 FDR ^a sons recruited from probands				At least some worry about being at increased risk prostate cancer because of father's diagnosis reported by 60% sons Interest in genetic testing more likely in sons who worried about inheritance & sons with less education.
Bratt et al. (2000)	Sweden	Cross-sectional	110 FDR ^a recruited from prostate cancer families with 3+ connected cases of prostate cancer and who had pedigree consistent with hereditary prostate cancer	FDR ^a	68%	regularly	Screening associated with the number of relatives with prostate cancer Majority of men estimated risk to be high with 40% overestimating their risk Risk associated with number of relatives deceased from prostate cancer

Study	Country	Study Design	Sample	PSA Screening Prevalence	Main Findings	
Bratt et al. (2003)	Sweden	Pre-screen & post-screen follow-up	57 FDR ^a participants in Bratt et al. (2000) who indicated that they screened frequently		No significant experiences of psychological adverse effects as a result of participating in prostate cancer screening	
Cormier et al. (2003)	USA	Cross-Sectional	138 FDR ^a recruited through contact with affected relative	FDR ^a 72% 69%	ever last 2 years	Perceived risk not associated with screening Age, having regular physician, number of men first-degree relatives knows with prostate cancer, knowledge of PSA, and discussing screening with physician predicted prostate cancer screening
Cormier, Kwan et al. (2002)	USA	Cross-sectional	139 FDR ^a recruited through contact with affected relative			Physician recommendation were not associated with greater knowledge about familial risk Only 62% of sons who answered correctly about familial risk believed their personal risk was greater than that of the average man
Cormier, Guillemin et al. (2002)	France	Pre-screen & post-screen follow-up	220 FDR ^a recruited through contact with affected relative Recruited for screening program			Moderate deterioration in anxiety and minimal deterioration in health-related quality of life for 20% of first-degree relatives over the course of PSA screening process
Cormier, Valeri et al. (2002)	France	Cross-sectional	277 FDR ^a recruited through contact with affected relative Recruited for screening program			64% worried a little or not at all about risk of getting prostate cancer Men with sons, men who had screened in the past, and men with higher trait anxiety were twice as likely to be worried about their risk of getting prostate cancer
Gaff et al. (2004)	Australia	Cross-sectional	141 men with self-reported family history obtained from the Australian Prostate Cancer Family Study (ACPFs)			The majority (82%) of reported prostate cancer cases were verified Men were generally accurate in reporting their family history of prostate cancer

Study	Country	Study Design	Sample	PSA Screening Prevalence			Main Findings
Gaff et al. (2006)	Australia	Cross-sectional	280 men with family history obtained from ACPFS (Gaff, et al., 2004) and a self-selected family history group, and 174 partners				Majority of men reported having not received enough information about prostate cancer risks High interest in obtaining information about personal risk Some interest in attending support services for men with a family history of prostate cancer
Jacobsen et al. (2004)	USA	Cross-sectional	83 FDR ^a recruited through contact with affected relative and 83 GP ^b through peer nomination				Perceived vulnerability to prostate cancer mediated relationship between family history and PSA intentions Intention to have PSA test predicted by number of past PSA tests, time since last PSA test and perceived vulnerability
Miller et al. (2001)	USA	Cross-sectional	56 FDR ^a recruited through contact with affected relative 100 GP ^b community group members	FDR ^a GP ^b	63% 61%	ever	No difference in screening for first-degree relatives and general population men First-degree relatives had greater perceived vulnerability to prostate cancer and lower expectations about prevention of prostate cancer
Pruthi et al. (2006)	USA	Cross-sectional	112 FDR ^a recruited through contact with affected sibling (42% African American)				31% of brothers improve prostate cancer knowledge after their sibling's diagnosis Improvements in knowledge predictive of screening 85% of brothers did not begin screening
Roumier et al. (2004)	France	Longitudinal	640 FDR ^a recruited through contact with affected relative Annual screening program (3 years)				Men under 60 were 2.3 times more likely to participate in screening program; sons were 1.4 times more likely to participate than brothers; men with several relatives with prostate cancer 1.5 times more likely to participate 88% adherence rate (69% initial participation rate)

Study	Country	Study Design	Sample	PSA Screening Prevalence			Main Findings
Sanders et al. (2003)	UK	Qualitative	16 FDR ^a of prostate cancer patients, 12 of breast cancer, 15 of colon cancer recruited through contacted with affected relative				FDRs did not necessarily perceive themselves as being at risk of developing cancer Emphasised physical and lifestyle differences between themselves and affected relatives to reduce their concerns about cancer
Schnur et al. (2006)	USA	Cross-sectional	33 FDR ^a and 176 GP ^b attendees at screening appointment in urology clinic				Relationship between family history of prostate cancer and perceived risk of prostate cancer Perceived risk of prostate cancer mediated relationship between family history of prostate cancer and prostate cancer worry
Shah et al. (2007)	USA	Cross-sectional	226 FDR ^a and 3769 GP ^b sampled as part of a population-based health survey	FDR ^a GP ^b	52%* 35%	ever	First-degree relatives aged 50+ years almost twice as likely to have participated in screening than general population men
Spencer et al. (2006)	USA	Cross-sectional	492 FDR ^a and 8221 GP ^b sampled as part of a population-based health survey	FDR ^a GP ^b	56%* 42%	last 12 months	First-degree relatives more likely to have participated in screening than general population men Men with multiple high-risk factors (African American men with family history) no more likely to screen than were men with only one high-risk factor
Sweetman et al. (2006)	UK	Cross-sectional	128 FDR ^a recruited through contact with affected relative Recruited for screening program	FDR ^a	41-46%	some previous	Past screening behaviour only reliable predictor of adherence to screening program Prior screening associated with having a father and brother with prostate cancer, having realistic or elevated risk, higher perceived benefits of testing, higher social class, and agreeing to take part in screening program to get more information about prostate cancer

Study	Country	Study Design	Sample	PSA Screening Prevalence			Main Findings
Taylor et al. (1999)	USA	Cross-sectional	41 FDR, 10 second-degree relative and 75 GP men recruited for prostate cancer screening program				<p>Self-referral the main reason identified for attending screening for both men with and without a family history</p> <p>Men with family history more likely to report attending screening because they elected to on their own compared to men without a family history</p> <p>Men with family history no more distressed than without a family history</p> <p>Family history did not predict perceived risk but interacted with perceived risk to predict distress: men with family history who had higher risk perceptions reported greater distress</p>
Vadaparampil et al. (2004)	USA	Longitudinal 14mth follow-up	82 FDR ^a recruited through contact with affected relative	FDR ^a	50% 50%	at any time 14 month follow-up	<p>63% of men who had prior PSA test had a PSA test during 14 months follow-up</p> <p>Risk perceptions did not predict prior or follow-up screening behaviour</p>
African American FDR Studies							
Bloom et al. (2006)	USA	Cross-sectional	88 FDR ^a and 120 GP ^b recruited through contact with affected relative and peer nomination or from churches and African American social groups	FDR ^a	3.03OR*	last 12 months	<p>African American men with a family history of prostate cancer were more likely to report having a recent PSA test</p> <p>First-degree relatives did not perceive their risk to be higher than men without a family history</p>
Ross et al. (2005)	USA	Cross-sectional	43 FDR ^a and 693 GP ^b sampled as part of a population-based health survey	FDR ^a GP ^b	64%* 42-50%	ever	<p>African American men with a family history of prostate cancer more likely to have heard of a PSA test and to have had a PSA test than African American men without a family history</p>

Study	Country	Study Design	Sample	PSA Screening Prevalence			Main Findings
Weinrich (2006)	USA	Cross-sectional	134 FDR ^a participants in the African American Hereditary Prostate Cancer Study (AAHPC) who had 4+ relatives with prostate cancer and 411 GP ^b African American participants from population-based health survey (National Health Interview Survey; NHIS)	FDR ^a	44%	ever	Comparison between screening prevalence in AAHPC participants and NHIS African American participants indicated that African American men with a strong family history of prostate cancer reported lower PSA testing behaviour
				GP ^b	65%		

^a First-degree relatives ^b General population men ^c Family History. *Indicates significant difference in prevalence rates between first-degree relatives and general population men

As discussed above, there have been no studies examining how men weigh up the pros and cons of early detection screening or the influence a family member's cancer experience has on this process. However, in light of the current research available, answers to the following questions (see Figure 2.2) will provide some insight into how first-degree relatives conceptualise their heightened risk and what factors are informing their screening decisions in this complex decision context:

- Are men with a family history of prostate cancer knowledgeable about their heightened risk, the risks and benefits of early detection screening, and if so, are they more knowledgeable than men from the general population?
- Do men with a family history perceive their risk to be higher than men from the general population and what predicts greater risk perceptions?
- Do men with a family history participate in prostate cancer screening more than do men from the general population?
- What predicts participation in prostate cancer screening and how do risk perceptions play a role in predicting screening uptake?

Figure 2.2. Questions to be addressed in the review of FDR research.

Answers to these questions will provide the foundation for arguing that judgements about personal cancer risk and the processing of information to make decisions about prostate cancer screening are influenced by personal experience with a family member's cancer experience.

2.4.1 *Family History and Prostate Cancer Knowledge*

In order to understand whether FDRs are making informed decisions about screening, a first step is to determine what information FDRs have available to them to use in their decision-making. The influence of a family member's cancer on the acquisition of knowledge about personal risk and screening benefits would be relevant to our understanding of screening decision-making, particularly as people use their personal experiences to attain knowledge and to construct and reinforce their beliefs (Bettman & Park, 1980; Goldberg, 2006; Keys & Schwartz, 2007; Weinstein, 1989). Further, if men with a family history are bringing additional knowledge about prostate cancer into their screening decisions, we need to know whether the knowledge is accurate and what knowledge is weighing into their screening decisions.

Unfortunately, knowledge about prostate cancer and early detection screening has not been well assessed in men with a family history and therefore it is not clear whether they are informed. Only three studies have examined knowledge of prostate cancer screening (Cormier, et al., 2003; Pruthi, et al., 2006; Ross, et al., 2005), none of which have assessed knowledge or awareness of the risks, benefits, and uncertainties associated with early detection testing. Although these studies do report that FDRs are knowledgeable about prostate cancer and screening, the knowledge assessment instruments are inadequate and tend to reflect attitudes about PSA testing rather than actual knowledge (e.g., questions assess perceptions of how frequently men should be screened, with *annually* considered to be the correct response despite screening guidelines mentioning screening frequency only if a patient has made an informed decision to undertake screening). As well, no studies have made direct comparisons between the knowledge of FDRs and that of men from the general population to

determine whether having personal experience with prostate cancer, owing to a family history, results in differences in prostate cancer knowledge.

There is some evidence to suggest that unaffected family members prefer to learn about prostate cancer from their affected relative's experience and do not seek additional information from external sources. Pruthi et al. (2006) reported that 69% of brothers of men recently diagnosed with prostate cancer reported that they did not seek to improve their knowledge about prostate cancer following their brother's diagnosis. As well, when examining prostate cancer risk and screening issues for men with prostate cancer and their families, Arar et al. (2000) reported that, rather than seeking out information from alternative sources, FDRs preferred to learn about prostate cancer through their relatives' experiences. These findings suggest that the family context is an important source of information for family members and may contribute to the nature of the information FDRs use to make judgements about their risk and to guide their screening decision-making. However, additional research is needed to determine whether FDRs use their personal experience with prostate cancer as a source from which to attain knowledge about prostate cancer to use in their screening decisions.

For FDRs to be considered to have adequate knowledge about PSA testing requires that FDRs are aware of the risks, benefits, and uncertainties of early detection testing, and for this reason greater knowledge may not necessarily influence screening decisions. Guidelines for prostate cancer screening do not advocate that men participate in screening and therefore it is not anticipated that having higher knowledge of the risks and uncertainties of PSA testing will necessarily result in an increased uptake of screening. Accordingly, owing to the lack of assessment of the risks and benefits of prostate cancer screening in previous knowledge measures, the finding that greater knowledge about prostate cancer predicts participation in screening in FDRs (Cormier,

et al., 2003) must be interpreted with caution. In summary, more adequate prostate cancer knowledge assessments are needed to determine what information is available to FDRs to utilise in their screening decision-making. However, there is support for the argument that men with a family history of prostate cancer draw on the experiences of their affected relatives to attain knowledge about prostate cancer.

2.4.2 Family History and Risk Perceptions

Results from quantitative and qualitative assessments of perceived risk in relatives of men with prostate cancer provide for a unique understanding of how men construct their risk perceptions, suggesting that both methodological approaches should be considered for examining risk perceptions. The results from both methods support the argument that unaffected relatives make judgements about their personal risk of cancer in consideration of the nature of their family history. However, a criticism of previous approaches to the measurement of risk perceptions is that assessments tend to be unidimensional and rely on point-estimates to examine direct effects of risk perceptions on behaviour (e.g., Weinstein, 2007). As the following discussion illustrates, risk perceptions are not finite and are constructed in response to the information available within the individual's environment. The discrepant findings relating risk perceptions to screening behaviour (discussed below) suggest that the operationalisation of the construct needs further consideration. Examining the results from both quantitative and qualitative risk assessments demonstrates the need to consider aspects of the external environment in the construction of risk perceptions and suggests more indirect approaches are needed.

With regard to quantitative assessments, first-degree relatives do report high risk perceptions (Beebe-Dimmer, et al., 2004; Bratt, et al., 2000; Cormier, et al., 2003;

Jacobsen, et al., 2004; Miller, et al., 2001; Schnur, et al., 2006; Vadaparampil, et al., 2004). Further, FDRs perceive their risk of being diagnosed with prostate cancer to be higher than men from the general population. Four studies compare the prostate cancer risk perceptions of men with and without a family history and all four report that first-degree relatives have higher risk perceptions than men without a family history (Jacobsen, et al., 2004; Miller, et al., 2001; Schnur, et al., 2006; Taylor, et al., 1999).

However, a large proportion (between 30-40%) of first-degree relatives over-estimate their risk when single-event probability scales (e.g., 0-100%) are used and under-estimate their risk when comparative risk scales (e.g., personal risk compared to that of the average man) are used (McDowell, et al., 2009). For example, approximately 40% of FDRs estimate their risk to be the same as or less than the average man when asked to make a comparative judgement (Bratt, et al., 2000). The potential for risk estimates to be affected by presentation format is widely recognised (Eibner, Barth, Helmes, & Bengel, 2006; Levy, Shea, Williams, Quistberg, & Armstrong, 2006; Lipkus, 2007; Ranby, Aiken, Gerend, & Erchull, 2010; Schapira, Davids, McAuliffe, & Nattinger, 2004) and a recent meta-analysis concludes that higher quality measures of risk perception (e.g., composite, multiple-item measures) have greater relationships with preventative health behaviour than poorer quality measures (Brewer, Chapman, Gibbons, Gerrard, & McCaul, 2007). Although results generally support the link between greater risk perceptions and having a positive family history of prostate cancer, care should be taken to consider the measures used to assess perceived risk.

Certain aspects of a person's family history, such as the nature of the relationship with an affected relative, have been found to predict risk perceptions. People draw on their personal beliefs and experiences to help interpret risk information

(Leventhal, et al., 1999) owing to difficulties in understanding probabilities and statistics (Rothman & Kiviniemi, 1999). Predictors of risk perceptions in men with a family history of prostate cancer support this notion. Having multiple relatives diagnosed with or deceased from prostate cancer (Beebe-Dimmer, et al., 2004; Bratt, et al., 2000) and being a younger versus an older brother of a sibling with prostate cancer (Beebe-Dimmer, et al., 2004) are associated with higher perceptions of risk. Although actual familial risk increases with the number of affected first-degree relatives diagnosed with prostate cancer (Johns & Houlston, 2003; Zeegers, et al., 2003), having a relative die from prostate cancer has not been shown to increase actual risk, and older brothers are at greater risk than are younger brothers owing to the increasing risk associated with age (Parkin, et al., 2005). The authors of the latter finding speculate that this result may be attributable to a mistaken belief by older siblings that their risk has passed (Beebe-Dimmer, et al., 2004), thus basing their judgement of prostate cancer risk on their family member's experience.

Further, these findings support research from qualitative studies exploring how unaffected family members of people with cancer interpret familial risk and construct risk perceptions. Unaffected family members make judgements about their cancer risk dependent on their perceived likeness to an affected relative (Sanders, et al., 2003; Walter, et al., 2004). For example, lesser perceived physical similarity between a family member and their affected relative is associated with reductions in risk perception. A recent systematic review of qualitative research on lay understandings of familial risk in general concluded that: experience with a family member's illness, premature or sudden death of an affected relative, perceiving a pattern of the illness associated with a relative's age at diagnosis or death, and comparisons between affected and unaffected family members were influential in interpreting personal vulnerability to

a disease (Walter, et al., 2004). Together, these results provide evidence for the influence of family history experience on the construction of risk perceptions. In addition, the interesting contrast between the heightened risk perceptions recorded using quantitative assessments and the reinterpretations of heightened risk using qualitative measures (e.g., based on perceived likeness to an affected relative) suggests the need for a mixed approach to truly capture the process of constructing risk perception in the family context. A better understanding of how men construct risk perceptions about prostate cancer may also improve our understanding of why men participate in prostate cancer screening, for example based on the experiences of an affected relative.

2.4.3 *Family History and Screening Prevalence*

The prevalence of prostate cancer screening in first-degree relatives appears to be high with prevalence rates ranging between 41-95% across 12 studies (Bloom, et al., 2006; Bock, et al., 2003; Bratt, et al., 2000; Cormier, et al., 2003; Miller, et al., 2001; Ross, et al., 2005; Shah, et al., 2007; Spencer, et al., 2006; Sweetman, et al., 2006; Taylor, et al., 1999; Vadaparampil, et al., 2004; Weinrich, 2006). Screening prevalence rates vary in part owing to differences in recruitment methods (e.g., population samples versus recruitment for participation in a screening program), sample composition (e.g., strong hereditary prostate cancer families versus samples of men with at least one affected first-degree relative), and assessments of screening prevalence (e.g., having *ever* had a PSA test, tests *regularly*, tested in last 12 months; see Table 2.3). Only one study has included a follow-up assessment of screening behaviour over a 14 month period and found that most of the FDRs who screened at baseline screened during the follow-up (Vadaparampil, et al., 2004).

The relationship between family history and screening uptake is generally positive such that three of the five studies comparing the screening prevalence rates of men with and without a family history report that family history is associated with greater screening (Jacobsen, et al., 2004; Miller, et al., 2001; Shah, et al., 2007; Spencer, et al., 2006; Taylor, et al., 1999). The studies finding a positive relationship between family history and screening tend to have been conducted more recently and used population-based samples (Jacobsen, et al., 2004; Shah, et al., 2007; Spencer, et al., 2006) compared to those studies finding no relationship (Miller, et al., 2001; Taylor, et al., 1999). However, all five studies were conducted on samples of men from the USA and thus results may not generalise to other countries where screening rates tend to be lower (Baade, et al., 2009; Parkin, et al., 2005). There is generally support for a relationship between a positive family history of prostate cancer and the uptake of prostate cancer screening and further studies are needed to generalise these findings beyond North American samples.

Another avenue of research into whether the diagnosis of prostate cancer in a family member prompts screening in unaffected male family members has been through the examination of cancer registry data and the time between diagnoses of relatives in multiple cancer families. Two studies using data from the Swedish Cancer Registry (Hemminki, Rawal, & Bermejo, 2005) and the Swedish Family Cancer Database (Bermejo & Hemminki, 2005) reported that diagnoses in family members of affected relatives (fathers, sons and brothers) were most likely to occur within five years from the diagnosis of the initial affected relative and around half of diagnoses occurred within one year (Bermejo & Hemminki, 2005; Hemminki, et al., 2005). The diagnosis of prostate cancer in a family member may prompt screening in unaffected male relatives and lead to the early diagnosis of prostate cancer in offspring and siblings of

affected relatives. Although one can only speculate as to why unaffected relatives were diagnosed so soon after the first family member was diagnosed (e.g., greater risk perceptions, family pressure to be tested), these findings highlight the need to consider the salience of family history as an influential factor in the decision to screen.

2.4.4 Family History and Predictors of Prostate Cancer Screening

The majority of research on men with a family history of prostate cancer has sought to find out what predicts the uptake of early detection screening and most explore the contribution of individual characteristics such as socio-demographics and risk perceptions (e.g., Cormier, et al., 2003; Shah, et al., 2007). Socio-demographic variables that suggest greater access to healthcare have been found to predict participation in prostate cancer screening across numerous FDR studies (see Table 2.3). Older age, higher socio-economic factors (e.g., education, income), physician discussion, and past screening behaviour have all been shown to be predictive of prostate cancer screening or intentions to screen in first-degree relatives (Bloom, et al., 2006; Cormier, et al., 2003; Jacobsen, et al., 2004; Miller, et al., 2001; Ross, et al., 2005; Roumier, et al., 2004; Spencer, et al., 2006; Sweetman, et al., 2006; Vadaparampil, et al., 2004). Although these predictors provide some insight into the characteristics of first-degree relatives who are more likely to screen, these characteristics are found also to predict screening in men from the general population (Ross, et al., 2004; Steele, Miller, Maylahn, Uhler, & Baker, 2000; Weller, Pinnock, Silagy, Hiller, & Marshall, 1998) and therefore do not provide any unique information about what is prompting FDRs to screen.

A fundamental issue when examining the evidence amassed on the relationship between risk perception and prostate cancer screening is that many of the studies to be

discussed below contain only two of the constructs (e.g., family history status and screening outcomes or risk perceptions and screening outcomes). An assumption underlying these studies (e.g., Beebe-Dimmer, et al., 2004; Cormier, et al., 2003; Sweetman, et al., 2006; Vadaparampil, et al., 2004) is that men with a family history of prostate cancer will participate in screening more than men without a family history owing to their high-risk status, evident in heightened risk perceptions. Risk perceptions are purported to be a key determinant of health behaviour according to many theories of health behaviour including Protection Motivation Theory (Rogers, 1975) and the Health Belief Model (Rosenstock, 1966). Although only five of the family history studies applied a health behaviour theory as a basis for their study (Jacobsen, et al., 2004; Miller, et al., 2001; Schnur, et al., 2006; Sweetman, et al., 2006; Vadaparampil, et al., 2004), the high-risk status of first-degree relatives of men with prostate cancer was posited to lead to greater risk perceptions and/or screening uptake in all but three studies (see Appendix A; McDowell, et al., 2009; and Wakefield, et al., 2008).

Jacobsen et al. (2004) have conducted the only study to look specifically at risk perception as a mediator of the relationship between family history and screening intentions (but not behaviour) and they found this model to be significant. However, of the six studies exploring the direct relationship between perceived risk and participation in screening for men with a family history, only three report that higher risk perceptions predict screening (Beebe-Dimmer, et al., 2004; Cormier, et al., 2003; Jacobsen, et al., 2004; Miller, et al., 2001; Sweetman, et al., 2006; Vadaparampil, et al., 2004). Thus, having higher risk perceptions is not necessarily the reason men with a family history of prostate cancer make the decision to undertake screening.

A potential explanation for the discrepant findings linking risk perceptions and screening behaviour is that operationalisation of the construct needs further

consideration and needs to consider indirect relationships. For example, in further support of the argument that men with a family history of prostate cancer consider the nature of their family history when making judgements about screening, family history characteristics found to predict risk perceptions are also found to predict screening in first-degree relatives. Having multiple relatives diagnosed with prostate cancer (Bratt, et al., 2000, Roumier, 2004 #95, Sweetman, 2006 #270), being a son as opposed to a brother (Roumier, et al., 2004), and being a younger brother as opposed to an older brother of an affected relative (Beebe-Dimmer, et al., 2004) are associated with increased screening. Men with a family history consider the decision environment around them when making their judgements which necessarily includes the specific experiences of affected relatives. Thus, indirect relationships between family history, risk perceptions, and screening behaviour should be explored to better understand the risk perception construct and how it relates to health behaviours.

2.5 Summary and Conclusions

Informed decision-making guidelines for prostate cancer screening emphasise that men should make personal decisions about early detection testing by weighing the risks, benefits, and uncertainties associated with screening. As evident in the review of screening in Section 2.1, the information about the benefits of early detection screening are complex and filled with uncertainty, and screening guidelines do not offer guidance as to the optimal screening decision beyond that it should be an informed decision. This uncertain decision context is amenable to the application of judgement and decision-making theories to describe the process that men use to work their way through the information and to make their decisions. Surprisingly, there have been no studies that

examine the actual decision-making process men go through or how they understand, interpret, and weigh screening efficacy information. For men with a family history of prostate cancer, the implications of risk information on the screening decision process has not been explored and therefore there is very little understanding of how such men make judgements based on their heightened risk.

To summarise the findings of prior research, men with a first-degree family history of prostate cancer perceive themselves to be at greater risk of being diagnosed with prostate cancer and participate in prostate cancer screening more than do men from the general population. However, contrary to many theories of health behaviour, having greater risk perceptions is not necessarily the reason that relatives are prompted to screen following the diagnosis of a family member. Rather, unaffected relatives make judgements about their personal risk of cancer and base their screening choices on the nature of their family history, such as using the age of a relative at the time of diagnosis as a referent for their personal risk. Both quantitative and qualitative research findings have provided evidence for the importance of the family context in the construction of risk perceptions and suggest both methods are capable at detecting the ways in which family experience can influence risk perceptions.

Risk judgements and decisions about prostate cancer screening occur within a wider social context. Specifically, men with a family history of prostate cancer have more information available to them when making decisions compared to men without a family history and do not simply focus on an additional piece of information about their heightened risk. The consequence of a diagnosis of prostate cancer in a family member can affect a first-degree relative's experience with cancer and this experience can influence their knowledge, beliefs, attitudes, and emotional reactions related to prostate cancer. Basing judgements on personal experiences that are not representative or

accurate can bias decision-making (Kahneman & Tversky, 1973) and potentially lead to poor quality decisions. The following chapter proposes that we need to incorporate first-degree relative's family history of prostate cancer into the context of their decision-making.

2.6 Research Questions

Considering the literature reviewed above, the current thesis seeks to answer the following research questions:

- (a) How do men with a family history differ from men from the general population in the way that they approach their decisions about participating in prostate cancer screening?
- (b) How do men with a family history differ from men from the general population in the way that they consider and conceptualise their risk of developing prostate cancer?
- (c) How does having a family history of prostate cancer influence the way men consider their broader social context (such as social and familial factors), including the effect on cognitive and affective factors, and how do these factors influence their approach to decision-making about prostate cancer screening?

As discussed in Chapter 3, the thesis will attempt to address these research questions by drawing on multiple approaches to the study of formal and everyday reasoning. In particular, the thesis will focus on mapping the social context men consider when

making judgements about their personal risk of prostate cancer and when considering whether to participate in prostate cancer screening.

CHAPTER 3

Perspectives on Judgement and Decision-Making

The goal of research into medical decision-making is to understand the processes underlying health decisions in order to improve or facilitate the selection of an optimal decision for the patient. The potential for error and bias to occur during decision-making has been well documented (Shafir & LeBoeuf, 2002; Tversky & Kahneman, 1974; Tversky & Kahneman, 1981) and these biases are considered to be particularly concerning when they occur in the context of medical decision-making (Amsterlaw, Zikmund-Fisher, Fagerlin, & Ubel, 2006; DiBonaventura & Chapman, 2008; Fagerlin, Zikmund-Fisher, & Ubel, 2005). Health decisions often involve complex information, probabilistic risks, ambiguity about whether benefits outweigh harms, and uncertainties about decision outcomes that have the potential to lead to adverse personal consequences for the patient (Patel, Kaufman, & Arocha, 2002). Specifically, health decisions are high in personal relevance and hedonic value. Accordingly, a better understanding of the decision processes patients use to navigate through complex health information to reach a decision can provide a framework for improving decision-making in practice (Patel, et al., 2002; Ubel, 2010).

3.1 Assumptions of Informed Decision-Making

At present, informed or shared decision-making approaches are considered best practice standards for guiding patients through medical decisions, particularly when there is uncertainty within the medical and scientific community as to the best course of action, where individual preferences guide the decision as to the optimal strategy, and

where individual preferences for outcomes vary (Bowen, et al., 2006). According to Rimer and colleagues, informed decision-making (IDM) occurs:

“... when an individual understands the disease or condition being addressed and also comprehends what the clinical service involves, including its benefits, risks, limitations, alternatives, and uncertainties; has considered his or her own preferences, as appropriate; believes he or she has participated in decision making at a level that he or she desires; and makes a decision consistent with those preferences” (Rimer, Briss, Zeller, Chan, & Woolf, 2004, pg 1216).

However, a strong assumption of IDM is that patients are capable of understanding and integrating information about risks, benefits, and uncertainties to reach a quality decision, and are aware of their preferences when making these decisions. There are two main issues that make this assumption particularly problematic. First, the characteristics of what constitutes a good quality decision are not easy to define, particularly when there is no gold standard for the appropriateness of many medical decisions, such as those about prostate cancer screening. Despite medical and statutory bodies finding insufficient evidence to endorse population-based screening for prostate cancer or to recommend screening for those at heightened risk of developing prostate cancer, a large proportion of men report having participated in screening (Bratt, et al., 2000; Cormier, et al., 2003; Spencer, et al., 2006). It is unclear whether these decisions have been made based on an understanding of the risks, benefits, and uncertainties of prostate cancer screening (see Chapter 2) or have been guided by additional information or an alternative decision process. Further, judgements of decision quality may be dependent on whether rationality is considered to be based on patients adhering to normative standards for decision-making, as the

IDM process suggests, or on making decisions that are consistent with their decision-making goals.

Second, IDM approaches have derived in part from normative theories of decision-making that propose idealised models for how people *ought* to make decisions under conditions involving risk and uncertainty rather than taking into consideration the ways in which people *actually* make decisions. Normative decision models are associated with logical, mathematical principles specifying how rational people should make decisions given information about risks, benefits, and probabilities (Bell, Raiffa, & Tversky, 1988). The attractiveness of these approaches is that they provide detailed probabilistic models for rational choice and thereby standards by which to compare or improve decision-making (Patel, et al., 2002). However, these approaches do not address the potential for a patient to be influenced by information other than that conveyed in the medical context or how this information may lead to biased processing that could affect decision quality.

3.1.1 Violations of IDM Assumptions

In this regard, an extensive literature documents the potential for decision-making to deviate from normative standards and for people to rely on biases and heuristic strategies to guide their decision-making (Gigerenzer & Gaissmaier, 2011; Kahneman & Tversky, 1973; Keys & Schwartz, 2007; Tversky & Kahneman, 1974). For example, people's motivations and goals can influence judgements, dictate what information is sought or disregarded, and determine the depth of processing involved in attending to information that is either supportive or conflicting with their goals (Kunda, 1990; Molden & Higgins, 2005). People are known to draw on information not directly related to their current decision (Bastardi & Shafir, 1998; Simonson, Nowlis, &

Simonson, 1993), to be influenced by anecdotal information while neglecting base-rate probabilities (Denberg, Melhado, & Steiner, 2006; Kahneman & Tversky, 1973), and to make judgements based on the availability or salience of information (Tversky & Kahneman, 1973). These findings are characteristic of research into the ways in which people *actually* make decisions and distinguish descriptive from normative approaches to decision-making (Bell, et al., 1988).

Most important to the current argument, the impact of having a family member with prostate cancer on men's judgements of risk and their consequent decision-making processes has been largely neglected, particularly when considering the application of IDM guidelines to prostate cancer screening. More broadly, contextual factors have been neglected in decision-making research in general. A widely held criticism of research associated with decision-making (both normative and descriptive approaches) is the neglect of exploring real world decisions and a reliance on results obtained from carefully controlled studies conducted within the laboratory (Hammond, et al., 1975; Hastie, 2001). People make decisions in messy environments in which probabilities are often changing or unknown, in which complete risk and benefit information is not always available, and in which prior beliefs and experience permeate the current decision context (Shafir, et al., 1993; Ubel, 2010; Wroe, Salkovskis, & Rimes, 1998). Further, decisions vary according to their personal relevance to the decision-maker, the affect one associates with a specific decision, and characteristics of the environment where the decision is to be made (e.g., family pressure, male role norms). For men with a family history of prostate cancer, these factors may alter the decision context such that the strategies FDRs apply to make decisions about screening may differ to those of men without a family history. For example, men with a family history of prostate cancer have additional and potentially more salient information about prostate cancer available

to use in their judgements owing to their interactions with an affected relative and the potential awareness of the implications on their personal risk. In order to improve patient decision-making about prostate cancer screening, these factors need to be identified and potential biases addressed to enable them to be considered in the IDM setting.

3.2 Aims and Overview

Consequently, there are two broad aims for the current chapter. First, the application of both normative and descriptive models to exploring decision-making about prostate cancer screening will provide for a greater understanding of the decision context as experienced by men with a family history of prostate cancer. Normative approaches to understanding screening decision-making will help to establish whether men are making decisions based on the consideration of perceived risks and benefits associated with screening and can distinguish what information is being weighted more heavily by FDRs compared to general population men (e.g., exploring how heavily FDRs weigh familial risk in their judgements). Descriptive models can be applied to understand better the potential for bias to permeate the decision-making process and influence the processing of information pertaining to prostate cancer and screening. Specifically, descriptive approaches will provide an opportunity to examine the different strategies men use to navigate through the complex information about prostate cancer screening and examine the sources of information utilised to reach decisions (e.g., the strategies men use to construct their perceptions of personal risk of developing prostate cancer). Multiple theories and methodologies will be proposed to achieve this aim. The second aim is to address criticisms related to the application of decision-

making models to real world decisions through utilising methodologies that enable the examination of the context of the decision for the decision-maker.

3.2.1 Outline of the Current Chapter

The following sections provide an overview of reasoning and decision-making theories and describe how they can be applied to understand the current decision context for men with a family history of prostate cancer. Normative and descriptive approaches are described as is the capacity for their contributions to complement one another in best understanding FDR decision-making about prostate cancer screening. Emphasis on motivations, goals, and associated factors that influence conceptualisations of rationality are considered followed by a discussion of dual-process theories for examining the mechanisms by which intuitive and analytic thought influence judgements. Finally, three major theoretical models are described and their application to the current thesis is discussed. Specific methodological applications of these theories will be described in detail in subsequent chapters.

3.3 Current Perspectives on Rational Choice

Decision-making theories have evolved to recognise two different types of rationality: rationality that prescribes to principles of formal logic, and rationality that serves the purpose of achieving one's goals (Evans, 1993). The purpose of the current thesis is to discuss assumptions relating to conceptualisations of rationality and the implications each has for understanding decision-making as it occurs in the real world (as opposed to the laboratory). Specifically, the current thesis proposes that the decisional context that FDRs face is different from that of men from the general

population and as such, the strategies FDRs apply to make judgements and decisions are influenced as a result. Accordingly, the following sections describe the different approaches to examining decision-making and judgement, consider alternative conceptualisations of rationality, and discuss how to integrate these considerations into the understanding of the decision-making strategies used by FDRs.

3.3.1 Normative and Descriptive Theories

Research in the field of decision-making has generally been concerned with two distinct questions: how *should* people make decisions and how *do* people make decisions (“...the ought and the is...”, respectively [*italics in original*]; Bell, et al., 1988, pg 9). Normative analysis developed in response to the first question, drawing on economic theories of probability and uncertainty to suggest models for human judgement (Savage, 1954). For example, according to the principle of transitivity, if a decision-maker prefers option A to option B, and option B to option C, then they should prefer option A to option C. Normative theories proposed that decisions under risk and uncertainty could be represented as gambles and that assigning probabilities and utilities to decision outcomes should lead people to select the option that maximised expected utility (von Neumann & Morgenstern, 1947). For example, how are utilities being assigned to the perceived probability that one will be diagnosed with prostate cancer? In this regard, normative theories describe how an ideal person might behave should they conform to the principles of the theory.

Normative models have received substantial criticism for their neglect of cognitive limitations in human reasoning, such as the observation that people are often unable to make implicit complex mathematical calculations (Bell, et al., 1988). Further, people’s preferences are not simply revealed in the decision process but can be

constructed with respect to the nature and context of the decision (Shafir & LeBoeuf, 2002; Slovic, 1995). Most importantly, normative models are poor at predicting real world decisions and are focussed on the decision process as an assumption of decision quality; normative theories are concerned not with whether a person is making a correct decision, but with whether they are making the decision correctly (Beach & Lipshitz, 1993). However, normative models do provide the foundations for informing *prescriptive* theories of decision-making with the goal of finding ways to help people make good decisions (Bell, et al., 1988). Examining how people should make decisions in contexts of risk and uncertainty, for example when considering the risks and uncertainties of early detection screening for prostate cancer, has led to the development of research aimed at improving decision-making, as is evident in the IDM approaches described in the preceding section.

By contrast, descriptive approaches to decision-making address the description or prediction of behaviour and are concerned with the question of how and why people make decisions in the way that they do (Bell, et al., 1988). Descriptive approaches to decision research emerged to explain the finding that people frequently do not conform to principles of normative theories. For instance, a key principle of normative theory is that of description invariance: different descriptions of the same decision problem should not lead to different preferences (LeBoeuf & Shafir, 2003). However, people have been shown to prefer different decision outcomes when they are framed positively as opposed to negatively. In the classic *Asian disease* problem, Tversky and Kahneman (1981) demonstrated that, despite equivalent contingencies, the majority of participants would prefer to be risk-averse when options were framed in terms of lives saved but risk-taking when options were framed as lives lost. These results have relevance for how the communication of risk information to men may influence their judgements

about prostate cancer screening. Further, these results suggest that people do not seek to consider or reframe problems from alternate perspectives, accepting the provided frame and violating the principle of description invariance (LeBoeuf & Shafir, 2005). Research into such violations led to the development of the descriptive model Prospect Theory (Kahneman & Tversky, 1979) describing decision-making under risk and the tendency for people to treat outcomes as departures from a current reference point, to be risk-averse for gains and risk-seeking for losses, and for losses to appear larger than gains (LeBoeuf & Shafir, 2005).

3.3.1.2 The role of heuristic strategies in judgement. Tversky and Kahneman (1974) are also widely recognised for their heuristics and biases approach to understanding intuitive judgements about probabilities and the likelihood of uncertain events (Laibson & Zeckhauser, 1998). Further, the heuristics and biases approach acknowledges how people draw on information from memory to formulate judgements. The judgement heuristics of representativeness, availability, and anchoring and adjustment were proposed to explain people's insensitivity to probability information and other violations of logical principles of prediction (Kahneman & Tversky, 1973; Tversky & Kahneman, 1973, 1974). For example, the representativeness heuristic captures how people make judgements based on the perceived similarity of an event or object to a known class of events or objects (Kahneman & Tversky, 1973). In the now classic Tom W. experiment, a group of participants were asked to rate the relative frequencies (base-rate group) of graduate students across nine areas of specialisation (e.g., computer science, law, humanities). Two remaining groups were presented with the following personality description of Tom W.:

Tom W. is of high intelligence, although lacking in true creativity. He has a need for order and clarity, and for neat and tidy systems in which every detail finds its

appropriate place. His writing is rather dull and mechanical, occasionally enlivened by somewhat corny puns and by flashes of imagination of the sci-fi type. He has a strong drive for competence. He seems to have little feel and little sympathy for other people and does not enjoy interacting with others. Self-centered, he nonetheless has a deep moral sense. (Kahneman & Tversky, 1973, pg 238)

The similarity group was asked to rank the nine specialisations in terms of how *similar* Tom W. was to the typical graduate student in each of the nine areas. The prediction group was given additional information questioning the validity of the preceding personality sketch and were asked to rank the fields in order of the *likelihood* that Tom W. was a graduate student in each of the nine areas. Kahneman and Tversky reported that judgements of similarity and likelihood were highly correlated and did not reflect the base-rate judgements. Participants judged Tom W. to be more likely to be studying computer science than humanities based on the likeness of his description to a representation of a computer scientist. This experiment provided support for the premise that people neglect base rate probabilities in favour of perceived similarities to make likelihood judgements. Further, the results suggest ways in which men with a family history may use an affected relative as a representation of the type of person who develops prostate cancer and construct judgements of risk and make screening decisions in response to their referent.

Similarly, the availability heuristic is associated with frequency or probability judgements made on the basis of the ease with which events or associations come to mind (Tversky & Kahneman, 1973). For example, judging the likelihood of being robbed to be high based on available information about the recent spate of home invasions reported in the media. In this regard, the availability heuristic explains

people's tendency to be insensitive to sample size when making probability judgements (e.g., neglecting to consider the total number of homes not robbed). In relation to prostate cancer, basing judgements about the severity of a prostate cancer diagnosis on personal risk perceptions by drawing on the few available instances of prostate cancer one can easily recall would indicate an influence of the availability heuristic on judgements.

Heuristic principles simplify judgement by reducing the complexity of tasks and although heuristics are generally economical, reliance on heuristics can lead to systematic errors in judgement (Tversky & Kahneman, 1974). The representativeness and availability heuristics will be described in greater detail in Section 3.4.2. In particular, the representativeness and availability heuristics will be discussed with respect to their ability to explain how men may construct their personal risk perceptions based on the information available around them. The heuristic and biases approach has led to a broad and widely accepted field of research on intuitive judgement (Laibson & Zeckhauser, 1998) and has made a considerable contribution to our understanding of how people actually make decisions.

Both normative and descriptive approaches to examining decision-making provide valuable information about the process of decision-making and the strategies people use to form judgements under conditions involving uncertainty. The observation that people do not make consistent decisions that adhere to principles of normative or formal logic and rely on heuristic strategies to simplify complex decisions has led to a critique of the rationality assumption derived from normative approaches. In light of these critiques, the following section addresses current conceptualisations of rationality and what it means to be a rational decision-maker with specific emphasis on the achievement of decision-making goals (Kunda, 1990).

3.3.2 Distinguishing Between Different Types of Rationality: Rationality₁ and Rationality₂

Edwards (1954) describes Economic Man as possessing three qualities: (a) *He is completely informed.* (b) *He is infinitely sensitive.* (c) *He is rational.* (pg 381). On this view, men would always make a decision about prostate cancer screening based on and only on base-rates, the ratio of all of the pros and cons related to early detection screening, and on the weighting of utilities. Throughout the twentieth century, researchers examining human reasoning relied on the assumption that a rational person reasons in a way that conforms to the prescriptions of an economic theory. Deviations from the principles of these theories were presumed to indicate irrationality and as such, people were often considered to be largely irrational. In a recent review of reasoning, judgement, and decision-making research Shafir and LeBoeuf (Shafir & LeBoeuf, 2002) questioned the following assumption of rationality:

Common to most accounts of rationality is the notion that a person is largely entitled to his or her own views or preferences, but that these should cohere, should adhere to basic rules of logic and probability theory, and should not be formed or changed based on immaterial factors related to, for example, mood, context, or mode of presentation (pg 493).

Persistent empirical findings that people frequently violate tenets of this rationality assumption suggest that an alternative perspective on rationality is required, one that extends beyond normative principles of formal logic. Reasoning and decision-making theories have evolved to recognise that decision-makers are not always completely informed, that people have cognitive limitations in their ability to process information (Newell & Simon, 1972), and that consideration should be given to people's decision-making goals.

Accordingly, Evans (1993) proposed that decision-making and reasoning research map onto two different conceptualisations of rationality:

rationality₁ (rationality of purpose): reasoning in a way which helps one to achieve one's goals (decision-making);

rationality₂ (rationality of process): reasoning in a way which conforms to a supposedly appropriate normative system such as formal logic (reasoning).

Evans proposed that rationality₂ is based on the concept of rationality = logicity and is associated with theoretical reasoning whereby being rational is concerned with reasoning to acquire true beliefs about matters of fact. In this regard, rationality₂ is captured in coherence of beliefs such that a decision-maker is rational when their reasoning conforms to the prescriptions of formal logic (Beach & Lipshitz, 1993).

However, there are expansive literatures detailing the variety of ways in which people do not reason in a way that conforms to principles of formal logic (Gigerenzer & Gaissmaier, 2011; Kahneman, 2003; Kahneman & Tversky, 1984; Tversky & Kahneman, 1974; Tversky & Kahneman, 1981), yet people are quite competent at making everyday decisions that do not result in adverse outcomes (Evans, 1993; Evans, Over, & Manktelow, 1993; Kunda, 1990; McMackin & Slovic, 2000). Reasoning logically (rationality₂) will not necessarily lead to the achievement of goals; rationality₂ does not serve rationality₁. Evans's (1993) conceptualisation of rationality₁ is associated with research in the field of decision-making and considers that people are motivated to reason in such a way as to help them achieve their goals. For example, maximisation of subjective expected utility (reviewed in Section 3.4.1) is an idealised strategy aimed at achieving positive decision outcomes (Evans, et al., 1993) and is incorporated in current approaches to IDM in relation to prostate cancer screening.

3.3.2.1 Bounded rationality. People have limited cognitive capacity and although normative theories argue that one ought to maximise expected utility this should not imply that one always can. Evans (1993) draws on the work of Newell and Simon (1972) and their argument for *bounded* rationality, proposing that people seek to achieve their goals and when they fail this is a result of cognitive constraints. There are costs associated with accuracy including dedicating extensive cognitive effort to a decision task and people are often constrained in reaching optimal decisions owing to lack of resources, cognitive ability, time, or motivation. For example, many men facing the decision about whether to screen for prostate cancer would find themselves making this decision in a time-constrained context (e.g., in a time-limited doctor's consultation) and would not have the capacity to consider all alternatives, probabilities, and potential outcomes. Rather, men may be constrained to consider only the most salient or dominant motive. Owing to cognitive limitations, people are more likely to achieve their goals by selecting an adequate solution rather than constantly seeking to optimise utility, a strategy known as satisficing (Evans, et al., 1993). That is, people often select the decision that meets their decision-making goals or satisfies certain criteria (Evans, 2006). For example, there may be many reasons that an FDR is limited in their cognitive capacity to dedicate sufficient processing effort to decisions about screening (e.g., the experience of negative affect impedes their processing of subsequent risk information, see Section 3.4.1) and a satisfactory solution that achieves a specific goal may be most appropriate under these circumstances. The suggestion that decision-making is influenced by goals and motivations links with the propositions of motivational theories of reasoning put forward by Kunda (1990) and Molden (2005).

3.3.3 *Motivational Reasoning*

Motivation plays a crucial role in determining the cognitive effort and processing capacity people dedicate to different tasks. Given that human beings are limited in their capacity to process the vast amounts of information in their social world, they have evolved to rely on cognitive shortcuts to facilitate judgement and decision-making (e.g., schemas). Owing to these limitations, human beings are not only constrained by their cognitive capacity but need to be selective in the effort they dedicate to processing information. Motivation is considered an influential factor in determining the type and degree of processing effort dedicated to judgement and decision-making tasks.

Kunda (1990) proposed that people's motivations concerning desired outcomes affect the process of reasoning and making decisions. Specifically, people are motivated by accuracy and directional goals. When motivated to achieve accuracy in judgements, people attend to, process more deeply, and expend more cognitive effort to processing relevant information, and use more complex rules (Kunda, 1990; Molden & Higgins, 2005). People may be driven by accuracy goals when there are greater personal consequences for making a wrong judgement. For example, if driven exclusively by accuracy goals, FDRs would seek to understand accurately their likelihood of developing prostate cancer by considering probability information and attending to risk communications. Accuracy motivations are consistent with the concept of satisficing in that people will expend greater effort to reach an adequate (or accurate) solution.

By contrast, reasoning driven by directional goals is more likely to be influenced by motivational biases (Kunda, 1990). When reasoning to achieve a specific outcome, people are biased in the beliefs they access to support or refute an argument, the degree

to which they evaluate evidence, and their use of heuristic strategies. An extensive body of research examining the tendency for people to be unrealistically optimistic about future life events such as negative health states (Weinstein, 1980) demonstrates how people are resistant to change their (optimistically positive) risk perceptions when exposed to information about risk-increasing factors (Weinstein & Klein, 1995). For example, when motivated to reach a desired conclusion, people require less information to reach a preference-consistent conclusion than a preference-inconsistent conclusion (Ditto & Lopez, 1992) and are more sensitive processors of information that they do not want to believe (Ditto, Scepansky, Munro, Apanovitch, & Lockhart, 1998). Further, people are known to express a confirmation bias in that they are more likely to search for, select, and process information that supports rather than conflicts with their current view (Nickerson, 1998). These findings have implications for the ways in which men may construct their risk perceptions.

In addition to directional and accuracy goals (referred to under the broader category of outcome-motivated reasoning), Molden (2005) proposes that people are also motivated to use preferred reasoning strategies to reach conclusions. That is, using reasoning strategies that “*feel right*” (pg 306) and allow people to maintain their current motivational state (e.g., maintain a positive self-view through faster processing to gain greater quantity as opposed to quality of information). However, people attempt to be rational to the extent that they can *construct a justification of their desired conclusion that would persuade a dispassionate observer* (pg 482-3). For instance, in the third study conducted by Ditto et al. (1998), participants who received favourable diagnostic test results rated the accuracy of the test equally highly regardless of information suggesting that there was a high or low probability of the test returning a false positive result. By contrast, participants who received unfavourable diagnostic test results

judged the accuracy of the test results similarly to the participants who received a favourable result but only if the probability of a false positive was low. Thus, directional goals can only lead to a desired conclusion to the extent that one can gather sufficient evidence to support it.

In relation to the context of the current thesis, directional and motivational goals can help explain bias in medical decisions. Errors in medical decision-making have the potential to lead to negative or harmful consequences for the patient. However, even with respect to medical decisions one cannot assume that people are motivated by a goal of accuracy; directional goals may bias patient choice. Fagerlin, Zikmund-Fisher and Ubel (2005) presented participants with hypothetical cancer diagnoses and examined the proportion of patients who would undergo non-optimal treatments as opposed to watchful waiting even if these treatments decreased their overall chances of survival. When treatment was presented as harmful (e.g., treatment increased five year mortality to 10% compared to 5% for watchful waiting), 65% of participants chose to undergo surgery despite the reduction in the chance of survival. Moreover, the preference for surgery was stronger than that made by the 38% of participants who chose to take medication under the same conditions. Fagerlin and colleagues suggest that patients were motivated to act, and that this motivation was stronger than that for selecting the most effective treatment option. Further, the greater preference for surgery compared to medication suggests that participants acted based on their beliefs about or preferences for how cancer should be treated, as a quote from a participant illustrates: *I would want to try to cure the disease rather than just 'watch and wait' for symptoms to develop. I would feel like I had to try to do things instead of just letting it go.* (pg 681).

The notion that the desire for action is stronger than inaction may be a key reason men are motivated to undertake prostate cancer screening despite uncertainty

about mortality benefits and the potential for a diagnosis to lead to treatments that reduce overall quality-of-life. Men with a family history may experience greater motivation to take action considering their awareness of having an increased risk of being diagnosed with prostate cancer and a desire to act in relation to this belief.

Accordingly, their motivation to conclude that by screening they will be taking action in response to their prostate cancer risk may influence the way they reason about prostate cancer screening information to reach a desired conclusion to undertake screening. This may be problematic for the patient if they fail to consider information about potential risks and side-effects of prostate cancer treatment that may lead to negative outcomes for the patient should they be diagnosed.

To summarise the literature reviewed so far, judgement and decision-making research has evolved from classical theories of rationality where rationality = logicity, to suggestions that rationality can incorporate motivations and decision-making goals. Motivational theories have proposed that people use different processing strategies to reason about information dependent on whether they are driven by accuracy or directional goals. Specifically, motivational theories draw on research findings that suggest people dedicate more elaborate and effortful processing when seeking to achieve accuracy or when attempting to support a directional decision outcome. The following section proposes the mechanisms by which more, or less effortful processing is likely to occur.

3.3.4 Dual Process Accounts: Automatic versus Controlled

Distinguishing more elaborate from less effortful processing strategies has been the objective of research into dual-processing accounts of reasoning and decision-making (Evans, 2008). Dual-processing accounts draw on research from cognitive and social psychology to examine the basis and application of different types of information processing strategies on judgement. Specifically, dual-process theories have emerged to explain the cognitive, affective, and motivational basis of reasoning and the proposition that there are multiple routes to processing information.

In a recent review of dual-processing accounts of reasoning, judgement, and social cognition, Evans (2008) surmised that dual-process theories distinguish between cognitive processes that are unconscious, fast, and automatic, and those that are conscious, slow, and deliberate. Owing to an abundance of dual-process models in the literature, Evans referred to these groups of processes with the neutral terms System 1 and System 2, respectively. Cognitive heuristics, intuition or experiential reasoning, mental shortcuts, and belief biases are often attributable to System 1 processes whereas System 2 processes include controlled, elaborate, and rule-based reasoning strategies. The dual-process distinction functions to identify under what conditions people are more, or less likely to adopt analytic (i.e., System 2) compared to intuitive (i.e., System 1) reasoning. For instance, to examine for what types of decision-making tasks people are more likely to rely on automatic, intuitive judgement rather than use complex and elaborate processing. For example, providing men with information about the risks, benefits, and uncertainties of prostate cancer screening may be likely to cue analytic processing or alternatively, the complexity of the decision may cue intuitive processing.

Despite commonalities across many aspects of dual-process models, theories differ according to the mechanisms by which System 1 and System 2 processes are

perceived to be engaged. The theories of both Kahneman and Frederick (2003; 2002) and of Evans (heuristic-analytic theory 2006) propose that System 1 (or intuitive judgement) is the default process and is subject to the endorsement of System 2 (or analytic processes). According to Kahneman and Frederick's theory, judgement may occur in five ways (Kahneman, 2003, pg 717):

1. *An intuitive judgment or intention is initiated, and*
 - (a) *Endorsed by System 2;*
 - (b) *Adjusted (insufficiently) for other features that are recognised as relevant;*
 - (c) *Corrected (sometimes overcorrected) for an explicitly recognised bias; or*
 - (d) *Identified as violating a subjectively valid rule and blocked from overt expression.*
2. *No intuitive response comes to mind, and the judgment is computed by System 2.*

The theory draws together extensive research on the role of judgemental heuristics in intuitive judgement, the heuristics and biases approach, and considers the role of System 1 and System 2 in the application of different processes to reasoning.

According to Kahneman and Frederick's theory, whereas System 1 generates impressions and is associated with intuitive reasoning, System 2 is involved in all judgements whether deliberate or originating from impressions formed by System 1. In this regard, judgemental errors can result from both systems: from impressions generated by intuitive processes and from the failure of analytical processes to correct these judgements (Kahneman, 2003). Further, the theory relates System 1 processes to those of perceptual processes and, like percepts, intuitive thoughts should come easily and effortlessly to mind. Understanding why some thoughts are more or less accessible than others is the basis for understanding intuitive judgement (Kahneman, 2003).

Specifically, Kahneman and Frederick (2003) propose that intuitive judgement occurs as a result of *attribute substitution*: *A judgement is said to be mediated by a heuristic when the individual assesses a specified target attribute of a judgement object by substituting a related heuristic attribute that comes more readily to mind* (pg. 707). In particular, Kahneman and Frederick suggest that when confronted with a difficult question people sometimes provide a reasonable answer to an easier question that they have not been asked. In relation to the Tom W. problem described in Section 3.3.1, attribute substitution would explain why people faced with a judgement of probability appear to have substituted it with a judgement about similarity. The heuristic attribute (similarity) was easily accessible and its association with the target attribute was close enough to not be overridden by System 2. Unfortunately, conditions according to which corrective thoughts from System 2 are sufficiently accessible to intervene in judgement are largely described at the individual level, and include exposure to or training in statistical thinking, increasing monitoring activities, and stronger priming of relevant rules. The theory does not consider broader social contextual variables, such as perceived personal relevance of the decision or motivational considerations that may lead to System 2 intervention. For example, whether high-risk information leads FDRs to process information about prostate cancer risk with defense motivations that impedes analytic processing.

Similar to Kahneman and Frederick's theory, Evans's (2006) heuristic-analytic theory of reasoning proposes that heuristic processes cue a default mental model or response that draws on prior knowledge and experience that is most relevant to the decision task, and that this model may be revised, replaced, and heuristic responses inhibited by analytic system intervention. In this regard, heuristic and analytic processes compete for control of behaviour. Evans's theory considers aspects of the

decision-making task and instructional set as important in determining the type of processes people apply to make judgements. Features of the task including instructions and time restrictions, and individual goals influence the construction of the mental model and determine whether there is intervention from the analytic system.

The importance of the decision task to judgement is expressed most explicitly in relation to Cognitive Continuum Theory (CCT; Hammond, 1980). Although the majority of dual-process models argue for distinct systems, Cognitive Continuum Theory, drawing on research associated with Social Judgement Theory (Hammond, et al., 1975), has proposed that intuitive and analytic thinking are two ends of a cognitive continuum and that the degree of analytic (or intuitive) cognition is conditional on the features of the decision-making task. Everyday judgement is seen to occur at the centre of this continuum and represents quasi-rationality and is related to Simon's concept of bounded rationality (Newell & Simon, 1972).

According to CCT, properties of intuitive thinking include rapid information processing, low cognitive control or required effort, and a greater reliance on nonverbal cues. Intuitive thinking is most suited to task structures that are complex and with many alternatives, where there is greater ambiguity in the task content, where there are time pressures, or where judgement requirements are memory-driven (Hammond, 1986 as cited in; Cooksey, 1996). For example, intuitive judgement may be employed with respect to prostate cancer decision-making owing to the complexity and uncertainty inherent in the screening decision, and where time pressures may impede the processing of information in a medical consultation. By contrast, analytic thinking incorporates slower information processing, high consistency, and greater cognitive effort and is better suited to tasks that are less complex in structure (e.g., a few, dichotomous cues to judgement), when there is low ambiguity in task content, and where judgement

requirements are data-driven. Accordingly, intuitive cognition is better at dealing with intuitive tasks and analytic cognition with analytical tasks (Hammond, Hamm, Grassia, & Pearson, 1987). For example, intuitive judgement may be more suited to the selection of desserts whereas analytic judgement may be more appropriate to decisions about purchasing a car.

In this connection, Inbar, Cone, and Gilovich (2010), testing their task cueing hypothesis, explored the nature of the decision-making task to understand what led people to choose to decide rationally or intuitively. Inbar et al. found that participants were sensitive to features of the decision task when deciding what type of reasoning to apply. For example, when a task was described using precise terms (e.g., exactly 50 marbles) as opposed to imprecise terms (e.g., about 50 marbles), or serially (e.g., step-by-step) as opposed to holistically (e.g., consider all details), rational judgement was cued. The finding is similar to those reported on framing effects in judgement where the words used to describe a decision task (e.g., loss versus gain) affect the types of responses people provide (e.g., risk-seeking or risk-aversion) (Johnson, Hershey, Meszaros, & Kunreuther, 1993; Tversky & Kahneman, 1981). These findings are highly relevant to the presentation of information within medical decision aids in that the way in which prostate cancer information is presented may impede or promote analytical judgements. People's approach to reasoning about a task matches the characteristics of the task to a point along the intuitive-analytic continuum.

Although dual-process models have developed to consider the interaction between task characteristics and the dominance of different types of cognitive and intuitive processing, dual-process theories have largely ignored the wider social context including the role of affect, motivation, prior belief, and personal experience as guiding processing type. For example, emotion or affect is acknowledged to play a key role in

information processing and is assumed to be associated with System 1; however, it is often excluded from discussions about task or contextual conditions that tend to focus more on cognitive aspects of information processing (Finucane & Holup, 2006). Alternatively, affect has been considered as a general all-purpose heuristic that may be applied in a given context (e.g., dependent on the context). Further, the theories reviewed in the preceding sections do not address interactions between contextual, motivational, and situational factors and processing styles, nor do they specify when System 1 or System 2 processing is more likely to dominate. These considerations have guided the selection of the models as described in the following section.

3.4 Application of Judgement and Decision-Making Approaches to Prostate Cancer Screening Decisions

The selection of the following three approaches to examining decision-making about prostate cancer screening for men with a family history was based on a number of considerations. First, a combination of normative and descriptive models aimed to provide information about how men are approaching the decision-making process (e.g., weighting information in accordance with SEU theory) and what processing strategies are guiding their judgements (e.g., heuristic cues in accordance with the HSM). Further, decision-making models that were amenable to real world issues and could be modified to take into account the broader social context involved in everyday decisions were selected. For example, SEU theory was modified to examine the weighing of decision-relevant reasons as specified by participants, rather than on providing participants with decision-relevant reasons that were selected by the researchers.

Subjective Expected Utility theory is a normative approach to understanding the process by which men weigh information pertaining to prostate cancer screening according to subjective expected utilities. The theory is applied to the current decision about prostate cancer screening to better understand the information FDRs use in their decisions, to distinguish how information may be weighted more or less heavily by FDRs in comparison to general population men, and to consider the role of different motivational and affective sources of information in guiding judgements. Further, the importance of family history risk in determining judgements can be explored by examining whether FDRs consider family history in their judgements and if so, how heavily they weigh this information. The Heuristic-Systematic Processing Model (Chaiken, 1980) is a dual-process model that addresses why people are more or less motivated to process information and specifies cognitive, motivational, and affective influences on information processing. The application of the HSM draws on the two most widely recognised heuristics deriving from the heuristics and biases approach to judgement: the availability and representativeness heuristics. Finally, Social Judgement Theory (Hammond, et al., 1975) considers the decision environment when constructing decision tasks, emphasising that to understand how people make judgements one has to structure the task to adequately represent the ecology. For example, representing the decision environment faced by men and the cues considered relevant for judgements about prostate cancer risk and screening (e.g., symptom status, family history status) will provide an understanding of what cues men consider to be important for making decisions within this environment. The integration of a decision task within the decision-making environment is argued to provide for generalisations to be made about the relative importance of prostate cancer screening-related cues to decision-making for FDR and general population men.

3.4.1 Subjective Expected Utility Theory

Decisions that involve elements of uncertainty and risk have traditionally been explored with classical decision theories that apply normative models specifying principles of rational judgement or choice. These theories propose that under conditions of uncertainty, decision-makers are effectively forced to gamble and consequently, decisions can be represented as such. Utility Theory, one of the earliest normative models proposed by von Neumann and Morgenstern (1947), adopted mathematical methods drawn from theories of behavioural economics to formulate a theory of rational choice based on laws of probability. Utility Theory addressed uncertainty and risk in decision-making by applying concepts of probability and utility to achieve optimal choice through the principle of utility maximisation. When probabilities or risks are unknown or uncertain, the decision-maker assigns weights to these outcomes in the form of expected utilities. The decision-maker then selects the decision that maximises expected utilities.

Utility Theory was extended by Savage (1954) to incorporate the concept of *subjective* values in response to criticisms regarding the presumed objectivity of assessments of utility and probability. For instance, people may judge the probability of the same event to be different based on different beliefs or confidences in the likelihood of outcomes. For example, identical probabilities for developing prostate cancer (e.g., objective risk estimates) for two men may relate to different risk perceptions based on the specific beliefs or experiences of each individual (e.g., beliefs about personal protective health behaviours). Subjective Expected Utility theory took into account that a decision-maker's belief in the probable realisation of events or in the truth of propositions is subjective, and modified the theory to include subjective assessments of utility and probability:

$$\sum_i u(x_i) P(x_i). \quad (1)$$

where u = the utility assigned to each outcome x_i and P = the probability of outcome x_i occurring.

According to the principles of SEU, a man would make his prostate cancer screening decision based on the subjective probabilities he assigns to outcomes (e.g., to receive a positive or negative test result or not to test and not to know), the subjective utilities he assigns to information pertaining to the risks, benefits, and uncertainties of screening, and select the outcome that maximised positive outcomes. In this regard, a man with a family history may assign greater probability to the outcome of a prostate cancer diagnosis, assign greater utility to information about his risk of having prostate cancer, and consider *knowing* whether he has prostate cancer to weight heavily in his decision compared to knowledge that there is insufficient evidence to suggest that there may be no mortality benefit as a result of early detection screening.

Subjective Expected Utility theory is most amenable to examining the IDM process owing to the roots of IDM in normative theory and enables the examination of how men weigh the evidence about prostate cancer screening and consider their personal values or preferences in their decisions. Further, examining the information men use and the weightings assigned to risks, benefits, and uncertainties of prostate cancer screening can provide insight into how men with and without a family history of prostate cancer may be approaching their decisions. For example, the finding that men with a family history of prostate cancer report greater perceived risk but that risk perceptions do not consistently predict screening uptake may be understood by examining the weighting assigned to risk information or perceived probabilities of diagnosis in these men.

In a related context, Wroe and colleagues (1998) applied utility theory to decision-making about genetic testing for a variety of diseases to explore whether the weighting of risks and benefits predicted intentions to undergo genetic testing. Wroe et al., in research both with student and general public samples, found that the ratio of pros to cons that people listed about genetic testing predicted their interest in undergoing genetic testing and this ratio predicted interest more than did the participants' absolute risk perceptions. Further, the participants weighted utilities were the best predictor of interest in genetic testing for those participants who had previously contemplated testing for the disease. These results suggest that weighted utilities may be important predictors of health behaviour, particularly for people who have previously contemplated decision outcomes. The methodology used in Wroe et al. will be described in detail in Chapter 5 as that section of the present thesis pertains to the application of SEU theory for examining decision-making about prostate cancer screening for men with a family history.

However, normative models assume that people systematically explore and weigh up each decision alternative to produce a judgement that maximises positive relative to negative outcomes (Dawes, 1988; Savage, 1954; von Neumann & Morgenstern, 1947). Unlike gambles, real world decisions are not controlled or fixed, and cannot be easily represented as a single (or series of) discrete choices. In realistic settings, decision makers may conduct a serial assessment of options rather than evaluate a fixed set of alternatives or systematically weigh discrete pieces of information (Patel, et al., 2002). In particular, Hastie (2001) noted limitations in SEU in respect to its lack of explanation as to how the decision-maker constructs or comprehends the decision situation, the sources of input in the process, or where information about events, consequences, and alternatives derive from.

In response to these criticisms, Wroe et al. modified SEU theory to incorporate participant-derived reasons for and against participating in genetic testing to investigate differences not only in the process of decision-making but in the content of participant's reasons (1998). These modifications were aimed at making SEU theory more applicable to real world decision-making by allowing the participant to generate risks and benefits that they perceived to relate to genetic testing rather than rely only on those alternatives specified by the researcher. Specifically, Wroe et al. introduced to the decision situation the idea that people who had previously contemplated genetic testing decisions in the past may consider different and more (or fewer) reasons for or against genetic-testing. The results of Wroe et al. supported this conception, revealing that for people who had previously contemplated genetic testing, affectively-based risks and benefits were more important and were weighted more heavily in their decisions.

The finding that emotion was used as a basis for reasoning about risks and benefits is consistent with extensive research on the role of the *affect heuristic* in judgements that is highly relevant to prostate cancer screening decisions (Alhakami & Slovic, 1994; Finucane, Alhakami, Slovic, & Johnson, 2000; Slovic, Finucane, Peters, & MacGregor, 2002; Slovic, Finucane, Peters, & MacGregor, 2004). According to Peters, Lipkus, and Diefenbach (2006), affect can act as an information source, it can cause us to focus our attention on specific information, it can act as a form of common currency by providing a common evaluative system for weighing different values or pieces of information, and affect can motivate information processing and behaviour. In relation to understanding the concepts of risk and benefit, affect accentuates the judgement that risks and benefits are inversely related (Alhakami & Slovic, 1994). Unlike in the real world where high benefits are generally associated with high risks (e.g., financial investments), people perceive that high benefits equate to low risks and

vice versa. For example, experiencing negative affect can lead people to be more attuned to risk information and to adjust their judgements of the benefits of an outcome to be lower (Slovic, et al., 2004). Providing additional positive information about the benefits of a behaviour or stimulus will lead an individual to adjust their perceptions of its risks in a more negative direction such that risks or probabilities of a negative outcome occurring are considered to be greater. People will use their initial affective evaluation to guide the processing of new information (Peters, Lipkus, et al., 2006). Affect can determine whether a decision-maker is more likely to focus on risk versus benefit information.

Affect can stem from a variety of sources and can influence the processing of information in a variety of ways. For example, affect can arise from having had personal experience with a decision, affect can be experienced at the time of a decision or aroused as a result of the decision situation, and affect can be related to feelings that are anticipated to occur following a decision (Peters, Lipkus, et al., 2006). Affect may be particularly relevant to the ways in which men with a family history process information about prostate cancer screening. For example, first-degree relatives are able to draw on their family members' experiences with prostate cancer, an experience that involves a great deal of affect (Erblich, Bovbjerg, & Valdimarsdottir, 2000). As well, being at higher risk of prostate cancer themselves may also involve strong affect in FDRs. Further, FDRs may be exposed to more experiences that invoke affect about prostate cancer; they may experience more frequent and more intense affect; and for these reasons affect may be more salient to FDRs and therefore more likely to be used to guide their decisions compared to men without a family history. In addition, feedback regarding the nature and manageability of a risk can be provided through direct experience, thus amplifying or attenuating the risk (Kasperson, et al., 1988).

Affect can be a valuable tool in decision-making when it allows the decision-maker to reliably anticipate how they will be affected by a particular decision choice (Slovic, et al., 2002). In this regard, affect has been discussed as a judgemental heuristic through which affective information is considered as a basis for guiding judgements. For these reasons, the role of affect and its interaction with motivation and contextual factors in the decision task is discussed in relation to the Heuristic Systematic Processing Model (HSM; Chaiken, 1980) in Section 3.4.3.

3.4.2 The Heuristics and Biases Approach

Prior to examining the HSM in detail and the contextual and motivational conditions that lead to heuristic and systematic processing strategies, two well accepted heuristics deriving from the heuristics and biases approach (Tversky & Kahneman, 1974) are described in detail as to how they relate to FDR decisions. In addition to their application in determining screening decision-making, the availability and representativeness heuristics can account for the influence of personal experience on the construction of risk perceptions. Specifically, these heuristics can help to explain why specific family history characteristics (e.g., the number of affected relatives, perceptions of similarity to affected relatives) are associated with both objective and qualitative assessments of perceived risk. The HSM is then applied to discuss more generally where and why these heuristics are more or less likely to be applied.

3.4.2.1 Availability heuristic. Judgements about probability are influenced by how easily events can be recalled, associated or imagined (Tversky & Kahneman, 1974). People make judgements about risk based on the ease with which instances of an event come to mind (Tversky & Kahneman, 1973). For example, first-degree

relatives of people with cancer have been shown to evaluate the instances of cancer in their family and use this information to construct their risk perceptions and to make judgements about the necessity of screening behaviours (Emery, Kumar, & Smith, 1998; Kenen, et al., 2003). Men with a family history of prostate cancer report higher risk perceptions than men without a family history and men with multiple first-degree relatives with prostate cancer report still higher risk perceptions than men with only one affected relative (Bratt, et al., 2000; Cormier, et al., 2003; Jacobsen, et al., 2004; Miller, et al., 2001; Roumier, et al., 2004). The availability heuristic can lead to bias when reliance on available information to make judgements is misleading. For example, recalling the age of diagnosis of a relative to make judgements about age-related risk may explain Beebe-Dimmer et al.'s (2004) finding that men who are older than their affected relative report lower risk perceptions than men who are younger, despite prostate cancer being more prevalent with age.

The availability of information per se may not necessarily differentiate the use of the availability heuristic in men with a family history of prostate cancer. For instance, Gerend, Aiken, West and Erchull (2004) demonstrated how perceptions of health risks, such as breast cancer risk, can be based on information available from a number of sources. For example, women based judgements of breast cancer risk on the number of friends they identified as having been diagnosed with breast cancer. Montgomery, Erblich, DiLorenzo and Bovbjerg (2003) found that women used both family and friend disease histories to determine their risk of disease. By contrast, men with a positive family history of prostate cancer did not incorporate friend disease histories into judgements of their personal risk. However, women have been found to incorporate more non-health related factors into judgements of their health status (e.g., global versus health-specific negative affect) than do men (Benyamini, Leventhal, & Leventhal, 2000;

Gonzalez, Chapman, & Leventhal, 2002) and this may reflect a gender difference in the sources of information used by men and women in their health assessments. These findings contradict those from a qualitative study by Evans et al. (2007) examining men's experiences of prostate cancer testing in primary care that reported that men referred to their broader social networks including the experiences of friends and media exposure when thinking about prostate cancer screening.

Alternatively, the lack of relationship between friend disease histories and perceived prostate cancer risk may be attributable to the small number of men with a positive family history of prostate cancer included in the Montgomery et al. (2003) study. Further, Montgomery et al. dichotomised family and friend disease histories into positive or negative. Thus, the low sample size when stratified may have reduced the power to detect specifically the degree to which family and friend histories (the number of affected relatives and friends) differentially influence the construction of risk perceptions. However, in combination, the results of Gerend et al. (2004) and Montgomery et al. suggest that men could be making judgements about their personal risk of cancer based on the extent to which they can identify instances of cancer occurring immediately around them.

The accessibility and salience of available information is important for cueing heuristic judgements and it is conceivable that having a family member with prostate cancer may lead to greater ease with which to make associations with regard to prostate cancer. The process by which availability effects may influence judgements is through the ease with which outcomes can be imagined. Imagining the occurrence of an event leads people to make higher probability judgements that the event will occur (Gregory, Cialdini, & Carpenter, 1982). Further, the ease with which events can be imagined influences judgements of likelihood. Asked to consider a disease with symptoms that

are either easy or difficult to imagine, participants rated the likelihood of events to be greatest when symptoms were easy to imagine and to be lowest when symptoms were difficult to imagine (Sherman, Cialdini, Schwartzman, & Reynolds, 1985). Once an event is imagined, the event is more accessible and expectancies in relation to this event may be hard to extinguish (Gregory, et al., 1982; Sherman, et al., 1985). Imagining symptoms and outcomes of prostate cancer are undoubtedly more accessible for family members of men with prostate cancer. Depending on how salient these symptoms or outcomes are for FDRs may influence judgements about the likelihood of developing prostate cancer and the need for screening behaviours.

A family history of prostate cancer can provide a wealth of information to first-degree relatives about prostate cancer as they are more likely to be in close and more frequent contact with affected relatives and they can draw on readily available prostate cancer experiences when making judgements. In-depth interviews with family members of people with cancer show that unaffected relatives appear to adjust their risk according to whether they perceive their family member's disease progression to be stable or deteriorating (Sanders, et al., 2003). Further, higher risk perceptions are reported by first-degree relatives who have family members who are deceased from prostate cancer (Bratt, et al., 2000), suggesting that prostate cancer and mortality are more likely to be associated for these men.

Research has already examined how family members may evaluate the instances of prostate cancer in their families to make judgements about their risk and participation in health behaviours. However, the amount of contact with affected relatives, the frequency of discussions about prostate cancer in the family, and the degree to which prostate cancer risk information is communicated between affected and unaffected relatives are factors that have the potential to influence the availability of information

about prostate cancer for unaffected relatives. The influence of these factors on the use of heuristics to construct risk perceptions and to guide personal screening behaviours will be examined in Chapters 4 and 7.

3.4.2.2 Representativeness heuristic. The representativeness heuristic (Kahneman & Tversky, 1973) is also relevant to judgements about the probability of being at risk of prostate cancer and in guiding screening decisions, and it is argued that this heuristic may play a particularly important role in the judgements of men with a family history of prostate cancer. When making judgements under uncertainty, people tend to base their judgements on information they acquire from a small sample of experiences and presume these to be representative and reliable (Kahneman & Frederick, 2002). The application of the representativeness heuristic to the medical context has been proposed as a way to understand how family members make use of their family history experience to make judgements about personal health behaviours (Rees, Fry, & Cull, 2001). In this regard, the representativeness heuristic can be applied when judgements are made on the basis of stereotypical information and on the similarities a person perceives between their own situation and another's. Both qualitative and quantitative research that examines how people consider their risk of disease suggests that people use the representativeness heuristic as a strategy to make judgements about risk, and can be related to judgements about the need to participate in health behaviours.

For example, smokers have been shown to be unrealistically optimistic about their risks of experiencing a variety of smoking-related diseases such as lung cancer (Williams & Clarke, 1997), regarding themselves as at higher risk than the average person but at lower risk than the average smoker (Strecher, Kreuter, & Kobrin, 1995).

Hahn and Renner (1998) examined smoker's judgements about their personal risk of lung cancer and smoker's cough as well as their perceptions of the average number of years smoking, cigarettes smoked per day, and nicotine content that characterised the typical person at risk of these diseases (e.g., a smoker's personal risk stereotype).

Relative risks of smoking-related diseases were related to smoker's perceptions of their risk stereotype; smokers considered themselves more at risk if their smoking behaviours exceeded those of their risk stereotype and less at risk if their behaviours were favourable in comparison. Unrealistically optimistic judgements about health risks are associated with people comparing their risk behaviours to a target representation of a typical person more at risk than themselves (Helweg-Larsen & Shepperd, 2001).

People make judgements about their personal cancer risk depending on how similar they perceive themselves to be to a referent with cancer. Gerend et al. (2004) found that risk perceptions were predicted by perceived similarities between oneself and a person with cancer and these perceived similarities predicted risk perceptions beyond measures of medical risk and worry. Similarly, the representativeness heuristic may explain why older brothers of men with prostate cancer perceive their risk to be lower than brothers who are younger than their affected sibling (Beebe-Dimmer, et al., 2004) and why sons have higher risk perceptions than do brothers (Roumier, et al., 2004), owing to a lay representation that prostate cancer diagnoses occur to the latter, respectively.

Emery, Kumar and Smith (1998) and Sanders et al. (2003) found similar results using semi-structured interviews to explore how people with a family history of cancer construct risk perceptions. First-degree relatives made reference to similarities and conversely, differences in personality, lifestyle, and the physical characteristics of themselves and their affected relative and used these representations to reinterpret their

personal risk of developing cancer, even when such characteristics were not related objectively to risk. For example, first-degree relatives made statements suggesting that they had lower judgements about their risk if they perceived a lack of similarity between their personality and that of their affected relative (Sanders, et al., 2003). Further, first-degree relatives identified similarities between their affected relatives and other unaffected relatives and suggested that it would be more likely for other family members to develop cancer than themselves: *My surviving brother and I are very similar and my brother who died was different from us physically and by temperament... I don't really consider myself at risk... I regard myself as significantly different from my brother who died and my father* (Emery, et al., 1998, p82). First-degree relatives appear to use a pre-selection strategy (Kessler, Opitz, & Reynolds, 1988) to single out unaffected relatives who are more likely to develop cancer and thus tailor risk information in a way that defends the self by implicating others as more or most likely to be at risk of prostate cancer. If unaffected family members are constructing risk perceptions in this way, the implication for judgements about screening behaviours may not be optimal and may lead men to be either more or less likely to screen based on a biased assessment of the information in their environment. For example, judging oneself to be less likely to get prostate cancer than other unaffected relatives may lead to increased screening behaviour based on a belief that one is less likely (compared to other relatives) to return a positive result.

With respect to decision-making about prostate cancer screening, first-degree relatives may also rely on the experiences of their relatives to make screening decisions. When making decisions that involve ambiguity and uncertainty about decision options, people often refer to other's experiences as a guide for how to approach their own decision. Denberg, Melhado, and Steiner (2006) found that men who were faced with

selecting a treatment for prostate cancer made reference to the treatment preferences of relatives, friends, or strangers with prostate cancer and used these anecdotes as a basis for their personal treatment decisions:

Well, see what happened to my dad [who had prostate cancer], it didn't do him no good... He had the radiation and it went through his body anyway... But my brother just had his prostate removed last year and he is reading 0/0 on his count now and that was over a year now. So I like the results he got, so I feel that's what I'll do. (Denberg, et al., 2006, pg 625-626).

Further, men used other people's experiences to make treatment decisions without taking into consideration the fact that the referents did not necessarily have similar prognoses.

Additional research is needed to clarify how family members of men with prostate cancer refer to and use their relatives' experiences as a basis for constructing their risk perceptions and for guiding screening behaviours. If family members of affected relatives use heuristic reasoning strategies to reinterpret and reduce the salience of their personal prostate cancer risk, they may not make quality decisions about prostate cancer screening based on an adequate understanding of risk information. Further, the extent to which first-degree relatives rely on the experiences of their affected relative to guide their judgements about risk could have important implications for health professionals in how they are to approach informed decision-making about prostate cancer screening with these men. For example, if the salience of a patient's family history plays a role in how they conceptualise their personal risk of prostate cancer, health professionals may need to be sensitive when gathering information about family history from their patient. The conceptualisation of the availability and

representativeness heuristics as heuristic reasoning strategies that guide judgements fits within the decisional approach proposed by the HSM.

3.4.3 The Heuristic Systematic Processing Model

The Heuristic-Systematic Processing Model (HSM; Chaiken, 1980) is a dual-process social psychological theory originally developed to account for the effects of individual, task, and contextual factors on the effectiveness of persuasive messages. The HSM has been applied more broadly to understand the conditions under which people are more likely to dedicate greater effort to processing information to form judgements and make decisions (Chen & Chaiken, 1999). The HSM integrates many concepts discussed in the previous sections including distinguishing between automatic and intuitive processing, acknowledging the role of motivation in determining judgement, and considering the effort one dedicates to processing information to be reflective of goal achievement rather than an indication of rationality. Owing to its roots in social cognition, the HSM considers not only the accessibility and availability of information from prior knowledge structures, but also the contributions of motivation, judgement confidence, cognitive effort, and subjective experience on judgement. Specifically, the HSM considers the interaction between these factors in determining depth of information process, using empirical findings to support these premises.

According to the HSM, systematic processing (cf., System 2) is analytical and comprehensive with decision-makers carefully scrutinising and integrating information to reach judgements, whereas heuristic processing (cf., System 1) relies on existing knowledge structures, simple decision rules, or cognitive heuristics (Chaiken, 1980). Systematic processing is concerned more with the content of information (e.g., quality)

whereas heuristic processing is often associated with source variables (e.g., credibility of the source). Consistent with dual-process models that specify heuristic processing as the default system, the HSM acknowledges the predominance of heuristic cues in judgement and suggests that systematic processing is more likely to be engaged when the decision-maker perceives additional cognitive effort is required to ensure confidence in their judgements.

Consistent with Newell and Simon's (1972) conceptualisation of bounded rationality and the notion that people have limited cognitive resources, the HSM proposes that people are motivated to be economical in the effort they dedicate to judgement. People are more likely to dedicate greater effort to processing information when motivated to be more confident in their judgements. According to the *sufficiency principle* (Chaiken, Liberman, & Eagly, 1989), people exert the amount of information processing effort required to satisfy their processing goals (Jain & Maheswaran, 2000). Specifically, people aim to reduce the gap between their actual level of confidence and their desired level of confidence that they have sufficiently processed enough information to make their judgement (Chen & Chaiken, 1999). That is, if an individual does not believe they are confident that they have enough information to make a judgement (their actual level of confidence) they will continue to process information until they reach their desired confidence level. The larger the gap between actual and desired level of confidence, the more motivated an individual will be to process information and consequently, they will be more likely to process this information systematically. This premise assumes that people consider additional processing will lead them to be more confident in their judgements (Chen & Chaiken, 1999).

The HSM specifies not only under what conditions heuristic and systematic processing are most likely to occur but the model also outlines the process by which

these strategies can co-occur. In addition to having independent effects on judgement, heuristic and systematic processing can co-occur in a number of ways, through: additivity, bias, and attenuation. According to the additivity hypothesis, heuristic and systematic processing can have judgementally consistent, independent contributions on judgement. By contrast, according to the bias hypothesis, heuristic cues may colour the interpretation of subsequent information which may consequently bias the nature of systematic processing. For example, applying the heuristic cue *experts can be trusted* can result in the content of subsequent information provided by an expert to be interpreted to be of higher quality, particularly if the information is ambiguous (Steginga & Occhipinti, 2004). Alternatively, heuristic and systematic processing may work in opposition when implications derived from systematic processing conflict with the influence of those derived from heuristic processing.

Motivation plays an important role in determining the potential discrepancy between actual and desired confidence in judgement. Consistent with Kunda's (1990) motivational reasoning theory, the HSM also describes how different types of motivation can have distinct influences on information processing. Specifically, people are motivated by accuracy, defense, and impression motivations (Chen & Chaiken, 1999). Accuracy motivations are characterised by open-minded and even-handed evaluations of information, and when sufficient cognitive capacity is available and motivation is high more effortful processing may be needed to achieve desired confidence in judgements. For example, decisions that are personally relevant are associated with greater systematic processing and the elaboration of arguments (Chaiken, 1980; Claypool, Mackie, Teresa, Ashley, & Ashton, 2004).

Defense motivations are associated with preserving the self-concept and personal worldviews, and consequently information processing is selective. Heuristics

are applied selectively and, consistent with the bias hypothesis, scrutiny of arguments may be biased. For example, the study conducted by Ditto and Lopez (1992), mentioned in Section 3.3.3, illustrated how people displayed differential processing of preference-consistent and preference-inconsistent information. Further, the HSM specifies that people can be influenced by multiple motives. For example, personally relevant decisions that involve personally threatening information have been shown to increase reliance on biased systematic processing (Giner-Sorolla & Chaiken, 1997; Liberman & Chaiken, 2003). Liberman and Chaiken (2003) examined reasoning about health issues and found that participants who considered information to be both personally relevant and threatening processed information defensively. High relevance participants were less critical of arguments that were reassuring and were highly critical of arguments that were personally threatening. In the context of the screening decision faced by FDRs, risk information has the potential to be personally threatening as they must consider the higher probability that they will develop prostate cancer and it is conceivable that first-degree relatives may therefore process risk information with a motivation to be defensive.

Similarly, ambiguity can bias decision processing when decisions are personally relevant. Steginga and Occhipinti (2004) explored decision-making about treatment for prostate cancer and found that men who were uncertain about treatment decisions used systematic processing to process treatment information. However, when participants found treatment information to be confusing and ambiguous, systematic processing became biased as participants relied on heuristic cues to judge the validity of treatment information (e.g., reliance on the expert opinion heuristic). This finding is consistent with the predictions of the HSM, showing that systematic processing dominates when a decision is personally relevant (e.g., has direct personal consequences for the

individual), but that reasoning becomes biased when information is perceived to be personally relevant but ambiguous (Chaiken & Maheswaran, 1994).

In addition, first-degree relatives may be processing information more, or less systematically based on the potential for prostate cancer screening to be a personally relevant and familiar topic that invokes negative affect and defensiveness motivations. Claypool, Mackie, Teresa, Ashley and Ashton (2004) demonstrate that decisions that are personally relevant and familiar are likely to lead to more systematic processing as familiarity can provide people with additional opportunities for message elaboration. Being familiar with information about prostate cancer owing to a family history of prostate cancer could therefore lead first-degree relatives to process information about prostate cancer screening systematically. In addition, similar to the role of the affect heuristic in reasoning (described in Section 3.4.1), negative affect has been shown to lead to more systematic processing as negative moods decrease desired confidence in judgements and thus increase message scrutiny (Martin, Ward, Achee, & Wyer, 1993; Wegener, Petty, & Smith, 1995).

Further, similar to the conditions for heuristic judgement proposed in Kahneman and Frederick's theory (2002), the use of an heuristic cue depends on the accessibility, availability, and applicability of the cue to judgement (Chen & Chaiken, 1999). That is, the heuristic cue needs to be stored in memory, easily accessible, and be considered relevant to the judgement in order to be applied. People are posited to have different heuristic cues that meet these criteria. For example, people with greater knowledge or experience with an issue will be more likely to generate more applicable heuristic cues to guide their judgements. Men with a family history of prostate cancer may be able to generate more information that is relevant to a judgement about potential risk factors (e.g., based on associations made with respect to their affected relative's cancer) and

apply these to their judgements. Thus, the HSM integrates contextual, task, and motivational factors into consideration and proposes how prior experience and existing knowledge can contribute to decision-making. Specifically, the HSM considers the individual's environment as being influential on the decision-making process and can help to differentiate between those strategies most likely to be in use by men with and without a family history of prostate cancer.

3.4.4 Social Judgement Theory

Similar to Subjective Expected Utility theory, Social Judgement Theory (SJT; Hammond, et al., 1975) considers the process people use to make judgements based on available cues in their environment. However, SJT is a descriptive model that examines how people weigh the importance of information cues in their ecology by sampling the environment, as well as participants. According to SJT, if research is to make generalisations about people's behaviour in their environment, then research needs to take task parameters into account (Doherty & Kurz, 1996). Specifically, SJT considers the decision environment or ecology as equally important to measure as the organism (Cooksey, 1996).

Social Judgement Theory is derived from the work of Egon Brunswik (Brunswik, 1955) and his concept of the Lens Model (see Figure 3.1). According to the Lens Model, cues in the environment represent the true state of an underlying environmental event (Y_e) and, owing to the environment being uncertain, ambiguous, and messy we must examine how people integrate, combine, and weigh these cues (X_i) to ascertain the importance of each cue in judgement (Y_s). In this regard, SJT does not examine rationality but *achievement*, where achievement is defined as the degree to which a person's weighting of cues (e.g., judgements) corresponds to environmental

events. For example, understanding the success of a doctor diagnosing a single patient based on a single combination of symptoms will not allow inferences to be made about his overall achievement in combining symptom cues successfully, or for inferences to be made about the relationship of the symptom cues to his judgement about the prevalence or absence of the underlying disease. Providing a doctor with a representative sample of cases with different combinations of symptoms (e.g., fever versus no fever, fatigue versus no fatigue) however, will allow for generalisations to be made about the importance of different symptoms to judgements about the presence or absence of a disease, as well as give an indication of how successful the doctor was in achieving the correct diagnosis.

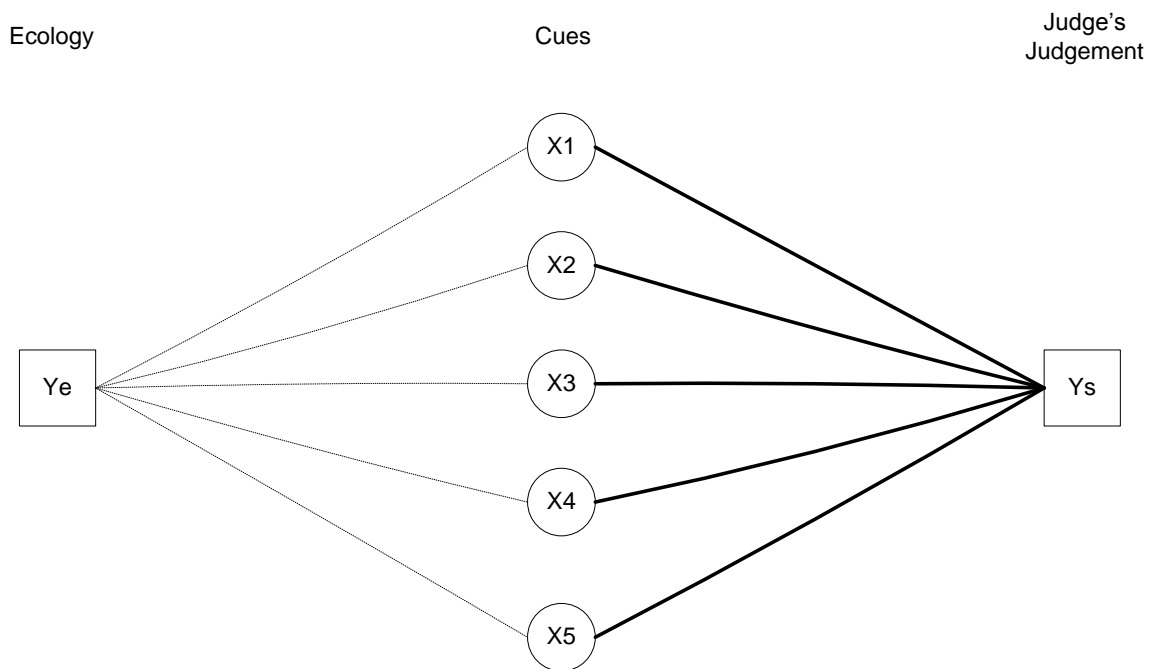


Figure 3.1. Brunswick's Lens Model. Note. From Judgment Analysis: Theory, Methods, and Applications (p. 56), by R. W. Cooksey, 1996, San Diego: Academic Press.

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The theory is based on two key themes: functionalism and probabilism (Brunswik, 1955). According to the principle of functionalism, understanding an organism's behaviour requires an understanding of their ecology and those aspects of the environment the person perceives and responds to in order to achieve their goals. The principle of probabilism recognises that people cannot know with certainty the relationships between judgement cues in their environment, and therefore understanding associations between an organism and their environment needs to be described in probabilistic terms. Accordingly, SJT proposes the methodological consideration of representative design. The environment should be sampled sufficiently to permit statistical generalisation, and the sample of the environment should reflect variations in the natural environment (e.g., realistic cue combinations). For example, the decision environment faced by men considering whether to screen for prostate cancer incorporates screening guidelines that mention cues relating to the presence or absence of symptoms, having a family history, and the consideration of one's age, all of which need to be combined to make a judgement. The principle of representative design proposes that the complete environment of cues (e.g., decision cues incorporated in screening guidelines) should be sampled and combined then judged by individuals within the environment to determine which cues are being used to inform judgements.

When there is uncertainty in the natural environment, such as when the cues mentioned in prostate cancer screening guidelines have an unknown relationship to optimal screening decisions, this reflects a potential for unreliability in judgement. In such cases, a single-system approach (represented by the bold lines in Figure 3.1) to understanding the relationship between cues and judgements can be applied. A single-system approach can examine the integration, combination, and weighting of cues when the goal of the study is to identify value systems or common judgement patterns across

different people and when measuring the criterion (Y_e or the optimal combination of cues for successful screening judgements) is not feasible. Current prostate cancer screening recommendations suggest that men with a family history and men who are of older age should discuss prostate cancer screening with their doctor before making an informed decision about testing, and symptomatic men should consider screening. The appropriate decision to screen for prostate cancer based on these factors is not known and the perspective of men who are likely to be faced with this judgement can provide valuable information about how important men perceive these cues to be to their judgements about prostate cancer risk and screening decisions. For example, FDRs, for reasons of defense motivation, may not consider a family history of prostate cancer as important a cue in making probability judgements about risk or in determining necessity for screening as men without a family history of prostate cancer. These findings could potentially feed directly to informing appropriate informed decision-making approaches that take into consideration the importance of screening recommendations and different risk factors to screening decisions. The further application of SJT to prostate cancer risk and screening judgements is described in detail in Chapter 6.

3.5 Summary and Conclusions

Decision-making is a complex and evolving area of research that has grown from highly logical normative models of how people *should* make decisions, to incorporate descriptive models that describe how people *actually* make decisions. Also, recognition of the roles of motivations, goals, and emotions in guiding judgements has challenged assumptions relating to traditional conceptualisations of rationality. However, the focus on laboratory studies has limited the application of many theories of

judgement and decision-making to explain real world decisions. The current thesis aims to apply multiple approaches to decision-making and judgement to understand the screening behaviours and the construction of risk perceptions for men with a family history of prostate cancer within a real world decision-making environment.

The following chapters apply Subjective Expected Utility theory, the Heuristic Systematic Processing Model and Social Judgement Theory to examine how having a family member with prostate cancer influences the construction of perceptions of risk for FDRs and guides decision-making about prostate cancer screening. Specifically, the current thesis applies the aforementioned theories with the focus on mapping the decisional context faced by FDRs as they make real world judgements about prostate cancer risk and early detection screening behaviours. Methodological considerations focus on the applicability of each of these models to real world decision-making, drawing on both quantitative and qualitative methodologies to achieve this aim. The HSM is applied both in Chapters 4 and 7 using quantitative and qualitative methodologies, respectively. Subjective Expected Utility theory is applied in a modified framework in Chapter 5 utilising a methodology that allows for the examination of the risks, benefits, and utilities men consider to be relevant in their screening decisions. Finally, the policy-capturing methodology (Chapter 6), informed by SJT, is applied to capture the judgement policies of men when considering judgements about prostate cancer risks and screening decisions with a focus on determining whether FDRs weigh informational cues differently to general population men in their policies.

CHAPTER 4

Study 1: Predicting Risk Perceptions and Screening Behaviour using Heuristic Strategies and Family History Contextual Variables

4.1 Introduction

Following the diagnosis of prostate cancer in a family member, first-degree relatives are likely to have additional information available to them about the experience of being diagnosed with and undergoing treatment for prostate cancer (see Chapter 2). Consequently, first-degree relatives may be responding to a different decision-making context where the information they have available about their relative's cancer experience is used to inform their judgements about prostate cancer risk and about undertaking prostate cancer screening. As discussed in Chapter 3, people draw on their personal experiences and prior knowledge when making decisions; make use of easily recalled and accessible information; and make judgements based on how they represent, integrate, and make associations between different pieces of information. Specifically, in complex decision environments, people make use of information from memory or simple decision rules to inform judgements often at the expense of objective statistical or probability information.

The heuristics and biases approach described in Chapter 3 demonstrates how the availability and representativeness heuristics can explain people's neglect of or insensitivity to probability information and how intuitive judgements are often made based on prior knowledge structures (Kahneman & Tversky, 1973; Tversky & Kahneman, 1973, 1974). For instance, although first-degree relatives may rate the probability of their being diagnosed with prostate cancer to be greater than the average man, they may also consider their lack of physical likeness to their affected relative and

judge that the extent of their familial risk is dependent on such factors. In turn, these beliefs may influence decisions about participating in prostate cancer screening. Such decision processes may explain why family history regularly predicts risk perceptions and screening behaviour but why risk perceptions do not consistently predict screening (see Sections 2.4.2-2.4.4).

The finding that contextual family history factors predict the risk judgements and screening behaviours of FDRs (e.g., age of relative at time of diagnosis; see Chapter 2) supports the argument that the availability and representativeness heuristics may be important decision processes through which FDRs make judgements associated with their family history. For instance, basing judgements about risk on a belief that prostate cancer diagnoses occur around the specific age that a relative was diagnosed and reasoning that risk decreases once this age has passed reflects the use of the representativeness heuristic. The current chapter argues that risk perceptions and screening behaviours are associated with family history contextual factors and result in the greater use of the availability and representativeness heuristics.

Accordingly, the present chapter seeks to address two broad aims. First, to examine quantitatively perceptions of risk and screening behaviours as a function of the family context (e.g., with respect to perceptions of a relative's disease prognosis). Second, the study seeks to introduce the heuristic decision strategies of availability and representativeness into a model representing the relationships between family history, risk perceptions, and screening behaviour to better account for the relationships between these variables. Further, the methodology applied in the current study will address criticisms of the measurement of key constructs including prostate cancer knowledge and risk perceptions, as discussed in Chapter 2.

4.1.1 An Integrated Model of the Relationships between Family History, Risk Perceptions and Prostate Cancer Screening Behaviour

Empirical findings from research that examines the risk perceptions and screening behaviours of men with a family history of prostate cancer were summarised in detail in Chapter 2. To restate the general conclusions of the literature review, prior research has generally focused on establishing individual and socio-demographic characteristics predictive of risk perceptions and screening behaviour (e.g., older age, higher income) and these predictors do not differentiate FDRs from men from the general population or demonstrate how heightened-risk information influences judgements for men with familial risk. Further, although prior research has given emphasis to the role of risk perceptions in determining increased screening amongst men with a family history, the evidence does not wholly support the predicted relationship between these variables. Men with a family history of prostate cancer screen more and have greater risk perceptions than do men from the general population, but greater risk perceptions do not necessarily translate to increased screening behaviour (Beebe-Dimmer, et al., 2004; Cormier, et al., 2003; Jacobsen, et al., 2004; Miller, et al., 2001; Sweetman, et al., 2006; Vadaparampil, et al., 2004). Figure 4.1 illustrates these relationships.

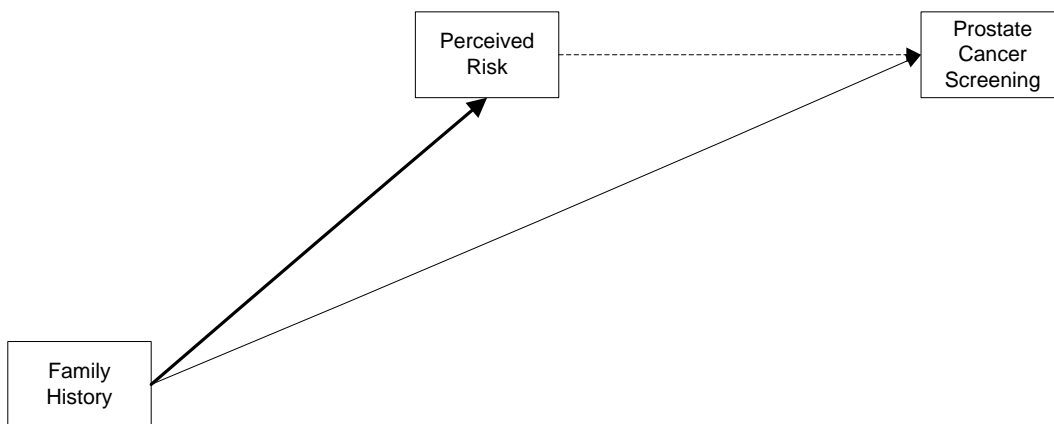


Figure 4.1. Relationships between family history, risk perceptions, and prostate cancer screening. Solid lines represent greater evidence for a relationship as discussed in Chapter 2.

A potential explanation for the indeterminate relationship between family history, risk perceptions, and screening behaviour relates to the way in which risk perceptions are constructed within the judgement environment. When measured, family history characteristics predict both screening behaviour and risk perceptions (Beebe-Dimmer, et al., 2004; Bratt, et al., 2000; Roumier, et al., 2004; Sweetman, et al., 2006) suggesting that the influence of having a family member with prostate cancer on risk perceptions and screening behaviour may be contingent on the specific, perceived circumstances of the family history. Thus, the judgement environment (e.g., the circumstances surrounding an affected relative's diagnosis) plays a role in the construction of risk perceptions and may also influence decisions about participating in prostate cancer screening. Accordingly, to understand the contribution of risk perceptions on prostate cancer screening behaviour for men with a family history,

greater understanding of risk perceptions as a construct and its role in the current decision context is needed.

4.1.2 Risk Perceptions as a Predictor of Health Behaviour

Risk perceptions play a central role in many theories of health behaviour whereby greater perceived risk is believed to motivate greater uptake of preventive health behaviours. As mentioned in Chapter 2, Protection Motivation Theory (Rogers, 1975), and the Health Belief Model (Rosenstock, 1966) posit that risk perceptions are a key determinant of participation in health behaviour. In particular, health behaviour theories such as the Health Belief Model and Protection Motivation theory propose that risk perceptions relate to other constructs and processes that lead to health behaviour, such as threat appraisals (the product of risk and severity perceptions), which in turn predict behaviour. However, despite different health behaviour theories utilising similar constructs (Weinstein, 1993) and positing differing processes for combining constructs to predict health behaviour (e.g., direct and indirect relationships), meta-analyses reveal weak to moderate relationships between the respective constructs of the theories and intentions or behaviour (Floyd, Prentice-Dunn, & Rogers, 2000; Harrison, Mullen, & Green, 1992). As well, these models are not often compared directly and it is not clear which variables are the most influential variables or for which behaviours the theories provide the greatest understanding (Armitage & Conner, 2000; Weinstein, 1993). In a meta-analysis of PMT, Floyd et al. (2000) reported that threat variables (severity and vulnerability perceptions) had stronger relationships with cancer prevention behaviours (compared to other diseases) and that vulnerability perceptions in particular had one of the strongest relationships to cancer prevention in relation to other PMT constructs.

This finding upholds the contention that risk perception is a health behaviour construct that may contribute particularly to the prediction of cancer screening behaviours.

In general, the results of meta-analyses have found that risk perceptions have a small to moderate positive relationship to health behaviour, with stronger relationships for health behaviours that are more controllable (Brewer, et al., 2007; Katapodi, Lee, Facione, & Dodd, 2004; McCaul, Branstetter, Schroeder, & Glasgow, 1996). For instance, Brewer et al. (2007) found risk perceptions had a moderate positive relationship with vaccination behaviour. In relation to cancer screening, Katapodi et al. reported a small but positive relationship between risk perceptions and mammography screening. However, results were confounded by the recruitment site of the sample (e.g., community sample or contact through affected relatives), the measures used to assess risk perception (see Section 2.4.2 for a review), and by interactions with family history (2004). In this connection, McCaul et al. (1996) reported that both having a family history of breast cancer and greater risk perceptions were related to increased mammography screening. However, more complex relationships between family history, risk perceptions, and screening could not be examined owing to the limited number of studies examining all three variables. Risk perceptions appear to play a role in influencing the uptake of health-related behaviours however the relationship is not strong and is related to family history, suggesting that other factors may determine whether risk perceptions will lead to participation in health behaviours.

4.1.3 Risk Perceptions as a Function of the Family Context

A critical process relevant to understanding risk perceptions that is neglected by health behaviour theories is that these theories do not provide an account of how risk perceptions are constructed or how they are modified within the judgement context. For

example, the Health Belief Model proposes that socio-demographic factors contribute to perceptions of vulnerability to health threats (Armitage & Conner, 2000; Rosenstock, 1966), providing little explanation as to how risk perceptions are formulated within a broader context that necessarily includes beliefs and prior knowledge. For instance, a family member who is currently caring for an affected relative may not perceive great urgency in participating in cancer screening despite acknowledging that their relative's diagnosis increases their personal cancer risk. In this connection, qualitative research suggests that risk judgements become more or less salient to family members according to the current circumstances of the affected relative's disease (Walter, et al., 2004). The nature and extent of these relationships has not been explored quantitatively and therefore their contribution to quantitative risk estimates is not known.

4.1.3.1 Evidence from qualitative research. Qualitative research findings associated with the construction and conceptualisation of risk for people with a family history of cancer support the argument that the family context plays a role in judgements of personal risk. People with a family history of cancer relate how aspects of their affected relative's illness affect the salience of their personal risk (Walter & Emery, 2005; Walter, et al., 2004). For example, Sanders et al. (2007) found that people with a first-degree relative with cancer did not necessarily feel concerned or more aware about their own risk of cancer because they were focused on taking care of or thinking about their affected relative. Witnessing a relative's illness and the course of their illness trajectory have been described across a number of qualitative studies as influencing perceptions of personal risk or as contributing to an unaffected family member's acceptance of being at risk (Chalmers & Thomson, 1996; d'Agincourt-Canning, 2005; Gorin & Albert, 2003; Sanders, et al., 2003; Walter & Emery, 2005).

For instance, a prolonged illness or a sudden or silent onset of an illness was described as contributing to unaffected family members' feeling at risk, whereas a perceived stable, uncomplicated illness trajectory or the return to a normal lifestyle for the affected relative following treatment were discussed as being less threatening to one's personal risk (Sanders, et al., 2003; Walter & Emery, 2005):

I think if I'd been really worried about it when my mum first contracted it I think I would have gone to my doctor straight away, but I wasn't. But then maybe you're asking the wrong person because with her she's been fine, she's gone back for regular check ups. I suppose they don't give you the all clear for a long time but she seems fine... (pg 60; Sanders, et al., 2003).

Further, perceptions of personal risk come into focus in response to the anticipated death or the memory of the death of an affected relative (Gorin & Albert, 2003; Sanders, et al., 2003). *I suppose I've never really worried about it. If it's going to happen to me, then it's going to happen... Whereas, if she died of it, I mean, yes I probably would have looked at it very differently, been more anxious about it* (pg 62; Sanders, et al., 2003). These qualitative findings are consistent with the results of quantitative research on first-degree relatives of men with prostate cancer where risk perceptions are greater for men who report having relatives deceased from prostate cancer (Bratt, et al., 2000). Of particular interest in terms of the relationship between risk perceptions and participation in preventive health behaviour, Gorin and Albert (2003) found that first-degree relatives of women with breast cancer who were classified as Normalisers (expressed a lifetime risk of breast cancer to be less than 50%) were more likely than Risk Adopters (lifetime risk greater than 50%) to be prompted to engage in surveillance behaviours in response to their experiences with a relative's cancer or in response to memories of deceased family members. This finding

emphasises how contextual factors relevant to the specific family history experience of a first-degree relative may motivate health behaviour independently of higher subjective risk estimates.

Personal experience with a relative's illness provides feedback to family members about the severity and manageability of the illness, offering an enhanced perspective on one's own capacity to cope with the health risk (Kasperson, et al., 1988). Risk perceptions may be modified in response to perceptions of the illness prognosis, side-effects, and outcomes and thus may be dependent on the relative's illness experience. Experience with an affected relative may serve to increase or attenuate risk perceptions with regard to the perceived seriousness of the illness and its possible trajectory. For these reasons, the specific circumstances of an affected relative's cancer experience provide valuable information to family members to use in judgements about risk, dependent on the particular phase of a relative's illness trajectory.

Further, perceptions about the controllability or manageability of the cancer through an affected relative's screening and treatment experiences may also influence judgements of the effectiveness of preventive health behaviours: *My mum has survived because she was being screened and she pulled through. If she hadn't been, there is no way she would have, and so I suppose I see screening as something positive to do about it* (pg 855; Kenen, et al., 2003). These findings further support the contention that risk perceptions are constructed and modified in response to prior beliefs or representations about cancer that can in turn influence cancer screening behaviours.

Despite persistent finding across qualitative studies that perceptions of a relative's disease experience contribute to the construction of risk perceptions for unaffected family members, these relationships have not been explored quantitatively. Accordingly, the current study aims to measure first-degree relatives' perceptions of

their affected relative's disease experience and apply these to their assessments of prostate cancer risk and screening behaviour. In particular, perceptions of the severity of a relative's cancer, perceived prognosis, and experience of treatment side-effects will be examined. Exploring how the family context influences judgements pertaining to personal risk and prostate cancer screening will provide further understanding of the mechanisms through which family history relates to risk perception and screening behaviour.

4.1.4 Proposed Model Integrating Availability and Representativeness Heuristics

The previous section provides qualitative evidence to suggest that risk perceptions are malleable and are the result of a dynamic process that is influenced by and modified within the judgement environment. In particular, for people with a family history of cancer, risk perceptions are responsive to the perceived experiences of their affected relative. In addition, not only are men with a family history able to draw on their experiences with prostate cancer to inform their judgements but it can be argued that the way in which men use their experiences to inform their judgements is consistent with conceptualisations of the availability and representativeness heuristics. For example, basing judgements about risk factors for prostate cancer on the specific circumstances of a single case (e.g., an affected relative) is indicative of the use of the representativeness heuristic. The following sections integrate the availability and representativeness heuristics into a more comprehensive quantitative model of the relationships between family history, risk perceptions, and screening behaviour to better understand the process by which the family context guides such judgements.

4.1.5 Availability, Risk Judgements and Screening Behaviour

A mechanism through which personal experience with and perceptions of a family member's illness may affect risk judgements and screening behaviour is by increasing the ease with which prostate cancer is imagined or accessible, consistent with the application of the availability heuristic. The availability heuristic is applied when judgements are made based on the ease with which instances or associations come to mind (Tversky & Kahneman, 1973, 1974). Imagining an experience leads people to judge that there is a greater likelihood that the event will happen (Gregory, et al., 1982; Sherman, et al., 1985) and the more vivid the information, the more salient and therefore the greater likelihood that the information will be used in judgements (Borgida & Nisbett, 1977). Recalling relatives who have passed away from prostate cancer may be a more vivid and salient image associated with the experience of prostate cancer than objective statistical estimates of prostate cancer mortality rates. This explanation accounts for the tendency for risk perceptions and prostate cancer screening behaviour to be predicted by knowing relatives who are deceased from prostate cancer (Bratt, et al., 2000).

Judgements of personal risk based on the ease with which one can recall other men who have been diagnosed with prostate cancer illustrates another application of the availability heuristic and explains why greater risk perceptions are found in men who have multiple affected relatives (Beebe-Dimmer, et al., 2004; Bratt, et al., 2000). The following quote provides further evidence for the availability heuristic being applied to judgements about health risks by unaffected family members in terms of ease of recall:

It depends what happens within your family isn't it? [sic] We've only had really one incident of cancer within a large family, so you think your chances are, well, you hope your chances are less really because there's more of us that haven't had it than have

had it (pg 515; Sanders, et al., 2007). This statement demonstrates how a participant judges their chance of developing a particular cancer to be lowered owing to the lack of instances of cancer that they recall to have occurred within their large family. In this regard, the number of family members one recalls as having prostate cancer can contribute to perceptions of personal prostate cancer risk and is consistent with empirical findings where having multiple relatives with prostate cancer increases risk perceptions and prostate cancer screening behaviours in first-degree relatives (Beebe-Dimmer, et al., 2004; Bratt, et al., 2000).

In this connection, the number of friends or acquaintances one knows with prostate cancer may also provide information to men about the prevalence of the disease and therefore contribute to judgements of personal risk of developing the disease. Gerend et al. (2004) applied the availability heuristic quantitatively to understand its relationship to risk perceptions amongst women across a variety of diseases (osteoporosis, heart disease, and breast cancer) and Montgomery et al. (2003) examined whether having friends with a disease influenced risk judgements. Both Gerend et al. and Montgomery et al. found that women incorporated information about the number of friends they knew who were affected by a disease into judgements of their personal risk for that disease.

In addition, greater exposure to news media, speaking to a health professional, or having increased family discussions about prostate cancer may also make prostate cancer risk more salient to men and consequently influence screening behaviour. For instance, Evans et al. (2007) found that men reflected on information about prostate cancer they had heard from the media when discussing their experiences with prostate cancer screening. On the other hand, Gerend et al. (2004) did not find that recent exposure to media communication or having recently received information from a

health professional predicted risk perceptions across diseases. However, Gerend et al. did not examine whether people with a family history of a disease were more likely to have information available about the disease and whether this information had a greater effect on their risk estimates. Having a family member with a disease should lead to increased availability of information about the disease from such sources. For example, physician discussion is a consistent predictor of prostate cancer screening amongst all men (Bloom, et al., 2006; Cormier, et al., 2003; Spencer, et al., 2006). However, having had a family member diagnosed with prostate cancer may prompt health professionals to discuss prostate cancer with first-degree relatives more frequently or to provide additional information to family members. Further, discussions about prostate cancer risk and screening decisions within the family may also be more frequent for first-degree relatives following a family members' diagnosis owing to a greater salience of prostate cancer information deriving from greater contact with or reminders of a relative's cancer.

The availability heuristic is a judgement strategy that has the potential to influence judgements of risk and to prompt screening behaviour across all men. Men may be exposed to information about prostate cancer from health professionals, from the news media, from friends or acquaintances who have been diagnosed with prostate cancer, through discussions about prostate cancer with family members, or during other social interactions. However, men with a family history of prostate cancer are more likely to have greater availability of and more salient information about prostate cancer owing to their experiences with affected relatives. Accordingly, it is proposed that the use of this heuristic strategy will be more likely to inform prostate cancer risk judgements and the screening behaviours for men who have a family history.

4.1.6 Representativeness and Risk Judgements

The representativeness heuristic is also associated with the application of prior knowledge to judgements and accounts for judgements that are made based on a small sample of instances that are presumed to be representative and reliable (Kahneman & Frederick, 2002; Tversky, 1977; Tversky & Kahneman, 1974). Support for the role of the representativeness heuristic in guiding judgements of risk is found across both quantitative and qualitative studies on risk perceptions. The representativeness heuristic has been examined quantitatively by Gerend et al. (2004) to assess the contributions of the availability and representativeness heuristics in guiding women's risk perceptions for osteoporosis, heart disease, and breast cancer. Greater risk perceptions across the diseases were found for women who judged there to be greater similarity between themselves and the typical woman they perceived as getting that disease. In relation to men with a family history of prostate cancer, perceptions of similarity between themselves and an affected relative in terms of personality, lifestyle, and physical appearance or physical characteristics are also available to use as representations of the types of people who get prostate cancer. For example, the following quote from a qualitative study illustrates how a man describes his father and sister who died from the same cancer as representing one another: *Well they both looked very similar and also, like I say, they both died of cancer, presumably in the stomach, and both diabetic. You know, so there is sort of two links there straight away. Plus the looks and the features, eye colouring, fair skin, you know* (pg 516; Sanders, et al., 2007).

Family members also describe the lack of similarities between themselves and an affected relative as a reason not to be concerned about their personal risk: *I'm a different personality to my brother, my brother is an entirely different individual to me. So presumably there is something genetically different between the two of us. Bits and*

pieces must be going in different ways mustn't they? (pg 64; Sanders, et al., 2003). The tendency for unaffected family members to make similarity comparisons with affected relatives is a consistent finding across qualitative studies exploring the understanding of risk perceptions across a variety of diseases (Chalmers & Thomson, 1996; Sanders, et al., 2007; Sanders, et al., 2003; Walter & Emery, 2005; Walter, et al., 2004). In particular, the motivation to find dissimilarities between oneself and an affected relative is a common strategy used to reduce perceptions of personal vulnerability (Chalmers & Thomson, 1996; Sanders, et al., 2003).

Gerend et al. (2004) explored quantitatively whether women agreed that the likelihood of a woman developing a disease was less likely if the women had not been diagnosed with the disease by the current age of the participant, referred to as the absent/exempt principle. Women who reported greater agreement with this principle reported lower risk perceptions (for osteoporosis and heart disease but not significantly for breast cancer). This result explains the finding reported in Chapter 2 that younger brothers perceive themselves to be at greater risk than older brothers owing to a representation that prostate cancer risk is related to the age at which a relative was diagnosed (Beebe-Dimmer, et al., 2004). The following quote from a qualitative study exploring the process of coming to terms with familial risk of breast cancer further supports the application of representativeness in this way: *It was sort of in the 40s where I realised I better start taking a look. I am getting older now. My mom died at 46... that breast cancer thing is coming into focus now* (pg 271; Chalmers & Thomson, 1996).

Consistent with the availability heuristic described in the preceding section, the representativeness heuristic helps to account for the influence of the family context on judgements about prostate cancer risk. However, unlike the application of the

availability heuristic to judgements of risk and screening where family history is argued to be associated with greater availability of information to inform judgements, the representativeness heuristic is anticipated to provide greater comparative information that will allow for stronger relationships with risk perceptions for men with a family history. Specifically, the application of the representativeness heuristic will be more pronounced in men with a family history of prostate cancer owing to greater and more specific information available about affected relative's to make references to and to associate with representations of the type of person who gets prostate cancer.

In light of the above mentioned findings, the following model is proposed (Figure 4.2):

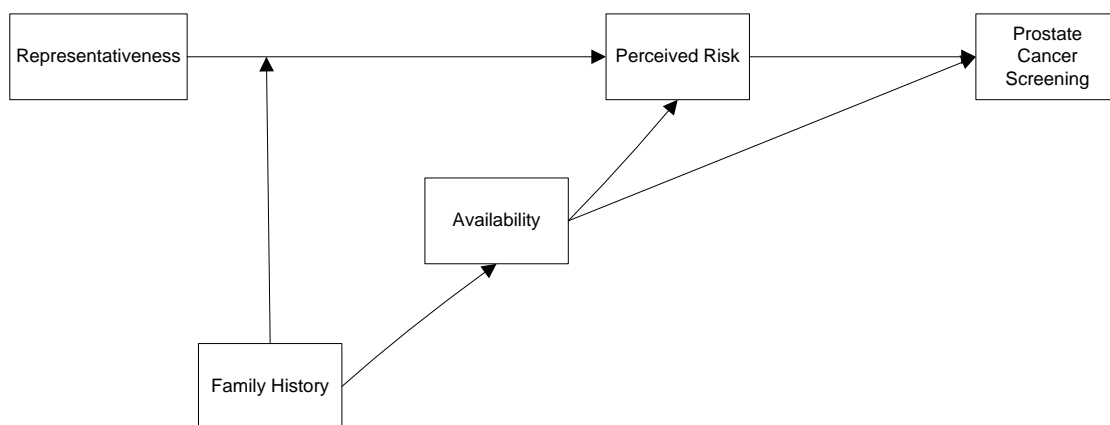


Figure 4.2 Proposed path model of the relationship between family history, perceived risk, and prostate cancer screening integrating representativeness and availability heuristics.

4.1.7 Hypotheses

The current study sought to address a number of hypotheses. Specifically, a key aim of the current study was to map the judgement context experienced by FDRs in relation to prostate cancer such as knowledge about and awareness of prostate cancer screening, the nature of the information received from health professionals, and

satisfaction with screening decisions and compare this with that of men who do not have a family history of prostate cancer (i.e., general population; GP).

In relation to the prostate cancer judgement context, in consideration of the influence of having a family history of prostate cancer on behaviour reported in previous research, the following hypothesis is proposed:

H4.1: First-degree relatives of men with prostate cancer will be more likely than men without a family history to report having spoken to a doctor about prostate cancer and to report that they were the one to first mention prostate cancer to their doctor. Owing to their being very limited research on the nature of prostate cancer discussions with physicians, analyses concerning these variables are exploratory.

Owing to a lack of adequate prostate cancer knowledge assessments in the literature and to a lack of endorsement of prostate cancer screening by medical and statutory bodies related to the considerable uncertainty about the risks and benefits of early detection testing, it is not clear whether greater knowledge will lead to the uptake of prostate cancer screening. Consequently, analyses relating to the influence of prostate cancer knowledge on screening uptake are exploratory.

In relation to the prediction of risk perceptions and screening behaviour for FDRs and GP men, the following hypotheses are proposed:

H4.2: Consistent with prior research on risk perceptions, first-degree relatives will report higher risk perceptions than men from the general population.

H4.3: Consistent with prior research on screening prevalence, first-degree relatives will be more likely to have participated in prostate cancer screening than men from the general population.

In a model including socio-demographic factors (e.g., age, education), urinary symptoms, and screening context variables (e.g., having spoken with a doctor about prostate cancer), and heuristic decision strategies, the following hypotheses are proposed:

H4.4: Consistent with prior research, socio-demographic factors and urinary symptoms will predict prostate cancer risk perceptions for both FDRs and GP men. The availability and representativeness heuristic items will contribute to the prediction of risk perceptions for both FDRs and GP men but will be stronger for FDRs.

H4.5: Consistent with prior research, socio-demographic factors, urinary symptoms and having spoken to a doctor about prostate cancer will predict prostate cancer screening behaviour for both FDRs and GP men. The availability

and representativeness heuristic items will contribute to the prediction of screening behaviour for both FDRs and GP men but will be stronger for FDRs.

Concerning the association between the specific characteristics of a first-degree relatives' experience with a family member's prostate cancer and prostate cancer risk perceptions and screening behaviours:

H4.6: Having a greater number of affected first-degree relatives, greater perceptions of disease severity, a more negative disease trajectory, the perception that an affected relative experienced more negative treatment side-effects, and less time since the relatives' diagnosis will be associated with greater risk perceptions and screening participation for first-degree relatives.

In relation to the application of the availability and representativeness heuristics to understanding the relationships between family history, risk perceptions and screening behaviour, the following predictions are made in accordance with the proposed model (see Figure 4.2):

H4.7: Quantitative measures of the availability heuristic will predict greater risk perceptions and screening behaviour for FDRs compared to GP men.

H4.8: The availability heuristic will mediate the relationship between family history and risk perceptions such that first-degree relatives will report having more available information about prostate cancer than GP men that will in turn predict risk perceptions.

H4.9: The availability heuristic will mediate the relationship between family history and prostate cancer screening behaviour such that first-degree relatives will report having more available information about prostate cancer than GP men that will in turn predict greater screening.

H4.10: The representativeness heuristic will moderate the relationship between family history and prostate cancer risk perceptions such that first-degree relatives will report a stronger association between similarity perceptions and judgements of prostate cancer risk.

4.2 Method

4.2.1 Participants

The present study recruited men with a first-degree family history of prostate cancer and a comparison sample of men from the general population, of which the majority were from Queensland, Australia. Participants were recruited to participate in a Computer Assisted Telephone Interview (CATI) or a semi-structured interview and policy-capturing booklet (VPA). Although the general recruitment processes for the CATI and VPA samples were similar, additional information about the characteristics of the VPA sample will be described in detail in Chapter 6. Funding for the studies was obtained from the Cancer Council Queensland.

4.2.1.1 FDR sample. The FDR sample was recruited through contact with an affected relative (proband) who was participating in ProsCan, a study being conducted

by the Cancer Council Queensland. ProsCan is a longitudinal study examining the effectiveness of a decision support intervention for prostate cancer treatment decision-making and assesses supportive care needs and quality-of-life outcomes for men diagnosed with prostate cancer in Queensland across five years post-diagnosis (Baade, Aitken, Ferguson, Gardiner, & Chambers, 2010; Chambers, et al., 2008). Probands were recruited at the time of their prostate cancer diagnosis from the major tertiary treatment centres in Queensland (centring around Brisbane and Townsville) with the assistance of Urologists from Brisbane, Townsville, and Mackay and in collaboration with 10 major hospitals across Queensland. Compared to all men diagnosed with prostate cancer in Queensland, men recruited through the ProsCan study were more likely to have low or medium risk cancers (i.e., Gleason score of 7 or less; 79.9% versus 72.9%), more likely to be aged under 70 (80% versus 58.2%), more likely to live outside the South-East Queensland corner (51.6% versus 45.9%), and more likely to have a radical prostatectomy (45.0% versus 25.9%; Baade, et al., 2010, P.D. Baade, personal communication, October 12, 2010).

Probands participating in the ProsCan study were contacted post-diagnosis and at 3, 6, 12, 24 and 36 months post-treatment. As the ProsCan men were participating in randomised control trial (RCT) decisional intervention study, contact with probands could only occur during their ProsCan assessment so as to limit the potential for additional contact with participants to influence reported outcomes for the ProsCan study. Consequently, the recruitment process for the contact details of first-degree relatives occurred over a 12 month period commencing April 2008.

Ethical clearance was obtained from eight of the ten hospital ethics committees involved in approving ProsCan to approach probands and ask for their consent to contact their first-degree male relatives to participate in a study to examine decision-

making about testing for the early detection of prostate cancer. One hospital ethics committee did not consent to the contact of unaffected male relatives and the remaining hospital ethics committee requested changes to the FDR study, however, approval from this committee was not pursued owing to the small number of ProsCan men it represented ($n = 4$ for each, respectively). If probands agreed to provide information about their relatives, the proband was asked for further details about their brothers and sons to determine eligibility and for consent to contact eligible relatives. Probands were given the option to discuss the study with their first-degree relatives prior to providing CCQ with permission to contact their relatives. Ethical clearance for the current study was obtained from Griffith University Human Research Ethics Committee (reference number: PSY/D3/07/HREC) and the studies were conducted in accordance with the approved protocol. Participants were eligible for inclusion in the study if they met the criteria presented in Figure 4.3.

- Participant's affected relative was diagnosed prior to 66 years of age as first-degree relatives are considered to be at greater risk when their relative is diagnosed prior to the age of 65 (Johns & Houlston, 2003; Zeegers, et al., 2003);
- The FDR was aged between 40-65 years old as this age range takes into account current cancer screening recommendations (see Table 2.1) as well as maintaining a sample of FDRs who are in a higher risk category;
- The participant not have a prior history of prostate cancer;
- The participant not have a prior history of cancer (excluding non-melanoma skin cancer) as a personal history of cancer may influence responses to interview questions;
- The participant lived within Australia so as to allow for a CATI to be conducted within reasonable business hours and to limit the potential for alternative cancer screening guidelines to be influential on the participant's screening behaviour;
- The participant had self-reported basic English literacy; and
- Permission to contact the FDR was obtained from the affected ProsCan relative.

Figure 4.3 Eligibility criteria for the FDR sample.

There were a total of 343 first-degree relatives who met the eligibility criteria and for whom a minimal amount of contact details were able to be obtained to allow for study assignment. Of these, 293 were allocated to the CATI. Additional eligibility criteria for assignment to the VPA study group required that the FDR lived within 50kms of Brisbane, Queensland and that a related family member was not already allocated to the VPA study (details are described in Chapter 6). Owing to a small proportion of men

meeting the additional eligibility criteria for the VPA study, at six months recruitment the randomisation process was ceased and all first-degree relatives who lived within 50kms of Brisbane (and whose relative was not already assigned to the VPA study) were allocated to the VPA group. Of the 293 men allocated to the CATI, approximately 21% met the VPA study criteria but were randomised to the CATI group prior to the randomisation process being discontinued. There were no significant differences across socio-demographic variables for FDRs assigned to the CATI compared to those assigned to the VPA.

Following study assignment, an information sheet (see Appendix B) and consent form (see Appendix C) were sent to eligible first-degree relatives. First-degree relatives whose address details could not be provided by probands were telephoned to request permission to send information about the study and to get contact details. If consent forms were not returned within two weeks of the date with which they were sent, a CCQ Project Officer called the FDR to confirm correct contact details, provide additional information about the study if requested, answer any questions the participant had about the study, and to request the return of the consent form. If the FDR indicated interest in the study but their consent form was not returned following this phone call, the Project Officer made a reasonable number of additional follow-up calls to the FDR prior to recording the FDR as a passive refusal. Once written consent from an FDR was received, a CCQ Project Officer called the participant to confirm eligibility criteria and to arrange a time to complete the interview. As shown in Figure 4.4, 207 first-degree relatives returned written consent and verbally consented to participate in the CATI at the time of the interview, indicating a 70.6% consent rate.

4.2.1.2 General population sample. An external market research firm was employed to recruit and interview a sample of men from the general population.

Identical eligibility criteria as that used in the FDR sample recruitment, where relevant, was applied to the general population sample. Sampling quotas were applied such that 50% of the sample was recruited from regional Queensland and 50% from metropolitan Queensland. As shown in Figure 4.5, 252 general population men verbally consented to complete the CATI and 239 men completed the interview, indicating a 94.8% consent rate.

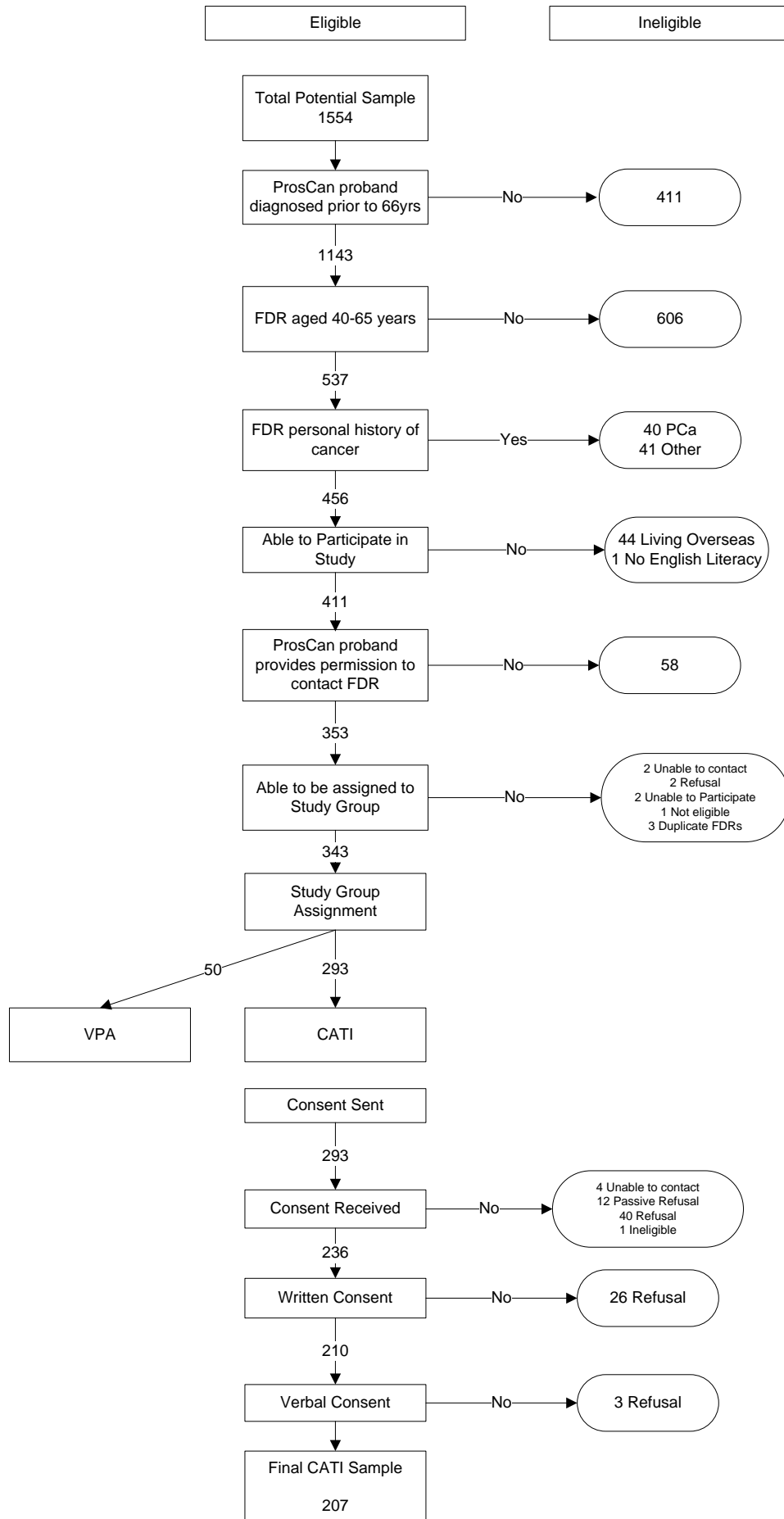


Figure 4.4. FDR sample recruitment flowchart for the CATI studies (Chapters 4 and 5).

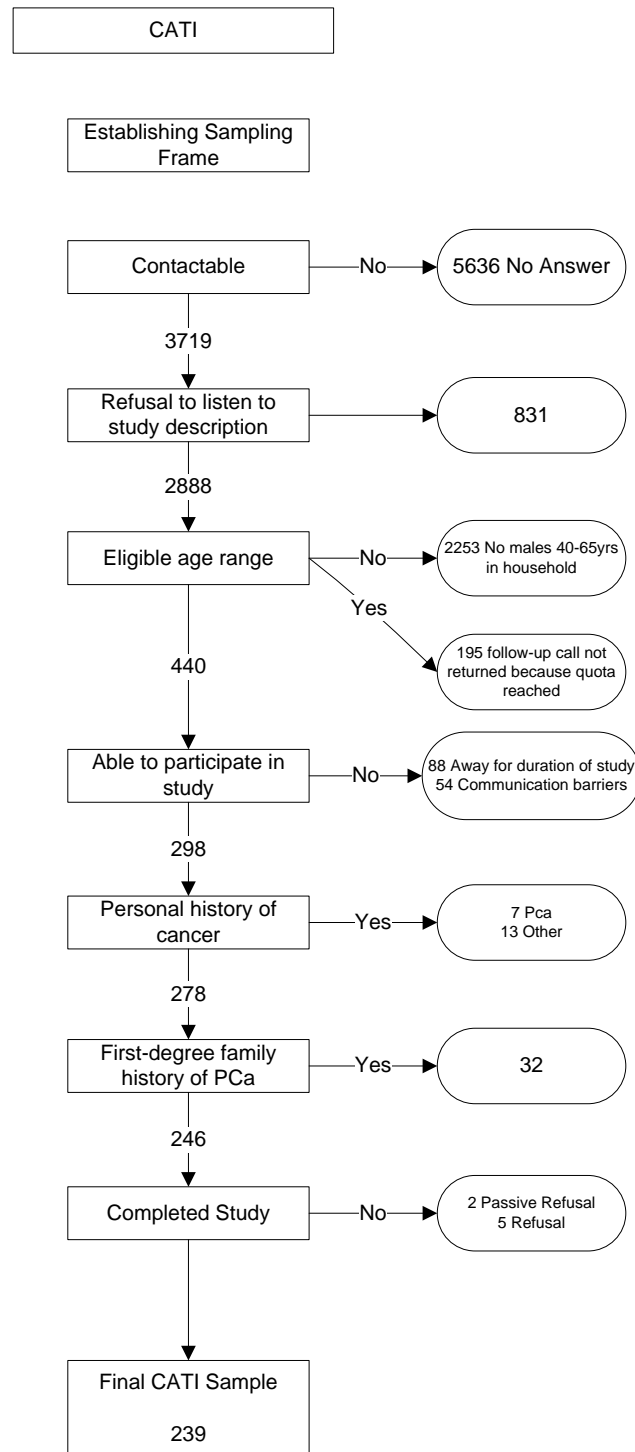


Figure 4.5 General population sample recruitment flowchart for the CATI studies (Chapters 4 and 5).

4.2.2 Materials and Design

Questions in the CATI appeared largely in the order presented below with the exception of some availability and representativeness heuristic items which were included in sections with conceptually similar items so as to enhance the flow of the interview (e.g., the item assessing the number of friends and acquaintances a participant knew with prostate cancer was included at the end of the family history questions).

4.2.2.1 Demographics. The following demographic information was collected from participants at the beginning of the telephone interview: marital status, country of birth, languages spoken, ethnic background, highest level of education, work status, income, smoking status and height and weight information to calculate a participant's BMI.

4.2.2.2 Family history and perceptions of affected relative's cancer experience. First-degree relative participants were asked a series of questions about their family's history of prostate cancer. Participants reported the number of first-degree relatives in their family (e.g., father, brothers, and sons) who had been diagnosed with prostate cancer; at what age their relatives were diagnosed; how long it had been since their relative was diagnosed with prostate cancer; and the number of their first-degree relatives who had passed away from prostate cancer. To assess participant's perceptions of their relative's prostate cancer experience, they were asked to indicate how they thought their relative was going with their cancer (stable, improving, deteriorating, or other); whether they were threatened by their relative's prostate cancer (1 = *not at all threatened* to 5 = *very threatened*); and how they would rate the severity

of the treatment side-effects experienced by their relative (1 = *no side-effects* to 6 = *very severe*). Participant's were also asked to indicate how their relative came to be tested for prostate cancer (*symptoms led him to have a test, no symptoms but requested to have a test, no symptoms but doctor recommended a test, or no symptoms but doctor performed a test as part of a routine check-up*). If the participant reported having more than one first-degree relative who had been diagnosed with prostate cancer they were asked to answer all questions relating to an affected relative with respect to their most recently diagnosed relative. First-degree relatives were also asked to rate their chances of developing prostate cancer in relation to other male relatives in their family (1 = *a lot lower* to 5 = *a lot higher*).

4.2.2.3 Urinary symptoms. The International Prostate Symptom Score (I-PSS; Barry, et al., 1992) is a validated and widely used instrument developed by the American Urological Association to evaluate lower urinary tract symptoms (LUTS). Seven items assess the frequency of urinary symptoms such as straining, urgency, and intermittency of urination, and one item examines quality-of-life pertaining to current urinary function. Internal consistency for the seven symptom items was found to be good ($\alpha=0.73$ across imputed datasets, see Section 4.3.2 regarding treatment of missing data) for the current study.

4.2.2.4 Physician discussion. The extent to which doctors had discussed prostate cancer screening with participants was assessed using a number of items. Participants who indicated that they had spoken to a doctor about testing for prostate cancer were asked: who first mentioned prostate cancer testing (*self* or *doctor*); how much time was spent discussing testing (1 = *we did not spend any time at all* to 5 = *we*

spent a great deal of time); approximately how many minutes the doctor spent discussing testing; and whether the doctor discussed any advantages and any disadvantages of testing for prostate cancer (*yes or no*).

4.2.2.5 *Prostate cancer screening behaviour and intentions.* Prior to the assessment of PSA testing practices participants were read the following statement:

As you might know, there is a blood test that may be used as an indicator for prostate cancer. This test measures a substance in the blood called prostate specific antigen or PSA for short. This blood test, called a PSA test, may be ordered even if a man does not have symptoms.

This passage has been used previously in a study examining men's health (Carmichael, et al.) and was used in the present study to ensure that participants were aware that the blood test used as an indicator for prostate cancer is known as a PSA test. Previous research has shown that a large proportion of men have not heard of a PSA test (Steele, et al., 2000) and the above passage was used to make sure that if participants had had a blood test to check for prostate cancer that they were aware that this test was the PSA test referred to in the subsequent questions.

To ensure a comprehensive assessment of prostate cancer screening practices, past prostate cancer screening behaviour was assessed using multiple response items. Past prostate cancer screening was assessed discretely (e.g., have you ever had a blood test for the purposes of testing for prostate cancer: *yes vs. no*) and continuously (e.g., throughout your lifetime, how many times have you had a blood test for prostate cancer). If the participant indicated they had screened at least once in their lifetime they were asked to indicate the number of PSA tests that were taken within the last two years.

To assess screening frequency participants were asked how often they have a blood test for the purposes of testing for prostate cancer (*more than once a year, once a year, once every two years, once every five years or more, or only had one test*). The reason for the participant's most recent PSA test was assessed with an unprompted item whereby the interviewer coded the participant's response into one of seven categories (e.g., *the doctor suggested you have a blood test for prostate cancer; because you have a family history of prostate cancer; you had urinary symptoms; it was part of a regular or general check-up; wife/partner/family member insisted you get a test; friend suggested you get a test; or other*).

Participants who indicated that they intended to have a blood test for prostate cancer in the future were asked when in the future they intended to have this test (*within the next 12 months, within the next 2 years, within the next 5 years, within the next 10 years*). Participants were also asked if they had ever had a digital rectal examination and if so, whether this examination occurred within the last 12 months.

4.2.2.6 Satisfaction with screening decision. The four-item effective decision-making subscale of the Decisional Conflict Scale (O'Connor, 1995) was used to examine the extent to which men felt informed and were satisfied with their decision whether or not to be tested for prostate cancer. Items were rephrased to be more suitable to administration by telephone (e.g., *I* was replaced with *you*). Further, the phrasing of one item *I expect to stick with my decision* was modified to better convey the meaning of the statement to participants for telephone administration: *You would go for the same choice if you had to do it over again*. The revised item has been used previously within a study examining men's health (Carmichael, et al.). Each item was measured on a 5-point Likert scale (1 = *strongly disagree* to 5 = *strongly agree*). In the

current study, reliability for the Decisional Conflict Scale indicated high internal consistency ($\alpha=0.89-91$ across imputed datasets, see Section 4.3.2).

4.2.2.7 Perceived risk. The assessment of perceived risk in the present study was based on a revision of the four perceived susceptibility measures utilised by Gerend et al. (2004) to assess perceived risk of breast cancer, heart disease, and osteoporosis. Previous research has shown that perceived risk can be influenced by the risk assessment measure (Eibner, et al., 2006; Lipkus, 2007; Mason, Prevost, & Sutton, 2008; Schapira, et al., 2004). This was illustrated in the review of research on men with a family history of prostate cancer cited in Chapter 2, where a large proportion of first-degree relatives overestimated their risk when single-event probability scales were used (e.g., 0-100%; Beebe-Dimmer, et al., 2004; Bratt, et al., 2000; Jacobsen, et al., 2004; Miller, et al., 2001; Schnur, et al., 2006) and underestimated their risk when comparative measures were used (Beebe-Dimmer, et al., 2004; Bratt, et al., 2000; Cormier, et al., 2003; Miller, et al., 2001). To address the potential for risk assessment measures to influence perceptions of risk, Gerend et al. combined three absolute risk measures and one comparative risk measure to form a perceived susceptibility scale and demonstrated that the four items were highly correlated (.59 to .87) and loaded on a single factor (minimum standardised factor loading .720).

Two items assessed absolute risk utilising Likert scales: how susceptible do you think you are to prostate cancer in your lifetime (1 = *not at all susceptible* to 5 = *very susceptible*); and what do you think is the chance that you will develop prostate cancer in your lifetime (1 = *very low chance* to 5 = *very high chance*). Contrary to Gerend et al. (2004), these items were measured on 5-point rather than 6-point Likert scales for consistency across the four risk items. Comparative risk was assessed by asking men to

indicate what they thought their chances were of developing prostate cancer compared to other men their age (1 = *a lot lower* to 5 = *a lot higher*). For FDRs, the present study included an additional comparative risk item assessing perceptions of the participant developing prostate cancer compared to other male relatives in their family and used an identical rating scale to the above comparative risk measure.

Contrary to Gerend et al. (2004), the third absolute risk item used in the present study did not utilise a categorical percentage scale (e.g., 0-100%). Rather, consistent with Lipkus et al.'s (2007) review of the risk communication literature, natural frequencies with the same numeric denominator (for the current study: *1 in 1000, 2 in 1000, 10 in 1000, 50 in 1000, 100 in 1000 or greater*) were used to assess perceived likelihood of the participant developing prostate cancer. Further, risk communicated in natural frequencies facilitates comparisons of risk with minimal cognitive effort for the participant (Lipkus, 2007) and is more easily interpretable than percentage rating scales.

4.2.2.8 Availability heuristic. Two of the items used in Gerend et al. (2004) to examine the availability heuristic were applied in the current study. Participants were asked to report the number of male friends or acquaintances they knew who had been diagnosed with prostate cancer and whether they had received any information on prostate cancer from a doctor or other health professional within the last three months. An additional item was included for examining availability of prostate cancer information and assessed how many times the topic of prostate cancer was discussed with family or friends in the past three months. Three month timeframes were chosen to ensure that the prostate cancer information available to participants was only that which was recently accessible by participants (Peters, McCaul, Stefanek, & Nelson, 2006).

4.2.2.9 Representativeness heuristic. Consistent with the two items measuring use of the representativeness heuristic in Gerend et al. (2004), participants were asked to rate on 5-point Likert scales how similar they perceived themselves to be to the typical man who gets prostate cancer (1 = *very dissimilar* to 5 = *very similar*) and to indicate their agreement with the absent/exempt principle (*Men who have not been diagnosed with prostate cancer by my age are not likely to get it*; 1 = *strongly disagree* to 5 = *strongly agree*). In the current study, FDRs were asked additional questions about perceived similarities between themselves and their affected relative using four separate items. One item asked participants to rate generally how similar they believed they were to their relative with prostate cancer and three items assessed perceived similarity in terms of physical appearance/physical characteristics, personality, and lifestyle (1 = *very dissimilar* to 5 = *very similar*).

4.2.2.10 Prostate cancer knowledge. A revised version of the PROCASE Knowledge Index (Radosevich, et al., 2004) was used to assess prostate cancer knowledge. The PROCASE Knowledge Index is a measure of prostate cancer knowledge covering knowledge on prostate cancer anatomy, efficacy of PSA testing, and treatment, and has been shown to have minimally acceptable reliability and construct and criterion validity (Radosevich, et al., 2004). The 10-item measure utilises a yes/no/don't know response format and has been used previously in a large-scale prostate cancer study undertaken by the Cancer Council Queensland (Carmichael, et al., November 2008). An eleventh item examines knowledge about how many men with abnormal PSA blood test results would have prostate cancer with three statements of which one is true (*most do not have prostate cancer*). Items are scored according to a true/false format with *don't know* responses scored as incorrect. Reliability and validity

data for the revised PROCASE Knowledge index was being assessed at the time the current study was printed and so reliability and validity results from the current study are reported.

4.2.3 Procedure

Following the determination of eligibility criteria, participants were taken through each section of the CATI by the Research Officers at CCQ or the telephone interviewers at the market research firm. Several measures that were unrelated to the current study were incorporated at the end of the CATI (e.g., stress appraisals, prostate cancer-related anxiety) and therefore details of these measures are not described. The interview took approximately 35-40 minutes to complete.

4.3 Results

4.3.1 Data Screening

Data were screened for outliers and checked for violations of basic normality assumptions. Preliminary checks indicated a small number (1-3 cases per item) of extreme values on items where respondents were asked to provide amounts (e.g., *How many times have you discussed prostate cancer with family and friends in the past three months*). To reduce the influence of extreme values on the normality of distributions, extreme values were right-censored at the highest value that fell within the range of the majority of the responses for that item. No multivariate outliers were identified. To facilitate interpretation, participant age was centred at the mean for each analysis, and the number of relatives diagnosed with prostate cancer was centred at one for the FDR-specific analyses.

4.3.2 Treatment of Missing Data

The pattern of missing data was assumed to be Missing at Random (MAR) and multiple imputation was used to treat missing data. Unlike listwise or pairwise deletion, or single imputation techniques (e.g., mean replacement) that can yield biased estimates owing to the underestimation of standard errors and overestimates of parameters, multiple imputation incorporates error based on the variance of parameter estimates across multiply imputed datasets and includes these variances in the calculation of standard errors. In accordance with the recommendations made by Graham (2009) for datasets with large numbers of variables, imputation at the level of whole scale scores was employed where: (a) data were available on more than half the individual variables; (b) when factor loadings for individual items within the scale were similar; and (c) when coefficient alpha reliabilities were high. Further, dummy variables were created for categorical variables with missing data prior to running the imputation model.

Multiple imputation was conducted on the complete dataset that included auxiliary variables that were not relevant to the current analyses but would contribute to the prediction of missing data on relevant variables. A data file containing only those variables with data from both FDR and GP men was used to impute missing data for analyses involving comparisons between the two groups. In total, 25% of variables (including auxiliary variables) contained no missing data, 47% contained missing data for less than 5% of cases, and 9% contained missing data for between 7-13% of cases. The remaining 19% of variables contained missing data owing to skip patterns in the questionnaire and were included in the imputation model so as to preserve hierarchical relationships between variables, but were excluded from analyses involving skipped variables. Further, variables conditional on skip patterns were deterministically imputed as zero for questions where a *no* response was consistent with a zero response

for the subsequent variable (e.g., the item asking how many of the recent discussions about prostate cancer with family and friends were about getting a blood test for prostate cancer). Missing data were not imputed for the items concerning having ever spoken to a doctor about prostate cancer (one missing value), having intentions to have a PSA test in the future (13 missing values) and the item asking participants what prompted their decision to have their most recent PSA blood test (a skip response with 166 missing values) owing to their inclusion in the imputation model resulting in collinearity. Any analysis using these variables was conducted using raw data.

A second file containing only the data for FDR participants was used to impute missing data for analyses involving FDR specific variables (e.g., family history questions). In the FDR file, there were no missing data for 38% of variables, 35% contained missing data for less than 5% of cases, and 5% contained missing data for between 6-22% of cases. Skip patterns accounted for missing data for the remaining 22% of variables. Skip variables were included in the imputation model so as to preserve hierarchical relationships between variables, and imputed values for these variables were excluded from analyses.

Multiple imputation was run in Stata version 11 (*mi impute mvn*) or using Full Imputation Maximum Likelihood (FIML) estimation in AMOS (version 18) and MPlus (version 4), where applicable. For multiple imputation in Stata, ten imputations were run for each data file. Frequency tables and sample descriptives are presented using raw data. Unless otherwise specified, all other analyses are reported for imputed data.

4.3.3 Statistical Analyses

Univariate analyses (chi-square or logistic regression) examined differences between FDRs and GP men on prostate cancer knowledge, urinary symptoms, heuristic

strategies, risk perceptions, and screening-related variables. Owing to chi-square analyses not being supported for multiple imputed data, logistic regression analyses are reported for comparisons made using multiple imputed datasets. Further, owing to multiple imputation, degrees of freedom for error are not always available for F statistics (in such cases, a decimal point is included in the reporting of degrees of freedom). Standard OLS regression analyses explored predictors of risk perceptions and prostate cancer screening for the data comparing predictors for FDRs and GP men. These analyses examined predictors found in previous research as well as the contribution of heuristic strategies to the prediction of perceived risk and prostate cancer screening. The prostate cancer screening outcome measure was the number of lifetime PSA tests reported by participants (those who had never screened reported zero lifetime PSA tests). Prostate cancer screening guidelines suggest annual screening for those men who have made the informed decision to participate in early detection screening and therefore the binary outcome measure of having ever screened was considered to be a weaker indication of *screening* than the continuous outcome measure. Standard OLS regression analyses also examined FDR-specific predictors of perceived risk and screening behaviour using all the predictors analysed in the comparison models except for the item examining *similarity to the typical man* who gets prostate cancer which was dropped in favour of the FDR-specific item examining perceived *similarity to an affected relative* (both similarity variables were highly correlated ($r = .35, p < .0001$) and the research question for this analysis concerned perceptions relating to an affected relative).

Structural Equation Modeling (SEM) was used to test the predicted model of the relationships between the heuristic decision strategies, risk perceptions, and screening behaviour for FDRs and GP men (see Figure 4.2). Structural Equation Modeling allows

for a set of regression equations to be analysed simultaneously such that direct, indirect, and total effects of presumed causal relationships between variables can be examined. Thus, the role of risk perceptions as both a dependent variable (predicted by heuristic strategies) and an independent variable (predicting prostate cancer screening) can be tested within a single path analysis. Estimation of the proposed structural model includes tests of individual parameter estimates as well as overall tests of model fit. Further, SEM allows for comparisons between structural models across multiple samples and tests the stability of models across groups. In this regard, multiple group SEM examines moderation relationships by exploring whether model parameters vary across groups. Specifically, by constraining parameters to be equal across groups (e.g., the relationship between perceived similarity and risk perception), group differences on parameters can be tested and comparisons between the fit of the constrained and unrestricted models reveal whether parameters are equal across the samples.

4.3.4 Sample Descriptives

A total of 446 men (207 first-degree relatives and 239 men from the general population) participated in the Computer Assisted Telephone Interview. The majority of participants were born in Australia, were married or in a defacto relationship, had completed a trade certificate or some form of tertiary education, were employed full-time, and more than half of the sample earned greater than \$60,000 per year (see Table 4.1). The FDR sample was more likely than the GP sample to be older ($F(1,442) = 4.63, p = .032$), to be born in Australia ($F(1, .) = 20.53, p < .0001$) and less likely to identify with a non-British/Scottish/Welsh/Irish ethnicity ($F(1, .) = 9.2, p = .002$). There were no significant differences between the FDR and GP samples on the remaining demographic variables.

Table 4.1
Participant Demographics for the CATI study samples (Chapters 4 and 5).

Demographics	FDR (%) N = 207	GP (%) N = 239
Age	<i>M</i> = 54.00, <i>SD</i> = 7.47	<i>M</i> = 52.49, <i>SD</i> = 7.37
Martial Status		
Never married	19 (9.2)	11 (4.6)
Married/defacto	166 (80.2)	201 (84.1)
Widowed	2 (1.0)	2 (0.8)
Divorced, separated	19 (9.2)	23 (9.6)
COB		
Australia	195 (94.2)	181 (75.7)
New Zealand	3 (1.5)	11 (4.6)
England	4 (1.9)	22 (9.2)
Scotland, Ireland or Wales	1 (0.5)	3 (1.3)
Northern Europe		4 (1.7)
Southern Europe	2 (1.0)	2 (0.8)
Eastern Europe		3 (1.3)
Asia		4 (1.7)
Middle East	1 (0.5)	2 (0.8)
Age arrived in Australia	<i>M</i> = 7.30, <i>SD</i> = 9.22 8 (3.9)	<i>M</i> = 25.10, <i>SD</i> = 14.45 58 (24.3)
Ethnicity		
British/Scottish/Welsh/Irish	146 (70.5)	179 (75.0)
Southern European	7 (3.4)	14 (5.9)
Central/Eastern European	3 (1.5)	8 (3.3)
Northern/Western European	12 (5.8)	21 (8.8)
Indigenous Australian	1 (0.5)	3 (1.3)
South-East Asian		
North-East Asian		
South Asian		5 (2.1)
Middle Eastern		2 (0.8)
Pacific Islander		
Other (more than one response)	38 (18.4)	
Language Other than English (yes)	2 (1.0)	19 (8.0)
Education		
Did not complete/no formal		1 (0.4)
Primary School	13 (6.3)	5 (2.1)
Junior High School	37 (17.9)	37 (15.65)
Senior High School	12 (5.8)	41 (17.2)
Trade or technical cert/diploma	86 (41.5)	99 (41.4)
University/college degree	58 (28.0)	55 (23.0)
Workstatus		
Full-time	145 (70.1)	167 (69.9)
Part-time	11 (5.3)	15 (6.3)
Casual	2 (1.0)	10 (4.2)
Home duties or carer	2 (1.0)	5 (2.1)
Unemployed	1 (0.5)	6 (2.5)
Retired	2 (1.0)	24 (10.0)
Unable to work	13 (6.3)	12 (5.0)
Smoker (yes)	32 (15.5)	45 (18.8)
Household income		
<\$20,000	15 (7.2)	17 (7.1)
\$20-40,000	31 (15.0)	35 (14.6)
\$40-60,000	51 (24.6)	37 (15.5)
\$60-80,000	35 (16.9)	40 (16.7)
>\$80,000	71 (34.3)	93 (38.9)
BMI	<i>M</i> = 27.71, <i>SD</i> = 4.58	<i>M</i> = 28.0, <i>SD</i> = 5.60
Underweight	1 (0.5)	4 (1.7)
Normal	51 (24.6)	49 (20.5)
Overweight	99 (47.8)	118 (49.5)
Obese	56 (27.1)	68 (28.5)

Note. Percentages may not equal 100% owing to missing data.

4.3.5 Family History Characteristics

Over 80% of the FDR sample was recruited from ProsCan men who were brothers and over 40% of FDRs reported that they had a father who had been diagnosed with prostate cancer (see Table 4.2). Almost a third of FDRs reported having multiple affected first-degree relatives and less than 10% of FDRs reported having an affected relative who had passed away from prostate cancer. The majority of first-degree relatives reported that their most recently affected relative had completed their prostate cancer treatment, were perceived to have experienced mild-moderate side-effects as a result of their treatment, and were described by FDRs as being in a stable condition with respect to their cancer progression. Approximately one third of FDRs reported that symptoms led their most recently diagnosed relative to be tested for prostate cancer or that a doctor performed the test as part of a regular or routine check-up. Over one fifth of FDRs did not know how their relative came to be tested for prostate cancer.

4.3.6 Urinary Symptoms

The majority of men reported experiencing only mild urinary symptoms (78%) and less than three percent of participants reported experiencing severe urinary symptoms. There were no significant differences in the severity of symptoms experienced by FDRs and GP men.

Table 4.2

Descriptives for FDR Family History Context Variables.

Variable	FDR (%)
Relationship to ProsCan proband	
Brother	170 (82.1)
Son	35 (16.9)
Maternal half-brother	2 (1.0)
No. first-degree relatives diagnosed with PCa	$M = 1.37, SD = .60$
one	143 (69.1)
two	53 (25.6)
three	10 (4.8)
four	1 (0.5)
No. FDRs who have a relative deceased from PCa	16 (7.7)
Relationships of affected relative/s	
Father	37 (17.9)
Brother/s	122 (58.9)
Father and brother	48 (23.2)
Average age father diagnosed	$M = 69.53, SD = 9.11$ Range (57-99)
Average age brother diagnosed	$M = 57.96, SD = 5.45$ Range (42-78)
Average age difference (yrs) – Father	$M = -18.42, SD = 9.80$ Range (-48-40)
Average age difference (yrs) – Brother (first mentioned)	$M = -.94, SD = 7.31$ Range(-17-55)
Most recently diagnosed relative	
Father	37 (17.9)
Younger brother	54 (26.1)
Older brother	116 (56.0)
Approx months since relative diagnosed	$M = 26.08, SD = 12.97$ Range (3-72)
Perceived phase of treatment of affected relative	
Newly diagnosed	
Undertaking treatment	15 (7.3)
Completed treatment	183 (88.4)
Not having active treatment (e.g., watchful waiting)	3 (1.5)
Perceived progression of affected relative's cancer	
Stable	161 (77.8)
Improving	34 (16.4)
Deteriorating	4 (1.9)
Threatened be affected relative cancer	$M = 1.90, SD = 1.04$
Not at all threatened	95 (45.9)
Slightly threatened	60 (29.0)
Moderately threatened	35 (16.9)
Quite a bit threatened	12 (5.8)
Very threatened	5 (2.4)
Perceived severity relative's treatment side-effects	$M = 3.55, SD = 1.34$
No side-effects	22 (10.6)
Very mild	9 (4.4)
Mild	51 (24.6)
Moderate	57 (27.5)
Severe	32 (15.5)
Very severe	11 (5.3)
How did affected relative come to be tested for PC	
Symptoms led him to have a test	63 (30.4)
No symptoms but requested test	19 (9.2)
No symptoms but doctor recommended test	10 (4.8)
No symptoms but doctor performed as part of check-up	69 (33.3)
don't know	44 (21.3)

Note. $N = 207$. Percentages may not equal 100% owing to missing data and don't know responses.

4.3.7 Prostate Cancer Knowledge

As expected, FDRs and GP men responded correctly on average to less than half of the prostate cancer knowledge items with FDRs responding correctly to a greater number of items than GP men (see Table 4.3). Specifically, FDRs were more likely than GP men to know that loss of sexual function is a common side-effect of prostate cancer treatment ($\chi^2 = 18.10, p < .0001$), that fewer men are likely to die of prostate cancer than heart disease ($\chi^2 = 4.65, p = .031$), that the PSA blood test will not pick up all prostate cancers ($\chi^2 = 4.21, p = .040$), and to know that PSA tests can pick up prostate cancers prior to a man developing symptoms ($\chi^2 = 4.61, p = .032$). By contrast, GP men were more likely than FDRs to correctly identify that most men with an abnormal PSA test result will not have prostate cancer ($\chi^2 = 9.21, p = .002$), although correct responses for this item were generally low amongst both groups. The item requiring participants to report whether they believed PSA tests are of proven benefit to men's health was the most poorly answered item with only 12 participants (2.7%) responding correctly to this item. The Prostate Cancer Knowledge Index had poor reliability ($\alpha=0.37$) in the current study, and iterative deletion of items from the scale did not improve the reliability of the scale to discriminate between respondents with good or poor knowledge. Accordingly, the PCK was not used in any further analyses.

Table 4.3

Frequencies of Responses for Prostate Cancer Knowledge Index (Revised) Items.

PCK Index	FDR (N=207) n (%)	GP (N=239) n (%)
Loss of sexual functioning common Tx side-effect	136 (65.7)	109 (45.6)***
Men more likely to die PCa than heart disease	113 (54.6)	106 (44.4)*
PCa most common cause of urination problems	31 (15.0)	43 (18.0)
Abnormal PSA blood test doctor will recommend biopsy	166 (80.2)	175 (73.2)
PCa is one of the least common cancers among men	183 (88.4)	219 (91.6)
PSA blood test will pick up all prostate cancers	144 (69.6)	144 (60.3)*
All experts agree that men should get annual PSA	52 (25.1)	56 (23.4)
PSA blood tests find PCa before a man develops symptoms	130 (62.8)	126 (52.7)*
Early prostate cancer commonly causes symptoms	80 (38.7)	86 (36.0)
PSA blood tests are of proven benefit to men's health	7 (3.4)	5 (2.1)
How many men with abnormal PSA blood test results have prostate cancer	12 (5.8)	35 (14.6)**
Total Knowledge Score (items 1-10), M(SD)	5.09 (1.62)	4.62 (1.73)**

Note. Complete data was available for all PCK items and analyses are based on raw data. Percentages indicate proportion providing correct response. Don't know responses are coded as incorrect.

* $p < .05$, ** $p < .01$, *** $p < .001$

4.3.8 Physician Discussion about Prostate Cancer

First-degree relatives were more likely than GP men to have spoken to their doctor about testing for prostate cancer ($F(1, .) = 24.96, p < .0001$) but were no more likely to have been the one to mention prostate cancer screening to their doctor.

However, both FDRs and GP men reported that the doctor spent only a small-moderate amount of time discussing prostate cancer testing with them and although more than half of all men recalled the doctor mentioning advantages of prostate cancer testing, less than a fifth of men recalled the doctor mentioning any disadvantages associated with prostate cancer testing (see Table 4.4).

Table 4.4

Descriptives for Prostate Cancer Screening Variables.

Variable	FDR (%) N = 207	GP (%) N = 239
Ever spoken to Dr about testing (yes)	178 (86.0)	154 (64.4)
Who first mentioned testing ^a		
Dr. (vs. self)	46 (25.8)	57 (37.0)
Time spent discussing testing ^a	<i>M</i> = 2.35, <i>SD</i> = 0.74	<i>M</i> = 2.25, <i>SD</i> = 0.72
Did not spend any time at all	13 (7.3)	12 (7.8)
We spent a small amount of time	102 (57.3)	102 (66.2)
We spent a moderate amount of time	54 (30.3)	28 (18.2)
We spent quite a bit of time	6 (3.4)	10 (6.5)
We spent a great deal of time	3 (1.7)	1 (0.7)
Approx how many minutes (M, SD) ^a	<i>M</i> = 4.74, <i>SD</i> = 4.62 range (0-30mins)	<i>M</i> = 6.44, <i>SD</i> = 10.77 range (0-90mins)
Dr discussed advantages of testing (yes) ^a	102 (58.6)	88 (57.9)
Dr discussed disadvantages of testing (yes) ^a	24 (13.6)	29 (19.2)
Ever had a DRE (yes)	135 (65.2)	101 (42.3)
Was DRE performed within past 12mths (yes) ^b	58 (43.0)	35 (34.7)
Ever had a PSA test (yes)	172 (83.1)	118 (49.6)
PSA lifetime total ^c	<i>M</i> = 3.58, <i>SD</i> = 4.28	<i>M</i> = 1.58, <i>SD</i> = 2.83
How many PSA tests past 2 years ^c	<i>M</i> = 1.85, <i>SD</i> = 1.14	<i>M</i> = 1.37, <i>SD</i> = 0.85
At least 1 PSA test in past 2 years ^c	164 (95.3)	107 (90.7)
PSA frequency ^c		
Only had one test	41 (23.4)	34 (28.8)
More than once a year	34 (19.4)	9 (7.6)
Once a year	74 (42.3)	46 (40.0)
Once every two years	20 (11.4)	25 (21.2)
Once every five years or more	4 (2.3)	3 (2.5)
What prompted most recent test ^c		
Dr suggested test	13 (7.4)	14 (11.9)
Family history	83 (47.4)	1 (0.8)
Urinary symptoms	6 (3.4)	12 (10.2)
Regular check-up	61 (34.9)	54 (45.8)
Wife/partner/family member insisted	1 (0.6)	6 (5.0)
Friend/acquaintance suggested	2 (1.1)	3 (2.5)
Other	8 (4.6)	16 (13.6)
PSA intention in future (yes)	203 (98.1)	206 (86.6)
When in future ^d		
Within the next 12 months	185 (91.1)	163 (79.1)
Within the next 2 years	12 (5.9)	28 (13.6)
Within the next 5 years	3 (1.5)	7 (3.4)
Within the next 10 years	1 (0.5)	2 (1.0)

Note. Percentages may not equal 100% owing to missing data and don't know responses. ^aFDR=178, GP=154. ^bFDR=135, GP=101. ^cFDR=172, GP=118. ^dFDR=203, GP=206.

4.3.9 Prostate Cancer Screening

As detailed in Table 4.4, first-degree relatives were more likely than GP men to report having ever had a PSA test ($F(1,443) = 46.04, p < .0001$), to have had a greater number of PSA tests in their lifetime ($F(1,429.8) = 31.26, p < .0001; R^2 = .067$), to have

had a greater number of PSA tests within the past two years ($F(1,286) = 14.94, p < .0001; R^2 = .049$), and to have intentions to have a PSA test in the future ($F(1, .) = 8.21, p = .004$). First-degree relatives were also more likely than GP men to report having had a DRE ($F(1, .) = 23.02, p < .0001$).

4.3.10 Prostate Cancer Screening Decision-Making

Some degree of personal involvement in the decision to order a PSA blood test for prostate cancer was reported by the majority of participants and FDRs reported significantly greater personal involvement than GP men ($F(1,380.1) = 5.0, p = .026; R^2 = .012$; see Table 4.5). Both FDRs and GP men reported high satisfaction across all items relating to their decision to test (or not to test) for prostate cancer and FDRs reported significantly higher satisfaction overall than did GP men ($F(1,414.4) = 10.57, p = .001; R^2 = .024$).

Table 4.5

Descriptives for Decisional Role and Decision Satisfaction Items

Decisional role	FDR (%) <i>N</i> = 207	GP (%) <i>N</i> = 239
Who made decision to order/not to order	<i>M</i> = 3.29, <i>SD</i> = 1.32	<i>M</i> = 2.95, <i>SD</i> = 1.57
Dr made decision entirely on his/her own	26 (12.6)	65 (27.2)
Mostly the Dr	20 (9.7)	18 (7.5)
Dr and you made decision on equal basis	78 (37.7)	51 (21.3)
Mostly you	22 (10.6)	25 (10.5)
You made decision entirely on your own	54 (26.1)	56 (23.4)
Decision satisfaction items (<i>M, SD</i>)		
You are satisfied with the decision	4.39 (0.77)	4.07 (1.04)
You feel you have made an informed choice	4.26 (0.84)	3.94 (1.12)
Your decisions shows what is important to you	4.18 (0.83)	4.07 (0.91)
You would go for the same choice if you had to do it over again	4.25 (0.85)	3.86 (1.26)
Decision Conflict total score (<i>M, SE</i>) ^a	4.23 (0.54)	3.92 (0.07)
	95% CI (4.13-4.34)	95% CI (3.79-4.06)

^a Calculated on imputed data

4.3.11 Risk Perceptions

The four risk perception items were all significantly correlated (see Table 4.6) and demonstrated good internal consistency ($\alpha=0.72-0.73$ across imputed datasets). Similar to the results of Gerend et al. (2004), there was no evidence to suggest that the risk perception items tapped different aspects of perceived risk. Consistent with Gerend et al., a composite of the four risk perception items was created using the Percent of Maximum Possible (POMP) method (Cohen, Cohen, Aiken, & West, 1999). The POMP scoring method involves the linear transformation of scale units to represent the minimum and maximum possible scores for the scale, ranging from 0-100. Relative to other scoring methods, POMP scores are not sample or population dependent and the meaningfulness of results are able to be communicated to other researchers through an easily understandable, common metric (Cohen, et al., 1999). The three absolute risk items and the comparative risk item were included in the multiple imputation model and POMP scores were calculated based on imputed data. First-degree relatives reported greater overall perceived risk ($M = 56.0, SE = 1.59; 95\%CI 52.87-59.13$) compared to men from the general population ($M = 41.0, SE = 1.32; 95\%CI 38.40-43.59; F(1,414) = 53.67, p < .0001; R^2 = .111$).

Table 4.6

Descriptive Statistics for Perceived Risk Scale Items

Item	1	2	3	4	<i>M</i>	<i>SE</i>	95% CI
1. Own prevalence	-				3.12	.09	2.95-3.29
2. Own susceptible	.38	-			2.94	.05	2.84-3.03
3. Own chance	.43	.72	-		2.69	.05	2.60-2.79
4. Direct comparative	.33	.44	.54	-	2.92	.04	2.84-3.01
Total POMP score					47.96	1.08	45.84-50.08

Note. All correlations were significant at $p < .001$ and were based on imputed data

4.3.12 Availability Heuristics

Table 4.7 details responses for availability and representativeness heuristic items. First-degree relatives reported knowing more acquaintances who had been diagnosed with prostate cancer than did men from the general population ($F(1,442) = 13.24, p < .001; R^2 = .029$), and were more likely to have discussed prostate cancer with their family and friends more frequently within the past three months ($F(1,442) = 19.31, p < .0001; R^2 = .042$). However, there were no significant differences between FDRs and GP men in terms of how many of these discussions were about testing for prostate cancer. In addition, only a small proportion of men indicated that they had received information about prostate cancer from a health professional within the past three months and there were no significant differences between FDRs and GP men in relation to this item.

The availability items were not highly correlated ($r = 0.06-.34$) and their reliability as a composite measure was poor ($\alpha = 0.36$ across imputed datasets). Accordingly, the utility of using the three items as a composite measure was examined from a theoretical perspective. The acquaintance item required participants to be aware of available instances of prostate cancer occurring around them and the family/friend discussion item was considered to measure accessibility of prostate cancer information to a greater extent than the item examining the receipt of information about prostate cancer from a health professional. Thus, the acquaintance item and the discussion of prostate cancer with family and friends item were retained as separate but distinct measures of availability.

Table 4.7

Means and Standard Deviations for Availability and Representativeness Heuristics

Variables	FDR (N=207) <i>M (SD)</i>	GP (N=239) <i>M (SD)</i>
<i>Availability Heuristic Items</i>		
Average no. friends/acquaintances PCa	2.13 (3.64) (range 0 – 30)	1.17 (1.78) (range 0 – 11)
PCa info from health professional past 3 mths (yes)	<i>n</i> = 20 (9.7%)	<i>n</i> = 30 (12.6%)
PCa discussion family/friends past 3 months	3.00 (5.23) (range 0 – 50)	1.62 (6.31) (range 0 – 90)
Discussions about PSA testing, specifically	2.18 (3.72) (range 0 – 25)	1.66 (3.63) (range 0 – 30)
<i>Representativeness Heuristic Items</i>		
Absent/exempt principle ^a	1.61 (0.63)	1.85 (0.81)
Similar typical man	3.57 (0.82)	3.47 (1.01)

^a Lower scores indicate greater disagreement with the absent/exempt principle. This item was reverse scored for analyses.

4.3.13 Representativeness Heuristic

There was no significant difference between ratings of perceived similarity to the typical man who gets prostate cancer between FDRs and GP men. However, FDRs were significantly more likely to disagree with the absent/exempt principle ($F(1,433.9) = 12.49, p < .0001; R^2 = .166$). The two representativeness heuristic items were not correlated ($r = .07$) and their reliability as a multi-item measure was poor ($\alpha = 0.09-0.17$ across imputed datasets). Of the two representativeness heuristic items, the perceived similarity item was chosen as most representative of the heuristic from a theoretical level and was used in the structural equation model (see Section 4.3.16).

4.3.13.1 FDR-specific items. More than half the FDRs perceived themselves to be similar to their most recently diagnosed relative generally (see Table 4.8). In terms of perceived similarity relating to physical appearance/characteristics and personality, approximately half the participants rated themselves as being similar to their affected relative whereas two thirds of FDRs rated their lifestyle to be dissimilar to that of their affected relative. In this regard, an inverse distribution was present for the perceived similarity variables, indicating that participants generally rated themselves as being either similar or dissimilar to their affected relative. Responses for these variables were dichotomised (the proportion of FDRs using the *neither similar or dissimilar* category was low, between 6.3-12.1% of responses, and these respondents were included in the dissimilar category). In terms of the chance of being diagnosed with prostate cancer compared to other male relatives in the family, almost three quarters of FDRs perceived their personal chance of being diagnosed with prostate cancer to be about the same as that of other male relatives in their family.

Table 4.8

Descriptives for FDR-Specific Heuristic Items

Variable	<i>M (SD)</i>	<i>N (%) Similar</i>
Similar to relative - General	3.46 (1.16)	126 (60.9)
Similar to relative - Physical characteristics	3.26 (1.28)	113 (54.6)
Similar to relative - Personality	3.02 (1.19)	97 (46.9)
Similar to relative - Lifestyle	2.75 (1.22)	79 (38.4)
Chance compared to other male relatives	2.89 (0.62)	

Note. *N* = 207. Means and standard deviations based on raw data. Percentages based on dichotomised variables.

4.3.14 Comparative Analyses for Predictors of Risk Perceptions and Screening

Behaviour

Prior to testing the structural equation model for the relationships between heuristic strategies, risk perceptions and screening behaviour across FDR and GP samples, standard OLS multiple regression analyses were run to explore multivariate predictors of perceived risk and prostate cancer screening. Analyses were run on the imputed datasets. The FDR and GP samples were treated as separate populations such that OLS regression analyses were run on each group separately to examine the contribution of predictors across each sample. Socio-demographic variables, urinary symptoms, physician discussion, and heuristic strategies were included in each analysis. For the prediction of prostate cancer screening, perceived risk was included as a predictor.

4.3.14.1 Predictors of perceived risk. Results from the multiple regression analyses for FDRs and GP men are presented in Table 4.9. Men who experienced greater urinary symptoms and men who perceived greater similarity between themselves and the typical man who gets prostate cancer reported greater risk perceptions in both the FDR and GP samples. In addition, for the FDR sample, men with tertiary education reported greater risk perceptions than did men who were educated up to junior high school. In contrast to previous research, increasing age was associated with decreasing risk perceptions for the FDR group. In relation to the availability heuristic, risk perceptions for FDRs and GP men were influenced by different availability items. For FDRs, reporting a greater number of recent discussions about prostate cancer with family and friends was associated with higher risk perceptions. However, for GP men, knowing more acquaintances with prostate cancer was associated with higher risk

perceptions. For the GP sample, the overall model was significant ($F(19,210.4) = 2.59$, $p < .001$) and explained 20.9% of the variance in risk perceptions. For FDRs, the model explained 28.9% of the variance in risk perceptions and was significant ($F(19,183.5) = 3.78$, $p < .0001$)

4.3.14.2 Predictors of prostate cancer screening. The outcome measure for prostate cancer screening was the total number of PSA tests men reported having had in their lifetime. The results from the analysis are presented in Table 4.9. The overall model for the GP sample explained 31.7% of the variance in screening behaviour and was significant ($F(20,209.9) = 4.41$, $p < .0001$). For FDRs, the model explained 31.3% of the variance in screening behaviour and was significant ($F(20,182.8) = 4.08$, $p < .0001$). Predictors of greater lifetime PSA testing were similar for FDRs and GP men. Consistent with prior research, screening behaviour increased with age for both FDRs and GP men, and knowing a greater number of acquaintances with prostate cancer was associated with greater screening. For the GP sample, having spoken to a doctor about prostate cancer was associated with increased screening behaviour. Perceived risk was not a significant predictor of prostate cancer screening for either sample.

Table 4.9

Predictors of Risk Perception and Screening (by Group)

Variable	Risk				Screening			
	FDR		GP		FDR		GP	
	Coef (SE)	95% CI	Coef (SE)	95% CI	Coef (SE)	95% CI	Coef (SE)	95% CI
Constant	-1.49 (16.65)	-34.34 – 31.37	6.16 (10.63)	-14.84 – 27.15	-1.02 (3.18)	-7.27 – 5.26	-2.10 (1.51)	-5.10 – .90
<i>Socio-demographics</i>								
Age‡	-.63 (0.22)**	-1.07 – -.20	.14 (0.21)	-.27 – .56	.27 (0.04)***	.19 – .35	.09 (0.03)**	.04 – .157
Marital status ^a	-1.93 (3.78)	-9.38 – 5.53	.21 (3.85)	-7.40 – 7.82	.59 (0.71)	-.81 – 1.99	-.47 (0.51)	-1.48 – .54
Ethnicity (non-British)	.06 (4.32)	-8.48 – 8.60	-.30 (3.41)	-7.06 – 6.46	-.41 (0.83)	-2.06 – 1.24	-.01 (0.43)	-.85 – .84
Education – Senior high ^b	10.56 (6.91)	-3.08 – 24.20	-3.08 (4.44)	-11.85 – 5.69	-1.14 (1.29)	-3.68 – 1.40	-.24 (0.59)	-1.41 – .93
Education – Trade Cert ^b	7.31 (3.79)	-.17 – 14.79	-4.32 (3.83)	-11.89 – 3.25	.07 (0.72)	-1.34 – 1.48	-.72 (0.51)	-1.73 – .29
Education – Tertiary ^b	13.81 (4.21)**	5.49 – 22.12	-.48 (4.51)	-9.39 – 8.43	1.28 (0.80)	-.31 – 2.87	.03 (0.61)	-1.17 – 1.22
Income \$20-39,999 ^c	-2.97 (6.93)	-16.66 – 10.71	.41 (5.88)	-11.23 – 12.05	1.59 (1.26)	-.89 – 4.08	.48 (0.86)	-1.23 – 2.18
Income \$40-59,999 ^c	-2.15 (6.43)	-14.85 – 10.55	5.74 (5.74)	-5.60 – 17.07	1.21 (1.19)	-1.15 – 3.56	-.07 (0.85)	-1.77 – 1.62
Income \$60-79,999 ^c	-.15 (6.89)	-13.76 – 13.46	3.87 (6.11)	-8.22 – 15.97	.77 (1.26)	-1.72 – 3.26	1.15 (0.85)	-.53 – 2.83
Income \$80,000+ ^c	.42 (6.60)	-12.61 – 13.45	9.19 (5.84)	-2.38 – 20.75	1.29 (1.23)	-1.14 – 3.73	1.27 (0.84)	-.42 – 2.95
Urinary Symptom total	1.06 (0.30)**	.46 – 1.65	.74 (0.26)**	.23 – 1.25	.01 (0.06)	-.11 – .13	.04 (0.04)	-.03 – .11
Smoke (no)	-3.37 (4.09)	-11.44 – 4.69	-.77 (3.45)	-7.57 – .04	.40 (0.77)	-1.12 – 1.91	-.66 (0.45)	-1.56 – .24
COB (not Australia)	4.30 (6.44)	-8.41 – 17.01	-.60 (3.51)	-7.55 – 6.35	.12 (1.21)	-2.26 – 2.51	.18 (0.44)	-.68 – 1.05
Spoken to Doctor PSA (no)	3.45 (4.43)	-5.29 – 12.20	2.85 (3.03)	-3.13 – 8.83	.83 (0.82)	-.79 – 2.45	.77 (0.42)	-.06 – 1.60
<i>Representativeness heuristic</i>								
Similar to typical PCa	7.77 (1.82)***	4.18 – 11.36	4.30 (1.49)**	1.34 – 7.25	-.10 (0.37)	-.84 – .63	.11 (0.19)	-.27 – .48
Absent/exempt principle†	2.41 (2.36)	-2.26 – 7.08	2.31 (1.75)	-1.15 – 5.77	.13 (0.44)	-.74 – 1.00	.40 (0.25)	-.11 – .90
<i>Availability heuristic items</i>								
No. acquaintances with PCa	-.58 (0.62)	-1.80 – .63	1.57 (0.77)*	.05 – 3.09	.28 (0.12)*	.06 – .51	.32 (0.11)**	.11 – .54
No. discussions about PCa	1.06 (0.39)**	.30 – 1.82	.06 (0.45)	-.83 – .947	-.06 (0.07)	-.20 – .09	-.03 (0.06)	-.14 – .09
Received info from HP (no)	4.36 (5.19)	-5.88 – 14.61	3.72 (3.99)	-4.15 – 11.58	1.10 (0.97)	-.81 – 3.01	1.47 (0.54)**	.41 – 2.53
<i>Perceived Risk</i>								
Model	$R^2 = .289$		$R^2 = .209$		$R^2 = .313$		$R^2 = .317$	

Note. Reference category for binary variables shown in parentheses. ^a reference category is never married/divorced/widowed. ^b reference category is no greater than junior high school. ^c reference category is < \$20,000. † reverse coded so higher scores indicate greater representativeness. ‡ centred at mean for each sample. * $p < .05$, ** $p < .01$, *** $p < .001$.

4.3.15 FDR Prostate Cancer Experience Analyses

Standard OLS multiple regression analyses examined predictors of perceived risk and prostate cancer screening for first-degree relatives for variables related to an affected relative's prostate cancer experience and perceptions of similarity to the affected relative. Owing to the large number of FDRs with multiple affected relatives, the age difference between FDRs and an affected relative was not included as a predictor of risk perceptions or screening behaviour (a separate analysis was run including an age difference variable calculated for those FDRs who had only one affected relative ($n=143$) and although the coefficient was in the predicted direction, it was not significant). To examine the additional contribution of the FDR-specific prostate cancer experience factors, these variables were included in addition to the variables considered in the comparative analyses described above. The analysis was run on multiply imputed data using a data file containing FDR specific items and excluding data pertaining to men from the general population sample. Outcome variables were the perceived risk composite score and the number of lifetime PSA tests.

4.3.15.1 Perceived risk. As shown in Table 4.10, the overall model was significant ($F(36,164.5) = 4.10, p < .0001$) and accounted for 48.7% of the variance in risk perceptions. Consistent with the comparative analyses, decreasing age and having greater urinary symptoms were associated with risk perceptions. Prostate cancer experience variables added to the prediction of risk perceptions. Specifically, first-degree relatives who reported a greater number of relatives who had been diagnosed with prostate cancer and who perceived their relative's cancer as more threatening reported greater perceptions of risk. In relation to perceptions of similarity between themselves and their most recently diagnosed relative, ratings of similarity (in general)

predicted perceived risk, and men who considered themselves to have an increased chance of being diagnosed with prostate cancer compared to other male relatives in their family reported higher risk perceptions. More specific items relating to ratings of similarity according to physical appearance, personality, and lifestyle were not associated with risk perceptions. Also, with the inclusion of prostate cancer experience variables education was no longer significant and the availability item concerning the number of recent discussions about prostate cancer with family and friends was also no longer significant. It is conceivable that prostate cancer experience variables were explaining some of the variance associated with having recently discussed prostate cancer with family and friends. Correlations between the prostate cancer experience variables and the amount of recent discussions about prostate cancer with family and friends were explored and revealed that perceived threat, chance related to other male relatives, the number of relatives with prostate cancer, and the prostate cancer phase and progression variables were all significantly correlated with recent discussions about prostate cancer.

Table 4.10

Predictors of Risk and Screening Including FDR-Specific Variables

Variable	Risk Perception		Screening	
	Coef (SE)	95% CI	Coef (SE)	95% CI
Constant	1.28 (18.40)	-35.07 – 37.65	-5.07 (3.72)	-12.42 – 2.28
<i>Socio-demographics</i>				
Age‡	-.71 (0.32)*	-1.35 – -.08	.28 (0.07)***	.153 – .42
Marital status ^a	-3.02 (3.60)	-10.14 – 4.10	.81 (0.73)	-.62 – 2.24
Ethnicity (non-British)	-.82 (4.41)	-9.57 – 7.93	.47 (0.89)	-1.29 – 2.23
Education – Senior high ^b	-3.26 (6.66)	-16.41 – 9.90	-2.42 (1.37)	-5.12 – .27
Education – Trade Cert ^b	1.61 (3.65)	-5.61 – 8.83	-.20 (0.75)	-1.68 – 1.29
Education – Tertiary ^b	7.77 (4.08)	-.29 – 15.83	1.02 (0.85)	-.66 – 2.70
Income \$20-39,999 ^c	-8.27 (6.51)	-21.14 – 4.59	.73 (1.32)	-1.88 – 3.34
Income \$40-59,999 ^c	-4.64 (6.11)	-16.72 – 7.45	.97 (1.23)	-1.47 – 3.41
Income \$60-79,999 ^c	-4.69 (6.62)	-17.78 – 8.40	.55 (1.36)	-2.15 – 3.25
Income \$80,000+ ^c	-6.21 (6.33)	-18.74 – 6.32	.93 (1.26)	-1.56 – 3.41
Urinary Symptom total	.67 (0.29)*	.09 – 1.25	-.03 (0.06)	-.16 – .09
Smoke (no)	-6.42 (3.79)	-13.92 – 1.07	.24 (0.78)	-1.29 – 1.78
COB (not Australia)	.36 (6.40)	-12.29 – 13.00	.43 (1.29)	-2.12 – 2.98
Spoken to Doctor PSA (no)	1.80 (4.38)	-6.88 – 10.47	1.15 (0.86)	-.54 – 2.84
Perceived Risk			-.01 (0.02)	-.04 – .03
<i>Representativeness heuristic</i>				
Absent/exempt principle†	2.34 (2.27)	-2.14 – 6.83	.10 (0.46)	-.81 – 1.00
Similarity to relative – general	7.68 (3.33)*	1.11 – 14.25	-.80 (0.71)	-2.20 – .59
Similarity to relative – physical	.20 (3.07)	-5.86 – 6.26	.24 (0.63)	-1.01 – 1.48
Similarity to relative – personality	-5.12 (3.19)	-11.42 – 1.17	.11 (0.67)	-1.21 – 1.43
Similarity to relative – lifestyle	.50 (3.41)	-6.23 – 7.23	.18 (0.70)	-1.20 – 1.55
<i>Availability heuristic items</i>				
No. acquaintances with PCa	.59 (0.58)	-.56 – 1.74	.59 (0.12)**	.12 – .59
No. discussions about PCa	.04 (0.38)	-.72 – .80	.04 (0.08)	-.28 – .02
Received info from HP (no)	-2.06 (5.00)	-11.94 – 7.82	.79 (1.02)	-1.23 – 2.81
<i>Relative experience</i>				
Chance compared other relatives	9.58 (2.45)***	4.74 – 14.42	1.29 (0.53)*	.24 – 2.33
Treatment phase – completed ^d	-10.03 (6.07)	-22.05 – 1.98	.05 (1.19)	-2.31 – 2.41
Treatment phase – No active ^d	-10.99 (15.20)	-41.03 – 19.05	4.40 (3.12)	-1.74 – 10.54
PCa progression – improving ^e	3.98 (3.92)	-3.77 – 11.74	.71 (0.81)	-.89 – 2.32
PCa progression - deteriorating ^e	-11.01 (10.49)	-31.74 – 9.73	-2.21 (2.10)	-6.35 – 1.93
Recent diagnosed - younger brother ^f	8.80 (16.15)	-23.17 – 40.77	.44 (3.14)	-5.75 – 6.64
Recent diagnosed - older brother ^f	11.03 (15.71)	-20.10 – 42.17	-.01 (3.01)	-5.96 – 5.93
Relationship – brother ^f	-6.35 (16.46)	-39.02 – 26.31	-2.42 (3.10)	-8.54 – 3.69
Relationship - brother & father ^f	-7.37 (15.82)	-38.81 – 24.06	-1.39 (2.94)	-7.19 – 4.40
Number relatives PCa‡	7.18 (3.51)*	.24 – 14.12	1.33 (0.73)	-.10 – 2.76
Months since relative's diagnosis	.21 (0.11)	-.01 – .43	.02 (0.02)	-.03 – .06
Perceived Tx side-effects	1.48 (1.22)	-.95 – 3.92	.06 (0.23)	-.39 – .51
Perceived threat	3.35 (1.50)*	.39 – 6.30	.70 (0.31)*	.09 – 1.32
Relative's deceased from PCa	9.26 (6.15)	-2.90 – 21.41	1.42 (1.26)	-1.06 – 3.90
Total Model	$R^2 = .487$		$R^2 = .407$	

Note. Reference category for binary variables shown in parentheses. ^a reference category is never married/divorced/widowed. ^b reference category is no greater than junior high school. ^c reference category is < \$20,000. ^d reference category is undertaking treatment. ^e reference category is stable. ^f reference category is father. †reverse coded so higher scores indicate greater representativeness. ‡centred variables. * $p < .05$, ** $p < .01$, *** $p < .001$

4.3.15.2 Prostate cancer screening. The results for the regression analysis are presented in Table 4.10. The overall model was significant ($F(37, 163.8) = 2.95, p < .0001$) and accounted for 40.7% of the variance in amount of prostate cancer screening. In addition to age and the number of acquaintances FDRs knew who had prostate cancer found to be predictors in the comparison analyses described above, two prostate cancer experience variables predicted increased screening behaviour. First-degree relatives who perceived that they had a greater chance of being diagnosed with prostate cancer compared to other male relatives in their family and perceiving a relative's cancer to be more threatening was associated with increased screening behaviour. There was a trend for the number of first-degree relatives with prostate cancer to lead to increased screening behaviour but this was not significant ($p = .068$).

4.3.16 Structural Equation Models

Two approaches were employed to examine the relationships between family history, risk perceptions, screening behaviour, and the heuristic strategies. The application of two approaches to the analysis of the proposed model allowed for the most complete examination of moderation and mediational pathways in the model. A multiple-group SEM focused on the moderation of similarity on risk perceptions by FDR status by conducting separate analyses for FDR and GP groups and examining whether allowing the path between similarity and risk perceptions to be unconstrained across groups improved model fit. Owing to the correlation between product terms and first-order predictors, using product terms to examine moderation effects is associated with lower power and multiple-group SEM is amenable to detect moderation effects for a binary moderator. However, because FDR status is the grouping variable in this analysis, mediational pathways could not be examined. To examine mediation

analyses, a second SEM analysis incorporating FDR status as an independent variable predicting the two mediator variables was conducted. A product term accounting for proposed moderation effect was included in the analysis. The stability of results across models further supported the results of each analysis. The focus of the second model was on the mediation pathways and therefore details of the moderation are not described.

4.3.16.1 Moderation using multiple-group SEM. Means, standard errors, and correlations between model variables are presented in Table 4.11. Multiple-group SEM using Amos (version 18) compared the relationships between heuristic decision strategies, risk perceptions, and screening behaviour across FDRs and GP men (see Figure 4.6). Specifically, the constrained model (Model A, not shown), whereby the path coefficient between perceived similarity and risk perceptions was constrained to be equal across FDR and GP groups was compared to the unrestricted model (Model B) where all paths could vary across groups. In both models, covariances between the heuristic strategies were included to account for effects of these variables on one another.

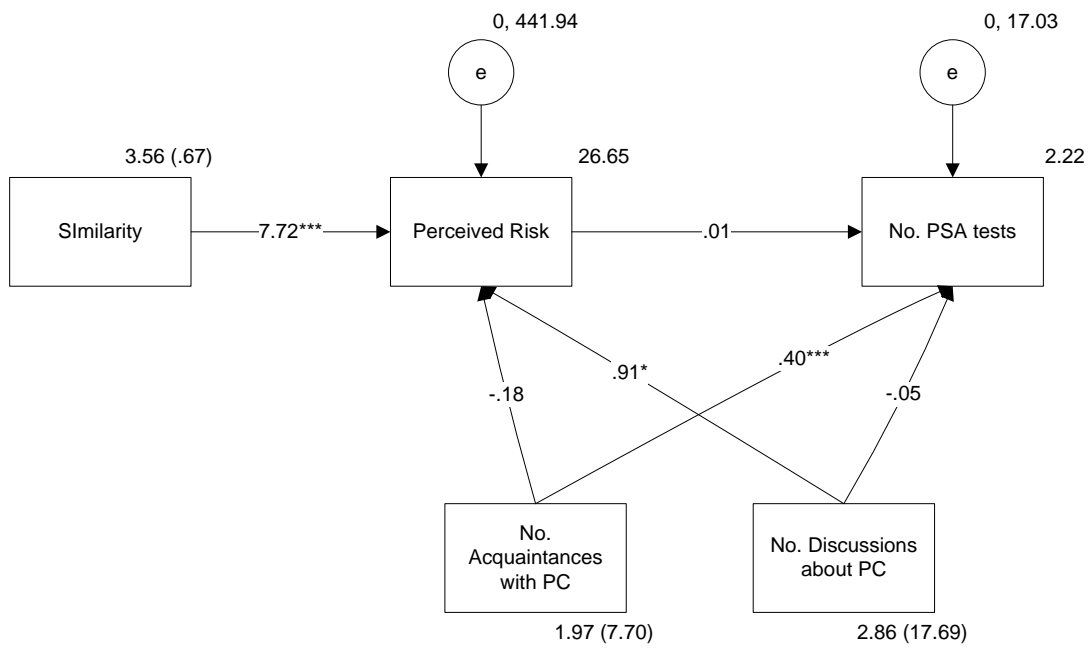
Table 4.11

Correlation coefficients, means and standard deviations for the SEM

Item	1	2	3	4	5	<i>M (SE)</i>	95% CI
GP							
1. Similarity	-					3.45 (.07)	(3.32-3.59)
2. Acquaintance	.13	-				1.17 (.12)	(.94-1.40)
3. DiscussionsFF	.15	.15	-			1.34 (.20)	(.96-1.73)
4. Perceived Risk	.22	.25	.13	-		40.99 (1.32)	(38.40- 43.60)
5. Screening	.05	.33	.11	.24	-	1.61 (.19)	(1.24-1.99)
FDR							
1. Similarity	-					3.57 (.06)	(3.45-3.68)
2. Acquaintance	.10	-				1.97 (.19)	(1.58-2.35)
3. DiscussionsFF	.10	.41	-			2.86 (.29)	(2.28-3.44)
4. Perceived Risk	.27	.08	.20	-		56.00 (1.59)	(52.87- 59.13)
5. Screening	.06	.25	.07	.07	-	3.54 (.30)	(2.95-4.13)

Model fit was determined by a non-significant chi-square and examination of additional fit indices, the Comparative Fit Index (CFI, >.90), Tucker-Lewis Index (TLI, >.90), and the Root Mean Square Error of Approximation (RMSEA, <.06). Model A was not an adequate fit of the data, indicated by chi-square ($\chi^2 = 4.65$, $df = 3$, $p = .200$) and according to other fit indices (CFI = .99; TLI = .86; RMSEA = .04). Model B was associated with a non-significant chi-square ($\chi^2 = .542$, $df = 2$, $p = .763$) indicating an improvement in fit between the constrained Model A and the unconstrained Model B (CFI = 1.00; TLI = 1.19; RMSEA = .00). The improvement in model fit by allowing the path coefficient for similarity perceptions and perceived risk to vary across FDR and GP groups (χ^2 difference test = 4.10, $df = 1$, $p < .05$) suggest that this relationship is moderated by FDR status.

(a)



(b)

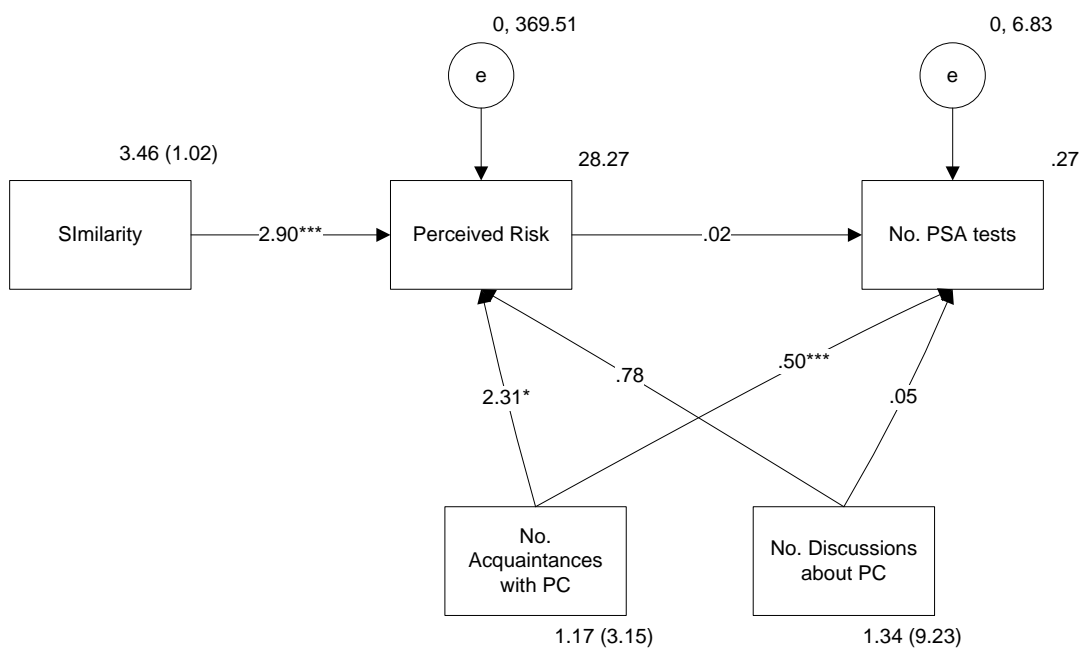


Figure 4.6. SEM parameter estimates for the unconstrained model for (a) FDRs and (b) GP samples. Correlations between predictor variables are not shown.

The path coefficient for the relationship between similarity perceptions and perceived risk was greatest in the FDR model where a stronger relationship was observed. Comparing the explanation of risk perceptions and screening behaviour in the FDR and GP groups, the variables explained 11.4% and 9.6% of the variance in perceived risk, and 6.5% and 14.0% of the variance in screening behaviour, respectively.

Not all paths for Model B were significant for the FDR or GP group. Specifically, the relationship between risk perceptions and screening behaviour was not significant in either group. The only significant predictor of screening behaviour was the number of acquaintances men knew with prostate cancer predicting screening behaviour for both FDR and GP models. Further, whereas the number of discussions with family and friends (during the past 3 months) predicted risk perceptions for FDRs, this variable did not predict risk or screening in the GP model. Rather, the number of acquaintances GP men knew with prostate cancer predicted perceived risk. Mediation pathways were explored in the following analysis.

4.3.16.2 Mediation analysis. A structural equation model incorporating FDR status as an independent variable regressed on the two mediator variables was conducted. The predicted moderation of similarity and risk perceptions by FDR status was incorporated in the analysis to account for its variance by using the product term, however specific results pertaining to this analysis are not reported in detail as they were described in the previous analysis. Consistent with the multiple-group SEM, residual correlations between heuristic variables (and the product term) were incorporated in the analysis. A nonsignificant chi-square ($\chi^2 = 4.17, df = 4, p = .383$) and other fit indices (CFI = 1.00; TLI = 1.00; RMSEA = .01) indicated better model fit

compared to the independence model. The model explained 17.6% of the variance in risk perceptions and 15.0% of the variance in screening behaviour. As recommended by Preacher and Hayes (Preacher & Hayes, 2008), mediation was tested using bias corrected bootstrapping (5000 samples) to obtain estimates of parameters and confidence intervals.

Direct effects for perceived risk. Perceived risk was predicted by greater similarity to the typical man who gets prostate cancer (estimate = 3.30, 95%CI .32-6.23) and the greater number of recent discussions about prostate cancer (estimate = .79, 95%CI .24-1.40). Although approaching significance, the interaction between FDR status and similarity on risk perceptions was not significant (estimate = 4.21, 95%CI -.63-8.92) and the inclusion of the interaction term in the model made the relationship between FDR status and risk perceptions non-significant.

Indirect effects for perceived risk. First-degree relatives reported having significantly more acquaintances with prostate cancer (estimate = .80, 95%CI .37-1.26) and having had a greater quantity of recent discussions about prostate cancer (estimate = 1.52, 95%CI .82-2.22). In relation to mediation relationships, the total indirect effect of FDR status on risk perceptions was significant (estimate = 1.69, 95%CI .76-2.89). This effect was explained by the significant specific indirect effect of FDR status on recent discussions about prostate cancer (estimate = 1.20, 95%CI .37-2.45). The specific indirect effect of FDR status and the number of acquaintances with prostate cancer on risk perceptions was not significant.

Direct effects for screening behaviour. Consistent with the multiple-group SEM, screening behaviour was predicted by the greater number of acquaintances with prostate cancer (estimate = .42, 95%CI .22-.65) as well as FDR status (estimate = 1.46, 95%CI .69-2.22). Risk perception was not a predictor of prostate cancer screening.

Indirect effects for screening behaviour. For the relationship between FDR status and screening behaviour, the total indirect effect of FDR status on screening behaviour was significant (estimate = .31, 95%CI .10-.57) and was explained by the significant specific indirect effect of FDR status on the number of acquaintances with prostate cancer (estimate = .34, 95%CI .15-.60). The specific indirect effect of FDR status and the number of discussions about prostate cancer on screening behaviour was not significant.

4.4 Discussion

The aim of the current study was to examine the contribution of heuristic reasoning strategies to the prediction of risk perceptions and prostate cancer screening behaviour and to compare the differential use of these strategies by FDRs and men from the general population. Specifically, the role of family history in leading to greater use of the availability and representativeness heuristics was predicted to account for greater explanation of risk perceptions and prostate cancer screening for FDRs compared to GP men. The proposed model (see Figure 4.2) was largely supported such that a greater relationship between similarity perceptions and perceived risk was found for FDRs than for GP men. Further, although the number of acquaintances men knew who had been diagnosed with prostate cancer predicted screening behaviour for both groups, a relationship with risk perceptions was found only for GP men. Rather, the number of discussions men had had with family and friends within the past three months predicted risk perceptions only for FDRs. The number of acquaintances with prostate cancer mediated the relationship between FDR status and screening behaviour but not risk

perceptions, whereas the number of recent discussions about prostate cancer mediated the relationship between FDR status and risk perceptions but not screening behaviour.

For the FDR group specifically, perceived similarity to an affected relative predicted risk perceptions as did ratings of the chance of developing prostate cancer compared to other unaffected male relatives in the family. However, contrary to hypothesis 4.6, only a few family history experience factors predicted risk perceptions and screening behaviour for first-degree relatives. Despite finding support for a number of predictors of both risk perceptions and prostate cancer screening, in no analysis was risk perception a predictor of screening. Possible explanations for and implications of these findings are discussed in the subsequent sections.

4.4.1 Family History as a Predictor of Risk Perceptions and Screening Behaviour

Consistent with previous research, men with a family history reported greater prostate cancer screening behaviour than did men without a family history and this finding supports more recent, population-based studies (Jacobsen, et al., 2004; Shah, et al., 2007; Spencer, et al., 2006). The screening prevalence rate for FDRs was one of the highest reported in prior research (see Table 4.4) with more than 83% of FDRs having had participated in at least one PSA test in their lifetime compared to approximately 50% of GP men. However, studies that recruit FDRs from their probands tend to report greater screening rates than population based studies (Shah, et al., 2007; Spencer, et al., 2006), likely a result of selection bias. Nevertheless, a strength of the current study is the comprehensive assessment of screening behaviour which will allow for greater comparisons of screening behaviour to be made across studies.

Despite the high rates of screening reported in the current sample, findings related to the prostate cancer screening decision context suggest that men may not be

making informed decisions about participating in screening and that having a family history of prostate cancer does not alter this decision context. First-degree relatives were more likely to report having ever spoken to a doctor about prostate cancer screening. However, having spoken to a doctor about prostate cancer screening was a predictor of screening behaviour only for GP men. Physician discussion is a predictor of screening behaviour in prior research (Cormier, et al., 2003; Han, Moser, & Klein, 2006; Jacobsen, et al., 2004; Slevin, Donnelly, Clarkson, English, & Ward, 1999; Steele, et al., 2000; Weller, et al., 1998). However, FDRs appear to make their decisions about screening based on additional factors independent of having spoken to a doctor, whereas for GP men speaking to a doctor is a key factor that determines screening.

Both FDRs and GP men reported that the doctor spent only a small-to-moderate amount of time discussing testing (between 4.7-6.4 minutes on average) and less than a fifth of respondents recalled the doctor discussing disadvantages associated with early detection screening. Despite these findings, both FDRs and GP men reported high satisfaction with their screening decisions and considered themselves to have made an informed choice. Whether or not the advantages and disadvantages of prostate cancer screening were actually discussed with men during the medical consultation, the small proportion of men who recalled having these discussions with their physician has important implications for public health initiatives. For instance, health professionals may consider the information too complex for patients and may therefore avoid discussing the disadvantages or alternatively, the complexity of the information may be too great for patients who select to focus entirely on the advantages of prostate cancer screening and disregard other information. In this regard, decisions about prostate cancer screening may not be based on an informed and balanced understanding of the

risks and benefits of screening. If research is to explore the process by which men make decisions about prostate cancer screening in light of uncertainties about the benefits of early detection and the influence of family history on this process, a greater understanding of what occurs during the screening consultation may be needed.

The lack of knowledge about prostate cancer and screening was evident in the results from the Prostate Cancer Knowledge Index where, on average, FDRs and GP men answered only half of the items correctly. The Prostate Cancer Knowledge Index has generally been used in the context of examining improvements in knowledge following prostate cancer screening decision aids and interventions (e.g., McCormack, et al., 2009; Partin, et al., 2004) and the one study examining knowledge of general population men in Ireland reported higher rates of knowledge (mean score 7.5; Hevey, et al., 2009) than the current study. However, the poor reliability of the measure in the current study means that the results from this index are unable to be taken as an indicator of prostate cancer knowledge. Although the PCK index incorporated assessments of the risks, benefits, and uncertainties of screening, unlike previous measures (Cormier, et al., 2003; Pruthi, et al., 2006; Ross, et al., 2005), the consistent lack of prostate cancer assessments to produce a reliable indicator of prostate cancer knowledge (Radosevich, et al., 2004) suggests that the knowledge construct may not be an appropriate assessment of the information that men are aware of and are using in their prostate cancer screening decisions. However, improvement in knowledge resulting from exposure to decision aids reduces participation in PSA testing (O'Connor, et al., 2009).

The aim of decisional interventions for prostate cancer screening (e.g., decision aids) is to improve values-based decision-making and to reduce decisional conflict while improving knowledge about the risks, benefits, and uncertainties of health

decisions and to examine the outcome on health behaviours (O'Connor, et al., 2009; O'Connor, et al., 2003). However, the majority of men in the current study are making decisions about prostate cancer screening in a medical context that does not appear to involve adequate discussion of the issues pertaining to screening. An alternative approach to examining whether knowledge about prostate cancer informs their screening decisions is to investigate the reasons men give for participating in prostate cancer screening which may be a better indicator of the information that is most salient at the time of decision-making.

Consistent with previous research, men with a family history of prostate cancer reported greater risk perceptions than did men without a family history (Jacobsen, et al., 2004; Miller, et al., 2001; Schnur, et al., 2006; Taylor, et al., 1999). Similar to assessments of screening prevalence, the measurement of perceived risk in the current study was also designed to facilitate comparison of risk perceptions across studies and to reduce the potential for risk perceptions to be affected by response format. Specifically, a multiple item measure assessed perceived risk using both absolute and comparative items that were linearly transformed to convey scores in relation to the minimum and maximum total possible scores for the scale (Cohen, et al., 1999; Gerend, et al., 2004). This more comprehensive measure of perceived risk demonstrated that FDRs do consider their personal risk of developing prostate cancer to be greater than that reported by men without a family history. These findings largely support previous research suggesting that men with a family history acknowledge their increased risk of developing prostate cancer and are more likely to participate in prostate cancer screening compared to GP men.

However, in contrast to many theories of health behaviour (see Chapter 2), the current study found no relationship between risk perceptions and screening behaviour

across any of the analyses. Risk perceptions are not associated with prostate cancer screening behaviour for men with or without a family history of prostate cancer. This finding supports the argument put forward in the introduction of the current chapter that decision processes may influence the relationship between risk perceptions and the decision to participate in prostate cancer screening. By contrast, alternative decision processes may be guiding screening behaviour and these processes may occur independently of risk perceptions.

4.4.2 The Role of Heuristic Strategies in Forming Risk Judgements and Predicting Screening Behaviour

Heuristic reasoning strategies appear to contribute to the construction of risk perceptions and determine participation in prostate cancer screening behaviour. Men from the general population referred to the number of acquaintances they knew with prostate cancer to inform both their risk judgements and to determine their screening behaviour. In terms of the use of the availability heuristic, it is conceivable that men from the general population, not having any relatives with prostate cancer, would refer to the instances of prostate cancer occurring around them to make judgements about prostate cancer risk and health behaviours.

The number of acquaintances FDRs knew with prostate cancer informed their decisions about screening but did not influence judgements of risk. Rather, first-degree relatives used the number of discussions they had about prostate cancer with their family and friends over the past three months to inform risk perceptions. This finding is still consistent with the use of the availability heuristic whereby people make judgements about screening based on the ease with which instances or associations come to mind. Greater accessibility of conversations pertaining to prostate cancer was

associated with greater perceptions of personal risk of developing prostate cancer. Having affected relatives with prostate cancer influenced the number of discussions FDRs had about prostate cancer and the frequency of these conversations appear to have made thoughts about the likelihood of developing prostate cancer more accessible to FDRs. The mediation of FDR status and risk perceptions by recent discussions about prostate cancer further supports this argument.

Further, supporting hypothesis 4.10, the use of the representativeness heuristic informed judgements about personal risk for FDRs more than it did for GP men. Greater perceived similarity to the typical person who gets prostate cancer was associated with increased risk perceptions for both FDRs and GP men, but risk perceptions increased more for FDRs in relation to similarity perceptions. Having a family history of prostate cancer exposes unaffected relatives to a type of person who gets prostate cancer and reference to this person may lead to judgements of similarity being more associated with perceptions of personal vulnerability.

This explanation is supported by the finding that in the FDR-specific analysis perceived similarity to an affected relative was associated with risk perceptions. A general rating of perceived similarity to an affected relative was associated with increased risk perceptions, however, more specific items relating to physical characteristics, personality, and lifestyle were not. This finding is in contrast to those from qualitative research whereby unaffected relatives compare themselves in terms of physical appearance, personality, and lifestyle characteristics to their affected relative to make judgements about their likelihood of being diagnosed with the cancer. A potential explanation for this finding is that FDRs may be better able to make global evaluations of similarity to their affected relative whereas more specific items may be more difficult to associate with personal risk. It is possible that more specific items may be difficult to

relate to actual risk factors (or an FDR's beliefs about risk factors) and therefore a more global evaluation encompasses perceptions of the likelihood that the FDR will develop the cancer of a relative who is generally similar to themselves in ways that cannot be quantified in a CATI assessment.

Consistent with previous research, the number of affected relatives an FDR had with prostate cancer predicted risk perceptions (Beebe-Dimmer, et al., 2004; Bratt, et al., 2000). Prostate cancer risk increases when an FDR has multiple affected relatives and increased risk perceptions in this regard are an accurate judgement. However, there was only a trend for the number of affected relatives with prostate cancer to predict screening behaviour, suggesting that the greater number of affected relatives in the family is associated with judgements about risk but not necessarily screening. Rather, the number of acquaintances with prostate cancer predicted screening behaviour for first-degree relatives and was found to mediate this relationship. First-degree relatives appear to increase their screening behaviour in response to greater prostate cancer diagnoses occurring outside their immediate family. This result contradicts that of Montgomery et al. (2003) where knowing friends with cancer did not contribute to the prediction of risk perceptions for men with a family history of disease once accounting for the influence of family history.

The influence of prostate cancer diagnoses in friends and acquaintances on screening behaviours suggests that a broader look at the first-degree relative's social network could provide some insight as to why social relationships predict participation in screening behaviour independent of family history. Although FDRs recognise that greater diagnoses of prostate cancer in the family increases personal risk of developing prostate cancer, they may refer to the behaviours of those in their social network to influence their personal health behaviours. This argument is consistent with the results

of Christakis and Fowler (2007) who examined the person-to-person spread of obesity and found that there was a 57% increase in the chance that an individual would become obese if they had a friend who became obese within a given interval. Family members are not necessarily in greater contact with each other than are members of a social group and a social group generally contains those people who an individual seeks contact with, for example through having similar interests. In this regard, social group members may be considered more similar to an individual in terms of lifestyle or personality and greater contact with social group members may therefore exert greater influence on beliefs, attitudes, and behaviours of the individual. Further, peer pressure to participate in prostate cancer screening following the diagnosis of a friend or acquaintance may be greater in social groups where there is greater contact with and exposure to the circumstances of a friend's cancer experience. The influence of social networks on the health behaviours of its members may provide further explanation for the pattern of predictors of prostate cancer screening and should be explored in future research.

4.4.3 The Contribution of Family History Experience

Contrary to hypothesis 4.6, few family history experience factors were associated with risk perceptions or with screening behaviour. Perceptions of a relative's illness experience did not affect ratings of personal risk nor did they determine the screening behaviour of first-degree relatives. Further, questions associated with the relationship to an affected relative (e.g., brother vs. son, most recently diagnosed relative) were not associated with risk perceptions or screening behaviour and therefore did not support the findings of previous research (Beebe-Dimmer, et al., 2004; Roumier, et al., 2004).

Perceived threat associated with a relative's prostate cancer was a predictor of risk perceptions which suggests that FDRs make an evaluative judgement about how their relative's prostate cancer experience may make them more vulnerable to developing prostate cancer. In qualitative research on the construction of risk perceptions for people with a family history of cancer (Sanders, et al., 2003), unaffected relatives referred to the stage of treatment and to the prognoses of their relative's cancer when they discussed their personal concerns about being diagnosed with cancer suggesting that an evaluation of the relative's cancer experience may take place. The individual items used to assess cancer experience in the current study may have been too specific to capture the evaluative process that unaffected family members use to judge their personal risk. Rather, a more general evaluative assessment such as perceived threat may have allowed FDRs to make a more global evaluation about the prostate cancer experience of their affected relative and appraise the experience in terms of a judgement about threat.

First-degree relatives made judgements about risk and screening behaviour based on their perceptions of the chance that they would develop prostate cancer compared to other male relatives in their family. Men who considered themselves to have a greater chance of being diagnosed with prostate cancer compared to other male relatives in their family reported greater risk perceptions and greater screening behaviour. Thus, unaffected relatives may draw on information about their specific family history to make judgements about their own chances of getting prostate cancer. This finding is supported by qualitative research which shows that unaffected relatives may use a pre-selection strategy to make judgements about who will be the most likely person to develop cancer in the family (Sanders, et al., 2003). Those first-degree relatives who consider that they are the most likely person in their family to be

diagnosed with prostate cancer may therefore judge their risk to be higher and decide to participate in screening.

4.4.4 Risk Perceptions and Screening Behaviour as a Complementary Process

The finding that, for first-degree relatives, age *decreased* risk perceptions contradicts prior research and does not reflect an understanding of current prostate cancer risk factors. A prediction in the current study was that first-degree relatives may associate an age (potentially based on the age of a relative's diagnosis) with a representation of prostate cancer risk and thus rate their own risk in relation to this representation. However, support for an association between the age of diagnosis of an affected relative and the unaffected relative's risk perceptions (Beebe-Dimmer, et al., 2004) was not supported in the current study owing to the great number of multiple relatives identified in the sample and the inability to examine to which relative the FDR referred to generate a representation. As well, analyses using only those FDRs who reported one affected relative were not significant. The absent/exempt principle attempted to determine whether men held a representation of the age of the typical prostate cancer diagnosis to use as a referent when making judgements about personal risk. However, the high rate of disagreement with this principle suggests this item may have been too obvious to participants to reveal such an underlying process. Decreasing risk perceptions associated with increasing age for first-degree relatives suggests that FDRs may judge their likelihood of developing prostate cancer to be lower for each year they remain undiagnosed. Age was associated with increased prostate cancer screening behaviour which is interesting considering the finding that risk perceptions decrease with age. First-degree relatives screen more as they get older despite considering themselves to be at lower risk. It is possible that FDRs were advised to screen with

increasing age, however the reduction in risk perceptions with age in spite of this possible screening advice suggests alternative explanations should be considered.

There are two potential explanations for these findings. First, as suggested by Weinstein (2007), the relationship between risk perceptions and behaviour are likely to be complementary and it is possible that participation in prostate cancer screening informs subsequent risk perceptions. The receipt of a negative PSA test result may provide men with feedback about their prostate cancer risk, in effect decreasing their perception of risk. Further, receiving a negative PSA test result at increasing ages may lead to a more marked decrease in risk perceptions as the participant judges the test outcome to indicate a lower likelihood of getting prostate cancer. However, risk perceptions were not directly associated with screening behaviour in the present study, suggesting that alternative factors may have prompted screening.

The relationship of threat to both risk perceptions and screening behaviour suggests that threat may be a factor that motivates men to participate in screening and thus the subsequent screening result may have been used to reinforce perceptions of risk. Threat has been shown to lead to a confirmatory information search (i.e., the selection of information supportive of one's position) when the source of the threat and the decision context are related (Fischer, et al., 2011). When faced with a threatening situation, such as having a relative with cancer, making decisions about early detection screening may be associated with a tendency to seek confirmatory information (e.g., that one does/does not have cancer). Although research associated with the conditions that lead to confirmatory information search generally examine the selection of pieces of supportive information or arguments as evidence of confirmatory information, the prostate cancer screening test itself may be conceived of as a piece or source of

confirmatory information. A prostate cancer screening test result can provide information to patients that can be used to confirm an expected outcome.

Prostate cancer screening has been found to provide reassurance value to men (Cantor, Volk, Cass, Gilani, & Spann, 2002). In this regard, Ransohoff, McNaughton Collins and Fowler (2002) discuss the prostate cancer screening context in terms of being a system without negative feedback where, despite uncertainties associated with the benefits of early detection testing, participation in a PSA test provides a patient with positive reinforcement regardless of the outcome. A positive PSA result can lead patients to feel grateful that they found cancer whereas a negative PSA result can be associated with a sense of reassurance that they do not have prostate cancer. Thus, prostate cancer screening can provide confirmatory information to men or alternatively, the test outcome can provide reassurance to men that the screening test was worth undertaking regardless of the outcome.

Although prostate cancer screening may provide reassurance value to all men who consider the prospect of having prostate cancer, this explanation alone cannot account for the finding that age was associated with decreased risk perceptions but increased screening only in the FDR group. However, greater reassurance from prostate cancer screening (preferring a negative outcome from a prostate biopsy compared to just a negative PSA test result and DRE) was sought by men with a family history or men who perceived themselves to be at higher risk (Cantor, et al., 2002). Also, considering again the role of perceived threat in predicting risk and screening behaviour for FDRs, perceived vulnerability has been shown to lead to more negative affect (i.e., threat) and negative affect has been associated with greater intentions to participate in a health recommendation, regardless of the attitude a participant holds towards the recommendation (Das, de Wit, & Stroebe, 2003). The authors suggested that perceived

vulnerability produced an emotional tension that resulted in an action tendency where participants were motivated to act on the health risk.

The role of the affect heuristic in informing judgements has been described in detail in Chapter 3 and negative affect in particular has been associated with greater systematic processing (Blanchette & Richards, 2004; Martin, et al., 1993; Wegener, et al., 1995). However, when reasoning about health risks, defense motivations may lead to more biased systematic processing to make judgements about the health risk (Ditto & Lopez, 1992; Giner-Sorolla & Chaiken, 1997; Liberman & Chaiken, 2003). Consistent with this view, Das et al. (2003) found that people with high perceived vulnerability to a health risk processed information about health recommendations with a positive bias that was unaffected by argument quality (2003). That is, despite being able to differentiate between weak and strong arguments supportive of health recommendations, people who experienced greater perceived vulnerability to a health risk held more positive attitudes and generated more positive thoughts towards the health recommendation even when weak arguments supported the recommendation. Unfortunately, Das et al. did not examine the influence of arguments that were not supportive of health recommendations on attitudes or processing biases, an issue of key relevance to a health behaviour such as prostate cancer screening where uncertainty about the benefits of the behaviour is inherent in the decision. However, the finding that vulnerability leads not only to negative affect but also to more positive attitudes, thoughts, and intentions towards participating in a health behaviour may explain why FDRs hold higher perceptions of risk and screen more than GP men, yet reduce their risk perceptions as they remain undiagnosed with increasing age. Holding favourable attitudes towards the capability of the prostate cancer screening test to detect cancers (owing to the diagnosis and treatment of an affected relative), despite the uncertainty

inherent in the PSA screening test, may lead FDRs to consider the test more positively and attribute negative test results to be a confirmation that they do not have prostate cancer, thus lowering perceptions of risk.

A third related but alternative account for why screening behaviour increased with age for FDRs while risk perceptions decreased relates to research on insurance, risk, and magical thinking in judgements of probability (Risen & Gilovich, 2007, 2008; Tykocinski, 2008). When people judge the probability of suffering negative health events in the future, they report lower probabilities if they are reminded of their health insurance status prior to making judgements (Tykocinski, 2008). In a series of experiments that examined the effects of insurance status on probability judgements, Tykocinski found consistently that the knowledge that one had insurance (e.g., health, travel or car) was associated with lower judgements of probability, particularly when reasoning was based on intuition or past experience. Specifically, an insurance policy was considered to provide a sense of safety or a feeling of coverage from the negative consequences associated with not having insurance or, as the author suggests, of *tempting fate*. Further, the tempting fate account extends explanations provided by research associated with anticipated regret (Miller & Taylor, 2002) because the effect of insurance on subsequent probability judgements was greater when insurance status was decided without the participant's control (Tykocinski, 2008).

The idea that by tempting fate bad things are more likely to happen is associated with both the availability heuristic and the experience of negative affect (Risen & Gilovich, 2007, 2008; Tykocinski, 2008). People attribute more negative outcomes to behaviours that are considered to tempt fate (e.g., swapping a lottery ticket) and this effect is mediated by the higher accessibility of negative outcomes (e.g., that the swapped lottery ticket is therefore more likely to win; Risen & Gilovich, 2008). In

relation to men considering prostate cancer screening, hearing about a friend or relative's misfortune (e.g., the diagnosis of prostate cancer) can lead to the awareness that one is not covered against this misfortune (e.g., not seeking early detection screening) and the potential negative outcomes that result from this realisation are more accessible (e.g., being diagnosed with later stage prostate cancer).

Like an insurance policy, early detection screening may offer peace of mind to men by reducing the anxiety associated with the perceived negative outcomes of not screening (or of tempting fate). In this regard, early protection screening may be acting as a form of insurance policy against the probability of getting prostate cancer whereby the act of testing is considered instrumental in reducing the probability of the negative outcome (more advanced prostate cancer). It could be argued that the negative consequences of not screening for prostate cancer is more accessible to first-degree relatives of men with prostate cancer owing to their family member's diagnosis and so these men seek peace of mind through early detection. This in turn results in the consideration of screening as a form of a preventive or protective strategy against the likelihood of negative outcomes. Greater investigation of the reasons men provide for participating in prostate cancer screening should shed light on whether this strategy is being utilised.

4.4.5 Limitations

There are a number of limitations inherent in the present study. First, the study was cross-sectional and the majority of first-degree relatives had already had a PSA test. Although a number of predictors of risk perceptions and screening behaviour were identified in the current study, what actually instigated screening behaviour cannot be determined. Second, recruitment of first-degree relatives from their probands would

likely result in a selection bias such that only those relatives who the ProsCan participant consented to be contacted for the study could be approached. Verbal reports from recruitment officers suggest that in some cases unaffected relatives may not know about the ProsCan participant having prostate cancer and some relatives were distant from one another or simply did not want some of the relatives to participate. Thus, the current sample may be more likely to be those first-degree relatives who interact with their affected relative and have been told about the presence of prostate cancer in the family: both situations may bias results towards an increased awareness of prostate cancer risk and encouragement of screening behaviour.

4.4.6 Summary

The current study examined quantitatively whether heuristic reasoning strategies contributed to judgements of risk and to decisions about prostate cancer screening for first-degree relatives of men with prostate cancer. The availability and representativeness heuristics were found to influence judgements of perceived risk and guide prostate cancer screening behaviours. Although these findings are promising and support the argument that men are using heuristic strategies to guide their judgements, the current study was limited to examining specific instances of the availability and representativeness heuristics and could not account for the variety of ways in which men may apply these strategies. For instance, men may use different heuristic strategies to make judgements about risk and screening behaviour that could explain why there is a lack of relationship between these constructs. For example, judging oneself to be dissimilar to an affected relative and concluding that one's personal risk of developing cancer is therefore low may be used in conjunction with a heuristic strategy whereby one associates a friend's screening test with a positive outcome that prompts positive

screening behaviours. The qualitative study described in Chapter 7 seeks to address the range and content of heuristic strategies in use during decision-making about prostate cancer screening and when men make judgements about personal risk.

The current study found only a limited number of predictors of prostate cancer screening which suggests that there may be alternative factors that determine whether men will participate in screening. Investigation of the actual reasons men provide for their prostate cancer screening decisions should shed light on the information that is salient and important to men when making decisions about screening. The following study investigates whether FDRs and GP men provide similar reasons for participating in prostate cancer screening.

CHAPTER 5

Study 2: The Application of SEU Theory to Prostate Cancer Screening Decisions

5.1 Introduction

The current chapter applies Subjective Expected Utility theory (SEU; Edwards, 1954, as outlined in Chapter 3) to decision-making about prostate cancer screening to identify the information and decisional processes men with and without a family history utilise in their decisions about screening. Although SEU theory has been applied primarily in experimental settings, the application is modified in the current study to be more amenable to real world decisions. Specifically, the design of the current study drew from the methodology utilised in Wroe et al. (1998) and the active information search (AIS) paradigm as it was utilised by Shiloh, Gerad, and Goldman (2006). The aim of the study is to describe the decision-making process men use to approach prostate cancer screening decisions and to examine differences in information content and the utilities or weights assigned to screening reasons between men with and without a family history of prostate cancer.

5.1.1 Application of Subjective Expected Utility theory to Decision-Making about Prostate Cancer Screening

Subjective Expected Utility theory has been applied previously as a framework to inform studies on medical decision-making (Goldberg, 2006). The premise of the theory is that people participate in a decision-making process in which they weigh up decision alternatives, estimate the probabilities of these outcomes occurring, and select the alternative that maximises utilities (i.e., maximises positive relative to negative outcomes). Thus, the SEU framework is inherent in prostate cancer screening decision-

making in that current prostate cancer screening guidelines recommend that men weigh information about the risks and benefits of early detection screening and make decisions based on their personal values (Cancer Council Australia, 2008; U. S. Preventive Services Task Force, 2008; Wolf, et al., 2010). The SEU framework has not been applied as a basis for understanding prostate cancer screening decision-making yet has the potential to provide insight into the process men use to make this decision.

A widely stated criticism of SEU theory is that it is a normative decision-making theory founded on results from experimental studies of mathematical gambles and thus may not apply to many real-world decision tasks (Evans, et al., 1993; Hastie, 2001; LeBoeuf & Shafir, 2005). People are not often faced with a decision scenario where all risks, probabilities, and outcomes are known, or where trade-offs can be represented as monetary gains or losses. An individual facing a decision about early detection screening and the possibility of a diagnosis of prostate cancer may not know the chances of experiencing various treatment side-effects or the expected utility to assign to the subsequent health states.

It is this criticism that Wroe et al. (1998) aimed to address in their study that examined decision-making about predictive testing (although focusing on Utility Theory as opposed to SEU theory, the authors did emphasise the subjective nature of utilities throughout their paper, as discussed below). Wroe et al. suggested that a reason Utility Theory has not received overwhelming research support in real world decision-making is because the application of the model has been too narrow. Prior researchers applying SEU theory to real world decisions have largely explicitly specified the elements that contribute to a decision situation (e.g., the probabilities, monetary values, or other decision-relevant information) and decision-makers are required to base their decisions on this information. For example, Amsterlaw, Zikmund-Fisher, Fagerlin, and

Ubel (2006) examined the choices participants made about hypothetical treatment options for a disease in response to probability information associated with the likelihood of experiencing successful treatment at the expense of a variety of treatment side-effects.

However, Wroe et al. (1998) proposed that the reasons people apply to a decision situation (as well as the probabilities and the weights assigned to these reasons) are determined idiosyncratically by the individual according to their internal logic. People appraise a decision situation based on information that is salient or available to them at the time of the decision (Weber & Johnson, 2009) and do not necessarily weigh all possible alternatives or outcomes. An individual who is asked to consider cancer screening may be influenced by thoughts of an affected relative and weigh information about early detection with their relative's experience in mind. For example, the individual may consider the severity of their relative's cancer at the time of their diagnosis and therefore assign great weight to the belief about the benefits of early detection. Accordingly, people base their decisions on different information that may not be shared by others but is considered important to the decision-making of the individual.

Wroe et al. (1998) further emphasise that the logic used by an individual in their decision-making process is subjective and may be regarded as illogical according to objective principles. For instance, a man who chooses not to screen for prostate cancer because he believes positive thinking will stave off disease is acting on his own internal logic about the causes of cancer. Whereas normative theories would generally consider that this individual is acting illogically, the individual may value positive thinking as a determinant of good health, associate doctor's visits with bringing about bad news, and may consider their risk of cancer to be lower if they maintain a positive attitude. For

this individual, making the decision not to participate in early detection screening may be the decision that maximises expected utility. Although Wroe et al. discussed the importance of subjectivity to Utility Theory, the subjective nature of probabilities and utilities is emphasised in SEU theory as well as in other theories of decision-making such as Prospect Theory (Kahneman & Tversky, 1979). Thus, Wroe et al. propose that for Utility theory to be applicable to real world decision-making, the decision-maker should determine the information pertinent to their decision and weigh these reasons according to their utility. In this regard, the decision-making *process* an individual uses may be fundamentally rational and adhere to the premises of SEU theory.

Results from the study by Wroe et al. (1998) support their application of SEU theory to decision-making about genetic testing for a variety of diseases including breast cancer, colon cancer, and heart disease. Wroe et al. provided participants (students from a university sample) with a brief description of a disease, risk information, and available early detection interventions. Participants were then asked to indicate the likelihood that they would develop the disease, the likelihood that they would be interested in the early detection interventions, and to list all the reasons relevant to their decision whether to be tested (and to consider reasons both for and against testing if they did not indicate that they definitely wanted or did not want to participate in the intervention). Responses were used to generate a list of pro and con reason-meaning categories. A second sample of participants (community sample), people who had previously contemplated genetic testing for a disease (contemplators), undertook a similar procedure with an additional section where they were asked to rate the importance of each of the reason-meaning categories identified by the initial sample (university sample) to their personal decision about whether to be tested. The samples were matched according to perceived likelihood of opting for testing and analyses

explored the ratio of pros to cons, weighted utilities, and affective content of the specified reasons.

Wroe et al. (1998) found that the ratio of the pros to cons as identified by the participants was predictive of testing intentions, and that the weighted utilities enhanced prediction. In addition, there were differences in the content and weighting of reasons identified by the two samples; contemplators listed affective-based reasons more frequently than did the initial sample. These results support the idea that although the *process* of decision-making for genetic testing may be consistent with the premises of SEU theory, the *content* of the reasons identified by participants as relevant to their decision-making differs across groups of participants. However, the results of the study were based partly on the results of a student sample providing the reason-meaning categories used to inform the contemplator's judgements.

The design of Wroe et al.'s (1998) study addressed a number of methodological issues limiting the application of SEU theory to real world decision situations. However, in turn, a limitation of Wroe et al.'s study is that the participants themselves did not weigh the importance of their own reasons for the decision and therefore the authors could not compare the weighting of reasons identified by the different samples. Further, Wroe et al. emphasised the importance of having participants list those reasons relevant to their decision at the time. However, by encouraging participants to consider both pros and cons relevant to their decision they may have prompted participants to think of alternatives that the participants had not previously had in mind. To assume that unless a participant is entirely certain of their decision that they do or do not want to participate in a test that they will consider both pros and cons to screening is a significant assumption. Ensuring participants specify only those reasons most salient to

their decision at the time and then rate the importance (or relevance) of each of their personal reasons would more closely align with the premises of SEU theory.

Further to Wroe et al.'s (1998) argument that the reasons people consider when making decisions should be those that are relevant to the individual at the time, recording the salience of the responses would provide additional information as to the importance and relevance of reasons to the screening decision. The reasons participants mention first could be assumed to be more salient and arguably more relevant to participants' decision-making than reasons mentioned further down their list. With regard to men with a family history of prostate cancer, an FDR who mentions family history as a reason for screening first in their list may consider this to be more relevant to their decision than an FDR who mentions family history last on their list, even if both groups rate the importance of this reason equally. The salience of one's family history (e.g., greater time spent with an affected relative, the recent death of the family member) is associated with greater distress (Erblich, et al., 2000) and perceptions of risk and inheritance (Kenen, et al., 2003; McAllister, 2003; Sanders, et al., 2003) across both quantitative and qualitative studies. Thus, the salience of and importance rating allocated to screening reasons are similar but distinct aspects of the decision process and should be measured accordingly.

Although Shiloh et al. (2006) applied a different methodological paradigm to examine the information needs and decision-making processes of patients considering genetic testing for prenatal reasons, the process of information elicitation is applicable to the current study. Shiloh et al. used the active information search (AIS) paradigm (Huber, Wider, & Huber, 1997), a structured interview technique to elicit questions from participants that would help them to make a decision, and explored the content of the questions participants asked as well as their importance rankings. The authors

recorded questions from participants in the order presented to them and then handed participants their questions to rank according to their importance in helping them reach a decision. This method allowed the authors to explore the content of the questions that were most salient to the participants as well as those questions ranked as most important by the participant to their decision-making. A combination of the methods utilised by Wroe et al. (1998) and Shiloh et al. would improve the application of SEU theory to examine real world decision-making in the context of prostate cancer screening for men with and without a family history.

5.1.2 Hypotheses: Predicted Differences in Information Content and Utility Weighting between First-Degree Relatives and Men from the General Population

The aim of the current study is to identify a list of reasons that first-degree relatives of men with prostate cancer and men from the general population specify to be relevant to their screening decisions and to describe the decision-making process men use to combine and weigh these reasons to reach their decision. Although the purpose of this study is primarily descriptive, the following hypotheses are made based on family history being a predictor of screening uptake, and the contribution of family context factors to screening participation and risk perceptions in Chapter 4.

H5.1: It is hypothesised that family history as a risk factor will be mentioned as a reason for considering prostate cancer screening by the majority of first-degree relatives, and family history would be weighted as higher or highest in importance compared to other screening reasons.

H5.2: It is hypothesised that men with a family history will generate more screening reasons that take into account the familial context (e.g., family pressure to test, a family member's experience with a cancer) and these reasons will be rated higher in importance and will be more salient compared to the family context reasons specified by men from the general population.

5.2 Method

5.2.1 Participants

The risks and benefits measure was included as part of the CATI and therefore the sample of participants described in Chapter 4 also completed the current study. There were no participants who did not respond to or were excluded from completing the risks and benefits measure. Accordingly, participant details provided in Chapter 4 are unchanged.

5.2.2 Materials and Procedure

The SEU theory measure was based on the methods used by Wroe et al. (1998) and Shiloh et al. (2006) to examine genetic testing decision-making. Similar to Wroe et al., participants were read the following question: *When deciding whether or not to have a blood test for prostate cancer, what did you consider to be important in your decision?* Interviewers were instructed to write down verbatim the reasons the participants stated and to clarify any statement for which the meaning was not clear. Each statement was recorded in the order in which it was mentioned to the interviewer. The interviewers were asked to elicit approximately five statements for each participant,

if possible. Once participants had exhausted their reasons, the interviewer read the following script:

I want to ask you about the things you have listed. I will read your responses out to you and ask you to rate how relevant each of these reasons are to your decision whether to test for prostate cancer on a scale of 0-10 where “0” means not at all important and “10” means extremely important.

The participant's responses were then read aloud by the interviewer, in the order they were mentioned by the participant, and the participant was asked to rate the importance of each reason to their decision whether to screen or not to screen for prostate cancer.

The SEU theory measure appeared in the CATI following questions about family history (in the FDR interview), prostate cancer screening, perceived risk, and heuristics questions.

5.3 Results

5.3.1 Analyses and Rationale

The aim of the current study was to examine the extent to which the reasons participants listed when considering their prostate cancer screening decisions were for or against screening (and the ratio between for and against reasons), the valence of the listed reasons, and the order and importance of each reason listed by the participant to their decision. The examination of multiple salience and importance indicators was to provide a sense of how SEU theory could be applied in real world decision-making by allowing the participant to guide the decision process rather than having the investigator determine decision-relevant material. As described below in subsequent sections, the order, valence, and importance indicators could not be incorporated into any analyses

because there were so few reasons listed by participants (see Section 5.3.4). Discussion with Research Officers and observation of the data collection process revealed that the limited number of statements made by participants was a result of participants not reporting multiple reasons (e.g., stating that no further reasons were relevant despite encouragement from Research Officers) rather than difficulties with the question or the process by which Research Officers attempted to elicit reasons from the participants. Given the aim of the study was to elicit decision-relevant reasons as generated by the participants themselves, the lack of multiple reasons was taken to indicate that those first few reasons listed by respondents were those reasons that were most important, salient, and relevant to the participant's decision process at the time. Further, the high ratings of importance for each reason listed, across FDR and GP samples (see Section 5.3.4), supports this argument. Accordingly, a coding scheme was developed to capture the content of the reasons listed by participants and Latent Class Analysis (LCA) was applied to examine whether there were specific classes of responses made by participants and further to determine whether FDRs and GP men provided different classes of reasons for their prostate cancer screening decisions. The LCA is described in detail in Section 5.3.5.

5.3.2 Development of Coding Scheme

Category units were developed according to two processes. First, prior research on prostate cancer screening was used to develop categories consistent with known risk factors for prostate cancer, predictors of prostate cancer screening, and attitudes towards health behaviours (e.g., the participant considers risk factors such as their age or family history of prostate cancer, or they stated their doctor recommended they get tested). Further, current prostate cancer screening recommendations were used as a basis for

developing categories about the prostate cancer screening test and to identify possible lay beliefs about prostate cancer and screening outcomes (e.g., the participant states a belief that early detection increases survival from prostate cancer). Second, a sample of the reasons stated by participants in the current study was used to generate a more exhaustive list of reason meaning categories that represented those reasons relevant to participants but had not been identified in prior research on prostate cancer screening. A total of nine categories representing 31 coding units were generated and are presented in Table 5.1. Detailed descriptions of the category units including example statements are provided in Appendix D.

Table 5.1

Category Units for Classifying Screening Reasons

Category of meaning	Category Definition	Category Unit
1. Perceptions of Risk	The participant makes an evaluation of their risk of being diagnosed with prostate cancer.	1.1 Family History ^a 1.2 Age ^a 1.3 Symptoms ^a 1.4 Lifestyle or other ^a 1.5 Evaluation of risk ^a 1.6 Prevalence of prostate cancer ^a
2. Early detection	The participant makes statements that prostate cancer screening is beneficial because of beliefs about early detection, health attitudes or beliefs about the outcomes of PSA tests.	2.1 Early detection 2.2 General positive health attitude 2.3 Enhance survival 2.4 Screening as info to take action
3. Resolution of uncertainty	The participant states that they want to know the outcome of the PSA test for reassurance value or to clarify an anticipated outcome.	3.1 Peace of mind/seek reassurance 3.2 Want to know ^a 3.3 Outcome as clarification
4. Social Influence	The participant refers to being influenced to get a PSA test by people in their social group or refers to being influenced by the media.	4.1 Doctor recommendation ^a 4.2 Family or friend recommendation ^a 4.3 Family pressures or considerations 4.4 Media influence ^a
5. Cancer representations	The participant refers to the cancer experiences of a friend or relative as a reason for ordering a PSA test.	5.1 Friend/relative cancer experience 5.2 Family or friend comparison ^a
6. Lay beliefs	The lay beliefs category includes beliefs or theories about the causes of cancer including behaviours, personalities, environmental factors, or beliefs that are not backed up by scientific evidence.	6.1 Lay beliefs about PCa and testing 6.2 Lay beliefs PCa screening/tx
7. PSA testing	The participant refers to the convenience of the PSA screening test, holds positive attitudes about screening for prostate cancer, or considers evidence pertaining to the benefits of early detection screening.	7.1 Convenience of testing 7.2 Evidence for PSA testing ^a 7.3 Positive attitudes towards testing
8. Barriers to testing	The participant refers to barriers to ordering a PSA test.	8.1 Barriers 8.2 Never thought about it 8.4 No need for the blood test 8.5 Avoidance of testing
9. Concern with testing	The participant experiences concern about prostate cancer, the PSA test, or an anticipated outcome or screening.	9.1 Concern ^a

^a coding categories were separated into positive and negative units.

5.3.3 Data Coding and Scoring

The complete list of all the screening reasons stated by participants in the FDR and general population sample were listed in a computer spreadsheet file with the order of response, importance rating, participant identification number, and study group removed. The statements were given a sequence number and were randomised to ensure that statements made by the same participant could not be identified and did not appear in order. Two independent coders received the list of statements in an A3 coding booklet and were asked to code each statement according to whether it met the criteria of each coding category. To facilitate the coding of prostate cancer screening categories, coders were provided with an information sheet containing basic information about prostate cancer risk factors and screening recommendations (see Appendix E). The information sheet served to provide a factual, unbiased report of current recommendations for the early detection of prostate cancer to coders. The coders were told to check with the research team if they found any statements relating to prostate cancer risk or screening that they were uncertain how to code. Coders were blind to the research hypotheses and were unaware of family history as a characteristic of the group of men whose transcripts they were coding. The two coders coded 100% of the statements so that the reliability of the coding categories could be determined. Binary responses were used to code each statement for meeting (code 1) or not meeting (code 0) the coding unit with additional coding specifications described below.

Coding categories 1.1-1.6, 3.2, 4.1, 4.2, 4.4, 5.2, 7.2, and 9.1 (see Table 5.1 and Appendix D) could be coded as having a positive or negative meaning and were coded accordingly (positive meanings received a code of +1 and negative meanings received a code of -1). Positive meanings were those responses that indicated taking or approaching action (e.g., *I have a family history*) whereas negative meanings were those

responses that indicated not taking action (e.g., *because I do not have a family history*). When a statement fit a category unit but it was unclear whether the meaning of the statement was positive or negative, the statement received a code of 9 (e.g., the statement “*age*” alone did not indicate a positive or negative interpretation but age was still mentioned so category 1.2 was coded 9). For the Friend or Family recommendation category unit (4.2), responses were coded according to the participant’s relationship to the person making the recommendation (1 = *wife/partner*; 2 = *father*; 3 = *brother*; 4 = *mother*; 5 = *friend*; and 6 = *other*). Category units were not mutually exclusive and statements could be coded multiple times as fitting multiple category units.

Owing to poor reliabilities for the coding categories 7.4 Discomfort of the test and 8.3 No need for prostate cancer testing ($\kappa < .05$ for each category) and the small number of statements coded according to these categories by either coder, the two categories were dropped. For the remaining categories, there was good to excellent agreement ($\kappa > .60$) between coders for 19 of the categories and moderate agreement ($\kappa > .44$) for 10 categories. Following initial reliability analyses, coders met with the research team to clarify interpretations of coding categories and the two coders discussed discrepancies between the coding of statements to reach concordance.

5.3.4 Frequency of Reasons, Importance Ratings, and Determination of Coding for Analyses

Every man in both the FDR and GP samples listed at least one reason they considered when deciding whether or not to get a blood test for prostate cancer. More than one reason was more likely to be listed for the FDR sample where 147 (71.0%) listed two reasons, 79 (38.2%) listed three reasons, 26 (12.6%) listed four reasons, and 2

(1.0%) listed five reasons compared to the GP sample: 86 (36.0%), 17 (7.1%), 4 (1.7%), and 1 (0.4%), respectively. Ratings of importance for each reason listed exceeded a rating of seven for the majority of respondents (e.g., >73% of respondents rated eight or above for the first two reasons) suggesting that the reasons participants listed were those reasons that they considered to be highly important when considering prostate cancer screening at the time of the study. Further, there were no significant differences in ratings of importance between FDRs and GP men for the reasons listed first through fifth (although the sample of men listing greater than two reasons was small and any analysis of these reasons would be unreliable and biased by the larger sample of FDRs).

Owing to the small number of participants in either sample reporting more than two reasons, a decision was made to limit analyses to examining the first two reasons mentioned by participants. Further, to facilitate data analyses, a decision was made to recode responses according to the presence or absence of the coding category owing to the large number of coding categories identified and in consideration of the variations in scoring across coding units (e.g., valence). The top three reasons reported by FDR and GP men were largely consistent for each group at reason one and two. As shown in Table 5.2, the top two reasons listed by FDRs were coded into the categories 1.1 Family History, 2.4 Screening as information to take action, and 6.1 Lay beliefs about PCa and testing. The frequency of these categories was consistent regardless of whether the reason was mentioned first or second. For GP men, 2.1 Early detection and 2.2 General positive health attitude were the most common reasons mentioned for both reasons one and two, and 1.2 Age was the second most common reason listed first and 6.1 Lay beliefs about PCa and testing was the equal most common reason listed second.

Table 5.2

Frequency of Coding Categories (Presence or Absence) for Reason One and Two, and Collapsed Across Two Reasons

Category of Meaning	Category Units	Reason 1		Reason 2		Mention at all	
		<i>N</i> (%)		<i>N</i> (%)		<i>N</i> (%)	
		FDR	GP	FDR	GP	FDR	GP
		<i>N</i> = 207	<i>N</i> = 239	<i>N</i> = 147	<i>N</i> = 86	<i>N</i> = 207	<i>N</i> = 239
1.Perceptions of Risk	1.1 Family History	38 (18.4)	1 (0.4)	30 (20.4)	3 (3.5)	60 (29.0)	4 (1.7)
	1.2 Age	17 (8.2)	23 (9.6)	7 (4.8)	6 (7.0)	23 (11.1)	29 (12.1)
	1.3 Symptoms	6 (2.9)	10 (4.2)	3 (2.0)	5 (5.8)	9 (4.4)	15 (6.3)
	1.4 Lifestyle or other	6 (2.9)	7 (2.9)	6 (4.1)	1 (1.2)	12 (5.8)	9 (3.8)
	1.5 Evaluation of risk	7 (3.4)	4 (1.7)	5 (3.4)	1 (1.2)	10 (4.8)	4 (1.7)
	1.6 Prevalence of prostate cancer	2 (1.0)	2 (0.8)	1 (0.7)	-	3 (1.5)	2 (0.8)
2.Early detection	2.1 Early detection	17 (8.2)	19 (7.8)	4 (2.7)	10 (11.6)	21 (10.1)	29 (12.1)
	2.2 General positive health attitude	12 (5.8)	28 (11.7)	11 (7.5)	10 (11.6)	22 (10.6)	38 (15.9)
	2.3 Enhance survival	7 (3.4)	8 (3.4)	6 (4.1)	2 (2.3)	12 (5.8)	10 (4.2)
	2.4 Screening as info to take action	20 (9.7)	5 (2.1)	16 (10.9)	1 (1.2)	33 (15.9)	6 (2.5)
3.Resolution of uncertainty	3.1 Peace of mind/seek reassurance	8 (3.9)	9 (3.8)	6 (4.1)	2 (2.3)	14 (6.8)	11 (4.6)
	3.2 Want to know	18 (8.7)	15 (6.3)	8 (5.4)	-	26 (15.6)	15 (6.3)
	3.3 Outcome as clarification	12 (5.8)	16 (6.7)	6 (4.1)	5 (5.8)	16 (7.7)	21 (8.8)
4.Social Influence	4.1 Doctor recommendation	10 (4.8)	12 (5.0)	5 (3.4)	7 (8.1)	14 (6.8)	17 (7.1)
	4.2 Family or friend recommendation	4 (1.9)	1 (0.4)	3 (2.0)	-	7 (3.4)	1 (0.4)
	4.3 Family pressures or considerations	5 (2.4)	3 (1.3)	10 (6.8)	5 (5.8)	14 (6.7)	8 (3.4)
	4.4 Media influence	7 (3.4)	5 (2.1)	3 (2.0)	1 (1.2)	10 (4.8)	6 (2.5)

Category of Meaning	Category Units	Reason 1		Reason 2		Mention at all	
		<i>N</i> (%)		<i>N</i> (%)		<i>N</i> (%)	
		FDR	GP	FDR	GP	FDR	GP
		<i>N</i> = 207	<i>N</i> = 239	<i>N</i> = 147	<i>N</i> = 86	<i>N</i> = 207	<i>N</i> = 239
5.Cancer representations	5.1 Friend/relative cancer experience	10 (4.8)	1 (0.4)	9 (6.1)	1 (1.2)	18 (8.7)	2 (0.8)
	5.2 Family or friend comparison	2 (1.0)	-	2 (1.4)	-	4 (1.9)	-
6.Lay beliefs	6.1 Lay beliefs about PCa and testing	19 (9.2)	14 (5.9)	12 (8.2)	10 (11.6)	28 (13.5)	23 (9.6)
	6.2 Lay beliefs PCa screening/tx	7 (3.4)	1 (0.4)	5 (3.4)	3 (3.5)	12 (5.8)	4 (1.7)
7.PSA testing	7.1 Convenience of testing	2 (1.0)	1 (0.4)	3 (2.0)	3 (3.5)	5 (2.4)	4 (1.7)
	7.2 Evidence for PSA testing	8 (3.9)	7 (2.9)	3 (2.0)	1 (1.2)	11 (5.3)	8 (3.4)
	7.3 Positive attitudes towards testing	3 (1.5)	5 (2.1)	3 (2.0)	1 (1.2)	6 (2.9)	6 (2.5)
8.Barriers to testing	8.1 Barriers	6 (2.9)	14 (5.9)	1 (0.7)	2 (2.3)	6 (2.9)	15 (6.3)
	8.2 Never thought about it	5 (2.4)	7 (2.9)	-	-	5 (2.4)	7 (2.9)
	8.4 No need for the blood test	1 (0.5)	1 (0.4)	-	1 (1.2)	1 (0.5)	2 (0.8)
	8.5 Avoidance	3 (1.5)	-	1 (0.7)	-	4 (1.9)	-
9.Concern	9.1 Concern	4 (1.9)	4 (1.7)	2 (1.4)	-	6 (2.9)	4 (1.7)

A technical issue with the instructions presented by the market research company in the conduct of the CATI resulted in less prompting of reasons from the general population sample which resulted in fewer reasons listed by GP men. However, although there are slightly more reasons identified in the FDR sample, the frequency of reporting more than two screening reasons was also low despite prompting from CCQ Research Officers. Thus, men from both samples did not appear to state more than two reasons for screening. Accordingly, the first two reasons that were mentioned by participants were collapsed such that any mention of a coding category for reason one or reason two would be coded as the presence (versus the absence) of that category and this collapsed variable was used in subsequent analyses.

5.3.5 Latent Class Analysis

As discussed at the beginning of the Results section, Latent Class Analysis (LCA) was applied to the current data to determine whether there were homogenous groups or subpopulations of individuals identifiable from the patterns of screening reasons. Latent Class Analysis is a statistical technique, similar to factor analysis, which examines the interrelationships between observed categorical items to identify whether there is an unobserved latent variable that explains associations between the items (McCutcheon, 1987). Successive models are run with increasing numbers of latent classes until a model is found to fit the data well while avoiding extra, redundant classes. The model parameters are probabilities of being in a class and the probabilities of meeting each criterion or coding category given class membership (Muthén & Muthén, 2000). Further, LCA provides posterior probabilities that indicates the probability that an individual belongs to each class. Individuals can be assigned to a class based on these posterior probabilities and multinomial logistic regression can be

used to examine whether background variables (e.g., FDR status) predict class membership.

Latent Class Analysis was applied using Mplus version 4 (Muthén & Muthén, 1998-2006). Identification of the most parsimonious and best-fitting model was determined by the examination of fit indices and the interpretability of the findings. Model fit was determined by lower values on the adjusted BIC (Bayesian Information Criterion adjusted for sample size) and higher values for entropy (an indication of the misclassification error). A single undifferentiated model was estimated and successively more complex models with more classes were compared until a best-fitting model was identifiable (up to a five class model).

The calculation of standard errors in the estimation of the three class model was unreliable and accordingly, new start values were set, and the number of random starts and iterations were increased to facilitate model estimation (these are reported in Table 5.3). Fit indices did not uniformly identify a single best-fitting model but rather suggested that either a three (i.e., based on lowest sample-size adjusted BIC) or a four (i.e., based on highest entropy) class model was the most appropriate fit. Comparing the four to the three class model, the Vuong-Lo-Rubin test and the Lo-Mendell-Rubin adjusted LRT approached significance (both $p = 0.09$), and the bootstrapped parametric likelihood ratio test (Van Der Heijden, Hart, & Dessens, 1997) was significant ($p = .03$) suggesting that four classes were better than three. Further, model estimates for the three and four class models were examined to select the most interpretable model based on classes with substantive meaning. On this basis, the four class model was selected.

Table 5.3

Fit statistics from the Latent Class Analysis (with Random Starts)

Classes	-2LL	AIC	BIC	BIC ^a	entropy	Number free parameters
1	-2572.79	5203.571	5322.481	5230.447		29
2	-2506.89	5131.784	5373.703	5186.462	0.701	59
3	-2459.06	5096.126	5461.054	5178.605	0.742	89
4	-2426.58	5091.156	5579.094	5201.438	0.753	119
5	-2393.4	5084.797	5695.744	5222.881	0.749	149

Note. Statistics presented are those applying LCA with set random start values and multiple iterations. AIC Akaike Information Criterion, BIC Bayesian Information Criterion, ^a BIC using sample size adjustment. Chi-square analyses were not computed for the models because the frequency table for the latent class indicator model part was too large.

The conditional probabilities for the items across the four classes are presented in Table 5.4. The properties of the four classes are discussed below.

Table 5.4

Conditional Probabilities for the Four Class Model

Category Unit	Class 1 Positive Health (13.0%)	Class 2 Conquering Cancer (10.3%)	Class 3 Outcome-oriented (52.0%)	Class 4 Evaluation of Risk (24.7%)
1.1 Family History	.065	.016	.051	.399
1.2 Age	.149	.000	.000	.358
1.3 Symptoms	.000	.087	.056	.060
1.4 Lifestyle or other	.000	.030	.010	.141
1.5 Evaluation of risk	.031	.000	.000	.101
1.6 Prevalence of prostate cancer	.000	.000	.017	.011
2.1 Early detection	.088	.187	.133	.053
2.2 General positive health attitude	1.000	.000	.000	.031
2.3 Enhance survival	.107	.000	.076	.000
2.4 Screening as info to take action	.018	.056	.158	.012
3.1 Peace of mind/seek reassurance	.035	.000	.083	.045
3.2 Want to know	.016	.077	.137	.056
3.3 Outcome as clarification	.052	.100	.106	.049
4.1 Doctor recommendation	.016	.000	.096	.081
4.2 Family or friend recommendation	.016	.000	.000	.058
4.3 Family pressures or considerations	.107	.000	.076	.000
4.4 Media influence	.000	.019	.018	.092
5.1 Friend/relative experience	.000	.000	.000	.164
5.2 Family or friend comparison	.000	.000	.007	.020
6.1 Lay beliefs about PCa and testing	.195	.673	.000	.014
6.2 Lay beliefs PCa screening/tx	.018	.208	.015	.000
7.1 Convenience of testing	.036	.000	.033	.000
7.2 Evidence for PSA testing	.000	.000	.083	.013
7.3 Positive attitudes towards testing	.000	.000	.018	.067
8.1 Barriers	.000	.000	.088	.020
8.2 Never thought about it	.000	.000	.057	.000
8.4 No need for the blood test	.000	.000	.000	.025
8.5 Avoidance	.000	.000	.019	.000
9.1 Concern	.000	.000	.041	.011

Class 1: Positive Attitudes to Health. Class 1 was characterised by statements that indicated a general positive attitude towards health. Individuals in this Class made statements that suggested they held positive attitudes towards looking after their health generally (coding category 2.2); they tended to endorse the lay belief that prostate cancer screening could be a form of preventative measure (coding category 6.2); that they were at an age when they should consider testing (coding category 1.2); that they thought screening would increase their chances of living longer (coding category 2.3); or that they listened to family pressures or considered their family when thinking about their health (coding category 4.3). Men in this Class were also not likely to report any barriers or concerns about prostate cancer testing. Thirteen percent of participants were classified as being in Class 1.

Class 2: Conquering Cancer/Risk. Participants in Class 2 made statements suggesting that the PSA screening test was a tool to help them conquer, prevent or take control of prostate cancer. Statements associated with Class 2 suggested the endorsement of a cancer model characterised by lay beliefs about prostate cancer, screening, and treatment (coding categories 6.1 and 6.2); the use of PSA testing for early detection reasons (coding category 2.1); and using the PSA test to clarify an anticipated outcome (coding category 3.3). Class 2 was the smallest class to which 10.3% of participants were assigned.

Class 3: Outcome-oriented. Fifty-two percent of participants were classified as being members of Class 3. Individuals in Class 3 were more likely to make statements about using the outcomes of the prostate cancer screening test as a means to take action (coding category 2.4); to want to know (coding category 3.2) or use the outcome to clarify one's cancer status (coding category 3.3); to obtain peace of mind or reassurance from the test (coding category 3.1); and to consider early detection (coding category

2.1). Participants in this category were also more likely to report that a doctor recommended (or had not recommended) the test (coding category 4.1), or that they experienced barriers to screening (coding category 8.1). This latter coding category consisted of statements about not being informed about the prostate cancer screening test or that the doctor had not informed them about the test. Participants were also likely to mention evidence pertaining to the PSA test (coding category 7.2) with statements in this category suggesting an awareness that the PSA test was not accurate.

Class 4: Evaluating Risk. Approximately a quarter of participants were assigned to Class 4 (24.7%). Class 4 was characterised by coding categories that indicated the individual was considered factors that would contribute to their risk or likelihood of prostate cancer. Four of the six categories in the risk perception coding unit (see Table 5.4) were found to have high probabilities in Class 4 compared to other classes. Statements concerned having (or not having) a family history (coding category 1.1); considering age as a reason for screening (coding category 1.2); making evaluations based on current lifestyle factors (coding category 1.4); and a general tendency to evaluate one's own risk (coding category 1.5). In addition, statements covered the contribution of a family member or friend's experience of cancer (coding category 5.1) and consideration of the risk or screening information the individual recalled having been mentioned in the media (coding category 4.4).

5.3.6 Multinomial Regression Analysis on Latent Classes

Individuals were assigned to a class based on posterior probabilities and a multinomial logistic regression examined whether class membership was discernable by FDR status. As shown in Table 5.5, the greatest proportion of both FDR and GP men were in Class 3 and this class was used as the referent. First-degree relatives were more

likely than GP men to be in Class 2 versus Class 3, and in Class 4 versus Class 3. The overall model was significant (Likelihood Ratio (LR) $\chi^2(3) = 21.03, p = .0001$).

Table 5.5

Results from the Multinomial Regression Analysis Predicting Class Assignment

Class	Proportion FDR in class N (%)		Parameter estimates	β (SE)	RRR	95% CI
	FDR	GP				
1	21 (36.2)	37 (63.8)	FDR	-.13 (.30)	.88	(.48-1.60)
			intercept	-1.34 (.18)		
2	26 (56.5)	20 (40.5)	FDR	.70 (.33)*	2.01	(1.06-3.82)
			intercept	-1.95 (.24)		
3	91 (39.2)	141 (60.8)				
Reference						
4	69 (62.7)	41 (37.3)	FDR	.96 (.24)**	2.61	(1.63-4.16)
			intercept	-1.24 (.18)		
			Pseudo R^2	.019**		

Note: RRR , Relative risk ratio of being in the class compared to the reference class.
* $p < .05$ ** $p < .001$

5.4 Discussion

The aim of the current study was to apply SEU theory to real world decisions about prostate cancer testing, with a focus on the information identified by participants. The study was designed to facilitate the collection of participant-identified reasons whilst incorporating order, utility or importance ratings, and the consideration of both pro and con reasons that are suggestive of the decision-making process proposed by SEU theory. However, there was a lack of screening reasons put forward by

participants such that the majority of men identified only one or two reasons they considered to be important when making their decisions about PSA testing. Consequently, the predictions associated with SEU theory and distinctions between the valence, weighting, and ranking of reasons could not be examined in the current study. Rather, the analysis of screening reasons focused on the content of reasons and identifying whether there was an underlying structure to these reasons that would suggest an approach to or reasoning strategy indicative of screening decisions.

There were a large number of distinct reason categories identified for the statements made by men in the current study and suggested four underlying classes of reasons men employed to make decisions about PSA testing. Also, class membership was predicted by FDR status such that FDRs were more likely than GP men to use certain reasoning approaches for their decisions. The findings from the study will be discussed in detail in the subsequent sections followed by the implications for applying SEU theory to real world decision-making.

5.4.1 Breadth and Frequency of Screening Reasons

The limited number of reasons mentioned by participants prevented the examination of many of the hypotheses proposed on the basis of SEU theory. The majority of both the FDR and GP men did not list more than two reasons that were important when considering the decision to test for prostate cancer. The implication of this finding is that the reasons identified by men in the current study may have been those reasons that were the most important or salient to them at the time that they were considering the decision. Support for such an argument is suggested by the high importance ratings men gave for each of the reasons they identified, particularly for the first two reasons. Wroe et al. (1998) also reported a small number of participant-

derived reasons in their study which suggests that fewer decision-relevant reasons are identified by participants in more naturalistic, real world decision tasks. Further, despite the small number of reasons provided by participants in Wroe et al.'s study, the study instructions asked participants to consider reasons both for and against predictive testing decisions, which allowed the authors to create a ratio of pros to cons. However, as the current study did not ask explicitly that men consider both for and against reasons related to testing decisions meant that the distinction between reasons that could be considered benefits (pros) or risks (cons) associated with the decision to have a PSA test could not be clearly determined and thus limited any examination of the ratio of pros to cons.

The extensive set of reasoning categories identified in the development of the coding scheme for the screening statements illustrates how the decision process men employ is more complex than that which can be represented in experimental and task-focused (versus person-focused) research designs. Although attempts were made to reduce or collapse the number of coding units prior to the analysis of the data, the distinctiveness of each of the reason categories prevented any data reduction that would maintain the underlying meaning of the broad range of statements. The lack of multiple responses (at least more than two reasons) listed by participants added to the complexity of the data analysis process such that importance ratings and order effects could not be examined effectively. However, the examination of the content of the first few reasons listed by participants provided partial answers to the research questions posed in the current study. Accordingly, the study focused on the nature and content of the statements to understand the decision process men used to guide their decisions about participating in PSA testing.

The frequency of reasons mentioned either first or second by participants provides some indication of those reasons that were most salient or important to men. For example, less than thirty percent of FDRs considered their family history as an important reason in their decisions about PSA testing. As described in Chapter 4, men with a family history are more likely to participate in prostate cancer screening, yet less than one third of these men report that their family history was the most salient reason for their screening behaviour. Many men stated that they simply wanted to know the results of the PSA test, or made statements that indicated that they generally had positive attitudes towards their health, or that they considered the aspect of early detection as a factor in determining their screening decisions.

Although there were a number of coding categories that received only a small proportion of codes, the broad range and subject matter of coding categories indicates that traditional approaches to that examine benefits and costs associated with health behaviours may not tap actual decision-related factors. For example, Cappelli et al. (2001) and Jacobsen et al. (1997) provided participants with statements pertaining to the pros (benefits) and cons (costs) of health decisions and concluded that the ratio of costs to benefits predicted intentions. However, participants may not actually consider all (or even many) of these factors when making their decisions and explicit mention of the pros and cons may adjust the underlying decision process such that a greater number of reasons are considered. Further, the content of the reasons people use to guide their decisions may be in many cases unrelated to those considered to be relevant to a health decision. For example, in the current study, the consideration of the cancer experience of a friend or relative could be conceptualised as a pro or con towards early detection screening (e.g., depending on the outcome of the cancer experience) but has not been explored in prior research as a decision-relevant pro or con. Focusing on information

that health professionals consider to be relevant to medical decisions may alter the underlying decision process and force people to incorporate information that they would not generally consider in their actual decision. Future research should explore whether the reasons identified by men in the current study would be endorsed by the broader general male population if assessed quantitatively (e.g., assessed in a series of Likert-type scales) and whether a similar distribution of responses would be found.

5.4.2 Distinct Classes of Reasons

The breadth of screening reasons identified in the current study suggested the presence of an underlying structure or process by which men approached their decision to have a PSA test. The reasons men described as important when considering the decision to participate in a PSA test were classified statistically into four distinct classes that illustrated different approaches to decision-making. Each class can be shown to represent a different complex of reasons that suggest men consider their decision according to separate internal models relating to prostate cancer screening.

The largest class was Class 3 where men tended towards wanting to know and act on the outcomes of the PSA test result. The reasons characterised by Class 3 suggest that men focused on the outcome of the test and the reassurance value the test outcome provided. The potential reassurance value provided by a PSA test was discussed in Chapter 4 as a possible explanation for why risk perceptions decreased with age for men with family history while screening behaviour increased. Specifically, Das, de Wit, and Stroebe (2003) proposed that the emotional tension produced by perceived vulnerability to health threats was associated with an action tendency to do something about the health threat. Further, Cantor et al. (2002) found that men associated reassurance with receiving negative PSA test and DRE results and preferred

this reassured state compared to one in which they had not been screened and did not know their cancer status.

The reasons most associated with Class 3 suggest a desire for certainty in knowing an outcome and the ability to act on the outcome if known. People seek certainty when making risky decisions and search for information that will resolve any uncertainty (Dawes, 1988). Further, people seek certainty even if their actions increase the probability of harm. Fagerlin, Zikmund-Fisher, and Ubel (2005) found that people were motivated to act on a generic cancer diagnosis even if the treatment (and particularly treatment involving surgery) was more harmful and increased the chance of mortality (e.g., 5% mortality rate without treatment but 10% mortality with treatment): *I would want to try to cure the disease rather than just 'watch and wait' for symptoms to develop. I would feel like I had to try to do things instead of just letting it go* (pg 618). Further, Amsterlaw, Zikmund-Fisher, Fagerlin, and Ubel (2006) reported that people preferred uncomplicated surgery to complicated surgery where the overall cure rate was identical but where uncomplicated surgery had a greater chance of mortality but lesser chance of treatment complications (e.g., 1% chance of wound infection). Preference for uncomplicated treatment persisted despite participants reporting clear preferences for survival with complications over death.

The coding categories 4.1 Doctor recommendation and 8.1 Barriers were also indicative of Class 3 reasons. Doctor recommendation was a predictor of prostate cancer screening in previous research (Bloom, et al., 2006; Cormier, et al., 2003; Spencer, et al., 2006) and statements made in coding category 2.4 Screening as information to take action suggest a monitoring process (e.g., regular monitoring of PSA levels) that would have been associated with speaking to a doctor. Many of the statements found in the 8.1 Barriers coding category indicated that men had not spoken

to a doctor or been informed about the PSA test and suggests a connection between the reasoning behind statements respondents made about making decisions based on a doctor's recommendation and those who had not yet made a decision and were seeking information from a doctor to make their decision.

The largest proportion of FDRs were classified as being in Class 3 where risk factors, specifically family history, were not mentioned with a high probability. Rather than considering family history or other risk factors as contributing to their screening decisions, men in Class 3 were concerned with wanting to know the outcome of the PSA test and to act upon the outcome. These men appeared to seek information that would lower their uncertainty about having or being diagnosed with prostate cancer. For instance, many men stated that they wanted to know the result of the PSA test or that the outcome would clarify that they did not have prostate cancer. Further, knowing the PSA test result was described as a way to inform subsequent behaviours, such as providing men with results that would allow them to monitor their PSA levels or to take action against prostate cancer should the result be positive.

In partial support of hypothesis 5.1, men with a family history of prostate cancer were more likely than GP men to be in Class 4 (compared to Class 3) and this finding is reflected in the high probability of mentioning family history as a reason associated with PSA testing decisions. Class 4 was characterised by a general assessment of risk and consideration of external sources of information that helped to guide decision-making. Family history, age, and lifestyle factors that may have contributed to an increase (or decrease) in risk were mentioned, as was a category associated with the explicit evaluation of risk. Men in Class 4 evaluated a range of factors that could contribute to their perception of being diagnosed with prostate cancer, drawing on multiple sources.

Further, consideration of information obtained from the media, a doctor, or the cancer experiences of friends or relatives supports hypothesis 5.2 and the arguments provided in Chapter 3 (and examined in Chapter 4) that men make use of the information available around them to make judgements (Tversky & Kahneman, 1973). Specifically, these categories provide further support for the influence of availability as an information source for judgements about prostate cancer screening or to provide additional information pertaining to perceptions of risk. The larger proportion of FDRs in Class 4 is consistent with the results reported in Chapter 4 where the availability heuristic was shown to mediate the relationship between family history status and risk perceptions and screening behaviour.

By contrast, the composition of Class 1 reasons suggests that participants may consider their screening decisions according to a similar process described in the Theory of Planned Behaviour (TPB; Ajzen, 1991). According to the TPB, behavioural intentions are predicted by attitudes towards a behaviour (e.g., positive outcomes), normative beliefs (e.g., approval/disapproval from important referent individuals), and perceived behavioural control (e.g., personal and psychological resources to participate in the behaviour). Men in Class 1 had a high probability of reporting general positive attitudes towards participation in health behaviour, associated prostate cancer screening with health benefits (e.g., prevention) and positive outcomes (e.g., enhancing survival), and considered subjective norms (e.g., family members, beliefs about screening at a certain age) when making decisions about getting a PSA test. However, TPB emphasises that attitudes towards a health behaviour need to be specific to the target behaviour (Ajzen & Fishbein, 1977) and positive attitudes towards PSA testing, specifically, were not likely to be mentioned within Class 1. Rather, Class 1 appears to be characterised by a broader social belief in the benefits of health behaviours in general

and includes beliefs about cancer screening in general that have been applied to prostate cancer screening (e.g., enhancing survival, early detection, and prevention). Further, FDRs were no more likely than GP men to be assigned to Class 1.

Although Class 2 was the smallest class identified, the reasons associated with this class suggest a preventative approach when considering prostate cancer screening. Statements associated with Class 2 were those that discussed participation in the PSA test as a preventative measure against getting prostate cancer, that early detection was a way to ensure that one did not get prostate cancer, and that early detection was associated with more successful treatment (these are erroneous beliefs). Further, FDRs were more likely than GP men to formulate these statements. The idea that cancer screening is a preventative measure that can reduce the risk or severity of cancer suggests men in this class may apply a specific mental model about their conceptualisation of prostate cancer and the role of cancer screening, or may seek reasons that defuse perceived negative outcomes.

The finding that statements reflected lay beliefs about prostate cancer prevention through screening is consistent with work by Huber and colleagues (Huber, Beutter, Montoya, & Huber, 2001; Huber, et al., 1997) on what they term a Risk Defusing Operator (RDO). Huber et al. explored active information seeking related to quasi-naturalistic risky decisions and focused on the content of the information identified by participants. When reasoning about a risky decision that involved some uncertainty, participants sought alternatives that were not presented (e.g., not part of the decision description) but that would allow them to have some control over potential negative outcomes or to make worst-case plans that would transform the negative outcome state. For example, in relation to making decisions about health behaviours, people sought information pertaining to pre-event RDOs (e.g., is there a possibility of vaccination

against the disease) or post-event RDOs (e.g., is there an acceptable treatment if the negative outcome occurs). Further, people tended to seek pre-event RDOs more than post-event RDOs (Huber, et al., 2001; Shiloh, et al., 2006).

The two highest probability categories in Class 2 suggest that men may use pre-event and post-event RDO's to guide their decision-making. Coding category 6.1 Lay beliefs about prostate cancer and testing incorporated statements that suggested the PSA test was a form of prevention against prostate cancer or that the PSA test provided some control over developing prostate cancer: *Early detection to prevent anything; to make sure that I don't get it; to minimise the risk of prostate cancer in later life; so you can detect the early traces.* Further, statements coded under category 6.2 Lay beliefs about prostate cancer screening and treatment outcomes include those that suggest the PSA test would lead to more acceptable treatment outcomes despite current scientific evidence not wholly supporting the outcome: *If it can be neutralised maybe I could keep my sexual function; if you detect it early it will keep you alive.*

Risk-defusing operators provide individuals with a sense of control over the decision by defusing the risk rather than requiring them to select the alternative that maximises expected utility (Bär & Huber, 2008; Huber, et al., 2001; Huber, et al., 1997; Shiloh, et al., 2006). Specifically, individuals seek information that provides some control over the decision outcome rather than considering probabilities and values. In their comparison of information seeking strategies and decision heuristics associated with successful or unsuccessful RDO searches (e.g., where the experimenter provided feedback as to whether the RDO was possible), Bär and Huber reported that finding a successful RDO for even just one alternative was a predictor of choice, and decisions were not related to other information, such as the subjective value of alternatives. Further, probability information was not often sought unless it was provided in the

decision description (which encouraged its use) or if RDOs were unsuccessful. When RDOs were unsuccessful, participants chose the alternative in which the negative outcome was least bad (e.g., statements included: *I want to play it safe; the risk of paralysis is not as bad as a disorder of the immune system*; pg 820-821) and was consistent with a decision strategy where the chosen alternative was the one in which the negative outcome was least bad (as opposed to an SEU theory strategy that included consideration of probability information).

The role of RDOs in defusing the risk of negative outcomes by providing individuals with a sense of control over a decision may explain why FDRs were more likely than GP men to be assigned to Class 2. First-degree relatives may seek to gain more control over their high-risk status by searching for reasons that suggest the PSA test can overcome the risk of or negative outcomes associated with prostate cancer. In related research, Kenen, Ardern-Jones, and Eales (2003) examined the potential for women at a high-risk of having hereditary breast or ovarian cancer to use heuristic strategies when discussing cancer risk and reported that women applied the illusion of control heuristic to make judgements about undergoing genetic testing. For example, qualitative interviews with family members revealed that the receipt of positive genetic test results could act as an assurance that the individual and their family would get the best treatment for cancer:

I just think that people will sit up and take more notice if I've had this testing. I'll get better treatment and, not necessarily better care, but better screening and everything I've mentioned before. So because my mum didn't get anything like that, I've got a stronger opinion on it... With my mum there was much that was missed. It was just unfortunate really. (pg 856)

Thus, men with a family history of prostate cancer may have been more motivated to consider reasons that defused the risk of being diagnosed with prostate cancer by considering the PSA test as a preventative measure or that the results would reduce the negative outcomes associated with a diagnosis.

Alternatively, the lay beliefs that characterised Class 2 may indicate that participants had constructed a specific mental model about prostate cancer, its diagnosis, and treatment. The mental models approach to understanding and communicating cancer risk proposes that people attempt to make sense of new information by integrating it with their existing beliefs, and organising the information within a mental model (Downs, Bruine de Bruin, Fischhoff, Hesse, & Mailbach, 2008). Downs et al. examined people's mental models about cancer risk factors, disease progression, testing, treatments, and outcomes, and through exploring metaphors relating cancer to other domains (e.g., like heart disease, infectious disease, contamination, or an accident). Participants perceived cancer screening as a way to detect cancers lurking in and polluting the body and as a way to find cancer before it would be too late. Eradication was a preferred approach to treatment, particularly surgery, because participants believed that cancer grows quickly and there was little chance to influence disease progression *once cancer has started* (pg 521). In this regard, eradication was seen to ensure effective treatment of cancer (some participants perceived cancer recurrence as the result of the cancer not being treated properly) and as a way to put cancer out of their minds.

Class 2 reasons reflect a similar conceptualisation of prostate cancer testing and treatment outcomes such that screening was seen as a way to prevent the development of prostate cancer or to facilitate better, more successful treatment. Further, Downs et al. (2008) reported that personal experience with cancer (either participants themselves

or in connection with a family member) had little effect on participants' general understanding of cancer. Rather, people with personal experience had less variability in their responses pertaining to the cancer process and were less likely to mention that risks were not known. This was suggested by the authors to be the result of having a particular example or referent to focus their thoughts. It is not clear why men with a family history of prostate cancer would be more likely than GP men to have a mental model composed of these lay beliefs about prostate cancer. It is possible that witnessing the experience of a relative with prostate cancer led unaffected relatives to view screening as a way to detect and get on top of the cancer and prevent its development (unlike their affected relatives), despite no scientific basis.

5.4.3 Limitations

The main limitation in the current study for testing the hypotheses as originally proposed was the lack of reasons elicited from men concerning their decisions about having a PSA test. The majority of men did not report more than two reasons that they considered when deciding whether or not to have a PSA test. Further, the broad range of distinct coding categories that could be identified within the data was greater than anticipated and, in combination with the limited number of reasons put forward by participants, the frequency and valence of categories could not be examined.

However, it is to be noted that in itself the low number of reasons is an important finding, particularly as it relates to the testing of SEU theory in relation to everyday and real world decisions. Identical instructions with an emphasis on eliciting multiple reasons (if possible) from men were conveyed to all Recruitment Officers working on the study and verbal reports from interviewers suggest that men did not offer multiple reasons. Even when men were encouraged to provide multiple reasons

that guided their prostate cancer screening decisions, the majority of men in both samples did not list more than two screening reasons. Although future research should examine the elicitation process and potential effects on the number of reasons identified by participants, it is also conceivable that men, and specifically men without a family history, do not have many reasons to report that pertain to their health decisions.

5.4.4 Implications for SEU Theory and Real World Decision-Making

The results of the current study demonstrate the complexity inherent in the translation of experimental findings to real world decision problems. Subjective Expected Utility theory has frequently been applied to examine decision-making using gambling tasks where choices and the availability of information and probabilities may not reflect the conditions of real world tasks (Evans, et al., 1993; Hastie, 2001; LeBoeuf & Shafir, 2005). The current study attempted to modify the protocol for examining SEU theory to be better applicable to everyday decision tasks. However, results from the study prevented the examination of SEU theory hypotheses owing to the low number of reasons proffered by men as having contributed to their decision-making about prostate cancer screening. This result suggests that, contrary to SEU theory, people may not consider or weigh multiple pieces of information in order to reach a decision in a real life scenario. Rather, people may rely only on a few salient reasons to make their decisions. Specifically, people may not consider numerous reasons for and against screening and may be motivated to make a judgement based on the select amount of information most salient to them. Further, the decision process men use to make prostate cancer screening decisions may be too complex to represent in experimental or task-focused research designs as is evident by the large number of reasoning categories identified in coding the screening statements identified in the

current study. Future research would benefit from the examination of the decision-making process at the time of the decision to understand the reasons and decision process that leads to the final decision.

CHAPTER 6

Study 3: Applying Social Judgement Theory to Capture Decision-Making Policies

6.1 Introduction

The previous chapter examined the reasons men specified as relevant to their screening decisions. The current chapter explores how men respond to information cues relating to prostate cancer risk and screening that are currently available in their environment. Specifically, prostate cancer screening guidelines make reference to age, family history status, prostate cancer symptoms, and recommend informed decision-making with a health professional, yet it is not clear how men integrate this information to form judgements about risk or screening behaviour. The research methodology applied in the present study is based on Social Judgement Theory (SJT; Hammond, et al., 1975, see Chapter 3) and is applied to explore how family history and other information is weighted as cues to judgements of prostate cancer risk and in determining prostate cancer screening recommendations.

Policy-capturing is a technique designed to capture how individuals combine, weigh, and integrate information to make a decision choice or judgement (Hobson & Gibson, 1983; Zedeck, 1977). Participants are presented with multiple hypothetical scenarios that consist of a set of information cues whose values vary systematically across scenarios (Cooksey, 1996). Utilising multiple judgement scenarios, an individual's rating policy can be modelled with multiple regression equations to predict the information cues most influential and important to one's judgement (Hoffman, 1960). Thus, policy-capturing allows for the examination of an individual's judgement policy as well as for the identification of and for comparisons between participants who possess similar rating policies (Cooksey, 1996).

Policy-capturing is based on the Social Judgement Theory (Hammond, et al., 1975) approach to human judgement and the premise that in order to understand how an individual is making a judgement, one must understand the environment the individual is perceiving and thus responding to (Doherty & Kurz, 1996). Drawing on the work of Egon Brunswik (1955) and his focus on the interrelationship between an organism and their ecology, SJT challenges the prevailing systematic approach to research whereby focal variables are carefully disentangled from the environment, isolated, and controlled for. Brunswik (1955) criticised the limited attention given to obtaining representative samples of an organism's environment (e.g., events, objects, tasks, or persons) whereas substantial attention is given to obtaining a representative participant sample for generalisability considerations. People make judgements in a messy, noisy, and interactive environments and SJT proposes that if researchers seek to generalise their results beyond the experimental setting, than their research should be undertaken within the environmental context (Hammond, et al., 1975).

Central to SJT is the methodological approach of *representative design*: the conditions of a study should be designed to be representative of the environment to which the results are intended to generalise (Araujo, Davids, & Passos, 2007; Brunswik, 1955). In this connection, Judgement Analysis (Cooksey, 1996) (of which policy-capturing is a specific case) is a method that employs systematic sampling of stimuli, as well as participants, through the identification of proximal information cues available to individuals within the judgement environment and the experimental manipulation of these cues across multiple judgement scenarios. Policy-capturing has many advantages over more direct, self-report approaches that measure individuals' decision-making policies including the use of an experimental, representative design to assess the effects of cues independently, reducing bias associated with social desirability responding, and

providing individuals with multiple cues more realistic to actual decision-making (Karren & Barringer, 2002).

Policy-capturing has been used previously in the domain of prostate cancer to explore judgement policies for prostate cancer screening by physicians (Sorum, et al., 2004). For example, Sorum et al. (2004) used policy-capturing to compare USA internists, family practitioners, and French generalists' judgements about ordering PSA tests for hypothetical patients utilising five information cues: age, urinary symptoms, size of prostate on rectal exam, prostate shape, and whether the patient had requested a PSA test. Sorum et al. found that there were slight differences in the importance of cues across US and French physician samples and that patient request for a PSA test, prostate shape, and age were important cues for recommending the ordering of a PSA test. Notably, Sorum et al. excluded family history information from patient profiles. Thus, policy-capturing has been applied to prostate cancer screening judgements to explore influential information cues that guide physician recommendations, and to make comparisons between the rating profiles of different judges.

One of the most important information cues found by Sorum et al. (2004) to predict physician's screening recommendations was whether the patient had requested a screening test and suggests that the patient's perspective is a key decisional factor that warrants further exploration. The patient's perspective is an important factor according to current screening guidelines that recommend that patients and practitioners engage in an informed decision-making process to reach a decision about screening (Sheridan, Harris, & Woolf, 2004). Sorum et al. (2004) explored prostate cancer screening decisions from the perspective of the physician and included information cues that are frequently unavailable to patients who are considering whether to undertake screening (e.g., prostate shape). It is unclear why Sorum et al. excluded family history

information from screening profiles, particularly in light of the fact that family history is one of the few known risk factors for prostate cancer (Bruner, et al., 2003; Johns & Houlston, 2003) and an increasing number of men are faced with this information when making prostate cancer screening decisions. If we are to understand how a family history of prostate cancer influences decisions about screening and the conceptualisation of risk for family members of men with prostate cancer, the importance of family history as a decision cue should be explored. Applying policy-capturing to the study of screening decisions and risk perceptions for men with and without a family history of prostate cancer will provide an opportunity to examine the weighting of family history as a cue to such judgements.

The application of the policy-capturing methodology to prostate cancer screening from the patient's perspective will add an additional level of explanation to the question of whether family history of prostate cancer is an important cue for determining prostate cancer risk perceptions amongst both first-degree relatives and men from the general population. Further, variables considered to be important for guiding screening recommendations according to current prostate cancer screening guidelines can be examined at the level of the patient to see whether these information cues are influential from the patient's perspective. Thus, the current study utilises policy-capturing to investigate whether variables considered to be related to screening recommendation and risk translate to be the important and influential variables in participant's actual judgement policies. Specifically, policy-capturing is employed to measure two outcomes: prostate cancer screening recommendation and perceived risk of developing prostate cancer. Based on prior research on risk perceptions, prostate cancer screening, and family history, the following hypotheses are presented.

6.1.2 Hypotheses

6.1.2.1 Perceived risk of prostate cancer. Age and family history of prostate cancer are well publicised risk factors for prostate cancer and the following hypothesis suggests that men will have an awareness of these factors when making judgements about risk. It is anticipated that men with a family history of prostate cancer will be more aware of and consequently more attuned to potential risk factors for prostate cancer owing to their experiences with affected relatives. In particular, men with a family history have been shown to base judgements of risk on familial factors that may lead to lower risk perceptions (Sanders, et al., 2003). Further, although urinary and erectile symptoms can be associated with prostate cancer they do not necessarily indicate an increase in risk of developing prostate cancer (Hamilton & Sharp, 2004; Young, Muscatello, & Ward, 2000). However, prostate cancer screening guidelines suggest PSA testing for symptomatic men and men with lower urinary tract symptoms do report a fear of being diagnosed with prostate cancer (Brown, et al., 2003). Therefore, the following hypotheses are proposed:

H6.1: First-degree relatives will rate perceived risk across scenarios as higher on average than will general population men.

H6.2: Policy scenarios with older aged stimulus men, a presence of symptoms, and a family history of prostate cancer will receive higher ratings of perceived risk. Specifically, it is hypothesised that the Family History cue will be weighted heavily by participants as a predictor of perceived risk but that FDRs will weight the Family History cue significantly less than will men from the general

population. There is no hypothesis predicting a relationship between perceived risk and having discussed prostate cancer with a doctor.

6.1.2.2 Prostate cancer screening recommendation. Hypotheses concerning prostate cancer screening recommendations are primarily exploratory in nature owing to minimal research associated with how screening guidelines influence patient decisions about testing. Nonetheless, the following hypotheses are presented based on reported predictors of prostate cancer screening:

H6.3: Policy scenarios that contain older aged stimulus men, a presence of symptoms, and a family history (compared to no family history) of prostate cancer will be associated with increased recommendation of prostate cancer screening. It is hypothesised that having discussed prostate cancer screening with a doctor will be positively related to screening recommendations.

H6.4: Further, there will be statistical equivalence in the endorsement of prostate cancer screening between FDRs and general population men and that the weighting of information cues will not be moderated by FDR status.

6.2 Method

6.2.1 Participants

As discussed in Chapter 4, a sample of first-degree relatives and men from the general population were recruited to participate in either a Computer-Assisted Telephone Interview (CATI) or a face-to-face interview (VPA). The recruitment

process for the additional VPA sample used in the current study (and in the study described in Chapter 7) was similar to the recruitment process described for obtaining the CATI sample (see Chapter 4), with additional criteria discussed below.

6.2.1.1 FDR sample. In addition to the eligibility criteria described in Chapter 4, the following eligibility criteria were applied to recruit a sample of FDRs for the VPA interview:

- Live within 50km of Brisbane CBD. A list of postcodes was generated for the greater Brisbane area using the computer software program *MapInfo*.
- A related FDR was not already assigned to the VPA study group.

To attain sufficient power for analyses resulting from the VPA interview data, a sample of 50 first-degree relatives was sought for assignment to the VPA study group. To reduce the potential for selection bias and maturation effects to influence the sampling and so as to provide enough time to allow the interviewer to organise and complete the interviews in a timely manner, the assignment of 50 men to the VPA study group was planned to occur over the entire 12 month recruitment process. Accordingly, a randomisation ratio was applied to assign FDRs to the VPA based on an estimate of the total number of FDRs likely to be eligible for VPA assignment.

An estimation of the number of FDRs who could be eligible for assignment to the VPA was calculated based on information attained from the proband: the proband's postcode, the proportion of probands who had been diagnosed with a cancer other than prostate cancer (approximately 20%), the predicted age range for unaffected brothers and sons, consent rates of ProsCan men who will provide permission to contact their relatives (approximately 80%), and consent rates for prior studies conducted by CCQ that utilised first-degree relatives of cancer patients (approximately 80% consent). Based on this estimate, an initial randomisation rate of 1 in 4 eligible FDRs was applied

for assignment to the VPA. At four months into recruitment the randomisation rate was increased to 1 in 2 to account for the overestimate of the proportion of FDRs who would be eligible for randomisation. At six months into recruitment the randomisation rate was removed and all eligible FDRs were assigned to the VPA. The main reason participants were deemed ineligible for allocation to the VPA was that their postcode was out of the 50km interview area (approximately 80%).

Following assignment to the VPA study, an information sheet (see Appendix F) and consent form (see Appendix G) were sent to eligible first-degree relatives. Consistent with the recruitment protocol for the CATI sample, participants whose address details could not be provided by probands were telephoned to request contact details and permission to send information about the study. First-degree relatives whose consent forms were not returned within two weeks were contacted by the researcher to confirm correct contact details, provide additional information about the study if requested, answer any questions the participant had about the study, and to request the return of the consent form. If the FDR indicated interest in the study but their consent form was not returned following this phone call, the researcher made a reasonable number of additional follow-up calls to the FDR prior to recording the FDR as a passive refusal. Once written consent was received from an FDR, the researcher called the participant to confirm eligibility criteria and to arrange a time to complete the interview. Interviews were completed at a venue most convenient to the participant and the majority of these interviews occurred at the participant's home. As shown in Figure 6.1, 32 first-degree relatives provided written consent and verbally consented at the time of the VPA interview, indicating a 64% consent rate.

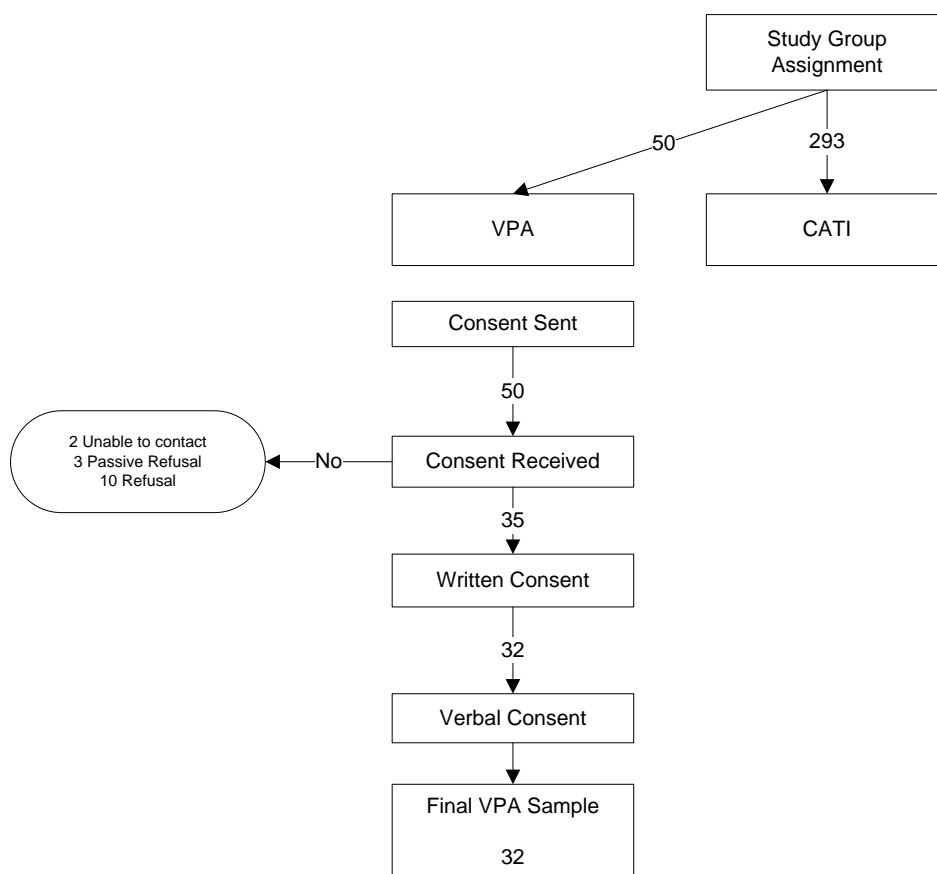


Figure 6.1. FDR sample recruitment flowchart for the Policy-Capturing and VPA studies (Chapters 6 and 7).

6.2.1.2 GP sample. Similar to the recruitment of the general population sample for the CATI, the general population sample for the VPA was recruited through an external market research firm. The additional eligibility criteria required for GP men to be recruited for the VPA interview was that the GP man lived within 50km of Brisbane CBD. The list of postcodes generated for use in the FDR sample recruitment process was provided to the external market research firm to apply to their recruitment protocol and these postcodes were used to establish the sampling frame. Further, as the VPA interview was to take approximately one hour to complete and was to be conducted at the participant's home or workplace, a \$20 retail department store gift voucher was offered to potential participants as a token of thanks for their participation. Unlike the

FDR sample, it was anticipated that men from the general population would be less likely to have a personal investment in the study (e.g., an affected relative) to participate without a token of thanks.

The external market research firm provided the researcher with contact details of potential participants who verbally consented on the phone to be contacted to arrange an interview. To be consistent with the quota applied to the FDR sample, recruitment of men from the general population ceased once 50 men had completed the VPA interview. As shown in Figure 6.2, 55 general population men verbally consented to be contacted and 50 men completed the VPA interview, indicating a 90.9% consent rate.

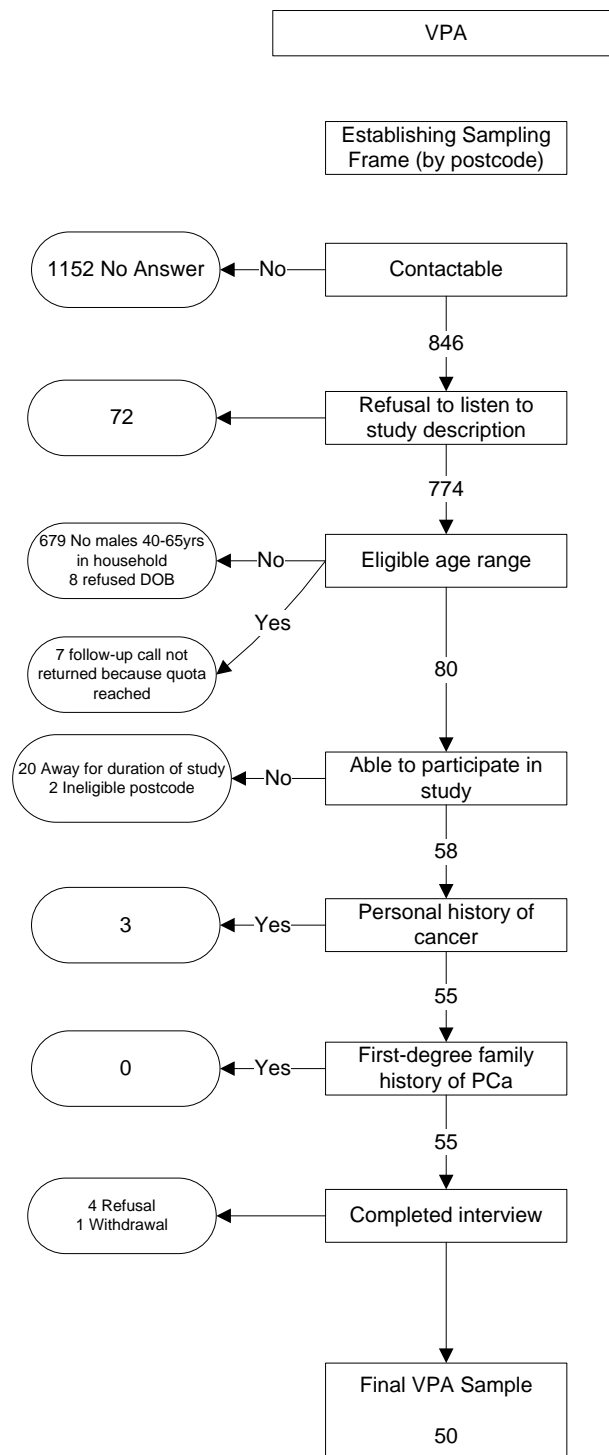


Figure 6.2. General population sample recruitment flowchart for the Policy-Capturing and VPA studies (Chapters 6 and 7).

6.2.1.3 Total VPA sample. A total of 82 participants (32 first-degree relatives and 50 men from the general population) were assigned to the VPA study group and completed the policy capturing booklet. Socio-demographic details for the two samples are shown in Table 6.1. Similar to the characteristics of the sample recruited for the CATI (see Chapter 4), the FDR sample was more likely than the GP sample to be born in Australia than outside of Australia ($\chi^2 = 6.70, p = .01$) and were less likely than the GP sample to report a non-British/Scottish/Welsh/Irish or Australian ethnicity ($\chi^2 = 10.30, p = .006$). There were no significant differences between the FDR and GP samples on the remaining demographic variables.

Table 6.1

Participant Demographics for Policy-Capturing and VPA studies (Chapters 6 and 7).

Demographics	FDR (%) <i>N</i> = 32	GP (%) <i>N</i> = 50
Age	<i>M</i> = 54.67, <i>SD</i> = 7.80	<i>M</i> = 52.79, <i>SD</i> = 6.43
Martial Status		
Never married	1 (3.1)	2 (4.0)
Married/defacto	30 (93.8)	45 (90.0)
Divorced, separated	1 (3.1)	3 (6.0)
COB		
Australia	30 (93.8)	35 (70.0)
New Zealand		3 (6.0)
England	1 (3.1)	4 (8.0)
Scotland, Ireland or Wales	1 (3.1)	3 (6.0)
Northern Europe		1 (2.0)
Southern Europe		2 (4.0)
Asia		2 (4.0)
Age arrive in Australia	<i>M</i> = 10.0, <i>SD</i> = 7.07	<i>M</i> = 20.33, <i>SD</i> = 17.04
Ethnicity		
British/Scottish/Welsh/Irish	28 (87.5)	27 (54.0)
Southern European	1 (3.1)	
Central/Eastern European		2 (4.0)
Northern/Western European	2 (6.3)	7 (14.0)
South Asian		1 (2.0)
Pacific Islander		1 (2.0)
Other (Australian)	1 (3.1)	11 (22.0)
Other (New Zealand)		1 (2.0)
Language Other than English (yes)	2 (6.3)	5 (10.0)
Education		
Primary School	2 (6.3)	
Junior High school	7 (21.9)	4 (10.0)
Senior High school	2 (6.3)	6 (12.0)
Trade or technical cert/diploma	8 (25.0)	19 (38.0)
University/college degree	13 (40.6)	20 (40.0)
Workstatus		
Full-time	21 (65.6)	41 (82.0)
Part-time	2 (6.3)	3 (6.0)
Casual		1 (2.0)
Unemployed	1 (3.1)	
Retired	5 (15.6)	4 (8.0)
Unable to work	2 (3.1)	1 (2.0)
Other	1 (3.1)	
Smoker (yes)	4 (12.5)	7 (14.0)
Household income		
<\$20,000		
\$20-40,000	4 (12.5)	6 (12.0)
\$40-60,000	8 (25.0)	4 (8.0)
\$60-80,000	5 (15.6)	4 (8.0)
>\$80,000	15 (46.9)	36 (72.0)
BMI	<i>M</i> = 27.7, <i>SD</i> = 4.99	<i>M</i> = 29.8, <i>SD</i> = 5.42
Underweight	1 (3.1)	
Normal	7 (21.9)	9 (18.0)
Overweight	18 (56.3)	21 (42.0)
Obese	6 (18.8)	20 (40.0)

6.2.2 Materials and Design

The construction of the policy-capturing measure closely followed the guidelines for conducting policy-capturing studies as described in Cooksey (1996), Aiman-Smith, Scullen, and Barr (2002), and Karren and Barringer (2002). In particular, care was taken to design the policy-capturing scenarios to be realistic, representative, and appropriate to men from the general population who may be faced with a judgement about prostate cancer screening and who may be considering their prostate cancer risk. First, according to Cooksey (1996) the selection of information cues should be based on the information that would be reasonably available to a judge within their natural ecology. Cue selection was based on known risk factors for prostate cancer and on current guidelines available regarding prostate cancer screening, that is, information that men facing a screening decision or considering their prostate cancer risk may be provided during informed decision-making. Cues were discussed with members of the research team who had extensive experience with prostate cancer research and policy. As shown in Table 6.2, four information cues were selected with 2-4 values for each cue.

Table 6.2

List of Policy-Capturing Cues and their Levels

Cue	Values	Selection
1. Age	40s 50s 60s	Prostate cancer risk increases with age (Parkin, et al., 2005). Current prostate cancer screening guidelines recommend men from age 50 years old (40 years for men with a family history) should consider talking to their doctor about prostate cancer screening (see Table 2.1).
2. Family History	No family history Brother with prostate cancer Father with prostate cancer Brother and father with prostate cancer	Men with a first-degree family history are at more than double the risk of being diagnosed with prostate cancer. Brothers of affected men are at higher risk than are sons and having multiple affected relatives increases risk further (Bruner, et al., 2003; Johns & Houlston, 2003; Staples, et al., 2003).
3. Physician Discussion	Had not spoken to doctor about prostate cancer Recently spoken to doctor about prostate cancer	Prostate cancer screening guidelines recommend men discuss prostate cancer with their doctor to make an informed decision about screening (Sheridan, et al., 2004).
4. Symptoms	Good health Experiencing symptoms (e.g., urinary problems and erection difficulties)	Prostate cancer screening is currently not endorsed for asymptomatic men. A list of 20 symptoms known to be associated with a risk of prostate cancer were compiled based on information available on prostate cancer information websites (Andrology Australia, 2005; Prostate Cancer Foundation of Australia, 2009; Renowned Doctors, 2010) and the American Cancer Society's Clinical Oncology handbook (Lenhard, Osteen, & Gansler, 2001). Two symptoms were randomly selected from this list to include in each profile.

The current study employed a full factorial design such that all values of the information cues were crossed across scenarios. A full factorial design allows for the independent effects of variables on an individual's policy to be assessed (Graham & Cable, 2001). A total of 48 distinct profiles (3 x 4 x 2 x 2) were created. The number of profiles was in accordance with recommendations for a cue to profile ratio of between 5:1 and 10:1 to maintain sufficient power, while not being too many profiles to risk fatigue (Aiman-Smith, et al., 2002; Cooksey, 1996). An additional 4 duplicate profiles were generated to assess consistency and reliability of judgement policies, thus there were a total of 52 profiles. Prior to the construction of the hypothetical scenarios,

each cue combination was checked to ensure combinations of cues were realistic (Cooksey, 1996). All 52 profiles contained realistic combinations of cues.

As recommended by Karren and Barringer(2002), to enhance the external validity of the task, the development of hypothetical scenarios for policy-capturing focused on creating scenarios that were realistic. The current study utilised a modified policy-capturing methodology, which incorporated elements of written vignettes to enhance the realism of the policy scenarios. Vignettes are *short stories about hypothetical characters in specified circumstances, to whose situation the interviewee is invited to respond* (pp. 105; Finch, 1987). A written vignette format was selected to present the policy scenarios as an alternative to the case profiles employed in studies with physicians and general practitioners. Men with a family history of prostate cancer and men from the general population are not expert judges who have experience with making judgements based on nondescript case profiles. Policy-capturing studies should match respondents' experience level and task familiarity with the group to which the results are to generalise (Aiman-Smith, et al., 2002).

A further criticism of policy-capturing studies is the lack of realism and an artificiality associated with hypothetical situations, as study designs cannot simulate the rich environmental context where real-life decisions are made (Gorman, Clover, & Doherty, 1978; Hobson & Gibson, 1983). Thus, the current study sought to include additional extraneous information to provide participants with an environmental context for the judgement and enhance the realism of the judgement task. According to Cooksey (1996), policy-capturing scenarios should only include information that pertains to the cues being examined and researchers should restrict the inclusion of additional information that may be perceived to influence participant's interpretation of the cues. However, Aiman-Smith (2002) suggests that when there are small numbers of

cue variables and the possibility of demand effects, extraneous information (e.g., hometown) can be included within policy-capturing scenarios to reduce the effect of demand characteristics. In the present research, as discussed above, the participants as lay non-expert judges could have been highly susceptible to demand characteristics induced by many stories with the same four cues.

Accordingly, written vignette included a name and short description of the stimulus incorporating extraneous information about where the stimulus person lived, occupation, and living arrangements. To reduce the potential for extraneous information to be perceived as additional information cues, careful consideration was given to the description of stimulus persons. As such, descriptions included age-associated names for older males (Kasof, 1993) and the names of large metropolitan towns in Queensland, with more populated cities being used more frequently. To reduce the potential for results to be influenced by order effects, four versions of the policy-capturing booklet containing all 52 vignettes were generated whereby scenarios appeared in a different random order across the four booklets. The final policy-capturing booklet was piloted on four men from the general population to check the style, format, length, and the appropriateness of the selected information cues and no changes were made to the booklets.

6.2.2.1 Outcome measures. According to Cooksey (1996), for judges who are unfamiliar or inexperienced with a judgement task, the outcome measures employed should be abstract (e.g., a scale ranging from low to high) rather than concrete or real measurement units (e.g., percentage risk anchored at realistic population risk levels). The participants were asked to make a judgement as to whether they thought the person described in the hypothetical scenario should consider prostate cancer screening by

ticking a box indicating either *yes* or *no*, and to indicate to what degree they believed the hypothetical person was at risk of developing prostate cancer measured on a 7-point Likert scale anchored at 1 (*very low risk*) and 7 (*very high risk*). A single 7-point Likert scale was selected to measure perceived risk as it is a more adequate single measure of perceived risk than percentage, visual, or comparative scales (Eibner, et al., 2006).

At the completion of the policy-capturing booklet participants were asked to rate how important each of the four characteristics (information cues) were when making their recommendations about prostate cancer screening and prostate cancer risk. Items were rated on a 5-point Likert scale ranging from 1 (*not at all important*) to 5 (*extremely important*). A final open-ended question asked for participants to comment on whether there was any additional information they would have liked to have known about the men in the profiles to assist them in making their recommendations (Aiman-Smith, et al., 2002). These final questions allowed for comparisons between the individual's rating policy and the policy the individual stated to have used, and to explore additional information cues perceived to be important to the respondents.

6.2.3 Procedure

The policy-capturing booklet was given to participants at the completion of the Verbal Protocol Analysis interview. Participants were asked to read the instructions on the front of the booklet and to respond to each scenario in the order presented to them. Instructions at the beginning of the policy-capturing booklet were sensitive to the task familiarity and experience of the judges, providing a clear description of the task and definitions of prostate cancer screening and prostate cancer risk (Cooksey, 1996).

In this first section, we would like you to read the following profiles and indicate whether you would recommend prostate cancer screening for the men in each of the profiles. In this context, prostate cancer screening refers to the participation in a prostate-specific antigen blood test (PSA test) to test for the presence of prostate cancer. As well, we would like you to rate the degree to which you believe each of the men to be at risk of developing prostate cancer at some time in their future. Even though you may want more information than that provided in the profile, we want you to base your ratings only on the information provided to you.

Participants took approximately 25 minutes to complete the policy-capturing booklet. The policy-capturing booklet was followed by a brief questionnaire that contained the same socio-demographic, physician discussion, prostate cancer screening behaviour, and decisional conflict questions they were asked in the CATI. The FDR sample was also asked how many of their first-degree relatives had been diagnosed with prostate cancer, how many of their first-degree relatives were deceased from prostate cancer, and their relationship to their most-recently diagnosed relative (father, younger brother, older brother, or son). Excluding the socio-demographic information reported above, responses to these questions were not a focus of the current study and therefore they are not discussed in the present chapter.

6.2.4 Statistical Analysis

Multiple analyses were run on the policy-capturing data to explore rating policies at the individual and group levels, and to check for reliability in ratings across policies. According to Cooksey (1996), idiographic analysis that explores individual

decision policies should be examined prior to examining group level relationships. Traditionally, multiple regression analyses have been used to predict linear regression equations for each individual rater and average regression weights to indicate the importance of each information cue (Aiman-Smith, et al., 2002; Cooksey, 1996). However, a hierarchical structure is inherent in policy-capturing studies with variance at the policy level nested within participants. Consequently, analyses that take into consideration the multi-level structure of the data are recommended (Klaas, Mahony, & Wheeler, 2006; Rotundo & Sackett, 2002). Recent analyses of policy-capturing studies have used hierarchical or multilevel linear models to examine relationships between information cues and higher level factors (Kristof-Brown, Jansen, & Colbert, 2002; Lievens, Highhouse, & De Corte, 2005; Mellor, Paley, & Holzworth, 1999; Morrison & Vancouver, 2000; Newman & Lyon, 2009). Accordingly, multi-level modelling (MLM) analyses were employed to predict the use of information cues on perceived risk ratings and on prostate cancer screening recommendations.

Multi-level modelling is a form of regression analysis suitable for data with a hierarchical structure whereby lower-level observations (policy scenarios) are nested within higher-level observations (participants) (Kreft & De Leeuw, 1998). Hierarchical models account for the fact that several judgements of perceived risk made by an individual are more likely to be related than judgements made by a selection of individuals chosen at random. Multi-level modelling takes into account outcome variance represented at each hierarchical level. In contrast to standard linear regression analyses, MLM accounts for variability in the outcome by allowing a policy scenario's intercept (e.g., average perceived risk) and slope (relationships between predictors and perceived risk) to vary between participants. Prediction of intercepts and slopes can then be determined from predictor variables at the scenario and participant levels. Cue

values, measured at the scenario level (level 1), therefore predict whether means or slopes within participants differ according to the values of the different cues (e.g., according to whether symptoms are present or absent). The regression coefficients can then be predicted by group level variables measured at the participant level (level 2 predictors such as FDR status) to explore whether the weight given to information cues differs according to FDR status. Further, the effect of FDR status on the relationships between perceived risk and information cues can be modelled to explore whether being an FDR moderates the weighting of information cues. Multi-level modelling can also be applied to data with dichotomous outcomes with regression coefficients representing odds ratios similar to logistic regression analyses. Prostate cancer screening recommendations were modelled using a separate MLM analysis.

The statistical package STATA 10/IC was used for all analyses. The categorical variables of Age and Family History were dummy coded prior to being entered as predictors. All other variables were binary and amenable to regression analyses as predictors. Correlation analyses for each of the four pairs of duplicate scenarios were employed to assess the consistency of participant judgements. Duplicate scenarios were excluded from subsequent MLM analyses with only the first instance encountered of each pair being retained in the data. Importance ratings for each cue variable were compared across the FDR and GP samples using *t*-tests.

6.3 Results

6.3.1 Perceived Risk Ratings

Table 6.3 presents the average risk ratings for information cues collapsed across the 48 policy-capturing scenarios. On average, perceived risk tended to be higher in relation to scenarios that incorporated a family history of prostate cancer and where symptoms were present.

Table 6.3

Average Risk Ratings for Information Cues Collapsed across Policy-Capturing Scenarios (by group)

Information Cue		FDR <i>N</i> =32 <i>M</i> (<i>SD</i>)	GP <i>N</i> =50 <i>M</i> (<i>SD</i>)
Age (40's)	40's	4.28 (1.46)	4.26 (1.65)
	50's	4.44 (1.43)	4.58 (1.57)
	60's	4.47 (1.43)	4.67 (1.59)
Family history	None	3.35 (1.39)	3.31 (1.56)
	Brother	4.53 (1.26)	4.75 (1.38)
	Father	4.60 (1.32)	4.79 (1.44)
	Brother & Father	5.18 (1.13)	5.24 (1.36)
Symptoms	No	3.95 (1.41)	4.08 (1.67)
	Yes	4.88 (1.31)	4.96 (1.43)
GP Discussion	No	4.47 (1.43)	4.47 (1.59)
	Yes	4.37 (1.45)	4.57 (1.64)
Total		4.42 (1.44)	4.52 (1.61)

6.3.2 Prediction of Perceived Risk by Information Cues and FDR Status

A two level multi-level model incorporating both level 1 (information cues) and level 2 (FDR Status) predictors of perceived risk was proposed using maximum likelihood approach to parameter estimation. Four models were constructed. First, a variance components model was fitted to the data to establish whether significant variability in perceived risk was represented at the participant level to warrant the multilevel approach. Examination of intraclass correlations revealed that 31% of the variance in perceived risk was explained at level 2 and confirmed the use of a multi-level approach to analysis.

Second, level 1 predictors Age, Family History, Symptoms, and GP Discussion were entered as fixed effects and as shown in Table 6.4 (Model 2), all the information cues were significant except for Physician Discussion, which was therefore dropped from subsequent models. Compared to scenarios involving stimulus men aged in their 40's, men aged in their 50's and 60's were rated as having higher risk, as were stimulus men who were described as experiencing symptoms. Stimulus men who had a brother, father, or both a brother and a father with prostate cancer were considered to be at significantly higher risk than stimulus men with no family history. Third, the level 2 predictor FDR Status was entered as a fixed effect and was not significant. However, FDR Status was retained as a fixed effect in the model owing to its theoretical importance as a moderator of the use of the Family History information cue. A model that treated the information cue Family History as random failed to converge and therefore all predictors were treated as fixed.

A cross-level interaction between FDR status and the information cue Family History was entered in a fourth model to examine whether participant's weighting of Family History cues were different for FDRs and men from the general population.

Specifically, the cross-level interaction addressed the research question concerning the prediction of differences in the importance of Family History as a cue to determine perceived risk by participants who have a family history of prostate cancer compared to men who do not have a family history. As shown in Table 6.4 (Model 4), the interaction between FDR status and the Family History cue values relating to brothers and fathers were significant.

The interaction results suggest that policy scenarios with information about any type of family history of prostate cancer (e.g., father, brother, or both) predicts greater risk perceptions compared to policy scenarios with no family history. However, this relationship is less pronounced amongst FDRs who seem to assign less weight to scenarios with brothers or fathers compared to scenarios with no family history. The interaction between FDR status and scenarios containing both fathers and brothers with prostate cancer was not significant, suggesting that FDRs did not differ from men from the general population when weighting this Family History cue. The statistical significance of covariates was tested using the likelihood ratio test after model estimates. The final model demonstrated a significant improvement in fit compared to Model 3 (LR $\chi^2 = 11.12, p = .011$). Assumptions of the normality of residuals were upheld at level 1 and level 2.

Table 6.4

*Summary Multi-Level Models for Prediction of Perceived Risk by Level 1 & Level 2**Predictors and Cross-Level Interactions*

	Model 1		Model 2		Model 3		Model 4	
	Coeff	SE	Coeff	SE	Coeff	SE	Coeff	SE
<i>Fixed effects</i>								
Intercept	4.48***	.098	2.64***	.105	2.68***	.130	2.62***	.132
<i>Level 1</i>								
Age 50's (40's)			.260***	.037	.259***	.037	.259***	.037
Age 60's (40's)			.407***	.038	.407***	.038	.407***	.038
FH brother (none)			1.337***	.043	1.337***	.043	1.441***	.055
FH father (none)			1.390***	.043	1.390***	.043	1.479***	.055
FH father & brother (none)			1.924***	.044	1.924***	.044	1.969***	.057
Physician discussion (no)			-.000	.031				
Symptoms (no)			.927***	.031	.927***	.031	.927***	.031
<i>Level 2</i>								
FDR (no)					-.111	.199	.042	.206
<i>Cross-level interactions</i>								
FDR*FH brother							-.268**	.089
FDR*FH father							-.228*	.088
FDR*FH father & brother							-.115	.090
<i>Random effects</i>								
Intercept	Estimate	SE	Estimate	SE	Estimate	SE	Estimate	SE
Intercept	.749	.122	.758	.121	.746	.121	.755	.121
Residual	1.644	.038	.911	.021	.911	.021	.908	.021

Note. FH= Family History for stimulus sets. Reference groups for dummy coded variables in

parentheses. * $p < .05$ ** $p < .01$ *** $p < .001$

6.3.3 Prostate Cancer Screening Policy

The frequency of *yes* and *no* responses to the prostate cancer screening outcome measure were calculated revealing that less than 4% of the total number of scenarios received a *no* response. The small frequency of *no* screening responses suggests that there was minimal variance in the outcome measure by participants across the scenarios. The number of participants who responded with a *no* to at least one of the 48 scenarios showed that only 46.3% of participants utilised at least one *no* response (31.2% of FDRs and 56.0% of GP men). The majority of the total *no* screening responses were made by men from the general population sample (72.1%). Owing to the small proportion of scenarios eliciting a *no* response from participants and the minimal variability in the outcome, additional analyses were not run on this outcome.

6.3.4 Policy Consistency

To control for subject burden, only four scenarios were selected to be repeated in order to examine the consistency in participants' judgements across duplicate scenarios. Therefore, the statistical measure of consistency (R_c), recommended in Cooksey (1996), that requires 10-20 profiles to be duplicated, could not be calculated. However, simple correlations between the four duplicate pairs were run to examine the reliability of participant's judgements across duplicate scenarios. Correlations between scenario pairs ranged between .63-.78 for ratings of perceived risk and all were significant at $p < .0001$, indicating a high degree of consistency in ratings across scenarios containing identical cue combinations.

6.3.5 Importance Ratings and Additional Information Cues Identified

Mean importance ratings of information cues were calculated to explore the reported importance of cues by participants. The Family History cue was rated as the most important cue by FDRs ($M = 4.66$, $SD = .59$) and men from the general population ($M = 4.54$, $SD = .73$), followed by Age (FDR: $M = 4.13$, $SD = 1.02$; GP: $M = 4.14$, $SD = 1.04$); Symptoms ($M = 3.32$, $SD = 1.28$; GP: $M = 3.58$, $SD = 1.02$); and Physician Discussion ($M = 3.03$, $SD = 1.49$; GP: $M = 2.98$, $SD = 1.32$). A comparison of importance ratings by FDRs and GP men showed that GP men rated Health Status as being more important to their policy judgements than did FDR men ($t(3886) = 6.92$, $p < .001$ (two-tailed, $\eta^2 = .012$) and FDR men reported that the Family History cue was more important to their policy judgements than did GP men ($t(3934) = -5.25$, $p < .001$ (two-tailed, $\eta^2 = .007$). There were no significant differences between importance ratings of the Age and GP Discussion cues.

Open-ended responses to the question about whether there were additional cues the participant would have liked to have known about the men in the scenarios to help with their judgements were examined. The majority of participants who responded to the open-ended item (FDR $n = 13$, GP $n = 20$) mentioned that they would have liked to have known about the stimulus' lifestyle (e.g., smoking, drinking, diet, or exercise), and greater detail about the symptoms. Men from the general population were more likely to mention lifestyle factors (GP 50%, FDR 31%) and FDRs were more likely to report a desire for additional information about the stimulus' symptoms or medical history (FDR 46%, GP 15%) or additional information about the doctor recommendation or PSA test (FDR 31%, GP 5%). A few FDRs ($n = 2$) and general population men ($n = 3$) stated that they wanted to know more about the context of the stimulus' family history (e.g., had

the relative died from prostate cancer, was the affected brother older or younger than the stimulus).

6.4 Discussion

The aim of the policy-capturing study was to understand how men make judgements about prostate cancer screening and risk within an environment representative of known prostate cancer risk factors and based on current prostate cancer screening recommendations. Hypotheses related to prostate cancer risk perceptions were generally supported. In relation to risk perceptions, Family History was an important and heavily weighted information cue for all men indicating that men with a family history of prostate cancer are considered to be at greater risk. However, the high endorsement of prostate cancer screening prevented the examination of hypotheses related to screening judgements. Methodological considerations and the implications of these results for understanding risk perceptions and screening decision-making are discussed.

6.4.1 Prostate Cancer Risk Policy Judgements

In support of hypothesis 6.2, ratings of the perceived risk of stimulus men increased with older age, the presence of symptoms, and having a family history of prostate cancer. These findings are generally consistent with what is known about prostate cancer risk factors. Risk of prostate cancer increases with older age and when there is a history of prostate cancer in the family (Bruner, et al., 2003; Johns & Houlston, 2003; Parkin, et al., 2005; Staples, et al., 2003). Policy scenarios with urinary and erectile symptoms were also weighted as indicating greater risk which suggests that

men perceive symptoms to be an important determinant of risk. However, although urinary and erectile symptoms can be associated with prostate cancer they are more likely to be related to other prostate problems (e.g., benign prostate hyperplasia) and do not necessarily indicate an increased risk of prostate cancer (Hamilton & Sharp, 2004; Young, et al., 2000).

Although urinary and erectile symptoms may not indicate a greater risk of having prostate cancer, the presence of symptoms may increase the chance that an incidental cancer is discovered through screening and thus, the risk of diagnosis of early stage prostate cancer may be greater (Hamilton & Sharp, 2004). Given the lack of knowledge about the risks and uncertainties of early detection screening (as discussed in Chapter 4) it is unlikely that an awareness of the greater risk of diagnosis through increased screening was the reason men in the current study reported greater risk for men with symptoms. Many men are aware that early stage prostate cancer is asymptomatic, however, the warning signs and symptoms of prostate cancer are poorly understood (L. Cormier, et al., 2002). The greater risk attributed to stimulus men with symptoms suggests that men should be educated about the role of symptoms in the diagnosis of prostate cancer and men should be made aware that other prostate problems are more likely to be the cause of urinary and erectile symptoms rather than prostate cancer.

The Family History information cue was the most heavily weighted cue for determining risk judgements. Compared to stimulus men without a family history of prostate cancer, stimulus men with a brother or a father with prostate cancer were rated on average to be almost one and a half scale points higher in risk, and stimulus men with both a brother and a father with prostate cancer were rated almost two scale points higher. These results suggest that both FDRs and GP men considered family history to

be an important information cue for judgements of prostate cancer risk, and this is reflected in cue importance ratings whereby both FDRs and GP men considered Family History to be the most important cue in determining their judgements.

Further, it was predicted that men with a family history would rate risk across all stimulus men to be higher on average owing to a greater awareness of potential risk factors for prostate cancer as a result of having a relative with prostate cancer, and therefore would be more attuned to information cues indicative of risk. However, in contrast to hypothesis 6.1, FDRs and GP men did not differ in their average ratings of risk across the stimulus men. Rather, in support of hypothesis 6.2, FDR status moderated the weighting of Family History information in judgements of perceived risk such that FDRs weighted stimulus men with a brother or a father with prostate cancer as having less risk on average than did GP men. Although Family History was the information cue weighted most heavily in judgements of risk by all men, FDRs applied less weight to Family History cue values pertaining to stimulus men with a brother or a father with prostate cancer.

When FDRs made risk judgements for stimulus men with a family history of prostate cancer they may have considered the broader context of having a relative with prostate cancer and incorporated this reasoning into their judgements. Judgements of personal prostate cancer risk are influenced by characteristics of a relative's family history of prostate cancer such as the age of an affected relative at the time of diagnosis, and the perceived progression or prognosis of a relative's cancer (Beebe-Dimmer, et al., 2004; Sanders, et al., 2003). Unlike men from the general population, FDRs may have considered these characteristics when they made judgements about the prostate cancer risk of stimulus men and adjusted judgements of risk accordingly. The finding that risk ratings for men with a brother or a father with prostate cancer were given lower (as

opposed to higher) weighting suggests that FDRs may have adjusted risk judgements in a direction that was less threatening in terms of the importance of familial risk.

Nevertheless, these results show that FDRs are modifying their judgements of risk based on the nature of the family history.

Alternatively, men from the general population may have rated the Family History cues as higher in importance for determining prostate cancer risk because doing so allowed them to maintain a lower perception of personal risk. As found in Chapter 4, and in support of previous research (Jacobsen, et al., 2004; Miller, et al., 2001; Schnur, et al., 2006; Taylor, et al., 1999), men without a family history of prostate cancer rate their personal risk of prostate cancer to be lower than do men with a family history. However, this explanation seems less likely when considering that FDR status did not moderate the weighting of stimulus men who had both a brother and a father with prostate cancer. Having multiple relatives with prostate cancer may be a clearer indication of familial risk than having a single affected relative and FDRs may have found it harder to deny the greater weighting of this information in risk judgements. This explanation is supported by the finding that men with multiple affected relatives rate their personal risk of prostate cancer as greater than do men with only a single affected relative (Beebe-Dimmer, et al., 2004).

The moderation of the Family History cue by FDR status challenges the finding that FDRs reported that they considered the Family History cue as more important to their judgements than did GP men (although the small effect size for this comparison suggests that this result should be interpreted with caution). However, reporting that the Family History cue was more important to FDR compared to GP judgements does not imply that the Family History cue values would translate to higher risk perceptions or greater screening recommendations in FDR judgements. Rather, this result merely

implies that FDRs felt that they considered this information cue to be more of a determining factor in their ratings than did GP men. As mentioned previously, FDRs may have considered the context of the family history, including the potential for disease characteristics and the lifestyles of affected relatives, to influence risks of developing prostate cancer. For these reasons, FDRs may have considered the Family History cue as a more important and determining factor in their judgements than did GP men and importance ratings reflect this judgement.

Sections 2.4.2 (Chapter 2) and 4.1.2 (Chapter 4) in the present thesis discuss the tendency for risk assessment measures to influence ratings of risk. Accordingly, a potential limitation of the current study is that a single risk assessment measure was employed and used a Likert rating scale to measure perceptions of prostate cancer risk across stimulus men. Consequently, perceptions of risk are likely to have been influenced by the presentation format. However, the aim of the current study was not to assess accuracy of risk perceptions but to make comparisons between the ratings made by FDRs and GP men. The current study focused on adequately mapping the judgement environment in accordance with Social Judgement Theory's concept of representative design (Brunswik, 1955; Hammond, et al., 1975). As the policies were designed using information cues available in the subjects' environment, the accuracy of risk judgements cannot be calculated. Unlike breast cancer risk which can be estimated using risk factors calculated according to the Gail model (Gail, et al., 1989), there is no known risk model for estimating actual prostate cancer risk (there is some evidence for risk models predicting a positive biopsy, however the model requires results of PSA tests and a DRE for their estimation; Karakiewicz, et al., 2005). For these reasons, selection of a risk assessment measure focused on methodological considerations such

as subjectivity and simplicity in visual presentation rather than on the presentation of multiple aggregate measures or to examine accuracy.

6.4.2 Prostate Cancer Screening Policy Judgements

The overwhelming endorsement of prostate cancer screening across policy scenarios prevented hypotheses 6.3 and 6.4 from being examined. Men endorsed prostate cancer screening irrespective of the cue values presented in the policy scenarios. However, the finding that the majority of policy scenarios warranted a consideration of prostate cancer screening is consistent with research that shows that men generally hold positive attitudes towards and perceive there to be benefits to prostate cancer screening (Arroll, Pandit, & Buetow, 2003; L. Cormier, et al., 2002; Gigerenzer, Mata, & Frank, 2009).

Alternatively, a limitation of the study that may have contributed to the overwhelming endorsement of screening relates to the wording of the prostate cancer screening outcome measure. Consistent with representativeness considerations for designing policy-capturing studies, care was taken when selecting the wording of the prostate cancer screening outcome to adequately reflect the ecology of the judgement situation faced by men making a screening decision. Current prostate cancer screening guidelines recommend that men should only consider prostate cancer screening following an informed decision-making process with a health practitioner whereby they are made aware of the risks, benefits, and uncertainties of early detection screening (Royal Australian College of General Practitioners, 2006; Wolf, et al., 2010). Further, men are encouraged to consider their personal values and preferences prior to making their screening decisions. For these reasons, the prostate cancer screening recommendation measure used conservative language that suggested men *consider*

prostate cancer screening rather than to recommend screening explicitly. Future research could explore potential differences in prostate cancer recommendations as a function of explicit screening recommendations (e.g., Edward *should* screen for prostate cancer). However, owing to the positive attitudes generally held by men towards prostate cancer screening, it is unlikely that the overall endorsement of screening would be affected by such a minor adjustment to the wording of the outcome measure.

6.4.3 Temporal Perspectives in Judgements

In the current study, the risk assessment measure and the prostate cancer screening recommendation examined global ratings and did not specify a timeframe for making the judgements (e.g., rate the likelihood that the stimulus man is at risk of being diagnosed with prostate cancer within the next 10 years). Temporal perspectives can affect the decision processes used to make judgements about outcomes that may occur in the near future compared to judgements about outcomes that may occur in the distant future (Ariely & Zakay, 2001). For example, Beebe-Dimmer et al. (2004) found that FDRs gave lower short-term (10 year) compared to lifetime prostate cancer risk estimates. Further, people are poor at anticipating how they will feel or be affected by different decision outcomes. For instance, women without malignant breast cancer overestimate the physical, economic, and social consequences of being diagnosed with malignant breast cancer (Anagnostopoulos & Spanea, 2005). If risk judgements are predicted to influence health behaviour, incorporation of the temporal dimension into measurements of perceived risk may alter the decision outcome and subsequent screening recommendations. Future research should examine the influence of temporal distance on risk judgements and screening recommendations.

6.4.4 Additional Information for Forming Judgements

Almost half of the participants listed additional information they would have liked to have known about the stimulus men to help them form their judgement policies. The two major categories identified by participants referred to lifestyle information (e.g., diet, exercise) and medical information (e.g., symptom history). Additional information about the stimulus's medical history was sought by almost half of the FDRs (compared to fifteen percent of GP men) who responded to this question, suggesting that FDRs may have been searching for alternative explanations as to the cause of the symptoms other than those attributable to prostate cancer.

Half of the men from the general population sample and a third of the FDRs who requested additional information wanted to know more about the lifestyles of the stimulus men. For example, the participants wanted to know whether the stimulus men were smokers as well as wanting information about their drinking and exercise behaviours. Men in the current study may have sought this information because it was relevant to their illness representations of the types of people who get prostate cancer. Related research by Buick and Petrie (2002), and Anagnostopoulos and Spanea (2005) found that healthy women made more environmental attributions as to the causes of breast cancer than did women with a breast cancer diagnosis. Anagnostopoulos and Spanea propose that healthy people may seek to focus on controllable and changeable causes of illness that can be modified. Alternatively, owing to a lack of information available about known risk factors for prostate cancer, men may have sought to attribute information they know about the causes of other cancers and apply these to prostate cancer risk. Future research should investigate the beliefs men hold about the risk factors for prostate cancer and how these beliefs contribute to their understanding of prostate cancer risk and judgements about the benefits of screening.

6.4.5 Summary

In the current study, asking men to make direct judgements about risk and to make recommendations for prostate cancer screening revealed similar judgements across GP and FDR men. However, FDRs reported that the Family History cue was more important to their judgements despite weighting information about stimulus men with a brother or a father with prostate cancer (but not stimulus men with both a brother and a father) lower in their judgements of risk than did GP men. These results suggest that FDRs may make judgements about the importance of family history as a risk factor based on the consideration of different or additional information about familial risk. Further, the greater tendency for GP men to request additional lifestyle information and for FDRs to request additional medical history and symptom information suggests that men use different decision processes to reach their judgements.

While the current study provided valuable insight into the interpretation and weighting of representative prostate cancer information to risk and screening judgements by FDR and GP men, it did not allow for an analysis of the actual content of information used in the judgement process. The results of the current study suggest that although all men may make similar judgements about risk and screening recommendations, they may reach these judgements through different decision processes. For example, men with a family history may refer to the greater family history context when making judgements about the role of family history in informing risk perceptions, as is suggested by the lower weightings given to specific cue values. Further, FDRs wanted additional information about the nature of the symptoms described in policy scenarios in order to make judgements about the weighting of this cue while GP men were interested in additional lifestyle factors. Accordingly, the following chapter uses a think aloud verbal protocol analysis to examine the content of

information, the process by which men search for information, and the use of information in reaching judgements about risk and when making personal decisions about prostate cancer screening. This final chapter will explore the decision processes FDRs and GP men use to make their risk judgements and to reach a decision about prostate cancer screening.

CHAPTER 7

Study 4: Verbal Reports of Decision Processes

7.1 Introduction

The preceding studies have identified that first-degree relatives of men with prostate cancer make use of heuristic strategies to guide judgements, that FDRs do not weigh certain contextual family history factors as heavily in determining risk judgements compared to GP men, and that FDRs report a range of reasons for participating in screening that are not necessarily based on consideration of risk factors. Specifically, the previous chapters have provided support for the argument that family history acts as an additional source of information for unaffected relatives to use to guide their judgements and decision-making. However, what remains to be explored is the actual information men use when they consider their prostate cancer risk and decide about participating in prostate cancer screening, the contextual use of the information (e.g., how is family history being related to judgements of prostate cancer risk), and whether the information utilised is being processed with bias. To answer these questions, the current study employs a methodology that seeks to identify the ways in which men process information through the utilisation of verbal reports obtained from men who were considering risk and screening decision-making.

Accordingly, the current chapter begins with a discussion of the conditions under which cognitive structures, such as information processing strategies, are able to be mapped through verbal reports. Two major approaches to eliciting verbal protocols, verbal protocol analysis (Ericsson & Simon, 1980; Ericsson & Simon, 1993) and the thought-listing technique (Cacioppo & Petty, 1981; Cacioppo, von Hippel, & Ernst, 1997) are described along with their respective methodological conditions for eliciting

adequate verbal data. Limitations associated with the applicability of verbal protocol approaches to real world decision-making will then be addressed and modifications will be proposed for the application of these approaches to the current decision-making context. It is argued that the modified verbal protocol analysis will enable the identification of information processing strategies indicative of heuristic, systematic, and biased systematic reasoning as suggested by the Heuristic-Systematic Processing Model (HSM; Chaiken, 1980).

7.1.1 Mapping Cognitive Processes

Cognitive psychologists have long been interested in the cognitive processes underlying the relationship between a stimulus and a subsequent response or behaviour (e.g., Kahneman & Tversky, 1979; Savage, 1954; Tversky & Kahneman, 1981). In particular, researchers have sought to explore and analyse the intermediate processes that occur during performance of a judgement task or that precede a solution (Ericsson & Simon, 1993; Payne, 1994). Insight into such processes is proposed to enable inferences to be made about the cognitive constructs underlying people's choices, judgements, and behaviours (Nisbett & Wilson, 1977). For example, examination of the process by which a person makes a choice between two alternatives can reveal how prior knowledge and experience is represented and applied in people's thought processes (Bettman & Park, 1980).

Asking people directly to report on the internal states that guide their behaviour, or introspective observation, was initially thought to be a valuable tool by which to reveal people's thought processes (William James, 1980, as cited in Fox, Ericsson, & Best, 2011). Unlike other self-report methodologies developed to assess cognitive processing whereby participants respond to items or measures designed by the

researcher, verbal protocols were thought to be able to provide richer data by allowing participants to report on thought processes that were not captured by existing measures or theories. However, early research that analysed introspective evidence of thought processes suggested that people reflect on, provide justifications for, interpret, and analyse their thoughts in ways that may distort the actual thought processes that guided their judgements (Nisbett & Wilson, 1977; Tordesillas & Chaiken, 1999).

In their seminal paper, Nisbett and Wilson (1977) argued that people are unaware of the cognitive processes that mediate the effects of a stimulus on a response. Nisbett and Wilson reviewed research on the accuracy of people's subjective reports about higher mental processes and concluded that people are often: *(a) unaware of the existence of a stimulus that importantly influenced a response, (b) unaware of the existence of the response, and (c) unaware that the stimulus has affected the response* (pg 231). Rather, the authors concluded that when people report on the processes that guide their behaviour, people generate or apply causal theories about plausible stimulus-response influences. Consequently, verbal reports and introspective evidence were not initially considered valid methods for revealing accurate internal thought processes.

Following Nisbett and Wilson's (1977) review, a number of research methodologies emerged to address the criticisms of verbal reports as tools for understanding thought processes. Cacioppo and Petty (1981) argued that verbal reports can provide valuable information about people's cognitive responses to a stimulus while acknowledging that no assumptions can be made about the causes of or motives for the reported mental contents (e.g., thoughts, ideas, feelings or appraisals; Cacioppo, et al., 1997). Similarly, Ericsson and Simon (1980; 1993) argued that, like other measurement tools designed to examine people's thoughts and behaviours (e.g., interview responses, ratings), the elicitation and interpretation of verbal data is sensitive to methodological

procedures that determine the validity of verbal reports. Specifically, Ericsson and Simon proposed that verbal reports can be understood if the process by which they were generated is understood (1993). The value of verbal report data as an adequate tool for understanding people's thought processes relies on the methods used to elicit and interpret the data, and extensive research now supports the validity of these applications (Fox, et al., 2011). The following section describes the theoretical and methodological considerations outlined by verbal protocol analysis and the thought-listing technique as best practice for producing valid verbal reports.

7.1.2 Major Approaches to Eliciting and Interpreting Verbal Protocols

Although developed around similar times, verbal protocol analysis and the thought-listing technique emerged from two different research backgrounds: experimental methods as applied in cognitive psychology and social psychology, respectively. Despite the different focus of the fields from which these approaches emerged, verbal protocol analysis and the thought-listing technique both sought to map cognitive and information processes through eliciting data from participants in such a way as to reveal the underlying processes that occur when a participant is responding to a stimulus. Accordingly, the two approaches focus on eliciting only the information most salient to and accessible by participants when completing a task, and the information obtained is that which is contained in short-term memory or can be retrieved from long-term memory through appropriate retrieval cues (Cacioppo & Petty, 1981; Ericsson & Simon, 1980; Ericsson & Simon, 1993).

Further, in order to map cognitive structures adequately, verbal reports need to be elicited in a way that is non-reactive and does not disrupt information processing or performance (Cacioppo & Petty, 1981; Cacioppo, et al., 1997; Ericsson & Simon, 1980;

Ericsson & Simon, 1993). For instance, probing questions that require the participant to describe or explain the reasons for their use of information processing strategies are considered by both approaches to disrupt and alter the cognitive process and lead participants to reinterpret, change, or evaluate the strategies they are applying.

Accordingly, methodological rigour is important in verbal protocol analysis and the thought-listing technique as necessary for eliciting adequate verbal reports. However, as discussed in subsequent sections, although the experimental methods described for each approach are considered best practice for eliciting verbal reports, the restrictiveness of these methods limits their application to real world decision-making. These restrictions are addressed in the current study whilst many of the methodological procedures required for maximising the validity of verbal reports are maintained.

7.1.3 Ericsson and Simon's Verbal Protocol Analysis

Ericsson and Simon (1980; 1993) proposed the information processing model for cognitive processing, conceiving of a cognitive process as a series of internal states that occur in sequence and are transformed by information processes. The information processing model rests on the assumption that there are two memory stores with different capacities and accessibility characteristics, short-term memory (STM) and long-term memory (LTM). During the conduct of a cognitive task, verbalisation can reveal the cognitive process by tapping the information stored in STM through direct articulation or can access information stored in LTM following completion of the task through recognition or associative processes. In these ways, the timing of verbalisations and experimental procedures designed to elicit verbalisations can determine from which memory store information is retrieved and whether intermediate processes, such as inference, influence verbal reports. According to Ericsson and Simon (1980),

verbalisations affect cognitive processing when they require a participant to verbalise information that they would have not otherwise heeded or attended to. In this regard, access to cognitive processes is sensitive to experimental procedures.

Specifically, Ericsson and Simon (1993) suggest that there are three different types of verbalisations that can be elicited with verbal reports. Level 1 and Level 2 verbalisations are most likely to reflect introspective thought (Fox, et al., 2011). Level 1 verbalisation reflects the verbalisation of inner speech and Level 2 verbalisation concerns the verbalisation of thoughts that require some kind of verbal referent prior to reporting (e.g., to report that one solved a mathematical problem by carrying the 1 in order to calculate the solution). By contrast, Level 3 verbalisations are those that require explanation or description and therefore change the sequence of thoughts (e.g., asking a participant why they performed a particular calculation). Level 3 verbalisations can result in reactivity and lead the participant to make inferences that alter their subsequent thought processes.

To capture cognitive processes adequately, Ericsson and Simon (1980; 1993) argue that the research methodology needs to be designed in such a way as to limit reactivity. Reactivity occurs when a participant's sequence of thoughts is disrupted, such as when an interviewer interrupts the participant while they are verbalising their thoughts, and the participant alters their cognitive processes as a result. For example, asking a participant why they are using a particular processing strategy requires the participant to reflect on or evaluate their current process, to instigate a self-observation process, or to produce an other-oriented explanation. In such circumstances, the verbal reports generated by the participant cannot be considered an adequate representation of their cognitive processing. Accordingly, Ericsson and Simon proposed that the researcher should minimise their influence on the participant by acting as a silent

observer (often out of sight of the participant), interacting with the participant only to provide instructions to keep talking if the participant falls silent during the experiment. Verbal reports provide valid, non-reactive assessments of information processing as long as they examine Level 1 or Level 2 verbalisation processes (Ericsson & Simon, 1993; Fox, et al., 2011) and experimental procedures can be designed to limit reactivity. The validity of verbal reports is based on comparisons to the task performances of silent control groups which demonstrate that despite a slight increase in the overall time taken to complete tasks, verbal reports do not lead to differences in task performance (Ericsson & Simon, 1993; Fox, et al., 2011).

7.1.3.1 Concurrent versus retrospective reports. Verbal reports have been examined for problems as they occur (e.g., whilst solving a problem, called concurrent verbal protocols) or as soon as possible after the completion of the task (retrospective protocols; Ericsson, 1993 #306}. Comparisons between the types of information processes elicited and the validity of verbal reports obtained through concurrent and retrospective research designs have been explored extensively (Ericsson & Simon, 1993; Fox, et al., 2011; Kuusela & Paul, 2000; Taylor & Dionne, 2000; Van Den Haak, De Jong, & Schellens, 2003; van Gog, Paas, van Merriënboer, & Witte, 2005) and suggest that concurrent protocols can provide greater information about process whilst retrospective protocols can provide more global assessments of thought processes. Many real world decisions are ongoing and cannot be classified specifically as concurrent or retrospective. However, elicitation of thoughts as they occur from participants can be facilitated by probing procedures that cue recognition and associative processes to retrieve information pertaining to the decision (Taylor & Dionne, 2000).

7.1.3.2 Applications of VPA to judgements. Traditionally, verbal protocol analysis has been applied in experimental studies to examine how people solved problems (e.g., mathematical problems or gambles) and more recently has been applied in studies to examine everyday judgements as well as to explore the influence of motivation and affect on judgements. Verbal protocol analysis has been applied to examine information physicians considered to be relevant to their clinical judgements about treatment outcomes for patients with diabetes (Lutfey, et al., 2008). In a factorial experiment that employed vignettes to describe hypothetical diabetes patients whose attributes varied across vignettes (e.g., race, gender, age, socio-economic status, symptoms), physicians thought-aloud as they considered clinical outcomes and treatment recommendations for patients. Verbal reports revealed that physicians did not rely heavily on patient characteristics to make assessments about patients; rather the majority of physicians made assessments about the cognitive, psychological, and motivational states of patients that they considered to be associated with adherence to medical recommendations and thus, relevant to their decision-making. For instance, physicians commented on the appearance of a patient as indicative of their cognitive and motivational state and considered these assessments when making judgements about the patient adhering to medical recommendations. The results of this study provide an understanding of why physicians may make varied treatment recommendations for patients by identifying the different decision-making routes through which physicians arrive at their decisions (2008). Specifically, this study applied verbal protocol analysis to elucidate decision processes that may not have been captured by other research methods such as survey assessments or studies that provide decision-relevant information or outcomes for the participant to judge.

Further, results from verbal protocol analysis studies have challenged assumptions of normative theories of decision-making (Cokely & Kelley, 2009). For instance, when participants were asked to verbally report their thoughts following completion of a risky choice problem (e.g., gamble) it was revealed that although expected-value options were frequently chosen, the calculations used to make these choices were associated with simple heuristic-type processes (e.g., simple transformations of probabilities). Also, in relation to consumer decision-making, people with greater knowledge and experience with a product make use of different processing strategies to guide product choice (Bettman & Park, 1980). For example, participants who were provided prior knowledge of microwave products employed greater brand-based processing strategies to make choices which suggests that their memory structure for products was more organised and represented in terms of brands compared to less knowledgeable or less experienced groups who focused more on attribute-based processing.

Cognitive processes have been examined using verbal protocol analysis across a variety of research disciplines including to examine: problem-solving (Taylor & Dionne, 2000; van Gog, et al., 2005); clinical decision-making (Lutfey, et al., 2008); the conduct of manual handling tasks (Ryan & Haslegrave, 2007); consumer decision-making (Bettman & Park, 1980; Kuusela & Paul, 2000); risky choice (Cokely & Kelley, 2009); and in usability studies (Van Den Haak, et al., 2003). Results from these studies illustrate how verbal protocol analysis can reveal information about the content and selection of processing strategies, and the effects of prior knowledge and experience on judgements that may not be obtained through existing experimental procedures. The thought-listing technique, described in the following section, extends the application of verbal reports to the study of social phenomena.

7.1.4 The Thought-Listing Technique

Independent of Ericsson and Simon (1980; 1993), Cacioppo and Petty (1981) applied verbal reports in the form of a thought-listing technique to examine social psychological phenomena, such as the influence of persuasive communications on attitudes. The thought-listing technique is based on the assumption that people's thoughts, ideas, and feelings, and the underlying cognitive processes can be examined through analysing people's verbal reports (Cacioppo, et al., 1997). Cacioppo, von Hippel, and Ernst proposed that the thoughts people list in response to a stimulus can provide information about: *a) the way in which a person views the world; b) his or her coping processes in response to different challenges, threats, and circumstances; and c) the motives and cognitive structures from which these coping processes originate* (pg 929). For instance, there are few alternative methods available to examine irrational beliefs about social phenomena other than to analyse the content of people's thoughts in response to the phenomena.

The thought-listing technique is not as methodologically restrictive as Ericsson and Simon's VPA approach, for example thoughts can be listed both verbally and through written communication (Cacioppo & Petty, 1981). Further, the thought-listing technique can also be applied to examine thought processes that occur in anticipation of an event or task (Cacioppo, et al., 1997). However, consistent with VPA, the thought-listing technique is also designed to limit reactivity and to focus only on the information that is most salient and readily accessible to a participant at the time of an assessment (Cacioppo, et al., 1997). Instructions used to describe thought-listing tasks need to be open and encourage participants to list *all* the thoughts that they anticipated or attended to as opposed to more specific instructions (e.g., list your thoughts about the problem). Such instructions presume that people are capable of distinguishing thoughts elicited by

a problem and thoughts that are not (Cacioppo & Petty, 1981). Further, the provision of an appropriate time interval for participants to report their thoughts increases the likelihood that only the most salient and accessible thoughts are listed. In relation to concurrent and retrospective measurement, Cacioppo and Petty suggest (1981) that retrospective protocols elicited after exposure to a stimulus are better able to capture the thought processes without disruption from reporting requirements during the completion of the task.

The thought-listing technique has been applied widely to examine the nature of thoughts elicited in response to social anxiety (Mahone, Bruch, & Heimberg, 1993), to distinguish different cognitions and affective thoughts between groups (e.g., women with eating disorders and controls; Hilbert & Tuschen-Caffier, 2007), and to determine whether negative thoughts act as a mediator for deficits in performance under stereotype threat (Cadinu, Maass, Rosabianca, & Kiesner, 2005). In relation to the cognitive processing strategies, Stephens and Russo (1997) applied a verbal application of the think-aloud technique to explore the influence of emotional responses or internal states on attitude formation. Stephens and Russo extended traditional cognitive response coding schemes that focused on the valence of statements (e.g., positive or negative responses) and included coding of the direct emotional response to advertisements (e.g., it made me sad) to predict post-advertisement attitudes.

The thought-listing technique and verbal protocol analysis continue to be developed to capture how people process information in response to a stimulus or task through the use of verbal reports. The information obtained from such approaches provides insight into cognitive processes whilst limiting the potential for reports to be influenced by inferences, evaluations, or self-observation processes. However, having originated in experimental research and the methodological rigour under which they

were designed limits their application to real world judgement and decision-making tasks. The following section discusses these limitations and provides evidence for subtle modifications to the elicitation of verbal reports that considers the sensitivity of cognitive processes to research methods whilst enabling real world decision-making to be examined. Specifically, the following section provides justifications for the research methods applied in the current study to examine decision-making about prostate cancer risk and screening.

7.1.5 Limitations of Verbal Protocols to Real World Decision-Making

There are two main criticisms of the experimental methods employed in verbal protocol analysis that limit its application to real world decisions. First, people are not often faced with judgements and decisions that are one-off or finite, or that are independent of context. For instance, classification of concurrent and retrospective decision processes can at times be indistinguishable as decisions are revised and re-evaluated over time, or when new information becomes available. For example, the decision to participate in prostate cancer screening may be dependent on one's age at the time of the decision, the recent diagnosis of a friend or relative, or subsequent to new information having been received from a health professional. Further, decisions may be made over longer time periods (e.g., days, weeks, or months).

However, it is argued that the value of verbal reports in their capacity to reveal cognitive processes need not be limited to experimental designs where the context, content, and judgement (or choice) can be controlled. Rather, when applied to real world decisions within the methodological framework for eliciting verbal reports, verbal protocol analysis can provide a snapshot of current cognitive processes and the information relevant to a decision at a particular point in time. For example, reactivity

can be reduced by using appropriate retrieval cues, such as using only those words that the participant uses themselves, and by avoiding questions that require descriptions or explanations (Steginga & Occhipinti, 2004). The verbal protocol analysis methodology can be applied to real world decisions in such a way as to limit reactivity and to increase the likelihood that the thoughts and information processing strategies elicited are only those which are accessible and salient to the individual at the time of judgement.

Second, restrictions placed on the interviewer to limit interactions with the participant and to remain an unobtrusive observer (often standing behind a participant) within the judgement context is unnatural and violates maxims of communication (Ranyard & Williamson, 2005; Schwarz, 1996). Grice's seminal work on conversational maxims (Grice, 1975) suggests that people seek to be informative (maxim of quantity), truthful (maxim of quality), relevant (maxim of relation), and clear (maxim of manner) when conversing with others. People operate according to assumptions about the principles of cooperative conversation when interacting with another person (Schwarz, 1996). Specifically, people assume that others attempt to be truthful, informative, clear, and relevant when conversing with one another and any indication that a communicator is violating these norms will lead the listener to attempt to interpret or search for the intended meaning of the communication. The lack of interaction with participants breaks conversational rules (Williamson, Ranyard, & Cuthbert, 2000).

Further, according to communication accommodation theory (Giles, Coupland, & Coupland, 1991), conversational roles exist any time words are spoken for another's benefit, and therefore each party is reactive to one another (Boren & Ramey, 2000). A participant will attempt to interpret the speaker's utterances, and in this regard, a participant will also seek to interpret the meaning of silences. As the goal of verbal

protocol analysis is to limit reactivity and to encourage the uninterrupted expression of cognitive processes, participant reactions to and interpretations of the intended meaning behind an interviewer's communications during the task should be avoided.

Both Schwarz (1996), and Boren and Ramey (2000) suggest that conversational approaches to conducting research are important for reducing reactivity and to enhance the quantity and quality of relevant information elicited from participants.

Conversational approaches to eliciting verbal reports have been applied previously in verbal protocol analysis (Ranyard & Williamson, 2005; Steginga & Occhipinti, 2004) and in other thought-listing techniques (Williamson, et al., 2000). The conversational technique employed by Williamson et al. elicited more statements about decision processes that were relevant to the decision task compared to conditions where no verbal think-aloud instructions were given, whilst producing little reactivity. Minimal encouragers such as responding with *uh hm*, maintaining an attentive expression, or nodding one's head in accordance with conversational norms can facilitate communication without altering the content or process of the participant's thoughts (Ranyard & Williamson, 2005). In this connection, responses such as *OK* or *yes* in response to statements should be avoided as they may suggest to the participant that they are providing information the interviewer wants to hear. Researchers need to be sensitive to the many ways in which their procedures provide information to participants, including through non-interaction.

Although the current study applies verbal protocol analysis to assess cognitive structures and information processing strategies, there are other research methods associated with eliciting people's thoughts, ideas, and feelings that could have also been considered. For instance, the Active Information Search (AIS; Huber, et al., 1997) paradigm described in Chapter 5 attempts to identify the information search strategies

used by participants as they seek to resolve a problem or to make judgements or choices. Further, there are many qualitative interview techniques, such as grounded theory, that elicit information from the participant to guide theory development. However, interview techniques that encourage participants to reflect on their thoughts through probing questions contrasts with the aims of the current study where the focus is on participants to reveal only the most salient information and processing strategies in use at the time of considering a judgement. The focus of the current study is on eliciting and analysing the information processing strategies men use when considering prostate cancer risk and screening decisions rather than guiding participants to reflect on or analyse their thoughts and feelings.

7.1.5 Information Processing Strategies for Prostate Cancer Risk and Screening

Judgements

The purpose of the current study is to reveal and categorise the nature of the information processing strategies men use to make judgements about their personal risk of developing prostate cancer and to make decisions about screening. Specifically, the influence of having a family member diagnosed with prostate cancer on the information available to and accessed by unaffected relatives during such judgements is argued to lead to the use of different types of or more frequent use of specific processing strategies. Accordingly, the Heuristic-Systematic Processing Model (Chaiken, 1980) is applied to delineate the types of information processing strategies utilised by such men as well as to describe the contextual conditions where particular types of strategies are likely to dominate.

As described in Chapter 3, the HSM proposes that people use systematic, heuristic, or biased systematic processing to make judgements under different

contextual conditions. For instance, greater use of systematic processing has been found when issues are personally relevant (Chaiken, 1980; Claypool, et al., 2004), when a participant is more familiar with information (Garcia-Marques & Mackie, 2001; Moons, Mackie, & Garcia-Marques, 2009), and when issues are associated with negative affect (Bless, et al., 1996; Bless, Mackie, & Schwarz, 1992; Martin, et al., 1993; Wegener, et al., 1995). However, systematic processing can become biased when people are motivated to rely on heuristic cues to guide their judgements about information, such as when reasoning about information that is threatening. For example, when information is personally relevant and threatening (e.g., health issue) people employ biased systematic processing whereby they evaluate arguments more critically if they are personally threatening (Ditto & Lopez, 1992; Liberman & Chaiken, 2003). In this regard, people are guided by defense motivations which influence the degree of processing and message scrutiny that they apply to evaluating personally threatening information (Ditto & Lopez, 1992; Giner-Sorolla & Chaiken, 1997; Liberman & Chaiken, 2003).

Further, the HSM provides a framework by which to understand the role that prior experience has on the selection of information processing strategies that can be revealed through verbal reporting methods. For instance, heuristic cues to judgement are used only if they are easily accessible, available, and applicable to the current judgement (Chen & Chaiken, 1999). In this regard, men with a family history of prostate cancer would have more information available to them about prostate cancer, greater interactions with their affected family member may make this information more salient, and the generation of more applicable heuristic cues would be possible based on associations formed from prior experience.

Steginga and Occhipinti (2004) used the HSM framework and a conversational approach to verbal protocol analysis to examine men's decision-making about prostate cancer treatment. Men were more likely to make use of the heuristic strategy, the *expert opinion heuristic* (trust in the opinion of an expert, such as a doctor), as well as more systematic processing when they expressed greater uncertainty about their treatment decisions. Further, men who used the expert opinion heuristic strategy were less likely to use systematic processing than men who did not use this heuristic strategy. The results of Steginga and Occhipinti demonstrate how the verbal protocol analysis method can be applied to examine use of systematic and heuristic processing in accordance with the HSM. In the current study, the HSM framework will be used to delineate use of heuristic and systematic processing strategies in relation to judgements about prostate cancer risk and prostate cancer screening. Specifically, verbal protocol analysis will be used to compare the information processing strategies used by men with and without a first-degree family history of prostate cancer.

7.1.6 Predicting Dominant Processing Strategies for FDRs

The HSM has been applied previously to examine differences in the processing strategies used by different groups of people who are motivated towards different processing goals. For example, Trumbo applied the HSM to a case study about people's perceptions of there being a cancer cluster in relation to the operation of small research reactor in Ames, Iowa between 1965 and 1981 (1999). Comparing people who self-classified as of high concern, of low concern, or uncertain about the existence of a cancer cluster in Ames, Trumbo reported that for people who were uncertain, motivation was associated with both heuristic and systematic processing and that heuristic processing predicted lower risk perceptions whereas systematic processing

predicted higher risk judgements. For the highly concerned group, both heuristic and systematic processing predicted lower risk perceptions while motivation predicted use of systematic processing. The potential for heuristic processing to be related to lower risk perceptions was supported in another field study that examined risk perceptions across three states in the United States where environmental hazards are perceived to be related to cancer risks (Trumbo, 2002). These findings would suggest that, if FDRs have higher risk perceptions compared to men from the general population, they may process information more systematically.

Further, in accordance with motivational approaches to processing information outlined in the HSM, Kim and Paek (2009) manipulated people's motivations to process information about genetically modified food and found attitude change to be predicted by different strategies across groups. Specifically, Kim and Paek primed participants to be motivated by accuracy, defense, or impression motivations and examined whether groups differed according to their use of heuristic and systematic processing.

Consistent with the bias and attenuation effects for integrating heuristic and systematic processing strategies described within the HSM, attitude change was not predicted by heuristic or systematic processing in the defense motivation group. For the accuracy motivated group, the ease or accessibility of the participant's prior attitudes prompted more systematic processing which in turn predicted attitude change, consistent with the bias hypothesis. Thus, accuracy and defense motivations resulted in a reliance on different processing strategies as a basis for changing (or not changing) previously held attitudes.

Based on these results, FDRs could process information more systematically or biased systematically dependent on whether they are guided by accuracy or defense motivations. It is possible that FDRs could be guided by accuracy motivations such that

they are motivated to seek to make accurate judgements about their personal risk of prostate cancer and the benefits of participating in early detection screening behaviours. In contrast, owing to heightened risk perceptions associated with familial risk, FDRs may be guided by defense motivations such that they are motivated to process information in a way that defends themselves against having a greater risk of being diagnosed with prostate cancer compared to other men. It is also possible that FDRs would be guided by both accuracy and defense motivations such that a motivation to base judgements on strong arguments or evidence (systematic processing) would be biased by a motivation to defend the self (heuristic processing). It is the latter hypothesis that guides the predictions for the current study.

7.1.7 Hypotheses

Although the use of heuristic and systematic processing across FDR and GP men can be influenced by a variety of factors including motivations, personal relevance, and perceptions of threat in relation to prostate cancer, a number of predictions are made. In relation to the use of non-systematic processing strategies the following hypotheses are proposed:

H7.1: First-degree relatives will be more likely to make use of heuristic strategies, such as the availability and representativeness heuristics, when discussing prostate cancer screening and prostate cancer risk, compared to men from the general population. Further, FDRs will be more likely to apply these heuristic strategies in ways aimed at reducing judgements of risk.

H7.2: First-degree relatives will endorse more lay beliefs about the causes of prostate cancer and the outcomes of prostate cancer screening than will men from the general population.

In relation to the use of systematic processing strategies the following hypothesis is proposed. If hypotheses H7.1-H7.3 are supported, it will provide support for the argument that there will be greater use of biased systematic processing by men with a family history:

H7.3: First-degree relatives will make greater reference to seeking or obtaining information about prostate cancer screening and risk factors than will men from the general population. Further, FDRs will report greater information about the known prostate cancer risk factors and current prostate cancer screening recommendations.

7.2 Method

7.2.1 Participants

The participants in the current study were those who completed the policy-capturing study described in detail in Chapter 6. There were no participants who were excluded or who withdrew from the verbal protocol analysis interview and therefore all participant details and socio-demographic information for the current study is identical to that described in Chapter 6.

7.2.2 *Materials and Procedure*

The interview was conducted according to a conversational approach to verbal protocol analysis. Care was taken to design the consent and information materials, interview instructions, questions, and guidelines to increase the likelihood that participants would provide only information that was accessible and salient to them in relation to their judgements. The information letter and consent form (see appendices F and G, respectively) described the study as examining preventive health behaviours rather than prostate cancer screening or PSA testing, and there was no mention of the assessment of risk perceptions in the study description.

Consistent with the suggestion by Boren and Ramey (2000), instructions provided participants with a context and purpose for the interview to convey the role of the participant as expert in the communication and to encourage the participant to be cooperative and open in their communications. Prior to the commencement of the interview, participants were told that the information they provided would help to inform the development of information and support services and that their responses would help to ensure that services were based on what they would want, rather than on what the organisation thought that they would want. As shown in Figure 7.1, participants were encouraged to list all of their thoughts (Cacioppo & Petty, 1981; Ericsson & Simon, 1993). Based on feedback from pilot interviews, instructions included information about the number of questions to expect during the interview (pilot participants reported that they limited their responses owing to uncertainty about how many questions were to follow) and that the interview questions did not seek to reveal correct responses or knowledge (pilot participants reported that they wondered if the organisation was looking for correct answers to the questions). Further, the pilot interview enabled the interviewer to practice conversational responses that were non-

reactive and facilitated the elicitation of valid verbal reports. Consistent with Cacioppo et al.'s (1997) suggestion for response time intervals, the interviewer attempted to limit responses for each question to 2-3 minutes.

Verbal Protocol Analysis Interview

We want to find out how men make decisions about testing for prostate cancer. In particular, we are interested in the things you think about when you consider testing for prostate cancer. I am going to ask you six questions about your thoughts on testing for prostate cancer. We're not looking for facts or for right or wrong answers. We're looking to hear ALL the thoughts that you have had about testing for prostate cancer. Please feel free to take your time.

What have you thought about when deciding whether or not to be tested for prostate cancer?

What do you think contributes to a person's risk of developing prostate cancer?

What do you think determines whether you will develop prostate cancer?

When you think of someone at risk of developing prostate cancer, what sort/kind/type of person or people do you think of?

What do you know about the pros and cons of prostate cancer screening?

Can you think of any issues in real life that could be obstacles and get in the way of men being tested for prostate cancer?

Figure 7.1 Verbal Protocol Analysis interview script.

In accordance with Ericsson and Simon's (1980; 1993) discussion of the different levels of verbalisation, interview questions were designed so as to not require explanatory or descriptive responses from participants. As shown in Figure 7.1, questions were not framed as *how* or *why* questions; rather questions were posed to elicit the thoughts the participant had actually been thinking. Further, consistent with recommendations made by Ericsson and Simon and based on the interviewer procedure employed by Steginga and Occhipinti (2004), the following interview guidelines were imposed on the interviewer to minimise the potential for reactivity whilst maintaining cooperative conversational norms (see Figure 7.2). These interview guidelines have been implemented previously in a similar study that employed a conversational approach to verbal protocol analysis (Steginga & Occhipinti, 2004). Following completion of the interview, participants were thanked for their time and contribution. All interviews were digitally-recorded and transcribed verbatim, including utterances and pauses.

- Do not introduce content participant themselves did not spontaneously recall
- Use only paraphrasing and reflecting (to elicit clarification or expansion of thoughts the participant recalls)
- Restate the original question, if required
- Use the same wording to discuss testing/risk the participant themselves uses
- Use minimal encouragers that are not negatively or positively loaded
- Do not probe with “Why” or “How” questions
- If the participant asks a question during the verbal protocol analysis or seeks clarification of their response the interviewer should respond with *we are interested in your thoughts* and request the participant to continue.

Figure 7.2 Interviewer guidelines for reducing reactivity in VPA responses.

7.3 Results

7.3.1 Data Coding Scheme

The development of the data coding scheme was guided by the Heuristic Systematic Processing Model (Chaiken, 1980) and prior research on decision-making about prostate cancer screening. The coding manual developed by Steginga and Occhipinti (2004) for analysis of verbal protocol data on prostate cancer treatment decision-making applying the HSM was used as a basis for designing the manual for the current study. As the focus of the interview was on both prostate cancer risk judgements and screening decisions, distinctions were made, where possible, between the information processing strategies that were applied by participants to judgements about prostate cancer risk and screening decisions (see Table 7.1 and Appendix H).

Theoretical considerations based on the HSM information processing framework led to the development of three broad categories to represent heuristic and systematic processing. As shown in Table 7.1, the *heuristics* category contained information processing or decision strategies that were mediated by mental shortcuts, including the widely researched representativeness, availability, and affect heuristics. Heuristic strategies that could be applied to make judgements that were either positively or negatively associated with an outcome or comparison were represented as distinct coding units (see Table 7.1). Systematic processing was represented across two broad groups of processes: *information-seeking behaviour* and *evaluation of medical information* known to relate to prostate cancer risk and screening (see categories 4 and 5 in Table 7.1). These categories captured awareness and knowledge of prostate cancer risk and screening information that was integrated into judgements as well as attempts to seek additional information for the purposes of guiding decision-making. Contextual uncertainty associated with prostate cancer risk factors and screening recommendations was captured in the *uncertainty* category.

Prior to the finalisation of the data coding scheme, members of the research team read through a random selection of transcripts to identify any additional coding concepts from the decision-making research domain that could be articulated in the coding scheme (Lutfey, et al., 2008; Strauss & Corbin, 1998). The coding category of *magical thinking* emerged from this process and represented processes that were based on beliefs about the causality of events that diverged from current scientific evidence. For example, the coding unit defined as *tempting fate* derived from participant statements that reflected how people make judgements about the likelihood of events found in research on gambles, insurance, and risky choice (e.g., the likelihood of a lottery ticket winning would increase if one swapped it with another person; Risen &

Gilovich, 2008; Tykocinski, 2008). Further, consistent with the mental models approach to cancer risk communication and the tendency for people to think metaphorically about cancer, the coding category *rusty car* was created that captured the potential for participants to conceptualise cancer and its treatment as they do rust on a car. For example, men who perceive that by detecting prostate cancer in its early stages (e.g., finding a section of rust on a car) they can prevent the development of prostate cancer (e.g., by cutting out the section of rust before it takes over the car). These beliefs were distinct from those represented in the *lay beliefs* category which was included to capture beliefs about the causes of cancer or the benefits of screening that were consistent with scientific evidence but were not currently found in relation to prostate cancer.

Table 7.1

Coding Units and Category Definitions for the VPA Coding Manual

Category of meaning	Category Definition	Category Unit
1. Heuristics	The heuristic category includes schemas, stereotypes, references to prior knowledge or expectancies, or commonsense rules of thumb that are invoked to help the person evaluate their risk or prostate cancer screening decision.	1.1 Expert Opinion ^b 1.2 Availability ^{a b} 1.3 Representativeness ^{a b} 1.4 Affect ^{a b} 1.5 Illusion of control
2. Magical Thinking	The magical thinking category includes statements that refer to beliefs about causality that diverge from scientific thought or modern conceptions of reality.	2.1 Tempting fate 2.2 Fate and luck 2.3 Rusty car
3. Lay beliefs	The lay beliefs category includes beliefs or theories about the causes of cancer including behaviours, personalities, environmental factors, or beliefs that are not backed up by scientific evidence.	3.1 Lay beliefs or theories about cancer causes/progression 3.2 Lay beliefs or theories for denying cancer risk 3.3 Lay beliefs or theories for need for screening
4. Information Seeking behaviours	Descriptions of seeking or obtaining information about risk/screening or prostate cancer from different sources.	4.1 Seeking information from the doctor 4.2 Seeking or obtaining information from family or friends 4.3 Seeking or obtaining information from sources external to family/friends or the doctor
5. Evaluation of Medical Information	Mentioning medical risks, screening recommendations, or weighing up the pros and cons of early detection screening consistent with current medical knowledge.	5.1 Consideration of medical risk factors 5.2 Consideration of factors related to screening recommendations 5.3 Consideration of pros and cons of screening
6. Uncertainty	Mentioning uncertainty about risk factors, screening recommendations, or just general uncertainty about prostate cancer.	6.1 Uncertainty about risk factors 6.2 Uncertainty about prostate cancer screening 6.3 General uncertainty

Note. ^a coding categories were separated into positive and negative units ^b coding categories were separated into risk and screening statements

Thus, the coding manual contained six major coding categories representing 30 distinct coding units. The manual included definitions of each category unit along with scoring criteria, examples of possible text segments, and other notes about coding categories that were designed to assist coders. The *heuristics*, *magical thinking*, *lay beliefs*, and *information-seeking* categories were scored multiple times according to each instance of the category unit found within the transcript. Multiple units allowed for the calculation of the extent to which the information processing strategies were used. The *availability heuristic* category was scored according to the reference group through which the participant made their judgement (1 = family member, 2 = friend or other, 3 = reading, viewing, or general media, 4 = general such as *they*). For the category *seeking or obtaining information from family or friends*, scores indicated from whom the information was obtained (1 = family, 2 = friend). For the *evaluation of medical information*, and *uncertainty* categories single scores were applied to indicate the presence or absence of the category (see Appendix H).

Similar to the coding protocol used in Chapter 5 for coding prostate cancer screening reasons, coders in the current study were provided with an information sheet containing basic information about prostate cancer risk factors and screening recommendations (see Appendix E). The information sheet served to provide a factual, unbiased report of current recommendations for the early detection of prostate cancer to coders. The coders were told to check with the research team if they found any statements relating to prostate cancer risk or screening that they were uncertain how to code. Coders were blind to the research hypotheses and were unaware of family history as a characteristic of the group of men whose transcripts they were coding.

Transcripts were coded in full and the segmentation of the data represented units of meaning, defined as a statement consisting of one main idea or unit of meaning

(Steginga & Occhipinti, 2004; Svenson, 1989). Although Ericsson and Simon (1993) recommend that coding segments be presented to coders out of context to reduce the influence of surrounding statements on the coding of each unit, these conditions were considered unsuitable for the current study. The coding categories were designed to capture thought processes that occurred within the context of the interview statements. Hassebrock and Prietula (1992) used a similar approach to analysing verbal protocols to determine the use of different canonical models by physicians in medical diagnosis. Consistent with the recommendations for coding statements made by Ericsson and Simon, irrelevant statements that did not relate to the question were not coded.

7.3.2 Reliability of Coding

To check the reliability of the coding scheme, inter-rater agreement was checked by utilising two independent coders to score the transcripts. Consistent with the coding agreement process implemented in Luftey et al. (2008) for managing the integrity of coding with multiple coders, a third of the transcripts were randomly selected to be coded by both coders, and bi-weekly meetings were held with the coders and the research team during the initial stages of coding to discuss inconsistencies and to clarify coding criteria. Agreement between the two coders with respect to the interpretation of coding categories and the segmentation of transcripts improved during these meetings.

Sixty one distinct coding categories were identified. These included the separate coding categories for each reference group mentioned as part of the availability heuristic (e.g., family, friend) and for each of the medical information categories (e.g., each separate risk factor). Of these categories, six did not receive any codes for a third of the transcripts coded by both coders. Of the remaining categories, 18.2% had good-to-excellent reliability (kappas above .60), and 32.7% had moderate reliability (kappas

above .40). Approximately 36% of the categories with low reliability across coders were categories that only received a small number of codes (e.g., only one code by one of the coders) or were categories that fell into the lay beliefs or medical information coding units.

Owing to the complexity of prostate cancer risk and screening information, and particularly the uncertainties associated with prostate cancer screening, transcripts were examined by the researcher and the principal investigator on the project to clarify discrepancies amongst coders and to check correct coding of screening-related statements. For example, because limited information was provided to coders about prostate cancer and screening, statements such as: *it's more likely to be slow growing and if it appears for the first time in early to mid 60's chances are it won't even be treated...*, were coded by coders as lay beliefs despite this statement being an accurate assessment of the slow growing nature of many prostate cancers. As described in Chapter 5, the decision to provide coders with a limited set of information about prostate cancer and screening issues was to avoid having the coders seek out additional information or to form a judgement about screening that may influence their judgements. The majority of recoded statements were those that fell into the *lay beliefs* category for the reasons stated above, and for the *expert opinion heuristic*, *uncertainty*, and *information-seeking* categories where the coders were over-coding passive statements (e.g., *I went to the doctor and got a test*) as opposed to strictly active statements (e.g., *I went to the doctor and asked him about the test*).

7.3.3 Frequency of Coding Categories

The frequencies of coding categories are presented in Table 7.2. The separate reference groups coded for the availability heuristic were collapsed to indicate the extent of use of any referent, and the total number of different medical information points mentioned within the coding categories 5.1, 5.2 and 5.3 were calculated. Further, the coding categories were recoded to indicate the presence or absence of men using each strategy for the purposes of reporting frequency of use at least once by a participant (see Table 7.2).

Heuristic processing strategies. Almost all men (96.3%) used at least one heuristic strategy with the availability heuristic being the most frequent heuristic strategy used (90.6% of FDRs and 82.0% GP men) followed by the representativeness (34.4% of FDRs and 40.0% GP men) and affect (31.3% of FDRs and 24.0% GP men) heuristics, and the expert opinion (31.3% of FDRs and 26.0% GP men) and illusion of control (25.0% of FDRs and 20.0% GP men) strategies. The majority of FDRs (68.8%) used at least one magical thinking strategy compared to 54.0% of GP men. Almost three quarters of GP men mentioned at least one lay belief (74.0%) compared to 62.5% of FDRs. First-degree relatives were more likely than GP men to report using family as a source for the availability heuristic for positive risk (40.6% and 16.0%, respectively) and screening judgements (65.6% and 12.0%, respectively).

Table 7.2

Frequency of Coding Categories Mentioned in the VPA

Category Unit		+/-	FDR ^a N (%)	GP ^a N (%)	FDR M (SD)	GP M (SD)
1.1 Expert Opinion	Risk		1 (3.1)	2 (4.0)	.03 (.18)	.04 (.20)
	Screen		23 (28.1)	12 (24.0)	.34 (.65)	.30 (.61)
1.2 Availability	Risk	+	20 (62.5)	18 (36.0)	.94 (.98)	.58 (.95)
		-	11 (34.4)	21 (42.0)	.50 (.80)	.50 (.65)
	Screen	+	23 (71.9)	21 (42.0)	1.41 (1.66)	.76 (1.12)
		-	4 (12.5)	7 (14.0)	.16 (.45)	.14 (.35)
1.3 Representativeness	Risk	+	7 (21.9)	10 (20.0)	.44 (.98)	.24 (.52)
		-	4 (12.5)	11 (22.0)	.16 (.45)	.26 (.53)
	Screen	+	2 (6.3)	1 (2.0)	.13 (.49)	.04 (.28)
		-	-	1 (2.0)	-	.02 (.14)
1.4 Affect	Risk	+	2 (6.3)	7 (14.0)	.06 (.25)	.14 (.35)
		-	5 (15.6)	2 (2.0)	.22 (.61)	.02 (.14)
	Screen	+	4 (12.5)	8 (16.0)	.13 (.34)	.18 (.44)
		-	7 (21.9)	6 (12.0)	.25 (.51)	.16 (.51)
1.5 Illusion of control			8 (25.0)	10 (20.0)	.31 (.59)	.22 (.46)
2.1 Tempting fate			9 (28.1)	10 (20.0)	.28 (.46)	.24 (.56)
2.2 Fate and luck			16 (50.0)	16 (32.0)	.59 (.67)	.38 (.60)
2.3 Rusty car			5 (15.6)	12 (14.0)	.25 (.67)	.26 (.49)
3.1 Lay beliefs cancer causes			18 (56.3)	35 (70.0)	1.22 (1.36)	1.5 (1.52)
3.2 Lay beliefs denying cancer risk			5 (15.6)	5 (10.0)	.22 (.61)	.10 (.30)
3.3 Lay beliefs need for screening			2 (6.3)	4 (8.0)	.06 (.25)	.08 (.27)
4.1 Seek info from Dr			8 (25.0)	8 (16.0)	.28 (.52)	.18 (.44)
4.2 Seek/obtain info family/friends			1 (3.1)	1 (2.0)	.03 (.18)	.02 (.14)
4.3 Seek/obtain info other			7 (21.9)	4 (8.0)	.22 (.42)	.10 (.36)
5.1 Medical risk factors ^b			30 (93.8)	46 (92.0)	1.72 (.81)	1.58 (.91)
5.2 Screening recommendations ^b			24 (75.0)	38 (76.0)	1.31 (1.00)	.98 (.68)
5.3 Pros and cons of screening ^b			25 (78.1)	32 (64.0)	1.56 (1.41)	1.24 (1.48)
6.1 Uncertainty risk factors			21 (65.6)	41 (82.0)	.66 (.48)	.82 (.39)
6.2 Uncertainty PCa screening			10 (31.3)	18 (36.0)	.31 (.47)	.36 (.48)
6.3 General uncertainty			-	4 (8.0)	-	.08 (.27)

Note. ^a Percentage of men reporting at least one unit of meaning. FDR $N = 32$; GP $N = 50$. ^b Total number of factors mentioned.

Systematic processing strategies. Men from both groups identified on average more than one piece of medical information about risk factors, screening recommendations, or the pros and cons of screening. The information most likely to be mentioned for medical risks (coding category 5.1) was age (43.6% of FDRS and 68.0% GP men) and family history (84.4% of FDRS and 60.0% GP men) as risk factors, and only age, family history, or symptoms were likely to be mentioned in relation to screening recommendations (coding category 5.2). Of a total of 10 possible screening pros and cons that could have been mentioned by participants (coding category 5.3), only two were mentioned by more than 20% of participants. Most men mentioned that early detection is a pro for prostate cancer screening (50.0% of FDRs and 46.0% GP men) and 23.2% of men mentioned that the PSA test is only an indicator for prostate cancer.

Information seeking was not reported by many participants; less than 20% of the total sample reported having sought information for the doctor, less than 14% having sought information from external sources, and less than two percent having sought information from a family member or friend. A larger proportion of FDRs reported having sought information from at least one external source compared to GP men.

7.3.4 Differences in Strategy Use Across Groups

Analyses were run using *t*-tests for coding categories where more than one response was coded (e.g., coding units 1-5). Chi-square tests were run for categories that were coded for the presence or absence of a unit (e.g., coding unit 6) or for categories where the range of responses did not exceed a maximum of more than one instance per participant. For the majority of analyses, there were no significant differences between the extent of heuristic or systematic processing reported by FDRs

and GP men. On average, first-degree relatives ($M = 5.06$, $SD = 3.69$) were more likely than were GP men ($M = 3.60$, $SD = 2.56$) to use a greater number of heuristic strategies overall ($t(80) = -2.12$, $p = .037$ (two-tailed), $\eta^2 = .053$). In relation to the affect heuristic, FDRs were more likely to report negative affect in relation to their risk compared to GP men ($t(80) = -2.23$, $p = .029$ (two-tailed), $\eta^2 = .058$).

For the availability heuristic, when collapsing across reference groups, FDRs reported greater use of the availability heuristic for positive associations related to prostate cancer screening ($t(80) = -2.12$, $p = .038$ (two-tailed), $\eta^2 = .053$). This result could be explained by FDRs using more instances of family as a source for positive associations with risk ($t(80) = -3.47$, $p = .0008$ (two-tailed), $\eta^2 = .131$). Recoding variables to indicate presence versus absence of a strategy revealed only one additional significant result: FDRs were more likely than GP men to report having used the availability heuristic for positive associations related to prostate cancer risk ($\chi^2 = 5.51$, $p = .019$). This result could also be explained by FDRs being more likely than GP men to have used at least one instance of family as a source of information to associate positively with risk ($\chi^2 = 6.21$, $p = .013$). Collapsing across risk, screening and valence categories, FDRs ($M = 1.81$, $SD = .21$) were more likely than GP men ($M = .96$, $SD = .20$) to use family more frequently as a source for the availability heuristic ($t(80) = -2.80$, $p = .006$ (two-tailed), $\eta^2 = .089$).

Biased systematic processing. Composites of heuristic and systematic coding categories were created to examine the extent of heuristic and systematic processing and to explore whether use of systematic processing was biased by the use of heuristic processing strategies. There were no significant differences found across any analysis (composites were created for coding units 1-5 separately and in combinations).

7.4 Discussion

In partial support of the hypotheses, FDRs were more likely than GP men to make use of positive availability heuristics, particularly when the source related to a family member, and were more likely to refer to negative affect in relation to judgements of risk. Further, FDRs used a greater number of heuristic strategies on average than did GP men. However, contrary to the hypotheses, in the majority of analyses men with a family history of prostate cancer were no more likely than were GP men to use more heuristics, use heuristics more frequently, or to bias their use of systematic processing with heuristic strategies. Systematic processing measured by the consideration of risk factors and screening recommendations was low amongst all men with age, family history, and reference to prostate cancer symptoms being the most frequently mentioned responses. Very few men knew many pros and cons related to the benefits of early detection testing. Also, references to information-seeking were low. When allowing men to discuss the information they used in their decisions about prostate cancer screening or when considering their personal risk of being diagnosed with prostate cancer, the majority of strategies men used were the same for FDRs and GP men. The implications of these findings for understanding how men with and without a family history approach their screening decisions and make judgements about their personal risk of prostate cancer are discussed.

7.4.1 Understanding Judgements of Risk and Screening Decisions according to the HSM

The heuristic information processing strategies of availability, representativeness, and affect were found to influence judgements about risk perceptions and screening behaviours for FDRs in Chapter 4. However, when measured with more qualitative methods, there were very few differences in the application of heuristic or systematic processing strategies between FDRs and GP men. Rather, all men applied a variety of heuristic strategies with FDRs being more likely to make use of the availability heuristic, particularly as it related to the family as a source of information, and to associate negative affect with judgements of risk.

It was proposed that defense and accuracy motivations would guide the selection of processing strategies employed by men with a family history of prostate cancer and lead to more heuristic strategies and potentially more biased processing of information. However, when reasoning about personal risk of developing cancer and considering the benefits of health behaviours, being a personally relevant and potentially threatening issue, the motivations for processing and utilising information may have been the same for all men. For example, all men may have been motivated to use whatever processing strategies they needed to satisfy themselves that they could reach a specific judgement, such as finding strategies that were consistent with their decisions to participate in early detection screening. Consequently, the current results could not really differentiate between those strategies used more frequently by men with or without a family history of prostate cancer.

Systematic processing as it was measured in the current study was low with few men mentioning more than a couple of risk factors, considering more than a few factors

associated with screening recommendations, or referencing more than a few issues associated with early detection screening. This finding has implications for how the HSM is applied to everyday decisions that occur outside of the experimental context. In previous research associated with the HSM, systematic processing is generally assessed by providing participants with information in the form of strong or weak arguments about an issue and examining which arguments are selected more often by participants or which arguments lead to greater attitude change (Chaiken & Maheswaran, 1994; Claypool, et al., 2004; Garcia-Marques & Mackie, 2001; Moons, et al., 2009), or by assessing responses to questions that would indicate greater beliefs or attitudes consistent with the systematic processing of an issue (Trumbo, 1999, 2002).

In the current study, the verbal protocol analysis methodology required men to discuss the information that they personally considered in their decisions about prostate cancer screening and in determining their conceptualisations of risk. A similar methodology was applied by Steginga and Occhipinti (2004) with men considering treatment decisions for prostate cancer who found that men used systematic strategies to reason through information about the various prostate cancer treatment options. However, unlike Steginga and Occhipinti, men in the current study were not facing a decision with immediate personal consequences where information would have been recently provided following a medical consultation (e.g., following the diagnosis of prostate cancer). Rather, as evident in the results from Chapter 4, men in the current study may not have been provided with a great deal of information about prostate cancer and screening in a consultation with their physician and therefore would have been less able to use relevant medical and screening information in their judgements. Alternatively, fewer than 20% of participants in the current study mentioned seeking out information about prostate cancer and screening suggesting that men were relying on

existing knowledge about cancer and screening to make their judgements. Thus, systematic processing strategies are difficult to assess in the current decision context if men were not provided with decision-relevant screening information to use when considering their screening decisions.

Support for the use of heuristic strategies to guide judgements made by men with a family history of prostate cancer can be derived from qualitative studies that examine the construction of risk perceptions and discuss screening behaviours in people at high-risk of disease (Emery, et al., 1998; Kenen, et al., 2003; Sanders, et al., 2003) as discussed in Chapter 4. The results from the current study support many of the findings reported in these qualitative studies such that men with a family history of prostate cancer made use of a variety of heuristic strategies and lay beliefs about cancer to guide their judgements. However, the current study extended previous research on risk constructions and the health behaviours of people at high-risk of disease by comparing strategies used by such men to those of people who were at average risk of disease. It is through this comparison that it can be argued that people at high-risk of cancer may not be approaching risk judgements or health behaviours with a different set of strategies to those people at average risk. Rather, the results from the current study suggest that all men are simply integrating information into their existing knowledge structures using similar information processing strategies. The focus of future research may be to determine into what existing mental models men are integrating information based on their personal experiences.

7.4.2 Revisiting the Mental Models Approach to Conceptualising Prostate Cancer

The mental models approach (Downs, et al., 2008; Morgan, Fischhoff, Bostrom, & Atman, 2001) to conceptualising cancer was described in Chapter 5 as a possible

explanation as to why some men consider prostate cancer screening as a preventative health behaviour. The results from the current study further support the applicability of mental models to the conceptualisation of prostate cancer risk and screening. The prevalence of a variety of heuristic strategies in the current study suggests that existing knowledge is being used as a basis for processing information to guide judgements. Specifically, men may use heuristic strategies to integrate information into a specific mental model about prostate cancer, its diagnosis, and treatment. An understanding of these mental models may clarify how FDRs and GP men differ with respect to their constructions of risk perceptions and their understanding of prostate cancer screening which in turn guides screening behaviour.

The majority of FDRs and over half of GP men used at least one reasoning strategy classified under the magical thinking coding scheme. Many men considered that one's risk of getting prostate cancer was a result of fate or the luck-of-the-draw. Further, consistent with the results from Chapter 5, a proportion of men considered that prostate cancer screening reduced the risk of developing prostate cancer (tempting fate) or conceptualised prostate cancer as one does rust on a car such that early detection screening was described as a way to find and treat signs or traces of prostate cancer, or to catch the cancer before it develops. Perceiving prostate cancer and screening in this way may further influence the way in which family history information is integrated into existing mental models. For example, men with a family history of prostate cancer may be more likely to consider that the later stage diagnosis of prostate cancer in a relative who did not participate in early detection screening supports the idea that prostate cancer screening can prevent or protect against the development of prostate cancer if detected early.

Men with a family history of prostate cancer are likely to not only use their family history experiences as a source of information about prostate cancer and screening but are also likely to construct a distinct mental model of prostate cancer based on a relative's experience which guides their processing of new risk and screening information. Although all men used a variety of heuristic strategies to process information about prostate cancer in the current study, the information contained within these strategies may have a differential impact on the risk perceptions of FDRs or on beliefs about the benefits of early detection screening. For example, it may not be that FDRs are more likely to use the representativeness heuristic to consider how their personal risk compares to their representations of the typical person (or affected relative) who gets prostate cancer, but that FDRs are more likely to integrate this information in a more enduring way that leads to more meaningful conceptualisation of personal risk. This may explain why the availability and representativeness heuristic strategies reported in Chapter 4 contributed to the prediction of risk perceptions and screening behaviour for FDRs more so than they did for GP men.

7.4.3 Intuitive versus Analytic Processing

Although it is not possible to conclude that men in the current study did not use systematic processing because they were insufficiently informed about the risks, benefits, and uncertainties of prostate cancer screening when making their judgements, a potential explanation for the prevalence of heuristic over systematic reasoning strategies in the current study is that the decision context is complex and better suited to intuitive judgements. A contrasting view to dual-system approaches to reasoning and decision-making is that the selection of heuristic strategies can be both intuitive and

deliberate, and one of the guides for selecting judgement rules (e.g., heuristics) is associated with their suitability, or their ecological rationality, to the judgement task (Gigerenzer & Gaissmaier, 2011; Kruglanski & Gigerenzer, 2011). That is, intuitive and deliberate judgement strategies are all part of a single system and people approach a given task with a set of rules by which they select the most appropriate rule for a specific judgement.

For example, the concept of satisficing (Simon, 1957), or reasoning about options to the extent that an option meets or exceeds a specific criteria or level may be applied intuitively when weighing multiple alternatives, or deliberately when seeking to make a decision in a time-pressured environment (e.g., deliberately selecting the first option that meets a criteria). Rather than conceptualising judgements as belonging to either an intuitive (e.g., heuristic) or deliberate (e.g., analytic) system, judgements are made within the constraints of the decision environment and strategies are selected based on their appropriateness to the decision (Kruglanski & Gigerenzer, 2011). Specifically, people have available a set of decision rules that can be acquired through personal experience (e.g., associating the concept of prevalence with greater risk based on previous instances where this rule was appropriate), social development (e.g., acquiring social rules), and acculturation (e.g., inferences about social stereotypes or representativeness). People then apply these rules to a given decision based on task (e.g., mathematical task) or memory (e.g., priming) constraints, and based on processing potential (e.g., attentional capacity and motivations to process information) and ecological rationality considerations (e.g., the rule that will lead to a better outcome given the specific task environment).

It is possible that judgements about prostate cancer and screening behaviours are better suited to heuristic or intuitive judgement processes rather than to deliberate or

analytic judgements that require adequate processing of complex information. For example, the provision of information about prostate cancer screening to patients via decision aids for PSA testing have generally been found to reduce preferences for screening (O'Connor, et al., 2009; O'Connor, et al., 2003). However, although decision aids increase medical knowledge, improve decision satisfaction and decisional involvement, and enable participants to clarify their decision preferences, decision aids do not necessarily lead to continuance or adherence to chosen options (O'Connor, et al., 2009; O'Connor, et al., 2003). Complex decisions involving risks, benefits, and uncertainties may not be suited to analytic processing and may be better approached with intuitive judgement strategies such as reliance on affective evaluations or selection of the first option that meets specific criteria (e.g., reassurance value). The finding in Chapter 5 that the majority of men simply wanted to know the outcome of a PSA test and viewed the PSA test as providing information with which to take action supports this argument.

7.4.4 Limitations

As discussed in the previous sections, it is not clear whether men were aware of the risks, benefits, and uncertainties of prostate cancer screening to be able to use systematic reasoning strategies (as they were defined in the current study) to inform their judgements. Knowledge of or awareness of prostate cancer screening issues was not examined in the current study, although results from Chapter 4 suggest that there are issues with examining prostate cancer knowledge and that consultations about prostate cancer screening with physicians do not necessarily include extensive discussions about prostate cancer screening risks and benefits. Therefore, conclusions about the prevalence of systematic processing amongst all men are subject to future research

where assessments of prostate cancer screening issues are considered or following consultations with physicians where screening issues are known to have been discussed.

Further, the different heuristic and systematic processing strategies used by men in the current study were not compared to actual judgements of risk or prior screening behaviour. Consequently, no conclusions can be drawn about how different information processing strategies guide actual judgements. It was determined that assessment of risk perceptions prior to or following the VPA with quantitative measures would undoubtedly be influenced by or influence the responses provided by participants in the VPA. Also, the focus of the current study was not on the prediction of risk perceptions or screening behaviour based on use of heuristic or systematic processing strategies. Rather, the current study sought to examine how men made use of different information processing strategies when they make judgements of prostate cancer risk and consider screening decisions.

7.4.5 Summary and Conclusions

Results from the current study suggest that in many ways, men with a family history of prostate cancer do not use different information processing approaches to reasoning about prostate cancer risk and screening than do men without a family history. Rather, there was a high prevalence of heuristic strategies used by all men, suggesting that the ways in which men may differ in terms of their processing of cancer-related information relates to how they integrate information within their existing knowledge structures. The potential for FDRs to use information in their environment differently to GP men (e.g., by assigning greater meaning or weight to this information) is discussed in greater detail in the following chapter.

CHAPTER 8

General Discussion

The current thesis examined the influence of a family history of prostate cancer on the construction of risk perceptions and on decisions to participate in early detection screening. It was proposed that having a family member with prostate cancer altered the decision context for unaffected male relatives such that the relative's experience with prostate cancer acted as an additional source of information to guide judgements. The application of three key theoretical approaches to judgement and decision-making: the Heuristic Systematic Processing Model, Subjective Expected Utility Theory, and Social Judgement Theory; provided unique yet complementary explanations as to how family history information influenced judgements, for example, through the use of heuristic strategies such as the availability, representativeness, and affect heuristics. Although not all hypotheses were supported, evidence for the applicability of these decision-making theories to real world decision problems was largely supported. Implications for informed decision-making approaches to prostate cancer screening are discussed.

8.1 Comparison of Judgement and Decision-Making Models

Three leading theoretical approaches to judgement and decision-making were applied in the current study to examine their unique contributions to understanding the influence of family history on the construction of risk perceptions and in informing screening behaviours. Specifically, methodological modifications were made to the Heuristic Systematic Processing Model (HSM), Subjective Expected Utility theory

(SEU), and Social Judgement Theory (SJT) to improve their application to and assess their utility in addressing the real world issue of deciding whether to participate in prostate cancer screening. Although as a result of the modifications not all models were able to be examined according to the specific tenets of the theories (e.g., SEU theory), a major strength of the current thesis is that through employing different methodologies and applying distinct decision theories to the current decision context, complementary explanations were found to provide a more compelling and comprehensive understanding of prostate cancer screening decisions for men with a family history.

For example, evidence for the use of heuristic reasoning strategies was found in those studies that specifically applied the HSM (Chapters 4 and 7), with additional evidence for how heuristic processes contribute to the construction of risk judgements found in the application of SEU theory in Chapter 5. Men in the evaluation of risk class reported considering information obtained from the media and the cancer experiences of friends or relatives as reasons for prostate cancer screening. Further, FDRs were more likely than GP men to be classified as being in the evaluation of risk class, consistent with the finding that greater variability in risk perceptions and screening behaviours of FDRs was accounted for by the availability heuristic as measured in Chapter 4. Further, the role of negative affect in influencing judgements of risk, particularly for FDRs, was found not only in the study documented in Chapter 7 where FDRs were more likely to report negative affect in relation to risk, but in Chapter 4 where risk perceptions were predicted by greater perceptions of threat related to a relative's cancer experience.

As well, potential explanations for some of the classes of reasons identified when applying SEU theory in Chapter 5 were explored and supported in the application of the HSM in Chapter 7. Specifically, a small proportion of men held lay beliefs about the causes or prognosis of prostate cancer and the outcomes of treatment, consistent

with the view that early detection screening could act as a preventative against developing prostate cancer. Although not strictly conceptualised as heuristic strategies consistent with the HSM, these magical thinking strategies were incorporated in the coding manual for the VPA and were also found in a small proportion of men discussing prostate cancer screening in Chapter 7. The idea that men held existing mental models about prostate cancer that were inconsistent with current medical conceptualisations receives support from both of these studies. Finally, the finding that family history contextual information, such as the relationship between an FDR and his affected relative (e.g., brother) did not predict prostate cancer risk perceptions in Chapter 4 is consistent with the finding that men weighed this family history relationship information less when assessed in accordance with Social Judgement Theory (Chapter 6). The complementary nature of the findings across four different studies employing three distinct decision-making approaches suggests that each theoretical approach contributed unique information to the understanding of prostate cancer screening decisions and validated key findings.

8.2 The Weighting of Family History and the Use of Decision Strategies

Based on prior research using both quantitative and qualitative methodologies (see Chapters 2, 4, and 7), it was argued that specific characteristics of an FDRs family history experience would contribute to the prediction of prostate cancer risk perceptions and screening behaviour. Having a family history was predicted to lead to higher judgements of personal risk and increased screening behaviour and it was anticipated that factors associated with the specific family history of an FDR (e.g., relationship to the affected relative, perceived severity of treatment side-effects) would account for

additional variability in FDR's judgements. Although FDRs drew on the specific instances of prostate cancer in their family (e.g., through the availability heuristic in Chapters 4 and 7), many contextual factors of an FDR's family history did not predict risk perceptions or screening behaviour, and did not lead to greater use of all heuristic strategies.

Men with a family history were more likely than men from the general population to use the availability and representativeness heuristics to inform risk perceptions and to predict screening behaviour, but only when assessed using quantitative measures and when assessing the influence on actual risk judgements and screening behaviours. The results from Chapter 4 demonstrated that the representativeness heuristic predicted risk perceptions and that this relationship was moderated by FDR status. Also, the availability heuristic items mediated the relationship between FDR status and perceived risk judgements and screening behaviour. Further, one of the classes of reasons for participating in prostate cancer screening identified in Chapter 5 suggested an approach based on an evaluation of risk using available information (e.g., family history, media) and FDRs were more likely to be assigned to this class than were GP men.

However, when examined with qualitative assessments, few heuristic strategies were more likely to be used by FDRs than by GP men. Apart from positive instances of the availability heuristic and negative affect associated with judgements of risk, FDRs were no more likely to use the representativeness, affect, expert opinion, or illusion of control heuristics than were GP men. Rather, all men employed these heuristic strategies to inform their reasoning about risk and screening decisions and FDRs were no more likely than GP men to report the use of systematic processing strategies. The

results from these studies would suggest contradictory results about the influence of family history on the selection of decision strategies.

By contrast, the results from the quantitative and qualitative assessments of decision-making can be considered complementary in that they provide unique yet corresponding explanations as to how family history impacts on the judgements about prostate cancer risk and screening decisions. The results from Chapters 6 and 7 revealed that men use similar judgement policies or decision processes to inform their judgements about prostate cancer risk and decisions about screening. Thus, men use a similar *process* to guide their decision-making by taking into account similar decision factors or information as a basis for their judgements. However, taken together, the results from Chapters 4, 5, and 6 suggest that men with a family history may consider this information differently or may attribute different meaning to this information as they integrate it into their existing knowledge about prostate cancer. For instance, men with a family history of prostate cancer may sample cues in their environment differently or according to a different pattern to those of men without a family history, such as considering the diagnoses of prostate cancer in friends and acquaintances to be a cue to action more so than having affected relatives. Having more acquaintances diagnosed with prostate cancer may hold greater meaning for men with a family history such that acquaintances represent a greater cue for determining need for action.

For example, although both FDRs and GP men weighed family history information as an important cue for determining prostate cancer risk in Chapter 6, FDRs also weighed specific contextual information about the family history less than did GP men. Further, although generally the availability and representativeness heuristics were used equally by FDRs and GP men as found in the results from Chapter 7, the availability and representativeness heuristics accounted for greater variability in risk

perceptions and screening behaviour in the results from Chapter 4, suggesting that they were used more by FDRs as a basis for judgements. As well, the four distinct classes of reasons identified in Chapter 5 suggests that men are weighing different information as important to their decisions, with FDRs being more likely than GP men to evaluate their risk of cancer (e.g., using family history information, the cancer experiences of friends or relatives, or information drawn from the media) for guiding judgements.

Specifically, not all FDRs weighed family history as one of the most important reasons for participating in prostate cancer screening. Rather, consistent with the results from Chapter 4, FDRs were more likely to consider the number of friends diagnosed with prostate cancer as influential in determining their screening behaviour, suggesting that FDRs may be integrating information based on their personal experiences with prostate cancer into their judgements differently to GP men.

8.3 Risk Perceptions and Health Behaviour

Although risk perceptions were consistently predicted by heuristic strategies and family history characteristics, the results of the current thesis do not support their role as a predictor of prostate cancer screening behaviour. In contrast to many theories of health behaviour (e.g., Health Belief Model; Rosenstock, 1966, Protection Motivation Theory), men did not use risk perceptions directly to predict screening behaviour. Rather, there was a tendency for men to construct risk perceptions in response to contextual information and personal experiences through the use of availability and representativeness heuristics (Chapter 4). Although some men gave reasons for screening that indicated they had made their judgement based on an evaluation of their risks (e.g., Class 4 in Chapter 3), risk perceptions did not predict screening when

measured quantitatively and men who acknowledged their heightened risk in more qualitative assessments were not necessarily relating risk factors to judgements about screening. Rather, a proportion of men considered screening as a preventative strategy and as a way to reduce one's risk of developing prostate cancer (Chapters 5 and 7) and there were few differences in how men approached making judgements of personal risk (Chapter 7).

These results question the validity of the risk perception construct for predicting health behaviour or alternatively, point to issues with the operationalisation of the construct. The fact that men with a family history of prostate cancer report greater risk perceptions and screening behaviours than do men without a family history suggests that there may be some informational value in risk perceptions that may not directly predict screening decisions. The question to ask is *what information risk perceptions provide to people and why this information might predict greater screening behaviour?*

Risk as it is conceptualised in many studies of decision-making, particularly those studies utilising gambles, is associated with probability information where participants make judgements based on varying probabilities of winning or losing (e.g., see Prospect Theory; Kahneman & Tversky, 1979; Kusev, van Schaik, Ayton, Dent, & Chater, 2009). Probabilities convey information about uncertainty or the risk of a given outcome. Similarly, risk perceptions are a subjective estimate made by participants as to the likelihood or chance that they will develop a disease. In fact, risk perceptions are often measured according to items that ask participants to rate the likelihood or chance that they will develop a disease (see Chapter 4). Risk perceptions may be a gauge for assessing the uncertainty associated with being diagnosed with prostate cancer and uncertainty may be a means by which people determine whether to take action in relation to participating in screening behaviour. Alternatively, numeric risk assessments

may not pick up on the subtleties in people's interpretations of risk and this may explain why risk perceptions do not consistently predict health behaviour.

Probability or risk estimates fulfil multiple roles: they are informative about the actual chances that one will experience an outcome and provide information in the form of value, such as for determining future behaviours (Keren & Teigen, 2001). People value larger (e.g., .90) compared to smaller probabilities (e.g., .70), owing to the perception that larger probabilities convey more certain and valuable information (Keren & Teigen, 2001). Further, people overuse the verbal phrase *fifty-fifty* chance as a way to communicate their uncertainty about the probability of an outcome rather than to indicate that they believe in a 50% chance (Bruine de Bruin, Fischhoff, Millstein, & Halpern-Felsher, 2000; Fischhoff & Bruine de Bruin, 1999). Feeling more certain (e.g., higher risk perceptions) that one will develop prostate cancer may instigate screening behaviour and a desire to take action which fits with the argument that risk perceptions are an important determinant of health behaviour. Risk perceptions are a tool for conveying information about the chance that one will develop a disease and future research should investigate how people interpret risk statements and the ways in which risk statements convey information and value to individuals.

For instance, people interpret probability information differently, particularly in relation to interpretations of verbal phrases such as *likely*, *possibly*, and *chance* (Keren & Teigen, 2001; Smits & Hoorens, 2005; Teigen & Brun, 2003). For example, framing effects (e.g., the task is described in terms of probabilities of admitting or rejecting applicants) determine whether statements such as *possible* are interpreted as having a greater or lesser probability of an outcome occurring (Teigen & Brun, 2003). Further, people interpret verbal phrases such as *likely* differently according to the perceived representativeness of the context (Windschitl & Weber, 1999). For example,

participants attributed higher probability estimates based on verbal scales (e.g., likelihood) compared to numeric scales if the context was representative, such as attributing greater probabilities of contracting malaria on a holiday to India as opposed to Hawaii. Greater variability in probability judgements was found with verbal probability scales where participants were more likely to use representativeness information to influence perceptions of the likelihood of an event occurring (1999).

Current measures of risk perceptions assess numeric outcomes anchored by verbal probability statements (e.g., chance or likelihood). Numerical scales may not capture the variability in people's judgements because they require participants to make an analytic judgement (degree of risk) based on verbal anchors that are subject to different interpretations according to the context, such as whether the outcome is representative. Further research into interpretations of risk perception measures is needed and clarification of what *risk perception* as a construct represents to both researchers and participants would help shed light on why risk perceptions are not a consistent predictor of health behaviour. This task may be greater than the scope of any one study.

8.4 Rationality and Real World Decisions

The methodology applied across each study in the current thesis sought to extend research findings based largely on experimental and laboratory studies to a real world issue that necessarily includes a broader social context. Specifically, attention was paid to designing the studies so as to elicit responses that were relevant to and guided by participants rather than restricting the conditions under which judgements could be made or by specifying decision-relevant information for participants to use. It

is through representing the natural decision environment or ecology within which decisions are made that allows for generalisations to be made to broader decision contexts (Hammond, 1980; Hammond, et al., 1987).

One important finding in the current study is that SEU theory was not amenable to examining the reasons men participate in prostate cancer screening. When allowed to specify the reasons that contributed to their decision to screen for prostate cancer, participants reported a fairly impoverished list of options which could not be easily classified as being for or against prostate cancer screening. This finding is particularly problematic considering that informed decision-making guidelines are based on normative approaches to decision-making that specify the ways in which men *should* be making their decisions by weighing information according to risks and benefits. Without explicitly defining the decision-relevant information to be used by participants in their decisions, participants did not appear to make decisions based on consideration of reasons for and against screening or on the values or utilities that they assigned to these reasons. Further, actual knowledge, awareness, or consideration of prostate cancer screening issues was low, as found in both Chapters 4 and 5. Rather, men were motivated by specific classes of reasons that represented distinct approaches to reasoning about whether to participate in prostate cancer screening (e.g., to take action).

In order to facilitate decision-making about prostate cancer screening, a decision that is complex and involves a great deal of uncertainty about what is the appropriate or optimal decision, future research needs to focus more on identifying those strategies most likely to be used in a particular context and on promoting the understanding of health information by matching the communication of information to fit the context. In this regard, researchers within the field of judgement and decision-making have started to recognise the importance of matching the decision task to the environment and that

decision strategies may be selected based on their perceived relevance to a particular task (Kruglanski & Gigerenzer, 2011; Payne, Samper, Bettman, & Luce, 2008).

Further, consistent with the two conceptualisations of rationality: rationality of process and rationality of purpose (Evans, 1993), heuristic or automatic reasoning strategies are being recognised as serving a valuable purpose in determining judgements (Gigerenzer & Gaissmaier, 2011). The following section discusses the importance of decision environment in determining rule-based processing strategies by considering an alternative approach to the dual-systems theories that specify two distinct systems (e.g., heuristic versus controlled) that promote more or less rational processing.

8.4.1 Single-System Approach: Intuitive and Deliberate Rule-Based Reasoning

Described briefly in Chapter 7, the single-system approach to conceptualising intuitive and deliberate reasoning (Kruglanski & Gigerenzer, 2011) may be a more appropriate model for examining whether prostate cancer screening decisions and risk assessments are based on optimal decision strategies. Further, the single-system approach may explain why heuristic reasoning strategies were frequently used both by FDRs and GP men in the current thesis. The single-system approach has been proposed in response to criticisms of dual-system theories where System 1 processes are assumed to be irrational and biased but yet also highly adaptive in that they enable people to function efficiently in everyday life (Keren & Schul, 2009; Osman, 2004). A single-system approach to rule-based reasoning suggests that people can both intuitively and deliberately select heuristic strategies to guide their judgements and in some cases heuristic strategies may exceed the performance of more analytic strategies (Kruglanski & Gigerenzer, 2011). In this regard, heuristic strategies can be equally effective in

guiding judgements depending on the judgement task and the process by which rules are selected.

Criticising the association of heuristic strategies with judgemental biases, Gigerenzer and Gaissmaier (2011) adopted the following definition of a heuristic: *A heuristic is a strategy that ignores part of the information, with the goal of making decisions more quickly, frugally, and/or accurately than more complex methods* (pg 454). Gigerenzer and Gaissmaier argued that heuristic strategies have not been treated as equals in statistical models for decision-making. Specifically, there are many cases in which the application of heuristic strategies exceeds the predictions generated by logic or statistical models. For example, experienced managers who used the *Hiatus heuristic* (recency-of-last-purchase) rule to predict the status of active versus inactive customers were just as accurate or more accurate at classifying customers and forecasting future best customers as statistical models where all information on customer histories was available (e.g., the frequency and spacing of previous purchases; Wübben & Wangenheim, 2008).

The idea that unconscious or automatic processing may lead to better decisions has gained attention in recent years as researchers investigate the effects of deliberation and justification on decision quality. Specifically, recent research findings suggest that for complex decision tasks, intuitive or unconscious processing may actually lead to better decisions (Dijksterhuis, 2004; Dijksterhuis, Bos, Nordgren, & van Baaren, 2006; Inbar, et al., 2010). For example, Dijksterhuis, Bos, Nordgren, and van Baaren (2006) found that customers viewed purchases of complex products more favourably when they had not consciously deliberated over the features of the products. Further, people with more knowledge about soccer were better at predicting the outcomes of soccer matches when they did not consciously process diagnostic information (Dijksterhuis,

Bos, van der leij, & van Baaren, 2009). When required to think analytically prior to making judgements on a task, decision quality increases when the task is analytical but decreases with the task is intuitive (McMackin & Slovic, 2000). By contrast, Inbar, Cone, and Gilovich (2010) found that more complex tasks were suited to rational processing but suggested that there may be a curvilinear relationship between task complexity and processing strategies such that analytic processing is better for complex tasks up to a point where greater complexity is facilitated by intuitive judgements.

The single-system approach to decision-making takes into account that people select decision rules based on constraints (e.g., memory or task constraints), based on processing capacity (e.g., motivations), and in consideration of the ecological rationality of strategies (e.g., whether the strategy will lead to a better outcome given the decision environment; Kruglanski & Gigerenzer, 2011). For example, for a given task an individual will select the rule that is available to them (in memory), that fits with their processing capacity or motivations, and that is suited to the decision ecology (e.g., matches the structure of the decision environment). For these reasons, research on judgement and decision-making should focus on establishing in what environments given strategies (e.g., heuristic or analytic) are more likely to lead to better decision quality.

For instance, a possible issue associated with making decisions according to normative approaches to informed decision-making is that decisions are set up as an analytic task (e.g., weighing risk and benefit information) but also incorporate instructions suggestive of intuitive processing (e.g., considering personal values). Further, the complexity of processing required to weigh information about the risks, benefits, and uncertainties of early detection screening may require too much processing capacity for men. Accordingly, men may select to employ intuitive strategies that allow

them to make judgements about prostate cancer screening, such as selecting the decision option that provides them with the most reassurance value. The influence of personal experience with decision strategies, motivation to process information, and perceptions of the complexity of the decision task may shed additional light on how men make decisions about prostate cancer screening and may provide further insight into how men with a family history of prostate cancer approach this decision in consideration of their heightened risk.

8.5 Static versus Dynamic Judgements: The Temporal Dimension

Although attempts were made in the current thesis to design research methodologies that incorporated contextual factors and the decision environment in the aim to extend previous research on judgement and decision-making to a real world issue, the studies were limited by their cross-sectional research designs that examined judgements at a single point in time. Thus, judgements did not reflect the temporal dimension of real world decision-making. Many studies on decision-making, particularly those using experimental designs conducted in the laboratory, examine single-stage, static decisions with a finite decision point or outcome. For example, the representativeness heuristic was established in laboratory studies involving responses to single written scenarios containing probability information and a set description of a decision problem with a finite judgement (Tversky, 1977; Tversky & Kahneman, 1974).

Decision-making about real world issues is a dynamic process that changes over time, particularly when the decision is ongoing and when judgement does not cease once the first decision has been made (Ariely & Zakay, 2001). Alternatives are evaluated differently and preferences change over time. For example, the relatively

simple decision about whether to consume a cake with your morning coffee might change in relation to the proximity to morning tea; an initial decision to select a healthier option may be modified as circumstances change. Thus, the salience of risks and benefits may be relative to the time of the implementation of a decision (Ariely & Zakay, 2001).

The complexity of real world decisions is captured best by dynamic approaches to decision-making (Edwards, Lindman and Philips, 1965, as cited in Ariely & Zakay, 2001). Dynamic decisions are those in which the decision-maker takes into account the dimension of time; making a judgement not only about what choice to make but when to make it (Ariely & Zakay, 2001). In relation to prostate cancer screening, the decision to participate in screening may fluctuate with changing circumstances at different points in time. For example, intentions to screen may be highest at the time at which a relative or friend is diagnosed with prostate cancer but may not lead to ongoing screening behaviour, particularly when the salience of this past experience is low.

Family history characteristics were anticipated to influence judgements about prostate cancer risk and participation in screening in the current study, potentially revealing under which circumstances FDRs were likely to judge themselves to be at greater risk and to determine early detection screening. However, the majority of first-degree relatives had participated in prostate cancer screening at the time the studies were conducted and only a few family history factors predicted risk perceptions or screening behaviour. If future research seeks to provide further understanding of the factors that trigger judgements about prostate cancer, more dynamic and longitudinal approaches would be necessary to capture which and at what point in time different circumstances prompt judgements. These approaches are likely to identify which

characteristics prompt screening and whether screening behaviour is maintained over time.

8.6 Implications for Informed Decision-Making about Prostate Cancer Screening:

Considering the Ecology

As discussed in Chapters 2 and 3, informed decision-making approaches to medical decisions make a number of assumptions about the capabilities of the patient to understand and integrate information to make decisions. Based on normative theories that describe how people *should* make decisions, IDM approaches cannot account for the *actual* decision-making approaches people take to medical decisions. Owing to discrepancies between how people approach decisions according to normative and descriptive decision-making theories, whether an idealised decision-strategy is the best strategy for improving the quality of decisions remains unclear. As demonstrated across all four studies in the current thesis, men focused on values or motivations when making screening decisions and knowledge of the actual known risks, benefits, and uncertainties of prostate cancer screening was low. It is not clear to what extent men were actually informed about the issues associated with early detection screening for prostate cancer, particularly given the results from Chapter 4 that indicated men spent little time discussing prostate cancer screening with their physicians. However, statements made by participants in the results from Chapter 7 suggest that even those men who had been informed about issues associated with screening had difficulty integrating the information into their decisions and expressed uncertainty about the meaning of the information.

If we consider the research question posed in the discussion of the single-system approach to decision-making, that is, to consider both task characteristics and information processing approaches, it would be pertinent to understand which decision processes are better suited to the prostate cancer screening decision. Informed Decision-Making requires an integration of information pertaining to the risks, benefits, and uncertainties of prostate cancer whilst considering patient values and preferences; the task requires both analytic (e.g., understanding and weighing risk and benefit information) and intuitive (e.g., values and preferences) approaches to processing information. Complex decisions are amenable to intuitive judgement, an argument supported by the finding that men tended to base their judgements on values and motivations when approaching screening decisions.

A recent theoretical approach to communicating information about cancer is that of the mental models approach which suggests that when constructing cancer communications one must consider how new information will be integrated into the intuitive formulations of cancer that people already hold (Morgan, et al., 2001). People integrate new information into their existing beliefs, and when existing knowledge is inaccurate, processing new information may be difficult and new information may further distort perceptions of the disease. For example, people who have had unpleasant experiences with cancer may overestimate the negative consequences or uncontrollability of the disease and select extreme treatments (e.g., women with genetic risk of breast cancer undergoing radical mastectomy). Alternatively, people may apply mental models that they associate with other diseases (or other cancers) to a specific cancer (e.g., the belief that all tumours grow rapidly, or that surgery is the best treatment) to decide about the benefits of early detection behaviours.

Making judgements about prostate cancer based on mental models incorporating beliefs or knowledge about other cancers could explain some of the findings reported in the current studies. For example, the belief that the early detection and treatment of prostate cancer (Chapters 5 and 7) are reasons for undergoing screening contradicts current medical knowledge and recommendations for prostate cancer, however many health communications associated with other cancers (e.g., bowel or breast cancer) promote the benefits of early detection. Inaccurate or confused mental models may also explain why some men consider screening as a preventative measure and that by not screening one is tempting fate, or why some men hold the belief that prostate cancer can be cured if caught early enough to prevent its development.

Downs et al. argue that providing factual information or risk communications to people without considering their existing mental models will lead to confusion and may result in people generating inconsistent inferences about information (2008). This argument would suggest that, consistent with the argument for single-system approaches to judgement, creating an analytic task environment for a complex decision that may be better suited to intuitive judgement will result in bias or the application of heuristic strategies to process information. In order to integrate new information about cancer successfully into existing mental models so that they lead to appropriate inferences to be made about cancer and screening behaviours, an approach that takes into account how people think intuitively would facilitate the creation of more coherent mental models.

Downs et al. suggest that conveying information through metaphors would provide people with a basis for integrating information about cancer into their existing mental models (2008). Downs et al. explored how people understood cancer in relation to existing metaphors such as infectious disease, contamination, heart disease, or

accidents and found that people could distinguish similarities and differences between cancer and each of the metaphors to describe their mental model of cancer. For example, cancer was seen to be similar to the idea of an infectious disease as the following quote from a participant illustrates: *With cancer, if treated properly and caught in time and everything, it, you could be in remission, so that means it will go away. Same with the virus, if treated properly it will go away. You will be cured.* (Downs, et al., 2008, pg 519).

However, the metaphors most endorsed by participants were not entirely appropriate, such as the contamination metaphor which treated cancer as a contaminant that infects the body, implying the need to completely remove cancer risk and placed impossible demands on expectations about screening and treatment. For example, considering prostate cancer to be similar to a contaminant may explain why early detection screening is considered a preventative measure by some men and why early treatment will prevent the development of cancer. Further, although Downs et al. (2008) reported that participants could identify terms related to cancer and treatment (e.g., remission), probing participants about these terms revealed that many participants did not understand the underlying concepts. In particular, participants were confused about risk factors (e.g., what it means to have a better diet), disease progression, screening, and treatment demonstrating that their mental models were incomplete and contained inaccuracies.

Downs et al. (2008) recognise that while mental models such as metaphors can be employed to convey information about cancer risks and screening outcomes they are at best a guide for promoting accurate inferences and cannot provide a complete account of all medically-relevant information. Rather, metaphors are an intermediate solution to the problem of providing medical information to patients that addresses the ways that

people think intuitively. Specifically, Downs et al. suggest that medical experts and policy-makers need to consider the ways in which people currently integrate information into what may be inaccurate mental models and consider the potential for metaphors to bridge this gap: *...experts would have to be convinced that: (a) a deliberately selected metaphor leads to better inferences and choices than the intuitively selected metaphors it replaces, and (b) a metaphor's limitations are understood well enough to avoid mistaken inferences (e.g., by explicitly contradicting them)* (pg 509). By comparing the mental models of experts with those of patients, gaps in knowledge are able to be determined and communications targeted at reducing this gap (Morgan, et al., 2001). We believe this is a promising avenue for future research on communicating information about prostate cancer risk and screening to all men and may be particularly beneficial for men with a family history of prostate cancer who may construct specific mental models of prostate cancer based on their experiences with an affected relative's cancer.

8.7 General Limitations and Generalisability

Owing to the marked increase in early detection screening following the widespread availability of the prostate-specific antigen blood test (Baade, et al., 2009; Jacobsen, et al., 1995; Parkin, et al., 2005), the focus of the present thesis was on the examination of decision-making about prostate cancer screening as determined by the PSA blood test. Men's perceptions of the digital rectal examination have been shown to be influenced by issues relating to threats to masculinity, particularly for different ethnic groups (Harvey & Alston, 2011; Rivera-Ramos & Buki, 2011).

Although not reported in the present thesis, a proportion of men participating in the Verbal Protocol Analysis (Chapter 7) mentioned that the thought of the digital rectal

examination may deter other men from prostate cancer screening and most men reported that the thought of this test did not deter their personal screening behaviours. This finding is consistent with the third-person effect (Davison, 1983) where people consider communications to have a greater effect on others (third-persons) compared to the self to the extent that the individual may overestimate the attitudes and beliefs of third-persons and behave differently as a result (Perloff, 1993). Determining the influence of men's perceptions of the DRE on how they approach prostate cancer screening merits further research.

Although a similar sampling frame was used to recruit a sample of first-degree relatives of men with prostate cancer, studies four and five, and studies six and seven used independent samplings. However, the results reported in the thesis may not generalise to the broader population of first-degree relatives. Future research would benefit from extending the findings reported in the thesis to additional samples of first-degree relatives and examine the applicability of the results to the broader population.

8.8 Implications for Health Decision-Making

Current approaches to improving medical decision-making for patients focus on finding ways to help patients make decisions through providing information on available options and potential outcomes relevant to the patient and suggesting patients consider their personal values and somehow incorporate these into the decision (O'Connor, et al., 2009; O'Connor, et al., 1999; O'Connor, et al., 2003). For example, decision aids provide information about a disease, probabilities relating to risks and the likelihood of potential outcomes, exercises to get participants to explicitly clarify their values, and guidance about the steps for making decisions (O'Connor, et al., 1999).

However, inherent in these approaches is the assumption that patients are capable of understanding and integrating information according to a similar process as experts. Specifically, owing to their basis in normative models of decision-making, decision aids are largely information-based and assume that patients can undertake an analytical approach to weighing and integrating information to reach decisions.

The implication of these approaches is that by focusing almost exclusively on the provision of information, they largely ignore the non-systematic or heuristic nature of patient decision-making and the potential for patients to make intuitive judgements about health decisions. This may in effect be limiting the effectiveness of such interventions. For example, if patients are going to make references to the health experiences of friends or relatives when deciding between decision options, then the provision of information about the benefits or costs of a particular option may not weigh as heavily in a patient's health decision as more vivid personal experiences.

The results from the current thesis suggest that medical decision-making approaches need to recognise the range of processes and contextual factors that affect and shape the uptake and integration of decision-relevant information. For instance, taking into consideration the way that patients actually understand complex medical information, such as asking patients to discuss their current conceptualisations of prostate cancer in order to correct lay beliefs or mental models, may be a better approach to integrating new information than simply presenting a range of information to patients and assuming that they can make sense of it. Future research should focus on alternative approaches to discussing decision-relevant medical information with patients in ways that take into account how patients actually understand and integrate health information.

8.9 Summary and Conclusions

The interactions between family history, risk perceptions, and prostate cancer screening behaviour are complex and further research is needed to identify the important mechanisms underlying these relationships. Mixed methodological approaches, such as those used in the current thesis, provide unique perspectives on the variety of ways in which family history influences the processing of information pertaining to prostate cancer both from their experiences within the family as well as through external sources (e.g., media, friends, and acquaintances). In particular, future research should examine how patients make decisions both within and beyond the context of the medical consultation. Further, exploring alternative ways of communicating information to patients that takes into account their existing knowledge or mental models pertaining to prostate cancer while promoting the integration of relevant screening information may point the way for a new paradigm of patient decision-making research and intervention.

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Appendix A

Appendix B

Information Letter for CATI

(The Information Sheet was sent on GU/CCQ letterhead)

Decision-Making about Preventive Health Behaviours for Men with a Family History of Prostate Cancer

INFORMATION FOR PARTICIPANTS

Chief Investigators: Dr Stefano Occhipinti
School of Applied Psychology, Griffith University
(07) 3735 3372; S.Occhipinti@griffith.edu.au

Associate Professor Suzanne Steginga
The Cancer Council Queensland

Project Manager: Ms Michelle McDowell
(07) 3735 3455

Why is this research being conducted?

In this study, we are interested in examining the preventive health behaviours of first-degree male relatives of men with prostate cancer who are aged between 40 and 70 years old. As well, we are interested in understanding how first-degree male relatives of men with prostate cancer think about prostate cancer. This research is being conducted at The Cancer Council Queensland and in collaboration with Griffith University as part of a post-graduate research program. The purpose of this program is to find ways to improve services for men who have a family history of prostate cancer.

What you will be asked to do

If you consent to participate in this research you will be asked to complete two telephone interviews, one now and one again in 12 months time. A project officer from The Cancer Council Queensland will contact you to organise the interview and you will be provided with the opportunity to discuss with the project officer any questions you may have about this research. As part of the telephone interviews you will be asked to provide demographic information, information about your family's history of prostate cancer and questions about your experiences with your relative's prostate cancer. It is anticipated that each telephone interview will require half an hour of your time.

Expected benefits of the research

This project will inform the development of an evidence based approach to the education and support of men with a family history of prostate cancer. Expected outcomes of this research include:

- The development of and recommendations for programs aimed at tailoring prostate cancer information to first-degree relatives of men with prostate cancer
- The development of a decision aid targeted specifically to men with a family history of prostate cancer that can be disseminated through The Cancer Council Queensland
- The development of supportive care programs aimed at addressing the supportive care and information needs of families of men with prostate cancer.

Risks to you

There are no foreseeable risks to you as a result of participating in this research.

Confidentiality

We guarantee that all the information you provide will be kept confidential and that no identifying information will be recorded in connection with your responses. If you have any questions, please feel free to contact one of the research team listed above.

Your participation is voluntary

Your participation is voluntary and you may withdraw at any time without penalty.

Ethical conduct of this research

Griffith University conducts research in accordance with the *National Statement on Ethical Conduct in Research Involving Humans*. If you have any concerns or complaints about the ethical conduct of the research project you should contact the Manager, Research Ethics on (07) 3735 5585 or research-ethics@griffith.edu.au

Privacy statement

The conduct of this research involves the collection, access and / or use of your identified personal information. The information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded. For further information consult the University's Privacy Plan at www.griffith.edu.au/ua/aa/vc/pp or telephone (07) 3735 5585.

Questions/further information

If you have any additional questions about this project you can contact the Project Manager, Ms Michelle McDowell on (07) 3735 3455. You may also contact the Chief Investigator, Dr Occhipinti with any question regarding the project.

Thank you for your time and consideration.

Dr. Stefano Occhipinti
Chief Investigator
Griffith University

Appendix C

Consent form for CATI

(The Information Sheet was sent on GU/CCQ letterhead)

Decision-Making about Preventive Health Behaviours for Men with a Family History of Prostate Cancer

CONSENT FORM

Griffith University Principal Investigator: Dr. Stefano Occhipinti
 The Cancer Council Queensland Principal Investigator: Associate Professor Suzanne Steginga
 Contact Investigator: Ms Michelle McDowell
 Telephone: (07) 3735 3455

.....
 Print Full Name

of
 Print Address

Home phone number:

Work phone number:

Mobile phone number:

I agree to participate in The Cancer Council Queensland's study to examine the preventive health behaviours of men with a family history of prostate cancer. *(tick if appropriate and sign below)*

1. I have read and understood the Information Sheet. This sheet describes the purpose of the project and what I'm asked to do if I take part. I know that I may ask for more information about the project as it goes on.
2. I understand that taking part in this project is voluntary, and that I may stop taking part in the project at any time without penalty.
3. I understand that although the purpose of the project is to improve the education and support provided to family members of men with prostate cancer, I may not directly benefit from taking part in this study.
4. I understand that all information will be treated in the strictest confidence and used for research purposes only. I understand that I will not be personally identified in any reports from this project.
5. I understand that this research will comply with the Griffith University's Statement on Ethical Conduct in Research Involving Humans.

6. I understand that this study has been approved by Griffith University's Human Research Ethics Committee. I understand that if I have any questions or concerns about the ethical conduct of this study, I can contact the Manager, Research Ethics, at Griffith University Human Research Ethics Committee on (07) 3735 5585 (or research-ethics@griffith.edu.au).

Participant signature: _____ Date: _____

Witness signature: _____ Date: _____

Witness name: _____

The Cancer Council Queensland Office Use Only

On initial contact with the above participant, I confirmed that, to the best of my knowledge, the participant has understood the information provided to him and the implications of this information.

Researcher: _____ Date: _____

- I do not wish to take part in The Cancer Council Queensland's study to examine the preventive health behaviours of men with a family history of prostate cancer. (tick if appropriate)**

Appendix D

Coding Manual for Screening Reasons

Category Units

1 Perceptions of Risk

1.1 Family History of Prostate Cancer

Definition: This is when the respondent states that family history was an important factor in their decision whether or not to get the PSA test. This category refers to any statement that mentions having a family member with prostate cancer.

Positive Example: “Because of the history of pc in our family.”

Negative Example: “I don’t have a family history of it.”

1.2 Age

Definition: This is when the respondent makes a statement regarding their age and prostate cancer risk or that their age is what motivated them to go/not to go and get screened.

Positive Example: “Every man knows that at my age you are susceptible to prostate cancer.”

Negative Example: “I didn't really need one at my age.”

1.3 Symptoms

Definition: This is when the respondent discloses or makes reference to urinary symptoms or prostate problems.

Positive Example: “It was important to know what was going on because of some urinary symptoms.”

Negative Example: “No symptoms.”

1.4 Lifestyle or other

Definition: The participant mentions lifestyle, environmental or other health factors as a reason for/against screening.

Positive Example: “I should have a psa test as it is logical along with my cholesterol tests.”

Negative Example: “I am very healthy and don't go to the doctor.”

1.5 Evaluation of risk

Definition: Statement evaluating current risk. The participant refers explicitly to their risk or likelihood of developing prostate cancer.

Positive Example: “I was definitely in a higher risk group.”

Negative Example: “Don't think I'm going to get it.”

1.6 Prevalence of Prostate Cancer

Definition: The participant states that the high/low prevalence of prostate cancer made them consider or undertake screening.

Positive Example: “High incidence of prostate cancer in males.”

Negative Example: There were no statements fitting this category.

2 *Early detection and Screening*

2.1 *Early Detection*

Definition: The participant refers to early detection, keeping a check on things, or generally *checking-up* as a reason for prostate cancer screening. This category does not include statements where a participant refers specifically to having a *general* health check-up. Further, this category should not be coded when a participant mentions early detection or having a check-up as part of a premise leading to up to a statement about treatment consequences, outcomes of screening, or development of prostate cancer (these statements may fit one of the subsequent screening categories).

Example: “The early detection of it is the most important thing.”

2.2 *General positive health attitude*

Definition: The test is described in the context of health maintenance or as a way to keep up the participant’s good health. A general positive attitude toward maintaining good health is used as a reason for testing. This category is different to statements where a participant mentions having a positive attitude towards screening or early detection.

Example: “Being well informed about my overall health.”

2.3 *Enhance survival*

Definition: The participant refers to getting tested as a way to enhance their survival, or to avoid dying.

Example: “To prolong my life because of my family”

2.4 Screening provides information to take action

Definition: The participant describes the reason for testing is to use the result as a basis for taking action against prostate cancer or using the outcome of the test to plan action. Participants may refer to the test as providing them with results to use to make future choices about treatment or they may speak of options for what to do with the result. This category also refers to statements where a participant speaks about the screening results as a way to get information about their blood levels (prostate antigen or PSA).

Examples: “To be able to decide what to do if I do get it.” “To give me information so I can act if I need to.”

3 Resolution of Uncertainty

3.1 Peace of mind/Seeking reassurance

Definition: The participant refers to the screening test as providing peace of mind or that the test would reassure them. This category refers only to participants who speak of the test providing them (and not others) with peace of mind.

Example: “To do it to have peace of mind.”

3.2 Want to know

Definition: The participant wants to know whether they have cancer or not and the screening test provides this. This category is different to peace of mind in that the participant simply wants to know a result and is not motivated by a goal of reassurance.

Positive Example: “Just to find out if I did have pc or not.”

Negative Example: “You don't want to know if I have it.”

3.3 Outcome as confirmation or clarification

Definition: The participant uses the screening test to gain clarity or to alleviate uncertainty about their risk of getting cancer or to confirm a positive/negative result. This category is different to seeking reassurance or simply wanting to know the result or outcome. Rather, the participant anticipates an outcome and having the test confirms this or provides information they can use to gauge the likelihood that they have or will get prostate cancer.

Example: “I needed to be certain there was no cancer.”

4 Social Influence or Recommendation.

4.1 Doctor Recommendation

Definition: The reason for testing/not testing is stated as a result of a doctor’s recommendation.

Positive Example: “Doctor said I had to do it.”

Negative Example: “No doctors recommendation.”

4.2 Family or Friend Recommendation

Definition: A family member, friend, acquaintance or other person advised the participant to test. The statement refers to an *active* recommendation or suggestion to screen. This category unit should be coded according to the participant’s relationship with the person making the recommendation.

Positive Example: “Dad told me to keep an eye and be tested.”

Negative Example: There were no statements fitting this category.

4.3 Family Pressures or Considerations

Definition: The participant reports specific pressure from family to test or that the participant considers their family members as important reasons for testing

Example: “To keep dad happy.”

4.4 Media influence

Definition: The participant refers to hearing, reading or being made aware about prostate cancer screening by the media or a health campaign.

Positive Example: “Advertising on tv putting it out there.”

Negative Example: “I saw a program on TV where they interviewed a Dr from John Hopkins who said the blood test was a lot of hogwash etc.”

5 Cancer Representations.

5.1 Friend or relative with cancer

Definition: The participant talks about or refers to a relative with cancer as a reason for undergoing the test. This category can refer to prostate cancer and/or other cancers. This category is different from the family history category such that it refers to cancer experiences of relatives or friends as reasons for screening rather than just having a family history. This category is similar to category 4.2 in that the participant considers the diagnosis of a friend or relative as a reason to screen, however the current category is passive such that the participant does not state that the friend or relative *actively* recommended or suggested that they get tested.

Example: “Having a cousin that wasn't that much older die of it.”

5.2 Family or friend positive/negative comparison

Definition: The participant compares themselves with an affected family member, friend or acquaintance they know who has had prostate cancer and uses this as a guide to their own risk or screening behaviour. This category can refer to statements where the participant talks about *not* wanting to be in the same health position as their affected friend or relative. The participant may suggest comparisons and/or contrasts between themselves and an affected friend or relative such as wanting to make a different decision or take an alternative action to that of their friend or relative. Alternatively, the participant may refer to the behaviours, actions, or the health position of an affected relative or friend and compare their health position either favourably or unfavourably to this referent.

Downward Comparison Example: “I didn't want to be like my father leaving everything to the last moment because by the time he was diagnosed it was aggressive.”

Upward Comparison Example: “Just the fact that I drank lots and lots of water and always have but neither of my brothers did.”

6 Lay beliefs.

6.1 Lay beliefs about controlling prostate cancer

Definition: The participant makes reference to testing as a way to control, prevent, or stop the development of prostate cancer. These statements are different to the early detection category such that testing is not simply described as a way to detect cancer early and do something about it, rather that testing per se can help to prevent the development of the cancer. Alternatively, the participant may refer to the screening test as a way to see whether they have any traces of cancer (such that the test catches the cancer before it develops). This category also includes statements where the participant

refers to screening as a preventative or precautionary strategy. This category also includes statements where the participant refers to avoiding *not* taking action.

Examples: “To make sure that I don’t get it.” “To keep a check so it didn't develop.” “General preventative.”

6.2 *Lay beliefs about prostate cancer screening or treatment outcomes*

Definition: The participant makes reference to aspects of screening that are not yet proven, such as treatment being easier if cancer is detected early through screening. These statements go beyond the belief that early detection is a benefit of screening, rather that catching prostate cancer early increases treatment success, reduces side-effects or prolongs survival.

Example: “I'd like to get it early enough to be able to use dietary controls to slow the process and reduce necessary treatment.”

7 *PSA testing.*

7.1 *Convenience of testing*

Definition: The participant talks about the PSA test or the blood test as a preferred method of testing or that the test is easy and convenient to do (for example, there may be reference to other forms of testing that are less convenient).

Example: “I thought it was less of a bother to have a PSA test than to have a digital exam.”

7.2 *Evidence for PSA testing*

Definition: The participant talks about the specifics of PSA testing such as recommendations for testing or aspects of the screening test. This category refers

specifically to known evidence for or against PSA testing and not to statements where the participant expresses a belief in there being evidence for PSA testing.

Positive Example: “I was led to believe the blood test was more thorough than the other tests.”

Negative Example: “From what I've heard and read most men die with it than from it.”

7.3 Positive attitudes towards testing

Definition: The participant shows a generic positive attitude toward testing and/or makes statements that men should be tested. These statements may resemble classic evaluative statements from attitude theory.

Example: “I am strongly in favour of testing.”

8 Barriers to testing.

8.1 Barriers to testing

Definition: The participant reports barriers to having a PSA blood test.

Examples: “I don't go to the doctor generally.” “Unaware there was a blood test.”

8.2 Never thought about it

Definition: The participant hasn't thought about or hasn't made a decision about getting the blood test.

Example: “Haven't really thought about it before.”

8.4 No need for the blood test, specifically.

Definition: The participant felt or feels that there is no need for getting the blood test because they have already had the physical test. It specifically refers to the digital

test as a preferred method or that the participant has more confidence in the physical test rather than ruling out testing for prostate cancer altogether.

Example: “Digital rectal examination is the better way to go.”

8.5 Avoidance

Definition: The participant shows a general avoidance towards getting the test.

This category does not include statements where a participant mentions not having made a decision to test or where the participant refers to *not* avoiding the test, rather the participant states explicitly that they are avoiding, putting off, or not wanting to think about the test.

Example: “I know it has to be done & I know I'll have to do it but I just keep chickening out.”

9 Concern with testing.

9.1 Concern

Definition: The participant appears concerned about getting prostate cancer, about the outcome of the test, or about the disease in general. This category includes any negative association with the test or with getting prostate cancer. Alternatively, the participant is not concerned about getting prostate cancer or the outcome of the test; this may be because of current health behaviours or concerns other than prostate cancer.

Positive Example: “I have heart disease & that's what's likely to get me in the end so whether I develop pc is hardly likely to interest me.”

Negative Example: “It does scare you so you have to find out.”

Appendix E

Information Sheet on Prostate Cancer Risk and Screening Recommendations Provided to Coders for Coding Statements for Chapters 5 and 7

What do we know about prostate cancer risk factors?

- Men with a family history of prostate cancer have an increased risk of being diagnosed with prostate cancer.
- Prostate cancer risk increases with age.
- African American men have a higher risk of being diagnosed with prostate cancer.
- Men who experience urinary or erectile symptoms may be at greater risk of being diagnosed with prostate cancer.
- There is some evidence that obesity may be related to a greater risk of prostate cancer.

What are the current recommendations for prostate cancer screening?

Men should consider screening if:

- They have a family history of prostate cancer
- They are aged between 50-70 years old (or 40-70 years old if they have a family history)
- They are experiencing urinary or erectile symptoms
- They are African American
- They are not in poor health and are expected to live for more than 10 years

What is the known about prostate cancer and early detection screening tests?

- Prostate cancer incidence is high but mortality rates are low
- Some prostate cancers grow slowly and don't threaten life. Conversely, detection and treatment for prostate cancer can affect quality of life
- At present, it is not clear to what degree PSA testing can save lives and whether men, as a group, who are monitored by testing live longer.
- Early prostate cancer has no symptoms
- PSA testing may lead to the detection of prostate cancer before it causes symptoms and/or when it is still confined within the prostate gland (localised)
- The PSA test cannot yet differentiate between life-threatening and non-life-threatening prostate cancers
- Treatment for localised prostate cancer can potentially cure the disease
- Prostate cancer that is still confined to the gland may progress over time
- Prostate cancer that has spread beyond the prostate gland is usually no longer curable and treatment for advanced cancer has significant quality of life diminishing effects
- A PSA test can be abnormal when cancer is not present (2 out of every 3 positive PSA test results are false positives), however a biopsy is needed to find out if the PSA test is a true positive.
- Prostate cancer treatments (for localised and advanced cancer) can lead to quality-of-life diminishing side-effects

Appendix E

Information Letter for VPA Interview

(The Information Sheet was sent on GU/CCQ letterhead)

Decision-Making about Preventive Health Behaviours for Men with a Family History of Prostate Cancer

INFORMATION FOR PARTICIPANTS

Chief Investigators: Dr Stefano Occhipinti
School of Applied Psychology, Griffith University
(07) 3735 3372; S.Occhipinti@griffith.edu.au

Associate Professor Suzanne Steginga
The Cancer Council Queensland

Project Manager: Ms Michelle McDowell
(07) 3735 3455

Why is this research being conducted?

In this study, we are interested in examining how first-degree male relatives of men with prostate cancer make their decisions about participating in preventive health behaviours. As well, we are interested in understanding how first-degree male relatives of men with prostate cancer think about prostate cancer. This research is being conducted at The Cancer Council Queensland and in collaboration with Griffith University as part of a post-graduate research program. We are seeking to recruit men aged between 40 and 70 years old to participate in this study.

What you will be asked to do

If you consent to participate in this research you will be asked to complete a face-to-face interview and a brief self-report questionnaire. A project officer from The Cancer Council Queensland will contact you to arrange the interview and you will be provided with the opportunity to discuss with the project officer any questions you may have about this research. The interview can be conducted at a time and location most suitable to you. It is anticipated that the study will require one hour of your time.

Expected benefits of the research

This project will inform the development of an evidence based approach to the education and support of men with a family history of prostate cancer. Expected outcomes of this research include:

- The development of and recommendations for programs aimed at tailoring risk information to first-degree relatives of men with prostate cancer
- The development of a decision aid targeted specifically to men with a family history of prostate cancer that can be disseminated through The Cancer Council Queensland
- The development of supportive care programs aimed at addressing the supportive care and information needs of families of men with prostate cancer.

Risks to you

There are no foreseeable risks to you as a result of participating in this research.

Confidentiality

We guarantee that all the information you provide will be kept confidential and that no identifying information will be recorded in connection with your responses. If you have any questions, please feel free to contact one of the research team listed above.

Your participation is voluntary

Your participation is voluntary and you may withdraw at any time without penalty.

Ethical conduct of this research

Griffith University conducts research in accordance with the *National Statement on Ethical Conduct in Research Involving Humans*. If you have any concerns or complaints about the ethical conduct of the research project you should contact the Manager, Research Ethics on (07) 3735 5585 or research-ethics@griffith.edu.au

Privacy statement

The conduct of this research involves the collection, access and / or use of your identified personal information. The information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded. For further information consult the University's Privacy Plan at www.griffith.edu.au/ua/aa/vc/pp or telephone (07) 3735 5585.

Questions/further information

If you have any additional questions about this project you can contact the Project Manager, Ms Michelle McDowell on (07) 3735 3455. You may also contact the Chief Investigator, Dr Occhipinti with any question regarding the project.

Thank you for your time and consideration.

Dr. Stefano Occhipinti
Chief Investigator
Griffith University

Appendix F

Consent form for VPA

(The Information Sheet was sent on GU/CCQ letterhead)

Decision-Making about Preventive Health Behaviours for Men with a Family History of Prostate Cancer

CONSENT FORM

Griffith University Principal Investigator: Dr. Stefano Occhipinti
 The Cancer Council Queensland Principal Investigator: Associate Professor Suzanne Steginga
 Contact Investigator: Ms Michelle McDowell
 Telephone: (07) 3735 3455

.....
 Print Full Name

of
 Print Address

Home phone number:

Work phone number:

Mobile phone number:

I agree to participate in The Cancer Council Queensland's study to examine the preventive health behaviours of men with a family history of prostate cancer. *(tick if appropriate and sign below)*

7. I have read and understood the Information Sheet. This sheet describes the purpose of the project and what I'm asked to do if I take part. I know that I may ask for more information about the project as it goes on.
8. I understand that in signing this consent form I am agreeing to participate in a face-to-face interview for The Cancer Council Queensland.
9. I understand that taking part in this project is voluntary, and that I may stop taking part in the project at any time without penalty.
10. I understand that although the purpose of the project is to improve the education and support provided to family members of men with prostate cancer, I may not directly benefit from taking part in this study.
11. I understand that all information will be treated in the strictest confidence and used for research purposes only. I understand that I will not be personally identified in any reports from this project.

12. I understand that my interview will be audio-taped and that only the research team will have access to this tape. I understand that the audio-tape will be erased following transcription.
13. I understand that this research will comply with the Griffith University's Statement on Ethical Conduct in Research Involving Humans.
14. I understand that this study has been approved by Griffith University's Human Research Ethics Committee. I understand that if I have any questions or concerns about the ethical conduct of this study, I can contact the Manager, Research Ethics, at Griffith University Human Research Ethics Committee on (07) 3735 5585 (or research-ethics@griffith.edu.au).

Participant signature: _____ Date: _____

Witness signature: _____ Date: _____

Witness name: _____

The Cancer Council Queensland Office Use Only

On initial contact with the above participant, I confirmed that, to the best of my knowledge, the participant has understood the information provided to him and the implications of this information.

Researcher: _____ Date: _____

- I do not wish to take part in The Cancer Council Queensland's study to examine the preventive health behaviours of men with a family history of prostate cancer. (tick if appropriate)**

Appendix H

Coding Manual for Verbal Protocol Analysis

Category Units

1.1 Expert opinion heuristic

Definition: judgement influenced by the rule “experts can be trusted” [Chaiken, 1994 #330]. This is when the person states that his decision will be guided or strongly influenced by his doctor’s advice.

Risk

Example: “My doctor said that I’ve got a greater chance of getting it so that gave me something to think about.”

Screening

Example: “My doctor just said I was of that age when I should get a test. He’d know more about it than me so, yeah I just got the test”

1.2 Availability Heuristic

Definition: when a judgement or decision is mediated through an instance that comes easily to mind [Kahneman, 1996 #7], or the frequency or probability of an event is judged by the ease with which similar instances or associations come to mind. This is when the man recalls an example of another person who had cancer or recalls something they read or heard about cancer. The example may be of a friend, relative or acquaintance who had cancer, or a celebrity or someone he has heard of but does not know personally. This includes both examples of people with prostate cancer or other types of cancer.

The availability heuristic may refer to positive (statements suggesting a positive association between the recalled information and the participant's judgement associated with risk or screening) or negative (statements suggesting a negative association between the recalled information and the participant's judgement associated with risk or screening) information and is coded accordingly.

Risk

Positive example: "I've had three friends who have had it. It seems to be very common."

Negative example: "I don't think many people get it. I don't know anyone who has had it."

Screening

Positive example: "My friend got screened recently and his turned out OK."

Negative example: "Well most people I've known with it have been fine after they got it treated. It's really not that bad."

1.3 Representativeness heuristic

Definition: The probability of an event is judged by the degree to which it corresponds to a previous instance in the same category (Tversky & Kahneman, 1974). Judgement is based on stereotypical information or on information obtained from a small sample of experiences that is presumed to be representative and reliable. Specifically, the participant makes a judgement with respect to a comparison between themselves and a prototype.

The representativeness heuristic may refer to a positive comparison where the participant compares themselves or a representation as being related positively to an outcome or a negative comparison where the participant compares themselves or a representation as being related negatively to an outcome, and is coded accordingly.

Risk

Positive example: “Well my mate drinks a lot, smokes a lot and he got cancer so, obviously that’d have to contribute.”

Negative example: “I’m a lot like my father, so I’ve got a good chance of getting it.”

Screening

Positive example: “I go to the doctor regularly to get checked up. My mate [who got cancer] hadn’t seen a doctor in 20 years, he said.”

Negative example: “Well my brother is very much like me and he got diagnosed. If I get the test, I’ve got a good chance of getting diagnosed too.”

1.4 Affect heuristic

Definition: When judgements are guided by positive or negative affective feelings (Finucane, et al., 2000). The affect heuristic can act in the following ways: (1) positive or negative feelings that are experienced as a conscious or unconscious feeling state; (2) positive or negative quality of a stimulus or a mental image. Participants consult or refer to affect when considering information. The affect heuristic may refer to positive or a negative affect and is coded accordingly.

Risk

Positive example: “I’m really not too worried about it.”

Negative example: “Well, my brother had it so of course I’d be concerned about my risk.”

Screening

Positive example: “I wanted the reassurance. It would give me piece of mind.”

Negative example: “I’m scared I’ll get a negative result.”

1.5 Illusion of control

Definition: The systematic attempt by an individual to control outcomes in circumstances where this is highly unlikely (Fenton-O’Creevy & Sloane, 2000; as cited in (Kenen, et al., 2003). The participant believes that they have a high level of personal control over an outcome despite no evidence that these perceptions are valid. This category is different to the lay beliefs categories in that it refers to a process; actions, behaviours or beliefs are thought of as a way to control the negative and enhance a positive outcome.

Example: “I just need to make sure I keep positive and don’t stress about it because when you’re stressed you get sick.”

2.1 Tempting fate

Definition: To tempt fate is to do something risky or to leave oneself exposed, and “applies to actions whose risk comes from the possibility of offending the gods ... the universe, or fate” (Risen & Gilovich, 2008) pg 294. Participants may believe that if they tempt fate, bad things are bound to happen. For example, those men who do not participate in regular testing are in fact tempting fate and are facing the consequence that something bad (a diagnosis of prostate cancer) will happen to them. Conversely, the participant may also talk about not wanting to tempt fate, the implication being that the act of testing allows one to avoid tempting fate and consequently avoid a negative outcome.

Example: “I think if I keep seeing my doctor and getting the tests than I’ve got a good chance of not getting it.”

2.2 Fate or luck.

Definition: When an outcome is perceived to be due to fate, luck or is considered beyond one's control.

Example: "You've just got to see what cards you are dealt. If you're supposed to get it, you're going to get it."

2.3 Rusty car.

Definition: Reference to an analogy from the physical world involving the removal of the cancer as a substance such as rust from a car. This category refers to statements about removing the cancer before it becomes bad by cutting it out or treating it early. The participant may refer to the process of early detection as a way of reducing one's chances of getting cancer. The analogy is such that cutting rust from a car as soon as it appears prevents the rust from taking over the car.

Example: "If I get it early I can get it before it develops."

3.1 Lay beliefs or theories about cancer causes or risk

Definition: Belief about the causes or risks of developing cancer that has no proven scientific basis. This category includes beliefs that reference cancers other than prostate cancer and are applied to prostate cancer.

Example: "If you drink, you smoke and eat fatty foods then that's got to increase your risk."

3.2 Lay beliefs or theories for denying cancer risk

Definition: Lay belief that one is not at risk of developing prostate cancer despite no evidence to suggest that the belief is valid.

Example: “If I was going to get it I’d have gotten it by now.”

3.3 Lay beliefs or theories for need for screening

Definition: Lay belief that one does or does not need to participate in screening despite no evidence to suggest that the belief is valid. Lay beliefs or theories about the need for prostate cancer screening including behaviours, personalities, environmental factors or beliefs that are not backed up by scientific evidence

Example: “Maybe if they do the test they’ll end up finding something by messing about down there.”

4.1 Describing obtaining information from the doctor

Example: “I knew I should be thinking about my health so I went to the doctor to ask him about getting tested.”

4.2 Seeking or obtaining information from family or friends

Example: “My brother got me information off the Internet.”

4.3 Seeking or obtaining information from sources external to family/friends or the doctor

Example: “I looked it up on the internet a few months ago.”

5.1 Consideration of medical risk factors

Definition: Description of the risk factors associated with prostate cancer. These include family history, older age, having urinary symptoms, or being African American. This also includes references explicitly excluding environmental factors the participant knows are not currently shown to be related to prostate cancer risk.

Examples: “The older you get, the more likely you’re going to get it.” “Diet, lifestyle, smoking doesn’t seem to increase your risk.”

5.2 Consideration of screening recommendations

Definition: Description of the factors associated with prostate cancer screening recommendations. These include family history, older age, having urinary symptoms, or being African American. This also includes references to environmental factors the participant knows are not currently shown to be related to prostate cancer screening recommendations.

Examples: “Now that I’m over 50 I know I’ve got to start thinking about it.” “I don’t have a family history of it so I won’t think about it unless I get symptoms.”

5.3 Consideration of the pros and cons of screening

Definition: Description of the pros and cons or the current uncertainty associated with prostate cancer screening recommendations. This category does not refer to participants who demonstrate a general weighing of pros and cons for why they personally would like to screen. Rather, this category relates to pros and cons that contribute to the current uncertainty about the overall benefits of prostate cancer screening.

Examples: “As far as I know the blood test is only an indicator for prostate cancer.” “A lot of men die with prostate cancer rather than from prostate cancer.”

6.1 Uncertainty about prostate cancer risk factors

Definition: Description and acknowledgement of being uncertain about prostate cancer risk factors.

Example: “I don’t know if exercise or diet contributes. I don’t know if you can take medications to reduce your risk. I just don’t know what is out there.”

6.2 Uncertainty about prostate cancer screening

Definition: Description and acknowledgement of being uncertain about prostate cancer screening recommendations.

Example: “My doctor said I don’t need to think about screening but I didn’t understand why not. Screening is good, isn’t it?”

6.3 General Uncertainty

Definition: Description of experiencing general uncertainty about prostate cancer, risk factors or screening decisions.

Example: “I just don’t know what to do. I just wish someone would say do this or do that.”