A mixed methods investigation of newly diagnosed prostate cancer patients' decision-making about treatment

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Declaration

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Summary

There are a number of successful strategies to manage prostate cancer, including monitoring or a number of active treatment options, but to date, there is no consensus on the optimal strategy. Patients are expected to actively participate in decision-making about treatment, and decide the strategy they will follow. As each option is associated with distinct adverse effects, making a decision can be difficult, with decision conflict and decision regret reported in prostate cancer survivors. Little is known about the psychological processes prostate cancer patients undergo to arrive at this decision. Some factors that may influence decision-making, identified within the empirical literature, include; sociodemographic factors, knowledge, health literacy, self- efficacy, and [perceived] social support.

The overall aim of this thesis was to explore decision-making in prostate cancer patients, using a mixed methods sequential approach within a pragmatic paradigm. The overarching research questions considered in this research were:

1. What information do prostate cancer survivors think those diagnosed with prostate cancer need in order to make a treatment decision?
2. What factors are associated with decision conflict at the time of decision-making?
3. How do men with prostate cancer describe their decision-making process about their treatment options?

Chapter 1 presented a brief background to prostate cancer, the factors that are considered by the clinician when selecting the appropriate management options for individual patients, and the clinical process prostate cancer patients follow once given their diagnosis.

Chapter 2 presented a narrative review of the literature in relation to decision-making models in healthcare, decision conflict and decision regret. Factors that may facilitate decision-making were considered and included: socio-demographic factors, information and knowledge of prostate cancer, health literacy, social support, and self-efficacy. One of the main outcomes from this review was the lack of evidence identifying the role of health literacy, social support, and self-efficacy in facilitating men in decision-making, and the nature of these associations was also unclear.

Chapter 3 detailed the specific aims, objectives, and hypotheses proposed in this research and the methodology utilised to address these aims.

Chapter 4 used the Nominal Group Technique, a structured type of focus group, to examine what information men should have in order to make treatment decisions. Data were collected from prostate cancer survivors (n = 7) and a list of 20 items was generated. Variation was found in the items identified, but some agreement was found between participants in relation to the topics that should be prioritised. The "*urgency of the condition, timeframe to make a decision"* scored highest and was prioritised by more participants than any other item. These findings identified the importance of providing the timeframe for decision-making, and taking an individual approach when

informing patients. Removing time pressures on patients faced with making this serious decision, may help to reduce decision conflict and allow patients time to participate in informed or shared decision-making.

Chapter 5 detailed the quantitative study (n = 68) used to test the conceptual framework which was devised from the literature. Higher levels of health literacy and higher levels of self-efficacy were both independently associated with lower levels of decision conflict. Self-efficacy moderated the relationship between health literacy and decision conflict, when controlling for age, relationship status, perceived social support and knowledge of prostate cancer; higher levels of decision conflict were seen in men with low levels of health literacy and low self-efficacy, in comparison to men with low health literacy but high self-efficacy. Support for the theory that higher social support is associated with better health outcomes was limited in this study; however, perceived social support from friends was significantly associated with the decision conflict *support* subscale; those with high perceived social support from friends had better scores on the decision conflict *support* subscale. This adds to the emerging literature which considers the role of homophilic relationship in influencing health care decision-making.

Chapter 6 presented the qualitative study (n=14) that was utilised to explore prostate cancer patients decision-making processes. A descriptive thematic approach was used to analyse the data. The themes identified were: (1) approach to decision-making, which for the majority appeared to be a quick ("rash") decision based predominantly on (2) attitude to and beliefs about surgery. This was followed by (3) a *post hoc* justification of the decision, which reflected some common biases. The fourth theme to emerge related to barriers to making an informed decision. Confusion and lack of consideration of the side effects of treatment was observed in participants. Slowing down the decision-making process, and facilitating deliberative processing may help to ensure men can be both active and informed decision-makers when contemplating prostate cancer treatment.

Chapter 7 integrated the empirical findings presented in this thesis and discussed the implications for understanding decision-making about treatment. The theoretical and clinical implications of this research were identified, and limitations of the research and directions for further research were suggested.

This research identified that prostate cancer patients are active participants in the decision-making process and experience minimal decision conflict. For most, the decision seems to be uninformed with little consideration given to the future consequences of this decision and the impact these may have on quality of life. Men appear to make rapid decisions, not based on systematically processing information, but on affective and cognitive heuristics and biases. Until these biases are investigated, any further research into patient education seems futile. Involving patients in a shared decision-making approach, which recognises possible biases from both the patient and the professional may help to actualise patient-centred care.

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Chapter 1: Introduction

Men in Ireland have a 1 in 8 chance of being diagnosed with prostate cancer during their lifetime, with more than 3,400 men diagnosed with prostate cancer annually (National Cancer Registry, 2016). Survival rates have increased from 65% in the 1990's to rates in excess of 90% more recently (2009-2013) (www.ncri.ie). There is a range of treatment options available to these patients, with no one option superior to another in terms of survival (Hamdy & Donovan, 2017). As each option is associated with distinct adverse effects (Chen et al., 2017), making a treatment decision can be difficult with decision conflict and decision regret frequently reported in prostate cancer survivors.

This thesis considers this decision-making task from the patients' perspectives at the time of the decision, and draws on the psychological theories and constructs of decision conflict, perceived social support and self-efficacy to explore the patients' preferences in decision-making, their understanding of the disease and treatment options available to them and their experience of decision-making in this context. The patients' health literacy level is also considered. Examining the experience of prostate cancer patients in this context may help to identify how patients currently are supported and how future prostate cancer patients can be further supported in decision-making. This is especially important considering the advances in personalised medicine increasing the number of options available to patients, the increase in responsibility on patients to make

health decisions and the number of patients who suffer from decision regret in the longer term.

This chapter presents details on the specific medical factors that are considered, details of the treatment options available, along with information on the side effects associated with each option. The path the patient follows from first investigation to diagnosis is outlined to give the context for the complex decision that follows.

1.1. Prostate cancer

Many men over the age of 50 can have urinary symptoms, which can include frequent or urgent need to urinate, increased frequency of urination at night (nocturia), difficulty starting urination, weak urine stream or a stream that stops and starts, dribbling at the end of urination, and an inability to completely empty the bladder. For most men, these symptoms can mean the prostate gland is enlarged, a condition known as benign prostatic hypertrophy, which is a common disorder in men over 50. But for some, these symptoms can indicate an enlarged prostate due to prostate cancer. However, many asymptomatic men may receive a diagnosis of prostate cancer after having a routine blood test in their GP clinic. Although a controversial screener for prostate cancer, the blood test that is used to screen for prostate cancer is the prostate specific antigen (PSA) test (Grossman et al., 2018). With PSA testing about 2 out of every 3 men with a raised PSA level will not have prostate cancer, and the PSA test can miss a prostate cancer in a number of men. Different factors influence the sensitivity and specificity of the test, with

varying degrees of sensitivity and specificity depending on the threshold PSA level, the patients age and other patient related factors such as medications and exercise before testing. A PSA of ≥4.0 ng/mL is an accepted standard which balances the trade-offs between issues with sensitivity and specificity. A PSA cut-off of 4.0 ng/mL has a sensitivity of 21% and specificity of 91% for detection of any prostate cancer, with the sensitivity increasing to 51% in the detection of a high-grade cancer (Porter, Stanford, &Lange, 2006).

The incidence of early prostate cancer continues to increase and mortality rates are dropping in most countries (Wong et al., 2016). This is partly due to increased screening, and also due to the effective management strategies now available for patients. These management strategies include monitoring strategies: watchful wait, and active surveillance; and active management strategies: radical prostatectomy, external beam radiotherapy, brachytherapy, and hormone therapy. Watchful wait and active surveillance are effective monitoring strategies used in the management of early prostate cancer. Due to the nature of prostate cancer, selective patients on these monitoring strategies have been found to have similar survival outcome to those treated with active management strategies (Jayadevappa et al., 2017) without the morbidity associated with the active management strategies. Patients following an active management strategy can have significant and long-lasting side effects including urinary incontinence, bladder issues, bowel issues, and sexual dysfunction, which in turn can significantly impact quality of life (Chen et al., 2017). However, the consequences of either a monitoring or active

strategy has been shown to impact negatively on quality of life (Pieterse et al., 2011; Xu, Neale, Dailey, Eggly, & Schwartz, 2012). The side effects, specific to each treatment option, are detailed in Table 1.1.

The specific strategy available to patients who present with localised prostate cancer (without metastatic disease), depends on a number of factors which categorise the patient into a specific risk category: low, intermediate or high risk (D'amico et al., 1998). The factors that are considered when categorising prostate cancer are: the PSA level, the results of the Digital Rectal Examination (DRE) and the results of the biopsy. The characteristics of low risk prostate cancer are:

- a tumour which is confined to the prostate and
- PSA level is less than 10ng/mL and
- Gleason score of 6.

Intermediate risk is categorised as:

- a tumour which is confined to the prostate and
- the PSA is between 10 and 20ng/mL, or a Gleason score of 7

This category is often divided into “favourable” and “unfavourable” intermediate risk, depending on the composition of the Gleason score (4+3 versus a score of 3+4).

The characteristics of high risk prostate cancer are:

- a tumour which extends outside the prostate, and
- the PSA level is greater than 20ng/mL, or the Gleason score is 8 to 10.

More recently, the risk categorisation has been expanded to include “very low risk” (which are very slow growing tumours with fewer than three biopsy tissue samples containing cancer cells and the cancer is not detectable by DRE and “very high risk”. This is when the tumour has extended into the seminal vesicles or the rectum or bladder), or there are multiple biopsy samples with high grade cancer.

Those in the low-risk category have a choice of active surveillance or active management and those in the high-risk category will have a number of active management options or combinations available to them, all with similar survival outcomes, but with different effects on their quality of life. For example, as detailed in Table 1.1, surgery is associated with a greater risk of urinary incontinence and erectile dysfunction, while radiotherapy is associated with increased risk of bowel problems (Donovan et al., 2016). Table 1.1 represents a simplistic view of the side effects associated with treatment. A number of other variables must also be considered, for example, the patient’s baseline issues (e.g., baseline urinary symptoms may improve with external beam radiotherapy, but can worsen with brachytherapy), and if treatments are scheduled alone or in combination.

Table 1.1: Main side effects associated with each modality.

Side Effect	Surgery * (radical prostatectomy)	Radiotherapy* (External beam)	Brachytherapy	Hormone therapy
Fatigue	✓	✓	✓	✓
Urinary issues	✓	✓		
Bowel issues		✓		
Sexual function	✓			✓
Fertility issues	✓	✓		✓

Note: Does not account for pre-existing issues.

* Likelihood of side-effects reducing with new techniques/ technologies but no data yet to quantify this

Based on the guidelines provided by the European Association of Urology (Mottet et al., 2017) and internationally (https://www.cancer.org.au/) when contemplating the relevant treatment strategies, a clinician must consider the following factors:

1. The tumour related factors:
    - The stage or anatomic extent of disease (tumour, nodes, metastasis)
    - The histologic grade (Gleason score) of the tumour
    - The serum PSA (Prostate Specific Antigen) level
2. The patient related factors:
    - Age
    - General medical condition and existing comorbidities

These factors will allow the clinician to estimate the risk category and the survival outcome for individual patients. Consideration of the possible toxicities (acute and late side effects) and other potential complications should also be considered as these will impact on the patient's quality of life.

In line with international guidelines (www.nccn.org), once the decision as to the most appropriate treatment options is made by the multidisciplinary team, the urologist will give the patient the cancer diagnosis, and discuss the treatment options with him. This discussion usually includes some information on the patient's stage of disease, the specific options applicable to him, and some details about each treatment option: the possible survival outcome, what each treatment option entails practically (procedure, time frame) and the associated consequences of the treatment options. Patients are generally encouraged to bring someone with them to this appointment. Following this, unless there are very strong clinical

grounds for one specific treatment over another available option (e.g., contra-indications for surgery), patients will be required to make a treatment choice. The specific timeframe for this decision can be individual but in general, for patients diagnosed with early stage disease, there is no urgency, as prostate cancer is generally not an aggressive disease needing urgent treatment.

For best practice, the international guidelines suggest that patients should receive information from all specialists involved in each treatment option available to them (www.nccn.org). This process is shown in a simplified flow chart in Figure 1. In line with these guidelines, the standard practice in Ireland is for patients to be given an appointment to meet with a radiation oncologist to obtain more information on their disease and the specific information on the radiotherapy options that may be used in their management (external beam radiotherapy or brachytherapy). In the meantime, they are encouraged to read some of the booklets and leaflets provided to them by the urologist or specialist nurse. Their ability to do this is dependent on their health literacy described as the ability to obtain, understand, process, and apply information to their situation (Sørensen et al., 2012), further detailed in Section 2.3.3.

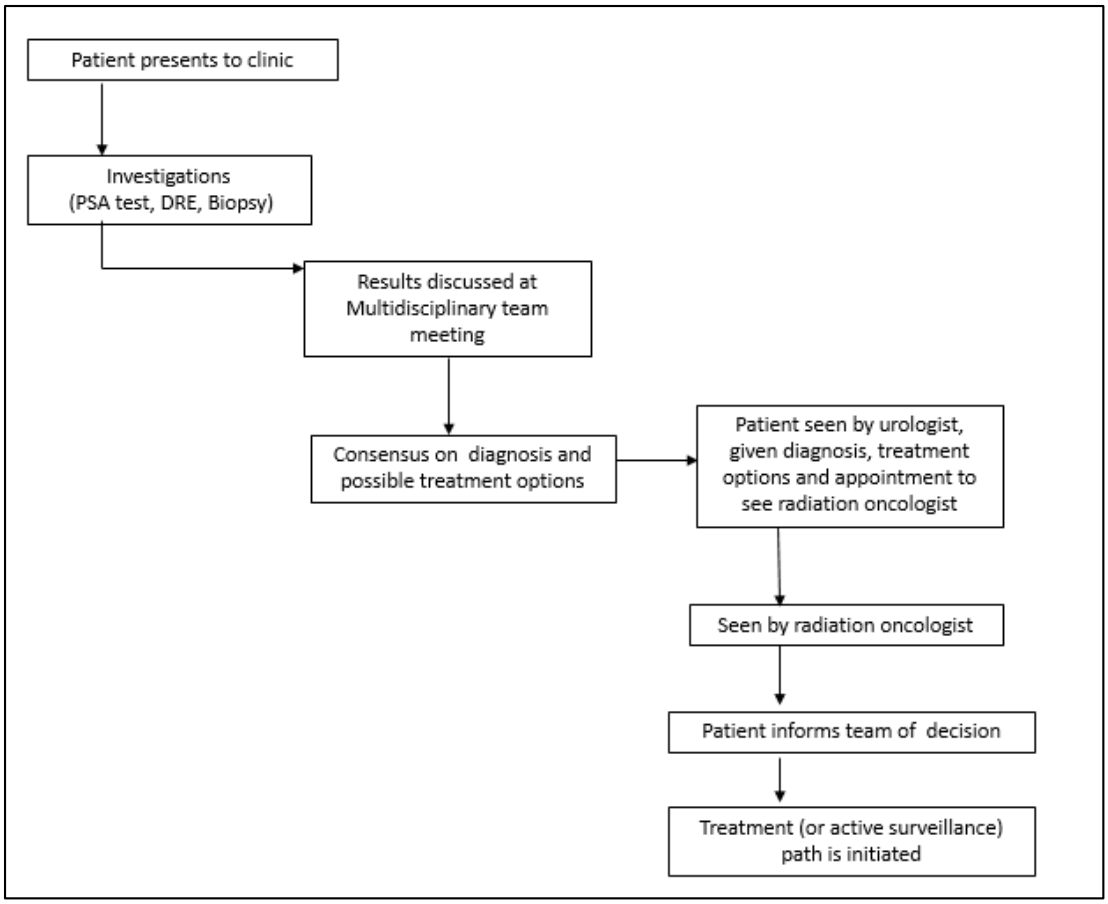

Figure 1.1: Flowchart showing patient pathway

At this second appointment, patients in Ireland, typically have had a couple of weeks to process their diagnosis and should be better placed to engage in a discussion on the treatment options and the implications with the radiation oncologist. However, in one centre, in Ireland, patients see both the urologist/surgeon and the radiation oncologist on the same day. The patients' ability to engage in a meaningful way with the clinician at their consultations will depend on their health literacy (Nutbeam, 2008). They may leave this clinic possibly with additional leaflets and booklets on cancer and now have to process this information to arrive at a treatment decision.

Active surveillance is a management strategy followed by fewer patients. In a recently published study of more the 3000 patients on the island of Ireland, only 5% of patients had followed an active surveillance pathway, in comparison with 25% following a surgical pathway and 63% having radiotherapy (external beam or brachytherapy). In Ireland, between 2013 and 2015, from the number of patients following an active management strategy, 28% had surgery, 28% had hormone therapy and 36% had radiotherapy (www.ncri.ie).

Little is known about the psychological processes prostate cancer patients undergo to arrive at this decision. Some factors that may influence decision-making have been identified within the empirical literature, (discussed in Chapter 2) including:

- the patients' capacity to understand, obtain, process, and apply information in order to make a health-related decision (*health literacy)*
- the patient's attitude to medical care and the role of the clinician-patient in decision-making (*Decision-making models)*
- sociodemographic factors such as age, relationship status and education level
- the patients' confidence in making a choice *(self- efficacy)*
- the support available to make a choice *([perceived] social support)*

1.2. Conclusion

To date, there is no consensus on the optimal strategy to manage early stage prostate cancer. Patients are expected to actively participate in decision-

making about treatment, and decide the strategy they will follow. As each option is associated with distinct adverse effects, making a decision can be difficult.

The next chapter presents a narrative review of the literature which considers decision-making about treatment. Factors thought to facilitate decision-making are presented, including; sociodemographic factors, knowledge, health literacy, self- efficacy, and perceived social support.

Chapter 2: Literature review

Men who receive a diagnosis of prostate cancer that is likely to be a significantly distressing occasion (Sharpley, Bitsika, & Christie, 2008), are routinely offered a number of treatment options, all with similar survival outcomes. However, each option carries the risk of different short and long-term side effects with an associated impact on quality of life (Chen et al., 2017). In the absence of a gold standard treatment, clinicians rarely decide on the treatment with patient preference dictating treatment course (Jayadevappa et al., 2017; Wang & Ranasinghe, 2017). Although the role of patients in decision-making varies, with a significant move towards shared decision-making models within healthcare (Makarov et al., 2016), patients being asked to make treatment decisions need to be adequately knowledgeable of their options, the short and long-term outcomes, and potential side effects in order to make an informed choice (Snow et al., 2007). Those who are inadequately informed may experience decision conflict, which is described as an individual's awareness of a state of uncertainty about a course of action to take when the choices involve risk, loss, regret, or a challenge to their life values and their confidence in making the decision (Carpenito-Moyet, 2000). Decision conflict can subsequently lead to decision regret when treatment is completed and the consequences of the choice become apparent. Decision regret is a negative emotion that involves remorse or distress following a decision (Brehaut et al., 2003) and has been associated with poorer quality of life and poorer health outcomes for cancer patients (Clark, Wray, & Ashton, 2001).

This chapter reviews the literature in the area of patients' involvement in decision-making, the incidence of decision conflict in cancer patients, the factors that can facilitate "good" decision-making and in particular focuses on the role of knowledge and understanding of health information (Health Literacy). Other factors thought to be involved in decision-making such as perceived social support and self-efficacy are also included, and the specific gaps in the literature around the role of these factors in prostate cancer patients' decision-making is highlighted.

2.1. Decision-making in health care

Although involving patients in decision-making was alluded to in the literature as far back as 1959 (Menzel, Coleman, & Katz, 1959), prior to the 1980's the general role of patients in decision-making in healthcare was passive within a paternalistic environment (Brody, 1980). The clinician was deemed the most suited to make decisions about health as they had the necessary expertise and followed a code of ethics in deciding the best interests of the patient (Charles, Gafni, & Whelan, 1999). With the evolution in the management of many diseases leading to an increase in the number of treatment options available to patients, the drive towards increasing patient involvement in decision-making began (Frosch & Kaplan, 1999). As the different options came with different consequences, patients were considered best placed to decide what trade-offs they were willing to accept in the management of their disease. This active involvement in decision-making can be within an informed decision-making approach or a shared decision-making approach as opposed to the passive approach historically associated with paternalism. The specific features of these three classic approaches to decision-

making are shown in Table 2.1. Within these classic approaches, the concept of shared decision-making varies across studies, but the definition provided by Charles et al. (1999) is the definition most cited in the literature (Makoul & Clayman, 2006). Charles' framework identifies three analytical stages as shown in Table 2.1, which are information exchange, deliberation, and deciding on which treatment to implement; these three stages can be distinct, overlap or iterate.

Table 2.1: Models of treatment decision-making, (adapted from Charles et al., 1999)

		Models	
Analytical stage	Paternalistic	Shared	Informed
Information exchange			
Flow	One way	Two way	One way(largely)
Direction	Clinician => patient	Clinician ⇔ patient	Clinician => patient
Type	Medical	Medical and personal	Medical
Amount (Minimum require)	Minimum legally required	All relevant information for decision-making	All relevant information for decision-making
Deliberation	Clinician alone or with other clinicians	Clinician with patient (plus potential others)	Patient (plus potential others)
Deciding on the treatment to implement	Clinicians	Clinician and patient	Patient

As shown in Table 2.1, the main difference between informed decision-making and shared decision-making relate to the information exchange. In informed decision-making one-way information exchange is used where the clinician informs the patient of the treatment options and the benefits and risks of these in order to obtain informed consent. In contrast, shared decision-making consists of a two-way exchange path with the clinician providing the relevant

clinical information and the patient sharing information about their values, beliefs and needs in an interpersonal interdependent process (Légaré & Thompson-Leduc, 2014). The decision is then made jointly between the patient and the clinician (Charles et al., 1999).

Prostate cancer patients, who traditionally preferred a passive role in treatment decision-making (Davison, Degner, & Morgan, 1995), are now showing a preference for more involvement in decision-making about their treatment (Tariman, Berry, Cochrane, Doorenbos, & Schepp, 2010). This change in decision-making preference is evident from research conducted in the late 1990's, which identified that over half the patients preferred a passive role and this was reduced to only one third of patients five years later (Davison et al., 1995). The same tool to measure patients' preference was used in both studies, allowing this time trend to be observed. The number of patients taking an active/shared role has further increased, with a recent review of 42 studies identifying that the majority of patients played either an active or a shared/collaborative role. Wang and Ranasinghe (2017) identified a preference for an active role as high as 71% in one study (Berry et al., 2006), and a shared role as high as 86% (Huber et al., 2011). In contrast, the highest reported preference for a passive role across these studies was 32% (Davison et al., 1995, 32%), and this is similar to reports from a second review which reported a preference for a passive role in cancer decision-making at 37% (Tariman et al., 2010). The variation in preferences for decision-making in these reviews was attributed to age, with older patients preferring a passive role. The percentage of prostate cancer patients in Ireland who reported a passive role

was 31%, with only 36% and 33% of patients reporting an active role or shared role respectively (Drummond, Gavin, & Sharp, 2018). In this cohort of more than 3000 men, both preferred role and actual role were recorded retrospectively, and discordance between preferred role and actual role was reported in almost 30% of patients, with 17% being more involved than preferred and 10% being less involved than preferred. Health-related quality of life was significantly lower in patients whose preferred role and actual role were incongruent, a finding supported by other research in prostate cancer with van Stam et al. (2018) reporting significant lower levels of health-related quality of life in patients whose preferred role did not match their experienced role. Health-related quality of life was also significantly lower in patients who played a passive role in decision-making in the Irish study, again consistent with van Stam's findings and a review by Joseph-Williams, Edwards, and Elwyn (2011). This highlights the importance of both congruence between patients' preference and their actual role but also the importance of involvement in decision-making, with those actively participating in decision-making reported to have higher quality of life scores. Regardless of preference, patients are likely to feel empowered and experience more positive health-related quality of life outcomes when their doctors facilitate them to participate in decision-making (Arora, Weaver, Clayman, Oakley-Girvan, & Potosky, 2009), whereas greater regret has been observed in those whose treatment decision is clinician led or driven rather than shared (van den Bergh et al., 2009).

Considering the increasing focus on prostate cancer patients making decisions about treatment and the importance of participation in decision-making

due to the association with better quality of life, facilitating patients to be active participants in decision-making is important. Thus, identifying the potential barriers and facilitators to decision-making can help to support patients play an active role in decision-making in this complex situation. This in turn will help to reduce the likelihood of decision conflict and decision regret after treatment is completed and the consequences of the decision become apparent.

2.2. Decision conflict and decision regret

> *"A good treatment decision is ultimately characterised by minimal decision related regret."* (Birnie & Robinson, 2010, p. 135)

The quality of a decision can be measured by assessing decision conflict and decision regret where decision conflict is a state of uncertainty about a course of action to take when the choices involve risk or loss or a challenge to one's values and one's confidence in making the decision (Carpenito-Moyet, 2000; O'Connor, 1995). Decision regret is a negative emotion that involves remorse or distress following a decision. Brehaut et al. (2003) suggest that decision regret is potentially modifiable through shared decision-making.

Patients who experience decision conflict at the time of or just after making a decision experience higher levels of decision regret (Becerra Pérez, Menear, Brehaut, & Legare, 2016; Downing et al., 2017), and decision regret has been associated with a reduction in quality of life scores (Brehaut et al., 2003). Furthermore, controlling for other factors, higher decisional conflict and less involvement in decision-making were significantly associated with increases in decision regret (Berry, Wang, Halpenny, & Hong, 2012; Collingwood et al., 2014;

Davison, Matthew, & Gardner, 2014). Similarly, patients with a decreased knowledge about prostate cancer displayed increased decisional conflict and lower perceived effective decision-making (Kaplan, Crespi, Saucedo, Dahan, et al., 2014). Accordingly, a review in 2016, which included 11 studies on prostate cancer, identified the association between decision conflict and decision regret: patients with higher levels of decisional conflict display higher levels of decision regret (Becerra Pérez et al., 2016). Although decision regret scores were relatively low within the 59 studies included in this review of mixed populations, those making decisions in relation to treatment, were more likely to suffer from higher levels of decision regret (scoring 18.4 out of 100) than those making decisions about screening and prevention (scoring 6.4 out of 100). This may relate to the perceived higher stakes involved when making decisions about treatment rather than decisions about prevention or screening. Overall these decision regret scores are quite low, but within the prostate cancer related studies included in this review, scores ranged from 11-24 with high standard deviations observed across the studies; 20 being the highest standard deviation observed in a study of 151 prostate cancer patients (M = 19.3) (Davison et al., 2014). This illustrates that decision regret is a matter of concern in prostate cancer patients.

In addition to decision conflict and less involvement in decision-making, lack of information and poor knowledge of prostate cancer have also been associated with decision regret (Downing et al., 2017; Joseph-Williams et al., 2011; Kaplan, Crespi, Saucedo, Dahan, et al., 2014), and similarly inadequate information about disease, treatment options and consequences of treatment was linked to decision

conflict in prostate cancer patients (Albkri et al., 2018). Orom highlighted the importance of greater knowledge and active involvement in decision-making to reduce decisional conflict and increase decision-making satisfaction. Greater knowledge was also associated with better quality of life in this study of 1500 prostate cancer patients (Orom, Biddle, Underwood, Nelson, & Homish, 2016). However, significant knowledge gaps have been identified in prostate cancer patients resulting in difficulty in decision-making and confusion and difficulty in discerning the specific side effects associated with each option (Daum et al., 2017). Notably, patient demographics have not been found to be associated with decision regret (Becerra Pérez et al., 2016).

To overcome the issues of decision conflict and decision regret highlighted in this section, the next section considers what facilitates patients to make treatment decisions. This is relevant firstly, because the research has identified that regardless of congruence between preference and actual role in decision-making, those not involved in decision-making will have greater decision conflict. Secondly, with the role of patients moving towards active involvement, especially in this situation when there is no clear evidence to suggest that one treatment option is superior to another, patients are expected to take an active role and make this complex decision.

2.3. Facilitating decision-making

Prostate cancer patients faced with making a treatment decision must play an active role, and whether this is in an informed or shared environment, they need to be facilitated to participate. From the different concepts investigated and

reported in relation to decision-making and decision conflict, within this thesis the psychological concepts of perceived social support and self-efficacy are investigated. Firstly, the factors relating to information and knowledge along with understanding are presented, as these have also been found to be associated with decision-making in healthcare.

2.3.1. Information

Information need in patients is high following a cancer diagnosis (Barber, Banks, McCaughan, & Baker, 2013). Information need is greater among patients with diseases like early stage prostate cancer, which is characterised by uncertainty and ambiguity around the optimal treatment (Steginga et al., 2001). Appropriate information and accurate knowledge have been associated with increased perceptions of control (Maliski, Heilemann, & McCorkle, 2002), decreased decision conflict, increased satisfaction with decision-making and increased quality of life in prostate cancer patients (Orom et al., 2016), with some evidence to support the benefits of decision aids in increasing knowledge.

2.3.1.1. Information and health status

With the increased expectation that patients will take an active role in medical decision-making, information is crucial to allow informed decision-making. Providing balanced and comprehensive information about the risks and benefits of treatment options helps to ensure that patients choose treatments consistent with their preferences (Hoffman, 2012). Satisfaction with information can also lead to improved health status with one Irish study finding a positive correlation between satisfaction with information received and overall global health status in prostate

cancer patients (Diver, Avalos, Rogers, & Dowling, 2018). However, lack of satisfaction with the amount and helpfulness of information has been associated with general dissatisfaction, and poorer quality of life in prostate cancer patients (Cuypers et al., 2016). In addition, adequate Information on the management strategies available to treat prostate cancer is essential, as the type of treatment selected has also been associated with quality of life, with those who chose an active strategy rather than active surveillance reporting a greater decline in quality of life (Cuypers et al., 2018).

Given the good overall survival rates for patients with early prostate cancer, the impact of the treatments on quality of life (e.g., sexual dysfunction, urinary issues, bowel issues) needs to be considered when deciding on treatment, yet significant gaps in knowledge about treatment and their associated side effects have been shown. Daum et al. (2017) report that more than a third of men from a sample of 200 patients who received surgery or radiation did not know that these treatments can have serious long-term side effects which can impact on quality of life. However, even though men report that side effects are important when making decisions, two systematic reviews of decision-making in prostate cancer patients identified that side effects did not influence patients in making their treatment decisions, (Feldman-Stewart, Brundage, & Tong, 2011; Zeliadt et al., 2006). As patients have been found to strongly overestimate the benefits of surgery over active surveillance, and view surgery as a better option in terms of survival (Kendel et al., 2016), perhaps the disconnect seen in these reviews may relate to the patient's underlying belief that one treatment is better than another

and are therefore willing to overlook side effects and quality of life for a perceived survival advantage. However, the authors of these reviews consider the disconnect to stem from the information that is provided and the methods used to provide information.

2.3.1.2. Information and decision regret

A lack of information, the type of treatment selected, and the adverse effects of treatment have all been found to be associated with decision regret in prostate cancer patients. Lack of information was associated with decision regret in prostate cancer patients in a recent Irish study and prostate cancer survivors were more likely to experience a fear of recurrence, if they were unsatisfied with the information received (Maguire, Hanly, Drummond, Gavin, & Sharp, 2017). Although the overall rates of fear of recurrence were low, higher fear of recurrence scores were reported in those with higher regret over treatment decision-making. Fear of recurrence was also associated with lower satisfaction surrounding the information they received. This is not surprising considering other studies which have highlighted the lack of knowledge around survival in prostate cancer (Daum, 2017).

Decision regret which has been reported in a 15 year follow up study of 900 prostate cancer patients (Hoffman et al., 2017), has been associated with the type of treatment selected, the rate of complications from treatment, and the adverse effects of specific treatments (Collingwood et al., 2014; Berry et al., 2012; Davison et al., 2014). Shaverdian et al.,(2017) found the rate of decision regret to be significantly higher in those choosing Intensity Modulated Radiotherapy or Brachytherapy over Stereotactic Body Radiotherapy. Although the rates of side

effects with both Intensity Modulated Radiotherapy and Brachytherapy are low, the side effects with Stereotactic Body Radiotherapy are significantly lower thus highlighting the importance of information about adverse outcomes in order to decrease decision regret. Given the impact of treatment side effects on decision regret, and the association of information with quality of life as detailed earlier, men need to be adequately informed in order to participate in making an informed decision. However, as greater knowledge was associated with greater decision-making difficulty (Daum et al., 2017), identifying patients' specific informational needs is also important to not burden patients, but facilitate informed decision-making.

2.3.1.3. Patients informational needs

Previous research supports the idea that the specific information men require to make a treatment decision needs to be customised to an individual's needs (Feldman-Stewart, Brundage, & Van Manen, 2001). This therefore means that healthcare professionals have to identify patients' needs and modify the information they provide on a case by case basis. However, this has proven difficult for healthcare professionals who typically underestimate the information needs of patients (Snow et al., 2007) and their preferred level of involvement in decision-making (Shepherd, Butow, & Tattersall, 2011). In addition, the specific information provided to patients is often designed and developed by healthcare professionals with little or no input or evaluation from patients (Wessels et al., 2010). Although patient advocacy is on the increase, patients are still not routinely included when designing, testing, and evaluating information services for patients. This can pose a

problem; as healthcare professionals may not be in the best position to make judgements on what information cancer patients need. Lack of agreement between cancer patients and oncology professionals in relation to patients' needs was highlighted by Wessels et al. (2010), with healthcare professionals overestimating the importance of some care issues (e.g**.,** 'Support, counselling and rehabilitation', 'Privacy', 'Patient habits',) and underestimating others (e.g., 'Physician and nurse expertise', including items concerning information, knowledge and experience; 'Physician attitude', including items concerning trust, empathy, opportunity for the patient to ask questions; 'Accessibility of services'; and 'Hospital equipment'). Furthermore, the issue with professionals designing information services for patients was also illustrated by Rüesch et al. (2014), who investigated agreement between patients and healthcare professionals on information needs of early prostate cancer patients. A lack of agreement was observed both among healthcare professionals and between healthcare professionals and patients. Healthcare professionals were only moderately in accordance with patients and differences were found across the professional groups (Rüesch et al., 2014). The particular differences related to information on cure *("if the cancer is not treated, how long will I live"- selected by patients only),* equipment (*"is the equipment at the hospital up to date"- selected by patients only*) and practical details on treatment combinations (*"if more than one treatment is needed, how much time does each treatment take"- selected by patients and oncologists but not nurses, urologist or radiation therapists*), with variation also seen across other items, consistent with previous literature (Snow et al., 2007, Feldman-Stewart et al., 2000, Feldman-

Stewart et al., 2011). Interestingly, large variation was also seen across the patient groups, further identifying that the information needs of patients can be quite individualised.

In addition to the debate on what information men require to make an informed decision, how patients get information must also be included when considering patient information needs, as this can also influence patients' knowledge and recall (McGregor, 2003). Factors such as the format of information (Holmes-Rovner et al., 2005), the ability to recall treatment discussions (Richard, Glaser, & Lussier, 2017), the ability to understand and process the information received (Nutbeam, 2000), the context in which the information is provided, and the skills of the healthcare professional in providing the information (Merckaert et al., 2005), all need to be considered.

It is also important not to overburden patients with unnecessary information, but how much information is required and the specific details that are necessary to make a decision is debated in the literature (Bobridge, Bond, Marshall, & Paterson, 2015; Rüesch et al., 2014). Where many studies report greater decision-making satisfaction and a reduction in decision conflict in men who are informed (Myers et al., 2018; Orom et al., 2016), some studies have found that increased knowledge can increase decision uncertainty and decision-making difficulty (Orom et al., 2016). It is possible that more knowledge highlights the importance of making the "right" decision, thereby making the process more difficult for those who are knowledgeable. As such, once understood, the realisation of how much may be at stake can make the task more daunting for

patients. In order to overcome the factors that influence knowledge recall, meet patients' informational needs, and facilitate informed decision-making, decision aids are often used.

2.3.1.4. Decision aids, knowledge and decision conflict

Decision aids have been defined as "interventions designed to help people make specific and deliberated choices among options (including the status quo), by making the decision explicit and by providing, at a minimum, information on the options and outcomes relevant to a person's health status as well as implicit methods to clarify values" (Stacey et al., 2017, p. 8). Common examples of decision aids include: information leaflets, videos, and web-based tools.

Decision aids and knowledge

High-quality evidence supports the use of decision aids compared to usual care in improving patients' knowledge, as identified in a Cochrane review in 2014 of decision aids across different healthcare settings (Stacey et al., 2014). Compared to usual care, decision aids increased knowledge and reduced the likelihood of choosing more invasive surgical treatment strategies across many healthcare settings. When more detailed decision aids were compared to simple decision aids, the relative improvement in knowledge was significant. Of the 115 studies included in this review, three studies related to decision-making about prostate cancer, however the influence of the decision aid on knowledge was not assessed as an outcome in these prostate cancer specific studies. An update to this review in 2017 included one further prostate cancer specific study (Stacey et al., 2014). This study, which assessed knowledge, used a decision aid in the form of a booklet, which

included information about treatment options, treatment consequences, patients' stories, and explicit values clarification guidance (Chabrera et al., 2015). Knowledge scores increased in this study, adding to the existing evidence base which supports the use of decision aids in increasing knowledge in various healthcare settings, and provides evidence for the use of decision aids to increase knowledge in prostate cancer patients. Patients were also more satisfied with the information provided, which helped with decision-making about treatment.

Decision aids and decision conflict

While the evidence to support the use of decision aids to improve knowledge in different healthcare settings is strong, the evidence on the role of decision aids in reducing decision conflict in the three prostate cancer studies included is less clear (Stacey et al., 2014). In one study of prostate cancer patients included in the Cochrane review no difference was found in the overall decision conflict score between groups (decision aid versus standard care) (Berry et al., 2013). In this study, the decision aid consisted of customized text and video coaching. Similarly, no difference was found in the second study, in this review, between those in the decision aid group (i.e. supplied with a written information package, a list of questions to ask their clinician, and an audiotape of the medical consultation) and the standard care group (i.e. supplied with a written information package alone) (Davison & Degner, 1997). The third prostate cancer study in this review was excluded due to bias (Auvinen et al., 2004). However, it should be noted that some benefit was seen in two of the subscales of the Decision Conflict Scale (O'Connor, 1995) in one of these study (Berry et al., 2013). The updated review in

2017, which included one further study prostate cancer specific study, identified a reduction in post intervention decisional conflict scores in the intervention group, thus conflicting with previous findings. Possible reasons for the conflicting nature of the findings include; the sample sizes in two of the studies were small (e.g. Davison study n = 30 in each arm, Chabrera study, n =70 in each arm), and the high risk of bias in all studies (assessed using the Cochrane Collaboration Risk of Bias Tool). The domains measured (for example, decision conflict and anxiety), and the instruments used, also varied across studies. Cultural influences may also explain some of the variation, as the study which had a positive outcome (Chabrera study) was conducted in Spain, as opposed to the United States or Canada. Similarly, mixed results were found when reviewing the impact of decision aids on decisional conflict in a meta-analysis on the effectiveness of decision aids for prostate cancer patients (Violette et al.,2015). Of interest, the decision aids included in these reviews merely provided information rather than facilitated shared decision-making through use of the decision aid in the patient-clinician encounter, and none of the included studies found a benefit in terms of quality of life.

2.3.1.5. Quality of decision aids

The quality of the decision aid may explain some of the mixed findings in relation to the benefits of decision aids as many decision aids lack crucial items such as a full description of risks, benefits, and outcome probabilities for all management options and many had readability issues because of complex language, which could inhibit a shared or collaborative decision-making process (Adsul et al. 2015). These items are considered essential for inclusion in decision aids in order to meet the

international criteria for decision aids, developed by the International Patient Decision Aid Standards (IPDAS), a collaboration formed in 2006 to develop a quality criteria framework for patient decision aids (http://ipdas.ohri.ca/).

A lack of adherence to guidelines such as the IPDAS, can impact on the quality and therefore the benefit of decision aids in decision-making. For example, only moderate quality evidence was found to support the ability of decision aids to facilitate patients to take a more active role in decision-making in the Cochrane review. In addition, the ability of decision aids to improve congruence between the chosen option and the patients' values was of low-quality. However, the quality of decision aids may be improving, as the update in 2017 concluded that there is growing evidence that decision aids may improve congruence between preference for role in decision-making, values and choices, all essential characteristics of shared decision-making (Stacey et al., 2017).

2.3.1.6. Summary

To reduce decision conflict and decision regret and facilitate patients to be active in the decision-making process, information should be individualised and clearly presented so that patients can be knowledgeable about their disease, the treatment options available to them, and the consequences of their choice in terms of both survival and adverse effects. The option of not choosing an active strategy must also be clearly explained to ensure patients are choosing from the full list of management options. However, the patients' level of understanding must also be considered, however, few studies have measured the patients understanding of the

information provided, and different factors such as the patients' health literacy can impact on understanding, as discussed in the next section.

2.3.2. Understanding information

When patients are adequately informed and understand information about their disease and treatment, they are better able to participate in active decision-making about their health and are more likely to comply with the management strategy they had a part in choosing (Miller, 2016). Given the mixed findings in the literature in relation to decision aids, simply providing information resources for patients is not sufficient, if these resources do not contain the information required by patients or are written at a reading level too high for the national average reading level. Previous research of patient education resources found that most of radiation therapy related materials available online are written at a readability level too high for a substantial portion of the general population to comprehend (Byun, 2013). In Ireland, considering the incidence of insufficient or problematic health literacy levels in the general adult population is in the region of 40% (Doyle & Fullam, 2012), 2 in 5 patients may struggle to understand information about their disease and treatment options. This will impact on their ability to actively participate in decision-making or be informed about their treatment options, with low health literacy considered an overlooked factor in the implementation of shared decision-making for prostate cancer patients (Kim et al., 2001).

2.3.3. Defining health literacy

Health literacy has evolved significantly since the term was first used in 1974 but there is still no universally accepted definition, with variation in the

conceptualisation and definitions of health literacy (Miller, 2016), making it difficult to measure health literacy level and fully quantify the extent of the consequences of low health literacy on treatment decision-making and health outcomes. A systematic review in 2012 identified 19 studies that aimed to define health literacy (Sørensen et al., 2012). Broadly speaking health literacy refers to literacy within a health and healthcare setting (Ishikawa & Yano, 2008). The definition most frequently cited in the literature (Sørensen et al., 2012), is the definition used by the Institute of Medicine *"The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions".* (Institute of Medicine & Literacy, 2004, p. 2)

The concept of health literacy, having initially focused on one's ability to manage words and numbers in a medical setting progressed to include the individual's ability to interact with healthcare providers (Sørensen et al., 2012). The newer concepts of health literacy focus on motivation as well as ability and cognitive aspects including comprehension, analysis, and application of health information (Berkman & Crotty, 2011). These skills include the social skills required to interact with other people and society and lead to the ability to make decisions about one's health (Ishikawa & Yano, 2008). As health literacy includes cognitive abilities as well as social aspects (Mancuso, 2008), and is based on the interaction of the individual with the healthcare setting/society in which they live, the concept includes both the individual and their health-care provider's ability to communicate health information in an appropriately targeted manner (Ishikawa & Yano, 2008). This evolution in the conceptualisation of health literacy follows the evolution of

the patient role in decision-making which now requires the patient to be an active participant in the patient-clinician encounter.

Nutbeam's model, used across a large number of studies, encompasses three dimensions of health literacy both from an individual and population perspective: (i) functional health literacy (basic), (ii) interactive health literacy (communicative), and (iii) critical health literacy (Nutbeam, 2000). Functional health literacy encompasses the basic skills sufficient for reading and writing in order to use the health system and function effectively within it. This dimension is broadly compatible with the earlier and narrow definition of health literacy and is the aspect of health literacy considered and measured in many studies. Within this dimension, higher order skills including critical thinking and decision-making are not encompassed. Interactive literacy incorporates cognitive, literary, and social skills, which allow one to extract information and derive meaning from different forms of communication, in order to actively participate in everyday activities and interact within the healthcare setting. Critical literacy refers to more advanced cognitive and social skills, which allow one to process, analyse and critically reflect on information to exert greater control over life events, situations and decisions (Nutbeam, 2000).

For the purposes of this thesis, within the Institute of Medicine's definition of health literacy detailed in Section 2.3.3, the three dimensions of health literacy in Nutbeam's model are applied to prostate cancer patients. The functional level applies to the patients' ability to attend for their appointments and read the information provided to them; interactive level relates to the patients' ability to

engage in a meaningful way with the clinician at their consultation; the critical level integrates the cognitive and social skills required to make informed and shared decisions about prostate cancer treatment. The next section discusses the role of health literacy in decision-making within this context.

2.3.3.1. Health literacy and decision-making

Research in health literacy and treatment decision-making for cancer patients is lacking and has been identified as an area requiring future work (Seo, Goodman, Politi, Blanchard, & Kaphingst, 2016). The majority of research in health literacy and cancer focuses on the general population in the area of prevention and screening. Much of the research that has been conducted in cancer patients used instruments that measure an older and narrow concept of health literacy in comparison to the full concept of health literacy as theorised by Nutbeam (Koay, Schofield, & Jefford, 2012). Research in the area of health literacy and decision-making has been conducted in other healthcare settings or in decision-making about cancer screening across different health literacy groups. Education level and functional health literacy has been linked to how people view their involvement in decision-making about colorectal cancer screening. Those with higher education level and higher health literacy level are more likely to take some responsibility for decisions and view their role as shared, than those with lower education and lower health literacy levels, who consider their role as either agreeing or disagreeing with what the clinician proposes (Smith, Doctor, Meyer, Kalet, & Phillips, 2009). This finding is supported in other healthcare settings; for example, diabetic patients (n = 168) with low literacy had less desire to participate in medical decision-making and

less diabetes-related knowledge (DeWalt, Boone, & Pignone, 2007), and in asthma patients where those with lower health literacy, although wanting information about treatment options, did not want to participate in decision-making (Mancuso & Rincon, 2006). Similarly, in a sample of 576 primary care patients, controlling for age, gender, and race/ethnicity, health literacy was significantly associated with decision-making preferences, with active participation in decision-making preferred among those with adequate health literacy compared to those with limited health literacy (Seo et al., 2016). Patient characteristics, including lower socio-economic status have also been linked with lower health literacy level in the National Adult Literacy Survey (NALS) (Kirsh, Jungeblut, Jenkins, & Kolstad, 1993), and different strategies have been developed to increase health literacy levels. This, in turn, can facilitate patients to become more informed and active in treatment decision-making.

Education interventions were shown in a meta- analysis to increase health literacy level across all sociodemographic groupings but were more effective in improving health literacy in patients with lower income than in those with higher income (Miller, 2016). Examples of such patient education interventions are information leaflets/booklets, audio-visual resources, online resources, and web-based educational applications, with some interventions incorporating strategies for increasing communication between patients and health care providers to better address patients' questions and concerns (Miller, 2016), thus of benefit in a shared decision-making setting. Patients who participated in these health literacy interventions reported a higher rate of treatment adherence than those who did

not participate, but health literacy training did not improve adherence as much in Caucasian patients as it did in ethnic minorities. This illustrates the complex relationships between health literacy, socio-demographic factors and healthcare (Miller, 2016), and may have implications for future prostate cancer patients in Ireland, given the increase in ethnic minorities in Ireland in recent years. Where patients with long-term illness can develop health literacy skills over time that enable them to make health related decisions (Edwards, Wood, Davies, & Edwards, 2012), prostate cancer patients, although not needing to make immediate decisions, may not feel they have the time to delay decision-making, given the general perception that one needs to act quickly when diagnosed with cancer. Therefore, finding the balance between what should be known to make a life-changing decision about prostate cancer treatment, and what is excessive and confusing is difficult, especially in low literacy populations, but an education intervention that can achieve this will facilitate patients to be "*cancer literate*", a concept proposed by Diviani and Schulz (2011, p. 489). This in turn will empower patients, reduce the likelihood of decision conflict and decision regret, and lead to better health outcomes as discussed earlier in Section 2.2.

The supports available to patients and their level of self-efficacy can also empower patients, making them feel confident to make this complex and serious decision. However, before examining these two constructs, a review of the established psychological social cognition models associated with health behaviour is presented. An examination of the role of support and self-efficacy and how these

constructs may moderate the relationship between health literacy and decision-making in prostate cancer patients then follows.

2.3.4. Social cognitive models and health behaviour

Psychological models, such as Leventhal's self-regulation model of health behaviour (Leventhal, Brissette, & Leventhal, 2003) and the Health Belief Model (Rosenstock, 1974) have been developed to predict, explain or change health behaviours. These social cognition models, stemming from Bandura's social cognitive theory, propose cognitive and affective factors in an attempt to identify the proximal determinants of health (Armitage & Conner, 2000). Although much research has examined the role of these models around behaviours in relation to screening, there is a dearth of research which has applied psychological models to understanding the decision-making process associated with treatment in newly diagnosed prostate cancer patients. Considering that decision-making is a complex and non-linear process where the patients' evaluation of their options and perception of the associated risks not only involves knowledge but also beliefs, past experiences, coping strategies, and regulation ability (Mazzocco, Masiero, Carriero, & Pravettoni, 2019), it may be important to consider the application of these models in prostate cancer patients.

Managing illness such as cancer, requires regulation of both emotional states and physical states. The psychological stress associated with a prostate cancer diagnosis can evoke a negative and maladaptive coping mechanism if the stress is perceived as a threat, whereas perceiving the stress as a challenge will evoke less negative emotions (Lazarus & Folkman, 1987). In the transactional

model of stress, Lazarus and Folkman view psychological stress as the relationship between the person and the environment with an emphasis on the appraisal of stress including a primary appraisal and a secondary appraisal. Within primary appraisal, the event or situation is analysed and may be judged as a "harm" which has already been experienced, a "threat" in which the harm is anticipated, or a "challenge" which has the potential for gain. The secondary appraisal consists of evaluating the benefits and risks associated with a specific coping strategy to judge how to deal with the situation. A problem-based coping strategy elicits control over the situation, and this is in contrast to an emotion-based strategy where the individual feels less in control. An individual who judges that they lack the resources or ability to cope with the situation will perceive the situation as stressful. A recent Irish study examining the role of perceived stress and self-efficacy in predicting emotional adjustment in newly diagnosed prostate cancer patients found higher levels of reported stress at diagnosis were linked to poor emotional adjustment. In addition, cancer-related stress rather than general stress best explained confusion and bewilderment in this sample (Curtis, Groarke, & Sullivan, 2014). Given the important treatment decision prostate cancer patients need to make at this time, the ability to reduce confusion is essential.

In addition to the transactional model of stress, the self-regulation model may also help explain prostate cancer patients behaviour at the time of diagnosis, as this model, specific to health behaviour, states that individuals form cognitive and emotional representations of health threats (Leventhal, Nerenz, & Steele 1984). Although a number of models of self-regulation exist, common across all models is

the expression of self-regulation as a systematic process involving conscious efforts to regulate thoughts, emotions and behaviours in order to achieve goals in a changing environment (Cameron & Leventhal, 2003). Self-regulation models include cognitive processes, affective factors and behavioural goals in addition to the dynamic elements of feedback, motivation and goal setting, and the self-regulation model has been identified as a useful framework in identifying modifiable factors that may lead to improved coping with cancer related fatigue in cancer survivors (Corbett, Groarke, Walsh, & McGuire, 2016). The inclusion of the emotional component in the self-regulation model differentiates it from other psychological models which only focus on cognitive or behavioural factors.

Leventhal's common-sense model of self-regulation varies from other models of self-regulation by providing a framework which details what is being regulated and how regulation is achieved (Leventhal et al., 2003). This model is an extension of the parallel processing model that aimed to understand how individuals respond to fear-arousing communications, and explains how individuals respond to health threats. This model includes critical aspects unique to health, including symptom experiences, survival threat and the complexities associated with medication use and treatments (Leventhal et al., 2003). It proposes that individuals actively problem-solve by developing mental models of health threats, subjective and objective treatment goals, and practices and procedures most likely to achieve their goals (Mora & McAndrew, 2013), by using two parallel interrelated representations of the stimulus: cognitive and emotional (Leventhal et al., 1997). Using self-regulation theory as a framework, a qualitative study,

which examined decision-making about treatment in prostate cancer survivors with rising PSA levels, found that patient-based cognitive and affective and interpersonal processes shape their decision-making (Shen et al., 2015). The authors highlighted the importance of guiding patients in making decisions under uncertainty and addressing the uncertainty experienced by patients.

Other useful models which have been shown to be useful predictors of health-related behaviour are the motivational models which include the Health Belief Model (HBM; Rosenstock, 1974), the Theory of Reasoned Action (TRA; Fishbein & Ajzen, 1975) and the Theory of Planned Behaviour (TPB; Azjen, 1991). These motivational models aim to identify the variables associated with health-related decisions and to assess their ability to predict behaviours (Armitage & Conner, 2000).

The HBM is a theoretical framework derived from psychological and behavioural theory in the early 1950's, and aimed to explain preventative health behaviours, such as the lack of participation in disease prevention and screening strategies (Rosenstock, 1974). It was later extended to explain responses to symptoms and compliance with medical treatments (Janz & Becker, 1984; Strecher & Rosenstock, 1997). The HBM which includes six determinants of behaviour: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, health motivation and cues to action, posits that a person's belief in a personal threat of a disease along with their belief in the effectiveness of a specific health behaviour or action will predict the likelihood the person will adopt a behaviour. In the late 1980's, self-efficacy was identified as an important independent construct

to add to the model (Rosenstock, Stretcher, & Becker, 1988). Previous research has utilised the HBM to explain intention to participate in prostate cancer screening, for example; four of the determinants (perceived susceptibility, benefits and barriers to prostate-specific antigen (PSA) test, and health motivation) explained intention to screen in a population of men in Jordan (Abuadas, Petro-Nustas, Albikawi, & Mari, 2017) and perceived benefits was a predictor of intention to screen for prostate cancer in Haitian men (Louis, 2019). In relation to decision-making about treatment, a qualitative study of pancreatic patients which aimed to identify the predictors of intention to undergo surgery found the main determinants to undergo surgery was a positive relationship with the clinician and support from the family. The HBM was used as a framework to derive the questions used within this study (Castillo-Angeles et al., 2017). However, similar to issues with other social cognitive models, researchers have identified limitations with the HBM's ability to predict health behaviour. For example, Armitage and Conner (2000) have identified that threat is a function of both severity and susceptibility, yet both are presented as separate constructs within the model. Another criticism is that the model does not identify how the explanatory factors are combined to influence behaviour or how the individual constructs influence or moderate one another (Baban & Craciun, 2007). The HBM has also been criticised for excluding the role of emotion in decision-making and for not providing a more complete conceptualisation of the perceived severity construct (Sutton, 2004). Finally, the influence of sociopsychological factors such as cultural beliefs is not included in the model, and this has been found to

reduce adherence to medication in some samples (Munro, Lewin, Swart, & Volmink, 2007).

In addition to the health belief model, the TRA and its extended theory- the TPB, also focus on attitudes, beliefs, and expectations of future events and outcomes as major determinants of health related behaviour, with the assumption that one will make choices that lead to positive outcomes (Munro et al., 2007). The TRA posits intention as a determinant of behaviour, for example; the stronger one's intention is towards a specific behaviour, the more likely they are to perform that behaviour (Fishbein & Ajzen, 1975). Intention is defined as the motivation needed to perform certain tasks, and is determined by one's attitudes and perception of social pressures (subjective norms). However, one's perception of their control over their behaviour was lacking in this model, therefore perceived behavioural control was subsequently included in the extended model- the TPB, which posits that intentions are determined by three factors; attitudes towards a behaviour, subjective norms beliefs, and perceived behavioural control (Ajzen, 1991). The ability of the TPB to help explain at-risk mens' intention to participate in screening for prostate cancer has previously been examined, with healthcare providers' recommendations seeming to have the strongest influence on decisions to attend for PSA testing, rather than men's beliefs about prostate cancer influencing intention (Hevey et al, 2009). Although decision-making about prostate cancer treatment is contextually different to intention to participate in screening, it is important to consider the role of others in influencing men in decision-making about prostate cancer treatment, as previous research has identified that men who

were uncertain about their decision are significantly more likely to use the expert to guide decision-making (Xu et al., 2011).

Although many psychological models have been developed to predict, explain or change health behaviours, few have considered these models in relation to decision-making about prostate cancer treatment. While previous research has used these models to explain some variance in decision-making about screening for cancer, some criticism of these models has been identified and is alluded to above. Due to these criticisms, the specific models identified above were not used in the current research; however self-efficacy, a construct thought to underpin many of these models, was considered along with the construct of perceived social support.

2.3.5. Social support

Social support is defined as, "the function and quality of social relationships, such as perceived availability of help or support actually received" (Schwarzer, Knoll, & Rieckmann, 2004, p. 2). The stress and coping theory (Lazarus & Folkman, 1991), posits that stressful events, such as a cancer diagnosis can negatively impact on health, and men with prostate cancer have been found to have high levels of psychological distress (Mehnert, Lehmann, Graefen, Huland, & Koch, 2010) with anxiety identified in 10-36% of prostate cancer patients (Dale, Bilir, Han, & Meltzer, 2005). Social support buffers individuals from the adverse effects of stress by promoting more adaptive and effective coping techniques (Paterson, Jones, Rattray, & Lauder, 2013). There is a distinction in the literature between received (or enacted) social support and perceived social support with each thought to link uniquely to other constructs and variables.

Health literacy has been directly linked to health and healthcare use, but Lee, Arozullah, and Cho (2004) argue for social support as a potential moderator in the relationship between health literacy and healthcare use. Within this review, they consider that those in a social network may influence health care, for example, friends and family can be important sources of information and information transmitted from someone in a social network can buffer the negative impact of low health literacy. In addition, this sense of belonging, and support from a social network, might help to overcome the shame of low health literacy and enable the patient to be more confident in seeking help. Support can also work by influencing people to act in accordance with their peers, which can be positive (e.g., participate in health screening) or negative (e.g., take up smoking). From the review, Lee et al. propose that positive social support moderates the relationship between health literacy and health outcomes, and this is more pronounced in those with lower health literacy than in those with higher health literacy. In addition, less support or negative support networks can increase adverse outcomes in low health literacy groups thus the adverse effects of low health literacy on healthcare use will be greater in those with less social support. However, there is a dearth of literature examining social support as a moderator in the relationship between health literacy and decision-making. Therefore, the nature of the association between social support, health literacy and decision-making, as proposed by Lee, is not clear. In fact, few studies have examined the association between social support and decision conflict in prostate cancer patients at the time of decision-making, with the literature to date focusing on social support in the context of other outcomes

including psychological adjustment, psychological distress and quality of life during or after treatment. The next sections briefly detail this research in perceived social support in these areas and concludes with the literature on the role of others in supporting decision-making in prostate cancer patients.

2.3.5.1. Perceived Social Support

Perceived social support is a construct that is used to describe the subjective judgement that social support will be available at a time of need in the future (Procidano & Heller, 1983; Sarason, Sarason, & Shearin, 1986); as such it is one's belief that they can count on others for assistance if in need. This assistance may be in the form of advice, emotional support or practical support.

Evidence illustrating the specific relationship between perceived social support and health-related quality of life is limited and unclear, with some studies identifying positive associations between social support and psychological wellbeing in prostate cancer patients, (Baider, Ever-Hadani, Goldzweig, Wygoda, & Peretz, 2003; Mehnert et al., 2010), but not on physical health (Mehnert et al., 2010), while others have found positive associations between perceived social support and health-related quality of life, which included physical domains (Paterson et al., 2013; Queenan, Feldman-Stewart, Brundage, & Groome, 2010). Supporting the idea that perceived social support is associated with psychological distress, couples in whom a partner had been diagnosed with prostate or breast cancer reported higher levels of psychological distress when perceived social support was low. Levels of psychological distress were similar for both patient groups even though female patients reported higher levels of perceived social support than male

patients in this study (Baider et al., 2003). Given that levels of psychological distress in cancer patients can increase over time (Ell, Nishimoto, Mantell, & Hamovitch, 1988; Kaye & Gracely, 1993), the importance of supporting patients at the time of decision-making is worthy of consideration, in an attempt to reduce long term distress in cancer survivors who may otherwise suffer from decision regret.

Perceived social support has also been linked to self-efficacy in decision-making. In a follow up study of over 1500 cancer survivors, Forsythe et al. (2014), using the Medical Outcomes Study Social Support Scale (Sherbourne & Stewart, 1991) as a measure of perceived social support, identified a modest association between tangible and emotional/informational support with self-efficacy in decision-making related to follow-up care in this sample. An effect of marital status on recent follow-up care, over and above perceived social support, was also observed in this study leading to the suggestion of a sense of obligation to manage one's health if in a close relationship. This role of others in decision-making is discussed in the next section.

2.3.5.2. Role of others

The role of partners in helping men cope with their diagnosis and in making decisions about treatment has been investigated, with Mehnert (2010) identifying partners as most helpful and listed in third place after medical treatment and doctor-patient communication. Supportive partners, relatives, and friends were perceived as a major resource in all phases from diagnosis to treatments, providing support both emotionally and practically (organizational) (Renzi et al., 2017). In a qualitative study of men in the pre-treatment phase, Boehmer and Babayan (2005)

reported that some men turn to partners for emotional and informational support; however, others were more likely to rely on male non-spouses for informational support. Where some agree that the patients' social support network is of immense value to patients (Gray, Fitch, Phillips, Labrecque, & Fergus, 2000), others highlight the negative consequences, of including a third party in the consultation process (Greene, Majerovitz, Adelman, & Rizzo, 1994). Examples of the negative consequences in triadic interactions included: reductions in interaction and participation, assertiveness, and expressiveness when compared with dyadic interactions.

Marriage has been found to be positively associated with the type of treatment selected (Denberg, Beaty, Kim, & Steiner, 2005), and men who were married were more likely to have made the decision actively and collaboratively and fared better in all decision-making outcomes than their unmarried counterparts in a study of over 1500 men (Orom et al., 2016). Men with newly diagnosed prostate cancer who discussed their diagnosis with family were more likely to select active treatment but were more likely to have greater decision-making difficulty (Reamer, Yang, & Xu, 2016). In an analysis of the extensive SEER database (Surveillance, Epidemiology and End Results–Medicare), married men were also more likely to select active treatment rather than active surveillance and specifically selected surgery over radiotherapy (Denberg et al., 2005). Possible explanations given for these findings include the possibility that married men, and/or their partners, advocate for what is perceived to have the best outcome in terms of cure, or that clinicians may be more likely to recommend aggressive treatment to married men

than to single men (Denberg et al., 2005). This highlights the issue that side effects or morbidity from treatment are not readily understood or considered when making treatment decisions, although O'Rourke (1999) found that prostate cancer patients differed from their spouses in their willingness to accept a treatment at any cost. The patients' partners were more likely to focus on cure rather than morbidity from treatment in this qualitative study. Contrary to the findings above, which provide evidence for the strong role of the partner in decision-making, a review by Zeliadt (2006) concluded that the evidence on the role of the partner in influencing treatment decisions is unclear and conflicting. Some evidence, as in the studies detailed above, conclude that partners are very involved almost to the exclusion of the patient from the process (Chapple et al., 2002; Holmboe & Concato, 2000). Other studies have found that although partners are involved in providing emotional and informational support, partners ultimately let the patient make the final decision, or other individuals such as friends or business colleagues who previously were diagnosed with prostate cancer were often found to have a stronger influence than spouses (Berry et al., 2003; Hall, Boyd, Lippert, & Theodorescu, 2003).

From the mixed evidence available in relation to social support and the role of others in decision-making, it seems that some patients have a preference for involvement of others in decision-making, while others do not; this variation may relate to other factors such as the patients' confidence and belief in their own ability to make the decision. The next section explores the role of self-efficacy in decision conflict and decision-making in the context of healthcare.

2.3.6. Self-efficacy

Self- efficacy, a construct most associated with Bandura, and social cognitive theory, is one's belief in one's ability to succeed in specific behaviours (Bandura, 1997, 1999), with four principle sources of information that influence perceived self-efficacy: (i) personal performance or mastery experience, (ii) vicarious experience, (iii) verbal persuasion, and (iv) physiological and affective states. A diagnosis of cancer and the accompanying impact on one's physiological and affective state can inhibit self-efficacy with low perceived self-efficacy found to impact on health-related outcomes including; decision-making, and quality of life (Haas, 2000).

Increases in perceived self-efficacy have been found to be associated with increased adherence to treatment, increased self-care behaviours, decreased physical and psychological symptoms, and increased quality of life (Haas, 2000). Prostate cancer patients with lower levels of self-efficacy have lower levels of health-related quality of life, with patients with the lowest self-efficacy scores having lower outcome scores across urinary, sexual and bowel bother, symptom distress, psychological well-being, and vitality (Heckman et al., 2011). The scores were seen to be clinically meaningfully different for both bowel and symptom bother distress, after adjusting for sociodemographic and clinicopathological characteristics. Given the high survival rates for prostate cancer patients, men may live for a considerable time with these bothersome issues. Kreitler, Peleg, and Ehrenfeld (2007) also found that self-efficacy had a significant positive effect on overall quality of life, in a sample of 60 cancer patients in a follow up clinic. Using

structural equation modelling, Kreitler identified that self-efficacy affects quality of life in two ways: firstly, self-efficacy was directly associated with quality of life with stronger self-efficacy associated with better quality of life. Secondly, self-efficacy was associated with reducing perceived stress, to the level of cancelling the negative effect of health stresses on quality of life. Self-efficacy was also measured in an Irish study of prostate cancer patients where high self-efficacy was found to correlate with good mood (Curtis, Groarke, & Sullivan, 2014). This finding concurs with previous research in the area that found higher self-efficacy correlated with lower scores of depression in the intervention arm of a group of prostate cancer patients after an eight-week supportive intervention (Weber et al., 2007). Curtis et al. (2014) concluded that prostate cancer patients low in self-efficacy and with high levels of global and cancer specific stress at diagnosis reported poor adjustment to their cancer diagnosis, which in turn could impact on their perception of their ability to engage with their medical team and make treatment decisions.

The ability of patients to participate in decision-making about prostate cancer screening has also been investigated. Patients with lower levels of self-efficacy were more likely to be doctor dependent than independent when making decisions about screening (Williams-Piehota, McCormack, Treiman, & Bann, 2008). Similarly, prostate cancer patients with low self-efficacy were found to be less able to communicate with their healthcare provider (Maliski et al., 2004). Equally, self-efficacy in patient–physician interactions was associated with participation in decision-making in breast cancer patients, with those with higher levels of self-efficacy more likely to interact and question their surgeon and more likely to

perceive themselves as the final decision-maker than those with lower self-efficacy who were less certain about their ability to interact with physicians (Maly, Umezawa, Leake, & Silliman, 2004).

As discussed above, self-efficacy has been shown to be associated with decision-making, but few have considered the nature of the association between self-efficacy, decision conflict and health literacy, especially at the level of communicative and critical health literacy required for decision-making about prostate cancer treatment. Self-efficacy is considered one of the richest sources of inner power (Bandura, 1999), and as the literature has identified the importance of patient empowerment in medical decision-making (Renzi et al., 2017), a main effect of self-efficacy on decision conflict is expected, but it is worth considering if self-efficacy can also have an indirect effect, by moderating the relationship between health literacy and decision conflict. Due to the shame associated with low health literacy (Parikh, Parker, Nurss, Baker, & Williams, 1996), patients lacking in self-efficacy may struggle to admit their difficulties, ask questions, or seek assistance, thus leading to difficulties in decision-making and decision conflict. Increasing perceived self-efficacy in patients with low health literacy, may help patients overcome this difficulty facilitating them to interact with the healthcare provider, thus increasing health literacy and reducing decision conflict. Possible interventions that can be considered include those proposed by Haas (2000) to increase perceived self- efficacy in the cancer setting. These include: support groups (affective state, vicarious experience, verbal persuasion), training sessions (verbal persuasion), controlling treatment side effects (physiological state), and use of

patient testimonials (vicarious experience) (Haas, 2000). Identifying the relationship between self-efficacy, decision conflict, and health literacy will help to identify the focus of future interventions that can be considered for prostate cancer patients making treatment decisions.

2.4. Conclusion

Due to the excellent survival rates for men diagnosed with non-metastatic prostate cancer, the number of long term prostate cancer survivors continues to increase. As each treatment option gives similar rates of survival but with different consequences on quality of life, men are expected to play an active role in decision-making and decide on the treatment path they will follow. Few consider active surveillance as a viable option, although the evidence suggests that the survival outcome is similar to active management. This highlights the gap in knowledge about the value of active surveillance as an appropriate management strategy, without the adverse physical side effects associated with an active management strategy. Confusion about the type and incidence of the adverse physical side effects associated with each treatment has also been identified; however, patients are continuously expected to make this life changing decision. This decision should be informed and preferably within a shared decision-making environment where both the clinician and the patient share information in order to jointly arrive at a decision. However, the literature has identified that patients who report a mismatch between their preferred role and the actual role they play in decision-making have increased levels of decision conflict and decision regret. Similarly, those who do not participate in decision-making, regardless of preferred role, are

reported to have high levels of decision conflict and decision regret. As the healthcare systems continues to evolve to a patient-centred system without a gold standard treatment option for men with prostate cancer, the expectation that men should decide on how their cancer is managed will continue. It is therefore, essential to identify the factors that will facilitate them in this decision, so that the incidence of decision conflict and regret will be reduced, ultimately benefiting prostate cancer patients' quality of life.

The literature has identified that adequate knowledge and understanding of prostate cancer and the treatment options available are essential to inform decision-making. A number of decision aids have been designed to facilitate this, however, men continue to be uninformed of the consequences of their decision. Large variation is seen in what healthcare professionals think men should know, and in the information men feel is important to help inform them. The role of health literacy, social support, and self-efficacy in facilitating men in decision-making, and the nature of these associations, is also unclear and worthy of exploration. Much of the research on these concepts has been conducted outside the prostate cancer setting or completed during or after treatment, and in countries with different healthcare settings to Ireland. As men's needs change throughout the cancer pathway, it is important to explore these concepts at the time of decision-making and examine possible interactions that may moderate the relationship between health literacy and decision conflict. Identifying these relationships will help to guide future resources and interventions that can be targeted to facilitate particularly vulnerable patients with decision-making.

This thesis aims to explore these concepts in a sample of newly diagnosed prostate cancer patients in Ireland and add to the literature around this complex area. The next chapter details the first study which was designed to establish the information men regard as important to know in order to make a treatment decision. Chapter 5 presents details of the study which examined the relationships between the independent variables and decision conflict and Chapter 6 details how men describe their decision-making process at the time of decision-making. Findings from these three studies are then integrated and discussed in Chapter 7, and the theory and clinical implications are presented.

Chapter 3: Aims, Objectives and Methodology

The overall aim of this research is to explore in an Irish population, the decision-making process of newly diagnosed prostate cancer patients, and to examine factors that may be associated with decision conflict which can arise from decision-making, including health literacy, perceived social support, self-efficacy, and prostate cancer knowledge (PrCaK). At an overarching level the questions considered in this research are:

1. What information do men think those diagnosed with prostate cancer need in order to make a treatment decision?
2. What factors are associated with decision conflict at the time of decision-making?
3. How do men with prostate cancer describe their decision-making process about treatment options?

To address these questions, the specific aims and research questions of this research conducted in three sequential studies is outlined below.

3.1.1. Study 1

In a population of prostate cancer survivors, this study aims to establish the information men regard as important to know in order to make a treatment decision.

Research question 1:

"What information do prostate cancer survivors think newly diagnosed prostate cancer patients should have in order to make treatment decisions and which aspects are more important?"

3.1.2. Study 2

In a population of newly diagnosed prostate cancer patients, this study aims to establish factors associated with decision conflict and explore possible models to predict decision conflict.

Research question 2:

"What factors are associated with decision conflict and can these factors explain decision conflict in this population of patients?"

The specific aims and research hypotheses of study 2 are as follows:

In a population of newly diagnosed prostate cancer patients:

1. Investigate the relationship between demographic variables (age and education level) and health literacy

   Hypotheses:

   1A. Older age is associated with lower level of health literacy

   1B. Lower education level is associated with lower level of health literacy

   1C. Variance in health literacy can be significantly explained by age and education level

2. Investigate the relationship between variables (age, education level and health literacy) with knowledge of prostate cancer disease (PrCaK_Disease)

   Hypotheses:

   2A. Older age is associated with lower level of prostate cancer knowledge (PrCaK)

   2B. Lower education level is associated with lower levels of PrCaK

   2C. Lower levels of health literacy are associated with lower levels of PrCaK

2D. Variance in PrCaK can be significantly explained by age, education level and health literacy

3. Investigate the relationship between the independent variables (i.e., Relationship status, health literacy, perceived social support, perceived social support_significant other, self-efficacy, PrCaK) and decision conflict

   Hypotheses:

   3A. Those in a significant relationship have lower levels of decision conflict.

   3B. Higher level of health literacy is associated with lower level of decision conflict.

   3C. Higher level of perceived social support is associated with lower level of decision conflict.

   3D. Higher level of perceived social support _significant other is associated with lower level of decision conflict.

   3E. Higher level of self-efficacy is associated with lower level of decision conflict.

   3F. Higher level of PrCaK is associated with lower level of decision conflict.

4. Explore the relationships between the independent variables (health literacy, self-efficacy, perceived social support, PrCaK, Relationship Status and the interaction of HL X SE, and HL X PSS) and decision conflict as depicted in the conceptual framework shown in Chapter 5 (Figure 5.1).

   Hypothesis:

   4A. Variation in the independent variables will be significantly associated with variation in decision conflict.

5. Using a self-designed test of knowledge of side effects associated with each treatment, explore:

   5A. Relationships between the variables and the self-designed test.

   5B. The self-designed test's ability to add to the conceptual model.

3.1.3. Study 3

In a population of newly diagnosed prostate cancer patients, this study aims to explore their decision-making process at the time of decision-making.

Research question 3:

"How do prostate cancer patients describe their decision-making about prostate cancer treatment, the barriers and facilitators to decision-making and their preferred level of involvement in decision-making?"

3.2. Methodology

A mixed methods approach integrating qualitative and quantitative methodologies was used in this study within a paradigm of pragmatism (Plano-Clark & Creswell, 2008). Pragmatism, as defined by Tashakkori and Teddlie (2003) focuses on "what works" as the truth regarding the research questions under investigation", was the position taken in this thesis due to its focus on real world practice-oriented problems where the research questions stem directly from clinical practice. Quantitative and qualitative methods will be combined to gain a broad understanding and insight of this complex healthcare issue. Quantifying the level of decision conflict in a sample of prostate cancer patients was useful before further exploring decision-making qualitatively. By "combining the power of numbers and

the power of stories" (Scarton et al., 2018), prostate cancer patients' experience of decision-making at the time of diagnosis was explored. Using a single methodological approach was considered not sufficient to comprehensively explore the specifics of the topic under investigation (Creswell & Plano-Clark, 2011; Ivankova, Creswell, & Stick, 2006). Specifically, a mixed methods sequential approach (Creswell & Plano-Clark, 2011) was used with data collected in three studies.

To address research question 1, Study 1 used the nominal group technique to gain insight into the information requirements of prostate cancer patients and the results were used to inform both the survey design in study 2 and the questions and topics for discussion in study 3. Due to the variation in the literature (detailed in Chapter 3), it was necessary to establish what men diagnosed with prostate cancer should know to make treatment decisions in an Irish population in relation to prostate cancer treatment. Likewise, when investigating sexual dysfunction in a cohort of prostate cancer patients, O'Shaughnessy, Ireland, Pelentsov, Thomas, and Esterman (2013) took a similar approach, using focus groups to guide the questionnaire design. After conducting a thematic analysis, the three key themes identified (sexual dysfunction, loss of libido and masculinity) were used to design a 70-item questionnaire. The survey identified a high rate of erectile dysfunction (65%) in participants (n= 115) with a quarter of men regretting their treatment decision. Similar qualitative approaches have been used prior to quantitative studies to guide and evaluate a breathlessness intervention service in palliative care, with the follow up quantitative study evaluating feasibility of the service

(Farquhar, Ewing, & Booth, 2011). Therefore, the literature supports the use of such methods to elicit key aspects of decision-making to inform the subsequent survey and interviews.

To address research question 2, a survey was used to measure the levels of health literacy and decisional conflict in prostate cancer patients. Knowledge of prostate cancer, perceived social support and self-efficacy were also measured and the analyses allowed associations between the constructs to be quantified. This was followed by study 3, wherein semi-structured interviews explored the decision-making process described by newly diagnosed prostate cancer patients and answer the third research question. A mixed-methodology approach has been used successfully in previous research, for example; investigating the benefits of a decision aid in a population of women attending a GP clinic (Protheroe, Bower, & Chew-Graham, 2007). Having quantified the benefit of the decision aid in their survey, the follow-up qualitative component confirmed this benefit of the decision aid and provided depth to the analysis, allowing further hypotheses to be generated. Furthermore, in investigating information needs and information seeking behaviours for complementary and alternative medicine, a follow up qualitative study using in-depth interviews expanded on the survey findings in a population of cancer survivors to answer detailed questions about motivations and decision-making around complementary and alternative medicine (Scarton et al., 2018). The use of qualitative methods in a mixed methods paradigm to explore patients' experience was also used in an investigation of breast cancer patients' decisions around hormone therapy with follow up interviews performed on 30

participants from the survey (n= 452), exploring the range of breast cancer patients' experiences with prescribed hormone therapy and to understand survivors' reasons to initiate, discontinue or maintain hormone therapy (Bluethmann et al., 2017). Adding potential richness to the objective measures of adherence to hormone therapy gained in the quantitative component, the interviews identified the diversity of experiences and the possible modifiable factors associated with adherence.

Mixed methods allow investigations of complex health situations, allowing for expansion and complementarity (Farquhar et al., 2011). In this study, the quantitative method investigated variables associated with decision conflict and the qualitative method helped to explore patients' experience of the process. Neither the quantitative nor qualitative component was given a higher priority in this research, with both study 2 and study 3 being complementary and having an equal weighting in the overall study design (Figure 3.1).

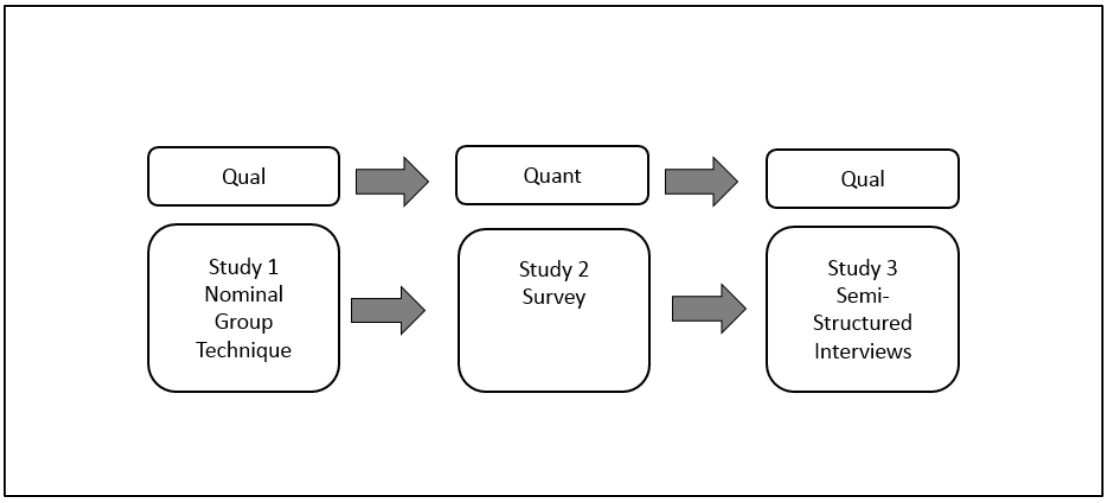

Figure 3.1: Research design: mixed methods sequential explanatory approach

3.3. Conclusion

Ireland has a high rate of patients presenting with prostate cancer with many options available to manage this disease. As all options have similar survival outcomes, but different side effect profiles, patients are expected to play an active role in deciding the treatment route they will follow. For an individual patient with a recent diagnosis of prostate cancer, this can be a daunting task. The shock associated with a recent cancer diagnosis, coupled with the complex medical language that may be used, in an alien environment places the patient in a very vulnerable position. This thesis focuses on examining decision-making in these prostate cancer patients, using a mixed methods study within a pragmatic paradigm. The following chapter presents the study which examined the information men previously treated for prostate cancer think newly diagnosed prostate cancer patients need to make a treatment decision. Chapter 5 presents the investigation and findings of the possible variables associated with decision conflict at the time of decision-making and Chapter 6 explores how prostate cancer patients describe the process they undergo to make a treatment decision. Chapter 7 is a general discussion of the findings from the three studies and the contribution this study makes to the literature on decision-making in prostate cancer patients. The theoretical and clinical implications from findings in this thesis are reported. For decision-making to be informed, it is important to know what processes are involved and the factors that influence this, so steps can be taken to facilitate patients when making this decision.

Chapter 4: What should prostate cancer patients know before deciding on treatment

This chapter considers what information men require to make a decision about prostate cancer treatment. The literature to date has identified that large variation is seen in what healthcare professionals think patients should know, and in what patients report is important to know in order to make an informed decision. This chapter presents a study that utilised the nominal group technique to examine what men in Ireland who have survived prostate cancer think newly diagnosed prostate cancer patients should be informed of to make a treatment decision. The data obtained in this study was used to guide the survey design in study 2, and the interview schedule used in study 3.

4.1. Introduction

Significant gaps in knowledge have been identified in prostate cancer patients faced with making decisions about treatment. Specifically, patients lack information about all the management strategies available to them and have poor knowledge of the side effects associated with each treatment (Birnie & Robinson, 2010; Bobridge et al., 2015; Feldman-Stewart, Kocovski, McConnell, Brundage, & Mackillop, 2000; McGregor, 2003). The role of active surveillance as an appropriate and relevant strategy to manage prostate cancer is largely unknown to men, with many choosing an active management strategy such as surgery or radiotherapy in the belief that these options offer a better chance of cure than active surveillance (Formica et al., 2017; Kendel et al., 2016). Considering these gaps in knowledge and the lack of satisfaction with information seen in Irish prostate cancer patients (Diver

et al., 2018), it is important to establish what information is required by prostate cancer patients to facilitate decision-making about treatment. Diver et al. (2018) in a study of men (n = 195) who had received treatment for prostate cancer found that almost one third wanted more information on side effects of treatment, particularly in relation on bowel, urinary and sexual function. This cross sectional study aimed to ascertain the quality of life and information needs of long term prostate cancer survivors. The survey included the European Organization for Research and Treatment of Cancer (EORTC) information module QLQ-INFO25 with the QLQ-C30. A high score in the EORTC QLQ-INFO25 represents a high level of information. The domain relating to "information received on medical tests" was scored high by participants, while the domain relating to "information about other services" scored lowest. Men who were unemployed were less happy with information about other treatments than men in employment, and those who had received an active management strategy were happier with information than those following an active surveillance strategy. One additional question in this questionnaire asks participants to specify which topics they would like to have received more or less information. From the 51 who chose to respond to this qualitative question, the majority wished to receive more information on side effects from treatment, and to receive information on prostate cancer and general health issues.

Decision aids have been developed to help inform patients of their disease and their treatment options and although these have been found to increase knowledge, reduce decision conflict, and increase satisfaction in many areas of healthcare, the findings in relation to prostate cancer patients are mixed (Adsul et

al., 2015; Violette et al., 2015). However, the specific decision aids used in some prostate cancer studies included in these reviews were reported to lack crucial items such as a full description of risks, benefits and outcome probabilities for all management options (Adsul et al., 2015), and this may explain the inconsistency between the prostate cancer studies and studies in other healthcare areas.

As specific guidelines identifying what information prostate cancer patients need to know to make decisions about treatment are lacking, the current study sought to identify this information in a group of prostate cancer survivors. Asking patients what information should be available is important as many studies have identified a discrepancy between the information healthcare professionals think patients should know, and what patients report is important for them to know (Feldman-Stewart et al., 1997; Feldman-Stewart, Kocovski, et al., 2000; Wessels et al., 2010). A mismatch was also seen between healthcare professionals with regard to the knowledge items men should be informed of (Feldman-Steward et al., 1997), further increasing the variability of information believed to be important.

Previous studies that have involved patients in the design of decision aids and information leaflets have been conducted outside Ireland in different healthcare systems. For example, the majority of the literature in this area originates in North America and the United States and the importance for men in checking which hospital or clinician to attend was identified. Within the Irish healthcare system, this is not usually a consideration as men typically follow the referral pathway relevant for their geographic region. Therefore, identifying the

specific information needs of men in Ireland diagnosed with prostate cancer is important, but to date an area of research which has been overlooked.

Additionally, most studies have been conducted in disadvantaged, lower socio-economic or minority groups (Deibert et al., 2007; Rees, Ford, & Sheard, 2002) and as prostate cancer in Ireland is seen across all socio-economic groups, the results are not generalisable to the Irish prostate cancer patient as different socioeconomic and cultural factors can potentially influence a patient's information needs (Tariman, Doorenbos, Schepp, Singhal, & Berry, 2014). Furthermore, a large number of participants included in these studies are African-American, because a higher incidence of African-American men present with prostate cancer. As prostate cancer is clinically thought to behave more aggressively in this population (Odedina et al., 2009; Powell, Bock, Ruterbusch, & Sakr, 2010), the information needs of this population may differ to primarily Caucasian patients in Ireland.

4.2. What information do men need?

To facilitate men to actively participate in informed decision-making, it is essential to provide accurate, reliable and accessible information (Tariman et al., 2014). For patients to remember information, it must be perceived to be of value (McGregor, 2003). To date, the literature has not definitely identified what information is required by prostate cancer patients, with inconsistencies seen across studies, in relation to what men should know (Feldman-Stewart, Brennenstuhl, & Brundage, 2008), how much information to give (Rüesch et al., 2014), when to give information (Herrmann et al., 2018), and the format that should be used (Feldman-Stewart, Kocovski, et al., 2000; McIntyre & Craig, 2015).

Additionally, too much information can be provided which can negatively impact on decision-making (Zeguers et al., 2012). For these reasons, there is a growing body of literature that recognises the value of individualising information for cancer patients (Feldman-Stewart, Brundage, et al., 2000; Feldman-Stewart, Brundage, Nickel, & Mackillop, 2001; Rüesch et al., 2014). However, this approach would be resource intensive (Tariman et al., 2014). Therefore, identifying the common items that all men require and ranking these in order of priority can help to streamline information provision.

A recent review of 30 studies investigating information needs priorities in patients with various types of cancer identified the top three information prioritises reported by patients (Tariman et al., 2014). Across all studies, the priorities were information related to prognosis (items included: likelihood of cure, survival, how long to live), disease stage (items included: cancer, disease, stage, causes, prevention), and treatment options (items included: side effects, treatment goals, treatment success, drug information). This review included three prostate cancer studies and similar priorities were listed in these studies: (i) likelihood of cure (ii) disease stage, and (iii) side effects/ risks and benefits of treatments (Davison & Degner, 1997; Davison, So, & Goldenberg, 2007). Providing information on these three key aspects as the core set of information could be the foundation to informing patients and aiding them in decision-making. As patients prefer personalized information rather than generic information, that may be irrelevant to their needs (Leydon et al., 2000), clinicians can then tailor additional information to

the patient's personal situation, to enhance understanding (Manning & Dickens, 2006), and facilitate shared decision-making.

The benefit of providing a core minimum set along with individualised information is supported by previous work that identified poor agreement on the information men considered essential (Feldman-Stewart, Brundage, et al., 2000). From a list of 93 questions (e.g*., "will the treatment cause pain", "what do we do if the cancer comes back, when will treatment start"*) proposed to newly diagnosed prostate cancer patients (n = 38), no question was relevant to more than 50% of participants but 91 questions were relevant to at least one participant, showing the variability in men's information needs. The study was repeated 10 years later, and similar findings were reported with wide variation again seen in what participants considered essential information; only 6 questions were considered essential to over 80% of participants in 1996 and 12 questions in 2005. At both time points, the most frequent reason for essential questions was (i) to help understand the situation (ii) to help decide on treatment and (iii) to help plan their future. The top 10 questions which were prioritised by participants at both time points are detailed in Table 4.1.

In these studies, the list of questions was generated by healthcare professionals, researchers, lay-people and cancer patients and given to prostate cancer patients to judge the importance of addressing each question. Asking patients to devise the list may have generated different findings. These studies were carried out with Canadian patients and given the influence of cultural and sociodemographic factors on information needs of men (Tariman et al., 2014),

identifying if the same core set of information is applicable in the Irish setting is warranted. Identifying the items prostate cancer patients in Ireland feel are necessary to inform the decision-making process and examining if a consensus can be reached on these items will add to the evidence base for decision-making in prostate cancer patients. The nominal group technique is a novel technique to use to ascertain this information, allowing participants opinions and views to be explored, without any participant taking a dominant role.

Table 4.1: Top ten questions at the two-time points, with the five questions common to both time points listed first

Questions	1996	2005
If the treatment is not successful, what are my options?	1	1a
If the prostate cancer is not treated, will I die from it?	3	1a
If the prostate cancer is not treated, how fast will it spread?	3	3a
If the prostate cancer is not treated, what parts of my body will be affected?	5	10
What is prostate cancer?	6	3a
If I delay treatment now, is there still a chance I can still be cured?	3	
How long can I safely take to make up my mind?	7[a]	
What type of monitoring will there be if I choose no treatment	7[a]	
If I delay treatment, will any treatment help me?	9	
What kind of follow-up will take place after my treatment?	10	
What do we do if the cancer comes back?		5
When and how will you know if the treatment is working?		6
When and how will you know I have been cured?		7
How long will I have to wait to start treatment?		8
If the prostate cancer is not treated, how long will I live		9

Note: [a] Tied rank (modified from Feldman-Stewart, 2009)

4.3. Aims

To address the first overarching thesis question, the aim of this study was to establish the information men regard as important to know in order to make a treatment decision. Obtaining this information is important in order to inform the

design of the survey in study 2 and provide context for the semi-structured interviews in study 3. The following research question was developed:

Research question 1:

"What information do prostate cancer survivors think newly diagnosed prostate cancer patients should have in order to make treatment decisions and which aspects are more important?"

4.4. Method

4.4.1. Design

In order to ascertain the data required to make a decision about treatment, a qualitative approach was taken using the Nominal Group Technique (NGT), a structured form of focus group, with a group of men previously diagnosed with prostate cancer, who had at least commenced treatment. The NGT is a qualitative form of analysis originally developed by Delbecq and Van de Ven in the 1960's for governments, businesses, and groups to come to a consensus on particular problems and issues (Delbecq, 1975). The NGT is a combination strategy of brainstorming and voting. Although initially developed for the business community, it is an efficient technique in the medical field (Potter, Gordon, & Hamer, 2004) and has been used to explore views and opinions in numerous healthcare settings with healthcare professionals, lay people and carers (Kleiner-Fisman, 2013; Miller, Shewchuk, Elliot, & Richards, 2000; Peña, Estrada, Soniat, Taylor, & Burton, 2012; Redman, Carrick, Cockburn, & Hirst, 1997).

As the NGT allows balanced participation and provides equal status to all participants, some of the disadvantages of focus groups can be overcome (Delbecq,

1975; McMillan, King, & Tully, 2016). The NGT avoids dominance from a single person, which can be a problem with focus groups. With the NGT, passive group members are allowed have equal input and the voting stage is anonymous thereby further protecting individuals in the process. The NGT is particularly useful when input from all participants is required and the items or themes can be ranked in order of importance to establish priorities. It can help achieve consensus about the relative importance of issues, therefore in the context of this study, it was used to elicit opinion and gain a consensus on what information is important and should be included and explained to patients prior to making a decision about treatment.

The NGT is a useful technique when there is concern that some members may not feel comfortable participating, some may be more vocal than others and the issue is controversial or emotional (Delbecq, 1975). As the participants did not know each other prior to the group session, and were not known to the researcher, the NGT was an appropriate method to use as it would facilitate each participant to have a voice and allow equal participation across the group. Additionally, as a personal diagnosis of prostate cancer can be considered a sensitive or emotional topic, it was a useful and efficient technique.

The NGT follows a strict structure that is overseen by a facilitator; for this study the researcher acted as the facilitator. By adhering to the protocol (outlined in Section 4.4.4) a wealth of valuable information that accurately reflects participants' thoughts can be produced (Delbecq, 1975). The advantages of this technique are that it requires minimal pre-meeting preparation for participants and participants are only required to attend one meeting, thus making it ideally suited

to this part of the current research and not too burdensome on this population of cancer survivors.

4.4.2. Participants

To be eligible for this study, participants needed to be male, over 18 years of age, with a previous history of a prostate cancer diagnosis, who had commenced treatment. No timeframe for completion of treatment was set, as some prostate cancer patients can be on hormone therapy for a number of years. Those without English as their first language and unable to give written consent were not eligible to participate in this study.

4.4.2.1. Recruitment

Ethical approval from the relevant ethical committee within the University (Appendix 1) was obtained. To access prostate cancer patients outside the hospital setting an Irish cancer charitable organisation was approached to support recruitment. An invitation letter (Appendix 2) and participant information leaflet (Appendix 3) were distributed to prostate cancer survivors (estimated n = 220) on the database by an administrator within the organisation. Those interested in participating were asked to contact the researcher directly. Further information on the study along with details of the date, time and venue for the session was then provided.

While group sizes of 2 to 14 participants have been used (McMillan et al., 2016), 7 is thought to be the optimum number of participants per group (McMillan et al., 2014). From the 11 who made contact with the researcher, 7 agreed to participate in the research therefore 1 session was held. A question and answer

session was conducted and written informed consent (Appendix 4) was obtained prior to the start of data collection.

4.4.3. Measures

At the start of the NGT session, social and medical demographic details were collected. Participants' views relating to decision-making were also assessed.

4.4.3.1. Demographics details

Participants filled in a short demographic sheet (Appendix 6). The demographic characteristics comprised age, education level and employment status.

Medical details. Characteristics relevant to their prostate cancer diagnosis were also assessed: date of diagnosis, stage of disease (including Gleason score and PSA level), applicable treatment options, treatment option chosen and current treatment status (on treatment or date of completion of treatment).

Decision-making. As stated previously in Chapter 2, the literature has identified that many prostate cancer patients feel uninformed about their treatment options, find it difficult to make a decision about their treatment and are dissatisfied with their decision, suffering from decision regret in later years. For these reasons the following three questions were devised to obtain contextual information on the participants. Participants were asked to rate the following questions on a scale of 1- 10:

1) *"How informed were you about your treatment options?", with 1 = not very informed, 10 = very informed*

2) *"How difficult did you find it to make a decision about your treatment?", with 1 = very difficult, 10 = not difficult at all*

3) *"How satisfied are you with your decision?", with 1 = not very satisfied, 10 = very satisfied*

4.4.4. Procedure

Having obtained consent and collected the demographic and decision-making data, the recorded NGT session began with an introduction to the schedule. The four-step protocol was explained to participants (Table 4.2) before handing out the work sheet, which contained the question *"Based on your experience, what do you think men diagnosed with prostate cancer should know before deciding on their treatment?"*

Table 4.2: Structure of Nominal Group Technique

Step	Detail	Comments
Introduction	Welcome, purpose and procedure.	Consent and Demographics
Step 1: Generating ideas – listing	Question given to participants. Participants -silently write down any ideas/items that come to mind.	5- 10 minutes
Step 2: Sharing ideas –recording	Share the ideas/items Round robin style feedback session No debate A written record is made of all the ideas generated	Until item listing is exhausted
Step 3: Group discussion - collating	Participants can ask for clarity on any of the ideas/items generated.	
Step 4: Voting and ranking -prioritising	Prioritising of ideas/items generated from the original question. The meeting concludes after reaching a specific outcome	Example of outcome- The top ten ideas from the discussion.

The four steps comprised of listing, recording, collating, and prioritising, and a specific script was used for each step, based on the script advised by Dunham (2006). The script used in each step is detailed below.

Listing: Participants were asked to work alone to consider the question and to write down items or ideas important to them, in answer to this question. There was no discussion during this step.

"I would like each of you to take five minutes to list your ideas in response to this question. Describe each idea in a brief phrase or a few words on the worksheet in front of you. Please work independently of other members. During this time of independent

thinking, I ask that you not talk to other members, interrupt their thinking, or look at their worksheets. Since this is an opportunity for each of you to prepare your contributions to the meeting, I would appreciate intense effort during the next five minutes. At the end of the five minutes, I will check in with you, call time and suggest how we proceed to share our ideas. Are there any questions? Let's proceed then with our individual effort for the next five minutes".

Recording: participants were next invited to share their ideas in a round-robin manner. No discussion on points was held at this stage. The facilitator merely listed the items on the flip-board.

"During the last five minutes, each of you used your worksheet to list ideas for dealing with the question. Now I would like to have each of you share your ideas with the other members of the group. To accomplish this goal as quickly and efficiently as possible, I am going to go around the table and ask each of you, one at a time, to give me one idea from your worksheet, summarized in a brief phrase or a few words. After the entire list is on the board, we will have the opportunity to discuss, clarify and dispute the ideas. If someone else in the group lists an idea which you also have on your worksheet, you need not repeat the idea. If, however, in your judgment the idea on your worksheet contains a different emphasis or variation, we would welcome the idea. You can also

"hitchhike" on other's ideas, should you think of something else as the session progresses. You can pass your turn at any stage, and you can come back in on a subsequent round if you think of something else. Are there any questions? [Turning to the first person in the group, the facilitator now asks:] Would you please give me one idea from your list?

Collating: all items were revisited to check understanding and obtain clarity. Perceived overlapping points were discussed and merged if it was agreed that the same meaning applied.

"Now that we have listed the ideas on the flip chart, I want us to take time to go back and briefly discuss each idea. The purpose of this discussion is to clarify the meaning of each item on our flip chart. It is also the opportunity to express our understanding of the logic behind the idea and the relative importance of the item. We should feel free to express varying points of view or to disagree. We will, however, want to pace ourselves so that each of the items on the chart receives the opportunity for some attention, so I may sometimes ask the group to move on to further items. Finally, let me point out that the creator of the idea being discussed need not feel obliged to clarify or explain an item. Any member of the group can play that role. [Going to the flip chart, the facilitator points to the first item and says:] "Are there any

questions or comments group members would like to make about this first item?" [This is then repeated with each idea.]

Prioritising: From the overall list, participants were asked to record the 7 most important items by giving careful thought and effort to the list.

"We have now completed our discussion of the entire list of ideas and have clarified the meaning of each idea. At this time, I would like to have the judgment of each group member concerning the most important ideas on the list. To accomplish this step, you should each take 7 index cards. I would like you to select the 7 most important items from our list of items. This will require careful thought and effort on your part. As you look at the flip chart sheets and find an item which you feel is very important, please record the item on an index card". [At this point, the facilitator goes to the flip chart and draws an index card.]

"Please place the number of the item in the upper left-hand corner of the card. For example, if you feel Item 13 [randomly picked] is very important to you, you would write 13 in the upper left-hand corner. [At this point, the facilitator should write 13 in the upper left-hand corner of the card she has drawn on the flip chart.] Then, write the identifying words or phrase on the card. [At this point, the facilitator writes the phrase for Item 13 on the card she has drawn.]

Please do this for each of the 7 most important items from our total list. When you have completed this task, you should have 7 cards, each with a separate phrase written on the card and in the top left-hand corner you should have an identifying number using the numbering system from our list of ideas on the flip chart. Do not rank-order the cards yet. Spend the next few minutes carefully selecting the 7 items. We will rank-order the cards shortly. Are there any questions?"

Following a demonstration from the facilitator of the above step and completion of this step, a ranking then followed with participants putting the number 7 next to the most important, followed by number 1 on the least important, and this process continued until 7 items were ranked.

"Please spread out your cards in front of you so you can see all 7 at once. Looking at your set of 7 cards, decide which one card is the most important. Which card is more important than the other 6 cards? [At this point the leader gives the group time to study their cards.] Please write a number "7" in the ***lower right-hand corner*** *of the card. Turn that card over and look at the remaining 6 cards. Of the remaining 6 cards, which is the least important? Write a number "1" in the lower right-hand corner. Now choose the most important of the remaining 5 cards and write the number "6" in the lower right-hand corner. Now choose the least important of the remaining cards and write the number "2" in the*

lower right-hand corner. Please continue this process until all 7 cards are ranked with 7 being the most important and 1 being the least important from your cards".

The cards were then collected, shuffled and a bundle was given to each member to read out along with the score, which the facilitator then recorded on the score sheet. The scores were tallied, and the priority list was drawn up. A brief informal discussion followed before the session closed.

4.4.4.1. Pilot phase

The success of the Nominal Group Technique is dependent on a competent facilitator, who is clear on the duties and the procedure (Dunham, 2006). For this reason, a pilot session was conducted to identify any possible issues relating to the procedure. This ensured all practical or logistical issues could be addressed prior to commencing the session. The pilot session was run with a group of 6 adults of mixed gender, profession, and education status.

During the pilot session the following issues were identified:

1) Issues with the question wording

The question used for the pilot was *"What should men diagnosed with prostate cancer know before deciding on their treatment?"* One participant questioned if the items to be generated should be based on their experience or could they be generic. This resulted in the addition of *"Based on your experience"* to the question, with the following question finalised for use in the actual session:

"Based on your experience, what do you think men diagnosed with prostate cancer should know before deciding on their treatment?"

2) Choice of pen colours

At the start of the pilot session, participants chose a pen from a box of mixed coloured pens. During the pilot session, it was identified that if a participant used a different colour to their peers, it would allow their items to be identified. Therefore, all participants were given a black pen to write with, to preserve the identity of participant's individual items and their ranking.

During step 2 (recording items), the facilitator wrote the items on the whiteboard using the available marker- green in colour. Two of the participants found it difficult to read the green writing on the white background, therefore for visibility, the facilitator should use a dark coloured pen when listing the items on the flip chart. During the actual session the facilitator, after checking visibility with participants, used a purple pen at the initial recording stage and wrote the clarification points in black.

In the collating stage, a participant in the pilot session identified that crossing out duplicates or similar items could be perceived negatively by participants with possible feelings that their point of view wasn't relevant or worthwhile. For this reason, points that were already expressed were given a tick.

3) Explanation on scoring

In step 4 (prioritising round), the pilot session highlighted the importance of giving a demonstration of the scoring system as the 2 numbering systems (item

number on top left-hand corner and rank number on lower right-hand corner) caused confusion for one of the participants.

For the demonstration, one participant suggested that the facilitator should randomly pick an item as an example when explaining how to fill in the score cards so as not to appear to be prioritising this item.

4.4.4.2. Analysis

Descriptive data were generated for the social and medical demographic data. For this study, scores for the 3 questions used to gain insight into participants' attitude towards their decision-making were collapsed into three categories to depict a negative, neutral, or positive attitude. This was done for descriptive purposes. For example, for the question *"how informed were you about your treatment options"*, those who chose a 1, 2 or 3, were categorised as poorly informed (negative), if selecting 4, 5, 6 or 7 moderately informed (neutral) and highly informed (positive) if selecting 8, 9 or 10.

As the NGT session ends with a list of priorities about a topic and a rank order of items men feel they require to make a decision about treatment for prostate cancer, minimal follow-on data analysis was required. In addition to the total score tallied on the day, the follow-on analysis consisted of counting the frequency of votes per item to determine how many participants placed a priority on each item and checking the recording to gain insight from the discussion on the specific items that were raised. The items were also grouped thematically, and this grouping was cross checked and discussed with a second researcher.

4.5. Results

4.5.1. Sample characteristics

The social and medical demographics of the 7 participants are summarised in Table 4.3. Participants' age ranged from 60-75 years (*M*= 70.2, *SD*= 5.41), with 2 of the 7 working part-time, and 5 retired. Education level ranged from primary level education (n=1) to third level or postgraduate level education (n=4), with 2 participants having second level education.

With regard to their prostate cancer diagnosis, all but 1 participant were able to use a descriptor for their stage of disease, this ranged from "early" to the specific staging detail used clinically. Five of the 7 were unable to list their Gleason score, and 3 of the 7 could not list their PSA. A variety of treatment options were followed including brachytherapy (n=1), hormone therapy alone (n=2), radiotherapy (n=1), surgery (n= 1), a combination of surgery and radiotherapy (n= 1), and 1 participant received proton therapy, a form of radiotherapy not available in Ireland. The timeframe for the diagnosis of prostate cancer was between 2001 and 2011, and 2 men were still on hormone therapy at the time of the NGT.

Decision-making. For the question, "How informed were you about your treatment options?", 4 participants stated they felt highly informed about their treatment options (between 9 or 10 on the rating scale), 2 participants stated they felt moderately informed about their treatment options (picking between 6-7 on the rating scale), whereas the remaining participant responded that he was not very informed (picking 1 on the 1-10 rating scale).

As one participant had no choice of treatment options available to him, due to his stage of disease, 6 participants answered the next 2 questions. For question 2 "*How difficult did you find it to make a decision about your treatment?"*, 3 participants reported moderate difficulty in making a choice (picking 4, 5, 6 on the rating scale) and 3 had no difficulty in making their decision, picking 9 or 10.

For the last question; *"How satisfied are you with your decision?", the* 6 participants who had a decision to make reported satisfaction with their decision (picking 9 or 10 on the scale).

Table 4.3: Demographics and decision-making scores

Pt. no.	Age	Education level	Work status	Time since Dx (years)	Stage	GS	PSA	Available trt options as listed by participants			Trt Option taken	Trt status (on /finish)	How informed about trt options*	How difficult to make a decision about your trt[&]	How satisfied with your decision[$]
1	67	Post graduate	Retired	13	Early	?	?	Sx	Brachy		Brachy	2004	9	6	9
2	74	Post graduate	Retired	5	T3bN0Mo	7	18	Proton	HT	IMRT	Proton +HT	2010	7	9	10
3	70	Primary	Retired	3	3	?	4.5	HT	Seed Imp	RT	HT	On	10	10	10
4	60	Upper 2nd level	Retired	5	Early	?	7?	Sx	RT		Sx	2009	6	4	9
5	75	Post graduate	Retired	5	Mets	?	95?	HT			HT	On	1	n/a	n/a
6	75	Lower 2nd level	Yes/part-time	5	?	?	31	HT	RT		RT	2010	10	10	10
7	71	3rd level	Yes/part-time	11	T1	6 or 7	4.3	Sx	RT	AS	Sx +RT	2005	9	5	10
Mean (SD)	70.29 (5.41)												7.42 (3.21)	7.17 (2.93)	9.66 (0.52)

Legend * 1 =not informed, 10= very informed. [&] 1= very difficult, 10=not difficult. [$]1=not satisfied, 10=very satisfied.

Pt. = Patient, DX=Diagnosis; GS= Gleason Score; PSA=Prostate Specific Antigen; Trt = Treatment, HT= Hormone Therapy; RT= Radiotherapy (when not further specified taken to mean external beam radiotherapy); Sx= Surgery; Brachy = Brachytherapy; AS = Active Surveillance; IMRT= Intensity Modulated Radiation Therapy (a type of radiotherapy); Seed Imp= Seed Implant (a type of brachytherapy); Proton= Proton Therapy, Mets = metastatic disease.

4.5.2. Items generated

By the end of the 2-hour session, 20 items in total were generated, listed and discussed. These items are shown in Table 4.4 and are presented in the order they were listed. All participants participated in at least the first round. Therefore, the first 7 items include an item from each participant, with item 1 being listed by participant 1, item 2 listed by participant 2 and so on… for the first 7 items on the list. As participants could drop out and drop back in at any stage, some participants contributed more items than others to the remaining 13 items. The items that were further clarified or elaborated on in the discussion round are also depicted in Table 4.4. To help give context to the items, some of the comments from the discussion of items during the clarification round are also included in this Table. Once the session concluded, a brief informal discussion was held and some comments from this open conversation are also included in Table 4.4.

4.5.3. Items prioritized and ranked

Results of the individual prioritizing of the top 7 items and total scores from the subsequent ranking in the voting is shown in Table 4.5. As a high total score does not necessarily reflect that an idea was frequently chosen by participants, both the rank by total score and the rank by number of scores is given in this table.

The item with the highest total score (27) and voted by the most participants (5 out of 7) is **"Urgency of condition, timeframe to make a decision"**. This is followed by **"Explanation of own condition"**, scoring a total of 22 with 4 out of 7 votes. **"Pros and cons of each treatment"** also had 4 votes coming third on the list with a total score of 20.

“Supports” and **“involve wife/family”** also had 4 out of 7 votes scoring 12 and 10 respectively. **“Possible pathways at initial diagnosis”** scored higher in total (17) but carried less votes (3 out of 7).

“When to know when to change treatment path”, clarified in the discussion as being important for those initially on active surveillance but needing to consider a more active management strategy if the disease progressed was not prioritised by any of the participants in the voting round.

Table 4.4: Results of step 2 and 3

Items*	Quotations from discussion (step 3 and after ranking round)
Pros and cons of **each** treatment	"what the advantages and disadvantages of each option are likely to be"
Urgency of condition->decision (timeframe to make a decision)	"cancer is slow growing but what's the definition of slow growing…. a timeframe must be put on it."
Best practice on current treatments available (consultants to advise)	"This overlaps with the 1st one, if you do the pros and cons properly it should be included"
Involve wife/family	"Men are more likely to pull down the shutters" "I'm surprised family support is so far down the list"
Side effects **(short-term)**	"during or around the time of treatment"
How to research +evaluate treatment available (worldwide)	"some of the stuff on the internet is crap, you have to weed it out" "you would want a health warning with it, and it depends on your stage too"
Supports	"personal support, like ARC counselling, a different level of support…. just to be able to talk to someone" "men are much less likely to talk about feelings and impact on sexual function"
Explanation of own condition	"everyone's cancer is different"
Life expectancy (before/after treatment)	"how the treatment will change that"
Cancer society/talk to Peers	"it is good to talk"

How to deal with situation after diagnosis	"no one prepares you for this…… what do you do next"
Costs and availability	"Access might be a problem for some, medical card holders are not represented here" "The timeframe to get treatment might influence the decision that is ultimately made, but initially the decision is based on many factors, but the actuality of what a patient might have may be different"
Long term effects/afterwards	"what the treatments will do to you in the long run……how they will affect you"
Treatment sequence and consequences	"what order will you get them in, this will impact on you too"
Non-medical language	"words like active surveillance and watchful wait are not very helpful when you have just been diagnosed with cancer"
Duration of treatments	"how long will these treatments go on for"
Possible pathways at initial diagnosis	"It very much depends on who you are referred to first, is it the urologist or the oncologist"
Alternative options/2nd opinion	"He might have been greedy to do work, some are more greedy that others, but he put the ball back in my court" "...well medicine is a business like any other "
When to know when to change treatment path	"in relation to Active Surveillance and when the approach should change to active management"
Quality of information -> open, honest	"the information here is bullshit if you have advanced disease, (it) talks too generally, full of ..., 'everything will be fine, you will be grand'…... Macmillan- tell you straight up what the situation is"

Note: *Items identified in Step 2 with text in **bold** font highlighting the text added after discussion round (step 3)

Table 4.5 - Results of step 4- ranked by total score, followed by number of votes

Item No.	Item	Rank by total score	Rank by no. of votes	Rank vote: 1 – 7 least important- most important	Total Score
2	Urgency of condition->decision (timeframe to make a decision)	1	1	5. 7. 5. 3. 7.	27
8	Explanation of own condition	2	2	6.6.5.5.	22
1	Pros and cons of each treatment	3	2	6. 3. 7. 4.	20
17	Possible pathways at initial diagnosis	4	6	4.6.7.	17
7	Supports	5	2	2. 2. 2. 6.	12
3	Best practice on current treatments available (consultants to advise)	5	9	7. 5.	12
20	Quality of information -> open, honest	7	6	4.6.1.	11
4	Involve wife/family	8	2	3. 2. 4. 1.	10
15	Non-medical language	9	6	1.1.7	9
5	Side effects (short-term)	9	9	3. 6.	9
11	How to deal with situation after Diagnosis	9	9	5.4.	9
12	Costs and availability	9	9	5.4.	9
6	How to research +evaluate treatment available (worldwide)	13	15	7	7
16	Duration of treatments	14	6	1.4.1.	6
10	Cancer society/talk to Peers	15	9	2.3.	5
13	Long term effects/afterwards	15	9	3.2.	5
9	Life expectancy (before/after treatment)	17	15	3	3
18	Alternative options/2nd opinion	18	15	2	2
14	Treatment sequence +consequences	19	15	1	1
19	When to know when to change treatment path	____	____	____	____

4.5.1. Themes

Following the session, the items were grouped based on the themes that emerged. These related to (1) the diagnosis and treatment specific options, (2) decision-making and (3) the possible facilitators and barriers that included items relating to information, supports and practicalities and logistics (Table 4.6).

4.5.1.1. Diagnosis and Treatment specific details

Of the 20 items generated, 9 were within the *"diagnosis and treatment specific details"* category (Table 4.6). Three of these items are in the top 7, with 2 of these coming 2nd and 3rd on the list, both with 4 votes each. All other items in this category were ranked lower on the list with the majority obtaining only 2 votes each, apart from the item *"when to know when to change treatment path"* which received no votes.

4.5.1.2. Decision-making

Two of the 20 items were categorized within this theme, with the item with the most number of votes also being the 1st on the ranked list. The *"urgency of the condition*" clarified in the discussion to mean *"the timeframe to make a decision"* was considered very important by the majority of participants. In the discussion, one participant stated that *"cancer is slow growing,…but is this weeks or months?"* A second participant stated that the most useful thing the doctor said to him was the timeframe he had to make the decision *"...you have time to make a decision, but we need to know your decision by Christmas"* (3 months' time).

Seeking an alternative or second opinion was the other item in this category, receiving only 1 vote and scoring 2 in total.

4.5.1.3. Barriers and facilitators

This category with 9 items overall, was further subdivided into aspects relating to information (3 items), supports (3 items) and practicalities and logistics (3 items).

Information. "Quality of information" ranking within the top 7, scoring 11 in total with 3 votes, was discussed in detail. One participant expressed his dissatisfaction with the information provided saying that it was not suited for men with advanced stage disease, the Irish literature shies away from the facts when the prognosis was not good. He perceived that this is in contrast with information provided by websites and cancer organisations in the UK. Consistent with the demographic details obtained at the start of the session, others commented on their satisfaction with the information they received. The overall feeling in the group was that the information provided should be open and honest for all patients.

The use of non-medical language was prioritised by 3 participants scoring 9 overall, with one participant saying, *"words like active surveillance and watchful wait are not very helpful when you have just been diagnosed with cancer"*.

One participant prioritised the importance of showing men *"how to research and evaluate treatment available"* in a worldwide context (total score 7). One participant had elected to travel abroad for proton therapy, a form of radiotherapy that was relatively new and not proven to be a superior method of treatment at the

time of this study. During the discussion round, one participant commented that *"we should be shown how to weed out the information"* as some should come with a *"health warning".*

Supports. Two items within this category received a high number of votes; "supports" and "involve wife/family" both obtained 4 votes each, with "support" ranking within the top 7. In the discussion, one participant stated the importance of involving family from the start before men *"pull down the shutters."*

Other supports that are available such as *"the cancer society/ talk to peers"* were prioritised by 2 participants scoring 5 in total.

Practicalities and logistics. Three items were grouped within this theme. The first item "possible pathway at initial diagnosis", ranked 4th overall and was prioritised by 3 participants, scoring 17 in total. Some discussion was held on this point with participants agreeing that the patient has little control over this, but that *"GP's should be educated as to who to refer patients to".* Other practical aspects of treatment including the "cost and availability" of treatment was prioritised by 2 participants scoring a total of 9 and the "duration of treatments" was prioritised by 3 scoring 6 in total.

Table 4.6: Overarching themes and specific items: number of votes and total scores

Theme	Item	No. of votes	Total Score
Diagnosis and treatment specific details:			
	Explanation of own condition	4	22
	Pros and cons of each treatment	4	20
	Best practice on current treatments available (consultants to advise)	2	12
	Side effects (short-term)	2	9
	How to deal with situation after Diagnosis	2	9
	Long term effects/afterwards	2	5
	Life expectancy (before/after treatment)	3	3
	Treatment sequence and consequences	1	1
	When to know when to change treatment path	0	--
Decision-making:			
	Urgency of condition->decision (timeframe to make a decision)	5	27
	Alternative options/2nd opinion	1	2
Barriers and facilitators:			
Information			
	Quality of information -> open, honest	3	11
	Non-medical language	3	9
	How to research +evaluate treatment available (worldwide)	1	7
Support			
	Supports	4	12
	Involve wife/family	4	10
	Cancer society/talk to Peers	2	5
Practicalities and logistics			
	Possible pathways at initial diagnosis	3	17
	Costs and availability	2	9
	Duration of treatments	3	6

4.6. Discussion

This study aimed to identify what prostate cancer survivors believe is important for newly diagnosed prostate cancer patients to know to make a decision about their treatment options. A list of 20 items was generated by participants and some agreement was found between participants in relation to the topics that men should be made aware of in order to make a treatment decision. The "*urgency of the condition, timeframe to make a decision"* scored highest and was prioritised by more participants than any other item. Six of the seven participants in this study had at least two treatment options available to them, and half recalled having moderate difficulty in making a treatment decision, but all were satisfied with their decision. This is consistent with other studies that have shown that prostate cancer patients faced with making a decision can suffer from decisional conflict, but for some this conflict does not always lead to decisional regret and a subsequent decrease in quality of life (Chien, Chuang, Liu, Li, & Liu, 2014). Decisional regret was not formally measured within this sample, but decisional regret was not mentioned at any stage during data collection, and all six participants who had a decision to make reported complete satisfaction with their decision.

The top scoring item in this study, "*urgency of the condition, timeframe to make a decision",* was an unexpected finding based on previous literature, but identifies that this sample's prioritised needs are different than previous studies completed in other countries, showing that this study was warranted. One study which did report findings in relation to timeframe, reported that men wanted more time to think about the diagnosis and treatment than their partners, (Bobridge et

al., 2015). Additionally, Feldman-Stewart listed timeframe to make a decision within the top ten items in 1996, but it wasn't identified as essential by men in 2005. If the timeframe is not explicit, patients may incorrectly assume they need to make a decision quickly, without the necessary knowledge to make an informed decision. Specific long held beliefs built on the language used around cancer, such as "fighting" the disease that is "invading" the body (McGregor, 2003), and ideas about "going to war on cancer" from awareness campaigns, may influence patients to act fast, when there is a diagnosis of prostate cancer. This could account for some of the knowledge gaps and decisional conflict found in the literature and discussed in Chapter 2. Identifying the "urgency" of the decision is therefore an important aspect to identify for men faced with decision-making. This will allow men the opportunity to source any additional information they require, process this and apply it to their own situation, thus enabling informed decision-making. Additionally, if health professionals can devote time to guide patients through the information, provide personal context to its content, and explore patient values, shared decision-making may be actualised (Flory & Emanuel, 2004).

The second item on the priority list for participants in this study was the importance of explaining the patient's own condition, rather than citing generic or broad statistics that may not apply to the patient. This corresponds to other research that highlights the importance of tailoring information to individual patients' circumstances and important to consider in this era of patient centred care (Edwards, Elwyn, & Mulley, 2002; Leydon et al., 2000).

The pros and cons of treatment was the third item prioritised by men in this study. It is not surprising that this item is listed, as other studies have also identified the importance of information on side effects for patients (Zeliadt et al., 2006). However, that it is only in third place is surprising, as all healthcare professionals would consider this crucial information for men to provide informed consent. Consent to treatment requires an understanding of the consequences of treatment so perhaps this explains why it is considered of primary importance by clinicians. However, interestingly, most research to date has identified that patients are confused on these facts which begs the question how informed is the consent that is provided. Lack of information on side effects related to bowel, urinary and sexual dysfunction was identified as a concern by more than a third of patients in a recent Irish study (Diver et al., 2018), with those undergoing active surveillance less satisfied with information, that those undergoing active management strategies. Younger participants (age of 55-64 years) in the Diver et al. study (2018) also expressed a greater need for information than those over the age of 64 years. As information on side effects is provided both verbally and in written format by all clinicians, this finding suggests issues such as too much information, time pressure to make a decision, or information not been personalised for patients, may have impacted on the patient's ability to retain this information at the time of decision-making. In addition, perhaps men disregard this information when not experiencing the side effects, but when the side effects materialise, they then require information on how to deal with them. Strategies such as the teach-back method should be put in place to check understanding before progressing with treatment,

even when consent has been obtained. The teach-back method, also known as "show me", checks understanding of information by asking patients to repeat back key points (Jager & Wynia 2012). The method involves a process of questioning to determine what the patient has learned and consists of 4 steps (1) explaining the issue, (2) sensitively asking the patient to repeat the information, (3) clarifying any misunderstandings, and (4) asking the patient to repeat the information. This strategy has been successfully used in healthcare settings to increase communication and aid understanding (Dinh, Bonner, Clark, Ramsbotham, & Hines, 2016). Strategies such as this will help to confirm that patients are adequately informed of the consequences of the treatment option they are selecting (Kripalani, Bengtzen, Henderson, & Jacobson, 2008; Sudore & Schillinger, 2009).

Pros and cons of treatment and many of the remaining items overlap with items considered in other studies and match the three key priorities for prostate cancer patients identified in the review discussed earlier: (i) likelihood of cure (ii) disease stage and (iii) side effects/ risks and benefits of treatments (Tariman et al., 2014). However, the importance of support and family involvement, prioritised by four participants in the current study was not identified in the Tariman (2014) review. Considering the deficiency in knowledge about prostate cancer and its treatment identified in at-risk men (Arnold-Reed et al., 2008), once diagnosed, supports from others may help to manage the situation and this was identified in previous studies (Boehmer & Babayan, 2005; Mehnert et al., 2010). Partners, families, and other individuals such as friends or colleagues previously diagnosed with prostate cancer, are called on when making decisions (Berry et al., 2003; Hall

et al., 2003). However, some evidence suggests this can result in exclusion of the patient from the process (Chapple et al., 2002; Holmboe & Concato, 2000). Therefore, guidance for the patient on managing this, and availing of more formal supports as identified in the current study would be of benefit.

The 20 items generated in this study contrasts considerably with the 93 questions proposed to patients by Feldman-Stewart, although Feldman-Stewart used a list generated by many stakeholders, including healthcare professionals. The reported discordance between what healthcare professionals and patients report as important may explain some of this variation (Rüesch et al., 2014). However, asking patients to pick from a list as opposed to generating their own items may also explain the difference observed in this study. The advantages of generating their own list helps to reduce priming bias but does not account for possible issues with recall. Considering the time frame since diagnosis in the current group, this could be perceived as an issue. More specifically, given the timeline since participants made their decision, it is possible that they may have forgotten issues that were important at the time. However, as this study aimed to generate items patients need to know, from those who have lived through the experience and experienced the consequences, it was deemed appropriate. It also recognises the core principle of Public and Patient Involvement, that considers the importance and benefits of involving the patient when devising clinical guidelines (Légaré et al., 2011).

The current study, which found agreement on some items, also found variation in information prioritised by participants. Four items ("treatment sequences and consequences", "alternative options/2nd opinion", "life expectancy",

"how to research and evaluate treatment") were prioritised by only one participant, and six items were prioritised by only 2 participants. This variation is consistent with the literature that has shown that an individual approach should be taken when informing patients because of the variation seen with respect to information needs (Berry et al., 2006; Feldman-Stewart et al., 2001; Rüesch et al., 2014). Some of the variation in cancer patients' information needs has been associated with age (Diver et al., 2018) and gender (Matsuyama et al., 2011), but as this cohort were similarly aged males, these factors cannot account for the variation found in this study. Xu found variation between black and white Americans but as the cohort of the current study was Caucasian, this again does not explain the variation (Xu, Dailey, Eggly, Neale, & Schwartz, 2011). Although the incidence of prostate cancer is higher in African-Americans, this sample of males is similar to the population of prostate cancer patients in Ireland (https://www.ncri.ie/). With respect to age, this cohort had a mean age of 70 years (SD=5.4) which is representative of the age category who present with prostate cancer (https://www.ncri.ie/). Thus, the variation seen in this study may relate to the individual nature of patients' information needs rather than demographic factors, supporting the argument for a core set of information with additional information individualised for patients.

From the list of 20 items generated, only 1 item was not prioritised by any participant *("when to know when to change path"*). This illustrates that the information needs vary across patients but that some items are considered key for most patients. This is consistent with other research. Studies by Feldman-Stewart across many countries, have highlighted the lack of consistency both within

countries and between countries in relation to information required for treatment decision-making (Feldman-Stewart, Capirci, et al., 2011), but that some items overlap. This pattern of findings supports the idea that information requirements are individual and perhaps it is better to provide the key/core elements that overlap in each study along with the resources to facilitate men to seek further information.

In an attempt not to overburden patients with unnecessary information at a difficult time, many studies have aimed to assess the ideal information required by patients to make informed decisions. Wide variation is seen across studies in what men consider is essential information. A mismatch between the information required and the information provided can make the decision process more difficult for patients but considering the wide variation in patients' information needs, determining what information is required is difficult. As others have done, proposing a core set of information that meets most men's needs and the need for informed consent is therefore a useful approach to follow, with opportunities then provided for more personalised information to be provided. Based on the discrepancy between different countries on what information is required, it was important to ascertain this from a sample of patients in Ireland.

The 19 items prioritised by participants from the list of 20 items generated in this study were used in designing the survey and interview schedule for studies 2 and 3, as shown in Table 4.7. Many of the items were incorporated into both the questionnaire in study 2 and the semi-structured interview schedule used in study 3, with the overarching concepts used in the development of the conceptual framework tested in study 2. Table 4.7 shows how each item is used in either a

question, or incorporated as part of a validated scale in study 2, along with the concept the item relates to, which is shown in bold text. Similarly, the questions used in study 3 are shown along with the overarching concept the question relates to. For example, “Explanation of own condition”; participants in study 1 identified the importance of the clinical team explaining details specific to each patient, rather than providing broad or generic information. This item was examined in study 2 by asking participants if they knew their stage and grade of disease, which in turn identifies the knowledge participants have about their disease. This item was also examined in study 3 by asking “How easy was it to know which information applied to your situation?”, which in turn aimed to identify if this information could act as a barrier or facilitator to decision-making.

Table 4.7: Relationship between items identified in study 1 and questions and concepts examined in study 2 and study 3

Items- study 1 (rank order)	Study 2 (Questionnaire)	Study 3 (Interview)
Urgency of condition->decision (timeframe to make a decision)	"Did your doctor tell you how long you had to make a decision about your treatment" **(Knowledge)**	"how long were you given to make the decision? " **(Treatment decision-making process)**
Explanation of own condition	Questions on own stage of disease, "what is the …stage of your disease, ……your PSA level…., …..your Gleason score .." **(Knowledge)**	"How easy was it to know which information applied to your situation?" **(barriers and facilitators to DM)**
Pros and cons of each treatment	Knowledge of side effects (self-designed questionnaire), DCS **(Knowledge, decision conflict)**	"Would you be able to tell me something about the treatment side effects What are they?...What is your understanding of the side effects of each treatment?" **(barriers and facilitators to DM)**
Possible pathways at initial diagnosis	"Please list all the treatment options that are available to you for your stage of disease?" **(Knowledge)**	----------
Supports	PSS, DCS **(decision conflict, social support)**	"Who was involved in the decision-making?" **(Treatment decision-making process)**

Best practice on current treatments available (consultants to advise)	"Did your Doctor tell you the pros/advantages and cons/disadvantages of each treatment? " **(Knowledge, decision conflict)**	----------
Quality of information -> open, honest	----------	"Did you get the kind of information you want/feel you need about (disease) and its treatment?" **(Treatment decision-making process; barriers, facilitators)**
Involve wife/family	PSS (**Social support)**	"Who was involved in the decision-making?" **(Treatment Decision-making Process)**
Non-medical language	HLS **(Health literacy)**	"how was the information provided to you? (verbal, written… language used…." **(barriers and facilitators to DM)**
Side effects (short-term)	Knowledge of side effects (self-designed questionnaire) **(Knowledge)**	"Would you be able to tell me something about the treatment side effects What are they? What is your understanding of the side effects of each treatment?" **(barriers and facilitators to DM)**
How to deal with situation after Diagnosis	SES, DCS **(Self-efficacy, decision conflict)**	----------

Costs and availability	----------	what practicalities would you have thought about……? would you have thought about the financial cost of the treatment?" **(barriers and facilitators to DM)**
How to research +evaluate treatment available (worldwide)	"What did you use to help you make a decision about the treatment" "Did your doctor tell you where you can find more information about your disease and your treatment options" **(Knowledge, decision conflict)**	"How easy did you find it to get information about **your** diagnosis and **your** treatment options?" **(Treatment decision-making process; barriers, facilitators)**
Duration of treatments	----------	"what practicalities would you have thought about?" Would you have thought about getting …the duration of the treatment…" **(Treatment decision-making process; barriers, facilitators)**
Cancer society/talk to Peers	"Did you discuss your treatment options with someone else?" **(Social support)**	".. did you talk with others.?." **(Treatment Decision-making Process)**
Long term effects/afterwards	"Did your Doctor tell you the pros/advantages and cons/disadvantages of each treatment? " **(Knowledge)**	"Would you be able to tell me something about the treatment side effects What are they?...What is your understanding of the side effects of each treatment?" **(barriers and facilitators to DM)**

Life expectancy (before/after treatment)		"What is your understanding of your prostate cancer (severity, prognosis)? what would you say is the likely outcome or prognosis for you?"
Alternative options/2nd opinion	"Did you discuss your treatment options with someone else" **(Social support)**	"Did you seek a second opinion? **(Treatment decision-making process)**
Treatment sequence +consequences	"Did your Doctor tell you the pros/advantages and cons/disadvantages of each treatment? " **(Knowledge)**	----------
When to know when to change treatment path	----------	----------

DM= Decision-making; DCS = Decision conflict scale; PSS= Multidimensional scale of perceived social support; HLS-=Health literacy scale; SES = General self-efficacy scale. Note: **bold** text signifies the overarching concept

4.6.1. Limitations and future research

When viewing the findings of this study, a number of limitations should be considered. Firstly, as a convenience sample of members of an Irish cancer charitable organisation was recruited to this study, the sample may not be representative of cancer survivors not belonging to this organisation. Patients attending or belonging to a support network may have different needs than those who chose not to join supportive organisations, such as this. Future studies of this nature, could aim to recruit from hospital follow-up clinics. This would allow a broader perspective to be obtained.

Secondly, given the number of potential participants that contacted the researcher, only one NGT session was run. A higher response rate would have allowed additional NGT sessions to be run, thus adding to the strength of this study as other NGT groups with similar findings would have reinforced these items, whereas different findings would have highlighted the individual nature and diverse range of patients' needs. Considering the variation in the literature of patient information needs, it is very likely that further sessions would have highlighted a broader range of items. However, this study did include a cohort of prostate cancer survivors with a similar age profile to those who present with prostate cancer in Ireland. In addition, both a range of treatment options was available to this sample and a range of treatment options was taken across the group. In addition, variation was seen in this sample in two of the decision-making questions regarding how informed participants were and their difficulty in decision-making.

In addition, a further consideration with the use of the NGT, is in how the voting is analysed to arrive at the overall outcome. No clear guidelines were found on a definite system to interpret the strength of consensus reached following NGT. One method that can be used is to focus only on the total score, but a limitation with this approach is that a few voters giving top priority to an item can sway the result from the items given a lower priority but by a greater number of voters (McMillan et al., 2014). An alternative option is to combine these approaches, by giving a weighting to both the total summed score and the number of votes (Redman et al., 1997), and complex systems have been developed for use when a number of NGT sessions have been conducted in order to combine findings across groups (Dewar, 2003; McMillan et al., 2014). As only one session was run in this study, a complex system was not required, and in order not to lose important data, a combined approach was used, with consideration of both the sum of the scores (total score) and the total number of participants voting included in the results and discussion.

The information resources available to those with advanced cancer is an area that is worth exploring in future research given the perception of one participant in this study who described the information available in Ireland as not honest. For example, he perceived that the information in Ireland was “too light”. This perception was not echoed by participants with early stage disease who would have used resources specifically designed for those with early stage disease. An assessment of information resources available to those with advanced or incurable cancer and comparing this with the approach taken in other countries would be an

interesting study. If, as perceived by this participant that a difference does exist, exploring patients views on which approach is beneficial would be worthwhile.

Future studies assessing what information men require could examine this in a longitudinal study, first assessing information needs at the time of decision-making, with a follow up study conducted following the completion of treatment and again at a time point when the side effects of treatment manifest. This would allow comparisons to be made on what men report is important at the time of decision-making, but also in hindsight what men feel they should have known. From this, the core set of information could be identified with options available for making the remaining information available for patients to access, perhaps by using an online app, which customises the information relevant to the patient's particular stage of disease.

4.7. Conclusion

This study used a novel technique to assess what information prostate cancer survivors in Ireland think men newly diagnosed with prostate cancer need to know in order to make a treatment decision. Consistent with the literature, variation was found in the items that men prioritise, supporting the need to individualise information, but the timeframe to make a decision was a surprising finding. Providing information on this to all patients who attend clinics would not be too onerous a task on clinicians and may help patients to realise they can spend some time on becoming informed. Removing time pressures on patients faced with making this serious decision, may help to reduce conflict and allow patients time to participate in informed or shared decision-making.

Chapter 5: Deciding on treatment- knowledge, health literacy and decision conflict

This chapter considers the factors associated with decision conflict in newly diagnosed prostate cancer patients. From the literature discussed in Chapter 2, it remains unclear what role relationship status, knowledge, health literacy, perceived social support and self-efficacy play in reducing decision conflict in prostate cancer patients, with much of the previous research carried out in other countries, in different cancer populations, or after treatment has been completed. Specifically, the level of decision conflict in this population in Ireland is not known, and the nature of the associations between the potential explanatory variables (listed above) and decision conflict have not been explored in this population at the time of decision-making. Perceived social support and self-efficacy as moderators of the relationship between health literacy and decision conflict have also not been examined previously.

5.1. Introduction

Decision conflict can arise for prostate cancer patients as there is uncertainty about the course of action to take and all choices involve risk or loss (O'Connor, 1995). Regardless, men are pressurised into making a treatment decision and, as detailed in Chapter 2, decision conflict can lead to decision regret and a reduction in quality of life. For example, for a patient choosing to follow an active surveillance strategy, the risk or loss can be physical and psychological (Mader et al., 2017). Living with the uncertainty of disease progression, and the

notion that the window of opportunity to treat may be lost can impact on mental health, and the ongoing monitoring and biopsies can impact psychologically and physically on patients (Formica et al., 2017). Those who chose an active strategy such as surgery or radiotherapy can also experience risk or loss, with the consequences or side effects adversely impacting on quality of life (Hamdy & Donovan, 2017). However, many men make this decision, succeed in completing treatment and report good quality of life scores with minimal or no regret (Chien et al., 2014). Identifying the factors associated with decision conflict is therefore important so the necessary resources can be designed and implemented for those considered at risk of experiencing decision conflict.

5.2. Factors associated with knowledge and information

Men with prostate cancer who are satisfied with information on the pros and cons of treatments report less uncertainty in decision-making (Berry et al., 2006). Similarly, greater decision-making satisfaction and a reduction in decision conflict have been reported in men who are informed (Myers et al., 2018; Orom et al., 2016), with poor prostate cancer knowledge associated with increased decisional conflict and lower perceived efficacy in decision-making (Kaplan, Crespi, Saucedo, Connor, et al., 2014). Consequently, Kaplan proposed that cancer knowledge may represent a modifiable target to reduce decisional conflict (2014). Identifying the relationship between sociodemographic factors (including education and age) and prostate cancer knowledge has implications for how to correct a lack of knowledge (Winterich et al., 2009). This may in turn lead to informed patients with lower levels of decision conflict. Older patients and those with lower

education level are reported to have less knowledge of prostate cancer and its treatment (Arnold-Reed et al., 2008; Deibert et al., 2007; Rees et al., 2002). However, much of this research has been conducted in general populations or in relation to prostate cancer screening (Price, Colvin, & Smith, 1993; Wilkinson, List, Sinner, Dai, & Chodak, 2003; Winterich et al., 2009). Studies that have been conducted on prostate cancer patients have focused on men in disadvantaged or low-income minority groups. One such study, using a prostate cancer knowledge questionnaire (Table 5.1), in a sample of 399 low income prostate cancer patients found increasing age and less formal education were associated with lower knowledge of disease (Deibert et al., 2007). However, as the majority of this sample were Latino, the authors concluded that further research was warranted in other populations: examining the role of age and education level on prostate cancer knowledge in patients in Ireland will therefore add to the literature.

Table 5.1: Prostate cancer knowledge questionnaire, (Deibert et al., 2007)

Item No.	Statements from Questionnaire	Correct response
1	The prostate is located between the bladder and penis, in front of the rectum.	True
2	If you have brothers or sons they are at higher risk for prostate cancer.	True
3	A man can have prostate cancer without having any pain or symptoms.	True
4	Antibiotics can be used to cure prostate cancer.	False
5	The goal of hormone therapy is to lower the levels of the male hormone, testosterone.	True
6	Surgery or radiation can cure prostate cancer in its early stage.	True
7	Chemotherapy is given to men with early prostate cancer.	False
8	Hormone treatment for prostate cancer can cause hot flashes.	True
9	Prostate cancer treatment can increase your sex drive.	False
10	Radiation treatment of prostate cancer can cause urinary or sexual problems.	True
11	Surgery of prostate cancer can cause urinary or sexual problems.	True
12	Eating soybean products such as tofu and soymilk can lower the risk of prostate cancer.	True
13	Eating tomatoes can decrease the risk of prostate cancer.	True
14	Experts recommend eating at least 2 servings of fruits and vegetables each day.	True

5.3. Health literacy

There is a dearth of research examining the relationship between health literacy and prostate cancer knowledge in prostate cancer patients. Kim et al. (2001), investigated this relationship in a sample of mixed educated participants and found a significant positive correlation ($r = .65$, $p < .01$) between health literacy scores and prostate cancer knowledge, with higher health literacy scores associated with higher knowledge scores. On analysing knowledge scores and education level; participants not completing high school diploma tended to score lower on the knowledge test when compared with graduates from high school and further education, however, this difference was not statistically significant. Knowledge

scores did not vary for any other demographic in this small sample (n=30). Patients' level of participation in decision-making was also assessed in this study, and the treatment option preferred by participants along with the actual treatment received, were recorded. From the results, the authors concluded that low knowledge about the disease and low health literacy limited patient participation in the shared decision-making process and that low health literacy may be an overlooked factor in the implementation of shared decision-making (Kim et al., 2001). This adds to the argument raised in Chapter 2 in relation to the benefit of decision aids. Due to the conflicting evidence available to support the use of decision aids, it is possible that other factors such as health literacy have a role to play when considering patient knowledge and information, as seen in the Kim et al. study.

However, the specific relationship between knowledge and health literacy is complex, as age and level of education have been found to be associated with both knowledge and health literacy. Patients who are younger and better educated are reported to have higher levels of health literacy (Baker, 2006) and a recent review of 8 studies measuring health literacy in older adults (over 65 years) across different health settings reported that age and education level affect health literacy in the older population (Chesser, Keene Woods, Smothers, & Rogers, 2016). However, before generalising these findings to a prostate cancer population, consideration must be given to the small age range included in these studies and the fact that these studies used various instruments to measure health literacy, with few

instruments measuring Nutbeam's (2000) three dimensions of health literacy as discussed in Chapter 2.

Although increased knowledge has been associated with reduced decisional conflict as stated above, others have reported that increased knowledge can increase decision uncertainty and decision-making difficulty (Orom et al., 2016), therefore other factors that may be associated with decision conflict also need to be considered.

5.4. Factors associated with decision conflict

In addition to the studies investigating the associations between decision conflict and knowledge, information and health literacy, others have examined associations between relationship status, social support, and self-efficacy. A qualitative study identified that men turn to their partners to provide support. Emotional support, which included help in deciding, as well as practical support, such as help with collecting relevant information was observed (Renzi et al., 2017). Decisional conflict was not measured in this study but availing of partners to obtain information should help in informing patients which in turn may reduce decision conflict, as discussed above. In addition, emotional support from partners in decision-making can also lead to lower decision conflict, as discussed in Chapter 2. However, relationship status has been negatively associated with decisional conflict with those in a relationship reporting higher levels of decisional conflict (Kaplan, Crespi, Saucedo, Connor, et al., 2014). Further supporting the conflicting nature of the findings from these studies, a review also highlighted conflicting results in relation to the role of partners in decision-making (Zeliadt et al., 2006). Given these

mixed findings, it is therefore important to ascertain the role of relationship status on decision conflict in patients making treatment decisions for prostate cancer.

In addition to received support, patient's perception of support from others may help with decision-making, as perceived social support has been associated with better quality of life and better psychological adjustment (Baider et al., 2003; Mehnert et al., 2010). As discussed earlier (Section 2.3.4), the stress and coping theory (Lazarus & Folkman, 1991) posits that stressful events, such as a cancer diagnosis can negatively impact on health, and men with prostate cancer have been found to have high levels of psychological distress (Mehnert et al., 2010). Support can help to alleviate some of these effects by promoting more adaptive coping mechanisms (Cohen & Wills, 1985). It can therefore be hypothesized that those who feel supported are more psychologically adjusted to their cancer diagnosis, therefore will be less conflicted when making decisions. However, the association between perceived social support and decision conflict has not been examined in the context of prostate cancer patients and is an interesting area to investigate. Recognising the role of perceived social support in decision-making will help to identify those patients who may need additional formal support if their perceived social support is low. Additionally, as discussed previously, as low health literacy limits a patient's participation in the shared decision-making process (Kim et al., 2001), it is worth examining the relationship between health literacy and decision conflict. In addition, based on the association between support and adjustment to cancer, it is worth considering if support can moderate the relationship between health literacy and decision conflict, previously proposed by Lee et al. (2004), but

not yet reported, as discussed in Section 2.3.4. Examining these relationships will advance the evidence on the strategies that can be taken to support patients who may be at risk of experiencing decision conflict.

Ultimately, to reduce decision conflict, patients need to be confident in their ability to make a good decision. Self-efficacy in decision-making has been positively associated with survivors' sense of control, asking questions of providers, and participation in treatment-related decisions (Arora et al., 2009; Maly et al., 2004). Older men and men with poor prostate cancer knowledge, have lower perceived efficacy (Kaplan, Crespi, Saucedo, Connor, et al., 2014), and patients with higher self-efficacy are less likely to express decision-making conflict as the result of uncertainty (Goh et al., 2012). This further illustrates, as discussed in Chapter 2, that many factors need to be identified when considering the variables associated with decision conflict. Given the literature to date, as presented in Section 2.3.5, it is important to establish the relationship between self-efficacy and decision conflict in prostate cancer patients making a treatment decision. Additionally, self-efficacy as a potential moderator of the relationship between health literacy and decision conflict is worth examining, as one's ability to ask questions and interact with the care giver are important components of communicative health literacy, and therefore patients' confidence in performing these tasks may alleviate some of the issues associated with low health literacy. However, this has not been considered in the literature to date.

In summary, many factors have been identified as possibly associated with decision conflict, including knowledge, health literacy, perceived social support and

self-efficacy. The influence of demographic factors such as age, education and relationship status have also been considered in relation to knowledge, health literacy and decision conflict in various healthcare settings. Given the evidence available, how these factors relate to decision conflict in a prostate cancer patient population is not well established. In particular, the relationships between these variables is not known in the Irish context but from the literature available to date, a conceptual framework (Figure 5.1) has been devised for examination in this study. Identifying these relationships will help to highlight the vulnerable patient groups that are at risk of experiencing decision conflict. These results can then be used to identify the specific resources that are required for this at-risk population. Reducing decision conflict can reduce decision regret and lead to better patient outcomes including quality of life. In the era of shared decision-making, it is essential patients are facilitated to have the confidence to make an informed choice, which is subsequently not regretted.

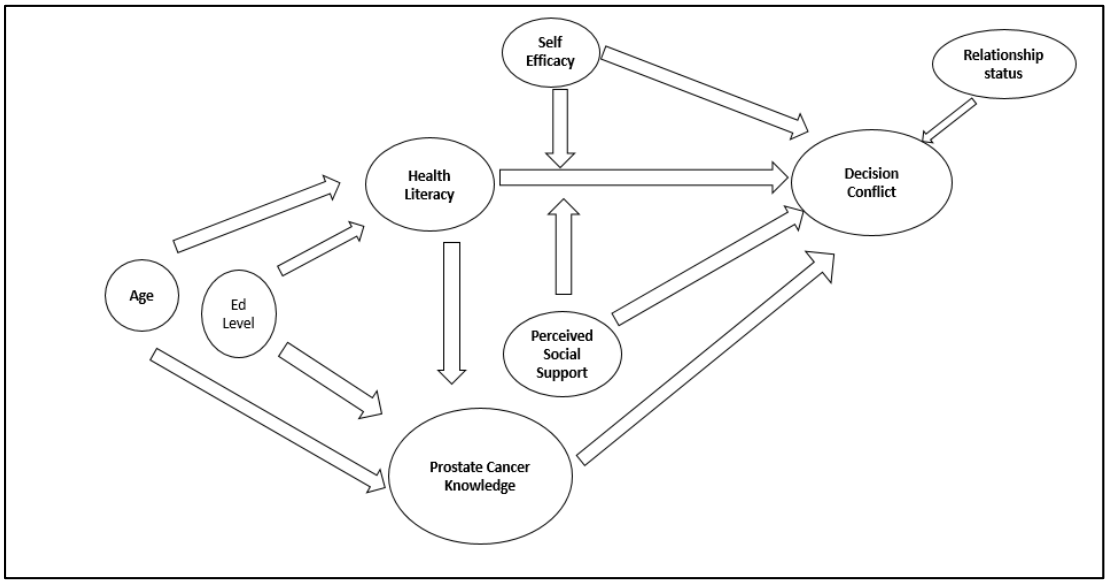

Figure 5.1: Conceptual framework

5.5. Aims and hypotheses

To address the second research question, *"What factors are associated with decision conflict at the time of decision-making",* the aims and hypotheses for this study in a sample of newly diagnosed prostate cancer patients were as follows:

1. Investigate the relationship between demographic variables (age and education level) and health literacy

   Hypotheses:

   1A. Older age is associated with lower level of health literacy

   1B. Lower education level is associated with lower level of health literacy

   1C. Variance in health literacy can be significantly explained by age and education level

2. Investigate the relationship between variables (age, education level and health literacy) with knowledge of prostate cancer disease (PrCaK_Disease)

   Hypotheses:

   2A. Older age is associated with lower level of prostate cancer knowledge (PrCaK)

   2B. Lower education level is associated with lower levels of PrCaK

   2C. Lower levels of health literacy are associated with lower levels of PrCaK

   2D. Variance in PrCaK can be significantly explained by age, education level and health literacy

3. Investigate the relationship between the independent variables (i.e., Relationship status, health literacy, perceived social support, perceived social support_significant other, self-efficacy, PrCaK) and decision conflict

Hypotheses:

3A. Those in a significant relationship have lower levels of decision conflict.

3B. Higher level of health literacy is associated with lower level of decision conflict.

3C. Higher level of perceived social support is associated with lower level of decision conflict.

3D. Higher level of perceived social support _significant other is associated with lower level of decision conflict.

3E. Higher level of self-efficacy is associated with lower level of decision conflict.

3F. Higher level of PrCaK is associated with lower level of decision conflict.

4. Explore the relationships between the independent variables (health literacy, self-efficacy, perceived social support, PrCaK, Relationship Status and the interaction of HL X SE, and HL X PSS) and decision conflict as depicted in the conceptual framework shown in Figure 5.1.

   Hypothesis:

   4A. Variation in the independent variables will be significantly associated with variation in decision conflict.

5. Using a self-designed test of knowledge of side effects associated with each treatment, explore:

   5A. Relationships between the variables and the self-designed test.

   5B. The self-designed test's ability to add to the conceptual model.

5.6. Method

5.6.1. Design

To investigate the relationships between the various psychological constructs and test the hypothesis outlined in Section 5.2, cross sectional data from a convenience sample of prostate cancer patients attending a radiation oncology clinic were obtained with validated measures included in a survey. The survey was constructed to gather social and demographic information, knowledge of prostate cancer disease, and knowledge of specific items identified in the NGT in Chapter 3. Levels of decision conflict, self-efficacy, perceived social support and health literacy were also measured. Ethical approval (Appendix 1) from the relevant ethical committees within the University and the hospitals was obtained prior to commencing this study.

5.6.2. Participants

Potential participants were identified by screening the referral letters sent to the radiation oncology team. To be eligible to participant in this study, participants needed to be male, over 18 years of age, with a diagnosis of non-metastatic prostate cancer who had more than one treatment option available to them and had not yet commenced treatment. Those without a good standard of English (as stated in the referral letter) or deemed by the radiation oncologist to be a complex case (e.g., distressed patient or complicated medical situation) or unable to give written consent, were not eligible to participate in this study. In total, 68 patients participated in this study.

5.6.2.1. Recruitment

A convenience purposive sampling strategy was used in this study. Patients due to attend a Radiation Oncology clinic across a network of hospitals in the Dublin area were screened for eligibility. Screening of referrals was conducted by the researcher in one department and a research nurse in the second department. Prior to this consultation with a member of a radiation oncologist team, all potential participants had received their cancer diagnosis from their surgeon/urologist. Those who met the inclusion criteria were flagged by the researcher (department one) or research nurse (department two) to the medical team, and at the end of their consultation the clinician discussed the study with the patient and provided them with a copy of the invitation letter (Appendix 2) and participant information leaflet (Appendix 3). In department one, those with an initial interest were then introduced to the researcher who discussed the study in more detail. The researcher followed up with a phone call to interested patients in department two. A copy of the survey (Appendix 7) and a stamped addressed envelope was then posted out to potential participants or if preferred by participants, a time was set to conduct the interview by telephone. Participants did not receive an incentive or reward for their participation.

5.6.3. Materials

A survey was designed to obtain scores for the constructs under examination and measure the items identified in the NGT as important to assist in decision-making. Before piloting the survey, the survey and associated documents (participant information leaflet and invitation letter were first cross-checked for

readability by NALA (the National Adult Literacy Association). The suggested changes were implemented as follows:

Invitation letter:

- Font was changed from Times New Roman to Arial
- Sentences were reduced in length and written with an active voice, e.g., *"Findings from this study may be used to improve information services for men diagnosed with prostate cancer in the future"* changed to "*I hope that findings from this study will be used to improve information services for men diagnosed with prostate cancer in the future".*

Survey

- Some words with capitalisation for emphasis were changed to lower case with bolding and underlining used for emphasis e.g. "*Please circle ALL that apply"* was changed to *"Please circle all that apply"*
- *"Please specify"* was changed to *"please state"*
- Minor formatting changes on line spacing

Following these changes, the survey was next piloted with a group of men of a similar demographic profile to those who typically present with prostate cancer (mixed socio-economic status, range of education level, age range 58-75); some had previously been diagnosed and treated for prostate cancer and some had been participants in study 1 and had agreed to be contacted again for this purpose. The invitation letter, participant information letter and a copy of the survey were sent to 10 men to review and provide verbal feedback to the researcher. Minor changes in terms of layout were suggested and implemented.

5.6.4. Measures

5.6.4.1. Demographic details

Social details. The social demographic characteristics comprised age, marital status, medical insurance, education level, employment status, other medical condition. (See Appendix 7)

Medical details. Characteristics relevant to their prostate cancer diagnosis comprised: stage of disease (including Gleason score and PSA level), applicable treatment options, and option chosen. Questions on information provided and sources used to help in decision-making were also included.

Previous experience with cancer. Information on family history of cancer, family history of prostate cancer and friends with prostate cancer was obtained.

Literacy. As a quick measure of literacy, a modified version of the single item screener (Chew et al., 2008) was used, *"Do you find it easy to fill out forms?"* An additional question "Did someone help you to fill out this form?" was also included.

5.6.4.2. Perceived Social Support

The Multidimensional Scale of Perceived Social Support (MSPSS), (Zimet, Dahlem, Zimet, & Farley, 1988) is a 12-item instrument that measures three sources of perceived social support: significant others, family, and friends. This instrument has been used extensively in both clinical and non-clinical settings with internal consistency ranges from .92-.94 in a series of clinical studies. Validity of the scale has also been established by examining subscales across three different groups

(Zimet, Powell, Farley, Werkman, & Berkoff, 1990), and examining relationships with the Social Support Behaviours Scale (Kazarian & McCabe, 1991).

Participants select their response from a 7-point Likert scale ranging from *"very strongly disagree*" (1) to *"very strongly agree"* (7), which are summed then divided by 12 to get a total score. Subscale scores are available for PSS_significant other, PSS_family, and PSS_friends (summing scores for the 4 relevant items in each category and dividing by 4). As established by the developers, the possible mean score can range from 1-7 and indicates perceptions of low support (1-2.9), moderate support (3-5) and high support (5.1-7) (Zimet et al., 1988).

5.6.4.3. Self-Efficacy

The generalized self-efficacy scale assesses a general sense of perceived self-efficacy with the aim to predict coping and adaptation after experiencing stressful life events (Schwarzer & Jerusalem, 1995). The 10-item instrument has been translated into many languages, has shown high internal consistencies with Cronbach's α ranging from .75 - .91 in a series of studies (Scholz, Doña, Sud, & Schwarzer, 2002) and it has been used successfully in a broad range of healthcare settings and in oncology (Curtis et al., 2014; Kreitler et al., 2007; Lev et al., 2001). Construct and criterion validity have also been confirmed by examining this scale with other social cognitive variables including outcome expectations, intention, implementation of intentions and self-regulation (Luszczynska, Gutiérrez-Doña, & Schwarzer, 2005; Luszczynska, Scholz, & Schwarzer, 2005).

Each item has 4 response options ranging from *"strongly disagree"* (1) to *"strongly agree"* (4); an example of an item is as follows: *"I can always manage to*

solve difficult problems if I try hard enough". The scores are added to give an overall score between 10 and 40, or a mean score can be used and the higher the score the greater the individual's generalized sense of self-efficacy. For comparison purposes the developers present results of a German study of 1,660 adults with a mean score of 2.92 (*SD* = 0.46) with no age or gender differences, and a world database with over 17,500 participants (*M* = 2.95, *SD* = 0.53) (http://userpage.fu-berlin.de/~gesund/gesu_engl/world_zip.htm).

5.6.4.4. Decision conflict scale

The statement format of the Decision Conflict Scale (O'Connor, 1995) was used to measure decision conflict as it is validated in healthcare and oncology and has been used to measure decision conflict in populations of men undergoing PSA screening (Murray et al., 2001) and decision-making about prostate treatment (Hacking et al., 2013; Kaplan, Crespi, Saucedo, Dahan, et al., 2014; Orom et al., 2016). Reliability (test-retest correlation of .81) and Cronbach's α of .78 to .92 have been reported and the Decision Conflict Scale (O'Connor, 1995) was consistent in discriminating significantly between those who delayed, accepted, or rejected an intervention, supporting the validity of the scale (O'Connor, 1995).

The 16-item scale consists of 5 subscales:

- Informed subscale; 3 items, e.g., *"I know which options are available to me"*
- Values clarity subscale; 3 items, e.g., "*I am clear about which benefits matter most to me"*
- Support subscale; 3 items, e.g., "*I have enough support from others to make a choice"*

- Uncertainty subscale; 3 items, e.g., *"I feel sure about what to choose"*
- Effective decision-making; 4 items, e.g., *"I expect to stick with my decision"*

Responses are on a 5-point Likert scale ranging from strongly disagree (score 4) to strongly agree (score 0) and in line with the instructions, scores were summed, divided by 16 and multiplied by 25 to give a total score range from 0 to 100, with higher scores indicating greater decisional conflict. Scores lower than 25 are associated with implementing decisions while scores greater than 37 are associated with decision delay or feelings of uncertainty (O'Connor, 1995).

5.6.4.5. Health literacy

The 16-item scale (HLS-EU-Q16) Health Literacy Survey EU questionnaire (Sørensen et al., 2015), constructed by the developers from the larger 86-item scale by Rasch modelling was used to measure 4 dimensions of literacy: obtain/access information, understand information, process/appraise information and apply/use information across three domains of health care, disease prevention, health promotion. This scale has been shown to have a Cronbach's α of .88. (Tiller, Herzog, Kluttig, & Haerting, 2015) and has been validated with other health literacy measures in a study of older patients and caregivers (Efthymiou, Middleton, Charalambous, & Papastavrou, 2017). From the 5 responses available for each item, *"very difficult"* and *"fairly difficult"* are coded with a zero and *"fairly easy"* and *"very easy*" are coded with a 1. *"Don't know"* is coded as a missing value. The scores are summed to give a range from 0-16 and participants can then be categorised into 1 of 3 levels of health literacy: 0-8 – *"likely inadequate health*

literacy", 9-12 – *"likely problematic health literacy",* and 13-16 – *"likely sufficient health literacy*" (Sørensen et al., 2012).

5.6.4.6. Prostate cancer knowledge

Prostate cancer knowledge (PrCaK) was assessed using a tailored version of the prostate cancer knowledge scale (Deibert et al., 2007). A test of prostate cancer knowledge of side effects was designed for use in an exploratory analysis.

Prostate Cancer Knowledge- Knowledge of disease. A modified version of Deibert et al.'s (2007) prostate cancer knowledge test, shown in Table 5.1, was used. Answer options were *"true"* or *"false"* for 9 items, e.g., *"A man can have prostate cancer without having any pain or symptoms" and "Antibiotics can be used to cure prostate cancer".* Each correct answer received 1 point, giving a total range of 0-9 with higher scores indicating a higher knowledge of disease specific prostate cancer knowledge (PrCaK_Disease).

The original instrument had 3 items relating to nutrition and prostate cancer development, these were collapsed into 1 item, *"Eating certain foods can lower (reduce) the risk of prostate cancer"*, for this study as the risk factors for developing prostate cancer were not of interest in this study of newly diagnosed prostate cancer patients. As only one simplified question about the side effects of each modality were included in the original scale, these questions were removed as knowledge of side effects from treatment were incorporated into a separate more comprehensive test of side effect knowledge. For example, the original question on the side effects of surgery, *"Surgery of prostate cancer can cause urinary or sexual*

problems", does not consider the severity or duration of these conditions, such as if these issues may be acute or long term effects of treatment.

Prostate Cancer Knowledge- Knowledge of side effects. As participants in study 1 (NGT) had identified the importance of knowing about both the short and long term side effects of each treatment, it was felt that the questions in the original prostate cancer knowledge test (detailed in Table 5.1) lacked the specificity to measure the full extent of knowledge of side effects. For this reason, a prostate cancer knowledge of side effects test (PrCaK_SideEffects) was designed by the researcher to assess participants' understanding of the terminology associated with the side effects (Section A) and the specific side effects associated with each treatment option (Section B).

Section A: The 3 terms that participants were asked to explain in their own words were urinary incontinence, erectile dysfunction, and infertility, as these are the side effects most associated with some treatment modalities and have a negative impact on quality of life. Each correct answer scored 33.33% to give a total score of 100 for Section A. Incorrect or blank answers were scored "0".

Section B: For each active form of treatment (Surgery, Hormone Therapy, External Beam Radiotherapy, Brachytherapy) participants were asked to pick from a list of eight options, all the long-term side effects that apply to that treatment. The eight listed options for each treatment modality were urinary incontinence, erectile dysfunction, bladder problems, hot flushes, diarrhoea/bowel problems, infertility, osteoporosis, weight gain.

To score this test, the researcher and a second rater firstly independently identified the side effects associated with each treatment option from the standard literature made available to all prostate cancer patients. Next, both researchers separately scored 12 surveys and discussed scores. This identified two issues, (1) the importance of introducing negative marking for those who ticked all possible side effects for a treatment option, and (2) how to score options left blank (agreed a score of 0).

A full score of 100 was available for each treatment modality, and participants were only expected to be knowledgeable of the side effects applicable to the treatment options available to them. Therefore, the total achievable score for Section B was the number of treatment modalities available multiplied by 100, e.g., 2 options x 100 = 200. Negative scoring was used when participants ticked an option that was not associated with the specific treatment modality. Blank answers were scored "0". The total score of applicable side effects for each participant was the sum of scores for each modality divided by the total achievable score multiplied by 100. See Appendix 9 for an example of this scoring system.

5.6.5. Procedure

For the majority of participants (n = 63), the study was conducted using hardcopy surveys with five participants choosing to complete the survey over the telephone. Consent was implied by completing and returning the anonymous survey. Participants were instructed to complete the survey after making their decision but before commencing treatment, and to return the questionnaire in the stamped addressed envelope provided, once completed.

The first page of the survey contained details on completing the survey. They were also informed that they could seek help with filling in the form if they wished, and one item asked if they had availed of help with completing the survey.

5.6.6. Analysis

Data were analysed using IBM SPSS Statistics (V. 24), all analyses were two-tailed and unless otherwise specified, an alpha level of .05 was used. All validated scales were administered and scored according to the developer's instruction as detailed in Section 5.6.4.

Prior to analysis, an inspection of boxplots, histograms, skewness, and kurtosis was preformed to explore distributions. In addition, comparisons of means (*M*) and medians (*Mdn*) were conducted to determine appropriate descriptive and inferential statistical analyses. Where data were missing within a scale, data were pro-rated within the scale. Data missing from all items within a scale were excluded from analyses.

For sample characteristics and outcome measures unless otherwise specified, continuous data are described using means and standard deviations, with percentages used to describe categorical data.

Independent sample t-tests were used to compare differences in Prostate Cancer Knowledge_Disease scores (PrCaK_Disease) between the two health literacy groups (inadequate/problematic versus sufficient) and differences in decision conflict scores for the two health literacy groups. Decision conflict scores were also compared for those in a relationship with those not in a relationship, using t-tests.

The one-way between-group analysis of variance (ANOVA) were used to compare health literacy levels across the three education groups, and to compare prostate cancer knowledge across the education groups. Levene's test for homogeneity of variance identified a violation of the assumption in the ANOVA for two tests; consequently, the ANOVA used the Welch *F* statistic, and estimated omega ^{2} is reported. Where significant results were obtained, *post hoc* analyses using Games-Howell test was used.

Pearson Product Moment Correlation Coefficients were used to test for relationships between the independent variables and dependent variables, and possible associations between the independent variables.

Regression analysis was used to test the predictors of health literacy, PrCaK_Disease and decision conflict. Durbin-Watson analysis and casewise diagnostics on the residuals were conducted to identify any outliers: cases outside 3 standard deviations were then removed from further analysis.

Multiple regression modelling with moderation was used to assess the impact of perceived social support and self-efficacy on the relationship between health literacy and decision conflict. For this analysis, perceived social support, self-efficacy and health literacy were first standardised to remove the probability of multicollinearity. The interaction terms (HL x PSS, HL x SE) were then created and entered in block 2 in the regression analysis. One case was identified by casewise diagnostics in the perceived social support moderation pathway model and was subsequently removed before completing the analysis.

Hierarchical regression analysis was conducted to test the conceptual model (Hypothesis 4A). Preliminary analyses were first conducted to ensure no violation of the assumptions of normality, linearity, and homoscedasticity. P-Plots of the residuals and scatter plots were examined. Durbin Watson values were found to be within 1.5 and 2.5 therefore serial correlations were unlikely, and the variance inflation factor (VIF) and tolerances were acceptable. Casewise diagnostics on the residuals was also conducted to identify any outliers (outside 3 standard deviations) which were then removed from further analysis. One case was removed for the prediction model for decision conflict. Next, the predictor variables: age, relationship status, PrCaK_Disease, perceived social support, self-efficacy, and health literacy were entered in block 1 followed by the interaction terms: PSS X HL, SE X HL in block 2. Due to the sample size and the number of predictor variables, the adjusted R^2 value is also reported. A sample size power calculation was conducted. To find a small to medium size effect; for example, to have power of .80 to detect a small to medium effect (e.g., *G*Power* f^2 =.08), 125 participants were required for the regression analyses. To find a medium size effect (e.g., *G*Power* f^2 = .15), 68 participants were required.

Having completed the analyses to test the hypotheses, the exploratory analysis using the self-design knowledge test (PrCaK_SideEffects Section A and PrCaK_SideEffects Section B) was then conducted using the same tests as detailed above, with PrCaK_Disease replaced by PrCaK_SideEffects Section A, followed by PrCaK_SideEffects Section B. A more conservative alpha level (p = .01) was used, to ensure balance between Type I and Type II errors.

5.6.6.1. Scale reliability

Cronbach's alpha was generated to test reliability of the validated scales (see Section 5.7, Table 5.4).

The self-designed PrCaK _ SideEffects scale was checked for interrater reliability. Agreement was reached between the researcher and the second rater on 98% of the scores. The remaining 2% were discussed and agreement was subsequently reached on scores.

5.7. Results

5.7.1. Sample characteristics

Of the 245 patients who appeared eligible on screening the referral letters, 150 potential participants agreed to take a copy of the survey and 68 surveys were returned, giving a response rate of 28% of those eligible (of note, 45% of those who took the questionnaire completed it). Reasons for not taking part included refusal for unknown reasons (n=49) or unsuitability (n=46) due to no choice in treatment options (n=29), cognitive impairment (n=5) or the cases were classed as too complex (n=12) by the clinician. The complex cases were those who required further testing as their disease appeared more advanced than when they initially presented, or the patient was too upset to discuss the study. Participants' social demographics are summarised in Table 5.2.

5.7.1.1. Social demographics

The mean age of participants was 66.33 years (*SD*=8.24) and all but 2 participants were Irish. Of the 56 participants in a relationship, 53 (78%) were living with their partner, and 12 participants (18%) were not in a relationship at the time

of data collection. Education level ranged from primary level education (19 participants, 28%) to third level/postgraduate level education (18 participants, 26%). In terms of employment, 40 were not working due to retirement (35 participants, 52%) or unemployment (5 participants, 7%), 16 were working full time (24%), 9 part-time (13%), and 3 were classed as other (such as semi-retirement). A third (32%) of participants (n= 22) had private health insurance. More than half of the participants (40 participants, 60%) have a family history of cancer, with 28% having a family member diagnosed with prostate cancer, and 51% have a friend/friends diagnosed with prostate cancer. One quarter of participants (n=17) answered "no" to the single item screener "do you find it easy to fill out forms", and 15 participants (22%) had help with filling in the survey.

5.7.1.2. Medical characteristics

As shown in Table 5.3, 40 participants (60%) were receiving treatment for another medical condition (including diabetes, respiratory or cardiac issues) and 5 participants had previously been diagnosed with another cancer (skin cancer = 4, colon cancer = 1). Regarding their prostate cancer diagnosis, half were unable to state their disease stage (35 participants, 52%), half were unable to state their Gleason score (35 participants, 52%) and 40 participants (60%) stated their PSA level. Almost half (48%) of the participants had at least 3 treatment options available to them and the options selected were radiotherapy (n=20), surgery (n= 16), a combination of hormone therapy and radiotherapy (n=14), active surveillance (n=3), hormone therapy alone (n=3), and brachytherapy (n=2). Ten participants did not specify what treatment option they had selected. These self-reported medical

details were not verified in participants' medical records in accordance with ethical approval.

5.7.1.3. Treatment decision-making

Just over half of the participants (34 participants, 52%) stated the doctor did not tell them where they could get additional information, and more than half stated they were not told how long they had to decide (39 participants, 61%); the majority (54 participants, 82%) stated the doctors told them the pros and cons of the treatments. The majority of participants (n=44, 68%) used the leaflets they were given to help make their decision and 9 participants (15%) used the internet. As shown in Table 5.3, the majority (58 participants, 87%) discussed their treatment options with someone else: wife (44 participants, 71%), family (33 participants, 52%), doctor (24 participants, 42%), friends (21 participants, 34%), nurse (12 participants, 22%), and 3 participants (5%) discussed their options with someone other than those listed.

Table 5.2: Demographic characteristics of the sample

Variable	Category	N (%)
		68 (100)
Nationality		
	Irish	66 (97.1)
	Other	2 (2.9)
Relationship status		
	Living with partner	53 (77.9)
	In relationship but not living together	3 (4.4)
	Not in a relationship	12 (17.6)
Level of education completed		
	Primary	19 (27.9)
	Secondary	31 (45.6)
	Tertiary level	18 (26.5)
Employment status		
Not working	Retired	35 (51.5)
	Unemployed	5 (7.4)
Working	Fulltime	16 (23.5)
	Part- time	9 (13.2)
Other		3 (4.4)
Private Health insurance		
	Yes	22 (32.4)
Single item screener: "Do you find it easy to fill out forms?"		
	Yes	51 (75.0)
Needed help with filling in the survey		
	Yes	15 (22.4)
Family History of Cancer		
	Yes	40 (59.7)
Family History of Prostate Cancer		
	Yes	19 (28.4)
	No	47 (70.1)
	Don't Know	1 (1.5)
Friends with Prostate Cancer		
	Yes	34 (50.7)
	No	32 (47.8)
	Don't Know	1 (1.5)

Table 5.3: Medical and decision-making characteristics of the sample

Variable	N (%) 68 (100)
Other Medical Condition	40 (59.7)
Other Cancer Diagnosis	5 (7.35)
Prostate Cancer Details	
Stage of disease known	33 (48.5)
Gleason score known	33 (48.5)
PSA level known	40 (59.7)
Number of Treatment Options	
3 or more	31 (47.7)
Information	
Advised on pros and cons of treatment	54 (81.8)
Advised on where to get additional information	31 (47.7)
Advised on timeframe to make decision	25 (39.1)
Help with decision-making	
Spoke with others	58 (86.6)
Wife	44 (71.0)
Used leaflets	44 (67.7)
Family	33 (52.4)
Another Doctor (e.g. GP)	24 (42.1)
Friends	21 (34.4)
Nurse	12 (22.2)
Used internet	9 (14.5)
Other	3 (5.1)

5.7.2. Descriptive statistics

Table 5.4 and Table 5.5 show descriptive statistics for the psychological constructs and prostate cancer knowledge. All data are presented as means (*SD*) unless otherwise specified.

5.7.2.1. Perceived social support

Participants reported high levels of perceived social support (*M* = 5.7, *SD* = 1.16) based on the criteria proposed by the scale developer (Zimet et al., 1988), and the scores were similarly high across the three subscales.

5.7.2.2. Self-efficacy

A mean score of 3.23 (*SD* = 0.52) was found for self- efficacy in this sample which is higher than the mean score (2.92) reported by the developers from normative samples (http://userpage.fuberlin.de/~gesund/gesu_engl/world_zip.htm).

5.7.2.3. Health literacy

Overall the sample showed high literacy levels (*M* = 13.39, *SD* =2.96), but more than a quarter (28.6%) scored 12 or less indicating insufficient or problematic levels of health literacy. Four participants did not answer this scale.

5.7.2.4. Prostate cancer knowledge

Scores on the modified version of the prostate cancer knowledge test of disease were high (*M* = 6.46, *SD* = 2.28), with more than half of participants (n = 43) scoring 7 or more out of a possible 9 (Table 5.5). The full version of this scale included 14 questions, but as detailed in section 5.6.4.6, the questions relating to

the nutritional risk factors associated with prostate cancer were combined into one question, and the questions on side effects were removed as these aspects of knowledge were included in the self-designed test. The self-designed prostate cancer knowledge of side effects, which tested knowledge of the terminology around side effects (PrCaK_ SideEffects Section A), showed a high level of knowledge (*M* = 72.43, *SD* = 39.49). More than half of the participants (n = 52) could explain 2 or more of the side effects correctly. One participant did not attempt this section. Knowledge of the specific side effects associated with each treatment modality (PrCaK_ SideEffects Section B) was lower (*M* = 30.96, *SD* = 33.07) and the observed range was much greater, ranging from a score of minus 50.00 to plus 100.00. In total, 19 participants scored 0 or negatively for this section of the test. Of note, some participants did not include Hormone Therapy as an option they had selected; however, from how questions were answered in other sections of the survey, hormone therapy was in fact part of their treatment regime.

5.7.2.5. Decision conflict

Indicating low decision conflict, the mean decision conflict score was 19.82 (*SD* =17.99), and the scores were similarly low for the subscales. One participant did not answer this scale.

Table 5.4: Descriptive statistics for psychological constructs

Variable	N	Possible range	Cronbach's alpha	Mean	SD
Perceived Social Support (PSS)	66	1-7	.93	5.67	1.16
PSS_significant other			.94	5.89	1.38
PSS_family			.91	5.83	1.35
PSS_friends			.83	5.25	1.29
Self-efficacy	68	1-4	.91	3.23	0.52
Health literacy	64	1-16	.91	13.39	2.96
Decision conflict	67	0-100	.97	19.82	17.99
Informed subscale			.90	18.78	17.61
Uncertainty subscale			.93	24.63	23.59
Values clarity			.85	19.78	19.57
Support subscale			.89	19.28	21.08
Effective decision-making			.93	17.26	17.79

Table 5.5: Descriptive statistics for prostate cancer knowledge

Variable	Possible range	Mean	SD
PrCaK_Disease	0-9	6.46	2.28
PrCaK_SideEffects Section A	0-100%	72.43	39.49
PrCaK_SideEffects Section B	Maximum 100%	30.96	33.07

5.7.3. Relationships between constructs

A number of tests were run to test the hypotheses as stated in Section 5.5.

5.7.3.1. Health literacy

No statistically significant relationship (r = -.055, p = .67) was found between age and health literacy (Hypothesis 1A).

A one-way between-group analysis of variance tested the difference between education groups in terms of health literacy level. As Levene's test for equality of variance was significant (F = 3.94, p = .03), Welch's test of equality of means was used. The test was statistically significant (Welch F (2, 33.98) = 5.95, p = .01, (est. ω^2 = .13). *Post – hoc* analysis using Games-Howell tests indicates that those educated to tertiary education (M = 14.76, SD = 1.30) had significantly higher health literacy scores than those educated to secondary level (M = 12.60, SD = 3.08), with an effect size = .13 (Hypothesis 1B). No difference was found in health literacy scores in those educated to primary level (M = 13.41, SD = 3.51) and those educated to either secondary or tertiary level.

A multiple linear regression was used to test the ability of age and education to predict health literacy (Hypothesis 1C): the model overall was not statistically significant (F (3, 57) = 2.64, p =.06, R^2 =.12).

5.7.3.2. Prostate cancer knowledge - disease

No statistically significant correlation was found between age and disease specific prostate cancer knowledge (r = -.03, p = .82) (Hypothesis 2A).

A one-way between-group analysis of variance tested the differences between education groups in terms of PrCaK_ Disease. No significant difference was found in prostate cancer knowledge scores among the 3 categories of education (F (2, 65) = 1.68, p =.19) (Hypothesis 2B).

An independent- samples t-test was used to compare PrCaK_Disease scores for those with inadequate/problematic levels of health literacy (n = 18; M = 6.78, SD =1.99) with those with sufficient level of health literacy (n=46; M = 6.57, SD = 2.06).

There was no significant difference in scores between the 2 health literacy groups (F (2, 65) = 1.68, p =.19) (Hypothesis 2C).

A multiple linear regression was used to test the relationship between age, education and health literacy and disease specific prostate cancer knowledge (Hypothesis 2D). The model was not statistically significant (F (4, 57) = 1.47, p = .22, R^2 =.09, adj. R^2 = .03).

5.7.3.3. Decision conflict

Associations between decision conflict and the demographic variables (education and age) were tested to determine which demographic variables needed to be controlled for within the regression model. As a statistically significant positive relationship was found between age and decision conflict (r = .258, p = .04), age was included in the model as a covariate. No significant difference was found in decision conflict scores among the 3 categories of education (F (2, 64) = 0.82, p =.45), therefore due to the sample size and the number of variables in the model, education was not controlled for in the model. Due to the small sample size, a Mann Whitney U test was used to compare decision conflict for those not in a relationship (n = 12; M = 10.65, SD = 10.22) with those in a relationship (n = 56; M = 21.62, SD = 18.68). There was no significant difference in scores between the 2 relationship groups (U= 197, p = .06) (Hypothesis 3A).

Before conducting the hierarchical linear regression, Pearson correlations were used to test the relationships between the dependent variable (decision conflict) and the independent variables (Table 5.6), (Hypotheses 3B-3F). There was a statistically significant negative relationship between decision conflict and self-

efficacy (r = -.39, p <.001), and decision conflict and health literacy (r = -.27, p = .04). Decision conflict was not significantly related to perceived social support (PSS), PSS_significant other or prostate cancer knowledge.

Table 5.6: Intercorrelations of the variables under study

Variable	DCS	Self-Efficacy	PSS	PSS_Sig other	HL	PrCaK_D	PrCaK_SE A
Self-Efficacy	-.39**						
PSS	-.20	.19					
PSS_Sig other	-.11	.07	.88**				
HL	-.27*	.32*	.44**	.35**			
PrCaK_D	.08	.03	.22	.15	-.13		
PrCaK_SE A	.06	.03	.20	.16	-.07	.71**	
PrCaK_SE B	.09	.06	.14	.05	-.11	.19	.37*

Note: *p < .05; **p< .01

PrCaK_D = PrCaK_Disease; PrCaK_SE A = PrCaK_SideEffects Section A; PrCaK_SE B = PrCaK_SideEffects Section B; DCS=Decision Conflict Scale; PSS= Perceived Social Support

5.7.4. Decision conflict

In order to test hypothesis 4 and examine the conceptual framework outlined in Section 5.5, a hierarchical multiple linear regression was used to investigate the ability of the 5 independent variables (perceived social support, self-efficacy, PrCaK_Disease, health literacy, relationship status) and the interaction terms (HL X PSS, HL X SE) to predict levels of decision conflict, with age controlled in the model.

All 5 independent variables and age as a covariate were entered into the model together in block 1, followed by the interaction terms (moderators) in block 2 (Table 5.7). Block 1 explained 27.9% of the variance in decision conflict and was statistically significant (F (6, 54) = 3.48, p =.01, R^2 =.28, adj. R^2 = .20). Of note, age (β

= .26, *t* (54) =2.19, *p* =.03) and self-efficacy were unique predictors (β = -.33, *t* (54) =-2.59, *p* = .01). Block 2 explained a further 5.7%, of the variance in decision conflict, which was not statistically significant (*F* change = 2.23, *p* = .12). Of note, self-efficacy significantly moderated the relationship between health literacy and decision conflict (β = .26, *t* (52) =2.08, *p* = .04), when age, relationship status, perceived social support and prostate cancer knowledge were controlled. Higher levels of decision conflict were seen in men with low levels of health literacy and low self-efficacy in comparison to men with low health literacy but high self-efficacy (Figure 5.2).

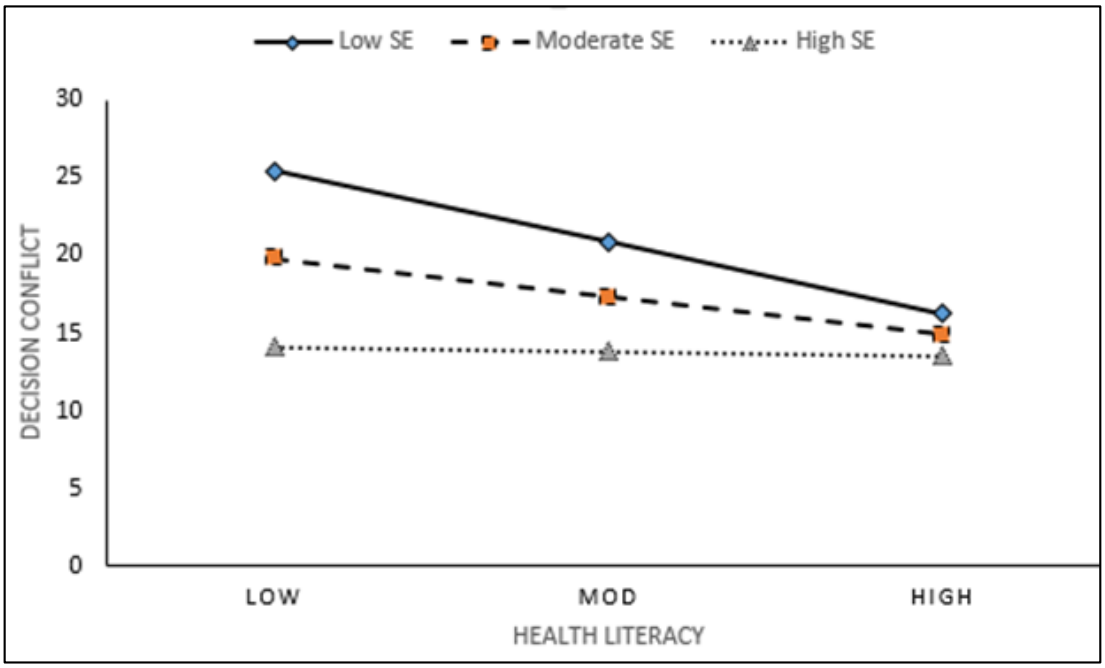

Figure 5.2: Self efficacy moderates the relationship between health literacy and decision conflict

Table 5.7: Hierarchical Regression Model for decision conflict

		r	R^2	Adj R^2	R^2 change	B	SE	β	t	Sig.
Block 1		.53	.28	.20						**.01***
	Constant					23.36	20.37		1.15	.26
	Age					0.47	0.22	.26	2.19	**.03***
	Relationship Status					5.32	4.82	.14	1.11	.27
	Perceived Social Support					-1.53	1.80	-.12	-0.85	.40
	Self-Efficacy					-9.67	3.74	-.33	-2.59	**.01***
	HL					-0.37	0.71	-.07	-0.52	.61
	PrCaK_Disease					0.68	0.82	.10	0.84	.41
Block 2		0.58	0.34	.23	0.06					.12
	Constant					9.67	20.99		.46	.68
	Age					.52	0.21	.28	2.44	**.02***
	Relationship Status					4.89	4.75	.12	1.03	.31
	Perceived Social Support					-1.79	1.77	-.14	-1.01	.32
	Self-Efficacy					-7.19	3.88	-.25	-1.85	*.07*
	HL					-.27	0.73	-.05	-.37	.72
	PrCaK_ Disease					.96	0.82	.14	1.17	.25
	HLxSE					3.74	1.80	.26	2.08	**.04***
	HLxPSS					.06	1.79	.01	.03	.97

Note *p<.05.

5.7.4.1. Exploratory analysis of knowledge of side effects of prostate cancer treatment and decision conflict

To explore the relationship between the constructs and knowledge of side effects, the tests reported in Section 5.7.2.3 were re-run with PrCaK_Disease replaced firstly by PrCaK_SideEffects Section A, followed by PrCaK_SideEffects Section B. The results are presented below.

No statistically significant correlation was found between age and PrCaK_SideEffects Section A (r = -.18, p = .15). The association between age and PrCaK_SideEffects Section B (r = -.28, p = .02), was also not significant, with the conservative alpha level (p = .01).

The one-way between-group analysis of variance was next used to compare side effect knowledge across the three education groups. For PrCaK_SideEffects Section A, as Levene's test for equality of variance was significant *(*F = 7.08, p = .002), the Welch's F test and estimated omega^2 are reported. The test was statistically significant (Welch F (2, 39.41) = 5.03, p = .01, (est. ω^2 = .11). *Post – hoc* analysis using Games-Howell tests indicate that those educated to tertiary education (M = 90.67, SD = 25.14) had a significantly higher knowledge of terminology associated with prostate cancer side effects than those educated to primary level (M = 55.95, SD =43.07), with an effect size = .11. No difference was found in knowledge scores between those educated to 2nd level (M = 71.94, SD = 40.49) and those educated to either primary or tertiary level. For PrCaK_ SideEffects Section B, no significant difference was found in scores among the 3 categories of education (F (2, 65) = 2.51, p = .09).

Independent- samples t-tests were used to compare PrCaK_SideEffects with health literacy groups. For PrCaK_ SideEffects Section A, there was no significant difference in scores (t (64) = 1.43, p = .16) between those with inadequate/problematic levels of health literacy (n = 18; M = 83.17, SD =28.71) with those with sufficient level of health literacy (n = 46; M = 70.17, SD = 41.14). For PrCaK_SideEffects Section B, no significant difference (t (64) = 1.39, p = .17) was found in scores for those with inadequate/problematic levels of health literacy (n = 18; M = 41.83, SD = 28.62) with those with sufficient level of health literacy (n = 46; M = 29.04, SD = 34.63).

A multiple linear regression was used to test the relationship between age, education, health literacy and PrCaK_SideEffects knowledge. For PrCaK_SideEffects Section A, age, education, and health literacy explained 13.8% of the variance (F (4, 57) = 2.28, p =.07, R^2 =.14, adj. R^2 = .078), but the model was not statistically significant. For PrCaK_ SideEffects Section B, age, education, and health explained 13.1% of the variance in PrCaK_ SideEffects Section B but the model was not statistically significant (F (4, 57) = 2.16, p =.09, R^2 =.13, adj. R^2 = .071).

Finally, to explore if the self-designed knowledge test could add to the model, the model regression was rerun firstly by replacing PrCaK_Disease with scores for PrCaK_SideEffects Section A, followed by replacing PrCaK_Disease with PrCaK_SideEffects Section B. No significant improvement was seen in the model's predictive ability with either side effect knowledge scores.

5.7.4.2. Exploratory analysis of decision conflict subscales

Due to the variation seen in the decision conflict subscales, a number of exploratory Pearson correlations were conducted. The informed subscale was not significantly related to health literacy or any of the prostate cancer knowledge scores (disease or side-effects scores).

The uncertainty subscale was not significantly related to health literacy or PrCaK_Disease, or PrCaK_SideEffects Section A. positive relationship was identified between the uncertainty subscale and PrCaK_SideEffects Section B, (r = .27, p = .03), indicating that as knowledge of the side effects associated with each treatment increased, uncertainty about decision-making increased, but this was not significant with the conservative alpha level (p = .01). A statistically significant negative relationship was identified between the uncertainty subscale and self-efficacy (r = -.33, p <.01), indicating that higher levels of self-efficacy is associated with lower levels of uncertainty.

The support subscale was not significantly related to perceived social support, but a negative relationship was identified between the support subscale and friends subscale of the perceived social support scale (r = -.28, p = .03), indicating that higher levels of perceived social support from friends is associated with lower levels of decision conflict when feeling supported in decision-making, but this was not significant with the conservative alpha level (p = .01).

The effective decision-making subscale was not significantly related to health literacy or any of the prostate cancer knowledge scores (disease or side-effects scores). A statistically significant negative relationship was identified

between the effective decision-making subscale and self-efficacy (r = -.33, p <.01), indicating that higher level of self-efficacy is associated with lower levels of effective decision-making conflict.

5.8. Discussion

This study which aimed to assess the variables associated with decision conflict and test the conceptual framework proposed in Section 5.4 found that self-efficacy moderates the relationship between health literacy and decision conflict, when controlling for age, relationship status, perceived social support and knowledge of prostate cancer. Some correlations were also found between the variables under examination and these are discussed in view of the existing literature.

5.8.1. Prostate cancer knowledge

Scores for the prostate cancer knowledge scale (Deibert et al., 2007) were high indicating that patients in this sample have good knowledge about the prostate gland and specific risk factors associated with prostate cancer but scores for the self-designed test were not as high. Inconsistent with the literature (Arnold-Reed et al., 2008; Deibert et al., 2007; Kim et al., 2001; Rees et al., 2002), age, education level and health literacy level were not associated with prostate cancer knowledge in the current study. However, as these studies were conducted on minority groups, in different healthcare settings and in other countries, the results may not be generalisable to the Irish healthcare setting. This scale captured knowledge of the prostate and risk factors associated with prostate cancer, both of which are

important for men to know and in particular, when investigating screening uptake for prostate cancer. However, once diagnosed, the emphasis shifts to the importance of knowing about one's individual disease and the side effects associated with the treatment options available to the individual. As the existing scale included only one item to test knowledge of side effects associated with each treatment, (e.g., *"Radiation treatment of prostate cancer can cause urinary or sexual problems"*), a new test was devised to comprehensively measure knowledge of the side effects of treatment. The self-designed test assessed knowledge of the terminology associated with side effects (Section A), and knowledge of the specific side effects associated with each treatment (Section B), both important aspects of knowledge to consider when testing patients' knowledge, and identified by prostate cancer survivors in study 1.

Scores for the self-designed prostate cancer knowledge test were not as high as the scores in the pre-existing scale, but in general, participants had a better knowledge of the terminology associated with the side effects of treatment, rather than a knowledge of the specific side effects associated with each option available to them. A greater range in scores was also seen in this test. Age was associated with a knowledge of the terminology of side effects, with those who were older having lower scores. Education was associated with knowledge of the side effects of treatment, with those educated to third level knowing more of the side effects associated with each treatment than those educated to primary level only. The association of these demographic factors with knowledge are consistent with the literature (Docherty, Brothwell, & Symons, 2007; Miller, 2016).

The range of scores in the self-designed test are not surprising considering that more than half of the participants in this study were unable to state their stage and grade of disease, and a few patients did not include hormone therapy as a management strategy available to them, although it was part of their management. Although not surprising, the implications of this are substantial as men are choosing treatment without a knowledge of the possible consequences of this choice on their quality of life.

Given the mixed results between the existing knowledge test and the self-designed test, the ability of the pre-existing instrument to measure the full concept of prostate cancer knowledge specific to patients making treatment decisions must be considered. The findings from study 1 also support the importance of including a more comprehensive knowledge of side effects than currently available in the existing instrument.

5.8.2. Health literacy

High levels of health literacy were found in this sample, but approximately one quarter of patients had problematic or insufficient levels of health literacy. Similar results were found for the quick measures of literacy with approximately a quarter of patients needing help with filling in forms and availing of help when filling in this survey. Although a higher incidence of problematic levels of health literacy exist in the general population in Ireland (Doyle & Fullam, 2012), this finding means that at least 1 in every 4 patients attending a prostate cancer clinic will have difficulties due to low health literacy. Considering the three levels of health literacy: functional, communicative, and critical, defined in Nutbeam's theory (2008), 1 in 4

participants will have difficulty in obtaining information about their options (functional), processing, questioning, and extracting meaning from this information (communicative), and understanding and applying this information (critical) in order to make a treatment decision. The implications of this were seen in the participants' inability to correctly answer questions related to the side effects of treatment.

Interestingly, considering that older age has been found to be associated with lower levels of health literacy in other studies (Gazmararian et al., 1999; Morrow et al., 2006), age was not found to be associated with health literacy level in this sample. Consistent with the general health literacy literature (Gazmararian et al., 1999; Kirsh et al., 1993; Morrow et al., 2006), and adding to the theory that education is associated with health literacy, this study found that education level was associated with health literacy. However, what is striking is that this effect was only present for those educated to third level when compared to second level, with no difference observed in health literacy level between those educated to primary level and third level. Based on the existing theory, it is difficult to find a possible explanation for this surprising result.

The inconsistencies between findings in the current study and the literature may be due to the different health literacy measures used across the studies and this calls in to question the way health literacy is firstly, theorized and secondly, measured. Older studies used measures of health literacy that focused solely on measuring one's ability to read about health information examined a very limited concept of health literacy. The concept of health literacy has since evolved to

include the functional component of health literacy, which is captured on newer instruments such as the Newest Vital Sign (Weiss et al., 2005). However, given the many facets required to make a treatment decision, the concept of health literacy proposed by Nutbeam was used in this study, with the utilised instrument selected on its ability to measure across the 3 dimensions of health literacy. In conducting future research on health literacy, the importance of aligning the instrument with the full concept of health literacy as theorised by Nutbeam is imperative and will add to the theory of health literacy which has evolved since first conceptualised. Specifically, it is important to measure Nutbeam's three levels of health literacy: (i) functional health literacy, the basic literacy and numeracy skills applied to health matters; (ii) interactive health literacy, which emphasises communication skills and use of information sources; and (iii) critical health literacy, which includes evaluation of risks and benefits in order to make decisions.

Similarly, when designing interventions to increase health literacy, the interventions should align with the three dimensions of health literacy. For example, in designing an intervention to increase health literacy and reduce decision conflict in the prostate cancer setting, an intervention which utilises the "Plain English" campaign (https://www.hse.ie/eng/about/who/communications/communicatingclearly/), which involves writing in simple lay-man's terms in order to make information more accessible, will improve functional health literacy. By teaching patients techniques such as the "ask me three" education programme, http://www.ihi.org/resources/Pages/Tools/Ask-Me-3-Good-Questions-for-Your-

Good-Health.aspx) which encourages patients to interact with healthcare professionals by asking three questions at every encounter (i.e. *"what is my problem?", "what do I need to do about it?", "why is it important for me to do this?"*), will facilitate patients to communicate and interact with the healthcare professional. Lastly, an intervention that highlights the pros and cons of each treatment in simple visual and text format, and identifies questions for patients to reflect on when weighting up the benefits and the risks, will help improve critical health literacy.

5.8.3. Decision conflict

Before testing the conceptual model (Figure 5.1), the relationships between the independent variables and decision conflict were tested. Of note, age was found to be associated with decision conflict: those who were older had higher decisional conflict. From the proposed explanatory variables, only health literacy and self-efficacy were significantly associated with decision conflict. Participants who had low health literacy or low self-efficacy had higher levels of decision conflict. These findings are consistent with the literature, with Kim et al. (2001) identifying a similar relationship between health literacy and decision conflict, and Kaplan, Crespi, Saucedo, Connor, et al. (2014) and Goh et al. (2012) both identifying the relationship between self-efficacy and decision conflict. Interestingly, Kaplan used a very similar sample size to the current study, but the research was conducted in economically disadvantaged patients. As Kaplan concluded that further research was warranted to better characterise the relationship, the current study adds to this evidence.

Further adding to this evidence, a significant association was found between self-efficacy and the uncertainty subscale of decision conflict, and self-efficacy and the effective decision-making subscale. Given Bandura's theory of self-efficacy which posited that self-efficacy is one's belief in their ability to carry out behaviours necessary to achieve an expected outcome (Bandura, 1997), the finding that self-efficacy is associated with decision conflict is not surprising. Furthermore, the finding that those with higher levels of self-efficacy had lower uncertainty, and those with higher self-efficacy have lower levels of effective decision-making conflict, is also not surprising and adds to the body of literature in the area of self-efficacy and health outcomes.

Considering the theory that social support leads to better adjustment to cancer and improved quality of life, the association between relationship status and decision conflict was examined but found to be not significant. Previous research has identified varying results with a review finding conflicting evidence of the association between relationship status and decision conflict (Zeliadt et al., 2006). However, a more recent study identified that those in a relationship have higher decisional conflict (Kaplan, Crespi, Saucedo, Connor, et al., 2014). As in the current study, the strength of the partners' relationship was not measured in these studies, and this may explain the variable results across studies. This is an area of research which warrants more investigation, based on the theory of social support. Qualitative research has identified that men turn to their partners for support in decision-making (Renzi et al., 2017), but partners/spouses have been identified as more likely to pick active management strategies and focus primarily on cure with

less regard for the morbidity associated with treatment (O'Rourke, 1999). Subsequently if the views of the partner and the patient are not congruent, the patient may feel more conflicted, which may account for some variation and supports the possibility of a complex relationship between relationship status and decision conflict.

Perceived social support was not found to be associated with decision conflict in this study. This is an area that has not been reported previously in this population but based on the theory that perceived social support is associated with psychological adjustment and health-related quality of life (Baider et al., 2003; Mehnert et al., 2010), it was worthy of consideration. Interestingly, perceived social support from friends was significantly associated with the decision conflict support subscale; those with high perceived social support from friends had better scores on the support subscale, but this association was not significant for perceived support from significant others or family. The role of others (outside the family, and healthcare professional setting), has not been extensively researched previously. One qualitative pilot study has identified that some men turn to other men rather than their partners for support (Reamer et al., 2016), but the role of influential-other in decision-making is an area of emerging research. Berry et al. (2018), drawing from the theory of homophily, postulate that homophilic relationships can influence health care decision-making. Homophily was first described by Lazarsfeld and Merton in 1954 (as cited in Berry et al., 2018), as a tendency for friendships to form between those who are alike in some characteristic. Based on this theory, Berry postulates that decision makers turn to others whom they identify with, when

faced with a list of options to manage health conditions. Findings in the current study advance this research and supports the theory of homophilic relationships influencing decision-making in prostate cancer patients. As the incidence of prostate cancer continues to increase, further research in this area could capitalise on this theory, by identifying how friends and peers can be utilised as a support network for newly diagnosed prostate patients, with the aim of facilitating informed decision-making and reducing decision conflict.

Although some studies suggest that informed patients have reduced decision conflict (Myers et al., 2018; Orom et al., 2016) others have found increased knowledge is associated with more decision-making difficulty and decision-making uncertainty (Orom et al., 2016). No association was found between knowledge and overall decision conflict in this sample. However, on analysis of the decision conflict subscales, knowledge of the side effects associated with each treatment was significantly associated with the uncertainty subscale; as knowledge of the side effects associated with each treatment increased, uncertainty about decision -making increased. Perhaps patients who have more knowledge of the specific side effects realise the potential consequence of their decision, and are therefore more uncertain than those who are not knowledgeable about the consequences. These findings illustrate the importance in recognising the complexity of decision conflict. As theorised by O' Connor (1997), the overall concept of decision conflict includes different facets: informed, uncertainty, values clarity, support, and effective decision-making, and based on the results of this study, it is pertinent to consider

results at the subscale level in order to fully understand the concept of decision conflict.

5.8.3.1. The conceptual framework

From the literature presented in Chapter 2, a conceptual framework was designed based on theory and the evidence to date (Figure 5.1). Although a number of the hypothesised associations were not significant, and the full model was not significant, a hierarchical multiple linear regression revealed that self-efficacy significantly moderated the relationship between health literacy and decision conflict when age, relationship status, perceived social support and prostate cancer knowledge were controlled. Higher levels of decision conflict were seen in men with low levels of health literacy and low self-efficacy in comparison to men with low health literacy but high self-efficacy. A number of associations were also identified, and these are shown in Figure 5.3.

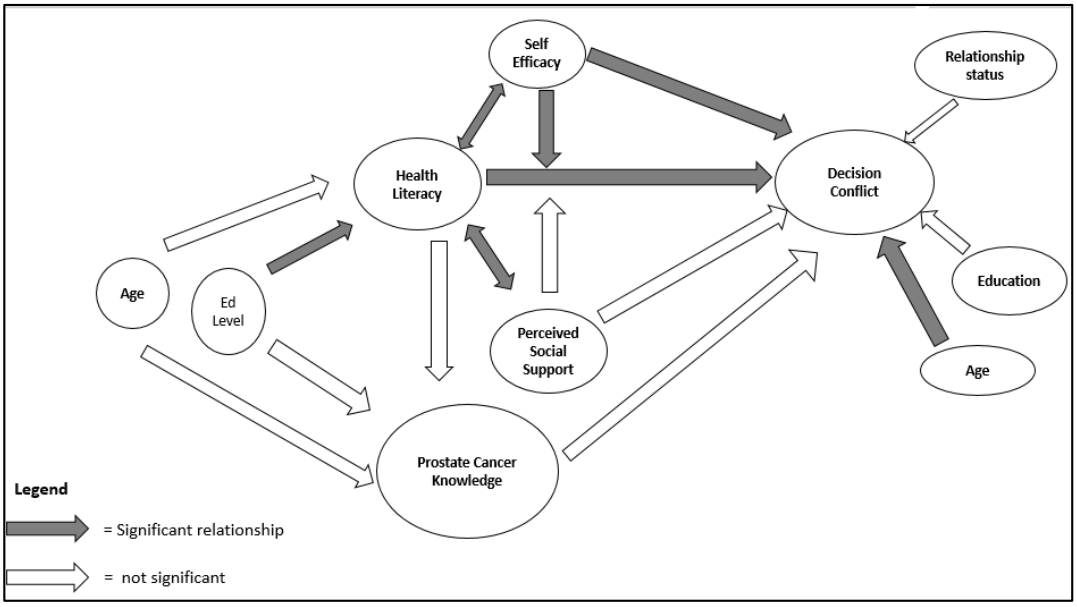

Figure 5.3: Conceptual framework showing results

Overall, the relationships between the constructs and the demographic factors (age, education, and relationship status) added little to the model, as it was constructed. This suggests that either these demographics are not associated or interact in ways different to what was conceptualised in this model. The finding in relation to education level and health literacy supports that some interaction exits. However, the nature of this interaction is not clear, based on the result in relation to third versus second level education being found to be significant, but third versus primary level education found to be not significant. Socio-economic status, typically measured by combining education level, income level, and occupation (Pollack et al., 2007) was not measured in this study. Due to the typical age profile of prostate cancer patients, it was assumed that the majority would be retired, therefore current income would not be a reliable surrogate to use. The ability to categorise last occupation is also problematic. However, as socio-economic status is a variable found to be associated with education level, health literacy and knowledge (Davis, Gazmararian, & Kennen, 2006; Gazmararian et al., 1999), future research should not exclude demographics and consider how socioeconomic status can be measured and considered within this population.

Based on the theory, which suggests that social support leads to better psychological adjustment and improved quality of life, it was hypothesised that perceived social support was associated with decision conflict, and perceived social support would moderate the relationship between health literacy and decision conflict. Although nonsignificant trends in the expected directions were observed, the findings do not add support to this theory. Perhaps a future study, conducted

with a larger sample size may help to identify if this finding relates to sample size, or if a more complex interaction exists between these constructs which was not considered or tested in this model. Supporting the latter possibility is the correlation found between perceived social support and health literacy; higher perceived social support was associated with higher levels of health literacy. However, this association needs further exploration to ascertain the nature and direction of the observed relationship, or if the correlation is an artefact of a third unmeasured variable. In addition, PSS_significant other was also associated with health literacy in the same direction. Although, overall these findings do not support the proposed framework based on Lee's theory that social support can moderate the relationship between health literacy and health outcomes (Lee et al., 2004), this study does provide evidence that perceived social support, and support from significant others are associated with health literacy, and worth consideration in future studies.

Based on the evidence to date, in relation to factors associated with knowledge, the finding in this study that prostate cancer knowledge was not associated with any of the variables considered in this framework is striking. A limitation of the pre-existing knowledge test was identified prior to the study, and for this reason, using results from study 1, a second test was designed to measure knowledge of side effects. However, the self-designed test added little to the conceptual model, and only some demographics were found to be associated with sections of the test (education associated with Section A, and age associated with Section B, both in the expected direction). Possible reasons that may be considered

is the pre-existing test was not generalisable to the current sample, and as it had been tested in low income minority men, this is a possible explanation. The system used to score the self-designed test, although checked independently by a second researcher, may not have been adequate, and further work on constructing and validating a test of knowledge of side effects is warranted.

Although not part of the conceptual framework, a positive relationship was found between general self-efficacy and health literacy. The nature and direction of this correlation is unclear and worth further exploration. In addition, considering self-efficacy also has a direct effect on decision conflict and a moderating effect on the relationship between health literacy and decision conflict, the role of self-efficacy in influencing health outcomes is significant and worth further exploration, so that appropriate interventions can be considered. Replacing the current instrument with a specific instrument specifically to measure self-efficacy in decision-making may further this research, leading to the identification of possible interventions that can be implemented to reduce decision conflict, if the association between self-efficacy and decision conflict remains, with the specific self-efficacy in decision-making instrument. Interventions to increase self-efficacy have been successful in other healthcare settings; for example, patients with chronic diabetes who participated in a 7-week self-management programme had an increase in self-efficacy in managing their condition (Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001). This 7-week programme consisted of peer instructors in a small group setting.

Overall from testing this conceptual framework, some interesting observations emerge in relation to possible “risk factors” that are worth considering

in prostate cancer patients making treatment decisions. From the data it is evident that those with low health literacy and low self-efficacy will have higher decision conflict that those with either high health literacy or high self -efficacy, but also, the implications of the association identified between health literacy and perceived social support are important from a clinical perspective. Formal supports such as psychological interventions, and access to support groups can be made available to help patients, especially those considered to have low levels of health literacy. This, in turn, may help patients to become more confident in their ability to interact with their healthcare provider and participate in decision-making. This is detailed further in the next chapter, which considers the findings of this study along with the results from study 1 and study 3 in order to identify both the theoretical and clinical implications from this research.

5.8.4. Limitations and future research

When viewing the findings of this study, a number of limitations should be considered, some of which have been identified in the preceding section. Other limitations and areas for future research now follow.

Participants completed this lengthy survey unsupervised at home, which may have led to a number of limitations. Participants need to be very motivated when surveys are lengthy, (Breakwell, 2000), and as this survey was nine pages in length, participants may have experienced respondent fatigue (Ben-Nun, 2008), limiting their motivation to complete the sections towards the end as accurately as possible. The health literacy instrument was on the last page of the survey, and participants may have chosen answers down the same column on the page (i.e.

straight-line responding) (Ben-Nun, 2008). Future research should consider including instruments such as this towards the start of the survey, when participants feel more motivated. Leaving demographic items to the end can help to overcome respondent fatigue, as responses to these items come more readily to participants (Breakwell, 2000). As the surveys were completed at home, participants may have used resources such as information booklets, or their families to help answer some of the questions, and therefore the responses may not be a true reflection of, for example, participants knowledge.

In addition, removing some questions from the prostate cancer knowledge scale may have reduced the scale's reliability and validity. Classical test theory notes that the removal of items can decrease Cronbach's alpha and fewer items may result in loss of construct validity (Worthington & Whittaker, 2006); additional research using larger samples can test both internal consistency and test-retest reliability. As discussed in section 5.6.4.6, the extent to which the scale meaningful measured knowledge of prostate cancer in the context of this study (construct-related validity) was questioned. Future research should seek to examine the factor structure of the scale and test the convergent and divergent validity across a number of sufficiently powered independent samples. In addition, Rasch modelling can also be applied to items to further test the items.

Similarly, the reliability of the self-designed side effects scale is not known and as psychometric testing was not performed on the self-designed knowledge test, results from this test were therefore only used for exploratory purposes. Further limitations associated with the self-designed side effects scale include the

scoring method used. Different scoring options could have been used, such as a weighting given to some questions, and this may have yielded different results. However, a pragmatic approach was taken in designing the scoring system and to reduce potential bias, the method was discussed with 2 researchers before scoring the returned questionnaires. In addition, as this scale was not used previously, it is not possible to compare results from this study with previous studies.

This study may also have been subjected to social desirability responding, which is the tendency for study participants to present a favourable image of themselves to the researcher, or those helping with the form (van de Mortel, 2008). This study did not include a scale to measure social desirability responding. While few health-related studies used a social desirability scale to detect or control for social desirability bias, almost half of those that used a social desirability scale found social desirability response influenced their results (van de Mortel, 2008). Therefore, future studies should consider including a social desirability scale in surveys, and control for this bias in the analysis.

In addition to the possible limitation due to the placement of the health literacy instrument at the end of the survey, the instrument, may have been limited by the scoring system. The data, analysed according to the authors instructions, suggest levels of health literacy in this sample, which are higher than expected in the general population in Ireland (Doyle & Fullam, 2012). This may suggest that the study sample is biased, or that the instrument, a shortened version of that used in the general population, is not able to discriminate levels of health literacy. A recent study has identified ceiling effects in this instrument with the authors questioning

the scoring system (Rouquette et al., 2018). Perhaps not dichotomising the responses as the developers instruct would help to reduce this effect and is an area that requires further investigation when considering health literacy.

The results of this study, carried out in a population of white males may not be generalizable to other ethnic groups. Additionally, as recruitment was carried out in radiation oncology departments, it is possible that there was a sampling bias; those availing of the radiation oncology consult may have more information to process and therefore may have higher levels of decision conflict than those deciding not to attend this appointment. However, as detailed in Chapter 1, unless contra-indicated, all patients should be given the details of radiotherapy before making their treatment selection. Future research in this area could aim to recruit patients in the urology department, to ascertain why they chose to not attend their radiation oncology appointment. This would add an extra dimension to this study, and would be of value clinically, considering that decision-makers should be fully informed, before making a decision.

Given the number of variables assessed in this model, a larger sample size would have increased the statistical power and the relationships that were showing a trend may have become significant. This research was designed as a sequential study with data from this study used in designing the questions for the subsequent study. With hind-sight, it would have been beneficial to continue to recruit participants to Study 2 while conducting the semi-structured interviews, with an interim analysis of this data used to inform the interview schedule in study 3.

From a conceptual perspective, other constructs could have been included in the framework. For example, associations between dispositional optimism and cancer threat appraisal with decision-related distress have previously been reported in prostate cancer patients (Steginga & Occhipinti, 2006). Based on their findings, and previous findings in relation to psychological adjustment to a cancer diagnosis in breast and prostate cancer patients, (Baider et al., 2003), it is possible that disposition and cancer related threat could also be directly associated with decision conflict, with higher levels of optimism associated with lower levels of decision conflict. Optimism could also interact with the explanatory variables, for example, higher optimism could be associated with higher perceived social support. However, these constructs were not included in this study to reduce participant burden in this lengthy survey. The constructs that were included are constructs that are considered modifiable, and from a clinical perspective, this seemed to be practical and pragmatic approach to take. Future studies should explore these additional constructs, in light of the findings in study 3 (discussed in the next chapter).

5.9. Conclusion

Health literacy and self-efficacy were both independently associated with decision conflict, and although the overall conceptual framework was not significant, self-efficacy moderated the relationship between health literacy and decision conflict, when controlling for age, relationship status, perceived social support and knowledge of prostate cancer. Interesting findings in relation to the perceived role of friends was observed and this adds to the immature body of

literature in this area and identifies an area worth exploring further. Limitations with the current test of prostate cancer knowledge were observed, with participants' knowledge scores on this test substantially higher than knowledge of the side effects associated with treatment. Although participants in study 1 identified the importance of knowing the timeframe to make a decision, more than half of the participants in this study were not informed of how long they had to decide on treatment. These results have serious implications in the era of informed and shared decision-making, when patients may be rushing into making this decision, without knowing the consequences of these treatments on their quality of life. To add depth to these quantitative findings, how participants describe their decision-making process at the time of decision-making is examined in the next study.

Chapter 6: Prostate cancer patients experience of decision-making

This chapter explores the decision-making process in prostate cancer patients. The literature around patient participation in decision-making is presented, followed by decision-making processes in healthcare in situations of uncertainty. Details of the study that explored how men describe their decision-making is then presented. Identifying the process men undertake to arrive at a decision is important as it will help to highlight areas of deficiency that may need to be addressed to improve the decision-making process for future patients diagnosed with prostate cancer.

6.1. Introduction

In the era of shared decision-making in the medical setting, more and more patients are given responsibility for actively participating in deciding how their disease is managed. This is particularly salient in prostate cancer patients as no one treatment option confers a significant survival benefit (Hamdy & Donovan, 2017). However, due to the adverse outcomes of treatment, a patient's personal preference is paramount (Tentori, Pighin, Divan, & Crupi, 2018). In those with low-risk disease, the fact that an active treatment strategy such as surgery or radiotherapy may not be necessary, as active surveillance/watchful wait has similar survival outcomes, is pertinent and adds to the complexity of decision-making in this context. Due to the historical approach to disease management where the patient is a passive recipient of medical care, many are uncomfortable with active participation in decision-making, viewing the doctor as the expert in devising the management strategy (O'Rourke, 2007).

6.2. Patients preference for decision-making

In tandem with the evolution of decision-making models from paternalistic to informed and shared (Charles et al., 1999), cancer patients are moving from a passive to an active role in the medical decision-making process (Tariman et al., 2010). This transition is also evident in prostate cancer patients (Davison et al., 1995; Wang & Ranasinghe, 2017), and is essential when considering the comparable cure rates but varying risk profiles of each management option (Wang & Ranasinghe, 2017). However, for some patients, decision-making under uncertainty with a perceived time pressure can be a daunting process (Hillen et al., 2017). For others, fear of appearing disrespectful to their clinicians can be a barrier to active participation (Cohen & Britten, 2003).

Differences in preference for involvement have been attributed by some researchers to age (Davison & Goldenberg, 2011; Meyer, Talbot, & Ranalli, 2007; Song et al., 2013). In comparison to men over the age of 70, younger men (those under 60 years) have been reported to take an active role in decision-making (Meyer et al., 2007). This finding may possibly be explained by the changing nature of decision-making in healthcare, as detailed in Chapter 2. Older men may be more familiar with the historic paternalistic approach from previous medical issues, whereas younger men are more aware of the active role associated with the recent consumerisation of healthcare. Meyer et al. explain that older patients may not respond as well to active participation due to the cognitive load associated with it. Given these findings, it is interesting to note that older men are more likely to make an immediate decision than younger patients (Davison & Goldenberg, 2011). One

possible explanation for this may be that younger men feel they have more to lose because of the side effects of treatment, and therefore may spend more time deliberating on their options, whereas older men may not be as concerned about some of the side effects such as sexual dysfunction (Wang & Ranasinghe, 2017). In addition, older patients may have well established views that cancer needs to be treated rapidly, therefore putting pressure on themselves to make a quick or immediate decision. Meyer et al. (2007) alluding to self-efficacy and mastery, postulates that this difference may relate to older patients' life experiences which facilitate less complex information searches and less time is consequently required to problem solve in older patients.

Given the many possible explanations for the findings to date in relation to preference for participation in decision-making, it is worthwhile to explore this in the Irish context, at the time of decision-making. A recent review on decision-making in prostate cancer patients identified that further research is needed to determine personal perceptions of decision-making (Wang & Ranasinghe, 2017).

6.3. Decision-making processes

When making decisions or judgements under uncertainty, dual-process models, such as Tversky and Kahneman's (1974) dual-system theoretical framework, are used to explain the approach taken. In this framework, System 1 refers to an automatic or intuitive, unconscious, fast and effortless process to make decisions, whereas System 2 makes deliberate, conscious decisions which are usually slow and effortful. In making decisions about prostate cancer treatment, the System 2 approach, where all possibilities and risks are considered rationally

with a thorough evaluation of the pros, cons, and the consequences, may not be the sole method used (Steginga & Occhipinti, 2004). It is proposed that non-systematic processes, where patients use short-cuts or heuristics such as calling on memories and resorting to lay beliefs about health, may also have a role, with Denberg et al. (2006) identifying that prostate cancer patients made early and rapid decisions because of flawed reasoning or incomplete knowledge. Based on this limited research in decision-making in prostate cancer patients, the use of dual processing in deciding on prostate cancer treatment is considered within this thesis, with heuristics and cognitive biases considered within the non-analytical approach to decision-making.

Heuristics are defined as strategies, or simple rules that include mental short-cuts, or rules of thumb, which are used in decision-making or problem solving (Tversky & Kahneman, 1974). Although the outcome is not guaranteed to be the best or optimal outcome, heuristic methods can be used to speed up the process of making a decision, or finding a solution. These rules work well in many situations, but in some cases, they can lead to systematic errors or cognitive biases (Lilienfeld & Lynn, 2014). Examples of common heuristics used in problem-solving include: The *availability* heuristic, the *representative* heuristic, the *anchoring and adjustment* heuristic, and the *affect* heuristic. The availability heuristic is a short-cut which is taken based on examples that easily come to mind. For example, patients who rely on previous experience and memories of cancer and illness, to arrive at a decision (Denberg et al., 2006; Xu et al., 2011) may be influenced by the availability heuristic. The representative heuristic is observed when judgements are

made based on prototype-based evaluations; something that seem similar to a certain category, is categorised as a member of that category, without giving any weight to additional information (Klein, 2005). The anchoring and adjustment heuristic describes the tendency to rely heavily on the first piece of information offered, for example; when making decisions, any information that follows is weighted up against this anchor or starting point, but modifications to the first evaluation based on this new information are limited. The affect heuristic is the tendency to evaluate something based on an emotional or "gut" reaction to it, rather than cognitively evaluating it (Slovic, Finucane, Peters, & MacGregor, 2007).

Biases are systematic errors and when heuristics fail, it induces a cognitive bias, or a judgement that lead to incorrect conclusions. Confirmatory bias is an example of a cognitive bias and is the tendency to select and remember information that fits with our pre-existing expectations and to neglect information that may contest it (Lilienfeld, Ammirati, & David, 2012; Nickerson, 1998). The hindsight bias is the tendency to exaggerate the extent to which a past event could have been predicted beforehand (Fischhoff & Beyth, 1975). The optimism bias is the tendency, when considering future events, to overestimate the likelihood of positive events, and underestimate the likelihood of negative events (Menon, Kyung, & Agrawal, 2009; Sharot, 2011).

Much of the research in decision-making which considers the influence of heuristics and cognitive biases has been conducted in healthcare professional making clinical decisions (Croskerry, 2002; Lilienfeld & Lynn, 2014; Saposnik,

Redelmeier, Ruff, & Tobler, 2016), but some recent studies of decision-making in prostate cancer patients has begun to investigate the theory of dual processing.

6.3.1. Heuristics and biases in decision-making about prostate cancer treatment

Prostate cancer patients' ability to process medical information can be biased by their previous beliefs about cancer and health, with patients systematically considering only a few items, which include cancer stage, mortality, and some side effects (Steginga, Occhipinti, Gardiner, Yaxley, & Heathcote, 2002), when making treatment decisions. Steginga and Occhipinti (2004), examining the systematic-heuristic theoretical model in a population of newly diagnosed prostate cancer patients found that many patients use the *expert-opinion heuristic* rather than systematic processing when deciding on treatment. The expert-opinion heuristic considers that patients, using a non-systematic decision-making strategy, are guided by the mental short-cut that the doctor (as expert) can be trusted. This is based on the opinion that the doctor is a reliable and credible source, and this opinion influences or biases the patients' systematic processing. Those likely to use the expert-opinion heuristic approach were patients who had a positive attitude towards their clinician and who had feelings of uncertainty about their decision. Those who had a low tolerance for ambiguity were also more likely to rely on the expert to direct decision-making. The use of the expert in guiding decisions has also been reported in other studies (Holmboe & Concato, 2000). This systematic-heuristic theoretical model of decision-making in prostate cancer patients, has also been proposed by Penson (2012), when investigating acceptance of active

surveillance in the management of prostate cancer. Within this model, Penson (2012) theorised that patients combine systematic and heuristic processes to arrive at a decision to undergo active surveillance. This combination approach to decision-making involves systematically identifying and prioritizing issues such as cancer cure and side effects while also being influenced by heuristic factors including the doctor's recommendation and partner's preferences (Penson, 2012).

From the limited literature available, the decision-making processes prostate cancer patients undergo to arrive at a treatment decision is not clear. The extent of System 1 and System 2 processing is not clear, but some heuristics and biases have been identified or alluded to in the literature (Denberg et al., 2006; Penson, 2012; Steginga & Occhipinti, 2004, 2006). It is therefore worthwhile to explore decision-making in this population, in an attempt to identify the processes involved. Recognising these may help to identify methods that can be implemented to encourage system 2 processing, given the errors that can occur from System 1 processing. Slowing down the decision-making process, and enhancing System 2 processing, can lead prostate cancer patients to take a more systematic decision-making approach (Volk et al., 2014). For example, debiasing strategies can be used to counteract biases in thinking; such strategies include "consider the opposite" or "consider an alternative", and these can help to reduce confirmation bias (Galinsky & Ku, 2004). Similarly adopting an outsider perspective can sometimes correct biases (Kahneman & Lovallo, 1993). Enhancing system 2 processing can result in choices which are factually based, rationalised, and informed rather than based on inaccurate information or misconceptions about cancer and treatment.

For the purposes of this study, as shown in Table 6.1, system 1 and system 2 processing are operationalised as intuitive versus analytical thinking, with system 1 meaning a response which is generated without much conscious effort, a decision arrived at subconsciously and is often described as a "gut feeling". In comparison, system 2 is slower, analytical, deliberative and rational, with the decision following a logical appraisal of the information which is processed carefully, therefore it requires more significant cognitive effort (Tay, Ryan, & Ryan 2016).

Table 6.1: Characteristics and strategies of system 1 and system 2 processing

	System 1	System 2
Characteristics	Fast	Slow
	Automatic	Controlled
	Effortless	Effortful
	Intuitive	Reasoned
	Gut feeling	Rules governed
	Limited cognitive load	Significant cognitive load
Strategies	Thinks instinctively	Thinks sequentially
	Acts impulsively	Acts after reflecting
	Follows rules of thumb	Follows rules
	Decision-making is based on habit	Decision-making is based on serial and logical problem-solving
	Decision-making is based on stereotypes	Decision-making is open-minded

6.4. Aims

In a population of newly diagnosed prostate cancer patients, this study aimed to explore the decision-making process at the time of decision-making and answer the following research question: *"How do prostate cancer patients describe their decision-making about prostate cancer treatment, the barriers and facilitators*

to decision-making and their preferred level of involvement in decision-making?"

The following objectives were defined to address the aims of this study:

- Explore participants' preference for involvement in the decision-making process.
- Explore the decision-making process described by newly diagnosed prostate cancer patients.
- Identify the barriers and facilitators experienced when deciding on treatment.

These objectives were examined in the setting of a broad range of contextual factors including demographic, clinical, decision-making preferences, and health literacy.

6.5. Method

6.5.1. Participants

Fourteen individuals with a prostate cancer diagnosis who had made a decision about their treatment participated in the current study. Data saturation, defined as the point at which subsequent interviews contribute no new concepts was decided using the method described by Francis *et al*. (2010). An initial analysis of 10 with a stopping criterion of three was decided in advance. After conducting 10 interviews and a subsequent 3 interviews, no new concepts occurred. However, arrangements had been made with the 14th participant, therefore this interview was also conducted.

6.5.1.1. Eligibility criteria

To be eligible to participant in this study, participants needed to be male, over 18 years of age, with a diagnosis of non-metastatic prostate cancer who had more than one treatment option available to them, but who had not yet commenced treatment. Those without English as their first language or deemed by their radiation oncologist to be unable to give written consent were not eligible to participate in this study.

6.5.1.2. Recruitment

A convenience purposive sampling strategy was used in this study. Over a 12-week period, prostate cancer patients due to attend a Radiation Oncology clinic across a network of hospitals in the Dublin area were screened by the researcher. The referral letter was used to ascertain eligibility. All potential participants had received their cancer diagnosis from their surgeon/urologist prior to this consultation with a member of one of six radiation oncologist teams in two departments within the network. Those who appeared to meet the inclusion criteria (n= 96) were flagged by the researcher to the medical team, and unless unsuitable for the study, the clinician discussed the study with the patient and if interested, introduced them to the researcher at the end of their consultation. Reasons for unsuitability included: no choice in treatment (12), had metastatic disease (5), needed further imaging before treatment options could be identified (18), had previously been treated with surgery (3), or needed a translator for the consultation (n = 2). Of the 56 patients who meet the eligibility criteria, 34 agreed to meet with the researcher. The researcher provided details about the study, the

invitation letter (Appendix 2) and participant information leaflet (Appendix 3). A telephone number was then provided by potential participants who consented to being contacted.

Those who provided contact details were then followed up with a phone call one week later. The main purpose of this call was to answer any questions about the study and to arrange a suitable time for the interview with those interested in participating. The interview was arranged to take place after a treatment decision had been made but before commencing treatment. From the 34 potential participants who provided contact details, 14 interviews were completed. The reasons for the variation in the number of potential participants who agreed to be contacted but subsequently were not interviewed are as follows:

- No interest in participating stating they had "too much going on" or were "too busy" to contemplate participating, (n=5).
- Could not be contacted by telephone despite numerous attempts, (n= 2).
- Agreed to be interviewed but were not contactable at the designated time, (n=3).
- Thought to have a choice in treatment option but subsequently had no choice due to co-morbidities which ruled out surgery, (n = 2).
- Delayed in making their decision until after the data collection period (e.g., awaiting further tests before options were confirmed or needing additional consultations), (n=8).

6.5.1.3. Data collection

Semi-structured interviews using an interview guide (Appendix 8) were conducted either face-to-face or by telephone at a time that suited participants. Having obtained verbal consent and before commencing with the interview, the interviewer completed a brief questionnaire for each participant to gather contextual data. This questionnaire consisted of demographic information, a decision-making preferences scale, and a measure of health literacy. Interviews were digitally audio recorded.

Before the first interview, a pilot interview was conducted with a male healthcare professional with a similar demographic profile to prostate cancer patients but without a prostate cancer diagnosis. He was selected based on his knowledge of the oncology environment and he was given a hypothetical scenario to work from. The main issue identified during the pilot related to the decision-making preference scale, the possible responses were too long for those who could not see the responses (telephone interviews). It was therefore decided to use a different scale, which is detailed in Section 6.5.2.4.

The majority of interviews were conducted by telephone, 3 interviews took place face-to-face (2 on the hospital site, 1 in the researcher's office). Interview length ranged from 31 minutes to 1 hour 24 minutes, but the majority of interviews lasted approximately 50 minutes. Following the interview, details of the debrief sheet (Appendix 5) containing relevant contact numbers were discussed and the consent form and debrief sheet were given to/posted to participants.

6.5.1.4. Questionnaire

The questionnaire comprised of a series of questions that the researcher read out to the interviewee. This questionnaire was designed by the researcher and included questions on social and medical demographic details, health literacy and participants' preferences for medical decision-making about health in general and prostate cancer specifically. The social demographic characteristics comprised age, marital status, medical insurance, education level, employment status.

Characteristics relevant to their prostate cancer diagnosis comprised: stage of disease (including Gleason score and PSA level), applicable treatment options and treatment option chosen. The participant's previous experience of cancer was obtained by asking:

- Have any of your family been diagnosed with cancer?
- Have any of your friends been diagnosed with cancer? with prostate cancer?
- Before your Prostate Cancer diagnosis, were you ever diagnosed with cancer?

Chew, Bradley, and Boyko's (2004), 3 questions to assess health literacy were also asked:

In general, when thinking about your health and hospital/doctor visits:

- How often do you have someone (like a family member, friend, hospital/clinic worker or caregiver) help you read hospital materials?
- How often do you have problems learning about your medical condition because of difficulty understanding written information?

- How confident are you filling out forms by yourself?

The questions used to obtain medical decision-making preferences were based on the Problem Solving Decision-making Scale developed by Deber, Kraetschmer, and Irvine (1996), which has been validated across a number of studies and a range of patient groups to measure preference for involvement in decision-making. Reliability of the scale is high with reported Cronbach's alpha ranging from .71 to .90 (Chewning et al., 2012). The 2 questions in this scale that examine decision-making preferences were used:

- When faced with making medical decisions in general, how would you like the decision to be made?
- When faced with making this decision about your prostate cancer treatment, how would you like the decision to be made?

The possible responses were: - *the doctor alone* (1), *mostly the doctor* (2), *you and the doctor equally* (3), *mostly you* (4), *you alone* (5). According to the authors, higher numbers indicate a preference for an active role while lower scores indicate a preference for a passive role. For the purpose of this qualitative study participants choosing “the doctor alone” or “mostly the doctor” were considered to prefer a passive approach, while those choosing “you and the doctor equally” were considered as preferring a shared approach. Those choosing “mostly you” or “you alone” were categorised as having a preference for an active role in medical decision-making.

6.5.1.5. Interview questions

The interview guide was designed from the findings in study 1 and 2 and the research literature, in particular the interview schedule devised by Xu et al. (2011). Pre-designed prompts and probes were used throughout the interviews, but the interview guide was followed flexibly.

Interviewees were first asked about their personal experience of receiving their prostate cancer diagnosis, which included as an opening question "Can you tell me a little about when you received your cancer diagnosis?" The treatment options, their efficacy and the associated side effects were discussed.

The treatment decision-making process was discussed to elucidate the factors that may had guided their decision. The factors that participants perceived as helpful and unhelpful when making their decision were also discussed. After discussing the advice participants would give to future patients and identifying what could be put in place to help patients in the future, the interviewer revisited the selected preference for decision-making which interviewees had identified before the interview began. This was done to cross check the response given earlier and see if participants had a different perspective on their preference having re-visited the decision-making experience throughout the interview.

Participants were then given the opportunity to ask any questions or discuss any further aspects around the topic that they felt important. Once the interview concluded, any issues highlighted during the interview (for example, in relation to concerns or practicalities of treatment/appointments) were then discussed with

supportive information and advice provided by the interviewer. Details of the debriefing sheet were then given to/posted out to participants.

6.5.2. Design

In-depth semi-structured interviews were conducted by the researcher with 14 men who had recently made their decision about treatment. Data were analysed using thematic analysis. Ethical approval from the relevant ethical committees within the University (Appendix 1) and the hospitals research ethics committees was obtained prior to commencing this study.

6.5.3. Analysis

A descriptive thematic approach as described by Braun and Clarke (2006) was used to analyse the data. This method was considered to be a suitable approach to identify, describe, analyse, and report themes and patterns within the data. Braun and Clarke distinguish between a top-down deductive or theoretical thematic analysis that is driven by the researcher's focus and specific research questions, and a bottom-up or inductive approach that is driven by the data. To explore the decision-making process of the sample, the researcher used the top-down approach guided by the research questions, the previous literature (e.g. preference for decision-making scale) and findings from study 1 (e.g. *"thinking back to the meetings with the Doctors…… how long were you given to make your decision?"),* and study 2 (e.g., "*would you be able to tell me something about the treatment side effects"*. (See Appendix 8 for the annotated interview schedule with more details). Themes were identified at a semantic rather than latent level, in order to examine patterns and their broader meanings and implications. The

semantic level allows the researcher to stay close to the participant's view trying to see the world through their eyes and analysing data at a surface level (Braun, Clarke, & Rance, 2014). As the aim of this study was to explore how prostate cancer patients describe their decision-making about prostate cancer, this method was deemed appropriate.

6.5.3.1. Data preparation

Interviews were digitally recorded and transcribed verbatim by the researcher. The transcripts were then cross-checked against the audio recordings by a subject expert, who is a radiation therapy professional with research experience.

6.5.3.2. Data analysis

The following 6 steps as identified by Braun and Clarke (2006) were taken in the analysis of the data. Although the steps appear linear, iteration was necessary for a flexible approach, thus the categories and initial themes evolved during the process.

Step 1: Become familiar with the data.

The transcripts were read and re-read to become familiar with the data. Notes of early impressions and observations were made during this step.

Step 2: Generate initial codes.

Codes were developed and modified as the first three transcripts were worked through manually by the main researcher and the subject expert independently. The codes were then compared, discussed and modified, and the data were transferred to qualitative data analysis software (QDA Miner Lite v2.0.5, (https://provalisresearch.com/) and the process continued for the remaining

transcripts, with codes for an additional 4 transcripts cross-checked by the subject expert.

Step 3: Search for themes

The codes were categorised, and initial descriptive themes were identified. The subject expert cross-checked the codes, and the categories that were developed, and verified that the initial themes seemed logical and clear. When disagreement occurred, the transcripts were reviewed and discussed before moving on to the next step.

Step 4: Review themes

The themes were reviewed by the main researcher and the subject expert together and considered in the context of the entire data set and the research questions. A number of subthemes were developed while those not relevant to the specific research questions were excluded.

Step 5: Define themes

During this step, the themes were reviewed and refined with the aim to identify the "essence" of each theme, how subthemes relate to the main theme and how the themes interact and relate to each other.

Step 6: Writing up

In order to integrate the analytic narrative and data extracts and present a coherent story about the data, the results and discussion will be presented together to contextualise the findings (Braun et al., 2014).

6.5.3.3. Credibility and trustworthiness

The researcher adopted a number of strategies to enhance credibility and trustworthiness of this qualitative research. The researcher:

- frequently summarised and paraphrased the responses and cross checked with the participants during the interviews. Member checking was not appropriate given the context of the research in this vulnerable population.
- followed the 15-point checklist of criteria for good thematic analysis (Braun & Clarke, 2006).
- used the subject expert in all stages of data analysis and interpretation to increase rigour and confirm the researcher's thought processes and decisions were clear and transparent.
- identified similarities and differences across the data to ensure different perspectives were represented.
- acknowledged her own biases and how they may have influenced findings and engaged with the subject expert to minimise bias, as detailed in the following section (Section 6.5.4).

6.5.4. Reflective practice of the researcher

This section will be written in the first person to describe my reflexive practice throughout this research.

During the research process I tried to be mindful of how my own personal and professional experiences influenced the research process. Conscious of the

inherent subjectivity of the qualitative research process, I had regular debriefing with my supervisor and my peers.

Firstly, I was mindful that some participants may not feel comfortable discussing all aspects and concerns with a researcher, who was female and had a clinical background. If I noticed that some side effects were not being mentioned, I would naturally introduce all possible side effects into the conversation. Once I had broached the issues and used the terminology such as bowel function and sexual function, I found participants were quite happy to discuss the issues. As most of the interviews were conducted over the phone, this may have made it easier for participants to discuss topics that they may otherwise have been less comfortable discussing with a female.

Secondly, as my background is in radiation therapy, I had to be careful in the analysis that I wasn't biased towards radiotherapy as opposed to surgery. I remained aware of the potential for bias during the analysis and discussed this with a peer and the subject expert. The subject expert acknowledged this and was vigilant when checking the coding I had applied. In addition, I had to be mindful of the challenges associated with my role as a researcher versus my previous role as a clinical radiation therapist. When patients questioned aspects of care, such as what specific tests were for, or asked for advice, I had to refer them on to the relevant services or healthcare professionals, rather than step in and give advice based on my clinical knowledge. Where possible, these issues were discussed after the interview with useful contact details given to participants to access the relevant resources, however if participants seemed distressed by their query during the

interview, I was careful to step back from the interview schedule and allay any fears participants had, before moving on to the next question.

Thirdly, as a number of people close to me lost friends and family members due to cancer during data collection I had to be thoughtful of how this could impact me during the research process. In particular, one friend lost her husband to recurrent prostate cancer. This resonated with me throughout the research and I had to take care not to let thoughts of this "take over" during the interviews and the analysis.

The debriefing sessions I had with my supervisor and peers helped me to see how my experiences were influencing the process and if any corrective actions were needed. Availing of a subject expert to cross check the analysis was also useful to ensure transparency and minimise possible bias in the analysis, while recognising the subjective nature of qualitative analysis and the role of the researcher in the process.

6.6. Findings

6.6.1. Sample characteristics

The social and medical demographics of the 14 participants are summarised in Table 6.2. Participants' age ranged from 62-78 years (*M*= 67.64, *SD*= 4.40), with 2 working fulltime, 3 working part-time, 1 semi-retired, 7 retired, and 1 participant on disability benefit. Education level ranged from primary level education (n=3) to tertiary level education (n=3), with 8 participants educated to secondary level. More than half of participants did not have health insurance (n = 9, 64%) and 11 of the 14 were in a relationship. In terms of age, this patient sample is predominantly

representative of the age patients present with prostate cancer in the Irish healthcare system, with 67 years being the mean age for patients diagnosed with prostate cancer between 2012-2014, (www.ncri.ie). One participant had a previous cancer diagnosis, 10 participants had family members diagnosed with cancer, and 9 had friends diagnosed with a range of cancers, including prostate cancer.

Concerning their prostate cancer diagnosis, 6 participants were not able to state their stage of disease, 6 were unable to list their Gleason score, and 4 could not list their PSA level. Knowing these facts is important, if patients are to research their treatment options, or compare their disease with others.

All participants had at least 2 treatment options available to them (to be eligible for the study), with the options including surgery, brachytherapy, active surveillance, radiotherapy with/without hormone therapy. A variety of treatment options were stated as the option selected: radiotherapy (n = 5), a combination of hormone therapy and radiotherapy (n = 5), surgery (n = 3), brachytherapy (n = 1). A greater proportion of patients in this sample selected radiotherapy than was reported for Ireland between 1994-2013; however, the number of prostate cancer patients receiving radiotherapy has increased from 11% to 43% during this period. Considering recruitment was carried out in the radiation oncology, it is not surprising that more patients in this sample selected radiotherapy or a combination of radiotherapy and hormone therapy. During data collection some potential participants, identified from the referral letter, cancelled their appointment stating they had decided to follow a surgical route and therefore, did not require a radiotherapy consult. Considering details of radiotherapy are not fully explained

until patients meet their radiation oncologist, these patients made their choice without all the facts. Given the literature discussed earlier in relation to informed choice and decision regret, this is unfortunate (Downing et al., 2017; Joseph-Williams et al., 2011; Kaplan, Crespi, Saucedo, Connor, et al., 2014).

Regarding the health literacy questions (Chew et al., 2004), 11 (79%) stated they never require help reading hospital material (Question 1), 10 (71%) never have problems learning about their disease because of difficulty reading (Question 2), and 10 are very confident filling in forms (Question 1), indicating high levels of health literacy in the sample (Table 6.2). However, one participant (P11) educated to primary level did not want to answer these 3 questions stating, "I would rather not say" for each question. This sample was more health literate, than the general population in Ireland, with 40% identified as having insufficient or problematic levels of health literacy (Doyle & Fullam, 2012). Therefore, findings from this sample may not be transferable to a broader population in Ireland, especially as individuals with low health literacy, appear to use less established criteria to evaluate information than those with high health literacy (Diviani, van den Putte, Meppelink, & van Weert, 2016).

Table 6.2: Sample characteristics

Pt. No.	Age	*Ed level	Work status	In a relationship	Stage	GS	PSA	[&] Trt. stated	[$] Help reading	[$] Help learning	[$] Confident with forms	Medical decision	Prostate Cancer Decision
1	68	3	Semi-retired	√	Early	√	√	RT	Never	Never	Very confident	Shared	Shared
2	64	3	Retired	√	Early	√	√	RT +HT	Never	Never	Very confident	Shared	Shared
3	70	3	Retired	√	Moderate	?	√	RT +HT	Never	Never	Very confident	Passive	Active
4	66	2	Retired	√	?	?	√	RT +HT	Never	Never	Very confident	Shared	Shared
5	67	2	Retired	√	?	?	?	RT +HT	Never	Sometimes	Somewhat confident	Shared	Shared
6	64	2	Disability Benefit	X	Early	√	√	Sx	Never	Never	Very confident	Passive	Active
7	68	2	Retired	√	Aggressive	√	√	RT +HT	Never	Never	Very confident	Shared	Shared
8	75	1	Fulltime	√	Moderate	√	?	RT	Never	Never	Very confident	Active	Passive
9	69	1	Retired	√	Early	?	√	RT	Never	Sometimes	Very confident	Passive	Passive
10	65	2	Part-time	√	Early	?	√	Sx	Rarely	Never	Very confident	Passive	Passive
11	62	1	Fulltime	X	?	?	?	Brachy	Rather not say	Rather not say	Rather not say	Passive	Passive
12	78	2	Retired	X	?	√	√	RT	Never	Sometimes	Very confident	Shared	Shared
13	64	2	Part-time	√	?	√	√	Sx	Never	Never	Somewhat confident	Passive	Shared
14	67	2	Part-time	√	?	√	?	RT	Sometimes	Never	Somewhat confident	Shared	Shared

Legend: *Ed level: 1=Primary, 2=Secondary, 3=Tertiary, GS= Gleason score, [&]Trt=Treatment, RT=Radiotherapy, Sx=Surgery, Brachy=Brachytherapy, HT=Hormone Therapy, [$] health literacy Questions 1-3

6.6.1.1. Decision-making preference

Preference in relation to decision-making based on the Problem Solving Decision-making Scale indicated that half (n= 7) of the participants prefer a shared role in decision-making about health in general and 6 indicated a preference for a passive role. The remaining participant indicated a preference for an active role in the decision-making process about health in general (Table 6.2).

Many participants wanted to be involved in decision-making about their prostate cancer treatment with 8 preferring a shared role *("you and the doctor equally"*) and 2 choosing an active role (*"you alone"* or "*mostly you*"). A passive role was preferred by 4 of the participants (Table 6.2). When comparing preference in decision-making in the 2 contexts (general health versus prostate cancer decision-making), all participants who chose "*shared*" in general decision-making chose "*shared*" for decision-making about prostate cancer. However, 3 participants choosing *"passive"* for general decision-making, changed to active or shared when decision-making about prostate cancer. Conversely, one participant who prefers an active role when making general health decisions would prefer a passive role when making decisions about prostate cancer.

Patients in the current study had a preference for active involvement in decision-making in comparison to a recently published study of prostate cancer patients in Ireland, where approximately a third of patients each wanted a passive, active, and shared role in decision-making (Drummond et al., 2018). However, patients in this retrospective study had been diagnosed between 1995-2010. Problems with recall could explain the difference in findings, but it is also

conceivable that the patients' role is shifting in line with the healthcare models with patients now expecting an involvement in decision-making, given the consumerisation of healthcare in recent years (Oliffe et al., 2011).

Participants' preference for decision-making, was revisited at the end of the interview. Most who initially expressed a preference for a shared or active role still agreed with their initial preference; however, for one participant if the outcome from the treatment options was not equal, he would probably prefer if the doctor made the choice (P3-RT). For the four participants who initially selected a preference for a passive role for prostate cancer decision-making, by the end of the interview three stated that they were happy to have been involved and if in a similar situation, they would prefer to be involved to some degree. The remaining participant (P13) was still happy with a passive role, preferring the doctor to choose, as "*They know what they are taking about, and I assume they will do the best for me" (P13).*

Patients' preferences are similar to other studies of prostate cancer patients (Steginga & Occhipinti, 2004), and to findings from a large secondary data analysis (Deber, Kraetschmer, Urowitz, & Sharpe, 2007), which pooled results from a number of studies and populations in Canada including prostate cancer patients. As in the current study, more participants wanted a shared role rather than a passive role. Where shift occurred in preference between the general setting to the current condition, it moved towards increased involvement as in the current sample. Considering patients' role in decision-making has been associated with treatment selection, with those who took a shared or active role more likely to select surgery

or brachytherapy than radiotherapy or hormone therapy, it is essential that patients are fully informed by all relevant healthcare professionals, including the radiation oncologist before finalising their decision.

Although many participants preferred to be involved in decision-making, for most participants being given a choice was surprising and unexpected (n= 12), initially disconcerting and somewhat confusing.

> *"I never heard of patients choosing their own treatment, I was quite surprised with that…… to be honest with you that confuses me" (P6)*

This participant (P6) who expressed a preference for a passive role in general medical decision-making stating that he *"would have preferred if the doctor said, 'I'm the doctor, I'm the expert, I have years' experience in this, and this is what you should do'"*, subsequently was grateful that he got to decide so he *"can be comfortable with my own mind".* Preference for involvement in the decision-making process was reflected by all participants who were happy to be involved to at least some degree with more preferring to take full responsibility as, *"it is my body after all"*, and "*I made the decision me-self on their advice"* (P4).

Perhaps fully explaining the patient pathway and the role of the patient within it at the time of the biopsy, will help to prepare patients for their role in decision-making and afford patients a chance to read about the available treatment options before their cancer is confirmed. The potential of using this process was alluded to by one participant during the interview, and has also been identified as a

method to consider in an attempt to empower patients (Martínez-González et al., 2018).

6.6.2. Themes: decision-making process

"The decision is easy when the outcomes are likely to be the same" (P3)

The themes identified were: (1) approach to decision-making, which for the majority appeared to be a quick ("rash") decision based predominantly on (2) attitude to and beliefs about surgery. This was followed by (3) a *post hoc* justification of the decision, which reflected some common cognitive biases. The fourth theme to emerge related to barriers to making an informed decision.

All participants reported that decision-making was easy for them because all treatment options were equal in terms of outcome. Participants' lack of surprise about their diagnosis due to the investigations and test they had undergone, belief that their condition was not serious, and that a good outcome was possible regardless of the option chosen, allowed participants to make what appeared to be a quick or rash decision. From the description given by participants the decision to select one option seemed to be made as a result of not wanting the alternative option due to their beliefs and attitude (positive or negative) about surgery. The specific heuristics that seemed to influence participants are highlighted in the next section. Demonstrating the ease of decision-making for this sample, a limited number of potential barriers were identified by a minority of participants. These were minimal and seemed to hinder making an informed decision, rather than generally hindering the decision-making process. For a few participants, the

decision was more deliberative, rationalised or systematically processed by considering their own specific circumstances or weighting up the pros and cons, with the choice then justified. Participants described approaches taken after decision-making that seemed to be used to justify the decision and these approaches were similar regardless of whether the decision appeared rash or rationalised. Aspects described by participants as facilitators of decision-making seemed to help participants to justify or validate their decision rather than help with making the decision.

These themes are shown in Figure 6.1 and presented and discussed in the next section, using quotations from participants for illustration. Where applicable, the type of treatment selected by the participant is included. Possible heuristics that may be at play are also identified in each section.

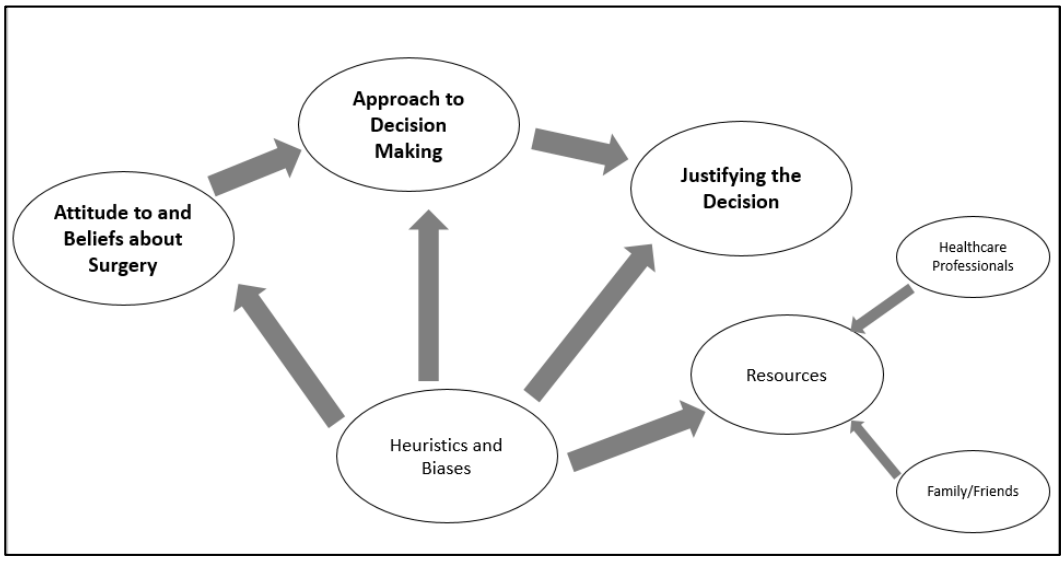

Figure 6.1: The decision-making process depicting 3 of the 4 main themes* (Bold text)
Note: Factors influencing these themes are shown in un-bolded text.
*The 4th theme, barriers to making an informed decision, is not shown.

6.6.3. Approach to decision-making

"[the] decision was made within 5 seconds ……. I had no decision to make cos I said you are not cutting me open, it was that fast I didn't need to be given any time" (P5-RT+HT)

6.6.3.1. Rash versus rationalised decision-making

For most participants, it seemed that a rash decision was made and this seemed to be a gut instinct (affect heuristic) or by a quick process of elimination; *"as he went through them, I put a line through them in my head, 'you are not going to do that to me, next one please'" (P 14-RT).* This is consistent with other prostate cancer studies that have identified that patients make quick decisions, which are not thought through rationally (Denberg et al., 2006), with patients focusing on only a subset of information (Steginga & Occhipinti, 2004; Jinping Xu et al., 2011).

Not being rushed to start treatment, comforted and reassured participants about their condition and seemed to reduce the gravity of the situation for them, allowing them to make their decision easily. Participants agreed that it was easy to make a decision because the outcomes were equal, their diagnosis was accurately considered as not being very serious, "*If you have a cancer, this [prostate cancer] is the best one to get" (P14),* the disease was *"slow burning",* manageable and curable with a range of treatment options available, which *"must be a good thing" (P13-Sx).* This contrasts with previous studies which have identified that patients' feelings of fear and uncertainty drive patients to want rapid treatment, *"you don't wait once you know you got cancer"* (Denberg et al., 2006, p. 623). Perhaps, due to the increased media exposure since this study was published, patients are now more

familiar with positive outcomes for prostate cancer, hence the positive outlook seen in this study cohort. Alternatively, they may be more informed about survival from their clinicians, than patients in the previous study.

For a minority of participants with the knowledge that the outcomes were equal, the decision was rationalised or processed systematically based on their own individual personal circumstances at the time (e.g., sick wife needing looking after) or by considering the pros and cons of treatment. These considerations included the timeframe to complete radiotherapy and hormone therapy, *"seems very long, two years"* (P13-Sx).

> *"…. once I was sure that the end result was coming out the same I would have if possible stayed away from the nappies and the incontinence type of thing." (P1- RT)*

6.6.3.2. Beliefs and attitude to surgery

> *"once there was another option surgery was blank to me, it was gone" (P14-RT)*

For many participants, the affect heuristic seemed to be at play with specific fears and "*cowardice*" (P3-RT+HT), the reasons given to rule out surgery and a fear of "*going under the knife*" (P7+P8) was enough to make many participants select an alternative treatment option. Fear of exposure to germs and infection and *"breaking the seal"* (P8-RT) seemed to strongly influence many participants away from surgery. Some participants' past experiences in hospital either with sepsis after the biopsy or previously from other surgeries were given as reasons for this

fear. The availability heuristic possibly influenced some participants who considered the experiences of others (easily recalled family members who developed significant hospital acquired infections) or neighbours /friends who developed septicaemia after the prostate biopsy, and subsequently decided to follow the non-surgical route.

> *"He [neighbour with prostate cancer] just went downhill rapidly …so I went, here we're both in the same boat here… I was looking at him through my eyes, so I just said no, no [to surgery]" (P5-RT+HT)*

Although participants mentioned some practical logistics and obstacles such as travel for treatment or finding accommodation as possible issues, all were strongly convicted to *"find a way"* to overcome these obstacles in order to stick with the non-surgical option. However, most reported that they would reconsider surgery if it offered a survival benefit, highlighting the overall importance of survival for participants.

> *"if they had said look you will be better to go with the surgery that it's a more sure way I'm getting rid of this …… then that's the road I would go to you now" (P8-RT)*

This fear of surgery has also been identified in the literature, with a number of prostate cancer patients, as in the current study, choosing a non-surgical approach to managing their disease due to this fear. Surgery, described as frightening, drastic, and extreme due to the fear of dying on the operating table was

undesirable (Denberg et al., 2006). It is possible that the fear of death on the operating table was present but not stated in the current cohort and this helps to explain why participants would consider surgery, if survival outcomes were better. Supporting this, one participant who was very certain he did not want to have surgery, stated he would have to reconsider it if the outcomes were different but *"…. I don't know what the percentages would need to be or what the difference would need to be but if someone was saying to me …… that surgery would be better...I couldn't walk out of there because I would not be prepared to take that responsibility on myself" (P3).* If this was the situation, this participant admitted he would no longer want an active part in decision-making, letting the doctor decide.

For some participants, their underlying view of surgery as a last resort, applicable only in advanced stages of disease, meant surgery was not necessary in their case due to their good prognosis. Conversely the three participants who opted for surgery reported that surgery offered a better chance of survival with less side effects and was the best, most effective way to treat cancer, *"getting it out" (P6, P10, P13)* and *"getting rid of the cancer" (P13).* This misconception of surgery as the best option is not surprising given other research identifying that surgery was considered the most certain, definite and tangible approach offering the greatest degree of certainty (Denberg et al., 2006), and explaining a key barrier for patients in accepting active surveillance in other research (Penson, 2012). O'Rourke (1999) describes a bias towards surgery, using the following patient's quotation to illustrate this bias:

"Prostate cancer is like a bad spot in an apple. If you don't get rid of the bad spot, pretty soon the whole apple will be brown" (O'Rourke, 1999, p. 355).

Although one participant who selected surgery subsequently reconsidered his options when he heard that all options offer the same chance of survival, he decided to stick with surgery as *"I think survival will be better with the surgery" (P10)*. The continued-influence effect (Johnson & Seifert, 1994) may have biased his decision, with his underlying view of surgery as the only effective way to treat cancer continuing to influence his decision even after the information was corrected.

Two participants who chose surgery as it offered the best chance of cure gave "*having a back-up plan"* (P13) as a further reason to follow this option, as radiotherapy could be a fall-back if the disease recurred. This is a logical and correct assumption to make and given the fear of cancer recurrence reported in the literature (van de Wal, Gielissen, Speckens, & Prins, 2013), it is surprising that others did not discuss a "plan B". An underlying fear of cancer recurrence, present in approximately a third of cancer patients (van de Wal et al., 2013), has also been identified in prostate cancer survivors in Ireland, with those who experienced decision regret and lower satisfaction with information displaying higher fear of recurrence (Maguire et al., 2017).

6.6.4. Justifying the decision

Once the decision was made, the majority of participants described a process of seeking external validation in order to justify their decision while some also sought to internally validate their decision. Although for some participants reflecting on decision-making in the interview may have imposed a need to justify the decision, from the accounts presented, it seems that at least some element of *post hoc* justification occurred for all participants prior to the interview and cognitive biases such as selective exposure and confirmation bias were a mechanism used to help justify the decision. Others also seemed to internally validate their decision drawing on either faith or general optimism to help justify their decision.

6.6.4.1. Cognitive biases

Selective exposure and confirmatory/confirmation bias seemed to underpin many participants' decisions. Participants' description of "*latching on and focusing on the things you want to remember and the things you want to hear" (P3)*, *"shutting out" (P7) some* of the information that they did not want to consider, and being selective about the use of materials and resources that were available, supports the selective exposure and confirmation bias theory (Frey, 1986). Additionally, one participant (P3-RT) identified that *"it was probably confirmation bias*" that had facilitated him to think he had made the correct choice as he *"wasn't interested in hearing anything that might change my mind"* once both options were equal in terms of survival.

This selective approach to information reflects findings from another qualitative study of prostate cancer patients, where some participants expressed a reticence to obtain information that might be unpleasant, confusing, and contradictory (Denberg et al., 2006).

To some extent, participants also sought to internally validate their choice, drawing on faith, *"I am not religious but I have great faith" (P7),* or luck and the idea that issues would not happen to them, "*it's the luck of the draw" (P1), you would want to be one of the unlucky ones, well there's a possibility but you have to hope for the best" (P8),* and that *"everyone is different" (P2, P5).* The optimistic bias or the belief that the self is at a lesser risk of experiencing negative effects than others seemed to be at play to some degree, with one participant feeling less at risk than what was stated in the information booklets:

> *"When the book says to me 3 out of 10 or 4 out of 10 have these effects …. it's going to be different for everyone" (P5).*

Considering one of the reasons given for not selecting surgery was the possibly of infection as experienced by others, it is interesting that in some situations patients compare themselves to others and expect a similar outcome, while in other situations patients assume they will be different to others. This apparent contradiction can perhaps be explained by the different underlying heuristics and biases, for example, availability in the first instance, and optimistic bias in the second instance. However, an alternative explanation for this apparent contradiction can relate to the level of control participants feel they have in a situation. In the case of the biopsy, with a suspicion of cancer, patients may feel

out of control, and for some, any subsequent surgery is associated with these feelings. Likewise, being under anaesthetic has been associated by prostate cancer patients as giving control over to someone else (Denberg et al., 2006). Conversely, being in control of making the treatment decision can instil confidence, allowing patients to be more optimistic and at a lesser risk of experiencing negative effects. Support for this explanation can be found in the literature that links perceived control one has over a situation to greater optimistic bias (Menon et al., 2009).

Further examples of possible underlying biases, along with possible heuristics are included in the next section which details the resources participants call on to justify their decision.

6.6.4.2. Resources that helped justify the decision

Resources reported as being useful regarding facilitating decision-making seemed to relate more to justifying the decision rather than facilitating the decision-making process, with many participants reporting using their healthcare professional or family and friends to validate that they had made the correct choice.

> *"the fact that the wife agreed with me, people that work with me agreed with me, that was a help…and when I was with the Doctor the last day, I said to him "well now seeing as I have made my decision, what do you think of my decision" and he said 'I think you have made the right decision" (P10-Sx)*

Although this sense of justifying the decision with the healthcare professional has not been alluded to in previous literature, other research has

identified that men who were uncertain about their decision are significantly more likely to use the expert to guide decision-making (Xu et al., 2011), with the expert opinion heuristic described in one study (Steginga & Occhipinti, 2004). In the current study, all participants stated they were comfortable with their decision, therefore this may have reduced the need to rely on the professionals to make the choice, but instead, participants seemed to use the expert to confirm their choice. The trusting relationship that participants had with their healthcare professional seemed to give participants confidence to make their decision, but although all participants reported confidence in and comfort with their decision, some seemed to cross-check or seek confirmation from the healthcare professional that they had made the right choice. Occasionally this was done in a straightforward manner but for others it seemed to be subtle, by "*reading between the lines*", or hearing what they wanted to hear, to justify their decision, further supporting the selective exposure and confirmation bias that seemed to have been part of the process.

> *"the way the whole thing was explained to me it sounded like I was being told without being told what was the right thing for me to do…… they are all happy with my decision ……I hope I didn't take him up wrongly but I don't think you could make a mistake about something like that, it was quite clear in my head, it was quite clear" (P3-RT)*

Participants' satisfaction with their care coupled with their view of the healthcare professionals as the experts allowed participants to be reassured in their choice, but all stated that should the expert disagree with their choice, then they

would reconsider their options, providing support for the expert opinion heuristic. The satisfaction with the care given by their clinical team was evident as no participant in this study sought an opinion from a second urologist or radiation oncologist. This is consistent with previous findings which have shown that patients who trust their doctor are less likely to seek another opinion (Denberg et al., 2006).

Although most stated that the verbal and written information was *"extremely practical, common sense" (P3-RT+HT)* and helpful in guiding the decision, some mentioned that they had not dwelled on the information as it could at times be quite scary, *"like a horror book" (P7-RT+HT),* or could *"swamp you…* [or] *…. confuse you" (P1-RT+HT)*. Likewise, the internet was regarded with caution and not used by most as it was considered not a useful place to seek information, *"foolish" (P7-RT+HT),* to look online, and *"the Internet can be dangerous" (P7-RT+HT)*. Issues with being *"computer illiterate" (P4-RT+HT)*, credibility of what might be on *"Dr. Google" (P2+P3)* and getting too much information or negative information were raised, again supporting the selective exposure and confirmation bias that seemed to be influential in this sample.

> *"I'm going to come across a lot of stuff and I'm going to get a lot of negative talk in there as well" (P12-RT)*

For the few participants who sought information online, it seemed to be to cross-check *"words that I didn't understand"* (P9-RT), or to check if the information was largely the same as in the booklets.

In addition to using the healthcare professionals and the information resources to confirm the decision, many participants reported using their family and

friends to facilitate them in decision-making. This is consistent with some literature, which has identified the role of partners, family, and friends in decision-making in this context (Berry et al., 2012; Maliski et al., 2002; O'Rourke, 1999). However, the role of partners/family and friends in the current study appeared to be in seeking validation of, or reassurance for their decision rather than to facilitate decision-making, as stated in previous studies. Family and friends were used to obtain emotional support, with one participant (P3) identifying using friends and family to rationalise his decision: *"I would have talked since about the rationale behind it to friends and to my wife" (P3)*. A few participants reported seeking informational support to help guide them in decision-making, by asking for information and advice from their partner or family; for example, one participant (P1) who spoke with his wife and two daughters (nurse and physiotherapist) said he would listen to his daughters' advice. However, this participant later confirmed that "*at the end of the day really, the decision would be made between myself and my wife" (P1)*. Using family members to gather information and provide advice has also been reported in the literature (Zeliadt et al., 2011), supporting the theory of social support in decision-making in this context. However, the role of partners in influencing the final decision is less clear, with Xu et al. (2011) finding that partners were not typically influential in decision-making. In addition, other studies which report partner involvement, stated that the patient ultimately makes the final decision, (Maliski et al., 2002; O'Rourke, 1999; Zeliadt et al., 2011)

Conversely, a few participants in the current study, considered their decision without involving their family and friends instead choosing to "*inform my wife of my*

decision, it is not a subject that's open for discussion, it's my body, it's my treatment, I decide" (P2-RT+HT). Considering some researchers have recommended involving the partner at consultations in order to open lines of communications between the patient and the partner (Zeliadt et al., 2011), given the findings in the current study, not all men may be receptive to this. Lacking in all studies, that investigated partner involvement, is a measure of the strength of the relationship, or a consideration of the dynamic between the patient and the partner. This may influence the patient's ability to include their partner in making decisions about their health and is an area which is worth further investigation.

Interestingly, an issue not highlighted in previous prostate cancer studies, is that of protecting loved ones; an issue stated by a few participants in the current study:

> *"Well I just told them …… the way I put it was 'I was threatened with prostate cancer', I didn't want to alarm them or anything, they have enough on their plate you know, so I just put it gently" (P12)*

Although no participant formally sought the advice of past patients through the available services some had informally spoken with friends who had been diagnosed and treated for prostate cancer and they were stated as useful resources. Participants described reliance on friends for support by seeking advice or reassurance that they were after making the correct decision. The support from friends found in this study adds to the previous literature in this area, with Xu et al. (2011) reporting that a number of men relied on friends, especially those who had a

personal experience of prostate cancer, to give information and advice, with the experiences of others strongly swaying patients on the route to follow. A more recent study also provides evidence for the role of friends in supporting men making this decision. A study of almost 300 prostate cancer patients, examining the theory of homophily in decision-making, and described in Section 5.8.3, found that approximately half turn to others in their environment, particularly those with whom they can identify: with friends and/or co-workers used as information sources or influencing the decision (Berry et al., 2018). The authors concluded that clinicians should consider the role of influential-others, inquiring if someone else known to the patient has been in a similar situation. From this, clinicians can then explain any differences between the two cases, which may help improve the quality of decision-making for the patient. However, for this to occur in clinical practice, patients would need to be advised to either have the influential-other accompany them to their appointment or have the specific details of their influential-other with them, as it is unlikely that patients will generally know the details about their colleague's diagnosis and treatment.

Considering this emerging evidence of the role of others in decision-making, it is interesting to note that some participants in the current study chose not to discuss their situation with their friends until they made their decision as *"a barstool accountant or a barstool solicitor are not good things…. If there are serious decisions to be made"* (P3). However, since making his decision this participant seeks and provides support for a *"good friend"* with recurrent prostate cancer. This

supports the importance of peer relationships, although the support required may vary for individuals, and occur at different time points in the cancer pathway.

6.6.5. Barriers to making an informed decision

6.6.5.1. Approach to decision-making

Because of the approach taken to make a quick decision and the subsequent methods to justify it, many participants were confused about the options, seemed unaware of, or had not considered the consequences of the option they had picked, or if aware then they minimised them. Many seemed unaware that they would also need hormone therapy as part of the treatment regimen. Rather than these aspects being barriers to decision-making in this sample, it seems they were barriers to making an informed decision.

Although provided with the information both verbally and in written format, few participants had considered the long-term side effects or if considered then they were minimised by many. This short-term view, and inability to consider the long-term consequences could be a result of myopic bias.

> *"the [side effects of RT] were so limited… you might get tired in the evening, so what, I will handle that for 3 months right, similarly with the hormone therapy I might put on a bit of weight I can deal with that" (P3- RT+HT)*

A previous review has also identified that patients tend to minimise side effects, whether intentionally or unintentionally (Zeliadt et al., 2006), and an explanation given for unintentionally downplaying side effects may be because they are not understood. This theory is supported by the studies which have identified

confusion with the specific side effects associated with each option (O'Rourke, 1999). An alternative reason for this can be that patients are selecting the information that backs up their decision and discrediting or ignoring discordant information.

As in previous studies, many participants were incorrect or confused when stating the side effects of the different treatment options. This was seen in the opposing views of two participants regarding sexual dysfunction. For one participant the main reason given to not follow the radiotherapy route was because it would *"turn you into a female…. and you, you would lose your mojo"* (P13-surgery). (From this description, it is more likely the patient is talking about hormone therapy, not radiotherapy). This contrasted with another participant (P5) who selected radiotherapy in order to minimize the impact of treatment on sexual function. Consistent with previous studies, incontinence was the side effect most cited as the issue to avoid by those who gave some consideration to the possible side effects when deciding on treatment (Davison & Breckon, 2012; Van Tol-Geerdink et al., 2013).

> *"…[I] would have been left completely incontinent if I have surgery and I didn't want that, the other one, the radium treatment, you have a lot better chance of getting back to a normal life" (P4-RT+HT)*

From the description given of surgery to this patient, he felt he could be left in a worse position after surgery in terms of urinary issues. This participant had presented initially with urinary symptoms which were impacting on his quality of

life and he felt further issues such as incontinence would prevent him from keeping up with his hobbies. Interestingly, because this patient was experiencing issues, he seemed to have given more consideration to incontinence than participants who presented with no urinary symptoms. The importance of putting the diagnosis and treatment decision in the context of the patients' lives has been described previously (Berry et al., 2003), and perhaps this patient was in a better position to do this, as this side effect was tangible.

After incontinence, sexual function was the next issue discussed most frequently, again consistent with the literature (Davison & Breckon, 2012). However, most participants (n = 12) stated that sexual dysfunction was not a major concern, with reasons given including: not in an intimate relationship with their partner due to their age or other illness, or because they were *"not going to have any more children" (P1-RT+HT).*

> *"yeah that was talked about [sexual function] a small bit but the way it is, the wife is nearly 70 and she is not interested in sex, we haven't had sex for about 2 years, so it doesn't worry me" (P4-RT+HT)*

The side effects of hormone therapy were very rarely discussed; in fact, hormone therapy was only mentioned by some incidentally, with one participant only identifying midway through the interview that he was to start the hormone injection soon, having only listed radiotherapy at the start of the interview as the treatment path that he was following. A second participant also stated at the start that he was *"going with the radiotherapy"* and during the interview when asked

was hormone therapy discussed, his response was: *"well I think I might be having that as well as the radiotherapy, yeah, I have just started it with a few days" (P8).* The idea that hormone therapy could have long term side effects did not seem to have been considered either, as this participant *"haven't found [any issues] so far".* This contrasted with one participant who had given some thought to hormone therapy. Although he thought the medical team might be considering starting him on hormone therapy, this was something he felt he didn't need. The idea that choosing radiotherapy for his stage of disease automatically meant he would also receive hormone therapy didn't seem to be understood. Those who had stated radiotherapy and hormone therapy as their treatment option again seemed to minimise the potential side effects to some degree, with one participant knowledgeable of the side effects of hormone therapy but the overall consequences of these on his health was not considered:

> *"…. I may put on weight, I may get man breasts, I may have mood swings, I may have hot flushes aah again most, all of those are temporary so from the hormones". (P2-RT+HT)*

Hormone therapy, as part of the management strategy for prostate cancer patients, is an area that is largely overlooked in the literature. Perhaps it is excluded from previous work, as it is not part of the management strategy for low-risk prostate cancer patients; however, as many studies seem to have included patients with intermediate-risk disease, some mention is expected. Metabolic syndrome, a clinical condition that can present as a complication from hormone therapy is associated with an increased risk of cardiovascular disease and diabetes.

Given this morbidity, men should be aware of this option and the side effects associated with it, in order to make an informed decision. In addition, the benefit of selecting radiotherapy in order to minimise the likelihood of experiencing sexual dysfunction, is somewhat negated if patients are prescribed a combination of radiotherapy-hormone therapy, which is a common treatment strategy in the management of intermediate and high-risk prostate cancer.

6.6.5.2. Embarrassment

Embarrassment, reported by two participants, seemed to be a barrier to making an informed decision. For one participant (P4) asking questions about sexual function prevented him from getting information about this side effect.

> *"but the biggest problem I found when talking with the doctors is that most of them are young girls….it is embarrassing talking about sex and that with them……you won't ask her questions about it" (P4-RT+HT).*

He also reported feelings of embarrassment around some of the investigations which he underwent, " *I mean, I had the scope put up the penis",* and although he understands that these tests need to be carried out, he felt it could have been dealt with better or would have been easier with a male doctor or an older female. Surprisingly, given the implications of treatment on urinary, bowel, and sexual functions, little emphasis is put on embarrassment in the prostate cancer literature. Perhaps men are choosing not to discuss concerns they have in relation to these functions, because of embarrassment. If this is the case, then the

concerns of patients in relation to the side effects of treatment may be under-reported and warrants further investigation in a broad population of men, including men from different cultural, socio-economic, and ethnic groups.

The second participant (P11) reported that he would be too embarrassed to ask the medical team if there was something mentioned that he did not understand, thus a barrier to making an informed decision. This participant did not want to answer the health literacy questions in the demographic section, and *"didn't really use the booklets".* Shame has been identified in patients with low health literacy level (Parikh et al., 1996). Patients who have low literacy and low self-efficacy are less likely to ask questions or to identify that they struggle with information (Clayman et al., 2010; Davis & Wolf, 2004; Manning & Dickens, 2006). Therefore, it is essential that healthcare professionals are aware of low health literacy and how this can reduce patients' interactions (Garcia, Hahn, & Jacobs, 2010). However, a recent investigation of radiation therapists in Ireland identified that many were unaware of the concept of health literacy and how it can be recognised and managed in the clinical setting (Quinn, Smith, Dhillon, Gillham, & Craig, 2018). This supports previous findings in relation to radiation oncologists (Smith, Petrak, Dhillon, Taylor, & Milross, 2014).

Using pictures and videos can help to inform patients and facilitate decision-making (Diefenbach, Mohamed, & Hall, 2011) and this patient (P11) found pictures and YouTube quite useful, stating that this is what helped him when he was diagnosed. He also said that although the doctors did not draw pictures to explain things to him, he would probably have found this useful. This participant relied on

his brother who had received surgery for prostate cancer to ask questions at the appointments and agreed that his brother had guided or swayed his decision to have brachytherapy. If brachytherapy wasn't an option for him, he would *"probably have gone with the radiotherapy"* because *"the operation is more of a bigger one"* which would *"probably be tougher to get over".* This highlights the use of influential-others in selecting treatment (Berry et al., 2018), and may be a particular strategy that can be utilised in those with low health literacy.

6.6.5.3. Delay in receiving information

For a few participants, the delay in hearing all the possible options was a barrier with some stating they were initially only offered surgery. Other possible options seemed to evolve when further tests identified that they may not be ideal candidates for surgery (e.g., due to comorbidities). Brachytherapy was only mentioned as an option for one participant when the medical team were asked specifically about this by the participant's brother. Another participant stated he only heard about radiotherapy as an option when he said he wasn't interested in having surgery.

> *"…… even my own doctor didn't tell me there's an alternative to this [surgery] and then I had words with the doctor and she said well there is a couple of other things you can have" (P5)*

As patients have been found to base their decision on the first information they receive (Hoffman et al., 2018), delayed disclosure of all treatment options is an issue. Firstly, it means all subsequent information is weighed up in relation to the

first option discussed (the anchor), and this may partly explain why more patients select surgery (Hoffman et al., 2018). Secondly, for those who are initially presented with surgery as the recommended option, finding out at a later stage that surgery is no longer suited, and a different path must be considered can be confusing and distressing. The impact of delayed disclosure on the patient has been illustrated in the literature, using a case study as an example (O'Rourke, 2007).

In Ireland, as in many other countries, the standard of care is for all prostate cancer patients to see both a urologist and a radiation oncologist. Patients routinely see the urologist first and are then given an appointment to see a radiation oncologist. However, some patients do not follow this standard procedure. This can relate to issues within the system, as seen in the above quotation, or it can be decided by the patient, as the researcher identified several patients due to see the radiation oncologist but who cancelled their appointment. The reason given was that they had selected surgery and therefore did not need to attend and hear about a treatment they were not going to avail of. This calls into question how informed patients were of the options available to them, and what they based their decision on.

6.6.5.4. Lack of understanding

Interestingly, although most participants stated they felt well informed and were satisfied with the information they had received, many participants had queries for the researcher when contacted to set up the interview, or at the start of the interview. From these queries it seemed there was a general lack of understanding about some aspects of the pathway, which could also be barriers to

making an informed decision. For one participant this related to the prescription he was given to prepare for the pre-radiotherapy planning scan. *"… I can't even pronounce some of the words … I don't understand that…I got a prescription but I wasn't sure what I was to start and that's why I'm here this morning to check what I must do" (P4-RT+HT).* This participant scored high on the quick measure of health literacy used, highlighting the inability of the test to measure functional health literacy.

For others, the queries related to prescriptions for hormone therapy or why they had appointments for other tests. For one participant who was waiting on results of further unrelated tests, he wondered who was keeping track of it or did he need to chase it up. *"I don't know is there any one person who is orchestrating the whole lot and keeping it together rather than me having to do it"* (P7-RT+HT). Of note, these participants scored high on the health literacy scale, further identifying the issue with this tool in measuring functional health literacy.

Advice on these queries was provided by the researcher as appropriate but serves to highlight that decision-making, although reported as easy by participants in this study, did not seem to be fully informed. Additionally, participants who scored lower on the health literacy scale did not query their disease, treatment path, or advice they were given. This is consistent with the literature that has identified that those who don't understand are less likely to ask questions (Clayman et al., 2010; Manning & Dickens, 2006; Wolf et al., 2004).

6.6.6. Summary

This study, which used a qualitative approach to explore the decision-making process in prostate cancer patients, found that most patients seem to make quick or rash decisions based on System 1 processing approach rather than a rationalised, analytical System 2 process. A number of heuristics and cognitive biases were identified, some of which have not been associated previously with patients in this context. In keeping with the literature, decisions seemed to focus on past or present considerations (e.g., past bad experience of surgery, get the treatment over with) rather than considering the future and the possible consequences of treatment. Interestingly, patients seemed to need to justify their decision, and used the medical team and their family and friends to do so. From the reports given by patients of the side effects associated with their chosen option, participants seemed to be confused about the treatment options to the degree that one needs to question how truly informed the decision-making was.

6.6.7. Implications of these findings

In this era of expecting patients to be active in the decision-making process and make informed decisions, it is essential that healthcare professionals understand the processes underlying patient decision-making. The extent that System 1 processing, influenced by heuristics and biases, seemed to be heavily involved in this sample's decision-making process adds to the limited literature in decision-making in prostate cancer patients. Although System 1 processing can be useful in many situations, given the poor understanding of the consequences of choice in this sample and identified in the literature, strategies to slow down

decision-making and enhance System 2 processing should be investigated. For example, debiasing strategies which can be used to counteract biases in thinking, should be considered and evaluated in this population. Such interventions could consider using guided reflection exercises which encourage patients to "consider the opposite" or "consider the alternative". For example, guided reflection interventions have been successful in decreasing biases and increasing accuracy in diagnostic accuracy in some studies of medics and medical students (Mamede, Splinter, van Gog, Rikers, & Schmidt, 2012; Myung, Kang, Phyo, Shin, & Park, 2013; Schmidt et al., 2014). Although others have found no main effect in using these strategies in these groups (Lambe, Hevey, & Kelly, 2018; Mamede, Schmidt, & Penaforte, 2008), it is worth investigating their benefit in the patient population. Similarly, exercises which encourage patients to adopt an outsider perspective could be investigated in an attempt to reduce biases. For example, this strategy has been proposed in principle as a strategy to reduce cultural stereotyping and non-conscious bias in healthcare professionals (Stone & Moskowitz, 2011). Enhancing system 2 processing can result in choices which are factually based, rationalised, and informed rather than based on inaccurate information or misconceptions about cancer and treatment.

Based on the findings of this study, it is essential that healthcare professionals check the reasons behind the patient's choice, so that any inaccuracies or misconceptions about treatment can be corrected, if necessary, before treatment proceeds.

6.6.8. Limitations

As in all research, a number of limitations were identified in this study. Firstly, this research recruited participants from the radiation oncology departments, and a higher proportion of men selecting RT was included in the sample, than would normally select radiation therapy. As discussed previously, some patients scheduled to see the radiation oncologist cancelled their appointment, as they had decided to follow the surgical management route, therefore these findings do not include the experiences of prostate cancer patients who selected surgery, without hearing of the alternatives in detail. It would be interesting to compare their experience, to those who attended radiation oncology to see if the approach taken to decision-making is different when more information is provided.

Secondly, for ethical reasons, the researcher did not access patients' medical records to cross-check the treatment options they listed as being available to them. Very few men in this sample listed active surveillance as an option available to them. However, as the literature has identified that many patients dismiss a non-active management strategy such as active surveillance (Pieterse et al., 2011; Xu et al., 2012), patients in this sample may also have done so. It would have been interesting to ascertain this information, as it would have added further depth to the study. If men are automatically disregarding what is considered inaction, then commission bias (Spranca, Minsk, & Baron, 1991) could have been an additional bias influencing decision-making in this sample.

Thirdly, using telephone interviews as the mode of data collection in this study was necessary in order to include patients who travel considerable distances to the main cancer centres, but introduced some limitations. The instruments used to measure health literacy and patients' preferences for decision-making had to be short and suitable to be used by telephone. For example, a quick and crude measure of health literacy was used, rather than the preferred option, the Newest Vital Sign, which is a more comprehensive measure of functional literacy (Weiss et al., 2005). As this test involves giving the participant a picture of an ice cream label and asking questions based on this label, it is not suited to telephone interviews. In a younger sample of participants, technology mediated interviews, such as VoIP (Voice over Internet Protocol) technologies (Skype and FaceTime) could be used to overcome this limitation, but this was not suited to the population of interest in this study, due to the age profile of prostate cancer patients who are not as familiar with these technologies, and may be ambivalent or disinterested in using these (Selwyn, 2004). Other possible limitations previously associated with telephone interviews, include issues with creating a rapport with participants and picking up on visual cues (Cohen, Manion, & Morrison, 2002). However, in comparing the data from the telephone interviews to the three face-to-face interviews, this does not seem to have impacted on the research, and this was verified by the second rater, who was not aware of which interviews were face-to-face. Furthermore, randomised studies which have compared modes of interview, have identified that both telephone interviews and face-to face interviews are equally effective methods of data collection, with mode of interview not impacting

on the data collected (Da Silva et al., 2014; Vogl, 2013). Additionally, the telephone interviews may have allowed some participants to speak more freely to the researcher about issues such as sexual dysfunction which may have been embarrassing in a face-to-face situation.

Fourthly, it is highly likely that consent/volunteer bias may have been present in this study, with those who volunteered being different to the non-volunteers (Salkind, 2010). Some potential participants declined to participate in this study, stating that they had *"too much going on",* therefore they may have not found the decision-making to be as "easy" as that described by the participants in this study. For this reason, these findings may not be representative of the decision-making process in all prostate cancer patients. Views of those who were too burdened by their decision-making task to participate in this study, would add to this research, but ethically, consideration must be given to the impact of the recent cancer diagnosis on patients. Perhaps future studies could investigate views of these patients once they begin, or complete their treatment, however, consideration would need to be given to the shift that may have occurred in their retrospective account of the decision-making process,

Lastly, it is assumed that participants subsequently received the treatment option they selected, but the researcher did not gather this information. Future studies in this area could follow patients longitudinally and see if they ultimately receive the treatment they selected. Based on the evidence to date, it would be interesting to explore the experience and attitudes of those that may end up

following a route different to that chosen, in order to see how they adapt to changes in this context.

Think-aloud methods of data collection, previously used to investigate decision-making strategies in healthcare professionals (Durning et al., 2012), could be employed in future studies of prostate cancer patients. This would allow further exploration of the specific heuristics and biases that may influence the System 1 processing seen in this study, and confirm what appears to be influencing decision-making in this sample. Confirming the specific heuristics and biases will help in designing guided reflection exercises as discussed previously, in an attempt at debiasing decision-making, ensuring patients make informed choices.

6.7. Conclusion

This study found that a majority of patients seem to make a quick or rash decision based on a System 1 processing approach rather than a rationalised, analytical System 2 process. A number of heuristics and cognitive biases that may influence decision-making were identified and areas of future research to confirm these heuristics and biases were identified. The finding that patients are unclear or confused about the specific side effects associated with their choice or downplay these side effects is worrying considering the impact these side effects can have on quality of life. Slowing down the decision-making process, and encouraging and facilitating System 2 processing may help to ensure men can be both active and informed decision-makers when contemplating prostate cancer treatment.

The next chapter summarises findings from the three studies used in this research and discusses the clinical and theoretical implications of these findings.

Chapter 7: General Discussion

The overall aim of this thesis was to examine decision-making about treatment in prostate cancer patients. This work combines findings across three studies to: 1) document the information prostate cancer patients in Ireland need to make treatment decisions, 2) identify the variables associated with decision conflict when decision-making, and 3) describe the processes patients use to make treatment decisions under uncertainty. For many men diagnosed with prostate cancer, the first decision required is whether to accept an active monitoring strategy (i.e., watchful wait, and active surveillance) or an active management strategy (i.e., radical prostatectomy, external beam radiotherapy, brachytherapy, and hormone therapy). While monitoring strategies result in fewer physical side-effects than active management strategies, a psychological burden of living with disease has been identified (Formica et al., 2017; Mader et al., 2017)). The morbidity associated with the active management strategy varies depending on the treatment option selected but can include, urinary, bowel and sexual issues (Hamdy & Donovan, 2017).

As highlighted in Chapter 2, the current evidence suggests that men making treatment decisions need to have balanced and comprehensive information in order to make informed decisions which are aligned with their preferences. Additionally, a lack of information can lead to decision conflict and decision regret in prostate cancer patients (Hoffman, 2012; Orom et al., 2016). However, there is no consensus in relation to what this information should include, and as much of the previous research has been conducted in the United States, focused on lower

socio-economic populations, and African–American men., it is not known what information men in Ireland require in order to make a treatment decision. As information needs can vary between context and culture, the needs of prostate cancer patients in Ireland may differ. For example, prostate cancer in African–American men can be more aggressive, and those in lower socio-economic groups present with more advanced stage disease (Allen, Kennedy, Wilson-Glover, & Gilligan, 2007; Bashir, 2015; Odedina et al., 2009), thus information needs in these populations may differ to prostate cancer patients in Ireland. The aim of study 1 was to address this gap in the literature, by identifying the information prostate cancer patients in Ireland need in order to make a treatment decision. This data was then used in constructing the survey for study 2 and the interview schedule in study 3.

The specific psychological constructs associated with the decision conflict that can arise in prostate cancer patients when making treatment decisions is unclear. How variables including health literacy, perceived social support, self-efficacy and knowledge are associated with decision conflict has not been demonstrated. Research in the area of health literacy and treatment decision-making is limited, with a focus to-date on research in the cancer prevention and cancer screening settings, or other healthcare setting (diabetes, respiratory and cardiac conditions). From these studies, there is evidence to support the relationship between health literacy and preferred role in decision-making, and actual role in decision-making, but these relationships in prostate cancer patients are not clear. How specific sociodemographic factors and the psychological

constructs (e.g., perceived social support, self-efficacy) may also be associated with health literacy and decision conflict in this context is also not clear, and possible interactions have been suggested but not tested. Based on these gaps in the literature, study 2 aimed to identify the factors associated with decision conflict at the time of decision-making, and test the conceptual model devised from the literature. Identifying these factors can help to inform interventions that may be designed and utilised to reduce decision conflict and facilitate decision-making in this population.

The decision-making process men undergo in order to make a treatment decision after diagnosis is not detailed extensively in the literature, with much of the research focusing on retrospective accounts obtained a number of years after diagnosis. In comparison, data for study 2 and study 3, in this thesis, were obtained immediately after the decision had been made and before treatment was initiated. Although much research has examined System 1 versus System 2 processing in medical decision-making from a clinician's perspective, few have considered this in prostate cancer patients. From the limited available literature, a small number of heuristics and biases have been identified or alluded to. Study 3 adds to this literature and identifies this area of research to prioritise in future studies. Adding to the literature in relation to healthcare professionals' biases in medical decision-making, identifying the biases and heuristics that the patients brings to the decision-making setting will help to advance shared decision-making.

This chapter firstly summarises the findings from the three empirical studies that were designed to answer the three overarching research questions. Exploiting

the benefit of mixed methods research, these results are next integrated and discussed to gain a broader understanding of treatment decision-making in the context of prostate cancer and to add to the decision-making literature. The clinical and theoretical implications of these findings are then deliberated, and the limitations of this research are noted.

7.1. Summary of the empirical chapters

Study 1 used the nominal group technique to ascertain what information a sample of prostate cancer survivors think prostate cancer patients need to make a decision about treatment. Consistent with the literature, the results identified variation in the information required (Feldman-Stewart et al., 2008; Rüesch et al., 2014; Tariman et al., 2014), but consensus was reached on a number of items that should be included when informing men about their disease and treatment. Interestingly, the item obtaining the highest score and prioritised by participants was *the "urgency of the condition, timeframe to make the decision"*. This has not been focused on in recent research but, considering that many patients may incorrectly feel a quick decision is essential when cancer is diagnosed (Berry et al., 2003; McGregor, 2003), it is important to highlight that there is no urgency in making a decision, due to the slow growing nature of the disease. For example, many patients with early stage disease may not need to make a decision to initiate active surveillance or treatment for a period of months. This will allow patients the opportunity to deliberate about their decision while availing of further information and support, therefore reducing the likelihood of decision conflict and facilitating informed decision-making. *"Explanation of own condition"*, the second item

prioritised in this study, underscores the importance of patient-centred care by personalising information and making it relevant to the patient's own situation (Leydon et al., 2000; Manning & Dickens, 2006).

Patients making decisions about treatment may experience decision conflict and decision regret, and both have been associated with negatively impacting on quality of life (Becerra Pérez et al., 2016; Downing et al., 2017; Kaplan, Crespi, Saucedo, Dahan, et al., 2014). A survey was used in study 2 to examine factors associated with decision conflict in prostate cancer patients at the time of decision-making and to test the conceptual framework proposed in Chapter 5. Higher levels of health literacy and higher levels of self-efficacy were both independently associated with lower levels of decision conflict.

In addition, although the hierarchical multiple linear regression used to test the conceptual framework was not significant, when controlling for age, relationship status, prostate cancer knowledge, and perceived social support, general self-efficacy was found to moderate the relationship between health literacy and decision conflict. Higher levels of decision conflict were seen in those with low health literacy and low self-efficacy in comparison to patients with low health literacy but high self-efficacy. This moderation pathway has not previously been reported in prostate cancer patients and addresses one gap in the literature, in relation to the psychological constructs which interaction with health literacy and decision conflict. As the instrument used in the current study measured general self-efficacy, it is important to note that further research using a measure of self-efficacy in decision-making is warranted. Should similar associations be found

between self-efficacy in decision-making and decision conflict, then designing interventions that aim to increase self-efficacy may be more effective than using decision aids to decrease decision conflict, as research on the benefits of decision aids is ambivalent (Adsul et al., 2015; Violette et al., 2015). For example, as self-efficacy can develop through vicarious experiences, affective states, and social persuasion (Bandura, 1977), interventions which use support groups, training sessions, and patient testimonials can help to increase self-efficacy (Haas, 2000). Peers who are similar to observers have been found to have the greatest influence on the observers' own capability (Simoni, Franks, Lehavot, & Yard, 2011), and considering the findings in this study in relation to influential-other in supporting patients, the role of peer-support groups, currently used by patients on treatment, is worth investigating for use at the earlier diagnosis stage. However, it is not enough to increase one's belief in their ability to make a decision about treatment, without ensuring that the decision takes into account consideration of the future consequences of that choice. Given the findings in the current study, it is clear that many prostate cancer patients lack knowledge of both the short and long-term consequences of treatment. Therefore, the benefit of interventions that help to increase health literacy, by increasing patients' ability to access, understand, appraise, and apply information in order to make an informed decision are also worth investigating. Such interventions could include campaigns to make information more accessible by using more visuals and writing in plain English, and teaching patients strategies to help facilitate communication and interaction with the medical team, (as detailed in Section 5.8.2).

Study 3 explored prostate cancer patients' description of the decision-making process, through semi-structured interviews. From the themes identified, the approach to decision-making appeared to be a quick decision for the majority of participants, with few giving much thought to the pros and cons of treatment. Once survival outcome is considered to be equal, for all treatments, beliefs and attitudes about surgery, either positive or negative, seemed to be the underlying basis for the decision. In line with the literature, participants used healthcare professionals, family and friends to support them (Renzi et al., 2017; Steginga & Occhipinti, 2004; Xu et al., 2011) but contrary to the previous evidence, participants reported that these resources were used to justify the decision rather than to influence or guide the decision. A number of cognitive biases and heuristics seem to be at play for many participants, in particular, selective exposure and confirmation bias, with participants seeking information that supported their decision, and dismissing or minimising information that was discordant. Although all participants reported having enough information to make the decision, from the interviews it was clear that a number of participants were confused on different aspects of treatment and the consequences of these on their future quality of life.

7.2. Making a treatment decision

Taken together, findings in the three studies have identified that most patients are active participants in making decisions about their prostate cancer treatment, and in this era of patient-centred care and personalised medicine, the paternalistic model with a passive patient seems to be relegated to history. Informed decision-making and shared decision-making are considered the gold

standard of care, especially in the context of early prostate cancer where multiple treatment options are available (Hamdy & Donovan, 2017). However, for many patients, the decision is not informed, and a shared decision-making process was not experienced by participants. In describing decision-making, Blumenthal-Barby, Lee, and Volk (2015) state that an "autonomous" decision, an important feature of informed consent, should be: intentional rather than impulsive; involve understanding of the situation and the possible outcomes, and the foreseeable consequences of the decision; and is not made under controlling influences. Given the evidence in the literature to date, and the findings from this thesis, by this definition, autonomous decisions are currently not being made by many prostate cancer patients. Considering the consequences of one's decision on one's quality of life, it is essential that patients fully comprehend the adverse outcomes associated with their choice and how these may impact on what is important to them and what they prioritise.

Providing adequate decision aids, written at a level appropriate for the expected reading ability and health literacy level of the population can help to overcome the lack of knowledge in prostate cancer patients; however, as can be seen from the literature discussed in this thesis, this is not enough to ensure informed decision-making (Adsul et al., 2015; Violette et al., 2015). Findings across the 3 studies in this thesis highlight the importance of individualising information and applying it to the patient's own personalised context. Focussing on the specific items relevant to the patient's own situation can reduce distractions and facilitate decision-making (Feldman-Stewart, Kocovski, et al., 2000; Feldman-Stewart et al.,

2001; Rüesch et al., 2014). In putting the diagnosis and treatment decision in the context of the individual's own situation (Berry et al., 2003), information that is irrelevant for that patient can be discarded. As health literacy was associated with decision conflict in this study, interventions aimed at increasing health literacy may help patients to access, process, understand, and apply information to their own situation, which may reduce decision conflict and facilitate informed decision-making. However, patients seem to rush to make intuitive decisions, in part, influenced by the "expert", family or friends, but also relying on System 1 processing, using affective and cognitive biases, and short-cuts. Emotions, fears, misconceptions, and anecdotes have also been reported by prostate cancer patients as influential in decision-making, in a previous qualitative study (Denberg et al., 2006). In addition, Steginga and Occhipinti's (2004) report that men who are uncertain about their decison are significantly more likely to use the expert-opinion heurstic when decision-making. Therefore, interventions are required to "slow-down" decision-making and allow rationalised and deliberative processing. Firstly, identifying the lack of urgency with the decision may facilitate patients and their families/friends to gather information and take advantage of the support networks available. However, based on the finding of study 3, this may not be enough to overcome a System 1 approach and encourage an analytical and systematic processing approach. It may also be necessary to implement debiasing techniques such as identifying to patients the possible biases that may be utilised, in an attempt to reduce non-systematic processing (Penson, 2012). In addition, strategies such as guided reflection exercises, "consider the opposite" or "consider

an alternative" may help in encouraging a System 2 approach to decision-making (Galinsky & Ku, 2004), ultimately leading to a "good" decision.

But what is a good decision? Quality of decision-making is currently assessed by healthcare professionals using instruments to measure decision conflict, decision satisfaction and decision regret, and based on the literature in the area of decision-making, decision conflict seemed an appropriate measure to utilise in this study. However, from the findings in study 2, where decisional conflict was low, and knowledge of side effects was also low, future studies should consider the criteria needed to measure quality of decision-making, given the impact these side effects may potentially have on quality of life. Based on the current literature, it would be expected that a follow-up study to assess quality of decision-making when treatment is completed, would use a decision regret scale, but again will this scale help to identify a good decision? When completing decision regret scales, analysing answers to questions such as *"the choice did me a lot of harm"* and *"I regret the choice that was made",* will not help in identifying if the regret is associated with the decision-making process or the outcome experienced. In addition, it is unclear if patients' views are based on consideration of what the outcome would have been if an alternative was chosen; and in considering an alternative, would patients compare to a worse option (e.g. death), or to one which may have less adverse outcomes (e.g. active surveillance). Counterfactual thinking, the psychological process of comparing the obtained outcome with other possible outcomes is more likely to occur when a negative outcome is experienced, and can influence individuals' emotional reactions to outcomes and events (Roese & Olson, 1995).

Therefore, it is an area of research worth exploring when considering quality of treatment decision-making and may help to explain levels of decision regret in prostate cancer patients who experience significant adverse outcomes.

The ability of decision conflict and decision regret to measure decision-making has also recently been questioned by Vickers (2017), who compares "easy decisions" to "rational decisions", and proposes that it is illogical to assume that lowered decisional conflict distinguishes good decisions from bad ones, because of the logic that good decision-making tends to lower decision conflict. Adding support to Vickers's argument is the finding in this study that those who had more knowledge experienced higher decision uncertainty, and in study 3, although all participants identified that it was easy to make the decision and they were comfortable with their decision, few had an understanding of the side effects associated with their decisions. Therefore, in the same way that the concept of quality of life is subjective (Lam, 2010) the quality of a decision needs to take account of what is important for the patient. For example, the Schedule for the Evaluation of Individual Quality of Life (SEIQoL) allows patients to name significant QoL domains, rate their level of satisfaction and determine the relative weight of each domain (O'Boyle, Höfer, & Ring, 2004). Rather than select items from a pre-determined list, this allows the individual to dictate what is important to them. Encouraging prostate cancer patients to identify their values and beliefs in the discussion on treatment choice would facilitate a shared approach to decision-making.

In a patient-centred healthcare system, it is important that healthcare professionals allow patients to express their personal values and concerns instead of offering purely factual information (O' Rourke 2007). Although this will take more of the healthcare professionals time, this approach will become more pertinent as the advances in surgery and radiotherapy techniques, and the drive towards personalised medicine, will offer more choice to patients. Given the rapid evolution of treatment and the length of time required to change evidence-based practice, it is important to coordinate care across the multidisciplinary team when arriving at an appropriate care plan. Recognition of the influence clinicians have on patients, the social factors influencing decision-making, and the heuristics and biases that influence patients and professionals, is vital along with considering the personal context of each patient. To actualise shared decision-making and patient-centred care, it is important to recognise what both the healthcare professional and the patient can bring to the discussion. The healthcare professional, with an extensive knowledge of the relevant facts and professional experience in managing this condition, along with the patient's individual knowledge of their personal condition, and an awareness of their personal goals and priorities can together identify what is the "best choice" for the patient.

Exploring models of shared decision-making is an area that can help to identify the benefits and resource implications of using shared decision-making in this population. Interestingly, although considered by most, that shared decision-making will increase the time burden for healthcare professionals, a review in 2014 reported that no evidence supports this claim (Légaré & Thompson-Leduc, 2014).

One such model of shared decision-making worth exploring is the SHARE approach, developed by the U.S. Department of Health and Human Sciences, (Agency for Healthcare Research and Quality, 2018). The SHARE approach is a 5-step process that encourages healthcare professionals to (i) **S**eek your patient's participation, (ii) **H**elp your patient explore and compare treatment options, (iii) **A**ssess your patient's values and preferences, (iv) **R**each a decision with your patient and (v) **E**valuate your patient's decision. This agency also advises on how to use the SHARE approach with patients with low health literacy levels, such as designing and assessing patient education materials. Culturally appropriate decision aids are also available to facilitate shared decision-making, and given the diversity in the populations requiring health service, this is an additional important consideration.

7.2.1. Implications and further research

7.2.1.1. Theoretical implications

This research found that prostate cancer patients are active but uninformed participants in decision-making, who appear to make quick, intuitive decisions rather than rationalised, deliberative decisions. This research tested a conceptual framework derived from a review of the literature and found that self-efficacy moderates the association between health literacy and decision conflict. These findings add to an increasing body of theoretical findings supporting the role of self-efficacy in decision-making (Heckman et al., 2011; Maliski et al., 2004; Williams-Piehota et al., 2008), and adds to the limited evidence available which explored dual-processing in decision-making in this context (Penson, 2012; Steginga & Occhipinti, 2004).

Within the conceptual framework tested in study 2, to the best of the author's knowledge, the identified moderation pathway has not previously been highlighted. As both health literacy and self-efficacy can be modified, implementing appropriate interventions could significantly reduce the level of decision conflict experienced by patients when making health decisions. However, as a general measure of self-efficacy was used in this study, re-testing this model using a specific instrument to measure self- efficacy in decision-making would be useful. Social support, theorized to promote adaptive and effective coping techniques to reduce adverse effects of stress, has been suggested as a potential moderator in the relationship between health literacy and healthcare use (Lee et al., 2004). This research found that perceived social support was positively and significantly associated with health literacy but was not associated with decision conflict and did not moderate the relationship between the two variables. However, perceived social support from friends was significantly associated with decision conflict and all subscales of the decision conflict scale (O'Connor, 1995), with higher levels of social support from friends associated with lower levels of decision conflict. Identifying that it is perceived social support from friends, not significant other or family, that is associated with decision conflict in this context, contributes to the body of evidence that has examined social support and outcomes, but is inconsistent with some previous findings in relation to the role of significant other in decision conflict. However, as with the current study, none of the previous studies categorised the strength of the couples' relationship, therefore, this may account for inconsistencies in findings across studies, in relation to the role of partners in the treatment

decision-making context. Based on the finding in this study in relation to the role of others, the importance of investigating the role of friends as influential-others advances the theory of homophilic relationships, an emerging area of research interest in prostate cancer patients (Berry et al., 2018).

The theory of homophily posits that friendships tend to form between those who are alike in some characteristic, or can identify with each other (as cited in Berry et al., 2018). The current study adds support to this theory that homophilic relationships can influence health care decision-making, and utilising friends and peers as a support network for newly diagnosed prostate patients, may facilitate informed decision-making and reduce decision conflict. In addition, as some proposed interventions to increase perceived self-efficacy rely on other people, it is worth exploring if the homophilic relationship is the mechanism underlying the vicarious source and the verbal persuasion source, within self-efficacy theory. The interaction between perceived social support from others and self-efficacy was not included in the conceptual framework derived from the literature, but based on the findings in this study, it is worth consideration in future studies.

Associations between decision conflict in the health care setting and specific demographics including age, education, and relationship status, have previously been reported, in particular in prostate cancer screening and in disadvantaged groups. Adding to this body of knowledge, this research conducted in a sample of prostate cancer patients in Ireland, identified that age, health literacy and self-efficacy, are associated with decision conflict. In contrast to the existing literature, neither education level nor relationship status were associated with decision

conflict, in this sample. However, as the strength of the relationship status was not measured in this or other studies, exploring how relationship status is associated with decision conflict could be considered in future studies.

The decision-making process described by participants in this research identified that heuristics and cognitive biases seem to underline the decision-making process. This adds to the limited research that has identified the influence of cognitive biases in this population (Steginga & Occhipinti, 2004). Considering the extensive but conflicting research that has focused on associations between knowledge and understanding and decision-making, shifting the focus to examining the biases that exist may help to advance research in decision-making in prostate cancer. If patients are not rationalising their decisions, but instead basing these on affective and cognitive heuristics and biases, having appropriate and adequate information, written at levels suitable for patients with low literacy levels, is not enough to encourage systematic and deliberative processing. Methods of debiasing have been investigated and found to be somewhat useful in other settings including clinical decision-making (Croskerry, 2002). For example, the use of guided reflection in reducing bias in clinical decision-making has been reported as useful in reducing System 1 processing and increasing rational decision-making in some studies of healthcare professionals (Myung et al., 2013; Schmidt et al., 2014). Based on these studies, it is worth considering if implementing a similar strategy with patients could encourage rational processing. This coupled with a healthcare professional who will engage in shared decision-making may help to overcome

some of these biases, so that patients can recognise the side effects that they may expect as a consequence of their choice.

7.2.1.2. Clinical implications

This research has identified that many men with prostate cancer are not making informed decisions about treatment, and as many men are unaware of the timeframe to decide, some may rush this serious decision. Considering the importance of informed consent before any treatment is instigated (www.hse.ie/eng/about/who/qid/other-quality-improvement-programmes/consent, http://www.europarl.europa.eu/charter/pdf/text_en.pdf), this finding has serious clinical implications. This research did not follow patients through to the start of treatment, but the expectation is that patients will again be given information about the outcome and the adverse effects of treatment before they sign the consent form and treatment is initiated. However, if understanding is not checked at this stage, men may be embarking on a treatment plan, which is ill-informed. As discussed previously, decision aids and their benefit in informing patients have been investigated, with conflicting results (Adsul et al., 2015; Stacey et al., 2014; Violette et al., 2015). Methods of informing patients, such as utilising computer-based systems in this technological era, have also been investigated but a review of these studies did not support these as a suitable method for educating patients (McIntyre & Craig, 2015). The best method to inform patients is therefore an area requiring further exploration. However, any undertaking should be in light of the present findings, by firstly, including patients in the design of the educational interventions and decision aids**,** and secondly, by considering the heuristics and

biases that are at play during the decision-making process, in order to minimise their influence.

Knowledge of hormone therapy and whether it was part of the planned treatment selected was alarmingly low in both study 2 and study 3. The fact that some participants (15%) in study 3 were due to begin this treatment but did not list it as part of their management strategy is concerning. Hormone therapy reduces circulating testosterone and, described as "medical castration" (Sharifi, Gulley, & Dahut, 2005), can emasculate men. The side effects (as detailed in Chapter 1, Table 1.1) associated with it can impact on the physical, psychological, and social, quality of life domains. The reduction in circulating testosterone can give rise to metabolic syndrome, a clinical condition that increases one's risk of cardiovascular disease and diabetes (Sharifi et al., 2005). Those commencing hormone therapy are often advised to consider making lifestyle changes to reduce the risk of morbidity. Additionally, a recent study reported that gender role conflict predicted higher distress in prostate cancer patients, thus impacting on the psychological and social quality of life domains (Lennon, Hevey, & Kinsella, 2018). Because of the impact of hormone therapy on quality of life, it is essential patients are adequately informed, so that they are aware of what to expect, can monitor their health and make appropriate lifestyle changes as necessary.

Based on the evidence in the literature, and what was revealed in study 3 in how men describe decision-making, consideration should be given to the referral pathways for urology patients. As observed by the researcher during data collection, many patients deciding to follow a surgical route do not wait to see their

radiation oncologist, choosing to cancel their radiation oncology consult. As described earlier, the feasibility of a multidisciplinary clinic, with patients seeing both the urologist and the radiation oncologist on the same day is worth investigating. This may decrease the anchoring effect where all subsequent information is anchored on the first piece of information received (Tversky & Kahneman, 1992), which is typically from the urologist and relates to surgery. This may reduce the current high proportion of men electing to have surgery, a decision that tends to be associated with more decision regret later than the other options available to men (Diefenbach & Mohamed, 2007).

In a bid to reduce decision conflict, interventions to increase self-efficacy and health literacy are worth exploring, based on the finding in study 2 that self-efficacy can moderate the relationship between health literary and decision conflict. Examples of these interventions have been detailed in Chapter 5. Similarly, how best to utilise "influential-others" (peers/work colleagues, friends) is also worth further investigation due to the findings in both study 2 and study 3 on the role of others in supporting decision-making, and the emerging evidence of the influence of homophilic relationships in decision-making (Berry et al., 2018).

7.2.2. Methodological critique

A mixed methods approach integrating qualitative and quantitative methodologies was used in this study within a paradigm of pragmatism. As discussed in Chapter 2, focusing on real world practice-oriented problems where the research questions stem directly from clinical practice, the mixed methods

approach was considered a suitable approach to gain an insight into decision-making about prostate cancer treatment.

From the results presented, the aims of the research have been met, and the theoretical and clinical implications of this research have been identified. The author believes the mixed methods approach allowed a depth and breadth of decision-making about treatment to be explored, which allows findings from previous studies to be reviewed in a new context, i.e. that of the "quick" but uninformed decision-making that men described. Limitations of this research have also been identified, and where some may consider it important to rerun this study accounting for the limitations encountered in this thesis, the author, within the pragmatic paradigm, and recognising that the findings in this research are one account of prostate cancer patients' decision-making, believes that the next step is to test some of the suggested interventions. This decision is based again on a pragmatic stance, which considers the patients' stories and the implications of their decision-making on their quality of life. Further limitations of this research and areas for future research now follow, before arriving at the conclusion of this thesis.

7.2.3. Limitations and future research

Although the findings from the current research meet the aims set out in Chapter 3, and contribute to thinking on decision-making in prostate cancer and provide some direction for future research and clinical practice, a number of limitations should be considered.

In all studies, the samples were fairly homogenous and therefore findings may not be generalisable to broader prostate cancer patients, such as the

disadvantaged or ethnic minority groups. In addition, all participants in study 2 had high levels of perceived social support, self-efficacy, health literacy, and prostate cancer knowledge and low levels of decision conflict, therefore the results may not be generalisable to patients with different profiles. The methodology chosen to meet the aims of study 2 may have excluded some from volunteering if their general literacy level was low. To overcome this issue, a questionnaire which is completed by the researcher based on the oral responses from participants may have helped to reduce possible selection biases.

In study 1, as participants were recruited through an Irish cancer charitable organisation, findings may not be generalisable to all prostate cancer survivors. Conducting a nominal group technique in only 1 group may have limited the number of items reported by this sample, or other participants may have prioritised different items, which would have added to the evidence of the individual nature of patients' information needs. Future research should consider using a number of NGT sessions, perhaps including a mix of patients who are at different stages of the treatment path. This may produce a more diverse range of items, giving a broader perspective. These items can them be ranked to identify the priorities. Comparing the priorities against the stage the patient is at on the treatment path would also be of interest in these mixed groups. This would identify if prioritises shift as patients progress from diagnosis to survivorship. However, due to the anonymous nature of the ranking and voting, this would not be possible in the current NGT structure.

The sample size in study 2 was underpowered to find a small to medium size effect; for example, to have power of .80 to detect a small to medium effect (e.g.,

*G*Power* f^2 =.08), 125 participants would have been required for the regression analyses. To find a medium size effect (e.g., *G*Power* f^2 = .15), 68 participants were required and although 68 participants were evaluated in this study, not all questionnaires were complete, which decreased the power of the study.

As participants in study 2 and study 3 were mainly recruited through the radiation oncology department, those who decided on surgery and who did not attend their radiation oncology appointment are not obtained. Future research in this area could aim to recruit patients in the urology department, thereby measuring decision conflict and decision-making in a greater sample of patients selecting surgery. A comparison of decision conflict in those who are provided with information from only the surgeon, and those who receive information from both the surgeon and radiation oncologist would be interesting to ascertain how additional information impacts on decision conflict and decision uncertainty. Similarly comparing decision-making experiences of those who see one versus both specialists would also be of interest to see if different heuristics and biases are at play. For example, it is expected that some participants in the current study used anchoring and adjustment, viewing all subsequent information in terms of the information received first from the surgeon; however, those who only see the surgeon are unlikely to use anchoring and adjustment.

A number of additional factors thought to be associated with decision-making were not included in this research. For example, and as described earlier, optimism has been reported to be associated with decision-making in prostate cancer patients, with higher levels of optimism associated with lower levels of

decision-related distress (Steginga & Occhipinti, 2006). Therefore, it is possible that optimism could have a direct effect on decision conflict or an indirect effect, through associations with other variables included in the conceptual framework, (i.e., perceived social support, or self-efficacy). The constructs examined in this research were guided by clinical experience and pragmatism. The chosen constructs are psychologically well-developed constructs consistently associated with health outcomes; robust measures are available to measure these, and they are amenable to change. Future research could examine these constructs in a longitudinal study, testing interventions to increase health literacy and self-efficacy and reduce decision conflict in a sample of prostate cancer patients, and following up with an assessment of decision regret in the same sample when the consequences of treatment are apparent. Using mixed methods in the follow-up study, as in the current study, will allow a broader exploration of decision regret, due to the limitations of decision regret in measuring the quality of decision-making, as identified earlier. This would help to identify what the regret relates to (for example, the decision or the outcome) and will provide insights into whether participants who express regret consider the consequences of the alternative option (counterfactual thinking).

7.2.4. Future research directions

Although not considered within this research as the focus was on the patient experience and perceptions of decision-making, future research could explore the healthcare professionals' role in the decision-making process. Specifically, examining how they manage patients who they perceive to be unable to make

decisions would be worth identifying, for example, those with low health literacy levels, or without social supports. Healthcare professionals' views in relation to adopting a shared decision-making approach would also help to advance the broader research in this area, as previous research in this area has identified difference in clinicians' approach to advising patients about treatment for prostate cancer (Davis et al., 2017). For example, clinicians' beliefs influenced their treatment recommendations, with some clinicians factoring patients' anxiety level into their recommendations about active surveillance versus active treatment.

Obtaining the views of loved ones, partners and friends is an area that has been investigated (Boehmer & Babayan, 2005; Zeliadt et al., 2011), however in light of the mixed findings and the findings in this study, it is worth revisiting the role of partners in decision-making. As partners have been identified as providing emotional and informational support in previous studies, it is worth considering the role of the partners' biases when providing these supports. Based on the limited emerging research and the findings in this study, in relation to the role of friends, a priority should be placed on exploring the views of the influential-other in this context.

Given the findings in relation to the heuristics and biases that appeared to underpin decision-making for many participants in study 3, it would be useful to obtain patients views and beliefs in relation to prostate cancer and treatment at the time of biopsy, and before a diagnosis is made. The decision-making process in those who are subsequently diagnosed with prostate cancer could then be explored using semi-structured interviews or think aloud protocols. Comparing the process

of decision-making described by participants with their initial beliefs and views of cancer and treatment may help to identify the possible heuristics and biases they draw on to make decisions. This would add support to the heuristics and biases that were speculated to be associated with decision-making in the current study.

7.2.5. Conclusion

The aim of this research was to elucidate the processes underlying prostate cancer patients' decision-making about treatment after diagnosis but before commencing treatment. A mixed methodology was used to address this aim, enabling an in-depth exploration of decision-making about treatment from the patients' perspectives, and identifying what men regard as important to know to make treatment decisions, the factors associated with decision conflict when deciding on treatment, and how men describe the decision-making process. From integrating findings from the three studies, this research identified that prostate cancer patients are active participants in the decision-making process and experience minimal decision conflict. For most, the decision seems to be uninformed with little consideration given to the future consequences of this decision and the impact these may have on quality of life. Within the devised conceptual framework, general self-efficacy was found to moderate the relationship between health literacy and decision conflict, and a number of additional associations were also found to be significant. This adds to the research in medical decision-making. Influential others, including friends are called on to help justify the decision, and patient's perception of support from friends, is associated with

decision conflict; with higher levels of perceived social support from others associated with lower levels of decisional conflict.

Men appear to make rapid decisions which are not based on systematically processing information, but influenced by affective and cognitive heuristics and biases. Therefore, it is pertinent to further examine these biases, and drawing from the literature in debiasing in medical decision-making, consider the possible methods that can be employed to reduce bias in prostate cancer patients. Until these biases are investigated, any further research into patient education seems futile. Involving patients in a shared decision-making approach, which recognises possible biases from both the patient and the professional may help to actualise patient-centred care.

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Appendix 1: Ethical approval letters for studies 1, 2, and 3

University ethical approval letter: Study 1

Agnella Craig

From: Fiona Mc Kibben
Sent: 10 December 2018 11:51
To: Agnella Craig
Subject: Agnella Craig Ethical Approval

Approval Agnella Craig 10264088 10th December 2018

Dear Agnella,

The School of Education received and considered your application in June 2014 for ethical approval of your Ph.D.research project entitled "Literacy Levels in Prostate cancer Patients: Relationship of Health Literacy Level, Understanding of Cancer Information and the Shared Decision Making Process".

It was the decision of the committee, prior to current policy and processed in accordance with School policy at the time that no additional information was needed regarding your application. Therefore, approval was granted for your research, (signed off by Dr Colette Murphy on 23/6/14) on the condition that it was carried out as indicated on your application. Should there be a change in the design of your research project, you will need to re-apply again for approval from the School of Education's Ethics Committee.

You are required to include a copy of this letter as an appendix to your thesis.

If you have any queries regarding this decision, please contact the current Chair of the School of Education's Ethics Committee and Director of Research, Dr Ann Devitt (devittan@tcd.ie).
We wish you all the very best with your research project.

Kind regards,

Fiona McKibben
Research Officer at the School of Education
on behalf of Professor Ann Devitt
Director of Research

3088 School of Education Arts Building

Trinity College Dublin, the University of Dublin

Dublin 2, Ireland.

Tel | + 353 1 8963583

University ethical approval letter: Study 2

Coláiste na Trionóide, Baile Átha Cliath
Trinity College Dublin
Ollscoil Átha Cliath | The University of Dublin

F.A.O. Agnella Craig

School of Psychology Research Ethics Committee

11th January 2016

Dear Agnella,

The School of Psychology Research Ethics Committee has reviewed your application entitled "Prostate cancer, health literacy, decision-making" and I am pleased to inform you that it was approved.

Please note that you will be required to submit a completed **Project Annual Report Form** on each anniversary of this approval, until such time as the research is complete and the thesis is submitted. The form is available for download from the Ethics section of the School website.

Adverse events associated with the conduct of this research must be reported immediately to the Chair of the Ethics Committee.

Yours sincerely,

Richard Carson
Chair,
School of Psychology Research Ethics Committee

SCHOOL OF PSYCHOLOGY
Arás an Phiarsaigh
Trinity College
Dublin 2

Scoil na Síceolaíochta
Dámh na nEolaíochtaí Sóisialta agus Daonna,
Áras an Phiarsaigh,
Coláiste na Trionóide,
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University ethical approval letter: Study 3

Coláiste na Tríonóide, Baile Átha Cliath
Trinity College Dublin
Ollscoil Átha Cliath | The University of Dublin

F.A.O. Agnella Craig

School of Psychology Research Ethics Committee

18th January 2018

Dear Agnella,

The School of Psychology Research Ethics Committee has reviewed your application entitled "Prostate cancer, health literacy, decision making" and I am pleased to inform you that it was approved.

Please note that you will be required to submit a completed **Project Annual Report Form** on each anniversary of this approval, until such time as an **End of Project Report Form** is submitted upon completion of the research. Copies of both forms are available for download from the Ethics section of the School website.

Adverse events associated with the conduct of this research must be reported immediately to the Chair of the Ethics Committee.

Yours sincerely,

Richard Carson
Chair,
School of Psychology Research Ethics Committee

SCHOOL OF PSYCHOLOGY
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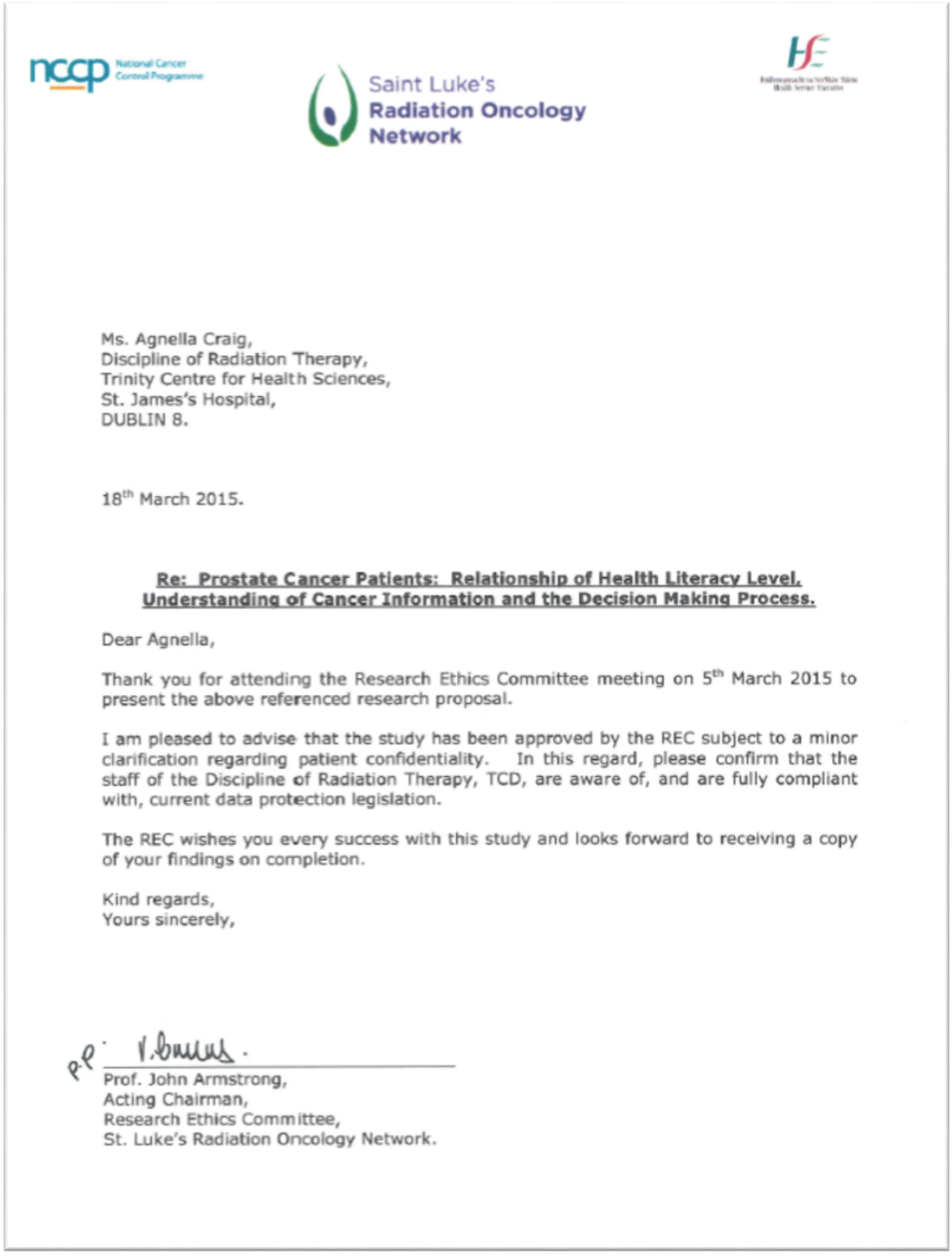
Hospital ethical approval letter for study 1- Not applicable

Hospital ethical approval letter for study 2: Survey



National Cancer Control Programme

Saint Luke's Radiation Oncology Network

Ms. Agnella Craig,
Discipline of Radiation Therapy,
Trinity Centre for Health Sciences,
St. James's Hospital,
DUBLIN 8.

18th March 2015.

Re: Prostate Cancer Patients: Relationship of Health Literacy Level, Understanding of Cancer Information and the Decision Making Process.

Dear Agnella,

Thank you for attending the Research Ethics Committee meeting on 5th March 2015 to present the above referenced research proposal.

I am pleased to advise that the study has been approved by the REC subject to a minor clarification regarding patient confidentiality. In this regard, please confirm that the staff of the Discipline of Radiation Therapy, TCD, are aware of, and are fully compliant with, current data protection legislation.

The REC wishes you every success with this study and looks forward to receiving a copy of your findings on completion.

Kind regards,
Yours sincerely,

p.p. V. Brennan

Prof. John Armstrong,
Acting Chairman,
Research Ethics Committee,
St. Luke's Radiation Oncology Network.

Hospital ethical approval letter for study 2: Survey

THIS NOTEPAPER MUST NOT BE USED FOR PRESCRIPTIONS OR INVOICING PURPOSES

SJH/AMNCH Research Ethics Committee Secretariat
Claire Hartin Ph: 4142199
email: claire.hartin@amnch.ie

THE ADELAIDE & MEATH HOSPITAL, DUBLIN
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TELEPHONE +353 1 4142000

Prof. John Armstrong
Acting Chairman
Research Ethics Committee
St. Luke's Hospital
St. Luke's Radiation Oncology Network
Highfield Road,
Rathgar
Dublin 6

27th March 2015

RE: Prostate Cancer Patients: Relationship of Health Literacy Level, Understanding of Cancer Information and the Decision Making Process

REC Reference: 2015-03 Chairman's Action **Action (16)** ***Please quote REC reference on all correspondence***

Dear Prof. Armstrong,

Thank you for your correspondence dated 25th March to SJH/AMNCH Research Ethics Committee in which you requested ethical approval for the above study.

The Chairman, on behalf of the SJH/AMNCH Research Ethics Committee has given ethical approval to this study.

Yours sincerely,

Claire Hartin
Secretary
SJH/AMNCH Research Ethics Committee

23/4/15

Hospital ethical approval for study 3: Interviews

Saint Luke's
Radiation Oncology
Network
St Luke's Hospital

Ms. Agnella Craig,
Discipline of Radiation Therapy,
Trinity Centre for Health Sciences,
St. James's Hospital,
DUBLIN 8.

18th July 2017.

Re: Prostate Cancer Patients: Relationship of Health Literacy Level, Understanding of Cancer Information and the Decision Making Process - Phase 3.

Dear Agnella,

Many thanks for your letter dated 2nd July 2017 enclosing your revised research proposal. The revised documentation has been reviewed and I am pleased to confirm the approval of the Research Ethics Committee for same.

The REC wishes you well with the final phase of the study and looks forward to receiving a copy of your findings on completion.

Kind regards,
Yours sincerely,

pp. S. Ryan.

Dr. Sheelah Ryan,
Chair, Research Ethics Committee,
St. Luke's Radiation Oncology Network.

St Luke's Hospital, Oaklands Drive, Highfield Road, Rathgar, Dublin 6.
Ospidéal Naomh Lucas, Baile Átha Cliath 6.
Telephone: 01 406 5000; Fax: 01 406 5222; Email: radiotherapy.stlukes@hrb.ie; www.stlukesnetwork.ie

Appendix 2: Invitation letter for studies 1, 2, and 3

Invitation letter for study 1: Nominal group technique

Discipline of Radiation Therapy,

Trinity Centre for Health Sciences,

St James Hospital Campus,

Dublin 8

10/07/2014

Dear Sir,

I am a member of staff in the Discipline of Radiation Therapy, Trinity College Dublin, and a part-time student in the School of Education, Trinity College Dublin. I worked clinically for many years as a Radiation Therapist and I am now doing research into prostate cancer. The title of my study is:

> ***"Literacy Levels in Prostate Cancer Patients: Relationship of Health Literacy Level, Understanding of Cancer Information and the Shared Decision Making Process".***

In part 1 of this study, I am interested in what you think men diagnosed with prostate cancer should know about their treatment options and how men can get more information before they decide which treatment to take. To find out, I am setting up a number of group interviews (called focus groups) where I hope to have, in each group, about 5-9 men who have had a prostate cancer diagnosis. Recommendations from this study may be used to improve services for men diagnosed with prostate cancer in the future.

The Irish Cancer Society has kindly agreed to forward this email and some details about my study to men who have or had prostate cancer. If you think you might be interested in participating in this study, please read the **participant information leaflet** which I have attached to this email. It will give you some more information about the study.

If you have any questions about the project or would like to hear more about it, please contact me at agnella.craig@tcd.ie or by telephone 01 896 3926 (or mobile 086 2709535).

It is anticipated that these sessions will take place in Dublin, between the 21st July and the 1st August. If you decide to volunteer to participate in this study, **please call or email me** so we can discuss when exactly would suit you.

Yours sincerely,

Agnella Craig.

Invitation letter for study 2: Survey

Trinity College Dublin

The University of Dublin

Discipline of Radiation Therapy,

Trinity Centre for Health Sciences,

St James Hospital Campus,

Dublin 8

Dear Sir,

I am a member of staff in the Discipline of Radiation Therapy, Trinity College Dublin, and a part-time student in the School of Psychology, Trinity College Dublin. I worked clinically for many years as a Radiation Therapist and I am now doing research into prostate cancer. The title of my study is:

"Prostate Cancer Patients: Relationship of Health Literacy Level, Understanding of Cancer Information and the Decision Making Process".

Research has shown that some patients find it hard to understand information about their health and this can make it difficult to make decisions about health and treatment. I am interested in looking at this in men with prostate cancer. Findings from this study may be used to improve information services for men diagnosed with prostate cancer in the future.

If you think you might be interested in participating in this study, please read the **patient information leaflet**. It will give you some more information about the study.

I will telephone you in about 1 week to answer any questions about this study. Then, if you are interested in being involved, we can make the arrangements for filling in the questionnaire.

At any stage, if you have any questions about the project or would like to hear more about it, please contact me by telephone 01 896 3926, or by email at agnella.craig@tcd.ie .

Alternatively, you can contact my supervisor, Dr. David Hevey at the School of Psychology, Aras an Phiarsaigh, Trinity College Dublin, Dublin 2: Telephone: 01 896 2406

email heveydt@tcd.ie

Yours sincerely,

Agnella Craig.

Invitation letter for study 3: Interview

Trinity College Dublin
The University of Dublin

Invitation to participate in a research study

Discipline of Radiation Therapy,
Trinity Centre for Health Sciences,
St James Hospital Campus,
Dublin 8

Feb 2018

Dear Sir,

I am a member of staff in the Discipline of Radiation Therapy, Trinity College Dublin, and a part-time student in the School of Psychology, Trinity College Dublin. I worked clinically for many years as a Radiation Therapist and I am now doing research into prostate cancer. The title of my study is:

"Prostate Cancer Patients: Relationship of Health Literacy Level, Understanding of Cancer Information and the Shared Decision Making Process".

Research has shown that some patients find it hard to understand information about their health and this can make it difficult to make decisions about health and treatment. I am interested in looking at this issue in men with prostate cancer. Findings from my study may be used to improve information services for men diagnosed with prostate cancer in the future.

If you think you might be interested in participating in this study, please read the attached **participant information leaflet**. It will give you some more information about the study.

I will telephone you in about 1 week to answer any questions about this study. Then, if you are interested in being involved, we can make the arrangements.

In the mean-time, if you have any questions about the study or would like to hear more about the study, please contact me by telephone 085 7216637, or by email at agnella.craig@tcd.ie .

Yours sincerely,

Agnella Craig.

Appendix 3: Participant information leaflets for studies 1, 2, and 3

Participant information leaflet: Nominal Group Technique

Researcher:

Agnella Craig Agnella.craig@tcd.ie 01 – 896 3926

1. Title of study:

Literacy Levels in Prostate Cancer Patients: Relationship of Health Literacy Level, Understanding of Cancer Information and the Shared Decision Making Process

2. Introduction:

Overall this research project will investigate mens ability to understand health information about prostate cancer and the methods used to treat it, and the processes men follow to decide which treatment to opt for.

You are invited to participate in **part 1** of this study which is set up to check what information you think men should have about their disease and the treatment methods available.

2. **Procedures:**

a) In order to be included in this study, you must have previously been diagnosed with prostate cancer.

b) Before the focus group begins, you will be given an opportunity to ask any questions about the study.

c) Once you are happy to proceed with this study, you will need to sign a **consent form.** (enclosed)

d) You can also decide to participate in a follow-up study which consists of one-to-one interviews. If you are interested in this, please circle **yes** on the consent form.

e) The focus group will then begin following a format known as the Nominal Group Technique. (details of this structure are also enclosed)

4. Benefits: This study will highlight the information men with prostate cancer should be given before they chose which treatment to opt for.

5. Risks: There are no known risks associated with participating in this study.

6. Exclusion from participation: You cannot participate in this study if any of the following are true:

- You have never had prostate cancer

7. Confidentiality:

Your identity will remain confidential. Your name will not be published and will not be disclosed to anyone outside the focus group. All data obtained will be stored in a safe and secure location for the 5 years in accordance with data protection laws.

8. Compensation:

This study is covered by standard institutional indemnity insurance. Nothing in this document restricts or curtails your rights.

9. Voluntary Participation: If you decide to volunteer to participate in this study, you can change your mind and withdraw at any time. If you decide not to participate, or if you withdraw, you will not be penalised in any way.

10. Stopping the study: You understand that the investigator may withdraw your participation in the study at any time without your consent.

11. Permission: This research project has Research Ethics Committee approval from School of Education, Trinity College Dublin.

12. Further information: You can get more information or answers to your questions about the study, your participation in the study, and your rights, from Ms Agnella Craig who can be telephoned at 01- 896 3926 or contacted by email on Agnella.craig@tcd.ie. If the study team learns of important new information that might affect your desire to remain in the study, you will be informed at once.

Participant information leaflet: Survey

Patient Information Leaflet

Study Title:	**Prostate Cancer Patients: Relationship of Health Literacy Level, Understanding of Cancer Information and the Decision Making Process**
Investigators' Names:	**Dr. Jerome Coffey, Consultant Radiation Oncologist.** **Ms. Agnella Craig, Discipline of Radiation Therapy, Trinity College Dublin** **Dr. David Hevey, School of Psychology, Trinity College Dublin**

Introduction:

You are being invited to take part in a research study involving patients with prostate cancer. In order to decide whether or not you would like to be part of this study, it is important for you to understand why the research is being done, what it will involve, as well as the possible risks and benefits.

This leaflet gives detailed information about the clinical research study that your doctor will discuss with you. Please take time to read the information carefully. If you would like to know more information, or have any questions about this research study, please be sure to ask your doctor or the researcher.

Background Information:

An increasing number of men are diagnosed with prostate cancer and there are many treatment options which are available to treat this condition. Your doctor will have explained about your disease and the treatment options that are available to you, and you probably have been asked to think about which treatment you will take. Research has shown that some patients find it hard to make this decision, and many aspects can affect this.

Your ability to understand medical jargon and information about your health is referred to as **health literacy**. It is known that your health literacy level is one aspect that can affect how you make decisions about your health.

We are using an anonymous questionnaire in this study. If you agree to participate, you will need to fill in this questionnaire which collects some information about you such as your age and marital status. We will also check your cancer knowledge and your health literacy level. You do not need to put your name or any identifiable information such as date of birth,

address or hospital number on this questionnaire. Where you fill in this questionnaire is up to you – you can chose to do it:

1. **By telephone** - the researcher will read out the questions to you

   or

2. **Face-to-face** -the researcher will meet you and go through the questions with you

   or

3. **By post**- the researcher will sent you a questionnaire in the post with a stamped envelope for you to return it, once you finish.

We hope that this research will help to identify the reasons some people find it particularly difficult to make decisions about their treatment. We can then look at what can be put in place to make this easier for men in the future.

A follow up study will be run at a later stage. This follow-up study will involve a face-to-face interview with the researcher. If you think you would like to be contacted in the future about the follow up study, you can give your name and contact details to the researcher.

Who is carrying out this research study?

The research is being carried out by doctors within St Luke's Radiation Oncology Network, St James hospital, and Beaumont hospital as well as researchers from Trinity College Dublin.

What is the purpose of the study?

The purpose of the study is to gather information about prostate cancer patients- what they know about their disease, their health literacy level and how they make decisions about their treatment.

How many people will take part in the study?

About 85 men will take part in the study.

Do I have to take part in the study?

No. It is up to you to decide whether or not to take part. If you decide not to take part, it will not affect your treatment. If you decide to take part, you will be asked to fill-in a questionnaire. If you decide to take part but later change your mind, you are free to withdraw up to the point that you complete and submit the survey.

Your decision to participate in this study will not affect the standard of care you receive. Also, your doctor may decide to withdraw you from the study if it is in your best interest.

What do I have to do to take part in the study?

If you decide to participate in our study, a researcher will give you a questionnaire to fill-in. This questionnaire involves answering questions about you and will take about 30 minutes in total. It is important to fill-in this questionnaire BEFORE you start your treatment but AFTER you make your decision about treatment. You can decide to fill in the questionnaire at home, over the telephone or with the researcher at a time and place that is convenient to you.

Are there any possible side effects from taking part in this study?

No. However if you become upset during the research, the research will stop and you will be provided with the contact details of the Irish Cancer Society support services.

What are the possible benefits from taking part in this study?

Participating in the study may be of no direct benefit to you; however participating in this study will help us to learn more about the information needs of prostate cancer patients. This research will hopefully allow us to improve the information we give to patients in the future.

What are the costs of taking part in this study?

There are no costs associated with taking part in this study

Will my taking part in this study be kept confidential?

Information about your participation will be kept confidential. Because you do not have to provide your personal details in this study, all the data is anonymous, and any results cannot be directly linked back to you. However there are statutory limits to confidentiality and any disclosure that indicates risk to you or others or illegal activity needs to be passed on to relevant authorities.

If you chose to provide your contact details for the follow up study, this information will be kept securely and not made available to anyone outside the research team.

The results of this study will be shared with other researchers and may be presented at conferences or published in a scientific journal, but your name or personal information will not be used.

Who has reviewed and approved this study?

This study has been approved by the Research Ethics Committees at Saint Luke's Radiation Oncology Network, and Trinity College Dublin.

Contacts for further information:

If you have any questions concerning the procedures of this study, or if any problems arise during the study, you should contact the study coordinator:

Study Coordinator: Ms. Agnella Craig Telephone: 01 896 3926

E-mail: craigag@tcd.ie Fax: 01 6712006

Study Supervisor: Dr. David Hevey Telephone: 01 896 2406

E-mail: heveydt@tcd.ie Fax: 01 6712006

For questions about your rights or if you wish to make a complaint whilst taking part in this study, call the **Corporate Services Officer** (01 4065000) and your complaint will be dealt with promptly.

Participant information leaflet: Interviews

Study Title:	**Prostate Cancer Patients: Relationship of Health Literacy Level, Understanding of Cancer Information and the Decision Making Process**
Investigators' Names:	**Dr. Jerome Coffey, Consultant Radiation Oncologist**
	Ms. Agnella Craig, Discipline of Radiation Therapy, Trinity College Dublin
	Dr. David Hevey, School of Psychology, Trinity College Dublin.

Introduction:

This Participant Information Leaflet gives detailed information about the study. Please take time to read the information carefully. If you would like to know more about anything mentioned in this information sheet, or have any questions about this research study, please be sure to ask the lead researcher- Agnella Craig.

Background Information:

An increasing number of men are diagnosed with prostate cancer and there are many treatment options which are available to treat this condition. Your doctor will have explained about your disease and the treatment options that are available to you, and you may have been asked to think about which treatment you would prefer. Research has shown that some patients find it hard to make this decision, and many aspects can affect this. This part of the study is interested in finding out how people make this decision. We are using a **semi-structured interview** to try and find out this information.

A semi-structured interview is the term given to a focused conversation where a set of questions are followed but other questions may also be asked. This will depend on your answers.

If you agree to participate in this part of the study, you will first be asked to sign a consent form, which states that you agree to being interviewed and that you agree to have this interview recorded. When and where this interview will take place is up to you, and it can be done face to face or over the telephone.

We hope that this research will help to identify the reasons some people find it particularly difficult to make decisions about their treatment. We can then look at what can be put in place to make this easier for prostate cancer patients in the future.

Who is carrying out this research study?

The research is being carried out by doctors within St Luke's Radiation Oncology Network, St James hospital, and Beaumont hospital as well as a researcher from Trinity College Dublin.

What is the purpose of the study?

The purpose of the study is to gather information about how prostate cancer patients make decisions about their treatment.

How many people will take part in the study?

About 12 men will take part in the study.

Do I have to take part in the study?

No. It is up to you to decide whether or not to take part. If you decide not to take part, it will not affect your care.

If you decide to take part, you will be asked to participate in a semi-structured interview. If you decide to take part but later change your mind, you are free to withdraw at any time up until the analysis of the interview is completed without giving a reason.

Your decision to participate in this study will not affect the standard of care you receive. Also, your doctor may decide to withdraw you from the study if it is in your best interests.

What do I have to do to take part in the study?

If you decide to participate in our study, you will be asked to participate in a semi-structured interview which will take about 40 minutes in total. Before the interview starts, you will be asked to fill in a short sheet which captures some information about you such as your age and marital status. You do not need to put any identifiable information such as your name, date of birth, address or hospital number on this form.

Are there any possible side effects from taking part in this study? No.

What are the possible benefits from taking part in this study?

Participating in the study may be of no direct benefit to you; however participating in this study will help us to learn more about the needs of prostate cancer patients. This research will hopefully allow us to identify ways to help patients make treatment decisions in the future.

What are the costs of taking part in this study?

There are no costs associated with taking part in this study

Will my taking part in this study be kept confidential?

Information about your participation will be kept confidential. Because you do not have to provide your personal details in this study, the results cannot be directly linked back to you. The results of this study will be shared with other researchers and may be presented at conferences or published in a scientific journal, but your name or personal information will not be used.

Who has reviewed and approved this study?

This study has been approved by the Research Ethics Committee at Saint Luke's Radiation Oncology Network, and the Research Ethics Committee at Trinity College Dublin.

Contacts for further information:

If you have any questions concerning the procedures of this study, or if any problems arise during the study, you should contact the study coordinator:

Study Coordinator: Ms. Agnella Craig Telephone: 01 896 3926

David Hevey Tel 01 896 3914

For questions about your rights or if you wish to make a complaint whilst taking part in this study, call the Corporate Services Officer on 01 4065000 and your complaint will be dealt with promptly.

Appendix 4: Consent form for studies 1 and 3

Consent form study 1: Nominal Group Technique

PROJECT TITLE: ***Literacy Levels in Prostate Cancer Patients: Relationship of Health Literacy Level, Understanding of Cancer Information and the Shared Decision Making Process***

PRINCIPAL INVESTIGATOR: Agnella Craig

BACKGROUND:

This project involves your participation in a focus group during which we will discuss information you think men with prostate cancer should be given before deciding on which treatment to opt for. This focus group will be audio-recorded and transcribed at a later date. It will last for about 1 hour. Your full name will be protected at all times through the use of a coding system, and other participants in your group will only be aware of your first name.

DECLARATION:

I have read, or had read to me, the information leaflet for this project and I understand the contents. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I am aware that my focus group will be audio-recorded. I understand that I may withdraw from the study at any time and I have received a copy of this agreement.

I understand that there may be a follow-up to this study which will consist of one-to-one interview.

I am interested in being contacted for the follow-up interview.

Please circle whichever applies to you. **Yes** **No**

PARTICIPANT'S NAME: .....

CONTACT DETAILS: .....

PARTICIPANT'S SIGNATURE: .....

Date:.....

Statement of investigator's responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

INVESTIGATOR'S SIGNATURE:.....
Date:.....

Consent form study 3: Interviews

Consent Form

Project Title:	**Prostate Cancer Patients: Relationship of Health Literacy Level, Understanding of Cancer Information and the Decision Making Process**
Lead Investigator's Name:	**Ms. Agnella Craig, Discipline of Radiation Therapy, Trinity College Dublin**

Background

This project aims to investigate how men make decisions about prostate cancer treatment. It involves filling in a short form and participating in a semi-structured interview during which we will discuss your decision-making about your treatment. These interviews will be audio-recorded and transcribed at a later date. The duration of the interview will about 40 minutes. Your identity will be protected at all times through the use of a coding system. Should you wish, you may access the transcript of your interview upon request. This material will not be used in future unrelated studies without further specific permission being obtained.

Declaration

I have read, or had read to me, the information leaflet for this project and I understand the contents. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I understand that my answers to the semi-structured interview will be recorded, but no identifiable characteristics are present on the recording and that I will be given an identity number to use should I wish to view a transcript of this recording. I understand that I may withdraw from the study at any time and I have received a copy of this agreement.

Participant's Name: ……..

Contact Details: ……..

Participant's Signature: ……..

Date:……..

Statement of Investigator's Responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

Investigator's Signature:…… Date:……

Appendix 5: Debriefing letter for study 3

Debriefing sheet

"Prostate Cancer Patients: Relationship of Health Literacy Level, Understanding of Cancer Information and the Decision Making Process"

Dear Participant,

Thank you for participating in this study which is investigating how men, recently diagnosed with prostate cancer make decisions about their treatment options. Your input will help us when designing information services for men diagnosed with prostate cancer in the future.

If you have concerns or questions in relation to your recent diagnosis, please remember to contact your medical team in St. Lukes Radiation Oncology Network.

If you have general concerns or questions in relation to prostate cancer, the Irish Cancer Society offers a confidential service-you can contact the Cancer Nurseline: on **Freephone** 1800 200 700 (Monday - Friday 10-4), or for General enquiries on 01-2310500

Or you can email them as follows:

- Cancer information enquiries cancernurseline@irishcancer.ie
- Support support@irishcancer.ie
- General enquiries reception@irishcancer.ie

Details of their online community are available at https://www.cancer.ie/community

Having completed this study, should you have any questions or concerns in relation to this study, please contact the researcher or the research supervisor, details as follows:

Researcher: Ms. Agnella Craig,

Email: craigag@tcd.ie

Supervisor: Dr. David Hevey

Email heveydt@tcd.ie

Phone 01 896 3914.

We appreciate your time and interest in this study.

Yours sincerely,

Agnella Craig.

Appendix 6: Nominal group technique – data collection

Details of structure given to participants:

1	Introduction- It is important to welcome participants and inform them of the purpose of the group session and the procedure that is carried out. Following the introduction participants are given written information on the topic so all participants have an equal background on the topic to be discussed.
2	Generating of Ideas- Each participant is supplied with a sheet of paper with the question to be addressed written on top of the page. Participants are asked to silently write down any ideas that come to mind when considering the question. This section is allowed approximately 10 minutes.
3	Sharing Ideas- The participants then share the ideas they have generated in a round robin style feedback session. The facilitator records each idea on a flip chart in the exact words spoken by the participant. This process continues until all ideas have been presented. There is no debate at this stage so all participants get the opportunity to make an equal contribution and a written record is made of all the ideas generated.
4	Group Discussion- Participants may look for clarity on some of the ideas generated. The facilitator must ensure that not too long is spent in this area but that discussion of all ideas is thorough. It is important to remain non-judgemental and non-critical of any ideas that are put forward.
5	Voting and Ranking- This is the prioritising of ideas generated from the original question. The meeting concludes after reaching a specific outcome e.g. the top ten ideas that men feel they ought to know before making a decision about treatment options for prostate cancer.

Structure of the Nominal Group Technique

Demographic sheet

1. **Age:** _____
2. **What level did you <u>complete</u> your education at? (please tick the box)**

   Primary school ☐

   Lower Secondary level (e.g. to intermediate certificate stage or equivalent) ☐

   Upper Secondary level (e.g. to leaving certificate stage or equivalent) ☐

   Third level ☐

   Post graduate level ☐

   Other please specify _____
3. **Are you currently working? (please circle)**

   Yes Is it Fulltime or Part Time?

   No Are you Retired or Unemployed?

   Other please specify : _____
4. **Please specify your current or last occupation (job)** _____
5. **Approximately when were you diagnosed** _____
6. **What was the stage of your disease when you were diagnosed** _____
7. **What was the Gleason score?** _____
8. **What was your PSA level?** _____
9. **Please list the treatment options that were available to you?**

   _____ _____

   _____ _____
10. **What treatment option/options did you follow?** _____
11. **When did you complete treatment, or are you still on treatment?** _____

Appendix 7: Questionnaire for study 2

(validated instruments listed but not included due to copyright)

Participant number _____

Lead Researcher: Agnella Craig

Telephone: 01 896 3926 Email: craigag@tcd.ie

Prostate Cancer Patients:

Relationship of Health Literacy Level, Understanding of Cancer Information and the Decision Making Process

How to fill in this questionnaire

To complete this, you will need to answer some questions about you, about your illness and about the treatment options for prostate cancer.

For some questions, you can:

- Tick the box to show your answer like this: ☐ **No** ☐ **Yes**
- Or like this:

True	False

- Or you may have to read a statement and show how much you agree or disagree with it like this:

Please read each statement carefully and indicate how much you disagree or agree with each statement	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
1. Read this statement then tick the box					
2. Read this statement then tick the box					

- Or you may have to fill in your answer along the dotted line .....
- If you **don't know the answer**, please put **?**
- If you **don't want to answer the question**, please put **X**

Thank you for taking the time to complete this questionnaire.

Section A Please answer some questions about you

1. What Age are you? .....

2. What nationality are you? .....

3. If English is not your first language , please tick how well you understand English

- ☐ Below average
- ☐ Average
- ☐ Above average
- ☐ Not applicable

4. What **county** do you live in .....

5. Please state your marital status.....

6. Which of the following best describes you? (please tick your answer)

- ☐ Living with a spouse or partner
- ☐ In a significant relationship, but not living together
- ☐ Not in a significant relationship

7. What level did you finish your education at? (please tick your answer)

- ☐ Primary School
- ☐ Lower Secondary level (e.g. to Intermediate Certificate stage or equivalent)
- ☐ Upper Secondary level (e.g. to Leaving Certificate stage or equivalent)
- ☐ Third level -non-degree (e.g. Certificate or Diploma)
- ☐ Third level- Degree or higher

If **third level** , please tick your main subject area

- ☐ Education
- ☐ Humanities and arts
- ☐ Computingg
- ☐ Social services
- ☐ Health
- ☐ Engineering, manufacturing and construction
- ☐ Social sciences, business, law
- ☐ Agriculture and veterinary
- ☐ Life science, physical science, mathematics and statistics

8. Are you currently working? (please tick your answer)

- ☐ **No** Are you Retired or Unemployed?.....
- ☐ **Yes** Is it Fulltime or Part Time?.....
- ☐ **Other** please specify: .....

9. Please state your current or last occupation (job) .....

(for example: Plumber, builder, factory worker, factory manager, secondary school teacher)

10. Please tick which option below best describes you

☐ Employer or manager	☐ Non-manual worker	☐ Unskilled
☐ Higher professional	☐ Manual worker	☐ Farmer
☐ Lower professional	☐ Semi-skilled	☐ Agricultural worker

11. How often do you listen to news items (Radio or TV)?

- ☐ More than once a day
- ☐ Once a day
- ☐ Every 2- 3 days
- ☐ Once a week
- ☐ Less frequently
- ☐ Never

How often do you read a newspaper (paper copy or online)?

- ☐ More than once a day
- ☐ Once a day
- ☐ Every 2- 3 days
- ☐ Once a week
- ☐ Less frequently
- ☐ Never

12. Do you have any medical conditions for which you are receiving treatment (please tick your answer) ☐ **No** ☐ **Yes**

If yes, please state the condition .....

13. Do you have Private Health Insurance (please tick your answer) ☐ **No** ☐ **Yes**

14. Is there a history of cancer in **your family** (please tick your answer) ☐ **No** ☐ **Yes**

If yes, what is your relationship to this person? (For example was it your brother/sister/mother/father **Details:** .....

What type of cancer did they have? ....

15. Have any of your family been diagnosed with **prostate cancer**?

☐ **No** ☐ **Yes** What is your relationship to this person? .....

16. Have any of your friends been diagnosed with **prostate cancer** ☐ **No** ☐ **Yes** How many friends? .....

17. Before your prostate cancer diagnosis, were you ever diagnosed with cancer? ☐ **No** ☐ **Yes**

If yes, when was this? .....What type of cancer was it? ..... What treatment did you have for it.....

18. Do you find it easy to fill out forms ☐ **No** ☐ **Yes**

19. Did someone help you to fill out this form? ☐ **No** ☐ **Yes** if yes, what is your relationship to this person.....

Please fill in as much as you can in relation to your recent diagnosis of prostate cancer (You might not know some of these details)

If you don't know the answer, just put ? **If you don't want to answer the question, please put X**

1. Approximately when were you diagnosed with prostate cancer Month .....Year.....
2. What is the stage of your disease .....
3. What is your Gleason score .....
4. What is your PSA level .....
5. Please list all the treatment options that are available to you for your stage of disease? .....

....

6. Which treatment option/options have you decided to take? .....
7. What did you use to help you make a decision about the treatment: Please tick ALL that apply and give some more detail along the dotted line....

- ☐ The leaflets that I was given What leaflets/booklets? .....
- ☐ Other leaflets/booklets that I found What leaflets/booklets? .....
- ☐ The internet Which websites? .....
- ☐ I didn't use any of these Why .....
- ☐ I used .....

8. Did your doctor tell you where you can find more information about your disease and your treatment options ☐ **No** ☐ **Yes**

Please give the details here .....

9. Did your doctor tell you how long you had to make a decision about your treatment ☐ **No** ☐ **Yes**

Please give the details here .....

10. Did your Doctor tell you the pros/advantages and cons/disadvantages of each treatment? ☐ **No** ☐ **Yes**

Please give the details here .....

11. Did you discuss your treatment options with someone else- ☐ **No** ☐ **Yes**

If yes: was this? (Please tick ALL that apply, and if applicable give details along the dotted line…)

- ☐ Your Wife/Spouse/Partner ……
- ☐ Your friend or friends ……
- ☐ Your family (children, brothers, sisters?) ……
- ☐ Another Doctor (GP/Specialist?) ……
- ☐ A Nurse ……
- ☐ Someone else not listed here, please give the details ……

- **The Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet, & Farley, 1988)**
- **The Generalized Self-Efficacy Scale (Schwarzer & Jerusalem, 1995)**
- **The statement format of the Decision Conflict Scale (O Connor, 1995)**
- **Adapted version of the prostate cancer knowledge scale (Deibert et al., 2007) is shown below**

Section B Please answer some questions about what you know about prostate cancer and how you feel about treatment

If you don't know the answer, please put ? If you don't want to answer the question, please put X

Please read the statement and tick true or false	True	False
1. The prostate lies below the bladder and in front of the rectum (back-passage).		
2. If you have brothers or sons they are at higher risk for prostate cancer.		
3. A man can have prostate cancer without having any pain or symptoms.		
4. Antibiotics can be used to cure prostate cancer.		
5. The goal of hormone therapy is to lower the levels of the male hormone, testosterone.		
6. Surgery or radiation can cure prostate cancer in its early stage.		
7. Chemotherapy is given to men with early prostate cancer.		
8. Prostate cancer treatment can increase your sex drive.		
9. Eating certain foods can lower (reduce) the risk of prostate cancer.		

10. Can you explain in your own words what **urinary incontinence** means?

11. Can you explain in your own words what **erectile dysfunction** means?

12. Can you explain in your own words what **infertility** means?

The possible long term side effects of Surgery are: (tick all that apply)	
☐ Urinary Incontinence	☐ Diarrhoea or bowel problems
☐ Erectile dysfunction	☐ Infertility
☐ Bladder problems	☐ Osteoporosis
☐ Hot flushes	☐ Weight gain

The possible long term side effects of Hormone Therapy are: (tick all that apply)	
☐ Urinary Incontinence	☐ Diarrhoea or bowel problems
☐ Erectile dysfunction	☐ Infertility
☐ Bladder problems	☐ Osteoporosis
☐ Hot flushes	☐ Weight gain

The possible long term side effects of Radiotherapy are: (tick all that apply)	
☐ Urinary Incontinence	☐ Diarrhoea or bowel problems
☐ Erectile dysfunction	☐ Infertility
☐ Bladder problems	☐ Osteoporosis
☐ Hot flushes	☐ Weight gain

The possible long term side effects of Brachytherapy (internal radiotherapy) are: (tick all that apply)	
☐ Urinary Incontinence	☐ Diarrhoea or bowel problems
☐ Erectile dysfunction	☐ Infertility
☐ Bladder problems	☐ Osteoporosis
☐ Hot flushes	☐ Weight gain

- **16-item scale (HLS-EU-Q16) Health Literacy Survey EU questionnaire (Sørensen et al., 2015)**

Appendix 8: Interview – data collection

Demographics

1. Age: _____
2. Which of the following best describes you:
   - ☐ Living with a spouse or partner
   - ☐ In a significant relationship, but not living together
   - ☐ Not in a significant relationship
3. Do you have private health insurance **yes** **no**
4. What level did you complete your education at? (please tick the box)
   - ☐ Primary school
   - ☐ Lower Secondary level (e.g. to intermediate certificate stage or equivalent)
   - ☐ Upper Secondary level (e.g. to leaving certificate stage or equivalent)
   - ☐ Third level
   - ☐ Post graduate level
   - ☐ Other…… please specify _____
5. Are you currently working?
   - ☐ Yes Is it Fulltime or Part Time?_____
   - ☐ No Are you Retired or Unemployed?_____
   - ☐ Other please specify : _____
6. Please specify your current or last occupation (job) _____

In general, when thinking about your health and hospital/doctor visits:

7. "How often do you have someone (like a family member, friend, hospital/clinic worker or caregiver) help you read hospital materials?" _____
8. "How often do you have problems learning about your medical condition because of difficulty understanding written information?" _____
9. "How confident are you filling out forms by yourself?" _____
10. When faced with making medical decisions in general, how would you like the decision to be made:
    - ☐ *the doctor alone*
    - ☐ *mostly the doctor*
    - ☐ *you and the doctor equally*
    - ☐ *mostly you*
    - ☐ *you alone*
11. When faced with making this decision about your prostate cancer treatment, how would you like the decision to be made- please circle your answer
    - ☐ *the doctor alone*
    - ☐ *mostly the doctor*
    - ☐ *you and the doctor equally*
    - ☐ *mostly you*
    - ☐ *you alone*
12. Have any of your family been diagnosed with cancer? **yes** **no**

13. Have any of your friends been diagnosed with cancer, that you know of **yes** **no**
14. Before your PrCa DX , where you ever dx with cancer? **yes** **no**
15. What stage is your prostate cancer?_____
16. What is your Gleason score? _____
17. What is your PSA level? _____
18. What treatment options are available to you?
    1._____ 3. _____
    2._____ 4. _____
19. What treatment option/options have you decided on _____

Interview questions, with <prompts> and [annotations on driver for question]

1. Personal Experience with Prostate Cancer: [LITERATURE]

Can you tell me a little about when you received your cancer diagnosis?

How did the doctor describe your disease

<can you think of any of the words he/she would have used>

What was your reaction when you heard it?

What is your understanding of your prostate cancer (severity, prognosis)?

< what would you say is the likely outcome or prognosis for you

Who would you say has the most control over your treatment

(doctor/medical team, self, God, no one)?

2. Thinking back to those meetings with the Doctors (about your diagnosis and treatment options) [LITERATURE]

Did you have many questions for the doctor

How easy was it for you to ask your doctors questions

What types of questions did the doctor ask you –

did he/she ask you anything that surprised you

Was there a discussion about what is important to you

your daily life things you like to do ,

how was the information provided to you?(verbal, written… language used…..

how long were you given to make the decision? [STUDY 1]

Was this timeframe ok for you

3. Treatment Options and Perceived Efficacy and Side Effects: [STUDY 2]

What treatments options do you have (or being offered)?

What do you think about each of the options?

Would you be able to tell me something about treatment side effects

< what do you understand by the term side effects>

What is your understanding of the side effects of each treatment?

What are they?

<Can you give me an example of how this might affect you>

4. Treatment Decision Making Process: [LITERATURE]

Tell me about how you made the decision to have _____ treatment.

<can you talk me through the steps that you took to arrive at your treatment decision>

Start from the beginning and tell me about all the things that entered into the decision- people, places, or moments that helped you or influenced your decision, and tell me all the way up to when you made your final decision.

Who was involved in the decision making?

What treatment options did you consider?

Why did you choose this option over the others?

did you change your mind at any stage?

< what do you think influenced you to change your mind>

What kinds of things did you consider when trying to decide?

How important was each of these considerations?

How much would you say, the doctor's advice guided you in coming to a decision

< did you make the decision based on what the dr said >

Would you have preferred if the dr made the decision for you?

<why is this, can you tell me a little more about this, is this usually how you feel when faced with making decisions about your health > connect back to earlier question

Did you seek a second opinion?

If yes, did you find it helpful? What was recommended and/or advice?

What would you say was the most important thing/factor that influenced your decision?

Would you have talked with others about your decision ….who did you speak with

< ascertain if support only or assist with decision making >

Had you decided on an option before discussing it with others?

Did you change your mind after speaking with others?

Would you have discussed your options and the treatments with someone else who had prostate cancer

Which treatment did they have? <.. this is the same treatment that you picked.. , had you decided on this treatment before you met them?>

When you were thinking about your options, to what extent did the side effects guide your decision?

Did you think more about the short term side effects, or the long term side effects?

When you were thinking about your options, to what extent did the practicalities of the different treatment options come into your decision making

< what practicalities would you have thought about…….

would you have thought about the financial cost of the treatment,

<Would you have thought about getting to hospital for surgery or RT, duration of treatment, time off work….>

How much would these have mattered to you, how much would you say they guided your final decision?

5. Perceived Facilitators and Barriers of Decision Making: [LITERATURE, STUDY 1]

Now thinking about things that helped you to make your decision,

What helped your decision making?/ What helped you to make your decision

Have you experienced any barriers? What wasn't so helpful ?

What hindered the decision making (probing resources/social support, knowledge/beliefs/trust/health literacy)?

Did you get the kind of information you want/feel you need about (disease) and its treatment?

Where did you get information about prostate cancer and its treatment?

How easy did you find it to get information about **your** diagnosis and **your** treatment options?

How easy was it to know which information applied to your situation?

How difficult was it for you to make the final treatment decision?

How confident or comfortable are you that you have made the best–decision possible for you?

Is there anything your doctor(s) could do or should not have done to make it easier for you to make a decision?

What would your advice be if a future patient asked you for advice on choosing a treatment for prostate cancer?

what do you think would make it easier for patients in the future,

< more discussion, return visit, more written information tailored info, having family /others involved , info on where to get information , online >

Just before we finish, if I can sum up ,

Earlier you mentioned that you prefer to _____when making decisions about treatment, and/but when making the decision about your pr ca treatment you would prefer _____

Is there anything else you would like to tell me or discuss with me ?

Close with: **Info on debriefing sheet**

Appendix 9: Example of scoring system – survey

Self-designed prostate cancer knowledge test

PrCaK_ SE Section A: participant correctly defines 2 of the 3 terms associated with prostate cancer treatment therefore scoring 66.6% for section A.

PrCaK_ SE Section B: having stated that 2 treatment options are available to him (Surgery and external beam radiotherapy), he has a total achievable score of 200 in section B.

For surgery - 3 side effects are associated (urinary incontinence, Erectile dysfunction and Infertility), therefore each correct response scores 33.3% and an incorrect response scores negative 33.3%. The participant below scores (33.3* 3 = 100 - 33.3) = 66.6 in total as osteoporosis is not an associated side effect of surgery. For external beam radiotherapy, as 4 options apply, he scores 25 for each correct response and negative 25 for each incorrect giving him a score of (25*4 = 100-25) =75 in total.

Table - Example of scoring for self-designed PrCaK_ SideEffects

Surgery *(3 apply x 33.3 per correct tick)*	
✓ Urinary Incontinence	Diarrhoea or bowel problems
✓ Erectile dysfunction	✓ Infertility
Bladder problems	✓ Osteoporosis
Hot flushes	Weight gain

External beam Radiotherapy *(4 apply x 25 per correct tick)*	
Urinary Incontinence	✓ Diarrhoea or bowel problems
✓ Erectile dysfunction	✓ Infertility
✓ Bladder problems	✓ Osteoporosis
Hot flushes	Weight gain

Scoring:

Surgery
33.3 x 3 (correct) = 100
- 33.3 (1incorrect)= **66.6**

Radiotherapy
25 x 4 (correct)= 100-25
(1 incorrect)=**75**

Scoring

Section	**Calculation**	**Total Score**
Section A (terminology)	**2 correct**	**66.6**
Section B:		
Total achievable	2 modalities x 100	200
Applicable side effects	66.6 (surgery) + 75 (radiotherapy)	141.6
PrCaK_ SE Section B:	**(141.6/200) x 100**	**70.80**