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SO ACTIVE

The impact of close interpersonal relationships on men with localised prostate cancer on Active Surveillance.

by

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Thesis for the degree of Doctor of Philosophy

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ABSTRACT

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Men with localised, slow growing prostate cancer (PCa) are increasingly being offered active surveillance (AS). AS involves closely monitoring the cancer with a view to delaying or avoiding active treatment and the associated side effects. Living with an untreated cancer can have a negative psychological impact on both the patient and their significant other (SO). Previous research suggests partners/SOs of men on AS are important in the men's experiences, acceptance and adherence to AS, and also have a big influence on treatment decision-making. Research encompassing both men on AS and their significant others is limited. This thesis explores patient and SO experiences of undergoing AS for PCa, the way in which dyads perceive each other's AS related feelings and reactions, and how these feelings and reactions impact each other.

A qualitative synthesis explored the evidence base for experiences of men on AS and their SOs. The synthesis of 28 studies revealed a large variation in perceptions of disease severity in men on AS ranging from perceptions that the cancer is 'insignificant', to something 'worse than a heart attack or stroke'. Similarly, levels of anxiety and uncertainty varied across the sample. The greatest expressed concern was missing the window of opportunity to treat. SOs were reported to be heavily involved throughout diagnosis, treatment decisions and subsequent lifestyle changes, and also reported feelings of anxiety and uncertainty.

A quantitative survey study was conducted with men on AS and their SOs. Participants (n=43) were recruited through charity advertising (Prostate Cancer UK (PCUK), Prostate Cancer Support Organisation (PCaSO) and Tackle Prostate Cancer). Recruitment was harder than anticipated and the small sample size resulted in an underpowered study from which limited conclusions could be drawn. Correlational analysis and paired samples t-tests were conducted and results interpreted with caution. The findings suggest that these men on AS and their SOs were not experiencing significant anxiety or depression, however, SOs appear more anxious than their male counterparts.

A qualitative interview study with 9 men on AS for PCa and their SOs (n=18) indicated the dyads function as an interconnected, interdependent unit with interlinked emotional responses, often triggering each other. Both members of the dyad experience PCa related distress, and both men on AS and SOs describe two-directional support. Differing feelings about AS and the decision not to pursue active treatment were common within couples, with the men prioritising the avoidance of active treatment side effects, and SOs keen to minimise the chance of disease progression, feeling less concerned about potential treatment side effects. More emotional support is needed for this population.

In conclusion, some find the AS pathway distressing, and AS specific support is needed for men and their SOs. SOs of those on AS often view themselves as also on AS, and suffer the same, if not more, distress. Responses and reactions to the PCa diagnosis and AS pathway of the men with PCa and their SOs are intricately linked, and this needs more recognition in clinical practice.

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DECLARATION OF AUTHORSHIP

I, Stephanie Hughes, declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

The impact of close interpersonal relationships on men with localised prostate cancer on Active Surveillance: an exploratory study.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. Parts of this work have been published as:
    - Hughes S, Kassianos AP, Everitt HA, Stuart B, Band R. Planning and developing a web-based intervention for active surveillance in prostate cancer: an integrated self-care programme for managing psychological distress. Pilot and Feasibility Studies. 2022;8(1):175.
    - Hughes, S., Everitt, H.A., Stuart, B., et al. (2024) The experiences of men on active surveillance for prostate cancer and their significant others: a qualitative synthesis. Psycho-oncology. https://doi.org/10.1002/pon.6324.

Signed:

Date:

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Secondly, Professor Hazel Everitt has been the most incredibly supportive person throughout both my career and PhD journey. Hazel became my main supervisor after George passed away. Hazel has always made space and time to listen to my ideas and concerns, she has seen me through some tricky times, and provided unwavering encouragement and support to ensure I continue on the best path for me.

I would also like to thank the rest of my supervisory team: Dr Becky Band for always allowing me the space to air my jumbled thoughts and helping me to order them into something that makes sense. Dr Beth Stuart has been such a positive and calming influence and always so incredibly helpful (especially with the statistics).

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Thank you to the charities who helped me recruit participants by advertising my study (Prostate Cancer UK (PCUK), Prostate Cancer Support Organisation (PCaSO) and Tackle Prostate Cancer). A special thank you to PCaSO for providing a grant to partly fund the research*.

On a more personal note, I am thankful to my family, friends and colleagues for spurring me on when I felt I might never reach the end. Thank you to my husband for encouraging me to keep going and for listening to me practice many presentations on repeat, my Mum for always believing in me even when I struggled to believe in myself, and my two children who both came along during my PhD to add to the chaos and fun.

Finally, my thanks extend to the participants who took part in my research studies, without whom this PhD would not have been possible.

*(PCaSO were not involved in the study design or interpretation of the results).

Definitions and Abbreviations

Acronym	**Full term**
AS	Active Surveillance
CLL	Chronic Lymphocytic Leukaemia
CNS	Cancer Nurse Specialist
CRN	Clinical Research Network
CRUK	Cancer Research UK
CSM	Common Sense Model (of Self-Regulation)
DCIS	Ductal Carcinoma in Situ
DRE	Digital Rectal Exam
ESRD	End-stage renal disease
GBM	Gay and bisexual men
IPQ	Illness Perception Questionnaire
MLM	Multi-level Modelling
NCRAS	The National Cancer Registration and Analysis Service
PBA	Person-based Approach
PCa	Prostate Cancer
PCaSO	Prostate Cancer Support Organisation
PCUK	Prostate Cancer UK
PIL	Participant Information Sheet
PPI	Patient Public Involvement
PROM	Patient Reported Outcome Measure
PSA	Prostate Specific Antigen
SEM	Structural Equation Modelling
SO	Significant Other
RCC	Renal Cell Carcinoma
RCT	Randomised Controlled Trial

Chapter 1: Introduction to my PhD

1.1 Personal background

1.1.1 My background and research interests

Prior to commencing this PhD, I completed a Health Psychology MSc at The University of Sussex and went on to work on various projects as a Senior Research Assistant at the University of Southampton, across the departments of Psychology and Primary Care, Population Sciences and Medical Education. The projects I have been involved in include the development, implementation and analysis of interventions for various populations and conditions, including fatigue in cancer, weight management, blood pressure management, antibiotic prescribing, cognitive behavioural therapy for irritable bowel syndrome, and the management of anxiety in active surveillance for prostate cancer. My specific research interests include illness prevention, self-management of illness and the psychological aspects of illness.

1.1.2 Why I chose this topic for my PhD

The initial idea for this PhD was sparked by qualitative findings from a previous project I was involved with, titled PROACTIVE (ACTIVE Surveillance in PROstate Cancer). Within my role as Senior Research Assistant on this project I contributed to the development of an intervention designed to support men on active surveillance (AS) for prostate cancer (PCa). With background research indicating that anxiety is the biggest predictor of converting to radical intervention without clinical indication, PROACTIVE aimed to support men with possible feelings of anxiety and uncertainty.

The intervention required participants to complete six weekly online sessions containing information and advice about improving lifestyle habits, approaching talking to others, managing work and dealing with feelings around living with an untreated cancer. In addition to the online sessions the men attended three group support sessions with a specialist nurse, which covered and reinforced the topics introduced in the web component.

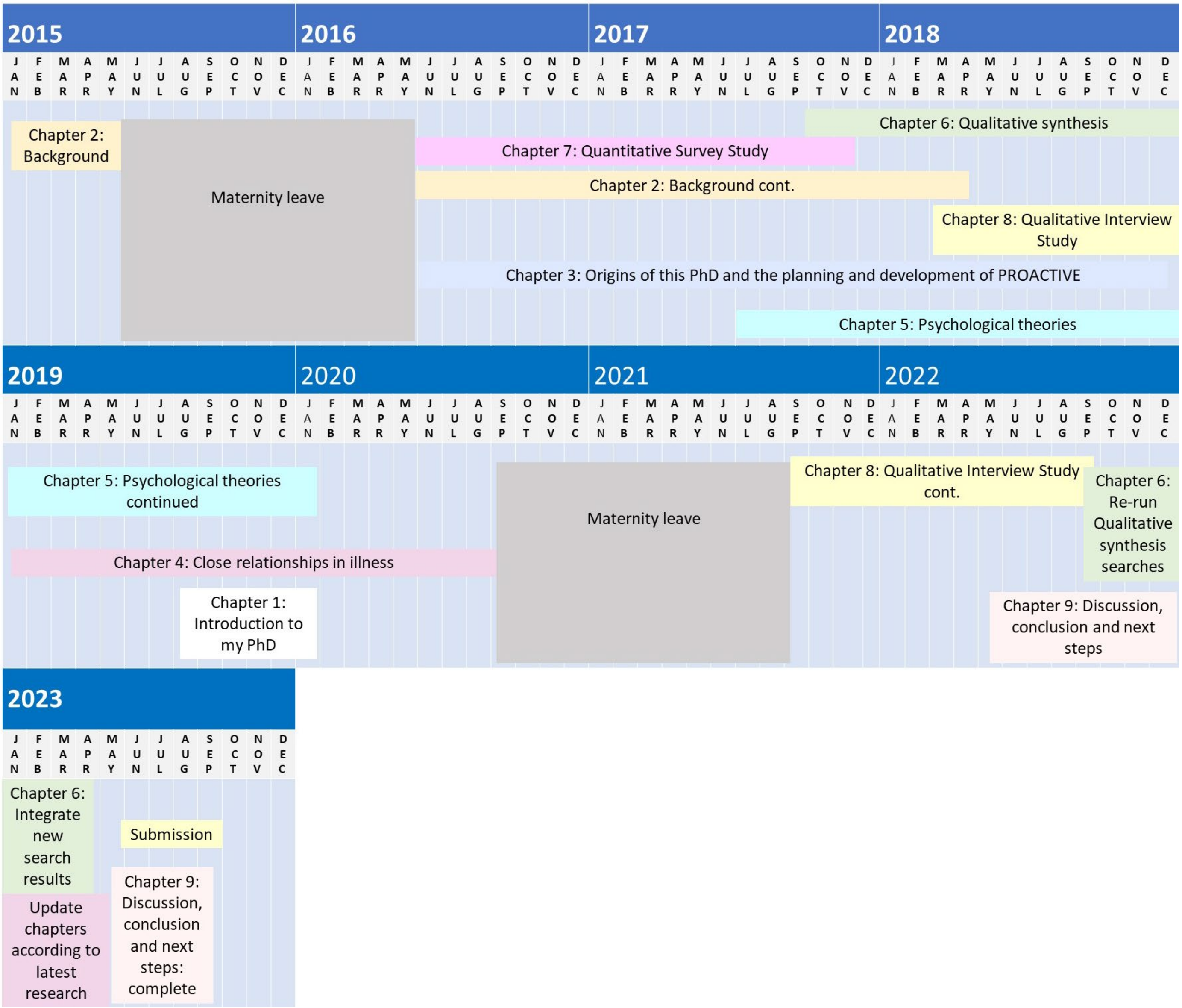
During qualitative interviews with PROACTIVE participants, it became clear that their significant others (mostly wives and partners) were intertwined throughout every part of their PCa journey. They were involved in appointments, treatment decision making, information gathering, talking to others about the cancer and supporting the patients. This was not a topic we had covered in either our quantitative or qualitative measures, but even so, significant others were repeatedly mentioned, and the theme developed naturally and powerfully.

I conducted some background reading around the area of significant others in AS for PCa. Although I came across papers which looked at aspects related to significant others in PCa, papers specific to AS in PCa were limited. Furthermore, I failed to find any literature about the impact of significant others on men on the AS pathway. Using this gap in the literature I drafted a plan for this PhD.

1.1.3 My supervisors' backgrounds and research interests

Professor Hazel Everitt (Professor of Primary Care Research) and general practitioner working clinically seeing patients was my manager for a different project when the idea for this PhD was conceived; with a good working relationship, and a keen interest in research on managing long-term conditions she agreed to be my main supervisor. The late Professor George Lewith (Professor of Primary Care Research) was Chief Investigator for the PROACTIVE trial. He was very supportive of this PhD idea, keen to expand on the findings from PROACTIVE and agreed to be a supervisor. Along with Professor George Lewith, I worked closely with the trial manager for the PROACTIVE study, Dr Sam Watts. Sam had completed a PhD relating to distress in AS for PCa and with this background knowledge he was ideally placed to be a supervisor. Dr Becky Band from the Psychology department completed a PhD examining the impact of significant others in chronic fatigue syndrome. Becky's Psychology background, and experience of researching significant others in chronic illness, became a valuable addition to the supervisory team. In March 2017 Professor George Lewith passed away, and in January 2018 Dr Sam Watts left the University and stepped down as supervisor. In June 2018 Dr Beth Stuart agreed to join my supervisory team. Beth is a medical statistician and quantitative methodologist and has been invaluable in guiding my methodology and providing general support and advice.

1.2 Thesis timeline



1.3 Chapter summary

Chapter 1: Introduction to my PhD

Chapter 2: Background

In chapter 2, I present an introduction to prostate cancer, describe the evolution of testing and treating the cancer, and the evolution of survival trends. I describe an overview of the current treatment available and the psychological impact of PCa, before bringing the focus to the option of active surveillance. I describe the evolution of active surveillance (AS) and the impact on men's lives whilst on an AS programme. I introduce the topic of the significant others (SOs) of those on

AS for PCa and signpost to later chapters where this is explored more in-depth. Finally, I explore the lack of diversity within PCa literature and the implications of this finding.

Chapter 3: Close relationships in illness

In chapter 3, I delve deeper into the intricacies of close relationships in illness. The chapter begins with an evidence-based description of the impact of close relationships in illness outcomes and the impact of chronic illness on significant others. I explore couple's communication in illness and how this might differ from their communication outside of illness. Following this I focus on literature specific to significant others in cancer, dyadic communication in cancer and then examine these issues specific to PCa, and AS for PCa.

Chapter 4: Psychological theories

Chapter 4 explores psychological theories relevant to close relationships in illness. It starts with an exploration of the link between social support and health using The Main Effect Model(1) and The Buffering Effect Model(1) and how these might be applicable to those on AS for PCa. I further explore The Lazarus Stress Theory(2, 3), The Revenson (1990) Ecological Framework, Self-Regulatory Theory(4) and illness perception(5) in relation to AS for PCa and provide critical appraisal of each theory as they are described. I then explore the idea of interdependence in illness before providing a conclusion detailing the implications for this PhD project.

Chapter 5: Methodology

In chapter 5 I describe the epistemological stance taken throughout this PhD. I introduce quantitative and qualitative research and how the methods can be combined in a mixed methods study. I describe the methodology considered for my qualitative synthesis, survey study and interview study, and why I chose to conduct the studies the way I did. I provide a reflexive insight into the challenges I faced and learning opportunities that presented themselves. Finally, I discuss the involvement of Public and Patient Involvement and Engagement (PPIE) throughout this PhD.

Chapter 6: Qualitative synthesis

Chapter 6 presents my qualitative synthesis which aimed to explore the experiences of both men undergoing AS for PCa and their SOs. I provide a detailed account of how I strategically searched bibliographic databases for relevant literature, screened potential articles for inclusion, performed quality appraisal on the included articles and synthesised the results to produce my own set of themes and implications for future practice and research.

Chapter 7: Quantitative survey study

In chapter 7, I provide a detailed account of the quantitative survey study I conducted to answer the main research question: What is the impact of significant others on men on AS for PCa? I present findings from correlational analysis and paired sample t-tests and conclude with recommendations for future research.

Chapter 8: Qualitative interview study

Chapter 8 presents my qualitative interview study. I provide a description of the semi-structured interview guides used for data collection, and present my results in the form of themes. I provide an account of how these results may have implications for future practice and research.

Chapter 9: Discussion, conclusion, and next steps

In this final chapter I reflect on the timeline I followed to conduct this PhD. I bring the quantitative and qualitative findings together and describe the key findings of this PhD in relation to previous literature. I discuss the strengths and limitations of this work, implications for future practice, and go on to discuss possible future research and next steps in this area. I describe my dissemination activities to date, my reflections on personal development, and provide an overall conclusion.

1.4 Overall aims and objectives of this thesis

1. To provide a background of the existing literature around experiences of active surveillance for prostate cancer for both the patients and their significant others.
2. To explore the relationship between significant other responses to, and perceptions of, active surveillance and patient anxiety.
3. To explore associations between relationship quality and illness related dyadic communication, and patient anxiety.
4. To explore the relationship between significant other prostate cancer-related anxiety, and patient anxiety, depression and quality of life.

Chapter 2: Background

2.1 Introduction to prostate cancer

This chapter provides an introduction to prostate cancer (PCa), disease prevalence, and an overview of available treatment options and how they have evolved. Subsequently, I focus on active surveillance (AS) for PCa, its evolution, the psychological impact of living on AS, and touch on the subject of significant others of those on AS for PCa.

PCa is the second most common cancer diagnosis in the UK after breast cancer, and the most common cancer diagnosis in men(6), making up 14% of all cancers(7), and 26% of all male cancer diagnoses in the UK(8). PCa is the fifth leading cause of death in men worldwide(9). The prostate gland can be found only in men, below the bladder. In young adult men it is about the size of a walnut but tends to get larger with age. The main function of the prostate gland is to secrete prostatic fluid which is a component of semen.

The exact causes of PCa are unknown, but risk factors include age, family history, race and obesity. Increasing age is a strong risk factor and PCa usually affects men over the age of 50 years(10) with the average age for diagnosis in the UK being between 65 and 69 years (11). Men with a first degree relative (father, brother or son) with PCa are at increased risk, especially if the relative developed PCa under the age of 60(10). PCa is more common in Black African-Caribbean and African men compared to Caucasian men, but the reason for this is unknown(8). It is thought that in the UK about 1 in 4 Black men (statistic calculated using information from men recorded as 'Black African', 'Black Caribbean' and 'Black other') are likely to develop PCa, compared to 1 in 8 Caucasian men(7, 12).

There is currently no national screening programme for PCa in the UK (see section 2.1.1 for rationale), however, men who request to be tested or present with symptoms (usually lower urinary tract symptoms such as difficulty urinating, or needing to urinate more frequently) should have a full history and examination undertaken and be offered a prostate specific antigen (PSA) test and a digital rectal exam (DRE) in primary care(8). PSA is a protein made by the cells in the prostate, and higher levels of PSA can indicate PCa. Raised PSA levels are treated with caution because although a raised level may indicate PCa, other factors, for example a urinary tract infection, recent vigorous exercise or DRE may raise PSA. PSA levels also increase naturally with age(13).

NICE guidelines advise clinicians to refer men with elevated levels of PSA to secondary care. The guidelines state the normal range for PSA varies by age(14):

Table 1: Age specific PSA thresholds for people with possible symptoms of prostate cancer

Age (years)	**PSA threshold (micrograms/L)**
Below 40	Use clinical judgement
40-49	0-2.5
50-59	0-3.5
60-69	0-4.5
70-79	0-6.5
Above 79	Use clinical judgement

Men with a PSA below the upper threshold may be referred if there are other PCa related symptoms or an abnormal clinical examination of the prostate or risk factors. Similarly, using clinical judgement, men under 40 may be referred if presenting with PCa related symptoms, clinical signs or elevated risk factors(14).

Secondary care assessment usually includes imaging and/or a prostate biopsy, which involves the removal and examination of a small sample of tissue(8). If cancer is confirmed, a Gleason score(15) will be given. Cancerous cells in the biopsy tissue are graded according to their aggressiveness. The Gleason score is calculated by adding together the most frequent grade with the highest grade and ranges from 2-10. The higher the Gleason score, the more aggressive the cancer(15). The table below (published by Cancer Research UK(16)) provides a description of the type of cancer in each grade group.

Table 2: The meaning of Gleason scores and grading

Gleason score	**Grade Group**	**What it means**
Gleason score 6 (or 3 + 3 = 6)[1]	Grade Group 1	The cells look similar to normal prostate cells. The cancer is likely to grow very slowly, if at all.
Gleason score 7 (or 3 + 4 = 7)	Grade Group 2	Most cells still look similar to normal prostate cells. The cancer is likely to grow slowly.

Gleason score 7 (or 4 + 3 = 7)	Grade Group 3	The cells look less like normal prostate cells. The cancer is likely to grow at a moderate rate.
Gleason score 8 (or 4 + 4 = 8)	Grade Group 4	Some cells look abnormal. The cancer might grow quickly or at a moderate rate.
Gleason score 9 or 10 (or 4 + 5 = 9, 5 + 4 = 9 or 5 + 5 = 10)	Grade Group 5	The cells look very abnormal. The cancer is likely to grow quickly.

[1] Sometimes the Gleason score is written showing the separate scores, i.e.: (most frequent grade) + (most aggressive grade) = Gleason score. For example, 3 + 3 = 6.

Cancers are assigned a clinical stage which is calculated using the PSA levels and Gleason scores as shown in Table 3 below based on the 2019 NICE Guidelines:

Table 3: Risk stratification for people with localised prostate cancer

Level of risk	**PSA**		**Gleason score**		**Clinical stage**
Low risk	<10 ng/ml	And	≤6	And	T1 to T2a[1]
Intermediate risk	10-20 ng/ml	Or	7	Or	T2b[2]
High risk	>20 ng/ml	Or	8-10	Or	≥T2c[3]

[1] T1: Tumour is contained within the prostate, too small to be detected on DRE. T2a: Tumour still contained, detectable with DRE, present in only half of 1 of the 2 lobes of the prostate.

[2] T2b: Tumour still contained in prostate, detectable with DRE, present in more than half of 1 of the 2 lobes of the prostate

[3] T2c: Tumour still contained in prostate, detectable with DRE, present in both lobes of the prostate

PCa incidence has increased rapidly over the last two decades(17) with statistics indicating a rise of 41% in the UK since the early 1990s(7). The increase in incidence may be attributed to an increased use and awareness of PSA tests(17, 18), along with an ageing population(19).

2.1.1 Evolution of PCa testing

PSA tests have been clinically available since the 1980s, initially to monitor progression of men with a diagnosis of PCa(20). PSA testing has been used as a diagnostic tool in the UK since the early 1990s(21). As previously mentioned, there is currently no national PCa screening programme in the UK. The UK is not alone in this approach; a 2018 study of high income countries showed considerable heterogeneity regarding PCa screening, with some countries (Iceland, Luxembourg, Switzerland, Belgium, Germany and Austria) recommending some kind of screening and some countries (UK, Sweden, Canada, Australia, France, New Zealand, Spain) explicitly recommending against it(22). The USA falls into both categories because recommendations from different USA organisations vary(22).

Current guidelines in the UK advise primary care practitioners to come to a shared decision about whether to utilise the PSA test with patients who have requested it, present with symptoms or have significant risk factors (such as a family history of PCa) weighing up the advantages and pitfalls(23). The main advantage/aim of screening is to catch and treat potentially dangerous cancer as early as possible, improving chances of survival. The biggest pitfall is overdiagnosis: a large proportion of diagnoses in men with localised PCa may never have developed clinical symptoms within their lifetime(24). This benefit-harm trade-off of PSA testing has been widely debated, views of urologists, oncologists and epidemiologists are divided, and testing rates vary(25). Some believe men should never have a PSA test without clinical indication, while others believe all men over a certain age with a life expectancy of 10 or more years should be screened with a PSA test(20). A large UK based randomised controlled trial (RCT) compared participants aged 50 to 69 undergoing a single PSA test (n = 189,386) with those not undergoing a PSA test (n = 219,439). Although results showed a higher proportion of diagnosis in the intervention group, there was no significant difference in 10-year mortality rates(26). The study findings from this study published in 2018 do not support single PSA testing for population-based screening.

There is a lack of available data monitoring the extent of PSA testing and patient referral rates(27). Acknowledging this issue, Moss et al. (2016) investigated the incidence of PSA testing in Primary Care and the subsequent patterns of referral in 2010 and 2011. In 2010, 22.4% of men with a raised PSA were referred to secondary care within 14 days and 36% of the remainder were re-tested within 6 months. Comparing the data to previous studies, the authors concluded that rates of PSA testing are increasing with time, and GPs are increasingly choosing to re-test PSA rather than refer immediately(27). The passive nature and subjective interpretation of the current guidelines means the decision to be tested is often heavily guided by the patient(23) and influenced by external factors such as the media and charity campaigns; for example, Prostate Cancer UK (PCUK) launched a campaign named ‘check your risk in 30 seconds’, which asks men about their risk factors and encourages them to seek a PSA test if the algorithm deems them ‘at risk’(28).

2.1.2 Evolution of PCa treatment

2.1.2.1 Prostatectomy surgery

Great advancements have been made in prostate anatomy understanding and the treatment of PCa over the last three decades(29). In the late 1800’s and early 1900’s various prostate surgery methods were explored, mostly only partially removing the prostate gland(29). In 1904 Hugh Hampton Young performed the first radical perineal prostatectomy using what would become the first systematic method followed for the next 40 years(30). In 1945 Terrence Millin introduced the retropubic approach for prostate enucleation. This new method was deemed easier to learn than the perineal approach and allowed surgeons to access the pelvic lymph nodes enabling more accurate tumour staging. However, surgery was not commonplace, largely because in using this method almost all patients suffered impotency and/or incontinence after surgery. The next significant surgical advancement was a modified version of the retropubic prostatectomy in 1983 developed by Patrick Walsh which allowed surgeons to reduce injury to the neurovascular bundles responsible for erectile function and sexual potency, and the surgery became much more common practice(30). However, post-operative issues are still common. Rates of erectile dysfunction and urinary incontinence vary widely in the literature, but one review indicates 44% to 75% experience sexual dysfunction(31) and 5-74% experience urinary incontinence(32).

Around the same time this new surgical technique became more widely used the PSA test was developed(33). The late 1980s saw the introduction of the ultrasound-guided biopsy allowing for several high-quality core biopsies to be obtained(34). These new diagnostic techniques and improved surgery outcomes resulted in a sharp increase in the number of patients who were treated by radical prostatectomy(30), with trends showing a more than twofold increase between 1989 and 1992 from 78 per 100,000 men to 206 per 100,000 men(35). However, more recently, the survival benefit compared to the potential side effects from surgery for many lower grade PCa has been questioned as discussed in sections 2.1.3, and 2.4.1.

2.1.2.2 Radiation therapy

The late 1800's saw the discovery of x-rays and subsequently radiation therapy. The use of radiation therapy to treat localised PCa was first reported in the early 1900s. External beam radiotherapy and brachytherapy are now commonly used to treat prostate cancer(36).

Early methods of brachytherapy methods were difficult to perform and uncomfortable for patients. An 'open implant' technique(37) was developed in the 1970s. The technique was initially appealing, but inconsistent dose distributions led to a high rate of local failure(30), and the use of brachytherapy in PCa declined until 1983 when a new technique was developed involving the implanting of radioactive 'seeds' under the guidance of transrectal ultrasonography(38). This technique has been developed and improved over the last three decades and this method of brachytherapy is currently a common approach to treating localised PCa(39).

Alongside the development of brachytherapy, another method known as 'external beam radiotherapy' was also being trialled and tested. External beam radiotherapy is given from outside of the body and has the advantage of delivering controlled and measurable radiation until the desired result is reached(36).

If a PCa patient is treated with radiotherapy they are most likely to receive external beam radiotherapy(36) and can expect to receive a course of treatment over either a 4-week or 7-week period. For the given duration (4 or 7 weeks) radiotherapy is usually given daily from Monday to Friday(40). Side effects include fatigue, weakness, painful skin over the treated area, loss of pubic hair, urinary issues and diarrhoea(40).

2.1.2.3 Cytotoxic chemotherapy

Chemotherapy for PCa has evolved from a palliative treatment with the main aim of reducing pain, to a treatment aiming to improve overall survival (41). It is generally only offered in cases of advanced PCa(30).

Results from the first national randomised controlled trial into the use of chemotherapy (5-fluorouracil versus Cytoxan versus standard therapy) for PCa were reported in 1975, indicating subjective improvement and minimal toxicity(30, 42). Since this study a large number of single agent and combination chemotherapy agent studies have been conducted(30) and currently docetaxel is the most commonly used chemotherapy agent/regimen for men with advanced PCa in the UK(43). Side effects of chemotherapy include fatigue, numbness or weakness in fingers or toes, hair loss, diarrhoea, nail changes, appetite loss, shortness of breath and fluid retention(43).

2.1.2.4 Hormone therapy

In the early 1940s the discovery that androgens are necessary for PCa to grow led to research into various methods of testosterone and dihydrotesterone suppression in men with advanced, symptomatic, metastatic PCa(44). The safety, efficacy and long-term impact of this approach are controversial topics and have generated much debate and uncertainty since the method first came into practice(45). Hormone therapy works by blocking the production of androgens, or by blocking the action of androgens(46), and can cause side effects such as erectile dysfunction, reduced libido, hot flushes, fatigue, insomnia, altered moods, and memory and concentration problems(43).

Currently hormone therapy is used to treat PCa at various stages of development(46):

1) Hormone therapy in early-stage PCa is sometimes offered when the cancer has an intermediate or high risk of recurrence. This may be offered alongside radiotherapy or prostatectomy and treatment may be given for between 6-24 months depending on the risk of recurrence(47).

2) Hormone therapy alone is the standard treatment for men with relapsed/recurrent PCa after previous treatment with radiotherapy or prostatectomy.

3) Hormone therapy alone is the standard treatment for men with metastatic disease.

4) Hormone therapy is sometimes used for palliation of symptoms.

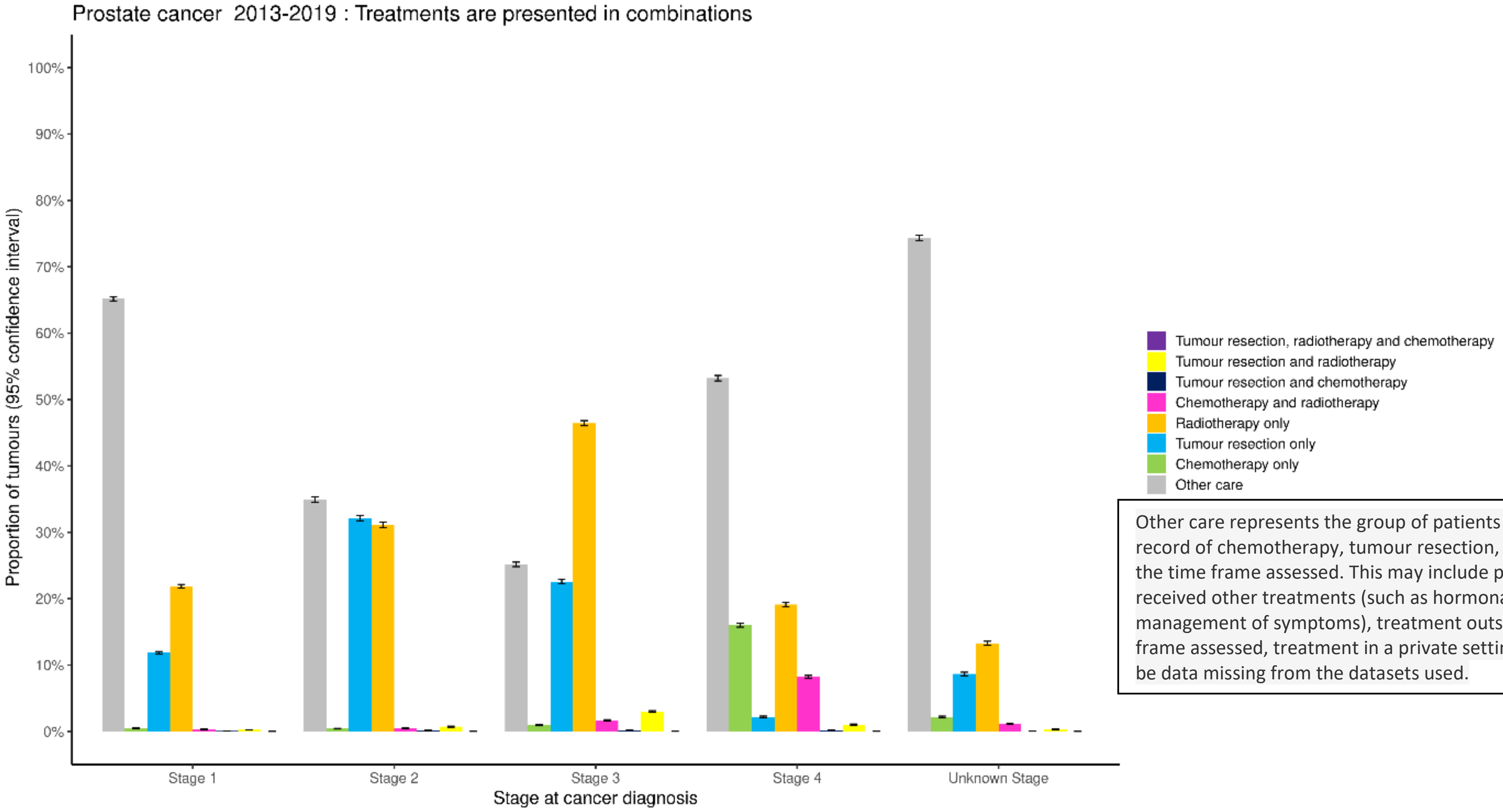
2.1.2.5 Prostate Cancer monitoring programmes

Active surveillance (AS) and watchful waiting are two PCa monitoring protocols offered to PCa patients in different circumstances (see section 2.2). Watchful waiting has traditionally been offered to patients as a form of palliative care, as the disease progresses and a cure is no longer possible, and the term is still used at present. AS takes place in secondary care and involves closely monitoring the cancer with a view to delaying or avoiding radical intervention and the associated side effects. (See section 2.4 and 2.4.1 for more detail and an overview of the evolution of AS.)

2.1.2.6 Prostate Cancer treatments – the statistics

The National Cancer Registration and Analysis Service (NCRAS) in partnership with Cancer Research UK (CRUK) collates cancer registration and treatment data. Figure 1 below (from the NCRAS webpage) shows the numbers and percentages of prostate cancers diagnosed in England in 2013-2019 recorded as receiving radiotherapy, chemotherapy or tumour resection split by stage at diagnosis. A diagnosis of low risk PCa would mostly fall into the ‘Stage 1’ category, with some ‘Stage 2’ incidences(43), see Table 3 for more information about staging. There are some limitations to this data representation; the data is from England only (not the whole of the UK), it does not include hormone therapy, and Active Surveillance and Watchful Waiting fall under ‘other’ making it difficult to accurately assess rates. However, it does provide useful information about the rates of radiotherapy, chemotherapy and tumour resection(48).

Figure 1: Treatment combination graph by stage for prostate cancer 2013-2019



This work has been produced as part of the Cancer Research UK - NHS Digital Partnership

Other care represents the group of patients who had no record of chemotherapy, tumour resection, or radiotherapy in the time frame assessed. This may include patients who received other treatments (such as hormonal therapy or management of symptoms), treatment outside of the time frame assessed, treatment in a private setting, or there may be data missing from the datasets used.

2.1.2.7 The changing nature of PCa treatment

As described above, PCa treatment has rapidly evolved over the past century, and it continues to do so as more research is conducted and understanding and methods improve. Over the last two decades uptake for AS has increased(49). The percentage of UK PCa patients on AS is not clear, however, figures from the USA show that in 2014 26.5% of men with low risk PCa were on AS, compared to 59.6% in 2021. This perhaps indicates physicians and patients are becoming increasingly more comfortable with the idea of monitoring rather than treating and trusting that progression will be picked up in a timely manner.

2.1.3 Evolution of PCa survival

Pre-1980s PCa was viewed as a deadly disease with survival rates of 1 in 2-3 men(25). PCa survival rates have improved significantly over the last fifty years with Cancer Research UK reporting an age-standardised survival rate in England and Wales at 1 year of 66% in 1971-1972 compared to 94% in 2010-2011; a 5 year survival rate of 37% in 1971-1972 compared to 85% in 2010-2011; and a 10 year survival rate of 25% in 1971-1972 compared to 84% in 2010-2011(7). See Appendix A for figures representing 1, 5 and 10-year survival rate patterns in England and Wales from 1971-2011.

Interpretation of survival rates is difficult as the introduction of PSA tests and increased awareness has resulted in an increase in lead-time (the difference in time between detection due to screening and clinical presentation)(50), see Figure 2 below. Lead-time bias varies depending on a man’s age at diagnosis, but a bias of 12 years is estimated when men are diagnosed aged 55, and 6 years for men aged 75 (51). As well as increased lead-time bias, improved effectiveness of PCa treatment will account for some of the rise in survival rates(52).

Figure 2: Diagram to demonstrate lead-time bias.

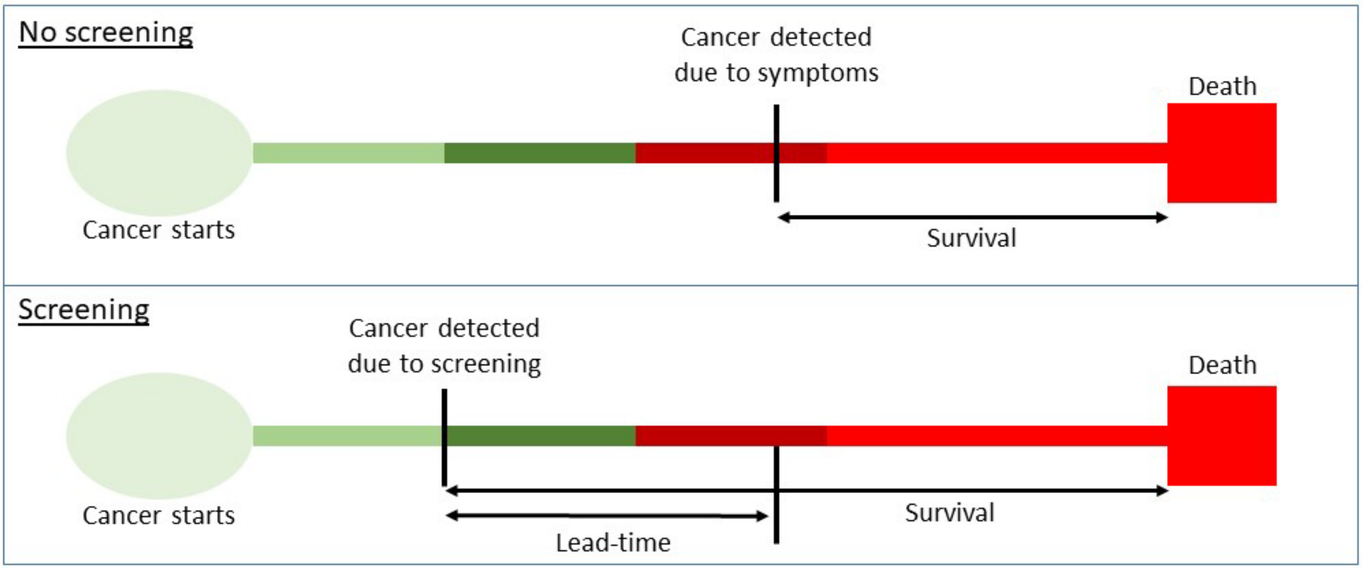


Diagram based on National Cancer Institute(53)

2.2 The psychological impact of prostate cancer

Previous literature suggests higher levels of depression and anxiety in men with a PCa diagnosis compared to the general population(54-59). A recent German multi-centre study with a large sample size (n=636) has used validated measures to capture levels of anxiety and depression (GAD-7 and PHQ-9)(60). This study found over 20% participants exceeded the clinical cut-offs for depression and anxiety, which is slightly higher than the German general population when matching participants by age and gender. They also found that younger PCa patients were at increased risk of distress, a finding which has been corroborated by other studies(60-62). Having metastases or receiving chemotherapy treatment also placed participants at higher risk of distress(60).

While this study has many strengths, such as the large sample size and the use of matched controls, there are some limitations. Firstly, the participants were spread fairly evenly in terms of early and late disease stages. Incidence rates have a higher percentage of patients in early stages(60), meaning the data might be skewed and the results should be interpreted with caution. In addition, the study utilised a cross-sectional design, capturing a snapshot of participants' psychological wellbeing, and limiting the conclusions that can be drawn about the psychological impact over the trajectory of the disease. With this particular limitation in mind, it is useful to look at the data produced by a longitudinal study published in the same year, by Ralph et al. (2020)(62).

Ralph et al., (2020) looked at symptom burden and health related quality of life (HRQoL) over 10 years. Measures of both physical and mental HRQoL were collected from newly diagnosed men with PCa over a 10-year period. The study had a large sample size with 598 participants completing the measures at 10 years. The results show 40.3% of men reported adverse mental HRQoL at 5-10 years, which is higher than the 20% displaying clinical levels of anxiety and depression in the study by Esser et al., (2020). However, this difference must be approached cautiously. Firstly, Ralph et al., (2020) used a different measure to assess psychological health (the Short Form-36 as opposed to the PHQ-9 and the GAD-7), which may have yielded different results. In addition, the study originated in a different country (Australia), and cultural differences, differences in treatment protocols and healthcare systems may impact levels of distress in PCa patients. Ralph et al., (2020) did not use matched controls to compare the findings to the levels of distress in the general population, which would have been useful when comparing the data from these two studies.

Despite the difficulties in comparing the results from Esser et al., (2020) and Ralph et al., (2020), there are clear indications PCa patients are significantly negatively impacted psychologically by their diagnosis and/or treatment, and the results from studies such as Esser et al., (2020) may underestimate the prevalence by failing to account for time since diagnosis and the changing psychological impact over the trajectory of the illness.

A barrier to researching the psychological impact of PCa is the possibility that men with cancer might be reluctant to discuss psychological wellbeing, which is supported by previous literature(63, 64). However, such literature is now over 20 years old and may be less applicable to present day.

2.3 Monitoring protocols for prostate cancer

The evolution of PCa treatment is discussed in section 2.1.2. Current treatment options vary depending on the severity of the cancer, and the age and general fitness of the patient. Treatment plans involving chemotherapy, radiotherapy, hormone therapy, cryotherapy or surgery may be offered. The two main curative treatments offered for localised PCa are radical prostatectomy (surgery) and radiotherapy(29) (See sections 2.1.2.1 and 2.1.2.2). For advanced metastatic cancer, the main treatment offered is hormonal(29) (see section 2.1.2.4) .

Prostate cancers classified as high grade usually require treatment, but men with lower grades may be offered a monitoring programme such as active surveillance (AS) or watchful waiting. Both AS and Watchful Waiting aim to avoid unnecessary treatment, but they are not synonymous. The term ‘Watchful Waiting’ tends to be used when offering no active treatment to men with incurable cancer, or with significant other co-morbidities that would make treatment difficult. 'Active Surveillance' tends to be offered to men with low-grade PCa growing so slowly that it may have no impact on quality of life or life expectancy if left untreated. PCa in those offered AS is usually deemed curable if treated. Table 4 shows the key differences between AS and Watchful Waiting:

Table 4: Differences between active surveillance and watchful waiting

Active Surveillance	**Watchful Waiting**
Involves regular PSA tests and periodic biopsies.	Involves occasional PSA tests.
Tends to be offered to men who could cope with surgery or other active treatment should the need arise.	Tends to be offered to more elderly patients, or those who have other co-morbidities.
If a man on AS chooses to convert to active treatment the aim will usually be curative.	Those on WW tend not to have curative cancer.
Offered to men with PCa growing so slowly it may have no impact on quality of life or life expectancy.	

As discussed in sections 2.1.2.1 - 2.1.2.4, treatments such as radiotherapy and surgery carry risks of side effects including erectile dysfunction, impotence and urinary incontinence. Post-surgery incontinence can take up to a year to improve, and some men never reach full recovery(65). The likelihood of experiencing these side effects varies in the literature. A systematic review by Kilminster et al., (2011) which included 33 studies (n = 12449) found impotency rates at 48 months were 49 – 74% for open, 58 – 74% for laparoscopic and 60 – 100% for robotic prostatectomy(66). These statistics, combined with the possibility of a low-grade PCa growing so slowly it may never cause any impact on quality of life or life expectancy, make AS an appealing option to some.

2.4 Active Surveillance

AS takes place in secondary care and involves closely monitoring the cancer with a view to delaying or avoiding radical intervention and the associated side effects. Table 5 shows the NICE Guidelines protocol for managing men on AS(40):

Table 5: NICE Guidelines protocol for managing men on AS

Timing	**Tests**[*1]
At enrolment in active surveillance	Multi-parametric MRI if not previously performed
Year 1 of active surveillance	Every 3-4 months: measure PSA (prostate- specific antigen)[*2] Throughout active surveillance: monitor PSA kinetics[*3] Every 6-12 months: DRE (digital rectal examination)[*4] At 12 months: prostate re-biopsy
Year 2-4 of active surveillance	Every 3-6 months: measure PSA[*2] Throughout active surveillance: monitor PSA kinetics[*3] Every 6-12 months: DRE[*4]
Year 5 and every year thereafter until active surveillance ends	Every 6 months: measure PSA[*2] Throughout active surveillance: monitor PSA kinetics[*3] Every 12 months: DRE[*4]

*1 If there is concern about clinical or PSA (prostate-specific antigen) changes at any time during active surveillance, reassess with multiparametric MRI and /or re-biopsy.
*2 May be carried out in primary care if there are agreed shared-care protocols and recall systems.
*3 May include PSA doubling time and velocity.
*4 Should be performed by a healthcare professional with expertise and confidence in performing DRE (digital rectal examination).

Where PCa is localised and slow-growing, choosing surgery over AS has not been shown to significantly improve 12-year survival(67). This finding has been replicated in the ProtecT trial, which randomised 1643 men with a diagnosis of localised PCa to active surveillance, radical prostatectomy or external-beam radiotherapy. Results showed no significant difference in 10-year mortality between groups(18). For this reason, and the prevention of physical side effects, AS is being increasingly recommended for slow-growing, localised PCa.

Although AS avoids the physical risks mentioned above, the biopsies involved in ongoing monitoring can be unpleasant(68), with some describing them as ‘stressful’, ‘exhausting’ and ‘extremely painful’(69). In addition, research has shown that men on AS may have heightened levels of anxiety, concern and distress due to living with an untreated cancer(70). Table 6 below summarises the advantages and disadvantages of AS(71).

Table 6: Advantages and disadvantages of AS

Advantages	**Disadvantages**
Avoids side effects of radical treatment such as erectile dysfunction and urinary incontinence	Possible heightened levels of anxiety, concern and distress
This is a flexible treatment programme allowing men to convert to active treatment if their disease progresses	It is possible that the cancer may develop and spread quicker than expected, and by delaying treatment the window for curative treatment may be missed
Provides a protocol for clinically insignificant PCa	

2.4.1 The evolution of Active Surveillance

Prior to the concept of 'active surveillance', 'watchful waiting' existed as the only monitoring programme for PCa. Watchful waiting is offered to older men, or men with comorbidities making curative treatment inappropriate. AS for low-risk PCa has evolved as a concept since the 1900s(72), and differs from watchful waiting as described in Table 4 above. Historically, clinicians and patients were wary of AS, fearing the opportunity to treat cancer progression may be missed. Over time a rapid increase in emerging research around localised PCa overdiagnosis, and a greater understanding of lead times has seen the medical community and patients alike become increasingly comfortable with the idea of monitoring localised PCa, even in the event that a patient is an appropriate candidate for curative treatment(72). Guidelines defining low-risk PCa were published in 1998(73), providing criteria to help clinicians identify those eligible for AS, and today AS is one of the options in standard care(74).

2.4.2 The impact of living on Active Surveillance

Although results from PSA tests are used to guide clinical decisions, the unreliability of these tests is well documented; a raised PSA is often not due to cancer, and some men with PCa have PSA results within the normal range(75). Due to sampling errors prostate biopsies run the risk of a PCa being under graded or under staged, potentially consequently incorrectly placing patients on AS(75). The diagnostic uncertainty, along with other anxiety provoking factors such as the risk of missing disease progression, can cause both patient and physician discomfort about the AS treatment protocol(76). To reduce uncertainty men often undergo more than one biopsy and a range of other tests before confirming their decision to proceed with AS(76).

Deciding whether to choose AS or whether to have interventional, active treatment can be challenging, and patients sometimes find the prospect of making the decision themselves distressing(76). Patients following an AS protocol have different emotional challenges to face compared to those undertaking active treatment; those on AS must find a way to live with an ‘untreated cancer’(77).

There is a dearth of literature exploring experiences of AS for PCa qualitatively, and an even smaller pool of literature including experiences of SOs, despite it being frequently reported that partners are the primary source of support for men with PCa(78, 79). The small number of existing studies have revealed that AS patients can experience the pathway in differing ways: patients feel living on AS is anxiety provoking(80, 81), a rollercoaster of emotions(82) and like ‘living under a shadow’(80, 83), whereas others experience AS much more positively, feeling optimistic they may never need further treatment(84) and comfortable conducting their daily lives as normal(85-89). It is not clear why patients react so differently, but factors such as confidence in their physician(76, 80, 90-92), and patient understanding of their PCa and the AS protocol(93) may be contributors.

A cross-sectional study exploring depression and anxiety prevalence in 313 PCa patients on AS across 7 UK urology centres(70) indicated a clinical depression prevalence of 12.5%, and clinical anxiety prevalence of 23% measured by the HADS. The results show a more than doubled depression prevalence, and almost tripled anxiety prevalence in men on AS for prostate cancer compared to men of a similar age in the general population (6% and 8% respectively(94)). Divorce was the only demographic predictor of anxiety and depression. At the time this study was published (2014) it was the largest multicentre assessment of depression and anxiety prevalence in AS patients to be undertaken, however, there are some limitations which need to be considered. The cross-sectional nature of the study means it is not possible to draw conclusions about the way anxiety and depression may change in this population over time, nor is it possible to draw conclusions about the causality of these conditions. It is important to note that these results originated from searches conducted over 10 years ago in 2013, and more recent literature might report different findings due to changes in the way the AS pathway is delivered and negotiated.

A more recent study conducted in Northern Ireland compared men with favourable-risk PCa on AS with those who had chosen active treatment, and a non-cancer control group. They corroborated findings reported by Watts et al., (2014) and found men on AS had significantly higher anxiety symptoms than those who had opted for active treatment and the non-cancer group(95). This study collected data at 4 timepoints over 9 months, providing a picture of AS related mental health over time. However, the sample size was small, consisting of 43 men having active treatment, 53 non-cancer patients and only 11 men on AS. Additionally, the majority of the sample were White and heterosexual limiting the generalisability of the findings.

Reviews looking specifically at experiences of AS for men with PCa provide wider insight by pooling existing literature(95-97). One such review originating from the US by Kim et al. (2018) included qualitative, quantitative and mixed methods papers to report patient and health care provider experiences of AS in prostate cancer (n=61) and three other types of cancer (ductal carcinoma in situ (n=2), chronic lymphocytic leukaemia (n=4), and renal cell carcinoma (n=6)). 22 of the 61 PCa papers reported findings related to the psychosocial aspects of AS. Findings from these 22 papers were mixed and conflicting. Compared to men undergoing radical prostatectomy or radiotherapy, some studies (n=10) showed men on AS reported lower levels of anxiety, better mental and physical health-related quality of life, and lower levels of dysfunction in work and daily activities. In contrast, other studies (n=4) found those on AS reported higher levels of anxiety and depression than those undergoing active treatment. As a consequence of these conflicting findings, the authors stated the need for future research to explore why the findings are so polarising, and to evaluate interventions aiming to improve factors which may influence experiences of AS, for example, interventions to improve AS communication(96). The characteristics of the participants included in this review are not clearly stated meaning generalisability cannot be assessed.

Replicating findings by Kim at al., (2018), a review published in 2023 reported conflicting findings within published literature(98). The review focussed on long-term health-related quality of life in men on AS, and studies had to have surveyed participants over at least 5 years to be included. They found no statistically significant difference in mental health between patients on AS compared to those undergoing active treatment in some studies (n=10), slightly superior mental health in the AS group compared to those undergoing radical prostatectomy in a couple of studies (n=2) and higher levels of anxiety, depression and emotional distress in a couple of studies (n=2). The authors conclude those on AS are not adversely affected in terms of mental health outcomes compared with patients undergoing active treatment(98). The longitudinal approach utilised in this review is a strength, providing a picture of mental health over a period of at least 5 years. However, the time parameter set on the search was 1974 to 2022, and the final included papers date back to 1986. This muddies interpretation of the findings because the 19 papers included (14 out of the 19 included data on psychological wellbeing) spanned a large period of time making their comparability questionable.

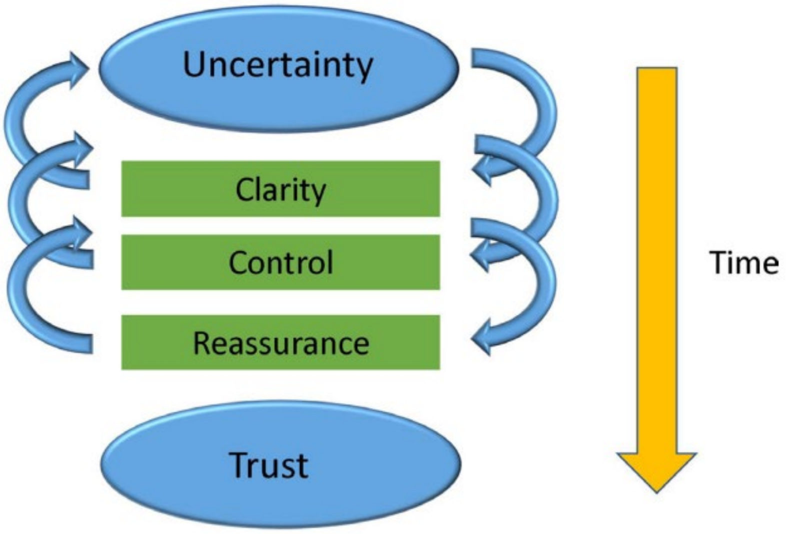
A Canadian review of 36 articles published in 2007 explored the psychosocial needs of men on AS for PCa and the barriers to its uptake(97). They reported that men with low-grade slow-growing PCa on AS displayed lower levels of distress compared to those with advanced PCa or those with other cancers, and only slightly more distress than the general population. Their findings indicate that lower age at diagnosis is an independent predictor of distress, as reported in non-AS specific literature(60-62). Feelings of anxiety in this population were mostly attributed to fear of disease progression, and concern around the inaccuracy of PSA test results used to monitor disease progression. Despite reporting the participants were not anxious or depressed, this review revealed men on AS often felt alone with the disease and experienced a negative impact on close personal relationships. The men in this review worried asking for help may be seen as a sign of weakness, and suggestions of support groups were disliked. Moving forward the authors advised that interventions to adjust ingrained attitudes about support groups should be developed to reduce the barriers to men on AS seeking peer support, placing immense value on the impact of support groups(97). The age of this review paper is a concern, and it is likely increased AS knowledge, understanding and changes in the pathway may lead to different results today. Demographics of the participants included in this review are not described, meaning generalisability cannot be assessed.

In contrast to the findings presented by Watts et al., (2014) and Ruane-McAteer et al., (2019), a review looking at quality of life in PCa patients on AS (n=966) across 8 different countries (Italy, UK, USA, Switzerland, The Netherlands, Lithuania, Finland and Australia) reported that men on AS did not appear to suffer negative psychological impacts, with participants showing anxiety and depression scores within the normal range, in line with the findings reported above by Pickles et al., (2007). Participants in the included papers were within the first three years of follow-up from the point of diagnosis, but no additional information about timescales is reported. The review stated that men on AS score similarly, and sometimes slightly better on quality-of-life scales compared to those undergoing radical treatment(99). The large sample size strengthens these findings, however, most of the studies included did not report ethnicity or sociodemographic data making generalisability difficult. In addition, searches were conducted 10 years ago in 2014 meaning the findings may be out of date.

The supportive care requirements of PCa patients on AS have been qualitatively explored(100) in 20 men recruited from a UK urology clinic. Two overarching themes were generated from the results: Theme 1: "The safety net has a hole in it" – problems of living with PCa and being managed with AS. Theme 2: Managing life/survivorship under AS. All 20 men in this study identified as white British and were recruited from the same clinic, meaning these findings might not be generalisable to other ethnic groups and geographical locations. However, these men reported high levels of emotional distress, a lack of knowledge about their condition or how to self-manage it, and a desire for more information and support.

A longitudinal serial in-depth qualitative study across four UK urology clinics investigating strategies for coping with AS revealed that trust in the medical team is critical(101). The main strategies men utilised were: seeking clarity, control (either taking control themselves, or seeking control from clinicians), and seeking reassurance. The authors acknowledged contextual factors mediate individual responses. The model below (Figure 3 demonstrates their findings. Clinicians providing clarity, control and reassurance were better able to guide men on AS through the process of emotions starting at uncertainty and ending with trust(101).

Figure 3: Strategies to manage uncertainties from Wade et al., (2020)

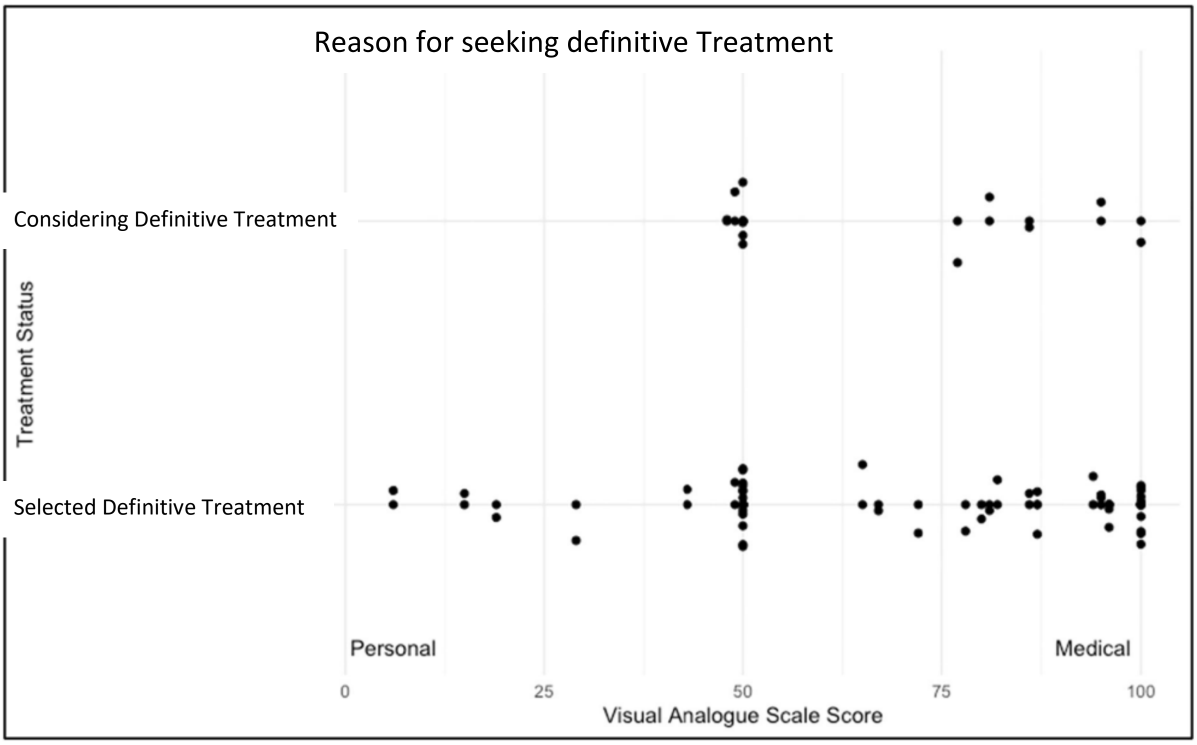


In summary, men on AS can experience psychological distress due to being on AS and living with an untreated cancer(70, 77, 80-83, 95, 102, 103). It appears supportive care needs are not being met(100). However, many studies in this area are difficult to generalise due to small sample sizes and a lack of participant ethnic diversity/underreporting of participant demographics(95-97, 99). As previously mentioned, Black men are more like to develop PCa than white men, making their lack of representation in the data even more pertinent. Suggestions have been made to help improve the psychological wellbeing of this population such as; increased education and good communication in relation to AS(104); interventions to reduce anxiety and uncertainty; support groups; the involvement of partners(97); and increased use of cancer nurse specialists(105).

2.4.3 Remaining on AS versus leaving AS

Around 50% of men diagnosed with PCa present with clinically low risk disease and are eligible for AS(106, 107). Roughly 50% men who opt for AS discontinue the protocol within 5 years, opting instead for active treatment(107-110). The reasons for discontinuation include disease progression, doctor recommendation, fear of disease progression and pressure from those close to them(110). A study exploring reasons for discontinuation from the patient perspective concluded men on AS draw on both personal and medical factors throughout the decision-making process(110). The authors of this study produced Figure 4 below displaying the visual analogue scale scores reflecting reasons for having/wanting definitive treatment in the study participants (those who discontinued AS to undergo definitive treatment (n=44) and, those who have considered leaving AS for definitive treatments (n=11)):

Figure 4: Visual analogue scale scores reflecting reasons for having/wanting definitive treatment in McIntosh et al., (2022)



(Note: each dot represents a participant)

Understanding the rationale for AS is key in acceptance and adherence to the monitoring procedures(88). Non-adherence, such as failure to attend medical appointments, could lead to progression to advanced-stage PCa, so ensuring men on AS are provided with sufficient information and understand the AS rationale is crucial(88). Although some patients appear to experience AS positively, those who find the pathway more distressing may benefit from the implementation of targeted support. The evidence discussed above suggests support with understanding PCa and the AS protocol may have the potential to ease distress(93, 111) and improve adherence(88) in this population.

2.5 Prostate Cancer and Significant Others

It is well recognised that the diagnosis of a chronic illness impacts family and friends as well as the patient themselves(91). Not only does the diagnosis impact those around the patient, but the opinions of friends and family with regards to the illness and proposed treatment plan can be influential in terms of both patient decision making and psychological wellbeing(112). SOs of men with PCa report similar psychosocial experiences to the patients themselves, including feelings of uncertainty(78, 113). Serious illnesses such as PCa can lead to changes in family communication and hence family relationships(79). It is clear from previous research that spouses play a major role in helping men negotiate the illness, and should be included in programs of care(78, 114) and treatment decision making(115).

In a 2018 review SOs of men with PCa reported feeling unsupported and side-lined both by their partners with PCa and healthcare professionals. With the patient being the focus in the hospital setting, they often felt their contributions were not acknowledged, and their needs were not addressed. Some partners described how the men with PCa withdrew emotionally and physically and sometimes asked them not to discuss the illness with anybody else. This led to partner feelings of isolation and being unsupported, and some would have liked to have sought support outside of the dyad to help them process the situation themselves(104).

Another key theme reported in this review titled ‘shielding me, you and us’ revealed some couples hid their feelings about the PCa from each other. The reasons for this varied; some hid their feelings from others as a coping mechanism, or as a way of continuing ‘as normal’. Others believed they were shielding their partner from their feelings to not cause any additional distress(104). Partners take on responsibilities such as providing PCa information for other close family members, providing practical and emotional support to the patient, and are sometimes so focussed on the patient they forget themselves, regarding their own needs as less important. Partners often reported feeling overwhelmed by the pressure on them to provide emotional support when feeling anxious and concerned themselves. The authors report that partners are fundamental in supporting men with PCa through this time, and many men view their partner as instrumental to their recovery(104). This review provides insight into how couples negotiate PCa and PCa treatment, and although there may be an overlap between experiences of this population and those specifically on the AS pathway, there is also likely to be differences.

The bulk of research in this area is not specific to AS and is not UK based (mostly studies originating from the US). Research applicable to the UK healthcare system is needed to explore SO involvement specific to AS for PCa. See Chapter 3 for a detailed account of close relationships in illness, including significant others in AS for PCa.

2.6 Black and ethnic minority men and Prostate Cancer

Black and ethnic minority men with PCa in the UK express considerable dissatisfaction with care according to National UK survey data(116-118). Black and ethnic minority men are underrepresented in PCa research(119). As previously mentioned, prevalence of PCa is roughly twice as high in Black men than White men(12), making the gap in the literature specific to Black men even more pertinent. In this section I will outline what is known from the small pool of existing literature and address reasons why there is a dearth of PCa research representing Black men.

2.6.1 What do we know from the existing literature?

Literature suggests that Black men are often unaware of the prostate, the possibility of PCa and that Black men are more likely to develop PCa in their lifetime than White men(120, 121). Black men have reported resistance in seeking help from medical professionals when symptoms such as urinary problems arise(120, 121). Reasons for this include a deeply engrained cultural notion that men should not seek care from doctors(121), distrust in medical professionals, a fear of diagnosis, a fear of investigative procedures such as Digital Rectal Examinations, fear of cancer-related stigma, fear of loss of sexual function and fear of becoming a burden on family(120-123). Wives of symptomatic Black men often encourage and insist on input from a medical professional(120).

Post-diagnosis and throughout treatment a hierarchy of power with men positioned as leaders and partners as supportive and accepting has been reported(122). Men have described ‘owning the illness’, feeling they should make all PCa related decisions with their partners minimally involved.

This finding has been reflected in interview data from health care professionals who say, in their experience, Black men are more resistant to including partners in their PCa journey than White men(122). Men often explain their response to the diagnosis in terms of religious faith, for example, that decisions of life and death belong to God(120, 124). To avoid cultural stigma around PCa negatively impacting masculinity and causing sexual dysfunction, Black men often keep their diagnosis private(124) and restrict their wives from public disclosure(122). Partners report feeling limited in their own support network due to not being able to talk about the diagnosis. Feelings of isolation and exclusion from their husband's PCa in terms of information, psychosexual support and marital communication are common, including difficulties discussing sexual problems within the couple(122). Men are often oblivious of the impact the PCa might be having on their partner(122).

The small base of existing literature provides an initial insight into PCa for Black men, but more research is needed. Some studies distinguish between Black African and Black Caribbean men(122), others do not, referring only to 'Black men' or 'African-Caribbean men)(120, 121), and it is not clear whether experiences may differ between these groups. One study described the cultural and social context of the participants(120) prior to reporting the PCa related results, which aids interpretation. However, this is not the case for the majority of research into PCa and Black men, limiting meaningful conclusions. Previous literature fails to consider similarities and differences between White and Black and ethnic minority groups with regards to PCa(124). It is clear PCa experiences and behaviours are shaped by factors such as ethnicity, social economic status, education, historical and cultural factors, yet these contextual factors are rarely considered(120, 124).

2.6.2 Barriers to recruiting Black men in PCa research

There are access and recruitment barriers for inclusion of Black men in PCa research(125). These barriers have been explored in a study of 205 men with PCa (92 Black men and 113 White men), which found Black men were significantly less willing to discuss participating in research than White men(123). The biggest reason behind this appeared to be mistrust in the medical community. Black men were more likely than White men to believe that their racial group should be suspicious of medical professionals(121, 123), and this resulted in a lower willingness to discuss research, making it harder to recruit Black men into trials(123).

In addition to mistrust in medical professionals, other barriers to recruiting Black men into research exist. Black men have reported fearing the stigma associated with PCa disclosure, stigma particularly around cancer fatality, a reduction in masculinity and sexual problems(122, 125). Research suggests 'gatekeepers' in religious communities and support groups can be reluctant to facilitate recruitment and have even been reported to request substantial payment for informing group members about research(125). Gatekeeping was also observed in a study aiming to recruit partners of men with PCa, where the men with PCa themselves declined their partner’s participation without asking them(125).

2.6.3 What can be done to improve recruitment in the future?

To improve the representative and ethnic diversity of future research it is helpful to explore facilitators in recruitment. Recruitment via NHS hospitals where clinicians have built rapport and trust with patients has been shown to facilitate recruitment to research in Black African and Black Caribbean men(125). Snowball sampling, where participants invite partners or other members of support groups or religious community groups has proven successful within Black groups(120, 125). Flexible data collection, for example, offering to conduct interviews face-to-face, by telephone or video call improves recruitment, along with building rapport with the researcher by ensuring the same researcher handles the recruitment and interview/study processes(125). It is also important to consider the researcher’s attributes, and whether potential participants may view them as an ‘insider’ or an ‘outsider’; patients may be more open to research if the researcher matches themselves in attributes such as gender and ethnicity(126, 127).

2.7 Summary

In summary, PCa is a prevalent disease which can be treated with surgery, chemotherapy, radiotherapy or hormone therapy. Treatment for PCa has developed and advanced over time and continues to do so. There is a growing understanding that some low-risk slow growing PCas may never need treatment and AS may enable men to safely avoid unwanted side effects of treatment. There is some research to suggest that being on AS and living with untreated cancer can have a negative psychological impact on both the patient and their SO. SOs need to be considered when assessing support needs, research is lacking specific to Black men, and for Active Surveillance in Prostate Cancer.

Chapter 3: Close relationships in illness

3.1 The significant other in cancer

In cancer, social support has been shown to be an important factor for patient quality of life(128), and partner support and marriage have a powerful positive effect on cancer survivorship(129, 130).

There is a growing body of research acknowledging the impact of cancer on the family of patients(131), recognising the importance of dyadic coping(132, 133). The disease is often described as a ‘we disease’(134-136) or a ‘family illness’ (137). Existing qualitative findings indicate that anxiety is mutually shared within dyads where one partner has a cancer diagnosis(131, 133). A meta-analysis of psychological distress in cancer patients and their carers found a positive association between patient and caregiver distress. What’s more, this study found no significant difference between levels of patient distress and caregiver distress(131), suggesting that patients and SOs are relatively matched.

This dyadic shared anxiety has been further explored in patients with stage IV non-small cell lung cancer by Hendriksen et al., (2015)(138). Uncertainty was found to be the primary driver of anxiety, more specifically the ‘not knowing’ what was going to happen, and the struggle to make plans going forward with so much unpredictability. Dyads also expressed shared anxiety about loss and impending loss; the loss of their previous lifestyle, as well as the potential loss of life. In addition, fears of decline and dying, physical symptoms, finances, conflict outside the dyad and changing roles all presented as contributors to anxiety in both partners(138).

It has been said that SOs of cancer patients engage in ‘emotion work’, defined as working to manage the emotions of the patient as well as their own(139). For carers most of the time this involves staying strong, positive, confident that recovery will take place and providing a sense of ‘being there’, i.e., ensuring the patient does not feel alone. Cancer is a shared journey with many SOs voicing the notion of ‘facing this together’(139).

SOs are particularly involved and important at the point of treatment decision making(115, 140-142). May et al., (2012) state that at present, the extent to which patients’ social support networks can influence clinical decision making is rarely acknowledged. They suggest that clinicians need to give attention to the non-clinical others in a patient’s life to enable optimal medical decision making(141).

In summary, SOs are usually hugely impacted by a cancer diagnosis; SOs suffer anxiety(138), distress(131), are involved in treatment decision making(141) and actively support the patient emotionally and physically(139).

3.1.1 The significant other in prostate cancer

Non-specific to treatment choices, research has been conducted into the psychosocial adjustment of partners of men with PCa. Distress in partners of men with PCa is common (143-146), and partners sometimes even report higher levels of distress than patients, co-existing with partner belief that the patient was more distressed(145, 147). Key post-diagnosis concerns include uncertainty about the future, shock, and the fear of death of their partner(148). Research suggests SO distress fluctuates over time(149), with the period around diagnosis identified as a particularly distressing time(142, 150).

PCa treatment carries the risk of erectile dysfunction, poor urinary function and poor bowel function, with 75% patients reporting issues 3 years after treatment(151). Previous research into SO experiences of men with PCa focus much of their explorations around the psychosexual implications of the diagnosis and treatment(104, 122, 150, 152-155). Impotency can have relationship implications with men feeling unable to 'perform' sexually, and subsequently men with erectile dysfunction have been found to report less intimate contact and lower scores on relationship togetherness and tenderness(156). For some dyads, partners of patients appear less worried about sexual side effects than the patients themselves(147, 157), but for other partners the decrease in intimacy is a significant loss(122, 158). An inability to accept the loss of sexual activity within couples has been linked to poorer adjustment to the diagnosis(104).

SOs are integral to the patient's PCa journey and patients often acknowledge how fundamental their partners are to their recovery(104, 159). Associations between spousal illness and treatment beliefs and the patient's quality of life have been found; more specifically, when spouses hold the belief that treatment will control the illness, patients tend to score better on QOL scales 6 months later(160).

In addition to feelings of uncertainty, anxiety, care-giver burden and grief related to the loss of sexual intimacy(145, 147, 148, 158), partners of men with PCa report feelings of being unsupported and side-lined by their partners and/or their partner's medical team(104, 158), which can contribute to feelings of isolation(158).

It is clear that a diagnosis of PCa has a substantive psychosocial impact on SOs(122, 152, 158). A systematic review and thematic synthesis of PCa partners reported three main themes/factors which influence partners' experiences(152). Firstly, how the partner views their own position; as part of a couple, as a provider of support to their male partner, as a resilient person, as a person guided by faith and spirituality. Secondly, how the partner positions themselves as a result of the patient's response; as a manager of their male partner's psychological distress; or as a person strengthened by their male partner's positive response. Thirdly, they reported the impact of broader contexts such as: family members and social support, experiences with clinicians and the health system, and their own cultural values and customs.

3.2 Dyadic communication in cancer

Previous research indicates illness communication in couples differs from general communication, and the way a couple communicate generally does not necessarily relate to how they will communicate about an illness(161). Therefore, it is helpful to explore dyadic communication in the context of illness.

Various aspects of communication in illness have been identified and explored, for example; 'protective buffering', where one partner attempts to protect the other from illness related worries(162); 'active engagement', where the healthy partner provides support as directed by the patient and their support needs (163); 'overprotection' which involves excessive shielding of the patient by the partner(162, 164); open communication(165); and perceived spousal support(166). To ensure literature most relevant to this PhD is described in this section, I have focussed on dyadic communication in cancer (rather than other chronic illnesses).

Open cancer-related communication between dyads has been associated with benefits such as higher quality of life, better psychosocial adjustment, family resilience and higher relationship functioning(165-170). Poor cancer-related communication has been shown to result in compromised relationships and psychological adjustments(168, 171). Research suggests distress, depression and anxiety are more prevalent in patients and partners who avoid communication or engage in self-concealment or protective buffering. A lack of illness related communication is associated with lower relationship satisfaction and reduced intimacy(165).

Protective buffering in the context of couples in cancer refers to an individual concealing their cancer related fears and concerns in an attempt to protect their partner from upset and/or burden(162). Protective buffering has been associated with increased fear of cancer recurrence for the individual reporting the buffering, and decreased intimacy in the relationship(162). Research has shown a positive association between perceived spousal support and family resilience in the context of cancer(166), perhaps because those who feel supported by their spouse feel increased security and cohesion, enhancing family functioning and positively influencing family resilience(166).

Increased levels of distress in breast cancer patients and their partners have been found when a ‘demand-withdraw’ pattern of communication exists(167). This means that when one partner wants to discuss the illness, the other withdraws. Findings from this study showed this pattern existed even in couples who reported high levels of marital satisfaction(167), however, it is important to note this study was conducted with female breast cancer patients and male spouses, and the findings may differ in male-patient female-partner or male-patient male-partner dyads.

Various factors may influence illness related communication, for example, how serious the dyad perceive the illness to be, the extent to which the diagnosis will impact on daily life and the future, and whether each member of the dyad perceives the diagnosis as a stressor that impacts the patient alone, or the dyad as a unit. Research has been conducted into how couples who viewed a cancer diagnosis as a ‘couple-related stressor’ and those that viewed it as an ‘individual stressor’ differ(134). Those who viewed the cancer diagnosis as a ‘couple-related stressor’ or referred to cancer as a ‘we-disease’ did not necessarily worry about the same things, but they demonstrated a sense of being ‘in it together’ and feeling the impact to a similar degree as each other(134). Those who conceptualise the diagnosis as an individual stressor tended to avoid talking about the illness, leading to a reduction in marital adjustment, independent of pre-diagnosis marital adjustment(134, 172). The study from which these insights are gleaned is a small qualitative study of 10 dyads: female breast cancer patients and male spouses who were interviewed together as couples(134). The findings must be interpreted with caution. It is important to consider how the findings may differ with different gender patient/partner combinations, different illnesses and alternate methodology, for example, separate patient and partner interviews. However, this research does highlight there are many external factors that influence how a couple communicate in illness.

A recent review of 55 articles explored communication between cancer patients and spouses (breast cancer n=22, prostate cancer n=7, mixed samples n=12). The review explored two overarching patterns of communication, firstly, ‘lack of communication’ and, secondly, ‘self-disclosure’. Lack of communication encompassed concealment, avoidance and protective buffering. The findings demonstrated a negative association between lack of communication and psychological wellbeing in terms of depression, anxiety and distress, as well as lower physical wellbeing(165). Avoiding communication and believing their partner was avoiding communication was associated with lower levels of marital satisfaction and intimacy(165). One exception was found in a study with breast cancer patients where male spouses reported lower caregiver burden with partners who reported more protective buffering behaviours(173).

Findings relating to self-disclosure were mixed. Although some studies found that increased self-disclosure was associated with better adaptation, more post-traumatic growth and lower levels of distress, others did not demonstrate such relationships leaving the authors to conclude there is limited evidence to support the notion that patient and partner disclosure improves emotional wellbeing(165). Hasson-Ohayon et al., (2022) reported more open communication in patients than spouses. However, this finding needs to be considered with caution because it does not take into account gender differences, and the majority of the data in this review is gathered from female-patient male-spouse dyads. Hasson-Ohayon et al., (2022) describe 'lack of communication' and 'self-disclosure' as patterns of communication at opposite ends of a scale. It is therefore interesting that while the negative impact of lack of communication seems compelling within the findings, the positive impact of self-disclosure is more complicated. The authors fail to break 'self-disclosure' down into different types of communication, for example, self-disclosure implies one being open about their own feelings, but does not encompass other aspects of communication, for example, being open to listening about how a partner feels, or being open to listening.

The literature described above provides an insight into the complexities of illness related communication, the various patterns of communication, and the way illness related communication can impact both the patient and their SOs. Much of the research in this area is with female breast cancer patients and male spouses. There is a need for more research into illness related communication in male-patient female-spouse, and male-patient male-spouse dyads.

3.2.1 Dyadic communication in PCa

It seems PCa related communication decreases over time, with numerous studies demonstrating this pattern(168, 170, 174-176). It is thought the diagnosis evokes discussions about imminent illness-related information and treatment decisions(170, 174). Once treatment is complete (or a monitoring programme underway) patients and their partners strive to continue with everyday life and discuss fears about long-term side effects and prognosis decreasingly(170, 174). One study showed those with localised PCa perceived significantly less communication at diagnosis than those with recurrent or advanced PCa. Authors attributed this difference to a less urgent need to communicate at diagnosis with localised PCa compared to recurrent or advanced disease status(170).

3.3 The significant other in active surveillance for prostate cancer

Section 3.1 discusses some of the relevant literature about SOs in PCa, with a focus on those undergoing active treatment, but for this PhD it is important to consider how these interactions might differ when the chosen pathway is active surveillance (AS). For men on AS, treatment side effects are less of an immediate concern and the sexual relationships of this population are less impacted(86). In addition, those on AS have been advised their cancer is localised and slow-growing (at least for the time being), with no need to rush into treatment. However, men on AS and their SOs face a different set of psychological hurdles to those receiving active treatment. For example, adjusting to the idea of living with an untreated cancer, concern over missing disease progression, and explaining or justifying to others why they are not undergoing active treatment(86).

Some research has emerged suggesting that partners of those on AS suffer higher levels of distress than the patients themselves(177) and often hold the perception they are also on AS(142). A study conducted in Switzerland demonstrated elevated SO distress using questionnaire results from 133 couples. Overall, they found both men and their partners displayed low levels of anxiety and depression, however, although still less than clinically relevant, the partners scored significantly higher than the patients on scores of distress. This mirrors earlier findings from non-AS specific PCa research(147), and suggests that partners of those on AS may have some emotional similarities to partners of those undergoing active treatment.

Partners of men on AS often report noticing physical symptoms before the men themselves and feel there is an element of denial where the men will ignore symptoms and delay medical advice(86). In some qualitative research partners explain how they are key in navigating AS; they ask the medical team questions, gather information(84, 86) and encourage check-ups(86). They express that their male counterparts are often overwhelmed by the situation(86), and AS requires a certain amount of self-management that is aided (or sometimes driven) by partners. Partners describe needing to be knowledgeable in part to help explain and justify the AS pathway to friends and family, who are sometimes concerned a more active approach is not being taken(86).

Conflicting opinions within couples about treatment pathways is not discussed in literature with patients seeking active treatment, perhaps because this is rare. However, the concept of AS can be harder to accept. As mentioned above, friends and family often feel a more active approach should be taken, but sometimes this conflict exists within the couple with the SO feeling AS is not the safest approach(142). In addition to the distress of a cancer diagnosis, this situation can place stress on the couple's relationship(142).

It is clear from the literature that SOs are involved, impacted, and impactful in AS for PCa and should be considered in clinical situations and future research.

3.4 Gay and bisexual men and relationships in prostate cancer

Literature exploring how gender impacts care-giving roles in illness, including cancer, exists(178), however, male SOs of male patients is the least studied gender dyad(178). The majority of research into SOs in PCa has included only female partners(152) and gay and bisexual men (GBM) with PCa have been referred to as a 'hidden population' or an 'invisible diversity'(179).

GBM are less likely than heterosexual men to have partners, children or religion-based support systems, meaning social support and SOs for this population can take a different form to those in heterosexual relationships(179); GBM are more likely to go through PCa alone, or with the support of hired help or chosen family members(180). In addition, GBM describe feeling uncomfortable in PCa support groups, feeling unsure how open they can be about their sexual concerns as a GBM and the stigma or prejudice they may encounter, increasing feelings of isolation(179). Participants in one qualitative study expressed a strong desire for a PCa support group specifically for GBM(180).

In GBM, erectile dysfunction contributes to emotional distress, has a negative effect on gay identities and leads to feelings of sexual dissatisfaction(179). Although research is limited, GBM in relationships suffering impotency due to PCa have admitted this issue could end a relationship or lead to an open relationship where the partner was free to find sexual satisfaction elsewhere(181). Although research with heterosexual PCa patients and couples describes loss of intimacy as a sometimes significant negative side effect(156), the possibility of this issue ending a relationship, or facilitating the consideration of an open relationship does not typically arise(178).

GBM and their partners are an under researched population and represent an important minority. The literature discussed above suggests supportive care needs for GBM in PCa may differ to heterosexual men(180), and more research is needed to see how these needs might be met. Research specific to AS and GBM is even more limited. Searches in online databases such as PsychInfo and Medline returned no relevant papers, highlighting a significant gap in the literature.

3.5 Can close relationships have a negative impact in the context of illness?

Close relationships and social networks can be beneficial; they provide emotional, material and informational support, enhance coping, and regulate behaviour. This notion is supported by a large body of literature(1, 4, 130). To further support this, social isolation has been described as a stressor in itself with feelings of loneliness, lack of control and lack of self-esteem(182). However, to assume social support is always beneficial is too simplistic. The literature around the negative impacts of social support specific to illness is complex, with many variables (e.g., type of illness, type of social support, gender, personality, context) feeding into outcomes. This section will explore this literature to provide an understanding of how support can sometimes have a negative impact.

Before picking apart some of the ways that relationships can impact negatively during illness, it is worth noting that some research suggests that those experiencing chronic stressors within their social networks (such as relationship problems with close friends or family) are more susceptible to disease including cancer(183). Negative interactions can increase psychological stress, impact behaviour and in turn increase risk for disease(182).

Social integration is largely regarded as beneficial and positive(183, 184) however, integration can provide opportunity for conflict, stress transmission, misguided attempts to help and exploitation(182, 185). Previous research in the context of cancer patients suggests a conflict between a patients' own feelings about their disease (predominantly negative), and how others react when told about their diagnosis (sometimes with attempts to be optimistic and cheerful). This conflict can be detrimental and lead to patients avoiding open discussion about their illness(185).

Couple interactions in the context of cancer have been explored using the term 'expressed emotion'. Expressed emotion encompasses negative responses such as criticism or hostility, and emotional overinvolvement(186). Partner's critical comments are linked to higher levels of psychological distress(187, 188). Within couples where one partner is living with cancer (breast or colorectal) a study explored the impact of criticism and found that both feeling criticised and criticising a partner is associated with lower relationship satisfaction(189). The carry-over effect of this type of communication behaviour impacted the patients more strongly than the partners. The authors speculate this may be due to vulnerabilities felt due to the illness and/or treatment(189), however, the sample contained more female than male patients (64.5%), and therefore gender cannot be ruled out as a confounder. Furthermore, although this study was conducted within the context of cancer, it's not clear whether this had any influence over the results, or whether the impact of criticism would be the same regardless of health status. It is hard to infer the context of these interactions, for example, if criticism about different topics impacted relationship satisfaction to different degrees, or whether resilience might buffer the effects, however, it is clear criticism within couples has a negative impact.

Social support and communication in cancer is a vast topic with many variables. For this reason, addressing specific aspects or areas of difficulty, for example, cancer related fatigue, is helpful to understand how the literature can have implications in certain situations. Cancer related fatigue and its impact on relationships has been explored in various studies, and partner responses to cancer related fatigue can impact fatigue severity(190), fatigue interference and relationship satisfaction(191). A study with colorectal cancer patients and their partners found an association between partner negative responses towards fatigue behaviour, (e.g., resting) and lower relationship satisfaction. Positive partner responses towards well behaviour (e.g., being active) was associated with lower fatigue interference and higher relationship satisfaction. If a partner showed positive responses towards fatigue behaviour, and negative responses towards well behaviour, there was an increase in fatigue interference(191). In breast cancer patients an association has been found between SO punishing responses to cancer related fatigue and poorer functioning and increased fatigue severity(190). The number of variables which can be entered into the statistical analysis for the described studies with breast cancer and colorectal patients are limited and it is important to recognise the many contextual factors which may have influenced the results. The study mentioned above by Hughes et al.,(2020), recruited breast cancer patients from one single UK clinic limiting generalisability to other geographical locations.

Self-disclosure (mentioned in section 3.2) within couples can be problematic when there is a mismatch in the amount each partner needs to self-disclose. One study looked at self-disclosure in relation to depressive symptoms where one partner was diagnosed with cancer(192). They found that depressive symptoms in couples with matched needs in terms of self-disclosure (high or low) reduced over time after the cancer diagnosis. However, the depressive symptoms of those with mis-matched needs to self-disclose reduced to a lesser degree. For this reason the authors recommend that if there is a mis-match in the amount each partner needs to self-disclose, the partner with the stronger need discusses their feelings with someone outside of the dyad(192).

Prostate cancer has previously been referred to as a ‘we-disease’(134), and the view that the illness is shared is beneficial (see section3.1). This concept has been further explored in a 2017 review which looked at differences between those who viewed the illness as the patient’s or whether it was shared(193). They describe parent or spouse involvement on a scale ranging from under-involvement to over-involvement with each extreme resulting in poorer outcomes(193). Overinvolvement includes controlling SO behaviours (e.g., pressure or overprotection), and literature suggests such behaviours threaten self-efficacy and undermine patients' self-management. Under-involvement often stems from SOs consumption with competing burdens or holding the view the illness is the patient's problem.

The body of literature exploring the negative impact of social networks in illness is complex, however, factors such as how social networks react to a diagnosis, criticism, mis-matched needs for self-disclosure, and the view that the illness is the patient's rather than a shared challenge can all have a negative impact on the patient. A recognition that social networks are not always positive is particularly valuable in the case of men on AS because anxiety and uncertainty are the biggest predictors for men converting to radical intervention without clinical indication(194); and if SO reactions and responses impact on illness anxiety and uncertainty, this could be a contributary factor.

Chapter 4: Psychological theories

Exploring psychological theories in relation to illness, self-management and social support facilitates an understanding of the important mechanisms underpinning emotional processing when individuals experience illness. Applying an understanding of the way in which illness variables interact enables researchers to use theory to guide future research, for example, by making predictions about groups of people who may be at greater risk and/or those who may benefit from specific interventions, and what the likely outcomes may be under certain conditions.

This chapter focusses on the link between social support and health; specifically the main effect model and the buffering effect model(1), Lazarus & Folkman's transactional theory of stress and coping(2), the common-sense model of self-regulation(195), and interdependence theory(1), and how these theories can be applied to the study population (men on AS and their SOs).

Reflexive monitoring

A large amount of literature exists around illness social support and coping, and ensuring the most relevant, useful and applicable theories were described in this chapter and applied in the research development process was key to the development of this research project. Although some theories were discussed in some of the background literature, there was little consistency, i.e., there was no theory that was coming up more than once. My choice of theories was guided by my background in Health Psychology, and my experience working on previous health-related research projects in the Psychology and Primary Care departments of the University of Southampton. To ensure my focus was not too narrow and the most relevant theories were drawn upon, I explored a broad range of illness-related theories, discussed these with my supervisors and colleagues (who have a wide range of backgrounds and expertise), and used their guidance along with my own background knowledge to narrow the results down to what I consider the most applicable theories and models which I describe below.

4.1 The link between social support and health

The positive relationship between social support and well-being is well established(184, 196-199). A review by Cohen and Wills (1985) explored the mechanisms behind this relationship and aimed to determine whether the beneficial effects could be attributed to a) the overall beneficial effect of support (the main-effect model), or, b) a ‘buffering effect’, i.e. support networks protect and ‘buffer’ individuals from adverse effects in the case of stressful events (the buffering model)(1, 200). Cohen

(2004) reviewed this theory in light of literature published in the 19 years after publication of the original model, and stands by the mechanisms the main effect model and buffering effect model propose(182).

4.1.1 The main effect model

The main effect model proposes that integration into a social network provides positive affect, a sense of self-worth, a sense of stability, may help individuals to avoid issues such as economic or legal problems, and these in turn reduce the probability of developing both psychological and physical illness(1, 182). Integration into a social network may also (through peer pressure and perceived normative actions) promote certain health or illness related behaviours (both positively and negatively) such as exercise, consumption of healthy food, smoking or taking illicit drugs(182). This model proposes a mechanism that is active even in the absence of stress, and as such can act as a preventative measure.

4.1.1.1 Critical appraisal of the main effect model

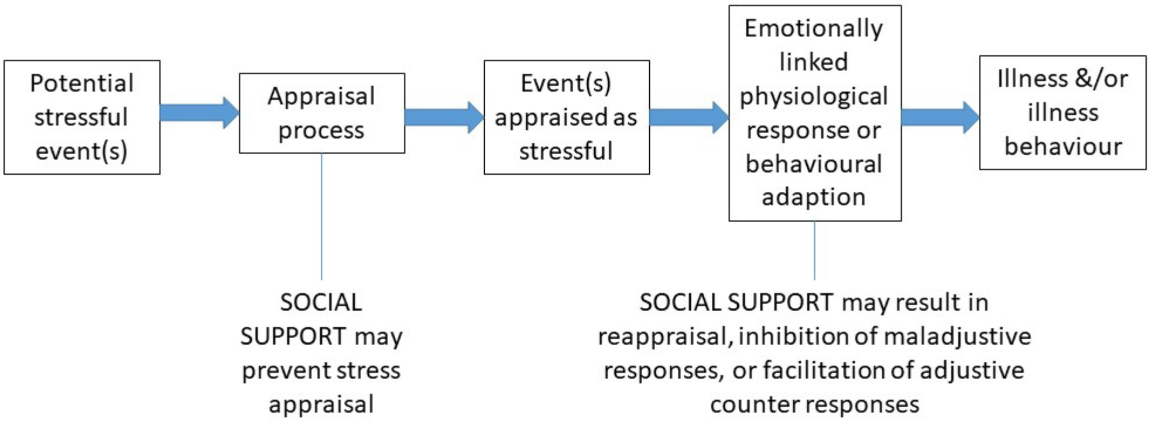
The main effect model provides a straightforward conceptualisation of how social support influences wellbeing, and its simplicity makes it accessible for researchers. However, the model may verge on being too simple and reductionist and overlooks the complexities between social support and stressors. The model is presumptuous in its claim that there is a uniform positive relationship between social support and wellbeing, failing to consider the factors which may moderate this relationship, for example, contextual factors, cultural variations, and individual differences. In addition, the model does not differentiate between different types of social support, for example, emotional, instrumental, and informational support which may impact to varying degrees. In summary, although the main effect model appears to be a clear and accessible model, it is overly simplified making it difficult to apply to real-life situations and their complexity.

4.1.2 The buffering effect model

The buffering effect model proposes social networks and SOs act as a protective shield to an individual when a stressful event occurs. ‘Stress’ in this model is defined by a situation an individual finds threatening or demanding and does not have an appropriate coping response for (3). Unsure about how to respond, an individual may experience a loss in self-esteem and feelings of helplessness.

Figure 5 below shows the chain linking stress to illness and/or illness behaviour, and two different points where social support may influence the outcome(1). The first point is early in the process, between the stressful event (e.g., diagnosis with cancer), and the individual's response. This may come in the form of offerings of help or reassurance about the situation, bolstering the individual's perceived ability to cope. The second point at which social support can be influential is in between the stress appraisal and the outcome. Adequate support at this point may reduce the stress reaction.

Figure 5: The buffering effect model



Four types of support have been identified as stress buffers(1) as shown in Table 7:

Table 7: Types of social support

Support label	**Description**
Emotional Support	Allowing the individual to vent their concerns, providing reassurance of self-worth and acceptance.
Informational support	Help in defining and understanding the problem, providing cognitive guidance.
Social companionship	Helping to distract from the stressor, facilitating positive affective moods, providing diffuse support and belongingness.
Instrumental support	Providing practical help, e.g., financial aid or material resources.

The types of support listed in Table 7 are usually not independent and intertwine with each other. For example, those who have social companionship may naturally have more resources for emotional, informational and instrumental support(1).

4.1.3 Conclusions from the Cohen and Wills (1985) review

Cohen and Wills (1985) concluded both models are valuable and valid, and the main effect and buffering hypotheses are not mutually exclusive. The review showed little evidence for any negative impact of social networks, with included studies consistently showing significant benefits of social support. The only aspect showing a negative impact was that of 'network conflict' for example, significant others disagreeing with treatment choices, or patient coping techniques. Network conflict can have negative effects on outcomes(201, 202).

4.1.4 Updates to the models proposed by Cohen and Wills (1985)

Cohen (2004) revisited the main effect model and buffering effect model in the context of more recent research. While the more recent literature corroborated the positive impact of social integration and social support, Cohen (2004) acknowledged the growing body of literature suggesting the impact that negative interactions can have on health (see 3.5 for more details).

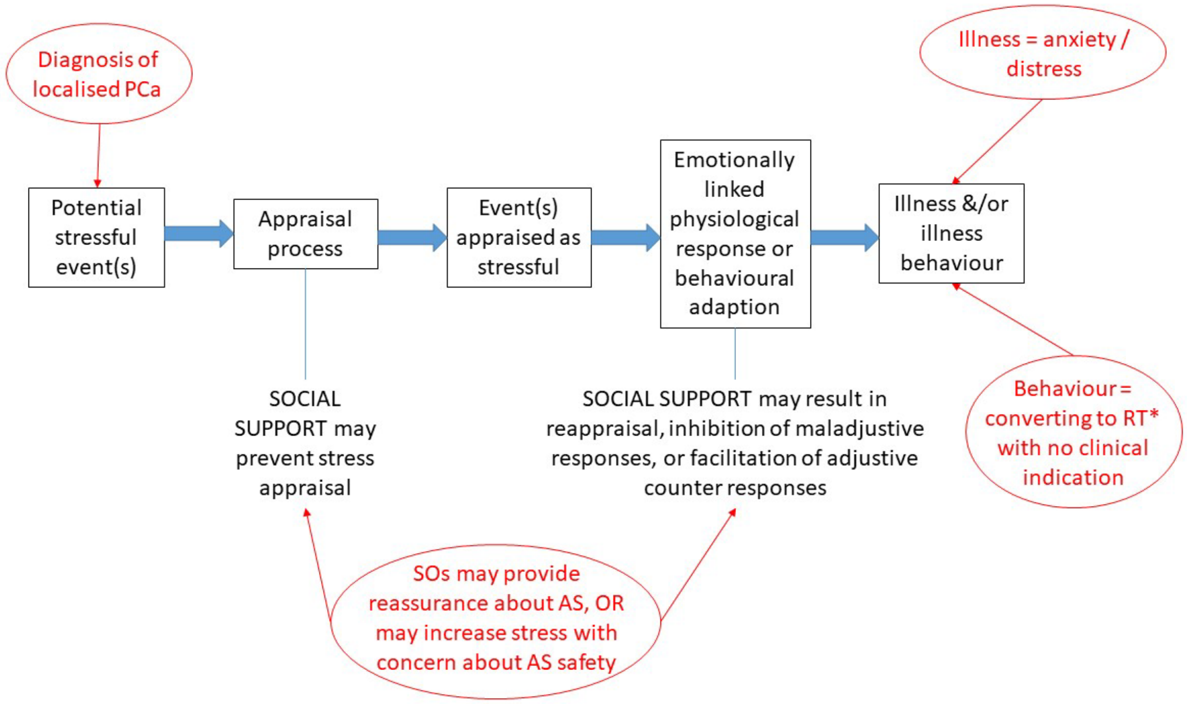
A few years later, Wills & Ainette (2007) reflected on social support and health research in relation to the main effect and buffering effect model. They found consistent support for the models and discuss how support can improve mortality, disease progression and recovery from illness. Wills & Ainette (2007) suggest processes of 'mediation' need to be considered when assessing mechanisms of support effects. This notion acknowledges that relationships between social support and health status are likely mediated by social variables. The authors break mediators down into three groups: psychological processes (e.g. perceived control), behavioural processes (e.g. alcohol intake), and physiological processes (e.g. stress reactivity)(203).

Despite the above literature discussing the potential negative impact of social support and the impact of mediating processes, to my knowledge an updated model has not been published.

4.1.5 The Buffering Effect Model in AS for PCa

I have found no published research exploring the buffering effect model in relation to men on AS and their significant others. However, I propose it can be helpful to insert the diagnosis of localised PCa into the 'potential stressful event' box; the social support buffering could include the types of support outlined in Table 7, and the illness/illness behaviour may include psychological distress and/or converting to radical treatment (RT) with no clinical indication. As outlined by Cohen & Wills (1985) (see 4.1.3), when conflict is present within the support system, the support can have a negative impact(1). In the case of AS for PCa, this may involve SOs feeling anxious about the AS pathway and disagreeing with the patient's treatment choice. Figure 6 shows a hypothetical model for patients on AS.

Figure 6: The buffering effect model in AS for PCa



* RT = Radical Treatment

4.1.6 Critical appraisal of The Buffering Effect Model

The four types of support (emotional support, informational support, social companionship and instrumental support) are well described and encompass many aspects of support. The model is straightforward to apply to different situations. However, there are some weaknesses. Firstly, the model presents two points at which social support can be influential. I propose it may be less linear, and influences are likely to have an impact repeatedly throughout the process. Although the authors state that the main effect model interacts with the buffering model, the influence of context is not acknowledged. Individual differences may also be important, for example, if the patient is very confident in their opinions they may be unmoved by those around them. A distinction is not made between SO support and other types of social support, and the difference between these two types of support may have an impact. Drawing on the more recent literature discussing these models and the influence of mediating processes(203), issues around context and individual differences may be negated. A model incorporating 'mediating processes' would offer a more complete picture.

4.2 The Lazarus and Folkman transactional theory of stress and coping

Since the 'Lazarus Stress Theory' was first published as a comprehensive theory in 1966, it has undergone several revisions(2, 3, 204, 205). In 1984, Lazarus & Folkman published an updated version titled 'The Lazarus & Folkman transactional theory of stress and coping'. It is this version that is discussed in this section. According to Lazarus & Folkman (1984) individuals constantly appraise stimuli in their environment according to how threatening, challenging or harmful they are, assessing whether they are 'stressors'. If a stimuli is identified as a stressor, individuals either initiate coping strategies to manage their emotions, or undertake activity to address the stressor itself(206). If an individual deems a stressor to exceed their capacity to cope, it will cause stress(2). In other words, the theory describes stress as a relationship between individuals and their environment with the processes of 'cognitive appraisal' and 'coping' as mediators(205):

> 'Psychological stress refers to a relationship with the environment that the person appraises as significant for his or her wellbeing and in which the demands tax or exceed available coping resources' (Lazarus and Folkman, 1986, p.63)

The process of 'appraisal' depends on an individual's expectancies. Personal and situational factors influence significance and outcome expectancies. Personal factors include motivational dispositions, goals, values and generalised expectancies. Situational factors include predictability, controllability and imminence, and in illness significance and likely outcome(3).
Lazarus went on to develop a comprehensive emotion theory(207) where the process of appraisal is further broken down into primary and secondary appraisal. Primary appraisal encompasses:

- *Goal relevance*: the extent to which the individual cares about the stressor/effects of the stressor.
- *Goal congruence*: the extent to which the stressor hinders personal goals.
- *Type of ego-involvement*: personal commitment, self-esteem, ego-ideal, ego-identity.

Secondary appraisal encompasses:

- *Blame or credit* for the stressful event.

- Perceived *coping potential*.
- *Future expectations*, and the extent to which the stressor will interfere with future goals.

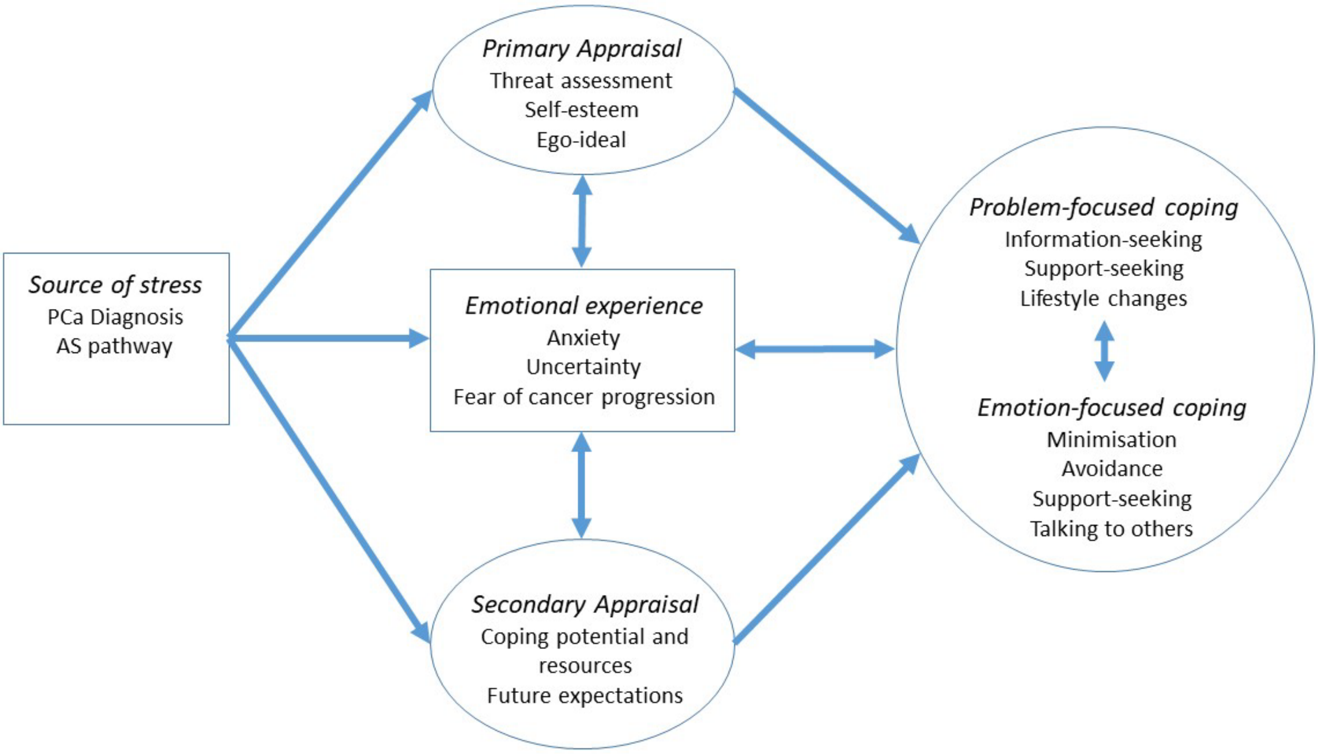
Folkman and Lazarus (1980) define 'coping' as follows(208):

> 'The cognitive and behavioural efforts made to master, tolerate, or reduce external and internal demands and conflicts among them.'

The concept of 'coping' can be broken down into 'problem-focussed coping' and 'emotion-focussed coping'. Problem-focussed coping involves trying to change the person-environment realities, for example, removing oneself from a stressful situation. 'Emotion-focussed coping' involves carrying out acts to reduce a negative emotional state and/or adapting the appraisal of the situation(2), for example, talking to others or practicing mindfulness.

Figure 7demonstrates my application of The Lazarus and Folkman transactional theory of stress and coping (1984) to men on AS for PCa. This is helpful because it provides information about where men may struggle, and at what point an intervention may be helpful.

Figure 7: The Lazarus and Folkman transactional theory of stress and coping (1984) in relation to men on AS



(Figure inspired by Lazarus & Folkman (1984)(2) and Poirel & Yvon (2014)(209))

4.2.1 Critical appraisal of The Lazarus & Folkman transactional theory of stress and coping

The Lazarus Stress Theory is strengthened by the acknowledgement of the two-way relationship between the appraisal processes and emotional experience, and between coping techniques and emotional experience. This demonstrates the non-linearity of the process, and the complex overlap between the stages. Some context is acknowledged at the appraisal stage, for example, existing self-esteem and resources to cope. One weakness of the theory is that although 'support-seeking' is identified as a form of coping, existing social support is not mentioned within the primary or secondary appraisal process.

4.3 The Revenson (1990) ecological framework for studying personality-disease relationships

Revenson (2003)(210) acknowledged the work by Lazarus & Folkman (1984) and aimed to expand the existing knowledge base by exploring how significant others may fit into this theory, specifically in the context of chronic illness making it particularly relevant to the current research. Revenson (2003) emphasised that a stressor does not only affect the individual, but also those around them. Family members are affected by the stressor itself, the effect it is having on their family member and the cumulative effect on family functioning(210).

A chronic illness is a chronic stressor(210, 211), and enforces on couples a series of interrelated life strains. Decades of research have corroborated the theory that 'coping' or 'coping behaviour' affects mental health outcomes(210). Revenson was particularly focussed on exploring how context (interpersonal, medical and temporal) affect patterns of coping with chronic illness within couples. Revenson developed an ecological framework for studying coping with illness in interpersonal relationships.

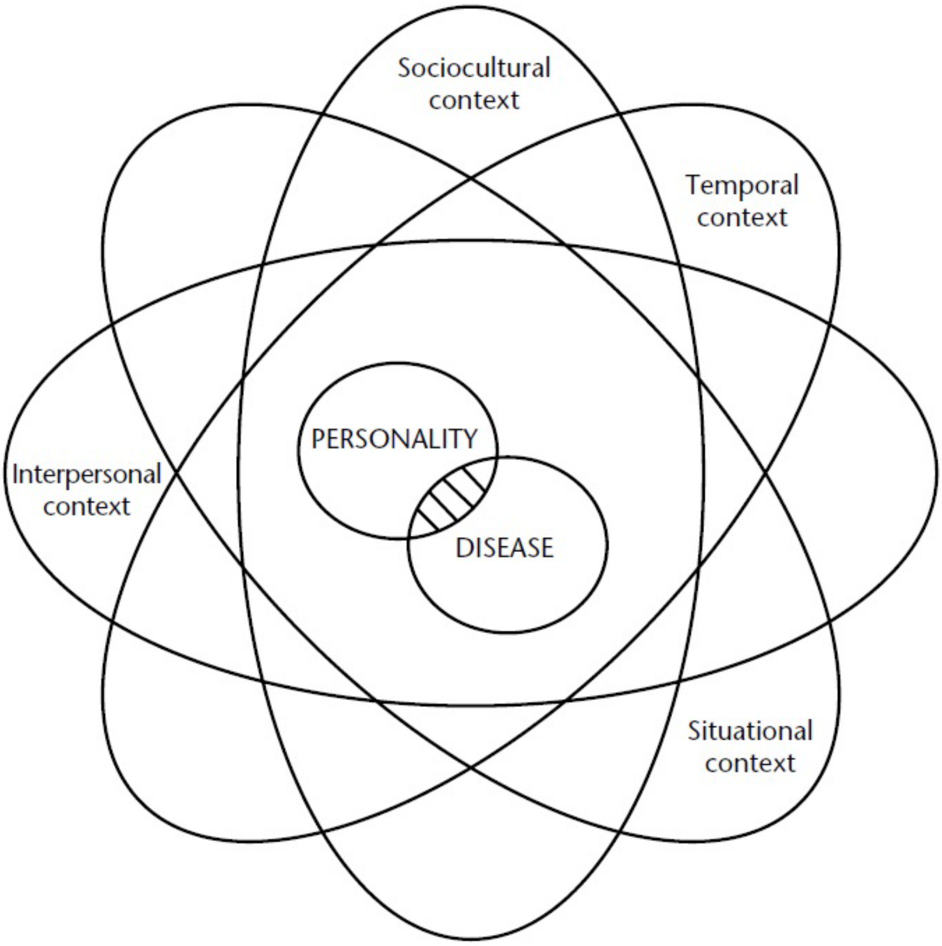
Four aspects of context feed into this framework:

- *Sociocultural context:* includes demographic markers such as age, gender, socio-economic status and educational level. Culture may influence acceptability of certain coping behaviours, for example, expressing emotion or talking about feelings.
- *Interpersonal context:* this represents the dyadic relationship, interpersonal relationships in connection with either partner, and interpersonal aspects of the health care environment, for example, the patient-physician relationship.

- *Situational context:* this encompasses the situation the illness imposes on the couple, for example, pain, disability or threat to life. Other stressors included in this category are changes to other situations due to the illness, for example, becoming unemployed or on sick-leave, and financial implications.
- *Temporal context:* this encompasses the timing of the illness within an individual's life, and how progressed the illness is when diagnosed. For example, a young person's diagnosis of an illness associated with increased age would be classed as an 'off-time' event, and as such be perceived as a larger stressor than an 'on-time' diagnosis. Off-time events reduce the likelihood the individual will have peers experiencing similar life situations. Similarly, being diagnosed with a slow-progressing illness may allow time to adjust to the situation, and to develop methods of coping in small, incremental stages, whereas a diagnosis of a rapidly evolving illness forces individuals to accommodate rapidly changing illness demands.

See Figure 8 below for a diagram depicting the Revenson (1990) ecological framework for studying personality-disease relationships(4).

Figure 8: An ecological framework for studying personality-disease relationships



4.3.1 Application of the Revenson (1990) ecological framework to men on AS for PCa

The ecological framework described above promotes ideas for consideration when studying the population of men on AS for PCa and their SOs. The following is my own application of the framework for this population. Firstly, from a socio-cultural perspective, all patients will be male, but coping may vary depending on various cultural factors such as education level, ethnicity, and gender of SO. Future research would benefit from capturing this demographic information to explore how coping is impacted. Secondly, using the situational context lens, effects on employment are usually minimal for men on AS; a large proportion of those diagnosed are retired, and although those in work will need time off for regular check-ups and appointments, most do not require prolonged periods of absence. Thirdly, the importance of the interpersonal context indicates that it would be valuable for future research to explore relationship quality, patient-physician relationship and other support available to the individual. Lastly, within a temporal context, although most men diagnosed are over 50, there are men on AS who are younger. Younger patients and their SOs encountering 'off-time' diagnosis may differ in how they cope and require a different level of support.

4.3.2 Critical appraisal of The Revenson Ecological framework

The Revenson Ecological framework embraces and promotes the importance of context, and the different types of context. The framework is a useful tool in research to ensure enough contextual data is collected. A potential weakness of the framework is its lack of 'appraisal' process acknowledgement.

4.4 Self-regulatory theory and illness perception

The Common-Sense Model of Self-Regulation originated from work conducted by Leventhal in the 1970's. Since then, the model has been updated and amended many times, and is known varyingly as the Illness Perceptions Model, the Illness Representations Model, Leventhal's model and the Common-Sense Model of Self-Regulation(212-215). Throughout this section I will refer to the model as the Common-Sense Model (CSM).

The AS pathway requires patients to self-manage an ongoing and future health threat (i.e., the threat of cancer progression). The CSM provides a theoretical framework for exploring the perceptual, behavioural and cognitive processes involved in responding to illness(195, 216), and is appropriate to apply to men on the AS pathway. This model was chosen because it applies specifically to health and illness and facilitates understanding of behaviours related to health-threats. It is a dynamic, multi-level model which aids understanding of behaviour in terms of representations of symptoms and illness.

The key construct in this theory is ‘illness representations’. These illness representations interact with an individual’s ‘existing schemata’, or previous knowledge and understanding. According to this theory cognitive illness representations are made up of the following dimensions(216):

1.) Identity: the label given to the illness and the associated symptoms.

2.) Cause: the individualistic perceived cause of the condition, regardless of the biomedical accuracy.

3.) Timeline: the perceived time the illness will last.

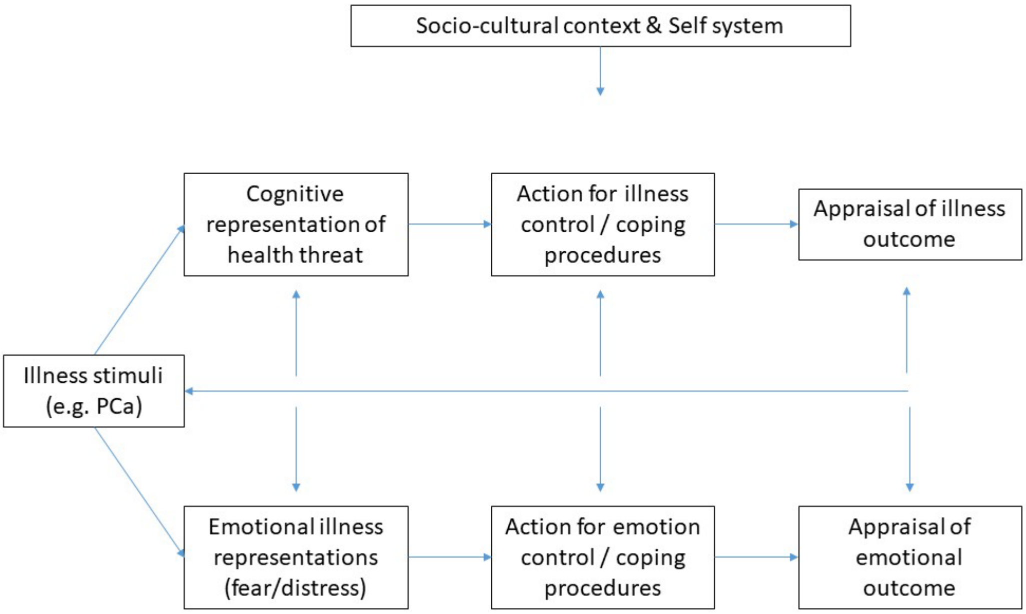
4.) Consequences: individualistic beliefs about how the condition will impact their lives physically and socially.

5.) Cure/control: beliefs about whether the condition can be recovered from/controlled.

In addition to these cognitive (sometimes referred to as ‘objective’) illness representations, the theory describes an independent emotional processing system, referred to by Leventhal et al., (1992) as the psychologically ‘subjective’ processing system. These two processing systems are thought to work together.

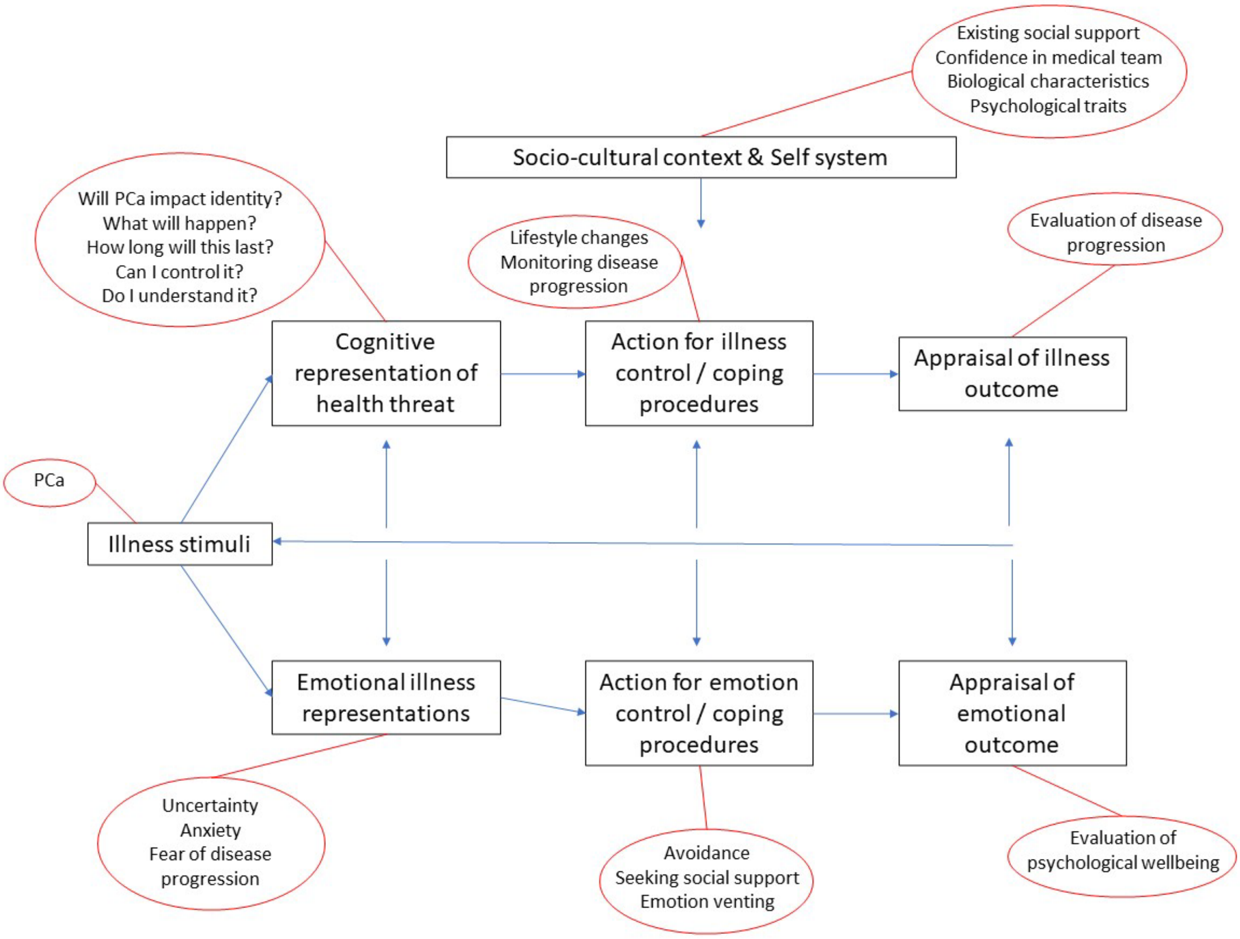
Figure 9 below shows how these processing systems translate into coping actions, which in turn leads to an appraisal of outcomes(216).

Figure 9: Common sense self-regulation model based on Leventhal et al., (1992)



The model acknowledges the self-system (biological characteristics and psychological traits), and that cultural influences will impact the whole process. For men on the AS pathway 'action for illness' will not involve treatments such as surgery or chemotherapy, but instead, regular monitoring, and possibly lifestyle changes to improve general health, for example, changes to diet and exercise. In Figure 10 below I have added my own application of this theory to men on AS for PCa.

Figure 10: Application of the common-sense self-regulation model for men on AS for PCa



The illness perception questionnaire (IPQ)(5) was developed to provide a quantitative measure of the five cognitive illness representations described above. The questionnaire was revised in 2001 to include a measure of emotional representations, a subscale assessing illness coherence, a scale measuring the extent to which symptoms fluctuate, and a differentiation was made between personal control over the illness and beliefs about treatment control. Presently, the revised illness perception questionnaire (IPQ-R)(217) is a widely recognised, validated and utilized tool. It has been used widely across different health conditions including heart disease(218), cancer(219), diabetes(220) and chronic fatigue syndrome(221).

The illness perceptions of the patient's support network have been shown to have a significant impact on health-related outcomes(221). It is important to take into consideration that those close to the patient have their own set of illness representations and beliefs because the extent to which they match or differ may impact outcomes(221). This is particularly relevant to men on the AS pathway because if close relatives are not on board with the monitoring pathway, men may be influenced to convert to radical intervention without clinical indication. The illness perception questionnaire has been adapted to capture the perceptions of spouses and carers of people with health conditions such as schizophrenia(222), chronic fatigue syndrome(221) and heart disease(223).

4.4.1 Critical appraisal of The Self-Regulatory Theory

The CSM has developed over several decades and its current structure is derived from comprehensive empirical research(195). The illness representations are thorough and clearly described. Context and the self-system are acknowledged as an 'overall' influencer, however, there is a lack of detail around the things that may impact the cognitive and emotional representations. Social support is not explicitly mentioned.

4.5 Interdependence

The theories discussed in this chapter so far are formed around how an individual responds to illness (or a generic stressor, such as illness). I have critically appraised each theory ensuring to note the extent to which close personal relationships are acknowledged. This PhD explores the way close personal relationships impact an individual in illness (PCa), and the way in which illness can impact SOs. Acknowledging the blurred lines between an individual in illness and those close to them, it is appropriate to include the theory of interdependence in this chapter. Interdependence theory aims to capture 'the process by which interacting people influence one another's experiences'(224).

Interdependence theory was first developed and published by Thaibaut & Kelley (1959), and has since been extended and amended into a comprehensive theory of social interaction(224, 225). In social psychology, interdependence theory is classified as a 'social exchange theory' and has four basic assumptions described in Table 8 below(224, 225):

Table 8: The four basic assumptions within interdependence theory

Basic assumption	**Dimensions of structure**
The principle of structure (the situation)	1) Degree/level of dependence: The level of reliance an individual has on another. 2) Mutuality of dependence: The extent to which dependence levels are matched within a dyad. 3) Covariation of interest: The level of gratification an individual receives within an interaction. 4) Basis of dependence: The extent to which one member of the dyad can influence the other. 5) Temporal structure: The impact of timing and the sequence of events. 6) Information availability: The amount of information a person has about another person's motives and potential outcomes.
The principle of transformation (what people make of the situation)	This principle encompasses four types of rewards and costs within a relationship: 1) Emotional: The positive and negative feelings experienced in a relationship. 2) Social: The extent to which the relationship requires involvement in positive and negative social situations. 3) Instrumental: The extent to which each partner contributes to life tasks, such as home maintenance. 4) Opportunity: The extent to which opportunities are opened or closed due to the relationship.
The principle of interaction	This principle is used to assess the variables that impact the outcome of any given interaction. The interaction is sometimes described using the formula: (I = f[A, B, S]) where the **I**nteraction is a function of person **A**'s motives, traits and actions, plus person **B**'s motives, traits and actions, plus the **S**ituation.
The principle of adaption	This principle refers to the impact of repeated social interactions which produce habitual responses.

Interdependence theory provides an understanding of the complexities of social interaction. It highlights an individual's response and reaction to any given situation is complex and tightly interlinked with both past experiences and those close to them.

Interdependence theory claims the dyad should be the unit of analysis, rather than the individual(225, 226). When exploring experiences, reactions and responses in the situation of chronic illness (such as PCa) through the lens of interdependence theory, it seems both appropriate and essential to consider close personal relationships.

4.6 Conclusions and implications for this research project

Exploring the above theories and their implications has been an important and useful process for the development of this research project.

The benefits of social support in illness are more widely recognised than the potential negative impact, however, Cohen and Wills (1985) touched upon the topic of network conflict and the negative impact it can have on the patient(1) (see 3.6 for more detail on the negative impact of close relationships). Specific to this research project, disagreements about treatment choices may cause network conflict and therefore it is important to capture the extent to which SOs are on board with the AS pathway in future research, and for future interventions to include strategies to aid shared decision-making. Underpinned by self-regulatory theory, the IPQ-R(217) may be particularly useful in capturing matched/mis-matched illness perceptions to gauge potential network conflict.

The buffering effect model implies social support can ‘buffer’ the appraisal of the situation as ‘stressful’ both in the stages of initial appraisal (i.e. immediately after diagnosis), and in an ongoing manner(1). This model implies support provision would be beneficial early in the process of diagnosis and treatment decision making, and the involvement of SOs from the early stages is imperative.

According to the Lazarus stress theory, interventions would benefit from the provision of strategies to enhance both emotion-focussed coping and problem-focussed coping(205). Context is particularly important(210), which points towards a flexible, patient centred approach.

Interdependence theory further corroborates the importance of including SOs in my research studies.

Chapter 5: Methodology Chapter

5.1 Introduction

This chapter presents the methodology of the thesis. The aim of this chapter is to present the context in which the study design, data collection and analysis took place, and how data collection and analysis answered the research questions. This chapter presents the philosophical stance taken in this thesis, the mixed methods approach, dyadic quantitative and qualitative methods, and describes how PPIE informed the research.

5.2 Epistemology

The research presented in this thesis involves exploring the experiences of men on AS for PCa, experiences of their SOs, and the impact SOs have on men on AS for PCa. To answer these questions it is important to understand the philosophical assumptions of different types of research methodology, identify and recognise my own philosophical stance, and select the most appropriate methodology. Philosophical stances are underpinned by ontology and epistemology. Ontology is concerned with the nature of reality and what constitutes a fact. Epistemology refers to the theory of knowledge and rationality of belief(227).

Positivism and interpretivism are research paradigms at opposing ends of the spectrum, with various positions in between. Positivist researchers believe knowledge can be discovered, i.e., there is an objective reality independent of the researcher. This objective knowledge is learned through rigorous methodology and experimentation. Quantitative research, scientific enquiry, numerical data gathering and experimental approaches are the preferred approaches of positivist researchers(228).

Interpretivist researchers believe in a subjective reality; that knowledge is developed based upon one’s own understanding of the world and life experiences. Methodology obtaining knowledge inductively from an individual’s (or group of individuals’) perspective is appropriate for interpretivist researchers, for example, qualitative, phenomenological and humanistic methods(228).

5.3 Philosophical stance: Pragmatism

The philosophical approach in this thesis is pragmatism. Pragmatism claims that every problem in life is practical and therefore problems in everyday life should be explored from practical perspectives(229). In research, social scientists have claimed pragmatism as a practical research paradigm with the ability to address social problems from different angles by applying multi-methods(229). Pragmatic research should produce results that are helpful in the understanding of a problem. Using this approach as an underpinning to research, pragmatism has been described as:

> *"A deconstructive paradigm that debunks concepts such as 'truth' and 'reality and focuses instead on 'what works' as the truth regarding the research questions under investigation. Pragmatism is a paradigm that rejects either/or choices associated with the paradigm wars, advocates for the use of mixed research methods, and acknowledges that the values of the researcher play a large role in the interpretation of the result." (Tashakkori & Teddlie, 2003, p. 713)(230)*

The pragmatic approach in research acknowledges the most appropriate research methods will vary depending on the context and research question(231).

5.3.1 Pragmatism and this study

The studies described in this thesis adopt a pragmatic approach. The design and data collection approach were informed by the research problem and questions. The mixed methods study presented in this thesis utilised an exploratory approach, meaning broad research questions were used in order to explore a field that is as yet poorly understood(232). This approach is the most appropriate because the qualitative synthesis identified that the field of SOs in AS for PCa is under-researched.

The pragmatic approach defends the notion that no one research method is better than the other, and knowledge can be gained through multiple methods. Furthermore, generating knowledge through multiple viewpoints is beneficial to overall understanding(233).

Quantitative measures were used to meet the following objectives:

1. To explore the relationship between significant other responses to, and perceptions of, active surveillance and patient anxiety.
2. To explore associations between relationship quality and illness related dyadic communication, and patient anxiety.
3. To explore the relationship between significant other prostate cancer related anxiety, and patient anxiety, depression and quality of life.

Qualitative measures were used to meet the following objectives:

1. To explore the experiences of men on AS for PCa and their significant others.

Secondary objectives:

2. To explore how the significant other responses to the PCa diagnosis and AS treatment plan impact on the PCa patient.
3. To explore the way in which the dyads perceive each other's AS related feelings and reactions.
4. To explore the feelings of both the patient and the SO around being managed with AS.
5. To explore the way in which both the patient and the SO see the PCa treatment plan longer term.

Mixed methods objectives:

1. To understand in more depth any relationships uncovered in the quantitative phase, enabling comparison and triangulation with the quantitative and qualitative findings.
2. To gain insights that may have been missed or difficult to capture within the quantitative phase to enable integration into a fuller picture.

5.4 Quantitative and Qualitative Research

Quantitative research seeks an objective truth using numeric data collected from, for example, questionnaires, structured observations or experiments(234). Quantitative data analysis consists of a variety of mathematical and statistical analysis.

Qualitative research seeks an in-depth understanding of social phenomena considering the wider context such as individual experiences, attitudes and beliefs. Qualitative data is collected in a number of ways including via semi-structured interviews and focus groups with open-ended questions to allow participants to speak freely, semi-structured surveys and ethnographies(234). Qualitative analysis methods include thematic analysis(235, 236), discourse analysis(237), interpretive phenomenological analysis(238), content analysis(239) and many more.

Quantitative and qualitative research methods have different strengths and limitations. Quantitative research can be conducted quickly and recruit a large number of participants. Hypotheses can be tested, and use of randomization, control measures and reliable data collection can mean the results are generalisable to that population(234). However, quantitative findings can be described as reductionist, lack context and fail to answer the 'why' questions when examining a phenomena(240). Qualitative research provides a richer understanding of context and meaning. This in-depth understanding is specific to the participant pool, and findings may not be generalisable to the wider population, but may be transferable to other contexts(240). It has been argued that that qualitative findings are too subjective and findings are not adequately ‘scientific’(240). Qualitative data collection and analysis can be time consuming compared to quantitative methods(241).

The differences in theoretical perspectives between qualitative and quantitative research methods need to be acknowledged, however, combining the two in the ‘mixed methods’ approach is becoming increasingly common, with advantages to using both forms of data collection and analysis(234, 240). Quantitative research can help to see the big picture, while qualitative can add depth, meaning and understanding(234).

5.5 Mixed Methods Research

Philosophical and technical challenges arise with the use of mixed methods methodology(242). The philosophical challenges arise due to the differing philosophical stances associated with qualitative and quantitative research. As described above (ref epistemology section), qualitative research traditionally draws upon interpretivist epistemologies(243), whereas quantitative research claims a positivist approach, with an underlying belief that there is an independent reality to be uncovered(228). These philosophical challenges are often addressed by taking a pragmatic approach(242). The technical challenges arise from questions around how qualitative and quantitative should or could be combined, and can be addressed by drawing upon formal mixed methods research designs(242).

Below I describe three key main mixed methods designs, as described by Creswell et al. (2018). Other typologies have been published(242) but are beyond the scope of this thesis. Deciding which methodology is best suited to a particular research project will depend on factors such as whether the qualitative and quantitative data were collected one after the other or simultaneously, or whether there is a particular theoretical perspective guiding the specific research.

Table 9: The three main mixed methods designs (adapted from Creswell, 2018)

Design Type	Implementation	Purpose
Explanatory sequential design	Quantitative followed by qualitative	To use qualitative results to add to and assist in the explanation and interpretation of the findings of the quantitative strand
Exploratory sequential design	Qualitative followed by quantitative	To use quantitative results to assist in the interpretation of qualitative

		findings, primarily to explore a phenomenon or test an instrument
Convergent design	Concurrent collection of quantitative and qualitative	To cross-validate or corroborate findings within a single study

The design type chosen for the mixed-methods study presented in this thesis is 'explanatory sequential design'. The quantitative results were available to inform the development of the qualitative interview schedule, therefore the exploratory sequential design and convergent design were not appropriate. I chose this design for a couple of reasons; firstly, because I planned to purposively sample from the quantitative study participants for the qualitative study, and secondly, if any relationships/correlations were present in the quantitative data I planned to explore these further qualitatively.

I chose to conduct a mixed methods study for the following reasons: the quantitative study was designed to explore the presence of statistical relationships between SO responses to AS, SO perceptions of AS, patient anxiety, depression and quality of life, illness related dyadic communication, and SO anxiety, depression and quality of life. If this study had recruited the proposed number of participants, relationships between these variables could have provided quantitative information about how dyadic relationships can shape AS experiences. The qualitative interviews were conducted to provide depth, context and a more holistic understanding of dyadic complexities in AS for PCa. The different methods produce complementary but different data to more fully understand the topic.

5.6 Methods for systematic review study

In this section I explain what a review is, some of the different ways it can be approached, the methods I considered, and a justification for choosing a systematic qualitative synthesis.

The purpose of a review is to bring together what is known about a particular topic to provide a broad understanding of the existing evidence base(244) and potentially reveal deeper insights or explanations that would not be possible from a single study(245). The two main types of review are known as 'narrative' reviews and 'systematic' reviews(246). Narrative reviews often address a broad aim, collating a wide range of literature aiming to give a deep understanding of a topic(247). Systematic reviews on the other hand are often used in research with a narrower research question and utilize rigorous methods including a pre-designed search strategy, inclusion and exclusion criteria and an assessment of quality of each study(248). Systematic reviews aim to summarise existing data(247).

In addition to the main types of review, there are various approaches which need to be considered to ensure the research question is being addressed in the most appropriate way. The approaches vary in their purpose, philosophical stance and whether they primarily re-interpret study findings, or aggregate existing findings(248). Some examples include a realist review, a meta-aggregative approach, and meta-ethnography (and many more). I will briefly describe the characteristics of these approaches, and why they were not chosen for the review in this thesis.

A realist review is undertaken when studying complex interventions, to answer questions around what works for whom, and under what circumstances(249). As I was not looking at how complex interventions might work in my target population, and the focus of my own review was their experiences, a realist review was not appropriate.

Meta-aggregation involves bringing together the findings of relevant literature, aggregating similar findings into categories and grouping categories into synthesized findings(250). In addition, meta-aggregation aims to generate generalisable statements of recommendations for practitioners and policy makers(251). The synthesis process in meta-aggregation differs from a systematic qualitative synthesis where the raw participant data and quotes are used in the synthesis process. Meta-aggregation was not an appropriate approach for the review in this thesis; the aim was not to form statements of recommendations, but instead to explore experiences, and to do this effectively drawing on the raw participant data was imperative.

The meta-ethnographic approach is one of the most commonly used qualitative synthesis approaches in healthcare(252). The approach is used to explore the conceptual or theoretical understandings of a particular phenomenon(253), and is particularly helpful when aiming to develop new conceptual models and theories(254). In a meta-ethnography the researcher re-interprets the themes and concepts presented in the primary studies, whilst also taking the primary data into account with the goal of creating higher level order themes(255). Although meta-ethnography is a common approach, there is a lack of clarity around the data analysis process(253). I chose not to undertake a meta-ethnography because my aim was not to explore conceptual or theoretical understandings of experiences of AS for PCa, but rather to explore experiences themselves and how they present in the raw data.

I chose the approach of a qualitative systematic synthesis for my review. My reasons for opting for purely a qualitative review rather than mixed methods are explained in section 6.4.1.1. Qualitative reviews using the systematic synthesis approach aim to present a comprehensive understanding of participant experiences and perceptions(256), fitting with my own research aim of ‘exploring experiences of men undergoing AS for PCa and their SOs’. A systematic synthesis provides a transparency of methods used in the process of systematically searching, appraising and synthesizing data(257). Standardised guidelines are available for researchers to follow when conducting a systematic synthesis(258-261), and the methods are well established(262).

5.7 Methods for quantitative study

As explained in section 5.5 a quantitative survey study was undertaken with the aim of revealing any relationships between SO responses to AS, SO perceptions of AS, patient anxiety, depression and quality of life, illness related dyadic communication, and SO anxiety, depression and quality of life. I considered the most appropriate design for this survey, and how to minimize errors in data collection and analysis.

5.7.1 Survey research designs

There are several designs or structures that can be used when creating a survey study(263). Table 10 below describes the main designs.

Table 10 Survey designs

Design	**Description**
Cross-sectional	The sample is drawn from the target population and is studied once, i.e. it provides a snap shot of that sample at that point in time. Using this design characteristics of that population can be described.
Successive independent sample	Multiple random samples from the target population at one or more times. For example, a group of people 3 months post cancer diagnosis, and a group of different people 1 year post cancer diagnosis. This design enables insight into changes within a population over time, but cannot provide information about changes within individuals.
Longitudinal	Longitudinal designs study the same sample at different timepoints. For example, a group of people 3 months post cancer diagnosis, and the same group at 1 year post diagnosis. This design can provide insight into changes over time, and potential reasons behind those changes.

A cross-sectional design was chosen. For the purposes of this study information gathered at different time-points was not necessary.

5.7.2 Errors in survey research

Another important consideration is the type of errors that can impact the quantity and quality of data gathered, how they can occur and how they can be minimized. Table 11 below has been adapted from Ponto et al., (2015) and describes these errors and how they have been considered in the survey study presented in this thesis(264).

Table 11 Sources of error in survey research adapted from Ponto et al., (2015)

Type of error	**Source of error**	**Strategies to reduce error**	**Application to quantitative study**
Coverage error	Unknown or zero chance of individuals in the population being included in the sample	Multimode design	Study advert was placed online, in email circulation lists and in charity newsletters. Participants were offered postal questionnaires.
Sampling error	Individuals included in the sample do not represent the characteristics of the population	Clearly defined population of interest; diverse participant recruitment strategies; large, random sample	Clear eligibility criteria: men had to be on AS for PCa.
Measurement error	Questions/instruments do not accurately reflect the topic of interest	Valid, reliable instruments; pretest questions; user-friendly graphics, visual characteristics	Used standardized questionnaires where possible.
Nonresponse error	Lack of response from all individuals in sample	User-friendly survey design; follow-up procedures for non-responders	Survey was user-tested by PPI. Survey was clear and simple.

The extent to which these errors may have impacted the present study is discussed in section 7.5.3.

Quantitative measures in the form of a cross-sectional survey were selected to investigate the following:

1. The relationship between significant other responses to, and perceptions of, active surveillance and patient anxiety.
2. Associations between relationship quality and illness related dyadic communication, and patient anxiety.
3. The relationship between significant other prostate cancer related anxiety, and patient anxiety, depression and quality of life.

Men on AS and their SOs completed surveys separately (see Appendix H). See Appendix G for full study protocol. The surveys consisted of standardized quantitative measures with the addition of a qualitative text box at the end of the survey where participants could add any additional information.

See section 7.3.2 for a description of the chosen measures and alternatives considered.

5.7.3 Quantitative analysis methods

5.7.3.1 Correlational analysis

Correlation, partial-correlation and regression analyses were planned to be the primary methods of statistical analysis. It was planned that descriptive statistics and graphical representations of the quantitative data would be used to explore:

1. Patient relationships between Patient Reported Outcome Measures (PROMs) (anxiety, depression, wellbeing, communication and illness perception).

2. Significant other relationships between PROMs (anxiety, depression, wellbeing, communication and illness perception).

3. Relationships between patient responses and significant other responses.

Correlational analysis investigates the relationships between variables and measures the strength and direction of associations. Correlation does not imply causation(265, 266). There are various methods of correlational analysis appropriate in different types of data. The methods below indicate the strength and direction of correlations by providing a number between -1 and 1, where -1 is a perfect negative correlation and 1 is a perfect positive correlation(265).

The most commonly used method for measuring linear correlation is the Pearson correlation coefficient (*r*). To use this analysis method assumptions of normal distribution and equal variances must be met and there should be no outliers. If the variables are not normally distributed, the data includes outliers, or the variables are ordinal, the Spearman Rank correlation may be more appropriate for analysis. The Spearman Rank correlation is a non-parametric test which evaluates the degree to which one variable tends to increase as another increases.

Kendall's Tau correlation coefficient, often denoted as τ, is an extension of Spearman's rho and a statistical measure used to assess the ordinal association between two measured quantities. This method is suitable for sample sizes n=10-25(267).

5.7.3.2 Paired sample t-tests

Paired sample t-tests are used to compare the means of two related samples. It may be used when the same group of participants complete measures at two time-points, for example, before and after an event, or they may be used when two groups of participants are related. The participants in the quantitative survey study described in Chapter 7 are men on AS and their wives or partners. The men and their partners are interlinked, related subjects, and data from each person within the couples cannot be treated as independent. However, they are also not truly paired. After consulting a statistician it was decided a paired sample t-test was the most appropriate method for exploring mean differences between the men and their partners, however, because the two sets of data are not truly paired the results must be interpreted with caution.

The paired sample t-test tests hypotheses are stated in Table 12.

Table 12 Hypotheses in paired sample t-tests

Hypothesis	**Formula**	**What this means**	**What this means in the context of this study**
Null hypothesis	H_0: $\mu_1 = \mu_2$	The two population means are equal	The mean scores for men on AS and SOs are equal
Two-tailed	H_1: $\mu_1 \neq \mu_2$	The two population means are not equal	The mean scores for men on AS and SOs are not equal
Left-tailed	H_1: $\mu_1 < \mu_2$	Population 1 mean is less than population 2 mean	The mean scores for the men on AS are less than the mean scores of the SOs

Right-tailed	**H_1:** $\mu_1 > \mu_2$	Population 1 mean is greater than population 2 mean	The mean scores for the men on AS are greater than the mean scores of the SOs

For valid paired sample t-test results the following assumptions should be met:

- Participants have been randomly selected from the population.
- Differences between the pairs are approximately normally distributed.
- There are no extreme outliers in the differences.

The paired sample t-test analysis is conducted by calculating the difference between scores in each pair of participants (couple in the case of this PhD study), computing the mean and standard deviation of the differences, and comparing the average difference to 0. If the outcome is significantly different to 0, the null hypothesis can be rejected.

5.7.3.3 Multi-level modelling and Structural equation modelling

Upon further reading about statistical analysis specific to dyads it became clear some further analysis would be needed to account for the interdependence within dyadic data. Conventional methods for data analysis (including analysis of variance (ANOVA), independent t-tests and general linear regression) assume data from participants are independent from each other(268). When collecting dyadic data it is important to recognise the interdependence between each pair of data sets(268-270), i.e., the data from each partner is neither independent nor paired. Instead, it is likely correlated in some way. Applying conventional methods such as independent and paired t-tests to dyadic data with the assumption that each participant's data is individual increases the likelihood of Type I errors(268). The two most common ways of analysing dyadic data are multi-level modelling (MLM) and structural equation modelling (SEM)(270).

Multi-level modelling

MLM is applied to data organised into hierarchical structured clusters. In the case of dyads there exists data from individuals (level 1) nested within dyads (level 2). MLM has the ability to account for interdependence while combining the variables from multiple levels into a single model(268). Statistical software packages such as SPSS and STATA have built-in routines for MLM analysis(271), making this kind of analysis accessible to non-expert statisticians. MLM can be effective even with relatively small sample sizes(271).

Structural equation modelling

SEM tackles the issue of interdependence with the construction of a model demonstrating the relationships between variables, and the implementation of statistical algorithms to account for these relationships(271). SEM is less accessible for non-expert statisticians using statistical packages, and often requires larger sample sizes(271).

5.8 Methods for dyadic qualitative data sampling and analysis

5.8.1 Sampling

The recruitment target for the qualitative study was set at 40 participants (20 dyads). Historically, data collection would have continued until ‘data saturation’. The term ‘data saturation’ in thematic analysis is used when no new codes or themes are being generated from qualitative data(235). The practice of data saturation is firmly embedded in qualitative research. It is the most common justification for qualitative sample size(272), and is listed as a criteria in multiple ‘quality checklists’ such as the Critical Appraisal Skills Programme(273). However, recent work by Braun & Clark (2021) questions the notion of ‘saturation’ being the unquestioned accepted gold standard for qualitative research(274).

Data saturation has been referred to as ‘information redundancy’(275), and it has been argued that the phrase ‘data saturation’ implies knowledge about the given topic is complete and with no more to learn or gain from further data, it is a fixed point to stop data collection(276). Braun & Clarke (2021) argue there is a risk that researchers claim ‘no new information’ is arising to rationalize sample size, and that this claim is misleading because there will always be possible new theoretical insights with further data collection(274). Researchers often use the term saturation because it is requested by reviewers for publication, it is listed on quality check lists, but it might not be appropriate in every situation. Data saturation is not a useful concept for all types of thematic analysis(274).

‘Theoretical sufficiency’ has been suggested as an alternative(276), meaning data categories and relationships between categories are explained to an extent that a theory can arise(277). The term ‘theoretical saturation’ is used to describe the full understanding of a concept, or understanding of a concept from which theory can be developed. In qualitative research it is often not clear whether researchers are referring to ‘theoretical saturation’ or ‘data saturation’, although there are clearly some overlaps(274).

With this in mind, rather than trying to achieve data saturation, I sampled pragmatically. This means I set my recruitment target at 40 as stated above, however, this figure remained flexible depending on recruitment, the development of analysis, the depth of the data and the opportunities for theoretical insights to arise. In other words, the figure remained flexible depending on the amount of information the interviews held, also known as 'information power'(278).

5.8.2 Considering methods of dyadic data collection

I considered various methods of dyadic data collection. Eisikovits & Koren (2010) detail the benefits and drawbacks of five different modes of dyadic data collection: separate interviews, separate interviews performed simultaneously by different interviewers, joint interviews, both separate and joint interviews with the same participants, and separate interviews with some informants and joint interviews with others (279). Although there are some limitations to interviewing separately (see section 8.4), I chose to conduct separate interviews for the following reasons:

- Some potentially sensitive topics were addressed, and individual interviews allow the participants to discuss their thoughts and feelings without censoring their answers due to the presence of their partner.
- To allow individuals to tell the story from their own perspective(279, 280).
- To enable the dyadic view (third version) to enrich the perspective(279).
- To provide the opportunity for triangulation in analysis, maximising the trustworthiness of the data(279, 281).
- As I was conducting all interviews myself, I was unable to carry them out simultaneously.

If for any reason it was not possible for an interviewee to be alone, or the participant was not comfortable being alone for the interview, it was decided that the presence of another person would be noted and taken into account in analysis.

5.8.3 Dyadic data collection and analysis considerations

Interviewing couples rather than individuals adds an extra dimension to the processes of data collection, analysis and publication (see section 5.8 for more detail on publication issues) and requires some additional considerations around maintaining confidentiality and data integrity.

5.8.3.1 Maximising the integrity of the data and maintaining confidentiality during data collection

When interviewing couples there is a risk data may be influenced by cross-contamination within couples, i.e., from a couple discussing the interview topics and/or content when one is complete and the other has not yet taken place. Researchers must work reflexively to acknowledge and manage any feelings of preference for one member of a couple. A recent publication recommends refraining from viewing researcher bias as a potential threat, and instead embracing subjectivity as a researcher resource(282). With this in mind, the process of reflexivity becomes even more important to aid transparency(282). Ummel & Achilles (2016) make recommendations to maximise the integrity of the data as follows:

- Organise interviews with the dyads separately and do not tell one that you have already interviewed the other (or have it booked in).
- Conduct the interviews as close together as possible to minimise risk of the dyad talking in between interviews.
- Interviewer needs to practice ‘fairness’ and try not to take one side or the other, stay neutral and not discuss the other’s interview.

I followed these recommendations, and in doing so minimised the risk of breaking confidentiality through the data collection process. Conducting the interviews as close together as possible (see Table 30) reduced the risk of cross-contamination, and the participants’ answers being influenced by discussions with their significant others.

5.8.3.2 PPI input in the analysis process

I consulted a member of my PPI team throughout the analysis process. I presented quotes from the data along with my proposed themes and ensured my interpretations matched those of the PPI member. Once I had a draft of my full results I held a face-to-face meeting with the PPI person on 22nd September 2022. I sent the draft to the PPI person in advance of the meeting so they had time to read and consider the content. We discussed the themes and the supporting quotes. The PPI person provided valuable insight into the meaning behind some of the quotes. No significant changes were made as a result of this meeting.

5.8.3.3 Confidentiality issues in publication of dyadic data:

Although interviewing dyads separately has advantages (as listed above in section 8.2), confidentiality issues in publication must be considered. The potential problem being, if one member of the dyad can identify their own quote in the published data, they can identify the quote of their partner by association. This issue is referred to as 'internal confidentiality'(283). Researchers publishing dyadic interview data find themselves caught between the need to protect internal confidentiality, and the desire to describe findings with sufficient detail to portray an accurate and meaningful representation of the data from the dyadic perspective(284). A body of literature discussing this issue and ways to minimise the risk of breaking internal confidentiality exists(284-286), but there seems to be no consensus on best practice(284). Table 13 below describes the ways in which the risk of breaking internal confidentiality can be minimised.

Table 13: Table of methods for minimising the risk of breaking internal confidentiality

Method	**Advantages**	**Disadvantages**
Publish without linking dyads.(284)	Reduces risk of breaking internal confidentiality, removes the issue of identification by association.	Difficult to convey the dyadic perspective when data is not matched.
Outline risk of compromised internal confidentiality in consent form, i.e., make participants aware their quotes may become identifiable to other study participants, and ask them to consent.	Researchers are free to explore the dyadic perspective in publication.	Participants may answer questions differently / not be as open if they know their data may be identified by their partner, potentially impacting the quality and depth of the data.
Disguise partial information, for example, use pseudonyms and change small details (like geographic locations or settings) that do not impact the essence of what is being said.(279)	Researchers are able to present the dyadic experience accurately using paired quotes.	Potential to break internal confidentiality if information is not adjusted sufficiently.

5.8.3.4 Examples of published research considering the risk of breaking internal confidentiality

When considering how to protect the internal confidentiality of the participants in my study I studied various example papers and the methods they implemented.

Ummel and Achilles (2016) conducted qualitative research with different types of dyadic relationships, for example, parent/child, sister/brother. For this reason, they explained that masking details or disguising partial information was challenging and the risk of identification too great. Therefore, they chose not to link dyads when publishing(284). They acknowledge this limited their ability to explore the dyadic perspective within their publication, but felt the decision was necessary to protect internal confidentiality. Eisikovits & Koren (2010) on the other hand did pair dyadic data in publication. Unlike the aforementioned study, the dyads in their study all constituted the same relationship, i.e., they were all male-female couples. To maximise internal confidentiality they disguised partial information(279).

Saunders, Kitzinger and Kitzinger (2015) voice concerns around the complexity of anonymisation and state that researchers need to do more than just change names and locations(286). In their publication on the topic of catastrophic brain-injury and end-of-life decision-making they describe the detailed considerations they made to maximise anonymity when publishing quotes. Although not a ‘dyadic’ study as such, they explore the views of relatives of those with a chronic disorder of consciousness, sometimes interviewing more than one relative of the same person. The authors were also aware that participants in their study may know each other or know of each other’s stories even if they were not related to the same individual. The internal confidentiality considerations they undertook are therefore relevant and helpful to consider in dyadic data analysis.

The following example demonstrates how protecting confidentiality can be complex, and situations may arise where extra precautions are necessary. Saunders et al., (2015) detail a situation where the authors wanted to publish two quotes by the same person. Published individually the risk of identification was low, however, due to the content of the quotes, the combination of the two would largely increase the chances of the individual being recognised. In situations such as this the authors described their options to; either use the pseudonym name for one extract, and leave the other without a name; or use different pseudonym names for each extract (also known as the smoke screen strategy(287)).

Saunders et al., (2015) consider issues around expressions of religious and cultural backgrounds. Often references to religion, faith and culture provided essential context to the narrative (this is true for other details, but particularly apparent in this topic), and swapping or excluding these references could impact the integrity of the data. In addition, participants of a particular religion may not appreciate being described in a way that implies they belong to another religion or faith. The authors describe the need to continually compromise to ensure they are walking the fine line between minimising the chance of breaking internal confidentiality and maximising the validity and integrity of their findings.

When deciding how to present the dyadic data in the present interview study I took all of these methods into consideration and understood situations were likely to arise where I may need to employ extra measures to protect confidentiality. I felt pairing the dyads in the current interview study would allow me to construct a patient, partner and dyadic narrative and provide the richest, most valuable results. All dyads in the study had the same relationship (male-female couples), reducing the concerns raised by Ummel and Achilles (2016). I used the Eisikovits & Koren (2010) paper to help guide the structure of my writing, and took the points made by Saunders et al., (2015) into consideration by continually assessing whether extra measures were needed to protect confidentiality, and I used pseudonyms.

5.8.4 Qualitative analysis methods

When considering which analysis method to use I recognised the need for the method to fit appropriately with a) my research aims, b) the nature of the data and c) the pragmatics of implementation. Before exploring methods specific to dyadic data sets, I considered methods which may help fulfil my research aims.

Interpretive Phenomenological Analysis (IPA)(288) aims to explore ‘experiences’ of a particular phenomenon, and to understand how individuals make sense of a particular situation. For this reason, I considered using IPA feeling it may aid the exploration of the experiences of men on AS and their significant others. IPA methodology recommends a small, homogenous sample, and a researcher/research team prepared to be completely immersed in the data(289). However, I had concerns that the IPA analysis process would not fit with the dyadic nature of the dataset; the sample was not homogenous to the desired level for IPA, consisting of a range of ages, education levels and a split of men on AS and their partners.

Although I used a semi-structured interview guide I encouraged participants to tell their story, allowing myself as the interviewer to be guided by the participant and what they were sharing. For this reason I considered the method of narrative analysis(290, 291), which is particularly appropriate for use with data sets where participants are free to tell their stories, rather than simply answering the questions. Narrative analysis requires an understanding of the participants’ background, setting, and social and cultural context. It is an interpretive, thorough, and multifaceted approach with a focus on ‘the story’ as the unit of analysis. I had similar reservations as above (for IPA); I had concerns about how appropriate this method would be for dyadic data sets, and how well I would be able to keep my supervisory team informed about analysis progress and interpretations while being transparent about my processes. I also felt the level of context needed for narrative analysis was beyond the scope of my study.

It seemed important to consider the widely used method of thematic analysis (235) because this is a method I am personally familiar with, and have implemented extensively throughout my career as a researcher. Thematic analysis has the ability to provide rich and detailed interpretations, and benefits from ‘theoretical freedom’ meaning the processes of analysis can be applied flexibly across different theoretical frameworks. Using this method researchers identify, analyse and report patterns (or themes) within data(235). Its benefits include; the ability to highlight similarities and differences across the dataset, it is relatively straightforward to carry out, results are generally accessible and understandable to others (e.g. my supervisory team), it usefully summarizes key features of the data, it allows for unanticipated insights, and the method allows for interpretation(235). Some potential limitations to thematic analysis have been documented; if used outside of a theoretical framework, interpretations are limited and compared to methods such as narrative analysis thematic analysis is unable to document continuity or contradiction through individual interview transcripts. Considering the strengths, and despite the limitations listed above, thematic analysis was a stronger contender than IPA or narrative analysis for this research. However, I was unsure how this would work within a dyadic data set. The idea of using thematic analysis as a ‘foundation method’(235) was of particular interest when considering methods for dyadic qualitative analysis.

Recognising the need for the chosen method to be appropriate for the analysis of dyadic data, I next focussed my search on methodology literature appropriate for qualitative dyadic data, and methods that would work pragmatically for myself and supervisory team. When commencing this interview study in 2018 I found a lack of clear methodology literature around dyadic analysis, particularly for couples interviewed separately. The small base of existing literature tended to focus on data collection and/or thematic content(279, 292). Two key papers were most relevant at the time; Eisikovits & Koren (2010) and Yosha et al., (2011). Both provided a demonstration of dyadic analysis with dyads interviewed separately. Table 14 below provides a brief overview of the methodology demonstrated in these papers.

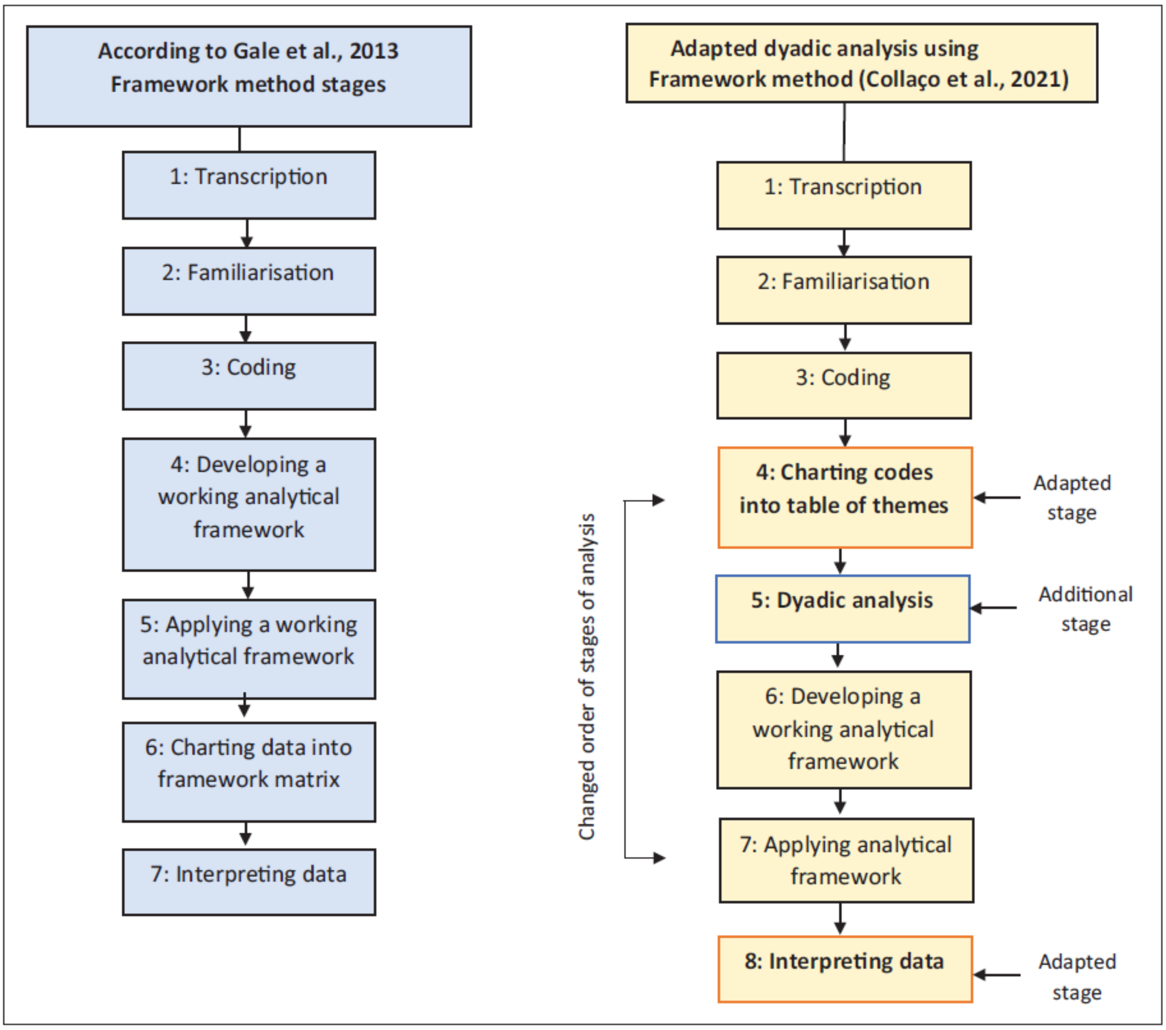
Table 14: Key papers in dyadic analysis

Author	**Key Methodology Processes**

Eisikovits & Koren (2010)	Dyadic research should ‘focus on the dyad as the unit of analysis’. Horizontalization (highlight significant statements, sentences and quotes). Develop clusters of meaning and construct themes. Examine themes developing from each couple’s individual narratives by assessing contrasts and overlaps between the individual versions.
Yosha et al., (2011)	Create an overall summary for each dyad. Use the summaries to generate a table of themes and enter relevant quotes to support each theme.

When I returned to the analysis in 2021, I conducted another search for literature to see if anything new had been published. I found a paper by Collaco et al., (2021) which presented a clear step-by-step method for dyadic qualitative analysis containing more detail than previous methodology literature. Collaco et al., (2021) evaluate the previously published techniques and conclude; the production of overall dyadic summaries as proposed by Yosha et al., (2011) is too simplistic; and alternate existing methods are not adequately described for replication(292). Collaco et al., (2021) incorporated techniques demonstrated by the papers listed in Table 14(279, 293) with the process proposed by the Gale et al., (2013) Framework Method(294) (not originally designed for dyadic data) and developed a replicable step-by-step method. Adaptations were applied to the Framework Method to make it suitable for dyadic data. Figure 11 below shows the original Gale et al., (2013) Framework Method(294) alongside the adapted Collaco et al., (2021) method.

Figure 11: The Collaco et al., (2021) adaptation of the Framework Method for dyadic analysis



To aid my decision about whether to analyse the data in my own dyadic study using The Framework method, and to further my understanding of the method in general, I conducted some background research into its origins and previous utilisation. Originally developed by Ritchie and Spencer (1994) for use in large-scale policy research(295), the Framework method has been used in qualitative research since the 1980s and is becoming an increasingly popular approach within health research(294). Gale et al., (2013) classify The Framework method as a type of thematic analysis, or qualitative content analysis, reasoning it is part of a broad family of methods facilitating the analysis of data thematically. The defining unique aspect of The Framework method is the systematic organisation of qualitative data into a matrix, facilitating analysis by case and by theme(292).

5.8.4.1 What are the advantages and limitations of The Framework Method?

Unlike many qualitative data analysis approaches, such as IPA and narrative analysis, framework analysis is not tied to a specific epistemological position(235, 294). In this sense, framework analysis is similar to thematic analysis which claims to be ‘essentially independent of theory and epistemology’(235). This provides a certain flexibility with how the framework can be applied across a range of theoretical and epistemological approaches(289). The Framework method provides a clear data management plan which aids transparency. The format of the organised data provides an audit trail back to the raw data, making it straightforward to see where interpretations originated. The Framework method is particularly useful for researchers working in a team, enabling those not at the centre of analysis to understand the analysis and how interpretations have stemmed from the data(289). Being able to systematically review the processes leading to interpretations promotes a feeling of confidence in the findings.

The limitations of this approach must also be considered. The systematic organisation of the data into a matrix may make it tempting for inexperienced qualitative researchers to attempt to quantify qualitative data, by stating for example “2 out of 12 participants said X”. This type of quantification is unhelpful and potentially misleading because qualitative research is not designed to provide a representative sample of the wider population(296). The Framework Method is time consuming and resource-intensive(294), and for new researchers unfamiliar with qualitative analysis the method requires training in processes such as coding, indexing, charting data and thinking reflexively(294, 296).

5.8.4.2 Why did I choose The Framework method?

As an experienced qualitative researcher, I understood the potential pitfalls of the method listed above (section 5.8.4.1) and did not require training in any of the processes within the analysis method. In addition to the advantages, specific to dyadic data and my own study The Framework method described by Collaco et al., (2021) provides a clear and pragmatic way to conduct dyadic analysis. Framework categories can be developed both a priori according to the research aims, and also in an iterative manner. This allowed me to address my research questions, but also further explore experiences and allow for the natural development of themes. Although the data organisation processes involved in The Framework method were new to me, the analysis process has much in common with the Braun & Clarke (2006) method for thematic analysis, with which I am familiar and experienced in. The decision to utilise The Framework method was led by myself and supported by my supervisory team.

5.8.4.3 The application of The Framework method

I commenced the process of analysis following the method outlined by Collaco et al., (2021)(292). During this process, I applied some further adaptations to the Collaco et al., (2021) method shown in Figure 12 (see Table 15 for more detail and reasons for each adaptation).

Figure 12: Adaptations to the Collaco et al., (2021) method

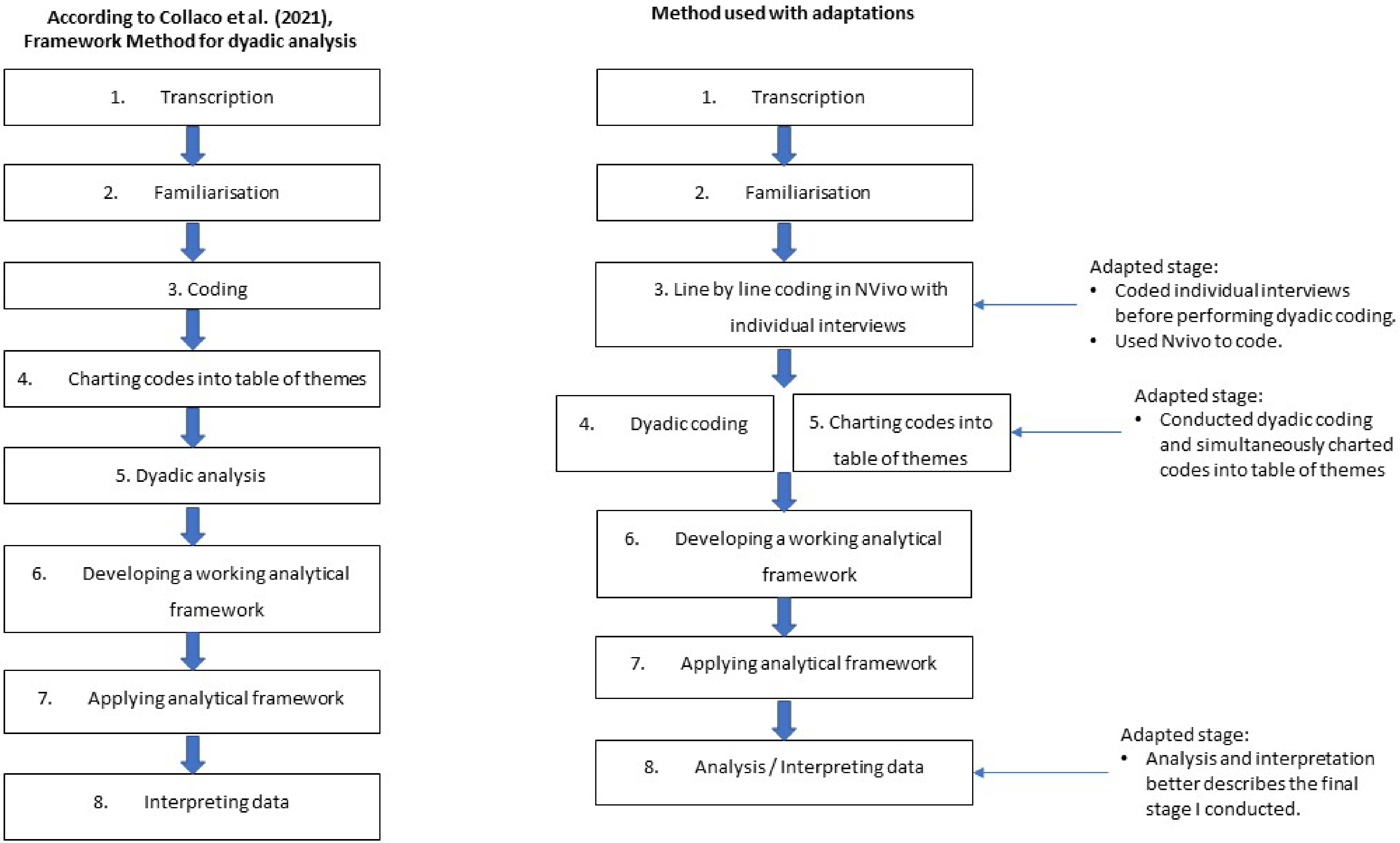


Table 15: Description of analysis stages and reasons for adaptations

Stage	**Description**
1. Transcription	Interviews were transcribed verbatim into a word document.
2. Familiarisation	I conducted the interviews and the analysis myself, aiding familiarisation. In addition, I re-read the interview transcripts to maximise familiarity.
3. Line by line coding with individual interviews in NVivo	Codes were applied to the transcripts line by line, for example, where a participant was talking about a lack of PCa support the relevant sections of the transcript would be coded to the parent code 'Supportive care needs' and the child code 'lack of support offered'.
4. Dyadic coding	To conduct the dyadic coding each pair of interviews were displayed side by side. Dyadic codes were created based on the individual interview codes, and new ones added as they arose. Where the same/similar topics were being addressed across the two transcripts, for example, 'PCa related communication', overlaps and contrasts were examined and noted. Where a topic was discussed in one interview, but absent from the other, this was included and noted.
5. Charting codes into table of themes	While coding the paired interviews side by side I copied relevant quotes over to a table of themes (in MS Word) and created a dyadic summary for each code (see Appendix B).
6. Developing a working analytical framework	Dyadic summaries were transferred into a working analytical framework (in MS Excel). Separate tabs were created for each broad topic, for example, 'supportive care needs' and 'PCa related communication' (see Appendix C).
7. Applying analytical framework	The analytical framework was used to develop a framework Matrix in word which summarised each broad topic with sub themes and subcodes. The Framework Matrix provided a clear summary overview facilitating discussions around possible themes within the supervision team (see Appendix D).
8. Analysis / interpreting data	Sub themes and subcodes in the framework matrix were explored alongside the dyadic summaries, allowing myself and my supervision team to assess the strength of each developing theme. The similarities between the couples' experiences, along with the way in which they varied were explored.

Throughout the process described above in Table 15 I consulted my supervisory team who double coded approximately 10% of the transcripts. They were consulted throughout the analytical process to ensure consistency and agreement within data interpretation.

5.9 Addressing the quality of research

Long-standing quality control measures used in quantitative research, for example, a sample size large enough to be statistically representative, or measures of reliability and replicability, are not appropriate for assessing qualitative research(297). It is not possible to qualitatively analyse a sample large enough to be statistically representative in depth; aside from the time that would be required to undertake such a task, the large quantity of data would mean it would be impossible to interpret inter-relationships between and within the data and it would be too complex to synthesise(297). More importantly than this logistical, practical barrier, trying to apply qualitative methods to a sample large enough to be statistically representative undermines the rationale for drawing upon qualitative methods(297). Taking the stance that qualitative research aims to develop one of many possible interpretations, measures of reliability and replicability are also inappropriate(297).

Although quantitative quality control measures are inappropriate, it is imperative that qualitative research can be assessed for quality. Yardley (2000) suggests characteristics of good qualitative research as below in Table 16(297):

Table 16: Characteristics of good qualitative research from Yardley (2000)

Essential qualities	**Examples**
Sensitivity to context	Theoretical; relevant literature; empirical data; sociocultural setting; participants’ perspectives; ethical issues.
Commitment and rigour	In-depth engagement with topic; methodological competence/skill; thorough data collection; depth/breadth of analysis.
Transparency and coherence	Clarity and power of description/argument; transparent methods and data presentation; fit between theory and method; reflexivity.
Impact and importance	Theoretical (enriching understanding); socio-cultural; practical (for community, policy makers, health workers).

The Critical Appraisal Skills Programme (CASP)(273) framework for quality appraisal was used to assess the quality of the papers included in the qualitative synthesis within this thesis (see section

6.4.4). Although the CASP does not map directly onto the qualities described above, there are many overlaps. For example, the CASP asks if the researcher has justified the methods chosen, whether the research methods are clear and transparent, whether the data collection was sufficiently rigorous, whether the relationship between the researcher and participants has been considered, and, how valuable the research is locally.

Whilst conducting my own research I strived to keep an awareness of the qualities described in the above table; I considered the context of the participants, for example, time since diagnosis and whether they felt AS was a choice. I described my methods in a detailed, transparent way, and have described the reasons for the methodological choices made. I have included a reflexivity section in this thesis (5.10), and enriched understanding in the topic of SOs of those on AS for PCa.

There are various mixed methods quality assessment tools which provide clear guidance in how to write-up a mixed methods study, for example, The Mixed Methods Article Reporting Standards (MMARS) provide clear guidance in how to write-up a mixed methods study(298). Although it was not possible to meet every standard, I followed this guidance closely to ensure I reported the process thoroughly.

5.10 Reflexivity

Reflexivity has been defined by Olmos-Vega et al., (2023) as:

> “a set of continuous, collaborative, and multifaceted practices through which researchers self-consciously critique, appraise, and evaluate how their subjectivity and context influence the research processes(299).”

Qualitative findings are shaped by subjectivity. A recent publication recommends embracing subjectivity as a researcher resource(282). The process and documentation of reflexivity provides transparency in how subjectivity shaped the findings(299).

I have considered my previous experience both personally and as a researcher in the design, data collection and data analysis of this PhD. Whilst undertaking this PhD I had no personal experience of PCa amongst friends or family, which meant my views on the topic area were based solely on the existing literature and my involvement in a related project (PROACTIVE).

Reflexivity in the studies presented in this thesis was undertaken through various methods. Firstly, when choosing my methodology I remained aware that I would naturally gravitate towards methods with which I was familiar, for example, online surveys, semi-structured interviews and thematic analysis. This awareness (and openness of this awareness within my supervisory team) ensured I considered methods outside of my expertise and chose the methods most appropriate to the study. This resulted in a mixture of methods I was familiar with, for example, semi-structured interviews and thematic analysis, and methods that were new to me, such as the process of dyadic data collection and analysis.

I strived to remain reflexive throughout the data collection and analysis process. I did this by noting down my own thoughts, feelings and reactions both during and after each participant interview. I discussed the interviews, codes, themes, ideas and beliefs with my supervisors and PPI, and remained open about my own preconceptions while exploring the analysis of data from other points of view. This worked to enhance my own interpretations of the data.

Throughout the process of analysis, I considered how my personal characteristics (such as age (30s) and gender (female)) may have impacted the quality and depth of data I was able to obtain, and the rapport I was able to build with participants. This may have been a barrier for older men and SOs discussing personal issues around personal topics such as relationship or sexual dysfunction, i.e., there may have been feelings of embarrassment or insecurities about how much information was appropriate.

5.10.1 Challenges and learning opportunities

Challenges presented themselves throughout the recruitment and interview process, such as, slow/low recruitment rates and ineligible men completing the questionnaire.

Although the participant information sheets (appendices L.1 and L.2) stated the study was for those on AS, some men who had received active treatment completed the questionnaire. On reflection, it would have been beneficial to better describe AS and how it differs from watchful waiting, and from monitoring following active treatment. In addition, a screening questionnaire could have been added at the start to ensure the eligibility of participants.

Recruitment to the quantitative survey proved difficult. I have learnt my selected recruitment methods are not effective for the target population. It may be that those on AS are less connected with charities than those who have received active treatment. It may be that as patient with PCa are generally older by nature, they are less likely to engage with online platforms such as Twitter. Improved recruitment methods may involve search and mail-outs within GP practices.

5.11 Patient and Public Involvement and Engagement (PPIE)

PPIE is the active inclusion of members of the public in research. Using the INVOLVE definition, PPIE in research is ‘research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’ or ‘about’ or ‘for’ them’(300). In health research PPIE members have experience of the condition being researched. Such inclusion is recommended by the National Institute for Health Research, British Medical Association and the Health Research Authority. PPIE inclusion is advisable throughout the different research phases, for example, throughout conception, design, development, delivery and analysis. PPIE input may vary depending on the type of research being conducted, but generally involves the provision of an external perspective; by drawing on their own experiences novel insights can be gained they may not have presented to the research team. More specifically, PPIE may provide feedback on proposed study procedures and participant facing documents. The benefits of such input include improved accountability and transparency, along with improved quality, relevance and acceptability to potential participants/stakeholders(300, 301).

5.11.1 PPIE and this thesis

PPIE influenced the development of this thesis. Their involvement in the qualitative synthesis is described in sections 6.4.3 and 6.4.5. Involvement in the quantitative study is detailed in sections 7.2.8 and 7.3.2.9, and in the qualitative study in sections 8.2.1 and 8.2.3.2.

Chapter 6: Qualitative synthesis

6.1 Introduction

In this chapter I report a systematic review of qualitative studies focusing on the experiences of men on AS for PCa, and the experiences of their significant others (SOs). I developed, designed and undertook this review myself, with input from my supervisors.

Men on AS for PCa can often experience distress living with an untreated cancer(77) (see section 2.4.2). PCa has been described as a 'we' disease, and it is important to recognise the diagnosis will have an impact on the patient and the SO both individually and as a couple(142) (see section 3.3). There is a lack of literature looking at the impact of the SO specific to men on AS for PCa. Anxiety (mostly about possible disease progression) is the biggest predictor of men converting from AS to radical intervention without clinical reason(194, 302), and there is evidence to show men are influenced by their partner's attitude towards their diagnosis(88, 101, 303). Therefore, factors that influence AS related anxiety and these decisions are important and need to be further investigated.

This systematic review is the first UK-based qualitative study to focus on experiences of men on AS for PCa, and the first to include experiences of SOs. The current review does not include analysis about treatment decision making and opting to convert to radical treatment. This is because it is not within the remit of the current review's research question and is covered extensively in previously published reviews(96, 97, 105).

6.2 Aim

The aim of this review is to synthesise the evidence exploring patient experiences of undergoing active surveillance for prostate cancer, and the experiences of their significant others.

6.3 Research question

What are the experiences of men undergoing active surveillance for prostate cancer and their significant others?

6.4 Methods

Originally it was planned the synthesis would focus only on the experiences of significant others because this is where the biggest gap in the literature exists. However, this search returned only three eligible papers. It was agreed within the supervision team, and with some external advice, that three papers were not sufficient to inform a systematic synthesis.
The following actions were taken to see if any additional appropriate articles could be sourced:

1.) The corresponding authors from each of the 3 papers were contacted to see if they knew of any other papers that may be relevant.

2.) The references in the thesis of Dr Sam Watts (original supervisor to this project and expert in the field) were reviewed to see if anything may be relevant.

The actions above did not result in any additional papers. Therefore, the decision was taken to widen the search. Two options were considered; to include quantitative papers about significant other experiences and convert to a mixed methodology review; or to remain qualitative and include experiences of the men on AS in addition to the significant others.

To gain an understanding of how including quantitative literature (specific to SOs) may add to the review the search was re-run removing the 'qualitative' search terms. This did not result in any additional papers. The decision was made to conduct a systematic search looking for qualitative experiences of men on AS, to add to the articles included in the previously completed search. This second search is referred to as 'search 2'.

Further reasons for making the review exclusively qualitative are explained in section 6.4.1.1.

6.4.1 Justification for using only qualitative articles

As described in the above introduction (6.1), previous reviews have included qualitative research in mixed method analyses but have not used qualitative research exclusively. I wanted to gain a rich, grounded, inductive insight into the experience of being on AS without results being shaped by questionnaire topics (such as anxiety or depression). I felt that to do this justice, I needed to focus completely on what was being said by patients on AS and their SOs and put all expectations and judgments to one side to allow the results to develop naturally. My analysis was conducted inductively, and the themes presented in the results section are my own, grounded in the data, i.e. I have not used the themes established in the published papers.

6.4.2 The Search Strategy

The acronym PICO (Population, Intervention, Context, Outcome) is often used in designing research questions for quantitative work. This can be modified to PCO (Population, Context, Outcome) to better fit qualitative methodology(304, 305), (see Table 17) and was used to design the research question for this qualitative synthesis.

Table 17: Modified PICO - PCO

Population of interest	Men undergoing active surveillance for prostate cancer and their significant others
Context of interest	Active surveillance for prostate cancer
Outcome of interest	Experiences (e.g., experiences about changes to day-to-day life, feelings experienced while on the pathway, support from others, impact on relationships)

The search terms for both searches 1 and 2 were created using the PCO framework (see Table 18 and Table 19). The following databases were searched: MEDLINE (Ovid), EMBASE, PsychINFO, CINAHL and Cochrane Library. Each database was searched by myself, in consultation with an expert librarian. Truncations and Boolean operators were used. See Appendix E.1 for the full search terms used in each database.

Table 18: PCO Search Terms for search 1

Population	**Context - illness**	**Context - treatment**	**Outcome**
Significant other Partner Spouse Wife Husband Family Friend Relationship Couples Dyad Support network	Prostate cancer Prostate tumour Prostate malignancy Prostate neoplasms	Active surveillance Watch and wait	Experience Perception Perspective View

Table 19: PCO Search Terms for search 2

Population	Context - illness	Context - treatment	Outcome
Men Man Patient	Prostate cancer Prostate tumour Prostate malignancy Prostate neoplasms	Active surveillance Watch and wait	Experience Perception Perspective View

6.4.3 Article selection

EndNote and Rayyan were used to undertake the extraction process. All retrieved articles were exported into EndNote and de-duplicated. All remaining articles were exported into Rayyan and screened.

To be eligible for inclusion, articles had to be published in English, published after 1990 and include: data from men (over 18) diagnosed with PCa being managed using AS or data from their significant others; experiences of AS; a qualitative component (see Appendix E.3 for more detailed inclusion/exclusion criteria).

The screening process followed the stages outlined below:

Stage 1: Articles were included or excluded based on the title and abstract. If eligibility was unclear from the title and abstract alone, the full text was reviewed. During the screening process, obtained articles and decisions were discussed with all reviewers at regular supervision meetings. I discussed the screening process with one of my PPI representatives: I described my screening process, provided an example of an included paper along with a selection of excluded papers. They approved the screening process and agreed the inclusion/exclusion criteria were appropriate.
Stage 2: The full text was obtained for all included and uncertain articles. The uncertain articles were reviewed, and an inclusion/exclusion decision was made. Where further information was required, the authors were contacted.

To aid the process a data extraction form was used to screen for eligibility. The extraction form constituted: study authors, year of publication, sample, country of origin, setting, study design, and analysis. See Appendix E.6 for the full extraction form, and Table 22 for summary characteristics.

To minimise personal bias a goal of double screening 10% of the articles was set. HE, BS and RB performed the secondary screens and the goal was exceeded; 22% of the articles in search 1 and 18% of the articles in search 2 were double screened. According to best practice the conflict rate must be below 25%(306), and if it is higher, more double screening should be carried out. The conflict rate was low (less than 2%), and the team agreed no further double screening was necessary.

6.4.4 Quality Appraisal

All included papers were assessed for quality using the Critical Appraisal Skills Programme (CASP)(273) framework for quality appraisal (see appendix F.1 for the full framework). The CASP provides a pragmatic, structured and widely recognised framework for appraisal, which aims to address the following broad questions by asking the researcher to answer the more specific questions in appendices C.2.1, C.2.2 and C.2.4:

- Are the results of the study valid?
- What are the results?
- Will the results help locally?

Papers were not excluded based on quality; rather the assessment was used to provide an indication of how each paper should be weighted. The results of the CASP analysis can be found in appendix F.1. None of the included papers were sponsored by drug companies.

6.4.5 Analysis

The eligible papers were imported into NVivo, and thematic analysis was performed on the ‘results’ section of each paper. The Thomas & Harden (2008) method for performing thematic synthesis was chosen for multiple reasons; firstly, the majority of the included papers had been analysed using thematic analysis, aiding the process of interpretation; secondly, thematic synthesis allows developing themes to be grounded in the data, minimising the influence of the researcher’s previous knowledge. Table 20 below describes the three steps of the analysis process.

Table 20: The process of thematic analysis

Stage	**Description**
Coding text	The results and findings sections of each paper were coded line by line
Developing descriptive themes	Using the first 5 papers initial codes were used as a guide to form new codes and a coding manual was developed. This coding manual was used to analyse subsequent articles and amendments were made to the manual when considered necessary. After all revisions were complete the final coding manual was created and applied to the whole data set.
Generating analytical themes	The descriptive themes that were developed inductively, were then grouped and analysed in a way that answered the research question.

Throughout the process described above in Table 20, I consulted my supervisory team who double coded 2 of the included papers. They were consulted throughout the analytical process to ensure consistency and agreement within data interpretation. I discussed the process with a PPI representative, described my findings as they developed and received helpful feedback regarding the relevance of findings and naming and organisation of codes.

6.5 Results

6.5.1 Search results

I first ran the searches in 2018 which resulted in a total of 1094 papers from search 1 and 873 from search 2. Search 1 was run in February 2018 and search 2 was run in May 2018. Search 2 was created by using the existing search 1 search terms, adapting the search to remove the 'significant other' terms and then removing the results that had already been screened in the previous searches. This yielded a very high, unmanageable number of papers. After discussion with an expert librarian, I decided to apply a qualitative filter to narrow the search down. This specific filter is used by reputable bodies such as NICE and SIGN and reviews of such filters have been conducted to provide evidence of their reliability and validity(307).

For continuity purposes, and to check the filter's validity, the qualitative filter was applied retrospectively to Search 1. This action reduced the results from 1100 to 402 papers (see Table 21 below). Importantly, the three papers included in the first round of screening were present in the updated search. Table 21 shows the impact of the filter on each database search.

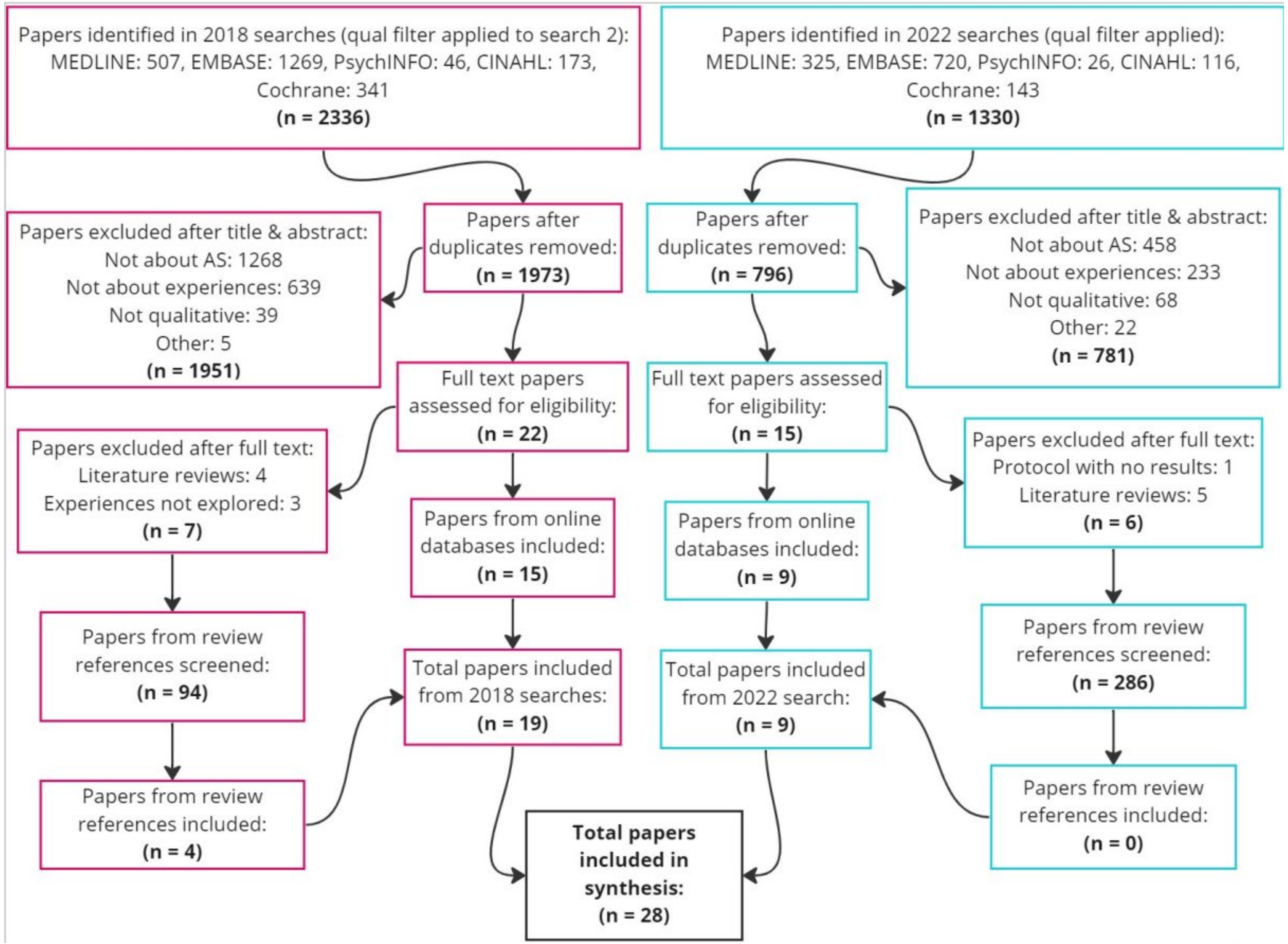
Table 21: The impact of the qualitative filter on search 1

Database	**Articles found**	**After EndNote De-duplicate**	**Articles found when qual filter applied**	**After EndNote De-duplicate**
MEDLINE	321	105	53	51
EMBASE	672	651	121	120
PsychINFO	29	16	10	10
CINAHL	115	60	31	31
Cochrane	272	268	192	190
TOTAL	1409	1100	407	402

6.5.2 Updating the searches

To ensure I had included the most up to date literature at the time of submission I re-ran the searches in November 2022. The 2022 searches were run using the same search terms as the 2018 searches, but with the added limitation of publication from 2018 to 2022. See Figure 13 for a full breakdown of the screening results.

Figure 13: PRISMA flow diagram to show screening results



6.5.3 The included papers

Full text eligible papers from searches in 2018 (n=19) and searches in 2022 (n=9) provided a total of 28 eligible papers for the review. Overall, the CASP analysis (appendix F.1) found that the papers had clear statements of aims, used qualitative methodology appropriately, used recruitment strategies appropriate to the aims, and collected the data in a way that addressed the research questions. However, most of the papers did not discuss how or if they considered the relationship between the researcher and the participants, leaving a context gap in how the data might be interpreted. All studies detailed in the research papers had gained ethical approval, and the majority of papers described the data analysis process sufficiently to be assured analysis was rigorous. Nearly all papers had a clear statement of findings. The majority of papers made suggestions for future clinical practice, with some making suggestions for future research. The CASP analysis (see appendix F.1) did not raise any major methodological concerns and the papers were treated equally throughout the analysis.

The authors of all 28 papers were contacted and asked if they had any additional relevant data to share. Although the authors were responsive (12 out of 28 replied), they were unable to provide any additional data.

Table 22 below provides a summary of the characteristics of the included papers. A total of 28 papers were included giving an overall sample size of 479. Of these, 428 were men on AS, previously on AS or eligible for AS, and 51 were spouses. All papers with spouses originated from the search conducted in 2018, meaning no studies conducted between 2018 and 2022 included spouses of those on AS for PCa. Papers originated from 8 countries with the largest number of papers originating from the USA (n=11). Semi-structured interviews were the most common method of data collection (n=18), and thematic analysis was the most common method of analysis (n=17). The majority of studies recruited from hospital settings (n=18). See appendix E.6 for detailed characteristics of each included paper and below (Table 22) for a summary.

Table 22: Summary characteristics table

Characteristics	2018 search	2022 search	2022 search combined with 2018 search and percentages
n	19	9	(19+9) = 28
Sample, n, (%)			(324*+155***) = 479
Total	324*	155	
Men on AS, previously on AS, or eligible for AS	273**	155	(273*+155***) = 428 (89.4%)
Spouses/partners	51	0	(51+0) = 51 (10.6%)
Year of publication, n			
2003	1	N/A	1 (3.6%)(83)
2005	1	N/A	1 (3.6%)(80)
2009	2	N/A	2 (7.1%)(91, 308)
2011	1	N/A	1 (3.6%)(309)
2012	1	N/A	1 (3.6%)(310)
2013	1	N/A	1 (3.6%)(93)
2014	3	N/A	3 (10.7%)(87, 90, 142)
2015	1	N/A	1 (3.6%)(311)
2016	3	N/A	3 (10.7%)(84, 149, 312)
2017	4	N/A	4 (14.3%)(82, 85, 86, 102)
2018	1	N/A	1(3.6%)(92)
2019	N/A	4	4 (14.3%)(88, 313-315)
2020	N/A	2	2 (7.1%)(101, 111)
2021	N/A	1	1 (3.6%)(316)
2022	N/A	2	2 (7.1%)(81, 110)
Country of origin, n, (%)			
USA	10	1	11 (39.3%)(80, 82, 84-88, 90, 92, 309, 310)
Canada	4	0	4 (14.3%)(91, 93, 102, 308)
Denmark	2	0	2 (7.1%)(149, 311)
Finland	1	0	1 (3.6%)(312)
Australia	1	1	2 (7.1%)(110, 142)
Northern Sweden	1	0	1 (3.6%)(83)
UK	0	6	6 (21.4%)(81, 101, 313-316)
The Netherlands	0	1	1 (3.6%)(111)
Design, n, (%)			
Semi structured interviews	10	7	18 (64.3%)(80-85, 87, 88, 90, 91, 93, 110, 111, 142, 308, 313, 314, 316)
Focus groups	3	0	3 (10.7%)(86, 92, 309)
Mixed (focus groups & interviews)	2	0	2 (7.1%)(102, 312)
Structured interviews	1	0	1 (3.6%)(310)

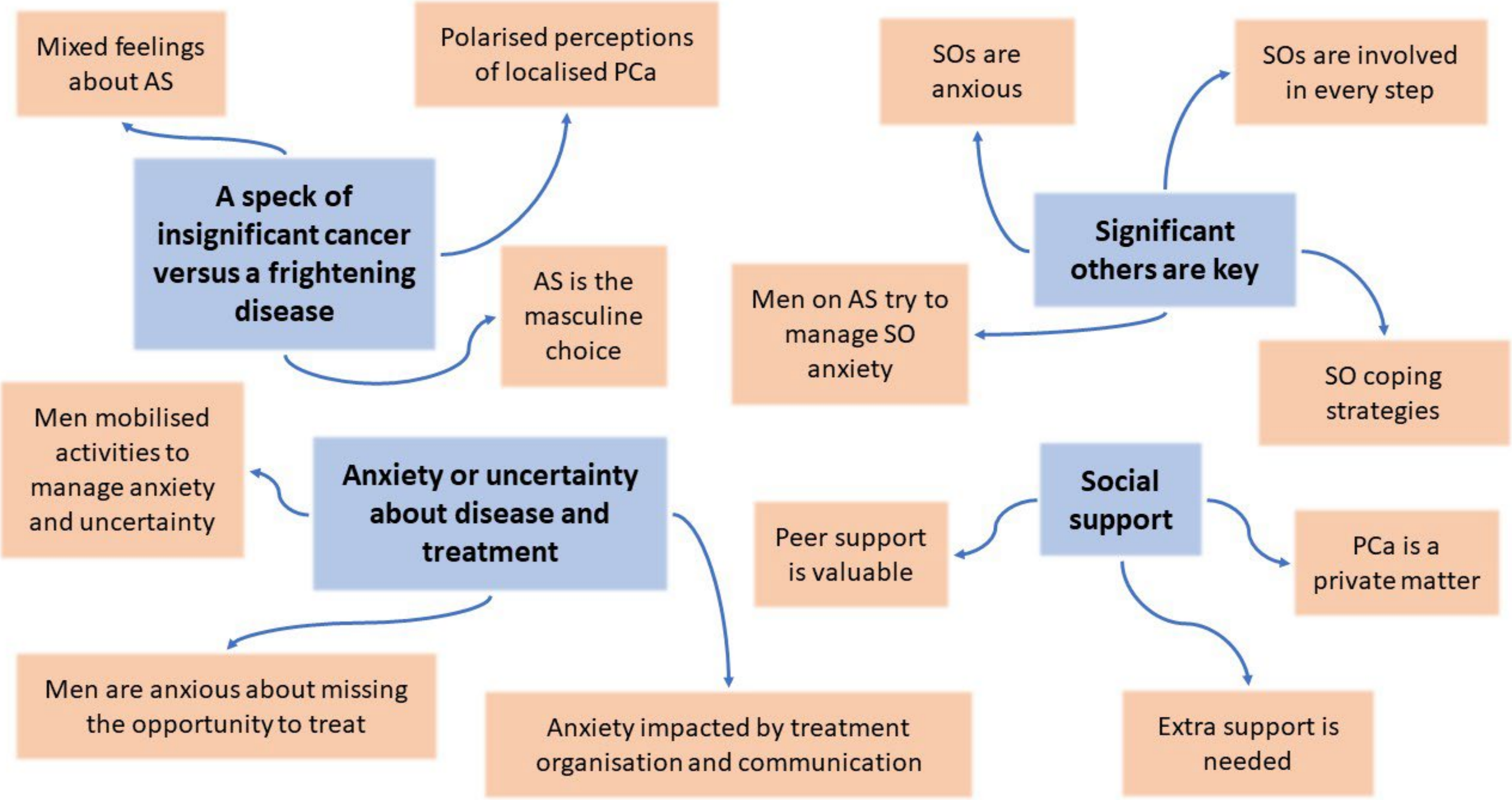
Mixed (semi structured interviews & open dialogue)	1	0	1 (3.6%)(149)
Other (mixed methods using HLQ as a framework)	1	0	1 (3.6%)(311)
Longitudinal serial in-depth qualitative interviews	0	1	1 (3.6%)(101)
Unclear	0	1	1 (3.6%)(315)
Analysis, n, (%) Thematic analysis	10	7	17 (60.7%)(81, 82, 84-87, 91-93, 101, 110, 111, 142, 311, 313, 314, 316)
Constant comparative analysis	1	0	1 (3.6%)(149)
Fundamental qualitative methodology	3	0	3 (10.7%)(80, 309, 310)
Modified grounded theory	1	0	1 (3.6%)(90)
Qualitative description analysis	1	0	1 (3.6%)(102)
Phenomenologic-hermeneutic approach	1	0	1 (3.6%)(83)
Interpretive description	1	0	1 (3.6%)(308)
Iterative content-driven approach	0	1	1 (3.6%)(88)
Other (unlabelled)	1	1	2 (7.1%)(312, 315)
Recruitment site, n Hospital setting	15	6	21 (75%)(80-82, 84, 85, 87, 88, 90, 91, 93, 101, 102, 111, 142, 149, 308-311, 313, 316)
Unclear (referred to as 'clinical sites')	1	0	1 (3.6%)(92)
Database of cancer registrations	1	2	3 (10.7%)(83, 110, 314)
Mixture (hospital setting + advert in magazine)	1	0	1 (3.6%)(312)
Mixture (hospital setting & local cancer registry)	1	0	1 (3.6%)(86)
Unclear	0	1	1 (3.6%)(315)

* Unclear sample overlap between two papers – may be 320 total.
** Unclear sample overlap between two papers – may be 269 men.
*** Unclear sample size in one paper, sample likely to be larger.

6.5.4 Themes and Subthemes

The 28 included papers were analysed using the methods described in the 'Analysis' section above (see 6.4.5). All 28 papers contributed to the development of the main themes, with five key papers providing the most relevant interview data; Bailey et al., (2007), Pietila et al., (2016) Mallapareddi et al., (2017) Beckmann et al., (2021) and Seaman et al., (2019). The content of these 5 papers aligned the most with the research question and provided more relevant raw data than the other papers. 3 of these papers originated in the USA, 1 in Finland and 1 in the UK. They provided a combined sample of 62 men on AS and 6 SOs. There was SO data in only one of these papers (Mallapareddi et al., (2017). Although these papers provided the bulk of the data, the remaining 23 papers contributed sufficiently to be included, and data from the remaining 23 papers did not conflict with the data from the 5 main papers. Therefore, implications for analysis and interpretations were minimal. Figure 14 shows the main themes and subthemes.

Figure 14: Themes and subthemes



6.5.5 Theme 1: A speck of insignificant cancer versus a frightening disease

6.5.5.1 Polarised perceptions of prostate cancer

Patient perceptions of prostate cancer varied, but the majority of participants described their cancer with words such as ‘small’ or ‘insignificant’, with a minority perceiving their cancer as serious or life threatening. One participant explained how he told his family that his localised prostate cancer was different to other types of cancer(80):

> *“Now remember, we’ve been through a cancer episode before. The first thing I told them was this is a very different story than the other one was [kidney cancer]. I told my children, and my wife as well, different game with this one. And then tried to put them at ease, somewhat, as I had become on the nature of the beast…it didn’t somehow indicate a flare-up or immediate problem.” (Bailey et al., 2007)*

Mroz et al., (2013) identified a pattern of patients ‘minimising’ the threat by using phrases like a ‘speck of cancer’ or ‘having signs of cancer’, and interpreted this minimisation as a mechanism to assist AS acceptance(93).

However, not all men across the studies felt this way, and, although a minority stance, some felt scared by ‘even the word cancer’(90). One participant described his fear as follows:

> *“Well, that [dying from a heart attack] really don’t bother me as bad as thinking about cancer. Anytime that cancer is mentioned, it’s frightening. A heart attack or stroke or something doesn’t worry me as much as knowing that I’ve got this.” (Bailey et al., 2007)*

6.5.5.2 Mixed feelings about Active Surveillance

Reflecting the pattern of patient perceptions of prostate cancer, feelings about AS and living with cancer seemed to vary across the sample with the majority of men feeling comfortable living with cancer and content being managed with AS, viewing it as safe. Participants felt the regular monitoring of AS provided reassurance and confidence that they were doing the right thing(88):

> *“Maybe you can call me crazy. . . .I feel very confident in the approach that I’m on with [my*

urologist]. . . .I haven't experienced anxiety. I mean, it hasn't really distracted [me] for more than a second, occasionally, from my normal routine. . . .I know some people that worry. I've just never been that way." (Seaman et al., 2019)

Davison (2009) reported specialists recommending to "just watch it for now" or "keep an eye on it" gave patients a sense of relief, indicating that their cancer was low risk and slow-growing(91). Other reasons for being content with AS included the opportunity to avoid the unwanted side effects associated with radical treatment(85, 88, 312, 315), giving themselves more time to better understand the disease(85, 87), giving time for new treatments to potentially become available(80, 82, 102), and avoiding the need for time off work to recover from radical treatments such as surgery(86, 308).

A small number of participants reported struggling with living with an untreated cancer and expressed that AS takes "an emotional toll over time"(101, 102, 110), and can be like living under a shadow, always "in the back of their heads"(83).

Those with a more negative view of AS tended to see it as temporary management protocol and considered it as an 'irrelevant' period of 'head in the sand' which avoided 'the inevitable'(88, 142).

6.5.5.3 AS is the masculine choice

Whilst exploring experiences of both men on AS and those who had undergone radical treatment one paper focused their exploration around ideals of masculinity in men's justifications for their treatment decisions(312). The authors of this paper reported that for some, the idea of choosing AS over radical treatment was seen as the 'masculine'(312) choice and a pathway only suitable for those 'resistant to stress'(312). One participant explained:

"not everyone wants or can cope with this idea. [..] It could be said that this is not indeed a choice for those who are nervous". (Pietila et al.,2016)

For a couple of interviewees, there was a belief that personality traits contributed to the decision of opting for RT or AS(312):

"Certainly a person who gets engaged in this [AS] has to be an optimistic personality. I'd think that a pessimist couldn't bear it at all. So that after hearing the word cancer, he'd go and have surgery right away." (Pietila et al., 2016)

Pietila et al., (2016) interpreted this verbalised distinction as a claim to masculinity and a 'celebration of masculine ideals of self-control, independence and stoicism'(312). These ideals of masculinity were present mainly in this one paper, but another (Mroz et al., 2013) interpreted the way some men minimalised their illness, and placed greater stress and importance on pressing work matters as an expression of masculinity(93).

6.5.6 Theme 2: Anxiety or uncertainty about disease and treatment

6.5.6.1 Men are anxious about missing the opportunity to treat

Although some participants appeared to be content with the AS plan, there were a high number of references to participant anxiety and uncertainty about the disease. By far the biggest concern was missing disease progression and consequently the opportunity to treat(80, 86, 87, 90, 101, 102, 110, 111, 310, 314, 316). One participant described hypervigilance around symptom perception due to this anxiety:

> *"I noticed that every time I went to the bathroom, I was wondering if it [prostate cancer] was any worse. There were times when urinating wasn't comfortable or the stream was very slow getting started. I was constantly concerned…was it getting worse." (Bailey et al., 2007)*

Another participant said simply:

> *"'My "fear" is that it (cancer) would get away. You'd miss your window of opportunity."*
> *(Mallapareddi et al., 2017)*

A common pattern of increased anxiety around the time of surveillance checks was apparent(81, 88, 101, 111, 308, 313). This pattern was described by one participant as follows:

> *"six months from now, I gotta get another test. I'd start thinking about it, and there'd be a little anxiety in the week or two before, but I really didn't think very much about it in between." (Seaman et al., 2019)*

Some men felt worried about whether AS was the right decision for them(80). One participant explained:

"I just don't know if I'm doing the right thing or not, just based on my age – I'll be 70 years old in May. But I just don't know to be honest with you. It's really a major decision. Of course, I still don't know if I'm doing the right thing, by observing." (Bailey et al., 2007)

Contributing to this anxiety was the perception that PSA tests are unreliable, and participants described them as 'useless'(142). The unreliability of these tests worry some men to the point of considering repeated checks:

"I keep saying to my wife, "Should I go and get another opinion … the best of three?"" (O'Callaghan et al., 2014)

6.5.6.2 Anxiety impacted by treatment organisation and communication

Negative experiences of treatment organisation and communication from medical teams were present in one paper originating from the UK(316). One participant reported how clinics were sometimes cancelled or rearranged, resulting in poorly timed scans and increased feelings of anxiety:

"…I would go to the effort of re-organising my scans so that they fitted around my appointments as often the scan date fell after the appointment, and then the hospital would call or send a letter cancelling the clinic. … That's definitely an area they could improve: at least reassuring the patient that their scan was ok, instead of leaving them in limbo…" (Beckmann et al., 2021)

Men felt anxious waiting for test results, and these feelings were exacerbated when results were not returned in a timely manner, or communication from the hospital was lacking. Men on AS were left feeling of low priority:

"…When I had to go for the MRI scan, I would be very anxious waiting for those results because it often took weeks to hear from the hospital. I don't know how long it takes for someone to review these things but if they knew how we felt waiting perhaps it wouldn't take so long. I felt quite resentful, like my cancer was being de-prioritised because it didn't need treatment …" (Beckmann et al., 2021)

Poor communication from the medical teams felt like a lack of consideration for how the patient may be feeling:

> *"…the doctor said he would ring me in a couple of days. A week went by so I rang the hospital and asked what was going on. I was told that the doctor would call me as soon as he was available as the nurse 'wasn't allowed' to give results over the phone…I wasn't very happy with that, I felt that anybody facing a possible cancer diagnosis is going to be stressed…so to leave me sitting there like a mug…" (Beckmann et al., 2021)*

6.5.6.3 Men mobilised activities to manage anxiety and uncertainty

To manage anxiety men mobilised activities such as lifestyle changes(81, 83, 92, 101, 309, 314), information gathering(92, 101, 102, 142, 309), continuing with work(80) and participating in religious activities(80, 83). This theme was common throughout much of the data.

The two most prominent activities men mobilised were lifestyle changes and information gathering(309). One participant said:

> *"I started taking some Lycopene tablets and also buying tins of tomatoes and broccoli" (Wade et al., 2020)*

Another described changes he had made to his diet in more detail:

> *"I immediately changed my diet... we had greatly reduced the consumption of red meat and other fatty foods and our diet was pretty much chicken, fish, pasta, salads and then when I was diagnosed with prostate cancer and getting information off the web, they were suggesting more soy-type products, tomato-type products - tomato sauce, three times a week, sometimes four times a week and I've added shitake mushrooms to it, which supposedly on the web, it's indicated that it's a cancer fighter" (Kazer et al., 2011)*

Many of the participants were organised in their prostate cancer related information gathering(80):

> *"I read continually on this. We were well versed before we came to (hospital name) because I had gotten information from Duke and this cancer hotline and from John Hopkins and somewhere else. I've got a folder probably half an inch thick on it, and we've read Dr Walsh's book." (Bailey et al., 2007)*

There was a desire for clearer and simplified information to help patients understand and interpret clinical results(92):

"There's a lot of jargon, and it's putting all the pieces together. Remembering what the Gleason score is. All I remember is that it exists and higher is bad." (Loeb et al., 2018)

There were a minority of participants however who did not feel the need to gather any additional information and were content with just the information provided by their physicians(93):

"He (doctor) went straight for active surveillance. It didn't make any sense going around looking for other opinions really . . . I was quite happy with the deal sort of set up here and I wasn't going to be bothered running around looking for alternatives." (Mroz et al., 2013).

6.5.7 Theme 3: Significant others are key

6.5.7.1 Significant others are involved in every step

Throughout the papers the importance of involvement of significant others in the prostate cancer journey of patients on AS was evident. Even papers that did not directly study significant other experiences reported data from the interviews and focus groups corroborating their importance. Spouses usually attended medical appointments and were heavily involved in treatment decision making(84, 85) saying for example:

"We say it's a joint effort – we are in this together. And, you know, figure out what is the best decision for us." (Mader et al., 2017).

Men on AS valued the support from spouses:

"They all haven't got a supportive wife; without her, it wouldn't have been such an experience for me where I felt confident about going forward. I think men who are on their own will find it much more difficult than maybe men who are married." (Eymech et al., 2022)

In concordance with this, spouses viewed themselves as important in their role(86) and stated that their husbands were sometimes 'overwhelmed' or 'unable to manage the large amount of information about prostate cancer that they gained while making a treatment decision'(86), highlighting their essential support and guidance.

In fact, spouses not only viewed themselves as important, but described themselves as also being under active surveillance(142):

> *"By using 'we', seven partners also depicted themselves on AS. One said, 'My partner does have a cancer and we both have to live with that." (Spouse in O'Callaghan et al., 2014)*

Some spouses expressed the opinion that their husbands or partners ignore health concerns and remain in denial about the situation(86), and many spouses actually noticed the prostate cancer symptoms before the men, encouraging them to get checked out(86).

6.5.7.2 Significant others are anxious

Similar to men on AS, significant others reported anxieties around disease progression and a heightened sense of anxiety around the time of surveillance checks(149).

> *"It's there, but I don't think about it all the time. It always comes to the surface at some point, when you lie awake and can't sleep. That's how it is for me, I think. But I don't think it is taking over our lives. It comes when it comes." (Spouse in Rossen et al., 2016)*

These feelings could interfere with everyday life, for example, work, but they eased over time(149):

> *"I thought sometimes at work, ''You have to get some work done now.'' My thoughts were all over the place. The further I came along, the easier it was to talk about it." (Spouse in Rossen et al., 2016)*

The men on AS recognised their spouse's anxiety and often viewed it to be greater than their own(110):

> *"My wife and I discussed it quite a lot… she was really concerned. And I guess I was as well a little bit that yeah it was internal, which was okay, so it was contained within the prostate, but there was always that fear… if it does get out and gets into your system elsewhere…" (McIntosh, 2022)*

6.5.7.3 Significant other coping strategies

Similar to the previously mentioned theme regarding men mobilising activities to manage uncertainty, significant other engagement in certain activities to cope with the situation were apparent. Spouses often participated in, and often initiated, lifestyle changes(149). For example, a participant explains:

"Sometimes we all eat rye, but we have other things on the table as well because the other family members don't always want to eat rye pasta. But it's not a problem." (Rossen et al., 2016)

Significant others also conducted their own searches for information, talked to friends and family, and tried hard to remain positive(149).

6.5.7.4 Men on AS try to manage significant other anxiety

Some patients felt a responsibility to protect significant others, either by keeping their own anxieties to themselves, or by opting for treatment in an attempt to reduce ongoing worry. The Berger et al., (2014) paper interviewed men who had previously been on AS but left the programme to pursue treatment. 3 out of the 14 participants in this situation reported making treatment decisions to limit the worry of their significant others(90):

"But having children, and people telling me that, 'Hey, you need to be there for the kids,' that sort of thing, I kind of thought of it differently than I would've if I were single or without children, I'd say. The children were a strong consideration in the decision making."

6.5.8 Theme 4: Social Support

6.5.8.1 PCa is a private matter

Some men were open and felt happy to talk about their prostate cancer(308), but most men preferred to keep it between themselves and their spouses referring to their situation as a "private matter"(91, 134).

Reasons for keeping quiet about the diagnosis included the feeling of having to justify choosing AS(87), wanting to avoid the perceived stigma around being a 'cancer patient'(312), wanting to avoid further confusing themselves with the opinions of others(142), and simply finding it hard to talk about(91).

The idea of stigma around being a ‘cancer patient’ presented strongly in the Pietila 2016 study. One participant explained:

> *“Well, you don’t talk about cancer openly, no you don’t. It’s still like a mark burned into your skin, that’s how I see it. And it’s much tougher than in cardiovascular diseases. Some people get infarcts and some don’t, it’s like business as usual and belongs to life, but if you have cancer then it is like you’re branded, sort of “now, that’s surely a serious case, isn’t it?””*

6.5.8.2 Peer support is valuable

Peers who had experienced prostate cancer themselves were a highly valued source of support and advice, and seen as providers of a ‘second opinion’(111, 312, 316):

> *“…Whilst there was plenty to read on the internet, it’s finding people that have been through it that I found most helpful. … Often you can read and read but, at the end of the day, talking to someone, is the most important part…” (Beckman et al., 2021)*

In fact, one participant did not see the point in discussing his situation with people who had not had experience with something similar:

> *“If I know that someone hasn’t got it [cancer], then it’s no use to talk about it at all.” (Pietila et al., 2016)*

Similarly, opinions and advice from peers who had links to the medical community were more highly valued than those who did not(85).

6.5.8.3 Extra support is needed

The topic of support for men on AS, and sometimes additionally for their spouses was present in most of the papers. Despite highly valuing PCa related discussions with others in similar situations(312, 316) , men on AS consistently disliked the idea of attending support groups. Reasons for this included the fear of stigmatisation and being seen as a ‘cancer patient’, and the idea that attending a support group would mean admitting they had cancer(312).

Spouses felt differently about support groups and one spouse in the Rossen et al., (2016) study expressed the desire for some extra support:

"That would have been good. Getting to know, ''Missus, your husband is in a very early disease stage. Don't worry so much.''

6.5.9 Broader impacts on everyday life

Although the papers explored anxieties around being on active surveillance, broader impacts on everyday life were not explicitly explored. There was one mention of a change in mood, and one about a change in sex drive:

"I'm not as happy as I was, by any means. I've always as I say been a pretty happy-go-lucky guy, and I haven't been as happy and satisfied since I found this out. My immediate family called me grouchy and this and that…it's been on my mind a whole lot." (Bailey et al., 2007)

"'The idea of sex after you've been diagnosed with Prostate Cancer, I just had a real problem with it. It was the idea that this ejaculating… No, it's not that, it's the fact that it could have Cancer in it, you're sitting there and you're talking about having sex with your wife and you're working through a bad piece of pipe here…" (Kazer et al., 2011)

The lack of reference to changes to everyday life may indicate little impact, but it is difficult to say as broader impacts were not explicitly reported in the included papers.

6.6 Discussion

6.6.1 Main findings

This synthesis of 28 papers provides a comprehensive overview of the published research on the experiences of men on AS and their SOs. Overall, the papers included in this study report that men on AS describe their experiences of being on the pathway in a positive light; as safe, organised and non-disruptive. They largely describe their cancer as minimal or insignificant. Despite these findings, anxiety and uncertainty were still strongly present in the data. Those that found being on AS difficult, frightening and distressing were somewhat the minority, but nonetheless these themes were present and powerful. It seems both men on AS and their SOs would like extra support, but the form it would take is not clear. SOs appeared intertwined throughout every part of the PCa journey, sometimes taking a leading role in information gathering, treatment decisions, and appointment organisation, and sometimes taking a back seat, letting the men on AS lead the process and protect them where necessary. Support groups did not appeal to the men with PCa; however, they value peer support.

6.6.2 Comparison to previous literature

As reported in previous literature(96, 97), feelings of anxiety and uncertainty are common in this population. That said, not all men on AS for PCa report psychological distress and it seems men on the same pathway can have very different experiences psychologically. The differing and conflicting findings regarding the psychological impact of AS mirror those of both Kim et al., (2018) and Pickles et al., (2007), who also reported a variation in acceptance and AS related distress(96, 97). It is not clear from current research why there is such variation in the way the pathway is experienced, but it is likely the reason is multi-factorial and contributing factors could include: a pre-disposition to anxiety, previous experiences related to PCa, and the extent to which patients were educated and supported by medical teams.

The current review shows SOs to be involved and crucial in the men's PCa journey, and the idea of PCa being a 'we' disease mirrors findings from Collaco at al., (2018), who found a strong sense of togetherness. As described in the introduction to this chapter (6.1) the Collaco et al., (2018) review revealed a contrasting theme around feelings of discontent among SOs, showing some felt isolated unsupported and sometimes excluded both by their partners and medical professionals. The feelings of isolation were sometimes exacerbated by requests from their partners that the diagnosis is not discussed beyond the dyad, restricting the SOs ability to seek wider emotional social support. The papers included in the current review did not report data about the extent to which SOs felt included or acknowledged, or how they might like things to be different, however, there may be some overlap with the subtheme 'PCa is a private matter'. This subtheme describes how some men prefer to keep their diagnosis between themselves and their spouses, uncomfortable with people in their wider circle knowing the situation. The papers in the current review did not report the SO side to this narrative, and it is not possible to say whether this is because SOs were content keeping the diagnosis within the dyad, or whether the SOs in the current review were not questioned in a way that would have elicited such information. Men in the Pickles et al., (2007) review reported the illness negatively impacted close personal relationships(97). This finding was not supported by the current review, however, it is important to consider participants in this current review self-selected to be interviewed for research knowing their partners would also be interviewed. This creates a potential bias and results may differ from those not offering to participate in an interview.

Previous literature has found that couples sometimes hide their PCa worries and feelings from each other as a way of protecting each other(83, 104), for example, the idea of protecting significant others was present in the interviews in the Hedestig (2003) study where participants described being solitary in their dealings with prostate cancer with an aim to ‘protect and not worry loved ones’(83). The current review corroborates these findings demonstrated by the subtheme ‘Men on AS try to manage SO anxiety’, which describes how some men keep their anxieties to themselves in an attempt to shield SOs.

Support groups aim to minimise feelings of isolation by bringing people with similar experiences together, providing the opportunity to share fears and concerns and gain emotional support(317). The finding in the current review that men dislike the idea of support groups is something that has been reported before, and the Pickles et al., (2007) review found men were vocal about their dislike for support groups, and see admitting a need for help as a sign of weakness(97). Previous literature indicates men have a preference for solution-focussed support over emotion-focussed support(318-320). Much of the previous literature about support for men living with chronic illness focusses on gender differences, finding that men are significantly less likely to attend support groups than women(320).

6.6.3 Study strengths and limitations

The most relevant medical databases were searched for literature using a rigorous search strategy and screening process. The inclusion criteria were detailed and strictly defined to obtain a homogeneous collection of the most relevant papers. The CASP process for quality appraisal(273) did not raise any major issues with the papers, and all were of adequate quality.

I acknowledge that the synthesis presented here is only one interpretation of the set of studies analysed, and other interpretations using the same data would be possible and could be equally valid. By sharing my evolving results and coding manuals with my supervision team throughout the process and discussing developing themes, I was able to gain additional corroboration that the results I have presented are representative of the articles analysed. In addition, I shared developing findings with a PPI representative who provided useful suggestions about the renaming of some initial codes in NVivo to better reflect the content.

The selection of studies included in this review represented PCa patients from eight developed countries (USA, Canada, Denmark, Australia, Finland, Northern Sweden, UK and The Netherlands). It is difficult to generalise the findings to other countries, especially those less developed, as differing healthcare systems, protocols for AS and cultural perceptions of AS may influence how the pathway is experienced. None of the papers originating from the UK included SO data, meaning it is not possible to generalise these findings to SOs and couples in the UK. As well as the issue of demographic generalisability, the age of some of the included papers may pose a problem when interpreting the results. Management with AS has rapidly changed over the past 20 years, and experiences reported in older papers may be outdated as the AS protocol has been updated and understanding improved. However, the more recent included papers did not produce any significant new themes that were not present in the older papers, perhaps indicating the way the AS pathway is experienced has not changed at the same pace.

6.6.4 Implications for future practice and research

Due to a lack of comments on the subject, interpretations about broader impacts living on AS may have on everyday life cannot be made. It is not clear whether participants failed to report broader impacts because AS does not significantly affect their lives day to day, or because this topic was not explicitly explored by any of the included papers.

Findings indicating participant feelings of anxiety were exacerbated due to inefficient and slow systems of feeding back surveillance test results suggest improvements in clinical practice organisation may be beneficial to the psychological wellbeing of men on AS. In clinical practice it would be beneficial for clinicians to be aware of how polarised the perceptions of PCa can be within patients, and address this specifically by asking about anxieties and concerns surrounding their illness. Future research into why these perceptions vary so much within those on AS may help to identify areas for improvement. For example, investigating whether some are more anxious than others due to factors related to the clinician or clinic administration, or whether the reasons are more internal, for example, personality factors and personal experience will the illness.

The idea that men on AS may convert to radical intervention without clinical indication to manage the anxiety of those close to them(90) is a strong argument for including SOs in clinical consultations as well as future AS psycho-social or educational programmes. Including and educating significant others with an aim to improving AS acceptance and understanding may allow the patients to focus on transferring to intervention only when clinically indicated.

Although men appeared to dislike the idea of support groups, the value they placed on discussing PCa related issues with men who had experience of the disease indicated their feelings were related to the stigma attached to the idea of attending a ‘support group’, rather than the activity itself. For future psycho-social interventions it would be advisable to take this into account and frame the idea of group support in a different light, perhaps refraining from the use of the term ‘support group’. Research into how peer support might be delivered in a way that is acceptable to patients (for example, one-to-one peer support) would be valuable.

6.6.5 Conclusions

It appears patients cope with living on AS for PCa in different ways, with some requiring little support and experiencing very low levels of distress, and others finding the idea so distressing they consider converting to radical treatment. The varying degree to which patients experience anxiety, depression and uncertainty suggests a person-centred approach to managing feelings around being on AS (or having a SO on AS) is necessary.

The results provide insight into how future clinical practice may be adjusted to reduce the negative experiences reported, and highlights areas which would benefit from further research.

Chapter 7: Quantitative Survey Study

7.1 SO ACTIVE overview

SO ACTIVE is an exploratory mixed methods study focusing on men undergoing AS for prostate cancer and their significant others. I designed and conducted the SO ACTIVE study myself with guidance from my supervisors.

SO ACTIVE recruitment opened in October 2017 and closed in September 2018. The study aimed to explore how significant other responses to, perceptions of and anxiety about the prostate cancer diagnosis and the AS treatment plan impact on the psychological wellbeing of the patient themselves. Dyadic relationship quality, and illness-related communication were also examined.

This chapter presents the quantitative research conducted as part of SO ACTIVE. The qualitative component is presented in Chapter 8.

7.2 A quantitative survey study to explore the impact of significant others on men on AS for PCa

7.2.1 Introduction

Previous research along with the results from the qualitative synthesis presented in chapter 6 suggest that psychological wellbeing of men on AS and their SOs is impacted to varying degrees(96); some reporting significant levels of anxiety around their PCa(80, 86, 142, 308) and others feeling content with the AS protocol(90, 93). Previous research has suggested that influences from SOs and SO personal anxiety can influence decisions to remain on AS or convert to active treatment(88, 90, 310). Therefore, to improve or maintain positive psychological wellbeing of men on AS SOs must be considered.

The current investigation aimed to explore the experiences of men on AS and their SOs, but also to go one step further by exploring the impact SO feelings, responses and reactions around the diagnosis and treatment plan have on the patient. If men are converting to active treatment without clinical indication and suffering side effects they may never have needed to encounter, it is vital research is conducted to find out why.

7.2.2 Research question and objectives

Research question: What is the impact of significant others on men on AS for PCa?

Research objectives:
1. To explore the relationship between significant other responses to, and perceptions of, active surveillance and patient anxiety.
2. To explore associations between relationship quality and illness related dyadic communication, and patient anxiety.
3. To explore the relationship between significant other prostate cancer related anxiety, and patient anxiety, depression and quality of life.

7.2.3 Hypotheses

This exploratory study aimed to explore the potential influence of the SO on the prostate cancer patient being managed by active surveillance. Therefore, the hypotheses below include both PCa patient outcomes, and SO outcomes.

7.2.3.1 Primary hypotheses:

1. There is a relationship between significant other responses to the PCa diagnosis and AS treatment plan, and patient anxiety.

2. There is a relationship between relationship quality and illness related dyadic communication and patient anxiety.

3. There is a relationship between significant other prostate cancer related anxiety and patient anxiety, depression and quality of life.

7.2.3.2 Secondary hypotheses:

1. There is a relationship between prostate cancer patients' beliefs about prostate cancer, and their own levels of anxiety and depression.

2. There is a relationship between the way in which significant others perceive the prostate cancer diagnosis, and their own levels of anxiety and depression.

7.2.4 Methods

7.2.4.1 Participants

Men with a biopsy confirmed diagnosis of prostate cancer being managed with active surveillance, and their significant others. The ‘significant other’ may be a partner or other close relative or friend.

7.2.4.2 Study design

A cross-sectional survey exploratory study to explore responses in men on AS for PCa and their significant others as dyads. Men on AS and their SOs completed a set of questionnaires separately (see Appendix H). See Appendix G for full study protocol.

7.2.5 Inclusion criteria

- Prostate cancer patient must be undergoing active surveillance
- Willing to participate/provide informed consent
- Fluent in English (written and oral)

7.2.6 Exclusion criteria

- Under the age of 18
- Unable to take part in telephone interviews
- Not fluent in English

7.2.7 Recruitment

Participants were recruited through three PCa charities (details of charities below). Recruitment through secondary care PCa clinics was considered, however, research funds were limited. It was hard to estimate how many people would respond to adverts placed by charities, however, I considered the reach of the organisations, for example, the number of followers on Twitter, and along with my supervisory team decided it was an avenue worth pursuing.

Recruitment opened in October 2017 and closed in September 2018. The three chosen charities, Prostate Cancer Support Organisation (PCaSO), Prostate Cancer UK and Tackle Prostate Cancer are charities aiming to support those with PCa. PCaSO (charity number 1170536) is a charity based in Hampshire, run entirely by volunteers who have been affected by PCa. PCaSO provide support, information and free PSA testing. Members of PCaSO acted as PPI throughout, and kindly provided a

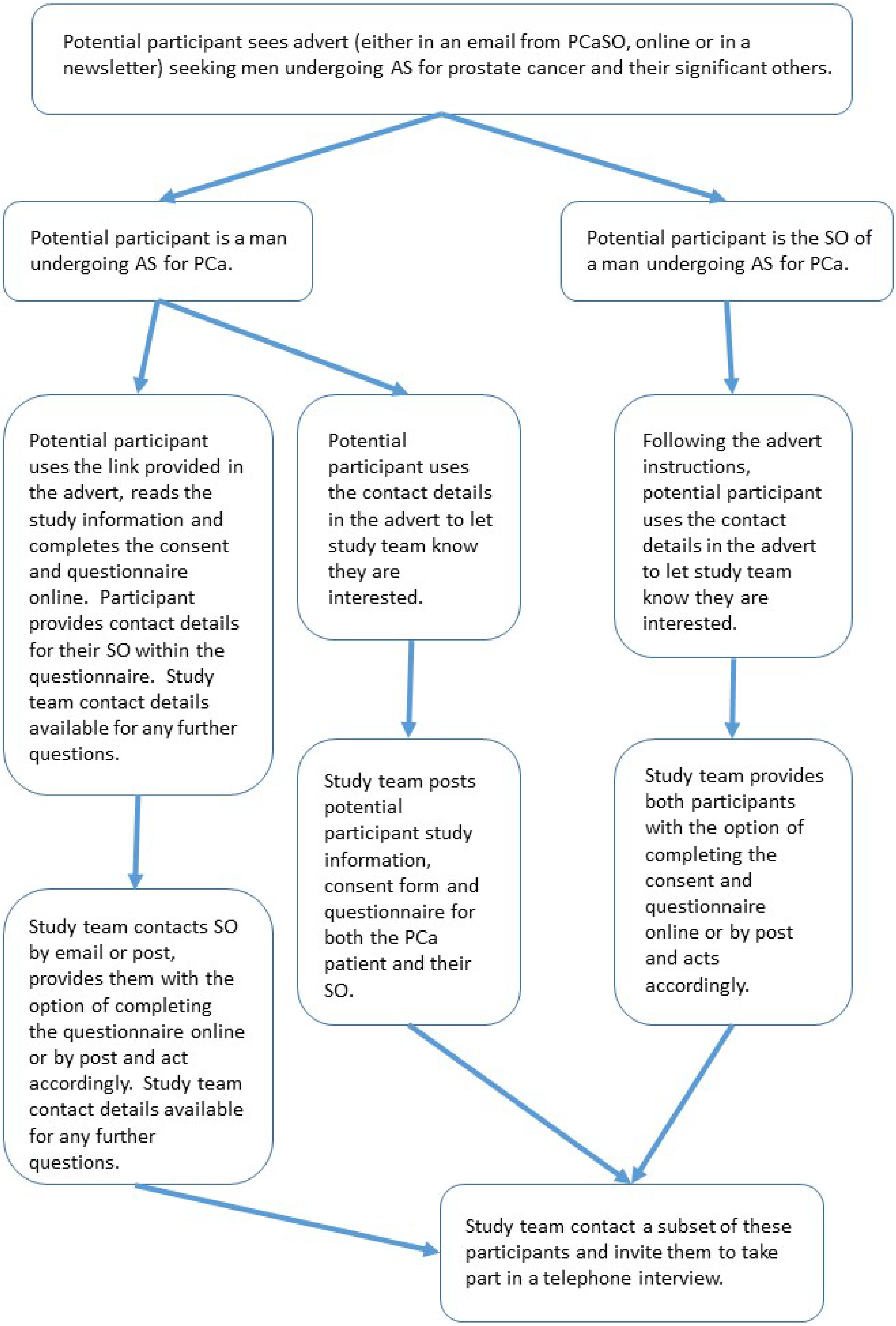
grant for this PhD study. Tackle Prostate Cancer (charity number 1163152) was launched in 2013 and aims to raise awareness of PCa, provide support to those affected and run campaigns to raise money. PCUK (charity number 1005541) is a large, well known, national charity founded in 1996. PCUK run national campaigns with adverts on television, radio and posters UK wide.
Participants were recruited through adverts placed in the following places (see Appendix J):

- PCaSO newsletter
- PCaSO email circulation
- PCUK newsletter
- PCUK Facebook and twitter
- Tackle Prostate cancer newsletter
- Tackle Facebook and Twitter

The advert asked men on AS to either follow a link to view the study information, consent form and questionnaire online; or to get in touch with the study team to express their interest and be posted a study pack. The study pack contained a study invite letter, participant information sheet, reply slip, consent form, questionnaire (see Appendix K, Appendix L, Appendix M and Appendix H) and freepost envelope. Participating men were posted a study pack to pass to their significant other containing an invite letter, participant information sheet, reply slip, consent form, questionnaire (see appendices Appendix K, Appendix L, Appendix M and Appendix H) and freepost envelope.

In case the advert was seen by the significant others of men on AS, the advert asked potential participants to get in touch with the study team to express their interest. The study team then provided the dyad with the option to complete the study online or by post and act accordingly.
See Figure 15 for the recruitment flow chart.

Figure 15: Recruitment Flow Chart



7.2.8 PPIE contribution to study document and procedure development

PPIE members contributed to the development of all participant facing documents. They provided comments by email, which were implemented wherever possible:

1. The lay summary in the protocol stated 'localised PCa usually grows very slowly…'. PPI suggested changing this to 'localised PCa sometimes grows very slowly…'. I implemented this change.
2. PPI suggested softening the wording in the section of the PIS describing the potential risks involved in participating as they were concerned the wording might be off-putting. I softened the wording and gained approval for the updated version with PPI input.

PPIE members were also given the opportunity to comment on recruitment and study processes. No significant changes were suggested.

7.2.9 Managing Dyads in Recruitment

The following processes were followed to ensure dyadic data could be matched:

1. If a participant used the link from an advert to complete the questionnaire online, the questionnaire gathered the details of their significant other (name and contact details). The study team allocated this participant and their SO an ID, before sending out the information and questionnaire to the SO. The study team linked the IDs for analysis.
2. If a dyad requested the information and questionnaires by post, they were each allocated an ID, which could be linked by the study team.

7.2.10 Sample Size and Power Calculation

A paper by Maas & Hox (2005) provided valuable insight into how to calculate a sufficient sample size for multilevel modelling(321). This was an exploratory study, but an ambitious potential recruitment target aim for the quantitative study was set at 404 dyads, 808 participants in total. A moderate correlation between each of the key measures of significant other anxiety/distress and patient anxiety/distress were anticipated. Based on a 95% confidence interval, a sample size of 404 completed pairs of questionnaires would allow an estimated correlation coefficient of 0.70 within a confidence interval of (0.65-0.75). This calculation was conducted by a statistician within the department of Primary Care, Population Sciences and Medical Education at the University of Southampton.

7.2.11 Ethical approval

SO ACTIVE received full ethical approval from The University of Southampton Ethics Committee on 29th September 2017: ERGO 29805.
REC's contact: Faculty of Medicine Ethics Committee, Southampton General Hospital, Mail point 801, South Academic Block, Tremona Road, Southampton SO16 6YD UK.
Email: medethic@soton.ac.uk

7.3 Quantitative Study Measures

7.3.1 Questionnaire overview

The set of questionnaires for the prostate cancer patient, and their SO differed slightly. See Table 23 for an overview of the included questionnaires, and Appendix H for the full questionnaires. The questionnaires were tested by one PPIE and two colleagues working within Primary Care at The University of Southampton. The questionnaire took approximately 20-25 minutes for the test participants to complete.

Table 23: The questionnaires

Questionnaire for men on AS	**Questionnaire for SOs**
Demographics	Demographics
Your significant other	Your significant other
Your prostate cancer	N/A
The Hospital Anxiety and Depression Scale(322)	The Hospital Anxiety and Depression Scale(322)
SF-12(323)	SF-12(323)
The Memorial Anxiety Scale for Prostate Cancer(324)	The Memorial Anxiety Scale for Prostate Cancer (adapted for SOs)(324)
The Couples' Illness Communication Scale (patient version)(161)	The Couples' Illness Communication Scale (SO version)(161)
Revised Dyadic Adjustment Scale(325)	Revised Dyadic Adjustment Scale(325)
N/A	The Revised Family Response Questionnaire (revised version)(326)

Illness Perception Questionnaire (IPQ-R)(217)	Illness Perception Questionnaire for significant others (IPQ-R-SO)(222)

7.3.2 Questionnaire description

7.3.2.1 'Demographics', 'your significant other' and 'your prostate cancer'

The 'demographics' section in the two questionnaires captured age, gender, employment status, relationship status, ethnicity and education level. The section titled 'your significant other' captured relationship type and length. The section titled 'your prostate cancer' gathered information about PCa history, e.g., time since diagnosis and previous treatment. These questionnaires were developed by myself with guidance and input from my supervisory team and experts in the field (for example, Urologist Mr Brian Birch). This data provides valuable information about the diversity of the sample and allows for the exploration of any associations between demographic values and the main outcomes.

7.3.2.2 The Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS)(322) is a 14-item multiple choice questionnaire designed to capture levels of anxiety and depression in hospital and outpatient settings. The questionnaire is divided into two dimensions: 7 questions designed to assess generalized anxiety, and 7 questions assess general depression. Scores between 0 and 21 can be obtained for each dimension, and scores of 7 or less (on either the anxiety or depression scale) are non-cases, 8-10 are doubtful cases and 11 or more are definite cases(322).

The HADS measure claims to capture two independent distinguishable psychological conditions (anxiety and depression), and I felt it was important to consider the validity of this claim before including the measure in the survey. The bi-dimensionality has been tested multiple times(327-330) and findings suggest the HADS is effective at distinguishing between anxiety and depression. Furthermore, the validity of the HADS has been assessed multiple times against established measures of anxiety and depression(329, 330) and has demonstrated a high level of validity in assessing depression and anxiety. A large meta-analysis examined the test-retest reliability of the HADS(331) and the results suggest the HADS is a reliable instrument.

7.3.2.2.1 Alternatives considered

There are many questionnaires available for the assessment of depression and anxiety, such as the Beck Depression Inventory(332), the State-Trait Anxiety Inventory(333), the Montgomery-Asberg Depression Rating Scale(334), the Clinical Anxiety Scale(335), the Hamilton Anxiety Scale(336) and the Hamilton Rating Scale for Depression(337). Although a combination of these questionnaires may have provided a valid and reliable assessment of depression and anxiety, the HADS was preferable for a couple of reasons. Firstly, many questionnaires assess depression and anxiety separately, and therefore it would have been necessary to use a combination of questionnaires to cover both anxiety and depression. The HADS is able to assess both anxiety and depression in a single 14-item questionnaire, reducing participant burden. Secondly, the HADS is widely used in research allowing for comparison. It was important to consider other options, but in the absence of any clear advantages of other measures it seemed sensible to utilize this widely recognised, reliable and validated tool.

7.3.2.3 The SF-12

The 12-item Short-Form Health Survey (SF-12)(323) assesses general health and well-being/quality of life in 12 items. The SF-12 contains a mixture of response options, for example, ‘yes/no’ responses, and a 6-point Likert scale ranging from (1) All of the time to (6) None of the time.

The SF-12 originates from the 36 item Short-Form Health Survey (SF-36)(338) which was developed to assess health status using a 36-item scale covering: 1) limitations in physical activities because of health problems; 2) limitations in social activities because of physical or emotional problems; 3) limitations in usual role activities because of physical health problems; 4) bodily pain; 5) general mental health (psychological distress and well-being); 6) limitations in usual role activities because of emotional problems; 7) vitality (energy and fatigue); and 8) general health perceptions. It was acknowledged that the SF-36 was too long for many research purposes and regression methods were used to select and reduce the question number down to 12(323). The SF-12 provides a summary of the physical component scales and the mental component scales with a substantial reduction in patient burden. Various tests have shown the SF-12 to be a reliable, valid measure of general health and well-being(323).

7.3.2.3.1 Alternatives considered

I considered using the EQ-5D as a measure of health-related quality of life (HRQoL) alongside the SF-12. Previous research has shown these measures to be strongly comparable(339, 340). The EQ-5D assesses HRQoL over five domains: mobility, self-care, usual activities, anxiety and depression. Respondents can answer ‘no problems’, ‘some problems’ or ‘severe problems’ in each area. In addition to these questions the EQ-5D presents a visual analogue scale which assesses overall current health asking respondents to rate their health from 0-100 where 0 is ‘worst imaginable health state’ and 100 is ‘best imaginable health state’.

Since both the SF-12 and the EQ-5D have been shown to be reliable, valid measures with minimal patient burden, I made my decision to use the SF-12 for practical implementation reasons. At the time of selecting questionnaires for inclusion there were some issues around the copyright of the EQ-5D when distributed online. Euroqol (the company that own the rights to the EQ-5D) had some rules in place which meant EQ-5D data completed online needed to be completed via their own website. It seemed sensible to avoid unnecessary complications and risks, especially as I planned to obtain a proportion of my responses online. Therefore, I made the ultimate decision to choose the SF-12.

7.3.2.4 The Memorial Anxiety Scale for Prostate Cancer

The Memorial Anxiety Scale for Prostate Cancer (MAX-PC)(324) is an 18-item measure of PCa specific anxiety designed to capture feelings about PCa and PSA tests. The measure uses a 4-point Likert-type scale asking respondents to select how frequently certain “comments made by men with PCa” were true for them. Responses range from ‘not at all’ to ‘often’ and are scored from 0-4. MAX-PC scores of 27 and above indicate significant levels of anxiety. I adapted the MAX-PC myself to make it suitable for SOs by adjusting the statements to “comments made by SOs of men with PCa”. I sought and received approval via email for the adapted version from the MAX-PC Author (Andrew Roth).

The MAX-PC is a valid and reliable measure which has been shown to correlate significantly with other validated measures of anxiety, such as the HADS(324). The MAX-PC differs from other measures of anxiety because it measures anxiety specific to PCa. To the best of my knowledge at the time I selected this questionnaire the MAX-PC was the only validated measure of PCa specific anxiety, and therefore I had no other alternatives to consider. I was familiar with the tool from the PROACTIVE study (0) and due to its PCa specificity felt its inclusion was valuable.

7.3.2.5 The Couples in Illness Communication Scale

Previous research has shown dyadic open cancer-related communication is important for quality of life, psychosocial adjustment and relationship functioning(167-170), and therefore I felt it was important to include a measure of communication in the current investigation.

The Couples in Illness Communication Scale (CICS)(161) contains 4 items designed to gain insight into patient and partner illness communication. Respondents are asked to rate the extent to which each of the four statements is true for them on a 5-point Likert scale from 1 (disagree strongly) to 5 (agree strongly). A score between 1-20 can be obtained, with higher scores indicating better illness-related couple communication.

7.3.2.5.1 Alternatives considered

I considered other couple communication scales such as the Communications Patterns Questionnaire(341), and the ENRICH couple scales(342), however, research suggests that illness-related couple communication may be different to general couple communication(161), and so the CICS seemed more appropriate. To the best of my knowledge at the time of questionnaire selection the CICS was the only couple communication questionnaire specific to illness(161). The internal consistency and validity of the measure has been assessed and shown to meet the majority of psychometric criteria for assessment measures in both a life-threatening illness (ovarian cancer) and a chronic progressive disease (multiple sclerosis). With only 4 items the measure requires minimum participant burden and captures valuable data relevant to the current investigation.

7.3.2.6 The Revised Dyadic Adjustment Scale

The Revised Dyadic Adjustment Scale (RDAS)(325) is a 14-item questionnaire measuring seven dimensions of relationships across three overarching categories;

- **Consensus** – in *decision making*, *values* and *affection*
- **Relationship Satisfaction** – with regards to *stability* and *conflict*
- **Cohesion** – measured by *activities* and *discussion*

Respondents are asked to rate certain aspects of their relationship on a 5 or 6-point scale. Scores in ‘consensus’ can range from 0-30, in ‘satisfaction’ from 0-20 and in ‘cohesion’ from 0-19. Higher scores indicate greater stability and satisfaction in the relationship, and lower scores indicate greater distress. Overall scores (adding together the scores from the three topics above) can range from 0-69 with a cut-off score of 48; scores of 47 and below indicate relationship distress.

7.3.2.6.1 Alternatives considered

When looking for a scale to assess relationship quality I considered various measures. When compared to (for example) the Relationship Assessment Scale (RAS)(343) I felt the RDAS was particularly well rounded in terms of the dimensions it explored. The RAS contains only 7 questions, and like many of the relationship assessment questionnaires seemed suited to intimate couples only. In the present study I planned to include non-intimate couples in the study (for example, other close relatives or friends), and although the RDAS includes some questions most appropriate for intimate couples, there are many which could be applicable to other types of relationships.

Published studies have shown the measure to be reliable and valid(325). The RDAS has the ability to provide a quick snapshot of the dynamics within a relationship along with a more general assessment of the stability of the relationship, and I felt it was the best fit for inclusion.

7.3.2.7 The Revised Family Response Questionnaire

The revised version of The Family Response Questionnaire (FRQ)(326) is a 25-item questionnaire measuring four categories of family responses to illness: sympathetic-empathic responses, active engagement, rejecting-hostile and concern with self. Respondents are asked to rate each statement on a 5-point scale ranging from ‘never’ to ‘very often’ depending on how often they have carried out the action/activity stated. Participants can score 0-40 on each of the four scales, and 0-160 overall.

The measure was originally developed within the context of chronic fatigue syndrome (CFS) initiated by research that suggested patients report poorer levels of coping and reduced social support when the patient-significant other relationship is sub-optimal(344, 345). This questionnaire is particularly applicable because it is aimed at and inclusive of close relatives and friends of those with chronic illness (rather than solely the partner). In addition, rather than looking at relationship quality like the RDAS, this questionnaire captures SO responses. I was unable to find any other questionnaire which captured significant other responses in the context of chronic illness and responses were key in the current investigation.

7.3.2.8 The Revised Illness perception questionnaire (IPQ-R) (and SO adapted version)

The illness perceptions of the patient's support network have been shown to have a significant impact on health-related outcomes(221). It is important to take into consideration that those close to the patient have their own set of illness representations and beliefs because the extent to which they match or differ may impact outcomes(221). This is particularly relevant to men on the AS pathway because if close relatives are not on board with the monitoring pathway, men may be influenced to convert to radical intervention without clinical indication.

The original Illness Perception Questionnaire(IPQ)(5) used to quantify patient illness representations contains questions across 5 dimensions (identity, cause, timeline, consequences and cure/control). Respondents are asked to rate the extent to which they agree with each statement on a 5-point Likert scale ranging from 'strongly disagree' to 'strongly agree'. Dimension sub-scale scores are calculated from the combination of these responses. A higher score reflects a more strongly held belief on that dimension. The revised version of this questionnaire (IPQ-R)(217) benefits from the addition of subscales assessing *illness coherence*, *emotional representations* and *timeline-cyclical* (a scale assessing the extent to which symptoms fluctuate). In addition, the original 'control' dimension was further developed to differentiate between *personal control* and *treatment control.*

The 38-item Revised Illness Perception questionnaire collects data across the dimensions of: *timeline (acute/chronic), timeline cyclical, consequences, personal control, treatment control, emotional representations* and *illness coherence (cause).* The higher the score for the timeline and consequence dimensions the stronger the participant's beliefs. I.e., a high score on the *timeline (acute/chronic)* scale represents a strongly held belief about the chronicity of the condition; a high score on the *timeline (cyclical)* dimension represents a strongly held belief the condition is cyclical; a high score on the *consequence* dimension indicates the participant feels strongly there are negative consequences as a result of the illness.

For the *person control* and *treatment control* dimensions high scores indicate positive beliefs about the extent to which their illness can be controlled. A high score in the *illness coherence* dimension suggests a high level of personal understanding of the condition.

The IPQ-R has previously been adapted to capture the perceptions of spouses and carers of people with health conditions such as schizophrenia(222), chronic fatigue syndrome(221) and heart disease(223). The SO version was included in the SO questionnaire in the current investigation.

7.3.2.8.1 Alternatives considered

When searching for the most appropriate measure to capture illness perceptions I considered the Illness Effects Questionnaire (IEQ)(346) alongside the IPQ-R. Although the IEQ has been translated and used internationally(347), there were far less published applications available compared to the IPQ-R which seemed a more established measure.

Another advantage of the IPQ-R over the IEQ was the theoretical underpinning of its development. The development of the IPQ-R was theoretically driven by the Leventhal's self-regulation model(348). As described in section 4.4this model provides a framework for exploring the perceptual, behavioural and cognitive processes involved in responding to illness. The revised illness perception questionnaire (IPQ-R)(217) is a widely recognised, validated and utilized tool. It has been used widely across different health conditions including heart disease(218), cancer(219), diabetes(220) and chronic fatigue syndrome(221).

Lastly, a major advantage of the IPQ-R was the existing adapted version for SOs.

In conclusion, I chose to use the IPQ-R to capture illness perceptions because: the questionnaire content is underpinned by theory; it is a widely recognized and validated tool; its application across several conditions has been published; and there was an existing SO version.

7.3.2.9 PPIE questionnaire input

3 PPIE members were sent the questionnaire for comments. The following comments were made and considered:

1. The published Revised Dyadic Adjustment Scale(325) uses the term 'mate'. PPI suggested to change this to 'significant other'. I agreed and changed this throughout.
2. PPI suggested adding a tick box to differentiate between a template biopsy and a trans rectal biopsy. I consulted Mr Brian Birch (Urology Consultant) and we agreed to leave it as 'biopsy' as this level of detail is not needed for the purposes of this study.
3. The MAX-PC questionnaire asks for participant feelings about prostate specific antigen testing. PPI suggested adding the abbreviation 'PSA' as people may be more familiar with this term. This was added.
4. PPI suggested changing 'occasionally' with '1-2 per week' and 'rarely' with '1-2 per month' in the Revised Dyadic Adjustment Scale. This change could not be implemented because this a standardized published questionnaire.

7.3.3 Survey development

The questionnaires were built in iSurvey, which is a University of Southampton secure development tool. Questionnaires for posting were developed in Microsoft Word.

7.3.4 Quantitative dyadic data analysis

Analysis plan

Given a large enough sample I planned to first explore the relationships within the data with correlation, partial-correlation and regression analysis, perform paired sample t-tests and then use MLM to account for interdependence and gather a more accurate picture of the relationships within the data. MLM was preferable to SEM because of the existing routines in statistical software packages, and the ability to run the analysis with a smaller sample size.

7.3.4.1 Data checking and cleaning

The data was checked to ensure that responses for each questionnaire were valid and lay within the response range for each item.

As the questionnaires were developed in iSurvey I was able to login at any given point to check data collection. For the first 5 participants I checked and downloaded each questionnaire as soon as it had been completed to ensure there were not any errors in the way the data was being stored or downloaded. Thereafter, I performed a data check once a week.

When saving the data, and sharing the data with the statistician helping with analysis I followed this data cleaning process:

1.) Removed column containing participants' full names
2.) Removed column containing email addresses
3.) Removed all postal addresses
4.) Removed telephone numbers
5.) Checked eligibility using questions about treatments received

7.4 Quantitative Study Results

The original recruitment target of 404 dyads (808 participants in total) was not met. Unfortunately, it proved hard to recruit participants to the study: 7936 men accessed the questionnaire, 7862 did not answer any questions, 31 partly completed the questionnaire, and 43 completed all questions. Of the 31 who partly completed the questionnaire, 8 had entered their postal address and were posted a paper copy of the questionnaire along with a SO paper questionnaire. None of these were returned. It is not possible to make assumptions about why such a large number of people accessed the questionnaire without answering any questions, but I have considered the following reasons:

1. The advert on social media was limited to a certain number of characters, meaning details of the study were limited and people needed to click on the link to read more. Anybody could click on the link and access further information about the study. Therefore, those interested in the study, but not eligible may have done this, for example, those with an interest in PCa, or research.
2. The questionnaire may have been accessed by people who were not sure if they were on AS, and only understood they were not eligible once they had accessed the questionnaire and read the eligibility criteria.
3. The 31 participants who started the questionnaire but failed to complete it may have found the questionnaire too long, or changed their minds part way through.

The number of completed questionnaires for the significant others was 19. 15 of these were SOs whose responses could be matched to a man on AS, resulting in a participant pool of 15 dyads (30 participants). In an attempt to boost recruitment, I asked PCUK to advertise the survey via twitter an additional two times, and PCaSO to re-advertise the study by email circulation. Unfortunately, this did not result in any extra participants and I did not have access to sufficient resources or time to explore other recruitment methods. The under recruitment had implications for analysis as explained below in section 7.4.3 and is discussed further in the discussion section 7.5.3.

7.4.1 Demographics

The average age of the sample (15 men and 15 SOs) was 67.7 for men on AS, and 54.1 for significant others. Over half of the sample were retired (60.0% of the SOs and 73.3% of the men on AS), and the majority were married or in a civil partnership (80%). The sample were all of white ethnicity, with 86.7% of the SOs and 100% men on AS being white British. Most couples had been together for over 20 years (73.3%). Education level was mixed and evenly spread across completing University, completing college or specialised training, and leaving education after secondary school. Although significant others who were not spouses were invited to take part (e.g., an alternate close relative or friend), all who participated were female spouses. See Table 24 below for full demographic information.

Table 24: Sample demographics

	Significant Others (n=15)	**Men (n=15)**
Age	54.1 (SD 8.6)	67.7 (SD 7.3)
What is your employment status?		
- *Full time employment*	2 (13.3%)	2 (13.3%)
- *Part time employment*	4 (26.7%)	2 (13.3%)
- *Retired*	9 (60.0%)	11 (73.3%)
What is your relationship status?		
- *Married/civil partnership*	12 (80.0%)	
- *Co-habiting*	2 (13.3%)	
- *Divorced*	1 (6.7%)	
White ethnicity	15 (100%)	15 (100%)
Education		
- *Left school before 15*	1 (6.7%)	3 (20.0%)
- *Secondary education*	5 (33.3%)	5 (33.3%)
- *College/specialised training*	5 (33.3%)	4 (26.7%)
- *University*	4 (26.7%)	3 (20.0%)
Time in relationship		
- *Less than 1 year*	0	
- *1-5 years*	2 (13.3%)	
- *6-10 years*	1 (6.7%)	
- *11-15 years*	0	
- *16-20 years*	1 (6.7%)	
- *Over 20 years*	11 (73.3%)	
Time of PC diagnosis		
- *Less than 1 year*	7 (46.7%)	
- *1-5 years*	7 (46.7%)	
- *6-10 years*	1 (6.7%)	
- *11-15 years*	0	

7.4.2 Sources of information

The men were asked about where they go to source prostate cancer related information. 60.0% of the sample consult with their GP about their PCa. Since diagnosis, 66.7% have utilised information leaflets given to them in clinic, 60.0% have used PCa information from the internet, and 73.3% have used information from PCa charities. Although 20% reported utilising information from PCa support groups, only 13.3% indicated that they belong to a support group. If the men had a prostate cancer specific query, they were most likely to seek advice from a specialist nurse (53.3%). See Table 25 for full details.

Table 25: Information sources (men only)

Question	**Results**
Do you consult with your GP about your PCa?	Yes: 9 (60.0%)
Since your diagnosis what sources of information have you used?	
- Leaflet given to you in clinic	10 (66.7%)
- Internet searches	9 (60.0%)
- Prostate cancer charities	11 (73.3%)
- Prostate cancer support group	3 (20.0%)
Other	1 (6.7%)
Are you a member of a prostate cancer support group?	2 (13.3%)
If you had a prostate cancer related query, where would you seek advice?	
- GP	2 (13.3%)
- Specialist nurse	8 (53.3%)
- Internet	0
- Others with PC	1 (6.7%)
- PC charity	2 (13.3%)
- PC support group	0
- Other	2 (13.3%)

7.4.3 Dyad results

Due to under recruitment and the small sample size I was not able to carry out the planned analysis. However, I performed correlational analysis to look for associations within the measures completed by the men and the SOs and between the two groups, and I conducted paired samples t-tests to look at differences between the men and the SOs on comparable measures.

7.4.3.1 Correlational analysis

As Kendall's tau is appropriate for use with small samples(267) it was the chosen method of correlational analysis. As described in section 5.7.3.1 correlation coefficients can lie between 1 and -1. The classification of r values in terms of strength of correlation is a debated topic, with literature advising different cut off points, or avoiding cut off points if possible(349), however, from a pragmatic perspective it is helpful to explore the strongest correlational relationships within this data. A coefficient value of r >0.7 (or negative correlations of r <-0.7) is generally considered a 'strong' correlation(265, 266, 350). Using this value I have selected the 'strong' correlations from the presented data to discuss and highlighted them in each table. The three tables below show the correlations within the data from the men on AS (Table 27)(), correlations within the data from the SOs (Table 28) and finally correlations between the two data sets (Table 29).

There were four 'strong' correlations within the data for the men on AS (see Table 27).

1. A positive correlation (r=0.75) between the HADS anxiety scores and the HADS depression scores for the men on AS.
2. A positive correlation (r=0.72) between the HADS anxiety scores and the emotional representation scores. This suggests the more the illness affects mood and emotions, the higher participants tend to score on the HADS anxiety scale.
3. A positive correlation (r=0.70) between the consequence domain in the IPQ-R and HADS depression scores. This suggests that the more perceived consequences of the illness, the higher the depression scores.
4. A negative correlation (r=-0.77) between couples' communication and treatment control. This suggests that as the men's perception of the effectiveness of treatment increases, their illness related communication decreases.

The data did not show any 'strong' correlations within the SO data (Table 28).

Table 26: Correlations using Kendall's tau for the 15 men on AS

				Revised dyadic Adjustment				IPQ-R						
	HADS-A	HADS-D	MAX-PC	consensus	satisfaction	cohesion	Couples communication	timeline	timeline cyclical#	consequence	personal control	treatment control	emotional representations	illness coherence
HADS-A	1													
HADS-D	0.7503	1												
MAX-PC	0.3808	0.3727	1											
Consensus	-0.1197	-0.3079	0.0323	1										
Satisfaction	0.1913	0.0196	0.1477	0.339	1									
Cohesion	-0.5551	-0.4922	-0.1588	0.3443	0.1334	1								
Couples' communication	0.3702	0.2941	0.411	-0.1486	0.4533	-0.2505	1							
Timeline	0.1018	0.0763	0.2081	0.1488	0.2017	-0.0163	0.2315	1						
Timeline cyclical	0.2736	0.3464	0.1291	-0.3	0.2034	-0.1967	0.4881	0.2479	1					
Consequence	0.6056	0.7005	0.2223	-0.4099	0.1334	-0.4677	0.4176	0	0.5902	1				
Personal control	0.3808	0.5217	0.125	0	-0.0328	-0.254	0.3082	-0.1761	0.1936	0.4128	1			
Treatment control	-0.5674	-0.5071	-0.4567	0.1139	-0.3474	0.336	-0.7664	0	-0.4717	-0.56	-0.3622	1		
Emotional representations	0.7229	0.6656	0.3876	-0.1761	0.3094	-0.4253	0.5913	0.3176	0.4644	0.6143	0.2946	-0.6876	1	
Illness coherence	0.1987	0.2981	-0.125	-0.1291	-0.2298	-0.3493	-0.0411	-0.048	-0.0645	0.1905	0.5625	0.0157	0.1705	1

Table 27: Correlations using Kendall's tau for the 15 SOs

			IPQ-R								Revised family response questionnaire					Revised dyadic Adjustment		
	HADS-A	HADS-D	timeline	timeline cyclical	consequence	personal control	treatment control	emotional representations	illness coherence	MAX-PC	sympathetic	active engagement	rejecting/hostile	concern with self	Couples communication	consensus	satisfaction	cohesion
HADS-A	1																	
HADS-D	0.4325	1																
Timeline	-0.1733	-0.1757	1															
Timeline cyclical	0.1932	0.1399	-0.414	1														
Consequence	0.1892	0.3562	0.1351	0.3217	1													
Personal control	0.0134	-0.068	-0.2013	0.5419	0.3401	1												
Treatment control	0	-0.1867	0.2632	-0.1498	-0.1601	-0.2252	1											
Emotional representations	0.3563	0.1667	-0.3837	0.1844	0.0972	-0.0138	0	1										
Coherence	0.2252	0.0671	-0.4636	0.4113	0.0269	0.5334	-0.1961	0.3131	1									
MAX-PC	0.4967	0.4218	-0.4967	0.4446	0.3401	0.2432	-0.2252	0.6484	0.48	1								
Sympathetic	0.4967	0.1497	0.1208	0.0556	0.3946	0.1081	-0.1855	0.2207	0.2134	0.2973	1							
Active engagement	0.2433	0.1781	0.1622	-0.1539	0.0685	-0.0136	0.0534	0.0695	0.0671	-0.0952	0.4218	1						
Rejecting/ hostile	0.3008	0.3629	-0.401	0.2372	0.0726	0.4902	-0.2827	0.0589	0.626	0.3316	0.2163	0.2758	1					
Concern with self	0.4937	0.6577	-0.1834	0.1314	0.3575	0.2556	-0.3341	0.116	0.3924	0.4119	0.4403	0.4004	0.6667	1				
Couples communication	0.1626	0.1798	-0.1478	-0.1683	0	-0.0447	-0.0875	0.0152	-0.0734	0	-0.0447	-0.015	0.1906	0.1564	1			
Consensus	0.1497	-0.3172	-0.1225	0.3803	-0.2207	0.2192	0.3089	0.0699	0.2298	0.0822	0.0548	-0.0552	0	-0.2448	-0.2263	1		
Satisfaction	-0.3197	-0.465	-0.0278	-0.0432	-0.2395	-0.1819	0.0274	0.0714	-0.29	-0.1539	-0.3499	-0.5213	-0.6421	-0.6324	-0.185	0.1277	1	
Cohesion	-0.0953	-0.2345	0.2313	-0.3521	-0.4276	-0.5206	0.0403	-0.042	-0.2974	-0.2192	-0.0685	-0.0966	-0.4239	-0.4175	-0.2565	0.1667	0.3405	1

‘Strong’ correlations between the data from the men on AS and the SO data (Table 29) were indicated as follows:

1. There was a negative correlation between the men’s scores in the consensus domain of the Revised Dyadic Adjustment scale and the SO scores on the rejecting/hostile domain of the Revised Family Response Questionnaire (r=-0.72). The suggests that higher levels of consensus and agreement within the relationship (reported by the men) is related to lower levels of hostility and feelings of rejection for SOs.
2. There was a negative correlation between the men’s scores in the consensus domain of the Revised Dyadic Adjustment scale and the SO scores on the concern with self domain of the Revised Family Response Questionnaire (r=-0.79). The suggests that higher levels of consensus and agreement within the relationship (reported by the men) is related to lower levels of SO preoccupation with the impact of their partner’s illness on their own lives.
3. There was a negative correlation between the men’s scores in the cohesion domain of the Revised Dyadic Adjustment scale and the SO scores on the rejecting/hostile domain of the Revised Family Response Questionnaire (r=-0.72). This suggests that the more cohesive the men on AS feel in their relationships, the less SOs report feelings of rejection and hostility.
4. There was a negative correlation between the men’s scores in the cohesion domain of the Revised Dyadic Adjustment scale and the SO scores on the concern with self domain of the Revised Family Response Questionnaire (r=-0.73). This suggests that the more cohesive the men on AS feel in their relationships, the less SOs report preoccupation with the impact of their partner’s illness on their own lives.
5. There was a negative correlation between the men’s scores in the timeline cyclical domain of the IPQ-R and the SO scores of treatment control in the IPQ-R (r=-0.72). This suggests that the less cyclical the men view their illness and symptoms, the more SOs feel treatment will control the illness.
6. There was a negative correlation between the men’s scores in the consequence domain of the IPQ-R and the SO scores of treatment control in the IPQ-R (r=-0.79). This suggests that the less impact and severity the men perceive, the more SOs believe treatment will control the illness.
7. There were positive correlations between men’s scores in the personal control domain of the IPQ-R and the SO scores in the consequence domain of the IPQ-R (r=0.72), the personal control domain (r=0.84), the coherence domain (r=0.89) and MAX-PC scores (r=0.71). This

suggests the more personal control the man on AS feels they have on their illness, the more SOs perceive their illness as having significant and severe impacts, feel they understand the illness and experience PCa related anxiety.

8. There were positive correlations between men's scores in the coherence domain of the IPQ-R and the SO scores on the HADS-A (r=0.73), the consequence domain (r=0.77) and the personal control domain (r=0.71) of the IPQ-R, and the MAX-PC scores (r=0.75). This suggests the more the men feel they understand their illness, the more anxious SOs feel, the more they rate the illness in terms of impact and severity, the more they believe their partners can control the illness, and the higher they score for PCa related anxiety

Table 28: Correlations using Kendall's tau for the 15 dyads

Men on AS															
					Revised dyadic adjustment				IPQ-R						
		HADS-A	HADS-D	MAX-PC	Consensus	Satisfaction	Cohesion	Couples' communication	Timeline	Timeline cyclical	Consequence	Personal control	Treatment control	Emotional representations	Coherence
Significant others	HADS-A	0.18	0.22	-0.09	-0.49	-0.68	-0.58	-0.28	-0.13	-0.29	-0.11	0.28	0.35	-0.05	0.73
	HADS-D	0.12	0.38	-0.06	-0.53	-0.83	-0.27	-0.39	-0.07	-0.07	0.13	0.32	0.41	-0.13	0.51
	Timeline	-0.45	-0.26	0.14	0.43	0.30	0.32	0.24	0.57	-0.04	-0.33	-0.37	0.21	-0.17	-0.26
	Timeline cyclical	0.43	0.50	0.24	-0.18	-0.53	-0.41	-0.10	-0.56	-0.29	-0.08	0.72	-0.16	-0.03	0.68
	Consequence	0.09	0.43	0.12	-0.45	-0.31	-0.39	0.28	-0.18	-0.06	0.13	0.57	-0.07	0.05	0.77
	Personal control	0.37	0.44	0.07	-0.43	-0.33	-0.56	0.21	-0.58	0.21	0.25	0.84	-0.41	0.06	0.71
	Treatment control	-0.45	-0.56	-0.27	0.67	0.17	0.50	-0.28	0.26	-0.72	-0.79	-0.45	0.42	-0.29	-0.20
	Emotional representations	-0.24	-0.15	-0.45	-0.13	-0.03	0.12	0.14	-0.39	-0.29	-0.18	0.30	0.03	-0.17	0.46
	Coherence	0.42	0.39	-0.02	-0.21	-0.33	-0.51	0.13	-0.48	0.31	0.22	0.89	-0.43	0.15	0.69
	MAX-PC	0.09	0.27	-0.22	-0.37	-0.52	-0.28	-0.05	-0.43	-0.08	0.04	0.71	-0.03	-0.11	0.75
	Sympathetic	-0.05	0.09	0.04	-0.21	-0.16	-0.45	0.29	-0.07	0.04	-0.13	0.39	-0.05	-0.10	0.57
	Active engagement	0.18	0.06	0.03	-0.27	0.06	-0.48	0.37	-0.29	0.26	0.12	0.25	-0.25	0.11	0.36
	Rejecting/hostile	0.58	0.58	0.26	-0.72	-0.65	-0.72	-0.16	-0.46	0.30	0.45	0.47	-0.09	0.07	0.42
	Concern with self	0.47	0.56	0.21	-0.79	-0.68	-0.73	-0.12	-0.33	0.25	0.42	0.46	0.01	0.06	0.54
	Couples' communication	-0.29	-0.13	-0.33	-0.41	-0.26	0.22	-0.16	-0.15	-0.11	0.05	-0.21	0.43	-0.31	-0.01

7.4.3.2 Paired samples t-tests

The men on AS and their SOs are interlinked, related subjects, and data from each person within the couples cannot be treated as independent. The data from couples will be correlated, however, the data is not truly paired. The correlation structures should be accounted for in the approaches outlined in section 7.3.4 above. Treating the data as paired allows some inferences to be drawn in a small sample, but may inflate Type 1 error, so results should be interpreted with caution. With this in mind, exploratory paired samples t-tests were conducted to look at differences between the dyads on comparable measures, (see Table 29 below).

Table 29: Paired t-tests

	Significant Others	**Men**	
	Mean score (SD)	**Mean score (SD)**	**p-value for paired t-test**
HADS-A	8.07 (3.64)	4.87 (4.02)	0.0353
HADS-D	3.73 (3.15)	2.87 (4.32)	0.6904
SF-12	0.74 (0.10)	0.73 (0.13)	0.815
MAX-PC	22.00 (7.58)	15.80 (3.84)	0.0012
Couples Illness Communication Scale	12.60 (1.72)	11.07 (2.25)	0.0261
Revised Dyadic Adjustment Scale			
- Consensus	23.80 (4.35)	20.93 (4.98)	0.1039
- Satisfaction	15.64 (3.00)	17.00 (2.35)	0.1778
- Cohesion	11.07 (2.79)	11.27 (2.52)	0.8383
IPQ-R			
- Timeline (acute/chronic)	3.93 (0.81)	4.14 (0.98)	0.3241
-Timeline cyclical	2.30 (0.64)	1.93 (0.63)	0.4205
- Consequence	3.07 (0.75)	2.91 (0.84)	0.9662
-Personal control	3.06 (1.04)	3.01 (1.06)	0.127
-Treatment control	3.78 (0.48)	3.38 (0.48)	0.0104
-Emotional representations	3.54 (0.67)	2.78 (0.87)	0.0503
-Illness coherence (or cause)	2.30 (0.62)	2.40 (0.56)	0.1448

The HADS scores for depression and anxiety for both the men on AS and SOs were relatively low (HADS-D mean score of 2.87(SD 4.32) for the men and 3.73(SD 3.15) for SOs; HADS-A mean score of

4.87(SD 4.02) for the men and 8.07(SD 3.64) for SOs), suggesting a low prevalence within this sample. The paired samples t-test showed SOs displayed significantly higher levels of anxiety according to the HADS-A (p = 0.035). Case analysis showed 1 man on AS (6.7%) and 3 significant others (21.4%) demonstrated significant anxiety scoring 11 or above. While none of the significant others individually displayed significant depression, 1 (6.7%) of the men on AS met the threshold.

SF-12 mean scores had the potential to range from 0-1, with scores closer to 1 indicating better health-related quality of life (HRQoL), and mid-range scores (around 0.5) indicating average HRQoL. Mean scores of the participants in this study suggest above average HRQoL with the men scoring an average of 0.73 (SD 0.13) and SOs scoring an average of 0.74 (SD 0.10), and the paired samples t-test showed no significant difference between the men on AS and SOs.

MAX-PC scores of 27 and above indicate significant levels of PCa related anxiety. The mean scores were below this threshold (15.08 for men on AS, and 22.00 for SOs) suggesting a low prevalence of PCa specific anxiety in this sample. However, reflecting results from the HADS-A, the paired samples t-test showed significantly higher levels of PCa specific anxiety in SOs than men on AS on the MAX-PC scale (p = 0.001). Case analysis revealed 20% (n=3) of the significant others scored above 27, suggesting high levels of PCa specific anxiety. None of the men met the threshold.

The published questionnaire scoring instructions for the CICS do not specify a cut-off score, however, the author advises a score of 16 or above is indicative of 'good illness-related couple communication' (information obtained through private correspondence with the author). Using 16 as a cut-off score it would appear the sample of dyads in the present investigation were experiencing sub-optimal PCa communication at the time of questionnaire completion. In fact, only two of the significant others met this threshold for 'good illness-related communication' with scores of exactly 16. None of the men on AS scored 16 or above. The paired samples t-test showed SOs rated illness communication significantly higher (better) than men on AS (p = 0.026), with mean scores of 12.60 (for SOs) and 11.07 (for men on AS).

Both overall, and within each subscale, higher scores on the RDAS indicate greater stability and satisfaction in a relationship, with lower scores indicating greater distress. The mean RDAS scores did not meet the overall threshold for distress (overall score of 47 or below), with a mean score of 50.51 for the SOs and 49.20 for the men on AS. The authors do not specify a cut off score for each individual subscale, however, the sample subscale scores do not appear to indicate distress. Scores of between 0-30 can be obtained for the 'consensus' dimension and this sample had mean scores of 23.80 for the SOs and 20.93 for the men. Scores of between 0-20 can be obtained for the ‘satisfaction’ dimension, and this sample had mean scores of 15.64 for the SOs and 17.00 for the men. Scores of 0-19 can be obtained for the ‘cohesion’ dimension, and this sample had mean scores of 11.07 for the SOs and 11.27 for the men. The paired samples t-test showed no significant difference between scores of men on AS and scores of SOs.

The Revised Family Response Questionnaire was completed only by the significant others. Originally, I planned to look for relationships between the results from this questionnaire and the results from the measures of psychological wellbeing using correlational analysis. Unfortunately, the study was underpowered due to the recruitment issues detailed above, and this was not possible. There are no published cut-off scores for this measure (confirmed by private correspondence with the author), however, the score for each subscale is out of a total of 40, with higher scores indicating an increased level of responses across each dimension. Without access to published cut-off scores, I am unable to classify the participants’ mean scores as ‘high’ or ‘low’.

According to the paired samples t-tests SOs scored significantly higher on the treatment control aspect of the IPQ-R ($p = 0.010$) suggesting greater perceived treatment control than the men. SOs also scored significantly higher on the emotional representations aspect ($p = 0.050$) suggesting stronger emotional reactions and concerns related to the illness. When looking at the mean scores for each dimension it is helpful to view these results with an understanding of where the mean scores are sitting (see section 7.3.2.8). Mean scores had the potential to range from 1-5, with ‘3’ sitting in the middle indicating responses of ‘neither disagree or agree’.

The differences reported by the paired samples t-tests must be interpreted with caution because the sample size is small and underpowered.

7.5 Discussion

7.5.1 Key findings

The findings from the current investigation suggest that these men on AS and their SOs did not demonstrate clinically significant levels of anxiety or depression, but SOs appear more anxious than their male counterparts. Levels of depression were higher in men who perceived more consequences as a result of the illness. SOs rated illness related communication higher than men, but overall there may be suboptimal illness related communication. Due to the small sample size and the fact the study is underpowered results must be interpreted with caution.

There were valuable lessons to be learnt in terms of recruitment; my recruitment methods were not an effective way to recruit from this population.

7.5.2 Reflections on the recruitment process

Within two months of recruitment commencing it became clear the recruitment target would not be met. In an attempt to boost recruitment, I asked PCUK to advertise the survey via twitter an additional two times, and PCaSO to re-advertise the study by email circulation. Unfortunately, this did not result in any extra participants. Recruitment through GP practices was considered, however, GPs within the department of Primary Care, Population Sciences and Medical Education at The University of Southampton advised the majority of patients on AS would not have AS coded on their notes, making a search using SNOMED codes futile. Placing myself in GP waiting rooms was also ruled out due to the large time requirement and likely very small gain. Recruitment through secondary care PCa clinics could have been considered; this would have required NHS ethics approval and a willing and able urology team within a secondary care setting. In hindsight, PPI could have been approached for suggestions to increase recruitment. Resources and time to explore other recruitment methods were limited. Shortening the questionnaire to reduce patient burden could have been considered, as could the use of incentives such as vouchers.

Participants were recruited through charities (PCaSO, PCUK and Tackle Prostate Cancer). This may have had implications for recruitment in a number of ways; firstly, patients involved with prostate cancer charities may primarily be those who have received active treatment (i.e., not those on AS). Secondly, recruitment through charities may have targeted a connected sample who had previously sought support from these organisations. On reflection, it may have been beneficial to recruit via NHS routes in addition to recruiting through the charities. It was difficult to gauge engagement through charity advertisements, and I was unsure of the numbers I was likely to achieve. NHS recruitment would have required extra resources and funding that was not available to me at the time, but it may well have improved the recruitment rate.

7.5.3 Strengths and limitations

The limitations to this investigation must be considered. The biggest limitation to the current investigation is the small sample size making the study underpowered and limits the conclusions I can draw from the results.

The potential sources of error in survey research are described in section 5.7.2. In relation to the present study it is important to consider the likelihood of a coverage error as recruitment may have missed individuals not engaged with PCa charities. Additionally, there were a few men with PCa who completed the questionnaire who were not on AS indicating a sampling error. The questionnaire asks men to list the treatment they have received for their PCa, and so were identified and removed from analysis.

An important limitation to this investigation is the lack of diversity within the recruited sample. The sample was highly homogeneous; all were in male-female spousal relationships and almost all were white British. Considering incidences of PCa in Black men are significantly higher than white men(351), a more ethnically diverse sample would be beneficial for generalisability purposes. The recruitment methods may have limited the diversity of the sample; the profile of those who are connected with charities (on charity mailing lists and following them on Twitter), may differ from the general population of men with PCa. There were some men who completed the questionnaire believing they were on AS, however, they stated they have received PCa treatment. This suggests a screening questionnaire prior to the main survey would have been beneficial.

The cross-sectional nature of this investigation, i.e., data in this study was collected at one timepoint, means the results provide a snapshot of participant thoughts and feelings. It is not possible to assess how the results may have changed over time. Previous research suggests those on AS feel heightened levels of anxiety around the time of progression check-ups(100), and psychological distress is highest 12-15 months post diagnosis(91). Results may have differed had the amount of time until the next check-up and time since diagnosis been controlled for.

The way I recruited meant I was unable to collect data on non-responders or assess response rates. Had I recruited via NHS routes response rates of eligible potential participants could have been recorded. In addition, this route would have allowed me to collect reply slips for those who did not wish to take part and subsequently improve understanding about what the barriers to participation may have been.

There are a variety of general limitations to research of this kind which cannot be explained by my chosen methodology. Previous research has shown those who are depressed and anxious are less likely to complete and return questionnaires than those who are not(352), suggesting the results generated in this investigation are likely to show an underestimation of psychological distress and may not be representative of generic AS patients. In addition, the self-selecting nature of participants in this type of research hinders the generalisability of the results. It may be that those on AS and their significant others who would not consider taking part in this kind of research would generate different results.

7.5.4 Findings in relation to previous literature

Previous literature exploring the psychological impact of negotiating the AS pathway is divided, with some studies showing this population experience heightened anxiety(80, 82, 83, 95), and others indicating men are not psychologically impacted(84, 85, 99). Although the sample in the current investigation was small, mean scores did not show high levels of distress, depression or anxiety.

Some previous research has suggested that partners of those on AS suffer higher levels of distress than the patients themselves(177). Although overall means did not meet clinical cut-off's, paired samples t-tests indicated SOs are more anxious than their male counterparts. Non-AS specific research mirrors these findings(147) suggesting partners of those on AS may have some emotional similarities to partners of those undergoing active treatment.

Results from the current investigation suggested participants’ illness-related communication between couples was sub-optimal.

7.5.5 Future research and clinical implications

Although this quantitative study did not recruit as planned, the process has provided valuable initial feasibility data on suitable combinations of questionnaires to gather the relevant data in this under-researched population and produced insights into how recruitment methods could be adjusted for a future larger feasibility trial. Future research should consider recruiting using a variety of methods, including NHS recruitment, and consider ways of reaching those who are less likely to take part in research with a focus on obtaining a more diverse sample.

Although the present investigation defined ‘significant other’ as a ‘close relative or friend’, all significant others were female spousal partners. Future research may benefit from the insights of other patient-significant other relationships (in addition to male-female spousal relationships), for example, male-male spouses, patient-adult child. Results from such research would provide insight into how responses from different types of SO may impact the patient, and how this interaction might differ depending on the relationship. Taking a network approach may also be helpful to explore the impact and influence of broader relationships and understanding the dynamics of peer support in this population.

As previous literature about the psychological wellbeing of men on AS is so mixed, the inclusion of a cohort of men on active treatment as a comparison group would be beneficial to future studies in this area. This would help to pick apart whether men on AS and their SOs have specific, different psychological support needs to those on active treatment, or whether existing support for those on active treatment needs to be more inclusive of those on AS.

On reflection, recruiting men (and their SOs) who had recently converted from AS to active treatment without clinical indication would have provided insight into the reasons behind conversion and the extent of SO involvement throughout this process. This would be a valuable next step to take this research forward.

Elevated anxiety is an independent predictor for opting for radical intervention in the absence of clinical evidence of disease progression(99, 194, 353, 354). In addition, there is research to suggest SOs influence treatment decisions(90, 310). Therefore, it is sensible to include SOs in clinical consultations to ensure they are correctly informed and on-board with the AS plan, and in addition, include SOs in any interventions to lower AS related anxiety. Further research is needed to determine how this might be achieved in clinical practice.

7.6 Conclusion

Although the sample was underpowered limiting meaningful conclusions, this research has provided some useful feasibility data on suitable combinations of questionnaires to investigate this area. It has also highlighted recruitment options that should be explored in further research. The participants in the present investigation were not significantly anxious or depressed but there may be an indication of suboptimal illness related communication. Further work to assess correlational relationships between SO responses and psychological wellbeing with a larger sample has the potential to provide useful data to inform clinical practice to support men on AS for PCa and their SO

Chapter 8: Qualitative Interview Study

With the intent to add context and meaning to the quantitative results, I conducted a qualitative interview study with a subset of participants from the quantitative survey study to further explore participants' experiences of PCa and AS.

8.1 Aims

The aims for this qualitative study are listed below.

Primary overarching aim:

1. To explore the experiences of men on AS for PCa and their significant others.

Secondary aims:

2. To explore how the significant other responses to the PCa diagnosis and AS treatment plan impact on the PCa patient.
3. To explore the way in which the dyads perceive each other's AS related feelings and reactions.
4. To explore the feelings of both the patient and the SO around being managed with AS.
5. To explore the way in which both the patient and the SO see the PCa treatment plan longer term.

8.2 Methods

If recruitment to the quantitative survey study was successful, and there was a large enough pool of participants, I planned to purposively sample the participants for the qualitative study to ensure a range of age, ethnic background, geographical location and time since diagnosis. The recruitment target for the qualitative study was set at 40 participants (20 dyads), however, this figure remained flexible depending on recruitment and the development of analysis. Participants were contacted by email or telephone to arrange a suitable time for a telephone interview to take place. All interviews were conducted by telephone, audio-recorded and transcribed verbatim. Transcripts were anonymised by removing all identifiable data, such as names and places. Each participant was made aware of this process and understood their data would remain anonymous throughout.

8.2.1 Semi-structured interview guides

I developed the interview guides myself with input and advice from a team of qualitative experts (Gerry Leydon: Professor in Primary Care, Lucy Brindle: Associate Professor in Early Diagnosis Research). In addition, two Patient Public Involvement (PPI) representatives, recruited from the charity Prostate Cancer Support Organisation (PCaSO), reviewed and approved the interview guides. Prior to developing these interview guides I had gained experience working on various qualitative projects both developing interview guides and conducting interviews. This experience gave me an understanding of how to gather the best qualitative data, for example, by ensuring my questions were open ended, using prompts to encourage more information and asking clarification questions when needed. The questions were open ended to allow the interviewees to share as much as they felt comfortable and to allow for a broad and detailed account to develop. Interviews were structured by the interview guide, but largely led by interviewees. Prompts and clarification questions were used to ensure all vital points were covered. When constructing the interview questions I considered the key areas that were not captured in depth by the quantitative survey data to fill in any potential gaps in my understanding. The interview guides were designed to explore the following topics:

- Involvement in the study and expectations
- Reaction to diagnosis and active surveillance treatment plan
- The significant other (i.e., questions around how they communicate with each other, and how their significant other reacted to the diagnosis and treatment plan)
- Further thoughts and anything to add

After each interview I listened back to the recording making reflections about how my interview technique could be improved and assessing whether adjustments needed to be made to the interview guide. Iterative changes were made where appropriate, for example, clarification questions or prompts were added where existing questions were not eliciting the intended details. See Appendix I for the full interview guides.

8.2.2 Qualitative sampling and analysis

See section 5.8, Appendix B, Appendix C and Appendix D for a detailed description of the qualitative sampling and analysis process.

8.3 Qualitative Study Results

Unfortunately, recruitment to the survey study was harder than anticipated and I was unable to purposively sample. Instead, I interviewed every participant who was agreeable. If one member of the dyad agreed to the interview and the other did not, I planned to go ahead with the agreeable partner and include their data, accounting for this in analysis. However, this situation did not occur and all interviewees were part of a dyad. All participants with PCa were on AS at the time of interview (i.e. they had not moved onto active treatment).

I conducted a total of 18 interviews with 9 dyads, all male-female couples, see Table 30 below for further characteristics.

Table 30: Characteristics of qualitative interview participants

Characteristics	**N**	**%**
Age		
• 51-60	3	16.7
• 61-70	14	77.8
• 71-80	1	5.6
Relationship status:		
• Married	16	88.9
• Partner unmarried	2	11.1
Employment status:		
• Retired	14	77.8
• Employed part-time	2	11.1
• Employed full-time	2	11.1
Ethnicity:		
• White British	17	94.4
• White other	1	5.6
Education level:		
• Left school before 15	2	11.1
• Completed secondary education	4	22.2
• College/specialised training	7	38.9
• University	5	27.8
Time between dyad interviews		
• 0 (interviews conducted directly one after the other)	16	88.9
• 7 days	2	11.1

Participant names have been replaced by pseudonyms in the results below to maintain confidentiality. All of the data in the results contribute to the understanding of the broad overarching primary aim exploring experiences of men on AS for PCa and their significant others. The results below are structured to facilitate understanding of the more specific aims (aims 2-5). I have provided a descriptive account of the participants' experiences.

8.3.1 Themes

Table 31 below provides an overview of the themes that developed throughout analysis.

Table 31: Themes

Group of themes	**Themes**
Exploring how the significant other responses to the PCa diagnosis and AS treatment plan impact on the PCa patient	PCa diagnosis reactions are complex
	Differing reactions to the diagnosis
	Concern for each other
	Putting on a brave face for each other
	Support two-directional
Exploring the way in which the dyads perceive each other's AS related feelings and reactions	Mismatch in perceptions of each other's feelings or saving face?
	Tensions in dyadic communication
Exploring the feelings of both the patient and the SO around being managed with AS	Living with uncertainty
	Men more concerned about treatment side effects than SOs
Exploring the way in which both the patient and the SO see the PCa treatment plan longer term	N/A
Results outside the secondary aims	Clinician interactions, and information and support received upon diagnosis
	Treatment decision making: patient-centred or clinician-led?
	Dissatisfaction with information received
	Self-initiated research

	Significant other involvement is crucial
	More support is needed
	What would help?
	Changes since the diagnosis

8.3.2 Exploring how the significant other responses to the PCa diagnosis and AS treatment plan impact on the PCa patient.

One of my aims was to explore how the significant other responses to the PCa diagnosis and AS treatment plan impact on the PCa patient. Even though the SO's reactions and feelings about the diagnosis and AS did not always match those of their husbands'/partners, overall, the men found the reactions of their partners appropriate and understandable. For example, when asked how Max felt about his wife's reaction he explained:

> *"I think it was positive, yes. I mean thinking of different scenarios, she could have fallen apart I suppose, which wouldn't have been very supportive at all, but no, she was – yes – she was supportive and positive about it, yes, definitely." (Max, male, 70)*

Mike (61) described feeling 'humbled' by his wife's response and reaction in a positive way.

Interviews with the men generally describe a story of 'togetherness' within the couples, and the partners' reactions seem only to have had a positive impact on the men themselves, with no hints towards the idea of the partners creating extra stress or pressure. Participants described two-directional support, concern for each other, and the notion of putting on a brave face for each other.

8.3.2.1 PCa diagnosis reactions are complex

Participants' reactions to the PCa diagnosis (for either themselves or their significant other) were tied up with a multitude of feelings. The overarching theme of shock, anxiety, distress and dismay hovered over most accounts regarding reactions to the diagnosis, but a tangled web of negotiating an illness as a couple showed a more complicated collection of thoughts and feelings mixed up in each individual's reaction.

8.3.2.2 Differing reactions to the diagnosis

Among couples interviewed it was common for each partner to have different reactions to the diagnosis. Stephen had been concerned he was going to be diagnosed with a higher grade, more aggressive cancer and describes feeling relief:

"I remember the day very well and I felt like it was a weight lifted off my shoulders – because it was – it was just … a very minor amount of cancer cells on the biopsy samples … and I thought, well, that's fantastic, nothing serious happening because that might never do anything that affects me." (Stephen, male, 62)

Stephen's wife, Sarah, felt very differently, partly due to her previous experiences with the disease as her own father had prostate cancer and died very quickly:

"my dad had prostate cancer and died very quickly, so … my reaction was less of a sigh of relief, more of a – oh my God – reaction." (Sarah, female, 66)

Similarly, Alex and Sophie reacted differently to the diagnosis. Alex felt the diagnosis was relatively minor compared to his other health issues:

"Well I suppose, particularly with all the other things, it felt like, in the scheme of things, it was actually – I wouldn't say trivial, but relatively minor compared with the other things and it seems that [at this early stage] that it was an early catch and therefore, you know, the prognosis was good. So from the beginning, didn't feel too bad, in the scheme of things, too bad." (Alex, male, 60)

Sophie however, felt very concerned and worried he should be operated on to remove the cancer straight away:

"I wondered whether they should do something straightaway – well – more – straightaway, the – you know – cut out all that." (Sophie, female, 60)

Mark had been conducting his own research prior to receiving the diagnosis and had become convinced the diagnosis was coming. He felt the process of gathering his own research and expanding his understanding allowed time for his acceptance of the situation to grow, and when the diagnosis came he did not feel shocked or surprised:

"Well I'd been sort of expecting it, because I'd looked up through all the different effects that it was having on me; I thought it's not just an enlarged prostate, it probably is something else… I just

[continued] to accept it in my own way, that that's what it was going to be, so I wasn't really surprised when they sat me down … and told me I had got it." (Mark, male, 64)

Mark's wife Mandy felt confused about the extent to which she should be concerned,

"it's difficult to say really, because – as I say – you've got different angles coming at you. So you don't want to be overdramatic but you don't want to be dismissive. So it's kind of – quite a fine line in between the two, really, and then – sometimes you fear the worst and then other times you're quite optimistic." (Mandy, female, 62)

The concern she felt was mixed with worry about how it would affect her, and guilt that she was worrying about herself rather than solely Mark:

"I found it difficult – you know – thinking about it, because ... it's not me that's got the problem, but, at the same time, it would affect me and then you start thinking, you know, you're being selfish and – so it's all sorts of thoughts." (Mandy, female, 62)

It is clear from these accounts the context surrounding the diagnosis impacts reactions. For example, whether the participant knew someone else who had PCa, whether they had ingrained opinions that cancer should be removed wherever possible, and whether they were expecting the diagnosis.

8.3.2.3 Concern for each other

Participants described many thoughts and feelings around worry and concern for each other. Ben explained a cycle of concern and worry that existed between himself and his wife Betty:

"she could see how I was handling or not handling it mentally and – that was causing – she was concerned and worrying about me and I was concerned and worrying about her. And we have an uncanny ability to transfer our emotions on to each other and sometimes… it really is uncanny about how one can impact on the other." (Ben, male, 78)

Betty corroborates this by explaining she finds it hard to see him anxious or upset:

"I would say that it's about the uncertainty, and difficult for me, seeing when he does get anxious about it or upset about it." (Betty, female, 66)

One of the wives described feeling very protective over her husband due to perceived poor care throughout the diagnosis period:

> *"I hate to see somebody not listened to; I hate to see somebody disempowered, whether that's through their own condition or through outside lack of awareness or taking advantage. Yes, I guess protective, very protective – sums it up." (Sue, female, 54)*

8.3.2.4 Putting on a brave face for each other

Sophie describes trying to mask her concern in front of Alex, feeling that she needed to support him:

> *"Well obviously I was upset for him. I tried to support him best I could and tried to show that I wasn't – you know – too worried; tried to support him. But again, you know, I mean it's hard isn't it, because you don't know if it's going to flare up or get worse or whether it's going to go on like that for years. So it's always hanging over you, isn't it?" (Sophie, female, 60)*

8.3.2.5 Support two-directional

The idea of the significant other staying strong and / or positive for the patient was not one directional. It was common for the men with the diagnosis to be the support for the significant other too. This was true for Mark and Mandy. Although Mandy feels the need to be strong for Mark and refrain from displaying too much emotion about the situation, she feels that Mark has been the one to support her, rather than the reverse:

> *"I think he responded very well. I think perhaps he's been a bit more supportive of me than ... he's been very reassuring most of the time; it's only now and again he gets a bit cross and a bit angry, and it's the – why me – sort of question that you're asking yourself. But, yes, I think he's perhaps been – I think he's been very positive; he's been more positive than I would have been." (Mandy, female, 62)*

The accounts provided by participants above suggest cohesive relationships; although they often describe different reactions to the diagnosis, they pull together, worry about each other and support each other.

8.3.3 Exploring the way in which the dyads perceive each other's AS related feelings and reactions.

8.3.3.1 Mismatch in perceptions of each other's feelings or saving face?

In addition to exploring the feelings of individuals, perceptions of partner feelings around both the diagnosis and idea of AS were explored. Some participants described each other's reactions and feelings accurately, mirroring how the other described their own feelings. For some however, a mismatch became apparent. For example, Dan describes feeling ‘dismay’ at the diagnosis, however, Emma describes his reaction differently:

> *“he’s incredibly broad shouldered and has dealt with all sorts of different crises … I felt he responded to this in his characteristic way, just with – without getting, you know, over – overly worked up about it.” (Emma, female, 67)*

It is difficult to attribute reasons to this mismatch. At face value, it seems Emma did not see Dan’s dismay, either because he’d hidden it, or she misinterpreted his reaction. Or, Emma may have felt unable to share this part of Dan’s reaction during the interview, so as not to break his confidence.

A mismatch also arose with Mandy and Mark. Mandy describes her husband Mark as ‘very angry’ with the diagnosis. Mark described himself as ‘unsurprised’ and ‘accepting’ at the point of diagnosis. Again, perhaps Mark did not feel comfortable sharing these feelings of anger in the interview, or he may have forgotten this part of his reaction, or in fact Mandy may have misinterpreted his reaction.

8.3.3.2 Tensions in dyadic communication

The majority of couples in the study described contentment with their PCa related communication, feeling they could discuss their feelings as much and as openly as they wanted to. However, this was not the case for every couple.

Sophie describes her husband Alex as a ‘strong man’ who does not talk much about his PCa related feelings. She tries to talk to him about it, more than he talks to her, and she wishes he would start the conversation off sometimes. Alex on the other hand describes not talking much about it because he feels there is not much to discuss:

> *“In truth, we haven’t discussed it a heck of a lot but, you know, I don’t think there’s a heck of a lot to discuss.” (Alex, male, 60)*

Mandy finds it difficult to talk about her feelings and tends to bottle things up. Although she’d like to be better at talking to Mark about the PCa, she also feels the need to remain strong for him and sees a conflict between these two desires:

> *“I don’t want to be crying and weeping and getting all emotional because I think I ought to be – try, you know, to not be, for Mark, because he’s the one who’s got – if anything needs to be done, he’s the one who’s going to have to have it done.” (Mandy, female, 62)*

It seems Mandy feels she has less of a right to be distressed about the PCa because she is not the one with the physical illness. Instead, she feels it's more appropriate to keep her feelings hidden, and remain strong.

It seems another barrier to communication can be the sensitivity of certain topics, for example, the impact PCa has had on a couple's sex life. Alice finds it hard to know how to best handle the negative sex-related side effects that have arisen as a result of PCa. Although she feels she needs to discuss the issue with Matthew, she is reluctant to do so in case it applies pressure. She fears making the situation worse, and feels unable to voice her concerns:

"(it) feels as though you're making matters more difficult by talking about it, rather than clearing the air, which is the wrong thing to do, I know, but I don't know." (Alice, female, 67)

She goes on to explain she can accept the situation, but feels it has caused an issue between them:

"it is – not an issue for me but I think it is an issue between us, if you know what I mean. And I think it's probably an issue for Matthew, as well. I can just sort of accept the situation but I think he feels uncomfortable and, again, we really should talk about it." (Alice, female, 67)

Matthew did not mention this topic in his interview and described feeling satisfied with PCa related communication between himself and Alice. The reason Matthew did not disclose this issue is not known; it may be that he did not feel comfortable discussing something so private in an interview situation, or perhaps for him the sexual side of things is not a concern.

8.3.4 Exploring the feelings of both the patient and the SO around being managed with AS.

8.3.4.1 Living with uncertainty

Proceeding with AS can evoke feelings of anxiety and uncertainty. Alex claims to not find AS associated uncertainty a problem, but his wife Sophie finds it hard and explains:

"I mean it's hard isn't it, because you don't know if it's going to flare up or get worse or whether it's going to go on like that for years. So it's always hanging over you, isn't it?" (Sophie, female, 60)

The majority of the couples find living with AS related uncertainty difficult, with some describing AS like being on a rollercoaster. Anxiety builds up in the lead up to a check-up, with couples becoming increasingly worried the cancer may have progressed. If positive results (positive news) come back there is a drop in anxiety, which then starts to build again before the next set of tests. Jan explains:

> *"Well it is something that you can never actually escape from; like the other night he was saying, when was the last blood test, when have we got to organise the next one? So it's always in your head; every three months, it comes up very quickly" (Jan, female, 61)*

8.3.4.2 Men more concerned about treatment side effects than SOs

Choosing the AS treatment pathway brought about a new wave of feelings and concerns for each couple. Some couples felt differently about the decision to monitor the cancer rather than intervening, for example, Mark was keen to proceed with AS, whereas his wife Mandy felt opting for surgery would be more sensible. These differing feelings for this particular couple were perhaps driven by differing levels of concern regarding active treatment side effects. Active treatments such as surgery and radiotherapy come with risks such as erectile dysfunction and urinary incontinence. Mark explains:

> *"… radical surgery or radiotherapy, I think that's something I'm hoping to avoid and I'm pleased that I'm on active surveillance because I'm hoping that it will stay like that, because I am worried about the side-effects if I have either of those treatments – or any of the alternative treatments, which I know are available." (Mark, male, 64)*

Mandy however, views Mark's survival as the priority and is less concerned about the possible side effects of intervention:

> *"the only thing I've ever said to him is that, if he needs to have treatment, I'd rather he have it, I don't care what – as long as you're here, does it really matter? We can manage." (Mandy, female, 62)*

Similarly for Bridget and Max, Bridget is not worried by the possible side effects:

> *"I would have said, well probably it's best removed, but I know that causes a lot of problems and Max would do anything to have that avoided, because he's heard so many stories and it wouldn't bother me either way… So if they took it out…then he may become incontinent, I understand that – and all the sort of sexual parts of it. I don't know whether you've had children, but once you've had children, you've lost all sort of sense of modesty, it's just a slab of meat on a butcher's slab, isn't it? I can't get excited about that. People are so funny about it, but – you know, it doesn't bother me." (Bridget, female, 69)*

As demonstrated in the quotes above the male participants show more concern about losing sexual function than their female partners. The men were less inclined to openly talk about this in the interviews. There may be fears about a reduction in masculinity attached to this topic and perhaps is something that is difficult for the men to verbalise outside of their relationships.

8.3.5 Exploring the way in which both the patient and the SO see the PCa treatment plan longer term.

There were large differences in the way participants saw the future of their PCa and treatment plan. Some expressed a belief they will stay on AS, and nothing will change, others believe intervention at some point is inevitable. Others sit in the middle, feeling unsure what the future will bring and willing to be guided by future test results.

When asked about the future Ben (78) responded simply by saying he felt the situation would remain as it is, and he will continue on AS. At the other end of the scale Alan feels inclined to believe that AS is a temporary measure and radical intervention is inevitable. For him, he feels the time to leave AS will be relatively soon:

> *"Well I'm thinking the number will probably go up and I'm thinking I'll probably have to go and get some treatment done this year; that's the awful truth." (Alan, male, 62).*

Somewhere in the middle, Matthew and his wife Alice are hopeful they can continue on the AS pathway but are unsure what will happen. When considering how the situation may change Matthew makes reference to both the medical progression of his cancer, and his emotional capacity to cope with living with an untreated cancer:

> *"I'd be more than happy to stay on active surveillance unless there was any change in my – circumstances, in terms of how I feel; both in terms of the medical condition and mentally. If I started to get concerns about this and – started worrying about it, then I think I'd have to review the position and see, you know, is active surveillance the correct route for me to be on." (Matthew, male, 67).*

Both Mark and Alex described a hope that new treatments may become available before the need for them to leave AS:

> *"I don't do much research but I do a lot of – just browsing on the web and keep referring back to Prostate Cancer UK website to see if there are any more developments, because obviously there are more treatments coming out and maybe in the near future. So therefore my preconceived idea of what I want may change if something radically different comes [along] and if the NHS were a bit slow to take it up, I might decide that - can I go privately and have something done." (Mark, male, 64)*

> *"I suppose partly my age, I'm not all that old, hopefully, at 60, that who knows what other treatments might be coming along in the next 5 or 10 years, that may be easier, better, whatever, have better outcomes, or even better outcomes, shall we say and – so there just doesn't seem to be any need to rush towards one of the other treatments, at this stage." (Alex, male, 60)*

Experience of others with PCa, and other contextual factors such as how the illness and its likely progression has been communicated by medical teams will all contribute to these differences.

8.3.6 Results outside the secondary aims

The next part of the results describe findings which fall outside of the specific secondary aims (aims 2-5). As explained above, all results contribute to the main overarching aim exploring experiences of men undergoing AS for PCa and their significant others.

8.3.6.1 Clinician interactions, and information and support received upon diagnosis

Understanding the participants' interactions with their clinicians, information the participants received and the support they were offered upon learning their diagnosis helps to add context to their feelings around their diagnosis and treatment plan.

8.3.6.1.1 Treatment decision making: patient-centred or clinician-led?

Roughly half of the participants felt their treatment pathway was decided solely by their consultant or medical team, with the other half feeling the AS pathway was a joint decision in which they were involved. Ben describes his experience:

> *"well I wasn't involved at all; I was just told, well, we think you're suitable for active surveillance. I mean – that decision, okay, clinically it may have been very obvious. From my age, my PSA results, the results of the biopsy; for a clinician, that may have been very clear and it was probably, probably it was, and is, still the right decision, but I played no part in it." (Ben, male, 78)*

Although Ben and his wife Betty felt they played no part in the decision to pursue AS, they agreed with the consultant it was the best way forward and did not verbalise discontent with the way the decision was made.

Sue and Mike also reported treatment decision making was conducted in a clinician-led manner, but they felt differently to Ben and Betty, feeling angry at the way the situation was handled:

"Had it been properly explained, had time been taken to say, look, you know, there are all these options; there's also the option of doing absolutely nothing right now and going home and talking it over with your partner. That would have been fine. As it was, it was incomplete information, it was very badly presented and it was not something Mike would have chosen and didn't at the time, and still doesn't. Again, care is supposed to be patient-centred and empowered and ultimately, you know, no decision about me, without me; that was completely and utterly ignored. He might have come to a fear-based decision, had he been by himself but – yes – it was very, very badly done and not suitable for him, as an individual. It didn't take into consideration what he might like or be happy with; so it was a box which he didn't fit in and that box wasn't even explained prior to being offered." (Sue, female, 54)

At the other end of the scale, Alex felt frustrated with the extent to which his consultant left the ball of treatment-decision making in his court, and really craved some clear advice about which route to take:

"Well, course, these days it's seems it's so difficult to get the consultant to actually advise you what to do, at all. So – which actually I found a little bit frustrating, because the pros and cons of the different options are obviously very significantly different, but I did find it very difficult to try and compare… So the first consultant I saw told me that I'd got the cancer, gave me really no guidance at all, it's much more just – this is a situation, these are your choices, which are – several choices active surveillance, to radiotherapy, to a full [prostatectomy] options… They gave me – here's a leaflet, here's your options, let us know what you want to do." (Alex, male, 60)

Also describing his treatment-decision making as patient-centred, Dan felt differently to Alex and appreciated his freedom to choose:

"He was helpful – because he offered me everything really from radical surgery through to radiotherapy, through to – referral, whatever it is; he offered me the range of stuff. But there, lurking at the end of the range of stuff, was the active surveillance… you know, he didn't recommend anything; he laid me out the spectrum of treatment that he reckoned I was eligible for and active surveillance was there at the end." (Dan, male, 70)

8.3.6.2 Dissatisfaction with information received

The majority of participants felt some level of dissatisfaction around the information they received at the point of diagnosis. Stephen and Sarah received a large bundle of information through the post after diagnosis and felt the large quantity, leaflet content and delivery mode of the information was inappropriate and could have been done better:

> *"I got the diagnosis and then a few weeks later there was a large parcel through the post which – was actually a bit alarming really, because there was a whole bundle of books, one of which was how to get my affairs in order, ready for dying, really, and I think without any explanation whatsoever. I think it was just a little bit blunt to have sent them all for through post like that." (Stephen, male, 62)*

Alex describes receiving PCUK leaflets, but wanted something to help him compare treatment options, and felt none of the information met his needs:

> *"I think when I originally saw the people in xxx, they xxx sent me leaflets from the – Prostate UK or whatever xxx, lots of leaflets, I think. So xxx leaflets which, again, are quite good but xxx try to compare, I found the most difficult thing. So I also had a chat with the Prostate UK people, but, to be honest, I didn't really get a lot from them because I don't think there was much more xxx already got it from the leaflets from them, in any case, at that point." (Alex, male, 60)*

8.3.6.3 Self-initiated research

It became clear that many of the men were conducting their own research and seeking information about their condition from sources other than their medical team to fill in the gaps. For Mark, his self-initiated research guided the type of tests he requested:

> *"Immediately I started reading articles on the internet myself, and Prostate UK and Cancer Research and so on; so I did that myself…I went for the trans perineal option; I started reading about it, I wouldn't have known about it had I not gone on the internet." (Mark, male, 64)*

None of the significant others were given information directed towards themselves, but all looked at the information given to their partners, and one significant other described conducting her own research:

> *"I work in cancer support myself, so I've got a little bit more overview and I've done hours and hours and hours and hours of research over the last year; so, yes, that's become not secondary, but less alarming" (Sue, female, 54)*

8.3.6.4 Significant other involvement is crucial

Universally all participants agreed that SO involvement in the PCa journey is necessary and important. There was some feeling that SO involvement was most important for treatment decision making, although the final decision needs to be that of the patient. The way in which significant others were involved varied from couple to couple, for example, for some it seemed the SO was driving the process (encouraging their husband to go for investigations, keeping track of PSA results, organising and initiating appointments) whereas for others, the SOs were more in the back seat, taking the lead from their husbands.

Level of content with level of SO inclusion

Generally, dyads were satisfied with the level of SO inclusion in their PCa journeys, however, there were feelings of discontent described by some. This discontent sometimes stemmed from the level of inclusion (or exclusion) demonstrated by the PCa patient, and sometimes it stemmed from the seemingly reluctant inclusion of SOs by healthcare providers. Most SOs reported attending appointments, however, for one couple the man prefers to go alone, causing tension:

"Sophie: He likes to do it on his own. I will go if he wants me to, I'd be happy to go, but he likes to go on his own. And I take him in the car if he needs to be driven, but usually I wait outside. I think if it was worse, he'd let me in with him, but he goes on his own.
Interviewer: And how do you feel about that?
Sophie: Again, I'd quite like to be in there with him but it's his choice." (Sophie, female, 60)

The amount SOs are included is a very personal preference, and when there is a mismatch in preferences for inclusion within the couple it causes conflict.

Sue and Mike felt dissatisfied with the level of SO inclusion by healthcare providers:

"Yes, I'm his advocate, if anything. I was never asked, I was never even considered, he was never even asked – have you got a partner, I was not asked my name at the results appointment; I was not asked who I was, I wasn't offered a chair... That's not how people should treat each other, let alone medics to vulnerable patients. So 120% crucial." (Sue, female, 54)

For Sue and Mike SO involvement was especially important because, as Sue explains, Mike suffers with Post Traumatic Stress Disorder (PTSD) and needs an advocate. It seems this was not taken into consideration throughout Mike's diagnosis period:

"I don't know how familiar you are with PTSD, but it can manifest in all sorts of ways; he's somebody who acquiesces very easily, because it's the path of least resistance and he almost disappears sometimes, as an individual, when put under pressure. So I think that's what happened, largely and, yes, he needs an advocate; he needs somebody to sit and he would just establish what it is he might like and want and that wasn't offered, that wasn't there. I've had to fill that role and it's been bloody hard, every step of the way has been a battle, even just getting to speak to relevant people, establishing who is in charge, establishing how we can talk to them." (Sue, female, 54)

Sue and Mike were not the only couple to describe dissatisfaction with the level of SO inclusion by healthcare professionals, and Jan felt unwelcome in the department while Alan was taken for his biopsy:

"I went up to the ward with him when he was going to have the biopsy and they said, oh right, off you go, you're not needed here now. And that I didn't like; I would like to have been able to stay in that area and read, rather than feel – I better go shopping" (Jan, female, 61)

8.3.6.5 More support is needed

Many of the participants felt their support needs were not met. Although most were given leaflets to take away from clinic, participants often described feeling lost between appointments. Mark explained that it's hard to ask all of your questions in the context of an appointment where anxiety might be running high and there are time pressures:

"Of course, at the time you're there, because it's done so quickly, you can't think straightaway because you don't know to ask, I suppose; that's the only problem. It's after you've gone, you realise, oh I wish I'd asked this, I wish I'd asked that. Why didn't they tell me this?" (Mark, male, 64)

Inadequate access to a Cancer Nurse Specialist

The majority of participants felt the support offered post-diagnosis was inadequate. Interviews revealed a dissatisfaction with access to a Cancer Nurse Specialist (CNS). Some couples were not aware of an allocated CNS, or there was a delay in allocation, or they had an allocated CNS but they were uncontactable. Stephen and Sarah were allocated a CNS, but the relationship broke down early in their PCa journey:

"Well I have got one allocated, but I've never met him and the only time we spoke was when I had that new diagnosis that I wasn't informed about, when I started asking questions about why I hadn't

> *been told and he got very aggressively defensive, so we don't speak really… So it does feel like we're off out on a limb, not really knowing what's happening between those three monthly spells." (Stephen, male, 62)*

Consequently, the couple feel rather alone without a professional point of contact. Sarah explains that following Stephen's initial interaction they found it difficult to reach the CNS:

> *"Even in the early days when we wanted to contact him, you couldn't get hold of him, he was never there. So I think that needs to be addressed, that professional support needs to be improved." (Sarah, female, 60)*

Sue describes a similar story in relation to their allocated CNS:

> *"So, yes, going round in circles and no contact numbers and the clinical nurse specialist exceedingly difficult to contact. When we did contact her, she did not seem to take on board that Mike has got both memory and hearing trouble, as well as suffering PTSD, which was down on his referral letter, which was marked non-urgent and refused to, first of all, conduct any further communication by email, said, no, we can't do that; refused to send us the pathology report of the PSA graph. She did retract that eventually and then it was, oh, of course we'll – we can email you but, yes, unhappy story, a very unhappy story." (Sue, female, 54)*

Dan and Emma also found the CNS support system did not work, and feel a better relationship with the CNS would have been beneficial, but Dan feels AS patients are probably far down their list of priorities as they are dealing with 'iller people':

> *"The bit of support that hasn't worked… is what do they call it – key worker (CNS). Technically I haven't met him; there's a nurse at [city] who is supposed to be my first port of call and know all about me, but he doesn't know me from Matthew. He's dealing with iller people, I'm sure, than I and actually I think I feel slightly embarrassed ringing him up because he'd have to wrack his brains to try and work out who I was, or pretend to remember." (Dan, male, 70)*

Although most reported teething problems as a minimum, some couples had more positive experiences with their CNS. Jan and Alan were not allocated a CNS until 4 years after Alan's diagnosis, but once they were, Jan found it helpful to have somebody to call with PCa related queries:

> *"it wasn't until later that I realised we'd not been given a cancer care nurse and whether that was – well I don't know why – but we didn't get one, so I felt we were sort of dealing with it a bit on our*

own. That’s helped because you’re just talking to somebody without having to go to hospital to discuss things; that’s much better.” (Jan, female, 61)

Despite the CNS allocated to Ben and Betty being on holiday at the time of diagnosis, she became a supportive and beneficial support:

“maybe a couple of weeks later, Ben got a phone call from a very nice specialist nurse at the hospital where he was diagnosed and I think it was just a blip at that time, because she had been on holiday. So otherwise she said he would have been given her name right away and I think that would be helpful. After that she was very, very helpful and that was open to me, if I wanted to speak to her.” (Betty, female, 66)

PCa charities provided valuable support

Some of the couples interviewed sought support from PCa charities and found the support they offered helpful and valuable:

“I have to say – the charity [Macmillan] were very supportive... They were actually very supportive in saying – if you’re finding it tough, if you’re needing any support, we have specialist nurses available to talk to, that sort of thing.” (Ben, male, 78)

There was a feeling that the specialist nurses were more accessible than those allocated to them by their medical team:

“Certainly the specialist nurses at Prostate Cancer [UK] were very, very helpful; I phoned them on a few occasions and they've been excellent. And they’ve got urology nurses that the hospital who, again, has been very good in basically answering any questions and any concerns.” (Max, male, 70)

8.3.6.6 What would help?

Although most couples felt the need for some additional support, not all felt that way. Matthew describes feeling confident in conducting his own research and explains he has not needed anything extra at this point. However, if the need to make some treatment decisions arises, he feels it would be useful to have a point of contact with whom to discuss various options:

“I felt okay – doing my own sort of research reading, but that’s just my approach and that wouldn’t necessarily suit other people. So it suits me; I’ve not needed to chat to someone to make informed decisions as to whether we go down the surgery route or chemo or radiotherapy. It’s never – that’s

> *never been particularly high on our sort of – list, really. But if I was in that position, then maybe I would feel that it would be really useful to have a chat with someone, but I've never felt that I've been in that position of having to get further support." (Matthew, male, 67)*

From a practical point of view there appeared to be a clear need for more guidance during the process of treatment decision making:

> *"I just would have expected the system to – have been able to – because, you know, they're dealing with people like me all the time, so they know the questions I should be asking, because – I don't even know the questions to ask, to some extent, in the first place. So – yes. So, because of that comparison, so because – I suppose – it listed different treatments, the pros and cons are quite different, it is difficult and it will probably vary from person to person and depending on their age and their health and various other aspects, I guess as to – so – it's not easy probably to do that comparison. But that's definitely the one area where I would liked to have seen something more." (Alex, male, 60)*

In addition to the lack of practical support and guidance, some described the need for additional emotional support. However, views about how this support should be delivered were mixed. Opinions about support groups were divided. Any existing support groups offered to the participants were not specific to AS, but rather PCa in general. Although many concerns may overlap, men who have undergone active treatment, and those on active surveillance have different supportive care needs, and groups specific to AS were not available to the participants. Max attended a support group, but found he was the only one on AS:

> *"I think I was a little bit sort of on my own there, on the active surveillance, because I think what happened was that they had a contact with the hospital and men then, who had gone through various treatments and so on, were given the support group details for them to join if they wanted to and get help that way." (Max, male, 70)*

Max feels those on AS are somewhat overlooked, and a support group specifically for those on AS has not been considered:

> *"Active surveillance tends to be a little bit glossed over, in other words it's summed up in a few words, in the sense that you're given a blood test every 3 - 6 months and then we're just keeping an eye on you." (Max, male, 70)*

Max’s wife Bridget feels joining a support group is the most important thing men on AS and their partners can do for their psychological wellbeing:

“You need to get a support group, which is the most important thing, I think, because then they don’t feel alone and wives go along, some of the wives go along and they can see that it’s just – it’s just a medical thing; it’s not personal, it’s not sexual and all this business, it’s just a thing that people have information to share. And it becomes a much more manageable thing, if you like and it’s seen as, you know, commonplace almost, rather than something people get all embarrassed about talking about.” (Bridget, female, 69)

Support groups did not appeal to all participants, and Ben demonstrated a clear dislike for the idea:

“I was not inclined to go along to a session with other men and talk about prostate cancer in detail.” (Ben, male, 78)

Instead, Ben felt it was better for his own psychological wellbeing to take a practical, proactive approach and help other men in similar situations by volunteering for PCa charities:

“I said I don’t want to sit there with a bunch of men who are all talking about their prostate cancer, I want to think about other things… as I got over the anxiety part of it, I decided, no, I did want to put something back, but because I was volunteering for Prostate Cancer UK, it meant that I wasn’t – I wasn’t sitting with a group of men, talking about prostate cancer; I was supporting people who had recently been diagnosed or were in the process of going through the pre-diagnosis stage. So I was doing telephone support for people who were being offered the option of active surveillance and I was also doing telephone support for those who had been on it but just wanted to talk a bit more about it and I found that okay.” (Ben, male, 78)

It is interesting Ben did not want to seek external support for himself, but providing support to others in a similar situation is something he wanted to do. It may be that these interactions are acting as peer support for himself, but framing it as ‘helping others’ is more acceptable to his own sense of self and identity.

8.3.6.7 Changes since the diagnosis

Diagnosis has inspired attitudinal changes

According to participants, being on the AS pathway has not resulted in any drastic changes to their day-to-day life, apart from some reported efforts to improve lifestyle, by eating healthier and moving more:

> *"I was already healthy eater but I've become even more aware of what I'm eating." (Mike, male, 61)*

However, changes in attitude and outlook did arise. Emma and Dan feel the diagnosis has given them both an increased awareness of their mortality and brought them closer as a couple:

> *"Well I suppose, you know, when you're faced with something that speaks of mortality, ultimately – you know – either frightens you or brings you closer together or – and I think, on balance, it's sort of brought us closer together" (Emma, female, 67)*

Mandy feels the diagnosis has made her see that life is too short to argue, and Bridget describes a new desire to make the most of life.

8.4 Discussion

8.4.1 Key findings

The thoughts, feelings and actions of men on AS for PCa and their SOs are intricately intertwined. While reactions within couples often differed, all participants seemed understanding and accepting of their partner's reactions. Feelings of concern for each other and the notion of 'putting on a brave face' were expressed by both the men and their partners and similarly, support was two-directional. Although most men and their partners said they were content with AS, feelings of anxiety were often expressed, and many found living with uncertainty difficult. PCa and AS related communication within dyads was largely satisfactory with only a few mentions of tensions or the desire for better communication. All felt significant other inclusion in all aspects of the PCa and AS journey was crucial.

The decision to pursue AS was sometimes clinician-led and sometimes a joint decision between clinician and patient, with clear alternate options. The information received at the point of diagnosis was mostly in the form of leaflets. Participants felt the leaflet volume and sometimes content was inappropriate with some receiving a large bulk of printed leaflets containing information about 'getting affairs in order' ready for end of life. Many conducted their own research to broaden their understanding. Generally, there was a feeling that more support from a trained professional, especially in the early days of diagnosis, would be beneficial. There were concerns voiced about the cancer nurse specialist (CNS) system with some unaware they had a CNS and others unable to reach them. It seems the CNS would have been ideally placed to provide the desired support, had they been accessible. Feelings about AS specific support groups were divided with some finding the idea strongly unappealing and others feeling they would be beneficial.

8.4.2 Strengths and limitations

The current investigation provides a novel insight into the experiences of men on AS and their SOs. However, there are some limitations to be considered when addressing the relevance of the findings.

My reasons for interviewing dyads separately are listed in section 5.8.2 however there are limitations to this approach. Firstly, no direct observations of couple interaction which may have been captured in a joint interview could be captured with this approach. In addition, as discussed above (section 5.8.3), interviewing separately increases the complexity of maintaining internal confidentiality.

It is important to consider the self-selecting nature of the participants included in this study. Our results revealed a level of 'togetherness' with couples demonstrating two-directional concern and support for each other. It is possible participants who felt less 'togetherness' in their relationships may have been less willing to take part in a dyadic interview study. Similarly, it is possible those who were more highly anxious, or those who perceived themselves as not anxious at all may have been less likely to agree to be interviewed. Participants interviewed in the current investigation were mostly open and willing to discuss the psychological and emotional impact of being on the AS pathway. According to previous literature older male medical patients, including those with PCa, are traditionally reluctant to discuss their psychological wellbeing(63, 64), indicating this may be another characteristic stemming from the self-selecting nature of this sample.

Data in this study was collected at one timepoint and therefore it is not possible to assess how AS related experiences and feelings may change over time. Participants described feelings of heightened anxiety around the time of AS protocol clinical tests. It is possible participants about to undergo some routine tests may have answered the questions differently to how they would have answered if I had interviewed them equidistant between progression checks.

All participants were on AS at the time of interview, and had not left AS for active treatment, therefore, experiences of and reasons for leaving the pathway could not be explored. All participants were part of a dyad. Interviewing participants who were not part of a recruited dyad (for example, if only one member of the dyad agreed to take part) may have provided extra insight.

Recruitment of dyads who took part in the quantitative study was a pragmatic decision, i.e. the quantitative survey provided a pool of eligible dyads negating the need to re-advertise and consent new participants. However, recruiting in this way may have resulted in a smaller number of willing participants, and advertising separately for people to take part in interviews alone (without a survey) may have resulted in a larger sample size. Interviewing dyads was valuable for analysis in terms of comparing and contrasting dyadic accounts, however, recruitment of individual men on AS, and SOs of those on AS may have added valuable information, and an increased volume of data.

I asked participants to recall their feelings and reactions to the diagnosis of PCa and introduction of AS retrospectively. For some this may have been many months or even years before the interview and this time-lag may have had an impact on their recollection. Difficulty in recruiting into the study did not allow me to choose participants based on time since diagnosis. To allow for a more accurate account a prospective methodology would need to be utilised with recruitment of patients recently placed on AS.

The lack of diversity within the recruited sample is an important limitation. All participants were in male-female spousal relationships, and experiences may be different for example, for those in same sex relationships, or those whose SO is an adult child or other relative. Participants were aged mostly 61-70 (77.8%), which reflects the age in the general AS population(355). A more ethnically diverse sample would have been beneficial for generalisability purposes. The chosen recruitment method may also have impacted the generalisability of the sample as those connected with charities may differ from the general population of men with PCa. Due to the smaller than expected sample size in the quantitative study I was not able to purposively sample participants for the interview study, limiting my ability to improve the diversity of the sample. The results present a descriptive account of the participants' experiences. With more time, resources and a larger and more varied sample size, a more interpretive account would be the ideal next step.

A strength of the current investigation is the way it provides a novel insight into the complexities of undergoing AS for PCa as a dyad. While previous literature has explored SO experiences of men with PCa(114, 115), there is a lack of research exploring these experiences specifically for those on the AS pathway. Furthermore, no previous literature to my knowledge explores the complexities within the dyads on the journey, for example, how they feel about each other's reactions and the impact their reactions and responses have on each other.

Another key strength is the transparency of the research processes. I followed a grounded, inductive approach to data analysis, remained reflexive throughout and discussed implications of my own previous knowledge and previous knowledge within my supervisory team. My supervisory team double coded approximately 10% of the transcripts and were consulted throughout the analytical process to ensure consistency and agreement within data interpretation.

8.4.3 The findings in relation to previous literature

The findings in the present investigation demonstrating the high level of involvement and importance of significant others replicate findings from previous qualitative findings(84, 85, 142, 310). Previous research has shown that partner support (along with one-to-one peer support) are the most valued forms of support for men with PCa(356), and the current investigation supports this notion. The findings in the current investigation go one step further and found this support was two-directional within the dyad, with the men on AS often supporting their partners, and often ‘putting on a brave face’ for those close to them.

Although as a qualitative study it is not possible to quantify psychological wellbeing, feelings of anxiety and discomfort around living with an untreated cancer were expressed. The AS protocol requires patients to undergo investigations such as PSA tests, biopsies and MRI imaging at certain time points following diagnosis. Previous literature has documented a pattern of increased anxiety around the time of such tests (97, 357) which was replicated in the findings of the current investigation. The current findings indicated this pattern of anxiety is not only present in the men undergoing the tests, but the feelings are replicated in those closest to them.

The qualitative synthesis I conducted as part of this PhD project (Chapter 6) found a lack of references to changes in everyday life, with only one participant describing a ‘grouchier’ disposition(80), and another expressing concerns about the impact on his sex life(309). As stated in the synthesis discussion (6.6) it was thought this was perhaps because being on the AS pathway has little impact. However, as the studies in the qualitative synthesis did not report any explicit exploration of the broader impact of being on AS it was not possible to draw any evidence-based conclusions. In the current investigation participants were asked explicitly about any changes that have occurred since the diagnosis. The question was framed in an open-ended way, and it was explained changes could be positive or negative. Participants described increased efforts to live a healthier lifestyle, and positive attitudinal changes stemming from an increased awareness of mortality and a reminder ‘life is too short’.

Previous literature exploring the need for extra support in the form of cancer support groups has demonstrated a divide between men on AS and their partners; the men on AS expressing a clear dislike for the idea(97, 312); and partners feeling they may be valuable(149). Although the current investigation did not show such a clear male/female divide, feelings about support groups were mixed, with the majority of men against the idea. Conflictingly, despite men on AS consistently describing a dislike of ‘support groups’ in both previous research(312) and the current investigation, they also consistently place value on the idea of discussing PCa related issues with men who have similar experiences with PCa(310). This suggests perhaps their feelings stem more from the stigma attached to the term ‘support group’ rather than actual activities undertaken within these groups.

Cancer nurse specialists (CNS) are ideally placed to offer holistic support(356, 358), and previous literature demonstrates CNS’ are highly valued by men with PCa undergoing active treatment(105, 356). The current investigation suggests the CNS system for men on AS is not delivering the desired support. Participants who were allocated a CNS felt perhaps they were lower priority than those with more aggressive forms of PCa and did not find their CNSs accessible.

8.4.4 Implications for future practice and research

To obtain a broader, more inclusive understanding of the points raised in the current investigation future research would benefit from a larger, more varied sample of men and significant others. For example, recruiting men recently diagnosed, and at different timepoints along the AS protocol might provide a more accurate understanding of the emotional journey that runs alongside the processes of diagnosis, treatment decision making, and ongoing clinical investigations. A longitudinal study utilising repeated measures may also contribute valuable insights. Although it is difficult to steer clear of the bias’s that exist due to the necessary self-selecting nature of sample in such studies, using a variation of recruitment methods, for example, a mixture of clinics, charities and social media may improve the diversity of participants.

Although the current investigation went some way to explore how SO reactions impact on men on AS, a more in-depth investigation into how SO reactions impact the men’s decision to remain on AS would be valuable. Perhaps interviewing dyads who have converted to active treatment without clinical indication would provide a valuable insight.

The current investigation raised concerns about access to CNSs for men on AS. Further research investigating how common these issues are, and how they may be resolved would be valuable to future practice.

Future research exploring clinician views about SO involvement specific to the AS journey would be valuable. Exploring the extent to which clinicians consider, include and value SOs, together with further research with patients and SOs would inform changes that may need to be made in clinical practice. Such changes may include for example: adding information to clinic letters encouraging patients to bring an SO to important clinic appointments; clinician training about the importance of including SOs for improved acceptance and adherence to AS; improved support aimed specifically at SOs; improved information at the point of diagnosis.

8.5 Conclusion

Significant others of men on AS are involved, important, and potentially influential in patient acceptance, adherence and decision making. Further research to explore how SOs can be better included and supported has the potential to improve men's experience of AS for PCa.

Chapter 9: Discussion, Conclusion and Next Steps

9.1 Introduction

The aim of this PhD was to explore the experiences of men undergoing AS for PCa and their SOs. More specifically, it aimed to explore how SO responses to the PCa diagnosis and AS plan impact on the patient, how dyads perceive each other's AS related feelings and reactions, and to explore the feelings of both patients and SOs around being managed with AS. To fulfil these aims I have explored and presented existing literature about close relationships in illness (Chapter 3), described psychological theories relevant to dyadic experiences of AS for PCa (Chapter 4), described the methodology chosen for my own research (Chapter 5), conducted my own qualitative synthesis of studies that have qualitatively explored patient and SO experiences of AS (Chapter 6), completed a quantitative survey study (Chapter 7) and qualitative interview study (Chapter 8) both exploring all of the above mentioned aims.

This final chapter brings together overall reflections, the findings from the quantitative study and the qualitative study, discusses the key findings of this PhD in relation to the theory presented in Chapter 4 and previous literature. I discuss the strengths and limitations of this work and go on to discuss possible future research and next steps in this area. I describe my dissemination activities to date and provide an overall conclusion.

9.2 Reflections on the timeline of this PhD

The order in which I wrote the chapters in this thesis and carried out the research studies was not traditional. I conducted this PhD without allocated PhD time, whilst working at The University of Southampton, and I needed to ensure I could carry out PhD related tasks alongside my job role. For this reason, I commenced data collection very quickly, at the start of the PhD. At that time, I had the time and capacity to write the study documents, complete the ethics application, and recruit (something which was not guaranteed at a later timepoint). I knew time to complete the PhD was going to be limited and myself and my supervisors believed it was important to take the opportunity to collect the data while my work project allowed, and I had the opportunity. This was a pragmatic decision, and as my role at the time was on the PROACTIVE trial (which was the development of an intervention to support men on AS for PCa), I was not going into the topic area blind. However, there were some disadvantages to doing it this way; firstly, I was not able to gather a rich understanding of the existing literature and interventions prior to developing my research questions; and secondly, I was not able to refine the design of my studies based on previous research findings and theoretical constructs.

If I had followed a more traditional order, i.e., background chapters, theory chapter, review study followed by my own mixed-methods study, I believe there are few things I would have done differently. However, I would perhaps have considered recruiting men on AS and SOs that were not part of a dyad. This is not something I observed in previous literature, however, previous studies mostly had small sample sizes (like my own) and reflecting on this may have prompted me to consider ways to maximise recruitment.

From a theoretical point of view, had I written the theory chapter before data collection I may have considered the context of the participants to a greater extent and strived to collect more information about their experiences outside of PCa to gain a richer understanding of their thoughts and feelings.

9.3 Bringing the quantitative findings and the qualitative findings together

The quantitative findings demonstrated various correlations between the data of the men and of the SOs. Because of the small, underpowered sample size these findings need to be interpreted with caution, however, they do demonstrate the existence of a complex web of interactions which is reflected in the qualitative findings. For example, the correlational analysis suggested that higher levels of consensus and agreement within the relationship (reported by the men) is related to lower levels of SO preoccupation with the impact of their partner’s illness on their own lives. There was a relationship suggesting the more SOs’ believe that treatment will control the illness, the less impact and severity the men perceived the illness will have. Although such specific findings cannot be directly mapped onto the qualitative findings, they do demonstrate the complexities behind how dyads negotiate the illness, which is something that is supported in the qualitative findings. Such complexities are shown in the qualitative data with descriptions of differing reactions to the idea of AS within the dyads, internal conflict around being open about PCa worries and being strong for each other, potential misunderstandings regarding the feelings of partners, and tensions in dyadic communication. The quantitative findings strengthen the argument that how an individual negotiates AS for PCa is interrelated with how their SO negotiates the illness.

Interviews revealed issues in relation to allocated Cancer Nurse Specialises (CNS), for example, some were not aware they should have a CNS, some experienced a delay in allocation, and some struggled to get hold of them. Despite these qualitative findings, the survey indicated that men on AS were most likely to consult a specialist nurse with PCa related queries. It's clear that once a specialist nurse is in place and contactable, they are valuable to patients, reiterating the importance of being allocated an accessible CNS efficiently.

Quantitative findings indicated that SO anxiety was greater than their partners'. Although it's not possible to quantify anxiety within the qualitative findings, SO anxiety did present strongly. Additionally, the qualitative data indicated some different causes for anxiety between the men on AS and their SOs; men were more concerned about side effects of PCa and future treatment whereas SOs anxieties were rooted in the fear of losing their partner.

Qualitatively, most participants described being content with their PCa related communication, however, some tensions were present. For example, one SO wanted her partner to be more open to PCa conversations, while her partner felt there was nothing to discuss. Another SO described feeling conflicted about being open about her feelings because she felt she should be strong for her partner. Overall illness related communication scores in the quantitative study were sub-optimal, suggesting that although the majority of participants did not describe issues with PCa communication in the interviews, there was some level of dissatisfaction.

The small quantitative sample size and its impact on the interpretation of results makes it difficult to synthesise the quantitative and qualitative findings meaningfully. However, no clear conflicts between the two data sets were apparent, and this section has described some areas of corroboration.

9.4 How this PhD adds to the existing literature, and how the findings relate to psychological theory

9.4.1 How this PhD adds to the existing literature

The qualitative synthesis, quantitative survey study and qualitative interview study contribute to the existing literature in different ways, described below.

9.4.1.1 Qualitative synthesis

When commencing the qualitative synthesis process, I found existing qualitative reviews for men with PCa who are not on AS and/or do not include SO experiences(81, 96, 97, 104, 356), but could not find any reviews that were specific to AS and included SO experiences. I also found a dearth of literature originating from the UK in this area.

The literature searching process conducted as part of the qualitative synthesis collated and reviewed existing qualitative research studies specific to men on AS including data from SOs(80, 82-87, 90-93, 102, 142, 149, 308-312). This systematic review is the first to focus on experiences of men on AS for PCa, and the first to include experiences of SOs.

The synthesis results corroborated previous findings indicating AS experiences and acceptance vary widely, with some feeling AS is a safe, non-disruptive, positive option and others feeling anxious and uncertain(96) thus highlighting the importance of patient centred care in AS. This synthesis also supports previous findings that couples sometimes hide their PCa worries and feelings from each other(83, 104) to protect and minimise the concern of those close to them. Previous suggestions about the need for increased SO inclusion(97) were supported, as was the notion that support groups were not appealing to men(97). However, it also highted that more AS for PCa research involving SOs is needed particularly in UK settings.

9.4.1.2 Quantitative survey study

Mirroring previous qualitative literature, previous quantitative literature has demonstrated a divide in the way men experience the AS pathway, with some reporting elevated anxiety(80, 82, 83, 95), and others reporting minimal psychological impact(84, 85, 99). Although the sample in the quantitative study conducted as part of this PhD was small, mean scores did not show elevated levels of distress, depression or anxiety in the men with PCa or SOs.

Some previous research has suggested that partners of those on AS suffer higher levels of distress than the patients themselves(177). In my own investigation, mean distress scores were less than clinically relevant, however, the SOs' mean score of 8.07 on the HADS anxiety scale is higher than the men's mean score of 4.87. A similar pattern developed in PCa specific anxiety (MAX-PC) with SOs scoring a mean of 22.0 compared to a mean of 15.8 for the men. Paired samples t-tests showed these differences to be significant. Due to the small sample size the conclusions I can draw are limited, yet this is an interesting observation worth further exploration in future larger studies.

There is a dearth of previous literature exploring illness related communication in the population of men on AS. Results from this quantitative survey study suggest participants' illness-related communication between couples is sub-optimal. This novel finding was further explored in the qualitative interview study and is an interesting avenue for further research.

9.4.1.3 Qualitative interview study

The findings from the qualitative interview study supported previous findings indicating SOs are highly involved and important throughout the AS for PCa process (84, 85, 142, 310). The investigation conducted as part of this PhD found this support was two-directional within the dyad, with the men on AS often supporting their partners, and often ‘putting on a brave face’ for those close to them. This was a novel finding.

A pattern of increased anxiety around the time of surveillance tests has been reported in previous studies(97, 357) and was replicated in the findings of this qualitative interview study. My interview study expanded on this previous knowledge by revealing this pattern of anxiety is not only present in the men undergoing the tests but is replicated in those closest to them.

Previous literature has failed to provide an in-depth exploration into how being on AS for PCa impacts day-to-day life. In my own qualitative investigation participants were asked explicitly about any changes that have occurred since the diagnosis. Participants described increased efforts to live a healthier lifestyle, and positive attitudinal changes stemming from an increased awareness of mortality and a reminder ‘life is too short’.

Despite men on AS consistently describing a dislike of ‘support groups’ in both previous research(312) and the current investigation, they also consistently place value on the idea of discussing PCa related issues with men who have similar experiences with PCa(310). This suggests perhaps their feelings stem more from the stigma attached to the term ‘support group’ rather than actual activities undertaken within these groups.

This qualitative interview study adds to the body of literature a greater understanding of Cancer Nurse Specialist (CNS) experiences for those specifically on AS in the UK. Previous literature demonstrates CNSs are highly valued by men with PCa undergoing active treatment(105, 356), but there is a lack of literature around CNS for men on AS. The current investigation suggests the CNS system for men on AS is not delivering the desired support. Participants who were allocated a CNS felt they were of lower priority than those with more aggressive forms of PCa and did not find their CNSs accessible.

9.4.2 Reflections of the main findings in relation to psychological theory

It became clear throughout my own qualitative work that the thoughts and feelings of men on AS and their SOs are intricately linked. Interdependence theory(224, 225) (see section 4.5) is particularly appropriate to consider in the context of this finding. The related nature of the data had implications for analysis as the data from the men and the data from the SOs were not independent, but also not truly paired (see section 7.4.3.2). Interdependence theory could be used to guide further exploration into how related the two data sets are, and the different dimensions of interdependence in relation to men on AS and SOs. For example, the level of dependence within the couple, the mutuality of dependence, and importantly, the extent to which one member of the dyad can influence the other. Variations in these dimensions within a couple on the AS pathway may influence their responses to the treatment plan and whether they stay or leave AS without clinical reason.

Reflecting on the main effect model(1, 184) considering this finding (thoughts and feelings of men on AS and SOs are complexly intertwined) leads me to corroborate my earlier critical evaluation of the model (see section 4.1.1.1); that it is too simplistic and reductionist proposing that simply being integrated into a social network improves wellbeing and health related behaviours.

There was a strong sense of emotional support within the dyads in this study. Emotional support is a dimension of the buffering effect model(1), which proposes social support (in this case SOs) act as a protective shield, helping to manage or reduce stress by providing different types of support. In the qualitative study there was evidence of two-directional emotional support. The two-directional aspect is not captured by the buffering effect model, which fails to account for SO stress and support needs (section 4.1.2). Evidence demonstrating the other types of support in the buffering effect model was less strong; the men on AS did not appear to need instrumental support; informational support did not tend to come from the SOs, but rather research conducted by the men themselves, or from medical staff; and the impact of social companionship was not discussed.

The participants in this study made a clear distinction between the different sources of support and their differing values. For example, men placed high value on peer support (those who are on, or have been on AS), and lesser value on those who do not have experience with the pathway. A clear dislike for support groups was found. Although some of the theories described in Chapter 4 break support down into different types (for example, emotional, instrumental, informational and social companionship)(1), the sources of support are not accounted for. Therefore, the idea that there may be stigma related to certain types of support falls outside of the remit of the described theories.

Participants in the studies presented in this PhD described making lifestyle changes and information-seeking. Such activities have been described as ‘problem-focused coping’ within The Lazarus and Folkman transactional theory of stress and coping (1984). The model proposes those facing a stressor may practice a combination of problem-focused coping and emotion-focused coping(2). There was evidence of emotion-focused coping in the findings of this PhD in the form of minimisation (men on AS only), support-seeking (mostly SOs), and talking to others (SOs). Actions for illness control and coping as described above are also a part of the self-regulation model(195), which proposes that cognitive and emotional representations feed into actions for control and coping (section 4.4).

Viewing the findings of this PhD through a theoretical lens has helped to identify ways in which future research (and even future theoretical models) might be shaped. For example, future research could explore the extent to which the data of men on AS and SOs are interdependent and gather more information about participant context and the wider support networks of participants. Future social support models might consider the two-directional nature of support, and the varying impact of support from different sources.

9.5 Strengths and limitations

My research set out to explore the experiences of men undergoing AS for PCa and their SOs – an under researched area. I have identified some important novel findings as discussed above through a focussed collection of exploratory studies that provide important information to inform future research in this area.

As described in Chapter 7, recruitment to the survey study was more difficult than anticipated resulting in an underpowered study from which we can draw limited conclusions but has provided valuable feasibility data to inform future work. Data gathered from my qualitative interview dyad study provided a rich and detailed understanding of the experiences of these participants and highlighted areas that could be addressed to improve clinical care.

One of the biggest limitations of this PhD project is the lack of diversity in both the PPI contributors and the recruited participants. All PPI who contributed to the development of my PhD studies were educated, heterosexual and White British. Recruitment to the survey and interview study was harder than I anticipated. Participants were mostly White British, married, male-female spousal couples. This is not representative of the greater population of those on AS for PCa. PCa is more common in Black African-Caribbean and African men compared to white men(8), therefore increased ethnic diversity within my sample would have improved generalisability. Throughout the recruitment process I was careful to be clear that a ‘significant other’ could be any person with whom the individual has a close personal relationship. In the participant information leaflet (PIL) I described the ‘significant other’ as ‘the person in whom you are most likely to confide about your prostate cancer’. I did not want to exclude those who did not have a spouse, or those in same-sex relationships, however, only those in heterosexual relationships volunteered to take part. It would have been beneficial to this PhD project to explore whether dyadic experiences differ depending on the nature of the dyadic relationship (e.g., parent and adult child, or male-male partners).

Treatment options and experiences are rapidly changing in the area of PCa and this PhD was conducted over a period of 8 years, making it important I kept my PhD work as relevant as possible according to AS related developments. To ensure the most up to date literature was included in the qualitative synthesis at the time of submission I re-ran the searches whilst in the final stages of writing my thesis and included any additional papers that had been published since my original searches were conducted. Unfortunately, it was not feasible to collect more qualitative and quantitative data towards the end of my research project and experiences of a sample recruited today may differ to those recruited 5 years ago.

The difficulties I had recruiting participants and the resulting small sample size for the quantitative study meant it was not possible to split participant data according to when the men were diagnosed. Men and SOs who were very recently diagnosed may have produced different results to those who were further down the illness trajectory. I collected the quantitative survey data and qualitative interview study data cross-sectionally meaning I was unable to capture changes that may have occurred over time since diagnosis.

I acknowledge that the results presented from my qualitative synthesis and qualitative interview study provide only one interpretation of the data, and other interpretations using the same data would be possible and could be equally valid. By sharing my evolving results and coding manuals with my supervision team and PPI throughout the process and discussing developing themes, I was able to gain additional corroboration of my interpretations and remain transparent.

PPI were consulted throughout the studies described in this thesis (see sections 5.8.3.2, 5.11.1, 7.2.8, 7.3.2.9), They were consulted throughout the development of all study procedures and participant-facing study related information, and feedback was implemented where appropriate. A PPI member reviewed the themes as they iteratively developed from the qualitative interview study. PPI input helps to bridge the gap between the researcher (myself) and the participants and the data and allows for transparency in the way subjectivity may have shaped the findings.

A key strength of the research conducted throughout this PhD project is the novel insight it provides into men on AS for PCA and their SOs specific to the UK. To the best of my knowledge, no previous studies have qualitatively explored SO experiences of AS within the UK, and in addition to the exploration of experiences I have provided an insight into the complexities of negotiating this pathway as a dyad.

9.6 Implications for clinical practice

The findings of this PhD raise some important implications for clinical practice. Firstly, the importance and influence of SOs needs more recognition in clinical settings. Clinicians need to understand the impact and power of SOs in relation to how men on AS respond psychologically to the pathway. Many clinicians may already understand the background literature, but to onboard those dealing specifically with AS patient education around the importance of SO support in terms of AS adherence would be beneficial. Making changes to the way consultations are conducted, for example, by encouraging SO attendance, by viewing the dyad as a unit, and acknowledging that SO understanding is vital would improve patient and SO experience. SO attendance could be encouraged by, for example, adding a sentence to appointment letters such as ‘You are welcome to bring a close friend or relative to your appointment.’

The psychological impact of living with an untreated cancer needs more recognition in clinical practice. Men on AS describe feeling unsupported and lower down the list of importance compared to those receiving active treatment. The men feel their cancer is viewed by professionals as less serious, and because they do not have to contend with the side effects of active treatment, they are offered less support. Living with an untreated cancer can result in a different set of anxieties to those facing treatment and this needs more recognition in clinical practice. There needs to be a professional, accessible point of contact for these men (for example, CNSs), and AS specific support, rather than general PCa support.

Open conversations about the psychological impact of AS need to be had between medical professionals and men on AS and SOs. In other words, patients and partners would benefit from being asked directly how they feel about the diagnosis and treatment plan. This would allow them space to talk about their concerns, and for the clinician to understand how they might best be able to help, for example, by providing reassurance or signposting to the most relevant support.

9.7 Future research and the way forward

When starting this PhD, psychological support for men on AS was limited. Existing research, and reports from the participants in the qualitative interview study (Chapter 8) revealed that although

PCa support groups existed, they were not specific to AS. Men participating in the qualitative interview study felt their supportive care needs were different to those receiving active treatment and these inclusive support groups did not meet their needs (seeChapter 8).

This PhD corroborates findings that men on AS dislike the idea of support groups(97). When planning future support it is helpful to examine recruitment methods of previous support interventions. One such intervention was trialled in the PROACTIVE study(313) which provided face-to-face support groups specifically for those on AS. Recruitment in this study proved difficult. There are a number of factors which may have contributed to recruitment difficulties: firstly participants were required to travel to an in-person meeting, requiring a level of commitment, time, organisation and money; secondly, although the term ‘support group’ was avoided when describing the PROACTIVE group sessions, perhaps they were still perceived as such; thirdly, perhaps the number of men on AS who want to attend a support group living in close enough proximity to the support group venue was low.

Since conducting the interviews for the qualitative study in 2018, PCUK has launched an AS specific online support group. I contacted PCUK with various questions about this group and they provided the following information:

- They were unable to tell me exact date the group was launched due to changes in staff, but they estimated sometime in 2020.
- The group runs via video call once a month and is open globally to those on AS.
- The group is usually attended by up to 15 men in each session, including some from overseas from places such as the US, Canada, The Caribbean, Iceland and Denmark.
- Each month the group tends to consist of a mixture of regular and new callers.
- The sessions are mainly for the men, but they do occasionally have partners joining too.
- The group facilitator employs strategies to put the men at ease to discuss their situation and aims to see if the group can help with any anxieties they may have.

PCUK have demonstrated a successful AS-specific support group. Conducting such a group online removes the barriers related to travelling to a group. Online, the men may feel less exposed and more comfortable sharing their concerns and anxieties. The option to attend just one, or repeated sessions again removes pressure and commitment and gives them a chance to try the group out before attending repeatedly. In addition, the online format means attendees are not restricted by their location, and the reach for potential attendees is much wider. How many men on AS who are aware of this group is unknown, and therefore it is hard to judge the level of demand. The participants interviewed in my own study were not aware of any similar groups either in secondary care or elsewhere (although interviews were conducted in 2018). Through my own research I have not been able to find any similar groups. It would be beneficial for future research to investigate these points further and improve understanding around the demand for this kind of support.

When reflecting on the literature suggesting men do not like the idea of support groups, while simultaneously voicing that talking about AS for PCa with others in a similar situation would be beneficial I came across the idea of a ‘buddy system’. A buddy system in this instance would involve being matched with somebody who is also on AS for PCa (or the SO of someone on AS for PCa) and being able to speak to that person either by telephone, email or face-to-face. The cancer charity Macmillan offer a buddy system which launched in 2020, after I conducted the interviews for my qualitative interview study. I contacted Macmillan for more information about their buddy system to see how it might go some way to fulfilling the needs of men on AS for PCa and their SOs. The service was launched during the Covid-19 lockdown period as a short-term service, but due to ongoing demand the service has now become permanent. This service is open to people with all types of cancer diagnoses (it is not PCa specific). A diagnosis of cancer is not a necessary requirement to become a Macmillan buddy volunteer, however, 60% of buddies are people living with cancer. Macmillan advised some service users (less than 3%) request a buddy who has experience of the same type of cancer as themselves, and where possible they try to accommodate those requests. The service is exclusively for people living with cancer (not SOs), however, they have alternative support systems for SOs of people living with cancer. Importantly, 23% Macmillan buddy volunteers identify as male.

The Macmillan buddy system sounds like a positive step in the right direction and may prove beneficial to some men on AS for PCa. However, the men in the qualitative interview study (Chapter 8) specified support from other men on AS was important, and it is unclear whether Macmillan would be able to fulfil this request.

It is clear from the information provided by PCUK and Macmillan that in the last 3-5 years support for people living with cancer, and specifically those on AS for PCa (PCUK) has improved. However, there are limitations to the new services described above: firstly, men who feel strongly that they would not like to be part of a support group may be reluctant to join the AS specific group led by PCUK, secondly, those without access to the internet would not be able to participate in the PCUK support group, thirdly finding another man on AS for PCa using the buddy system provided by Macmillan may be difficult, and lastly, neither of these services encompass the SOs as part of their support.

Future research into the feasibility and effectiveness of a buddy system specifically for men on AS (as opposed to all types of cancer), and a similar service for SOs, offered at the point of diagnosis may be beneficial. This system could be more inclusive (i.e. not exclude those without internet or transport) and flexible, for example, support could be given by telephone, email or face-to-face, and SOs could be included if desired.

Results from both my quantitative survey and qualitative interview studies suggest participants' illness-related communication between couples may be sub-optimal. This novel finding should be further explored through future research. Initially this would be a larger quantitative study with larger numbers, greater participant diversity, and more questions specific to communication compared to my own quantitative survey. In addition, a larger qualitative study focusing on illness related communication in this population with greater depth would provide a richer understanding. This improved understanding would be beneficial when thinking about new potential support for both men on AS and SOs.

In clinical practice, improved understanding and recognition of how intricately intertwined men's responses, reactions and adherence to AS are with those of their SOs would be beneficial. Future research into how this might be achieved is needed.

9.8 Dissemination activities

9.8.1 Conference presentations

Table 32 details the conferences I have presented the studies that have formed my PhD. The Primary Care, Population Sciences and Medical Education PhD conferences were particularly valuable in terms of receiving advice and feedback.

Table 32: Conference presentations

Date	**Conference**	**Presentation type**	**Status**
13th October 2017	PCUK Conference	Poster	Complete
31st January 2018	PCPS PhD Conference	10-minute oral presentation, 5 minutes questions	Complete
13th March 2018	SW SAPC Plymouth	Poster and 3-minute oral presentation	Complete

21st January 2019	PCPS PhD Conference	10-minute oral presentation, 5 minutes questions	Complete
13th March 2019	SW SAPC Southampton	10-minute oral presentation, 5 minutes questions	Complete
11th June 2019	Southampton Medical and Health Research Conference	Poster	Complete
21st January 2020	PPM PhD Conference	9-minute oral presentation, 4 minutes questions	Unable to attend due to illness. Presented to students separately.
5th March 2020	SW SAPC Bristol	Poster	Cancelled due to COVID
23rd – 24th June 2020	DHP Bristol	Poster	Cancelled due to COVID
24th January 2022	PPM PhD Conference	10-minute oral presentation, 5 minutes questions	Complete
4th – 6th July 2022	SAPC ASM UCLan	6-minute oral presentation, 4 minutes questions	Completed by supervisor
18th January 2023	PPM PhD Conference	10 minutes oral presentation, 5 minutes questions	Complete
16th March 2023	SW SAPC Conference	Poster	Complete

9.8.2 Publications

I have successfully published my work detailing the planning and development of PROACTIVE, see reference below:

> Hughes S, Kassianos AP, Everitt HA, Stuart B, Band R. Planning and developing a web-based intervention for active surveillance in prostate cancer: an integrated self-care programme for managing psychological distress. Pilot and Feasibility Studies. 2022;8(1):175.

I have successfully published my qualitative synthesis, see reference below:

Hughes S, Everitt H, Stuart B, Band R. The experiences of men on active surveillance for prostate cancer and their significant others: a qualitative synthesis. *Psychooncology.* 2024. https://doi.org/10.1002/pon.6324

See Table 33 for future publication plans.

Table 33: Future publication plans

Title	**Journal**	**Status**
Active surveillance for prostate cancer is a shared journey: The dyadic perspective	Psychology, Health & Medicine	Accepted subject to minor revisions

9.9 Reflections on personal development

When I commenced this PhD, I was working as a Research Assistant within the School of Psychology and the School of Primary Care, Population Sciences and Medical Education at The University of Southampton. I had been involved in research projects at various stages throughout my career, but always as part of a team, and my involvement had always had a focus around a particular aspect of the project (e.g. developing the content of an intervention, or providing technical support to online intervention users). Conducting this PhD project was different because I was able to design, develop and plan the project from start to finish. I had to think through every process, from the design of study documents and participant recruitment, right through to analysis and write-up and critically evaluating my research’s strengths and weaknesses and potential next steps.

I have had the opportunity to develop my presentation skills, presenting my research at conferences and within smaller groups (for example to PPI). I have been able to further develop my paper writing skills. Although writing papers for publication is something I do as part of my paid employment, leading on papers about research I have conceived, developed and conducted myself has meant a new level of freedom in how I present my work in published papers.

I believe I have grown in confidence throughout my PhD, becoming more knowledgeable with the different ways of conducting valid, high-quality research and disseminating it in a meaningful way. This has provided me with an important grounding to continue my research career.

9.10 Conclusion

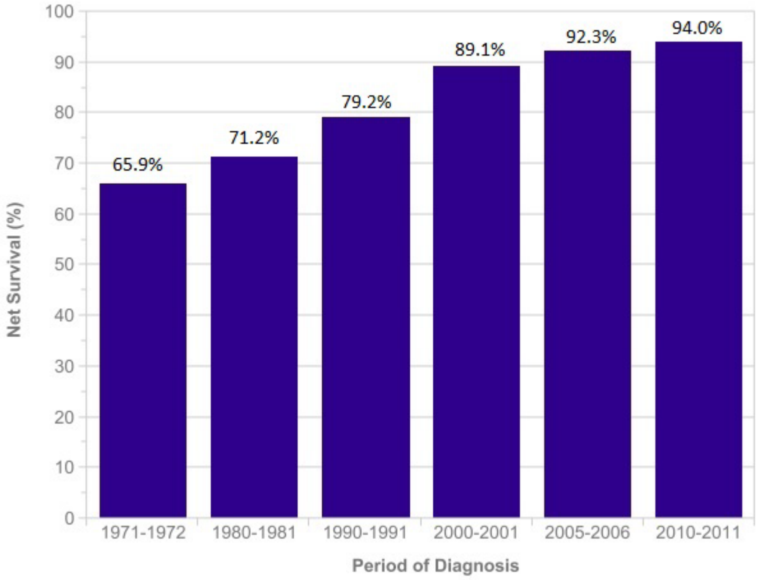
To conclude, some find the AS pathway and living with an untreated cancer psychologically distressing. Men on AS often feel existing support systems are geared towards those receiving active cancer treatment, and that their supportive care needs are not met. SOs report feeling side-lined by either their partner or medical professionals and report needing extra psychological support. More support specific to men on AS and their SOs is needed. SOs of those on AS often view themselves as also on AS, and suffer the same, if not more distress. Responses and reactions to the PCa diagnosis and AS pathway of the man with PCa and their SOs are intricately linked, and this needs more recognition in clinical practice.

Appendices

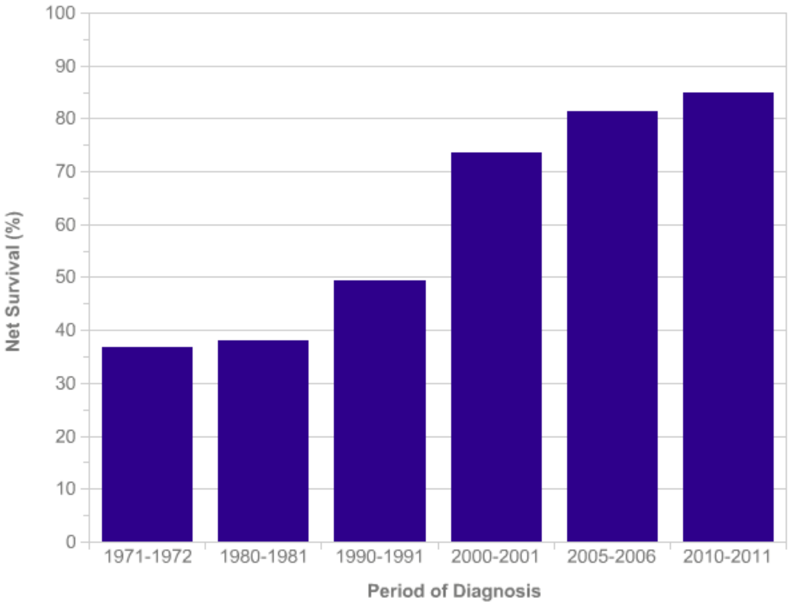
Appendix A Net survival rate patterns

Figures to show age-standardised net survival rate pattern in England and Wales from 1971-2011 at one-year, five-years and ten-years. Based on graphics created by Cancer Research UK(7).

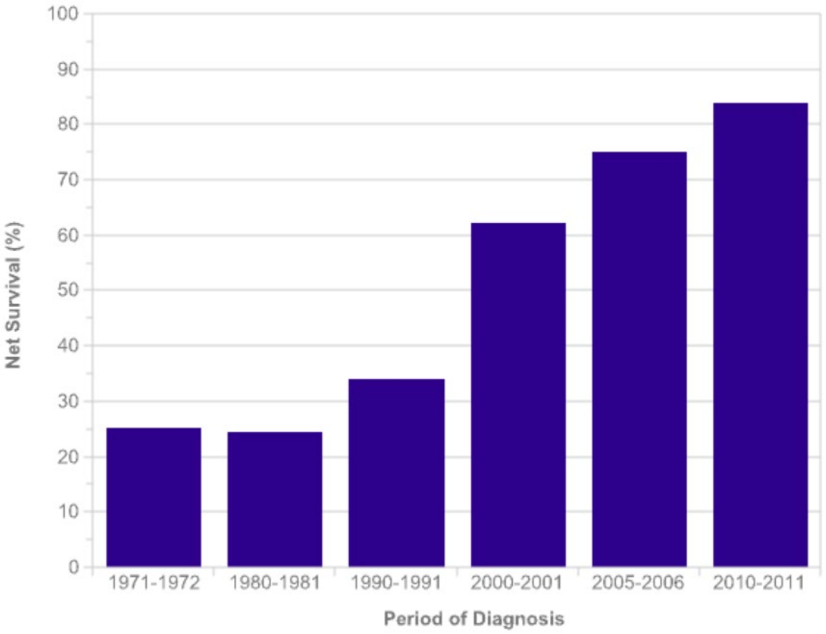
A.1 The age-standardised one-year net survival rate pattern in England and Wales from 1971 – 2011(7):



A.2 The age-standardised five-year net survival rate pattern in England and Wales from 1971 – 2011(7):



A.3 The age-standardised ten-year net survival rate pattern in England and Wales from 1971 – 2011(7):



Appendix B Table of themes

Table 34: Table of themes

Dyad	**Broad Subthemes**	**Man on AS**	**SO**	**Dyadic code / Summary**
1 Stephen & Sarah 2523601 & SIG002	Information received following diagnosis	I got the diagnosis and then a few weeks later there was a large parcel through the post which – was actually a bit alarming really, because there was a whole bundle of books, one of which was how to get my affairs in order, ready for dying, really, and I think without any explanation whatsoever. I think it was just a little bit blunt to have sent them all for through post like that.	we get a package of leaflets and booklets from the – support nurse, with no explanation whatsoever, with all kinds of things in it. And a lot of it was good, because it was information – but it was – put your house in order whilst – before your death and stuff like this, which – for crying out loud – we've just xxx because we understand that things aren't bad and then we get the stuff about – about – putting your financial affairs in order before your death. And you think – I kind of felt that could have been done better.	**Inappropriate amount, content and delivery of information** Dyad agree the large package of leaflets delivered was insensitive, inappropriate and could have been done better.

	Initial reaction to diagnosis	I remember the day very well and I felt like it was a weight lifted off my shoulders – because it was – it was just a – a minor – I think they said – initially it was a TRUS biopsy which just, from the 12 samples that they took, I think one of them had a very minor amount of cancer cells on the biopsy samples and they put it down as a Gleason 3+3 and I thought, well, that's fantastic, nothing serious happening because that might never do anything that affects me.	R was quite relieved but I kind of wasn't, because my dad had prostate cancer and died very quickly. He had the diagnosis and then died within a year, so I was xxx my reaction was less of a sigh of relief, more of a – oh my God – reaction.	**Dyad felt differently about diagnosis** Stephen felt relieved at the diagnosis, but Sarah felt more concerned.
	Initial feelings about AS	how did you feel about the idea of active surveillance? P: Well I'd looked at all the options, prior to seeing the consultant and I was hoping that that would be the route that he wanted to take, so I was quite happy with that.	I felt that that was actually really quite supportive, in a way, because at least they said there is very little cancer cells, very few cancer cells and they don't think they are active. And I feel that actually keeping an eye on the situation – you're actually in a very good position because if they're doing nothing for another year before they want to see you, then anything could happen. So I feel that this – this three month wait – initially I felt the three monthly PSA tests, going to see somebody – was a really good thing.	**Dyad both initially happy with AS** When AS was suggested Stephen was pleased, and was what he was hoping for. Sarah felt that the fact they wanted to put him on AS was reassuring, and that having checks every three months was good.

	Current feelings about AS	I'm feeling that the active surveillance is not very active; three months feels like quite a long time, but I don't know. Maybe three months, in the cycle of a developing cancer, isn't a long time; I don't know. That's something I want to talk to the consultant about, next time I see him.	I'm not as happy about it as I think I was in the first place I feel when it comes down to the PSA test time, I'm getting a bit – sort of – twitchy about it, because I'm thinking – oh God, I hope it's come down. And if it hasn't come down, if it's gone up again – so I get a bit twitchy about it. If something started to go wrong, if it started to become active, is three months a long time to leave it before you find out. I don't know; it's all a bit unsure. But R seems a bit – he's a very pragmatic person and a very calm person and he keeps me pragmatic and calm when he can.	**AS is a rollercoaster** Although both initially content with AS, living on this pathway is hard for them both. Anxiety builds in the lead up to a check-up. Although Stephen admits to feeling worried the cancer might progress in the 3 months between tests, Sarah describes him as 'calm' and that he keeps her calm.

	AS uncertainty	once I've had the meeting with the consultant, you think, well, that's good, everything's okay, but in the following weeks and months, you start to think – I wonder if anything is happening or if anything will happen. If the cancer did start to develop, could it develop to a point where it becomes critical in three months or is that three months nothing in terms of the cancer's development? I don't know, that's something I want to ask the consultant about, next time I see him – because I don't know what could happen in that three months. Could it go from – dormant and very small to – to something more critical? I don't know and they are the sort of things that go through my mind from time to time in that three month period.	I'm not as happy about it as I think I was in the first place, but – I: That's interesting. How do you feel about it now? P: There's a – it's a bit of a rollercoaster, because – some of it is due to the fact that the medical profession is not very good at sharing their knowledge and their information and so you're told about there'll be three monthly testing: they don't say – if it goes up, what is the point that you get worried at – if it's gone up? It's gone up from 4 to 8, which it did at one time, is that something we should be desperately worried about? And if it is, what does it mean for the cancer? There's no information about what to be looking out for, do you know what I mean?	**Living with AS uncertainty is hard** Both Sarah and Stephen feel concerned about the 3 month wait in between tests and fear progression. Sarah expressed a desire for an understanding of when action might be taken i.e. at what PSA result is action taken. Stephen wanted to understand if progression in 3 months could be dangerous.
	Relationship with specialist nurse	Well I have got one allocated but I've never met him and the only time we spoke was when I had that new diagnosis that I wasn't informed about, when I	Even in the early days when we wanted to contact him, you couldn't get hold of him, he was never	**Left out on a limb** Both Stephen and Sarah felt let down by their allocated

		started asking questions about why I hadn't been told and he got very aggressively defensive, so we don't speak really… So – yes – it does feel like – like I'm – like we're off out on a limb, not really know what's happening between those three monthly spells.	there. So I think that needs to be addressed, that professional support needs to be improved.	cancer nurse specialist, and feel they have nobody to ask questions in between consultant appointments.
	Perceptions of each other's feelings	how did she respond to the diagnosis? P: I don't think she was quite as – as I said – I felt like a weight had been lifted off my shoulders because it was only a fairly minor thing that might not develop, but I don't think it was quite the same for [name]. I think it was actually the realisation that I did have a cancer there – was a bit harder to take, but, at the same time, she took – I think she took her line from me and was positive about it. I: And how do you think she felt about active surveillance?	how do you feel about the way he responded to the diagnosis? P: Well – I'm a very emotional person and so I – I think it was helpful for me to see him being so matter-of-fact about it and thinking, oh my goodness, it's good and don't worry about it; it could have been an awful lot worse and at least they're keeping an eye. And his reaction actually helped me become much – less distressed about it. I think he feels a bit like me, you know, you get onto the rollercoaster and – he's a fairly [phlegmatic]	**Dyad accurately describe the other's feelings** Stephen understood Sarah did not feel the same as him when faced with the diagnosis. Sarah felt that Stephen's reaction helped her stay calm. In terms of AS feelings, Sarah accurately believes Stephen feels similarly to

		P: Again, she believed that it was the best option. It's something that we discussed rather than just me making that decision.	kind of guy and he just kind of gets on with it, do you know what I mean?	her, that it is like a rollercoaster.
	PCa and AS related communication	do you talk about it? P: We do, yes, yes – just – from time to time it crops up in the conversation. We talk about – I think it's this gap between that gets to us both a bit, from time to time, just wondering what's happening.	We don't talk about it all the time; we can't talk about it all the time, can we? But when we do, when we need to but – you can't let something like this rule your life; we just get on with our lives. But when the three monthly test is coming around, I think that's the time when it surfaces more; it's always in the background, but it surfaces more when you're coming round to that – right – we've got the test coming up and what will it say, you know, that kind of thing. I: So do you feel able to talk about it, if you want to? P: Oh yes, yes; we can talk about anything, yes.	**Good PCa and AS related communication** Both Sarah and Stephen feel they communicate well about the situation and feel they can talk about it as much as they like.

	Supportive care needs	can you think of anything that may have been helpful for you or for [name] when you were first given the treatment plan of active surveillance and kind of throughout; what would have been good? P: Probably a bit more time to talk about it with people that were informed. I: A bit more support? P: Yes, yes. I think – I think perhaps the role of the – specialist nurse could have - could have been better deployed, because as I say, I haven't actually met that person and the conversations we've had have not been very helpful.	having this specialist nurse who will be your person who will – you know – and talk to you and help you through all this, I think that needs to be improved no end. I know they're busy and they've probably got huge caseloads and I think that needs to be addressed, but – being a support – having support from a specialist nurse means more than just – putting leaflets in an envelope and putting it in the post: it means being available. Even in the early days when we wanted to contact him, you couldn't get hold of him, he was never there. So I think that needs to be addressed, that professional support needs to be improved.	**Need more support from a professional** Both Sarah and Stephen feel they need more support throughout the AS journey, and that the cancer nurse specialist would be ideally placed, if they were more contactable.
Dyad 2 Mark & Mandy	Patient initiated research	immediately I started reading articles on the internet myself, and Prostate UK and Cancer Research and so on; so I did that myself.	when C went to the hospital, when he saw the nurse, she gave him some booklets and leaflets to read, which he passed on to me, but then most of the information that I – that I've received, has come from C, because he's constantly on the internet	**Man proactive in information seeking and research** Mark is proactive in his own research and had read the

2529575 & SIG005		I went for the transperineal option; I started reading about it, I wouldn't have known about it had I not gone on the internet.	looking for things and reading things up, so he'll pass anything that he thinks I might find interesting on to me.	same information before it was given to him. His own research guided the type of tests he requested. Mandy does not mention doing her own research, but instead reads the information passed to her by Mark.
	Information / support given	Then when I went for the actual biopsy; they gave me some leaflets at that stage and also when I had the follow-up six weeks after the biopsy, they gave me quite a large amount of information to read up on that. To be truthful, it's exactly the same as what I'd already read on the internet and download myself. the – brochure – the booklet that they gave me was the one from the Prostate Cancer UK, but, as I said,	when C went to the hospital, when he saw the nurse, she gave him some booklets and leaflets to read, which he passed on to me, but then most of the information that I – that I've received, has come from C, because he's constantly on the internet looking for things and reading things up, so he'll pass anything that he thinks I might find interesting on to me.	**No new information provided** Mark had already read the information booklet provided by the hospital because he had downloaded it himself from the PCUK website. Mandy only received information through Mark.

		I'd already downloaded that and read it myself; so it basically duplicated what I ready had and knew.		
	Clinician conflict	when I saw the first consultant – when I had the blood test and then I got referred very quickly, within six weeks, to the first consultant, he told me I hadn't got cancer. He was that it was just BPH and so – he wanted to discharge me. And I said, well, is there anything else I can do to actually confirm? He said, well, no, because basically I'm telling you – you've just got a – an enlarged prostate and there's nothing else there at all. So I said – well I've read that I can have a biopsy, a transperineal, and he said, we don't offer that on the NHS, because we don't think you're sufficiently – down that road, [if I had cancer], he said we won't offer it to you and so I'm discharging you. And he said, but if you want to, I'll put you down for a TRUS biopsy. And I said, well, no, and he said, in that case, if you're declining treatment, we'll discharge you. I said I'm not declining treatment, I just don't believe that that's		**Clinician conflict** Consultant would not give Mark the test he requested and resulted in him paying privately.

		the right option for me and if necessary, can you recommend me to go privately. And so all of a sudden he then started giving me names of consultants. So I ended up going to see a private consultant and he said I can feel you’ve got a problem, anyway, just by the digital rectal examination. So he said – well you’ll need an MRI; so I had to pay for that privately myself. I’m not insured so I had to pay for that myself. And I thought that, once and for all, it’ll get it out of my system, it will reveal nothing because the first consultant said I haven’t got one; this guy is saying I have, but the MRI scan will probably tell me there’s nothing to worry about. And then, low and behold, bizarrely, the MRI came back showing there’s a shadow there. So he said, well the next stage is – the final stage was – I can feel, I can see it and now we need to take samples, so you need to go for the biopsy. And he said I understand your concerns about the TRUS biopsy. He said I’m pretty sure I can get you the transperineal one on the NHS and they’ll take you back on the NHS. And so he did just that. (I:		

		Okay) And then of course that confirmed that I'd got seven [cores] with cancer in both lobes.		
	Reaction to diagnosis	Well I'd been sort of expecting it, because I'd looked up through all the different effects that it was having on me; I thought it's not just an enlarged prostate, it probably is something else. So then you try and believe it's not going to be cancer because obviously that's the last thing you want to hear. But I just [continued] to accept it in my own way, that that's what it was going to be, so I wasn't really surprised when they sat me down on August 21st and told me I had got it.	I found it difficult – you know – thinking about it, because ... it's not me that's got the problem, but, at the same time, it would affect me and then you start thinking, you know, you're being selfish and – so it's all sorts of thoughts. You think you should be feeling this but you feel something else and then when you talk to other people, they're quite dismissive, because they tend to think that prostate cancer is – something that is easily cured nowadays, that there is no problem. how did you feel, initially? P: ... Confused really, because, as I say, people will tell you that, well, my father in law is a GP and he always said – don't have anything done, you'll die before the cancer kills you. I mean that isn't strictly true but – that was his take on it… So ... it's difficult to say really, because – as I say – you've got different angles coming at you. So you don't want to	**Reaction to diagnosis** Mark did not feel surprised about the diagnosis due to the reading he had done. Mandy felt worried about how it would impact her, and confused about how worried she should be.

			be overdramatic but you don't want to be dismissive. So it's kind of – quite a fine line in between the two, really, and then – sometimes you fear the worst and then other times you're quite optimistic.	
	SO Guilt around feelings		I found it difficult – you know – thinking about it, because ... it's not me that's got the problem, but, at the same time, it would affect me and then you start thinking, you know, you're being selfish and – so it's all sorts of thoughts. I'm not one – I'm not somebody who can – I find it difficult to discuss things, even with C, so I tend to bottle it up and then perhaps every now and again – my worries come to the surface. But then you – you try and – think, well, it's not me and I'm kind of projecting my fears and worries on to C.	**SO guilt around own feelings** Mandy expressed a sense of guilt about worrying what the diagnosis would mean for her, and explained that she finds it difficult to discuss worries.
	Cycle of anxiety		I think with the active surveillance, I think once we've been, perhaps in February, we'll both feel a bit happier if there is no progression, then you think, oh, you're going to be lucky, that it's going to	**Cycle of anxiety** Mandy is feeling progressively anxious in the lead up to the next set of

			be one of these non-aggressive forms of prostate cancer, and really that you haven't got anything to worry about. But then if it should turn out to be the other – the other way, then I feel that instead of being reassured in February, we'll be – we'll be more concerned. I: Yes, definitely. P: I think perhaps, come February, if everything is in our favour, then it won't be – we'll be pleased that we'll be doing, you know, going down this route.	tests, but feels she will relax more if they come back ok.
	Feelings about AS	I was rather hoping, from the list of all the various scenarios, that I just don't – I didn't, and I still don't want to have surgery. I think it's far too radical. One of my best friends has had that and he regrets it now, with hindsight, and my next best option would have been brachytherapy which, if anything changes in the future, that's the route I think I'd probably decide I'd like to go down. But, in the meantime, active surveillance appealed to me because – if I fell in that category of being able to be in there, I would,	I think if it would have been me, I'd want to get it removed; I'd want to have surgery, but then – from C's point of view, he doesn't want to do anything until he feels he has to. So, again, you're not sure – you can't predict how you feel on to somebody else because they obviously are feeling entirely different. And it did take me a while to ... to understand where C was coming from, because, as I say, if it was me, I'd want it removed, I couldn't – It's like when you see these people that have been in	**Differing feelings about AS** Mark was keen on the idea of AS from the start. Mandy felt differently, and if it were her she'd want it out.

		because it means in the future they're going to treat me, rather than just – like watchful waiting, you're on a one way ticket out of this world, as it were, but active surveillance, at least hopefully they're going to say, well you have moved down the line, we now need to do something and we're going to cure it rather than just keep it – xxx.	the jungle and they've got some insect that's got under their skin, if that was me, that would – that would really freak me out. I'd have to get that – the very thought of it makes my skin crawl. And I think the same with cancer; if I thought I'd got cancer, I'd have to have it – hopefully – removed, if I could, that would be my – I think – my first thought, whereas C, as I say, he's on the internet all the time, he's researching it, because it's directly affecting him. And he's of the mind of – active surveillance is the best route to go down.	
	Treatment decision making	the option is always mine and he said if you want to, we can do robotic surgery or we can offer you radiotherapy, but he said the choice is yours. If you want either of those two, we'll do it for you; if you want to stick with – if you want to go with active surveillance, that's entirely up to you.		**Decision made with clinician** Clinician advised AS, but made it clear he could change his mind at any time and if he wanted treatment they could go down that route.
	Current feelings about PCa	how do feel about your diagnosis now that a few months have passed?	I think we just want to get to February; it's just – it's like the goalposts have been moved. We feel as	**Differing feelings about PCa**

		P: Exactly the same; I just feel that I've got to get on with my life and enjoy it, make the most of it and see where the next sort of [journey] takes me.	though we'll get to February and we'll be a better position. So really, at the moment, I'm quite hopeful that things will be happier after February, that C will be more relaxed about it and hopefully, you know, some of our fears will ... you know – will disappear, so we won't be quite so concerned; that's what I'm hoping. I'm hoping that – that it [will change] xxx if any, I'm hoping there won't be any change, that the result is virtually the same, but whether – that's probably wishful thinking.	Mark's feelings about the diagnosis have not changed, he feels he just needs to get on with life. Mandy is hoping that the next set of tests will make her feel more at ease.
	Current feelings about AS	how do you feel about that as a treatment plan now? P: Well, the same really, I just feel as though it's – just a natural part of the – being actively surveyed and hopefully – when I go in February, all being well, that they're going to [tell] me of the tests they're going to do, they're going to tell me that nothing's changed and we'll see you in another six months. And if they have to do an MRI or another biopsy, as long as it's not the TRUS one, then that's fine by me.	As above.	**Cycle of anxiety** Mark appears more relaxed than Mandy about the next set of tests. Mandy is eagerly awaiting the next set of results to see which way things are going to go.

	Perceptions about each other’s reactions to the diagnosis	I think she quite – I think she was a bit shocked, because obviously it’s your partner and [didn’t have] more deep emotions, I guess, I don’t know for sure, but I think that she bottled it up more, so it was only fairly recently I realised that she had been more affected by it than I thought she had, to be truthful. I think she was very positive. I asked her - she came with me to make a few notes on my behalf, but she said she didn’t because she wasn’t listening properly because I think it sort of – the confirmation that I had got cancer was too much for her to take in that few minutes of the consultant and the nurse telling us. So I didn’t get any notes out of her. But I think, over the last few months, I think she’s accepted that it’s the best thing for me, really.	I think he was very angry with the diagnosis, but I think – he’s having – done all the research that he’s done, I think he feels that the active surveillance is the better prospect for him at the moment. (I: And what – sorry, go on) I was just going to say, he just wants to avoid any treatment for as long as he can, really. how do you feel about the way that C responded to the diagnosis and the treatment plan? P: I think he responded very well. I think perhaps he’s been a bit more supportive of me than ... he’s been very reassuring most of the time; it’s only now and again he gets a bit cross and a bit angry, and it’s the – why me – sort of question that you’re asking yourself. But, yes, I think he’s perhaps been – I think he’s been very positive; he’s been more positive than I would have been.	**Mismatch in perceptions and descriptions** Mark confessed he hadn’t realised how much the diagnosis had affected Mandy until recently. Mandy felt that Mark was very angry about the diagnosis, although he does not say this himself. **Man on AS a support to SO** Mandy feels Mark responded positively and has been a support to her rather than the other way round.

	Perceptions about each other's feelings about AS	Well I think she's - she's comfortable and pleased I'm on it as well, as far as I'm aware, rather than having to go down the other routes, because obviously surgery or brachytherapy, for both of us, the side-effects are not insignificant. I do worry about the changes to your sex life and also you can end being bladder or bowel incontinent, or both. And so it does – yes – that part does worry me, to be truthful.	I think he was relieved that the option was available to him. I think he would have been very upset if they'd have said no, we don't think that's suitable for you. I think if he'd have gone straight into treatment, I think he'd have been more worried than he is at the moment and I think, really, I think, at the moment – well I think we're both a bit more accepting of the situation than we were initially.	**Man with PCa more concerned about treatment side effects than SO** Both participants feel accepting of AS. Mark mentions the impact active treatment may have on the couple's sex life. Mandy believes Mark is more concerned about this than her.
	Looking for new treatments	it does really because you do think about it rather a lot, in terms of – am I going to be okay; is it going to affect my lifespan? Will J be alright on her own; what will she do? You have all those thoughts go through your mind, of course you do. So it's not that I'm blasé about it and don't think about it, I do think about it often and I still do a lot of – well not a lot, I don't do much research but I do a lot of – just browsing on the web and keep referring back to Prostate Cancer UK website to see if there are any		**Man on AS proactive in PCa research and updates in treatment options** Mark keeps abreast of current PCa information and an eye out for new treatment options.

		more developments, because obviously there are more treatments being – coming out and maybe in the near future. So therefore my preconceived idea of what I want may change if something radically different comes on xxx and if the NHS were a bit slow to take it up, I might decide that - can I go privately and have something done.		
	PCa related communication	So do you find it easy to talk to each other about it or –? P: Yes, we do, although I thought it was easier than it was. As I said, she – she had been bottling it up more than I realised but she has now said to me that if she needs to talk or ask anything about it, she will, but she hadn't done previously, which I hadn't appreciated. I: Okay. And is there anything that you would like to be different about how you communicate about it?	I find it very difficult to talk about how I feel, I always have done, even with C. As I say, I tend to bottle things up and then something will happen, probably totally unrelated, and then I just find that, you know, I'm having a tearful moment. But kind of matter-of-factly talking about it, I can – we'll do that, perhaps a few times a week. We lead pretty healthy lifestyles, so I think, in that respect, it was more of a shock, because I always think, oh no, we'll be alright, nothing the matter with us, sort of thing. So I think when something	**SO feels the need to be strong for man on AS and finds it hard to talk about feelings** Mandy finds it difficult to talk about her feelings and tends to bottle things up. Mark is aware of this, but only recently understood how much she had been bottling up PCa related feelings. Mandy feels that

		P: Not now, because I think we've had a few open discussions about it fairly recently and she said that she will open up a bit more, because she is quite a reserved person and she does seem to keep things to herself a lot. And I have to sort of try and tease things out of her quite often.	does happen, I find it's difficult to admit to myself that there is a problem, but, at the same time, I don't want to be crying and weeping and getting all emotional because I think I ought to be – try, you know, to not be, for C, because he's the one who's got – if anything needs to be done, he's the one who's going to have to have it done.	although she'd like to be better at talking, she needs to remain strong for Mark.
	AS uncertainty		what do you think the worst part about living with a partner on active surveillance is? P: It's the not knowing, isn't it?	**SO struggles with the uncertainty of AS** Mandy struggles with the 'not knowing'.
	Positive changes		I think you tend to think you'll make more use of your time, enjoy being together. ... I mean we don't, again – we don't tend to argue very much anyway, but I wouldn't pursue an argument deliberately, whereas perhaps you think, no, you're not going to get away with it, I'm going to make my point. Now I kind of don't bother, it's not worth it, life's too	**Attitude to life has changed** Mandy explains how the diagnosis has made her see that life is too short to argue.

			short. So there's that. I wouldn't think there's anything else, really.	
	Importance of SO involvement	I still think it's very important because it's – you're in a partnership, a long-term partnership together and so it's important that both partners understand the implications of what could happen, can happen and probably will happen. So you can sort of mentally prepare yourselves for changes as things change in the future.	I think you need to be with your partner when – you know – just to be there, really, to be supportive and, two of you, then afterwards you can say – well did he say this, compare what you think you heard. And then when you go in to see the nurse afterwards, C was asking her questions, but then I could ask her questions as well, if I thought C hadn't quite – covered it or – or ask a question and she answered it – kind of like the answer he was looking for or the reassurance he was looking for. Yes, that was helpful, actually seeing the nurse together.	**Agreement SO involvement is important** Both Mark and Mandy agree it's very important for SOs to be involved in consultations and treatment decisions.
	Feelings about side effects	obviously radical surgery or radiotherapy, I think that's something I'm hoping to avoid and I'm pleased that I'm on active surveillance because I'm hoping that it will stay like that, because I am worried about the side-effects if I have either of those treatments – or any of the alternative treatments, which I know are available.	Well ultimately whatever treatment C has, it'll be – it'll be his choice, but the only thing I've ever said to him is that, if he needs to have treatment, I'd rather he have it, I don't care what – as long as you're here, does it really matter? We can manage.	**Man more concerned about active treatment side effects** Mark is concerned about the prospect of erectile dysfunction or urinary incontinence. Mandy is less worried about this and sees

				his survival as the most important factor.
	Supportive care needs	Of course, at the time you're there, because it's done so quickly, you can't think straightaway because you don't know to ask, I suppose; that's the only problem. It's after you've gone, you realise, oh I wish I'd asked this, I wish I'd asked that. Why didn't they tell me this? And so that's – I don't know how you get round that though, because you don't know what to ask if you don't know what questions are to ask in the first place, do you. I: Did you have somebody you could contact when you went home? P: The nurse gave me her pack with her business card and she said that – at any time, you know, day or night, if she's not available you can leave a recorded message and she'll guarantee to get back on the same day. But I haven't done that because I haven't felt the need to, although I've been storing up and writing down some questions ready for when I do go in February		**Would like a point of contact** Mark explains it's hard to ask all of your questions in the moment and it would be good to have somebody you could contact after the consultations. He's aware of the nurse specialist, but has not utilised the service.

Dyad 3 2536432 & SIG011 Alice & Adam	Information given	When I was first diagnosed, I mean that was quite a shock and I was given an information pack by the urology sort of support nurse. I read the information in there, but I've not felt that I've needed to go elsewhere for information. I found the Prostate Cancer UK website quite useful for medical information, at a level which you can delve into, either at a low level information or you can delve deeper for more sort of technically medical information. So I think that's probably since – other than the information pack, which is quite sort of basic information, then I think I've probably got most of my information from Prostate Cancer UK, I think.	There's always been literature that has been brought home and there's always been searching on the internet and discussing, but not any support from people but I don't think we've actively sought to get support. The nature of things that we felt, you know, it turned out it wasn't as bad as we were anticipating, didn't involve the major decision of whether you had surgery and things like that.	**Dyad satisfied with information** The couple received an information pack and read information on the PCUK website. They did not desire more information.
	Access to cancer nurse specialist	Did you have a – contact, like a nurse specialist contact? P: Yes I have, if I've needed to use it, but it's – I've not used that very often. There was quite a good relationship with a nurse in [hospital], so he was my point of contact and he did sort of telephone chats		**Not needed CNS** Adam explains he has not needed to use the CNS support often, and he built a good relationship with another nurse in the hospital.

		with me a couple of times, as well, with the sort of results of the MRI scan etc.		
	Investigation side effects		But he's had a couple of incidences where, you know, I mean particularly after biopsies, it's caused a lot of problems. And he had a bad instance in November when his prostate ruptured and he sort of lost a lot of blood and a lot of blood in his urine, so we were very – obviously anxious about that.	**Adverse effects of tests** Alice describes some painful side effects of the biopsies Adam has had, and how they increased anxiety.
	Reaction to diagnosis	what was your initial reaction? P: Well, you know, sort of – a fair amount of shock and – I've now got a biopsy sample that indicates the presence of prostate cancer and, yes, I must have had half a dozen, so different types of biopsies and nothing has ever been found So is it a needle in the haystack – job or – there's a fair degree of randomness as to what part of the prostate sample and things; so there's an initial – a day of anxiety and then that sort of [decays] away a little bit	I was shocked and worried and sort of xxx [phone connection breaking up] xxx we were going to have to make some decisions on which route to go down and things have moved a lot since back then.	**Initial shock and anxiety at diagnosis** Both Alice and Adam felt shocked at the diagnosis. Adam describes a process where his anxiety diminished once he'd learnt a bit more about the situation.

		So it became relatively clear to me that, you know, hopefully, this thing isn't going to kill me and I'll probably die from something else: the classic die with prostate cancer rather than die from prostate cancer. So that's my sort of general sort of philosophy. As long as I get the reassurance from time to time, active surveillance, scans, biopsies, PSA.		
	Reaction to AS	to me, it felt like a sensible decision to go ahead with, rather than rushing into – more invasive treatment; you know, so they were ready to act if it was needed. I feel that the active surveillance is the right thing. We keep being reassured that it's a very low grade and there's been very little change, but the reassurance is that – well – as soon as there is a change, they'll be ready to do some action. But what action it will be, well, that will be a decision when we come to it. I thought it was something well-suited to my particular situation.	we did have a lot of anxiety that was self-inflicted at the beginning, because we chose to take that route, but if you look at it, to me, we made the sensible decision then and he's got this sort of – monitoring of his condition and if it does turn nasty, we couldn't have done anything ever. We've done the best thing that we can do at this stage, I think. it's not been an inconvenience; I suppose it's really a reassurance to have that. He wasn't told to go away and wait till it gets worse; it's a reassurance that, you know, somebody is keeping an eye on the	**Happy with AS treatment plan** Adam felt AS was a sensible way to go. **AS is a safety net** Alice feels that although they caused anxiety by requesting the tests and discovering the cancer, they are now in a better position because it can be monitored and the AS protocol is like a

			situation for him. That's the way I feel and I hope he feels that way.	safety net to catch any progression.
	Patient-centred decision making	At some time, I'm sure the consultant I chatted to would have said so, well, we can approach this – via surgery, radiotherapy, chemotherapy, hormone treatments or active surveillance and I think, you know, we briefly discussed the pros and cons of all of those, but it was fairly clear, in my mind, from the relatively low risk involved in this, that – the less intervention the better.		**Decision to be on AS made jointly with clinician** Although Adam does not explicitly remember, he thinks he had the option to go for more active treatment plans, but decided on AS with his consultant.
	Current feelings about AS	Quite happy. I mean obviously I'd rather not have the prostate cancer, but given – I am where I am – then I feel quite content to stick with the active surveillance unless – any information comes to light which would change that situation.		**Content with AS** Adam is happy with AS.

	Perceptions of each other's feelings	Well I think, you know, she was shocked, probably just as much as me. But I think – like me – with the xxx with the information we have about my prostate, that it is a relatively low-risk situation, I think, you know, she's – as content as I am we both feel contented, in terms of the feedback I get from her, that we carry on with the active surveillance. She's not indicated otherwise, to me. And I think we tend to be able to sort of read each other's minds reasonably well; so I get the impression that she is as contented as I am to carry on with the active surveillance. Been very supportive and, you know, there's no indications that she wasn't – she didn't think that I should go down an alternative of surgery	Obviously he was very anxious and worried about it But, you know, I think he coped with it very well, but he is sort of very practical, pragmatic, so, you know, I think – he is the sort of person who can cope with things. He doesn't cope with surgery very well, but I think sort of the active surveillance suits him.	**Perceptions of each other's feelings** Alice feels Adam was anxious and worried when first diagnosed, but coped well. Adam believed Alice was shocked, but reassured that it was a relatively low-risk situation, and she'd been very supportive. Adam believes Alice is content with the AS plan.
	PCa Communication	I can't think of any – way in which I'd like her to handle it in a different way.	Obviously he was very anxious and worried about it and so we did talk about it and he read up a lot on things and you start talking to other people who've	**Good PCa related communication**

			gone through the same thing and you hear – you know – the not nice scenarios. And it was just sort of like take one step at a time and let's see what we need to do. But we did – as far as I can remember - we talked through a lot of things; what would we do or what should we do? And it was hard telling people, as well, and telling friends and relatives and things We talk about it enough. I mean I hope he feels that he can talk whenever he wants to about it and I can sort of say what I feel; I don't feel that we keep things from each other.	Both Alice and Adam are satisfied with the PCa related communication and feel they can talk about it as much as they like.
	Importance of SO involvement	do you think it's important that significant others are involved? P: ... If it's just a straight, routine active surveillance; I've had a PSA blood test the week before in readiness for the consultation with the specialist, I don't think there's been any change in my condition, I haven't had a biopsy, so it's just	Oh, I think it is important. I mean I didn't go to the – some of the initial ones, but I have been with him whenever it's sort of moved to a different stage or when he went down to London for the MRI scan I went in and met the consultant as well, and results of things, I found that that's been reassuring. And sometimes I don't know whether I'm in the way but	**SO Involvement most important for treatment decision making** Alice and Adam agree it may not be necessary to go along to every test, but when it comes to significant

		simply PSA, which has been a bit of a random number indicator, so I can't really see the point in M coming in with me just for that, because it's – I don't think there's going to be any major decision-making. I'm not getting the results of a biopsy, it's just the - this random number, PSA machine that's inside me and so what, it's gone up, so what, it's gone down. I: So do you think it's more important for partners to be there when there's some treatment decisions to be made? (P: Yes, yes)	they always felt that – I felt quite relaxed about it afterwards. Yes, I felt that that was right and hopefully that I was supportive for D on that. I mean the relationship is such that – there shouldn't be any sort of lone decision; everything should be – we're a partnership, so everything that affects him, affects me. And so things that affect me, affect him; so I think it should be shared. there could have been a sort of more positive say – bring your partner along or something, to discuss; I honestly can't remember whether it was, but there isn't sort of – when I do go along, sort of say – will you wait outside – type of thing; there's never any question of that. But I think maybe there could be more encouragement that the partner is there, if they want to be; obviously, you can't force anything.	appointments, and treatment decision making, it is very important for the SOs to be involved. **SO would like to feel more included** Alice feels she could be made to feel more welcome/included in appointments with some explicit encouragement to 'include your partner'.
	AS anxiety		I mean I suppose it's looming over you all the time that it could turn for the worse, but the active surveillance is sort of like an insurance for us. So I	**PCa 'looms over you'**

			think that here we are in a better position than a lot of people. And it's not – well, to me, it's not intrusive because it doesn't take a great deal of time; it doesn't cause us a great deal of upheaval in sort of what we're doing in our lifestyle.	Alice describes how the PCa looms over them and it could get worse at any time.
	The future	I'd be more than happy to stay on active surveillance unless there was any change in my – circumstances, in terms of how I feel; both in terms of the medical condition and mentally. If I started to get concerns about this and – started worrying about it, then I think I'd have to review the position and see, you know, is active surveillance the correct route for me to be on. But it's steady as she goes, really, I think, for me.	Well hopefully it will just stay – sort of – very stable, as it has been for the last 10 years or so and if it does change, then we are in a position to be there at the beginning of that change, to get, you know, treatment more or less straightaway, rather than sort of – suddenly developing severe symptoms and having to go and – access the NHS for treatment, he's already on the books, if you know what I mean. I think we're in the best position and staying on active surveillance keeps us there.	**Hoping to stay on AS in the future** Both Alice and Adam are happy to continue on AS and hope that is how it will continue into the future.
	Sexual problems		It's sort of on – sort of – the sex side of things, it's a bit difficult because he was having problems, so I would – felt that I shouldn't sort of force any relationships and things and – so that did get a little	**PCa side effects and communication** Alice finds it hard to know how best to manage the

			bit difficult at times. And I think it has left – some problems for us, because it's not as it used to be and I – suppose – have sort of – I'm more passive than maybe I should be, but then I don't want to make him feel uncomfortable because things aren't quite the same as they were. That is – you know – it's something that we've just got to work through, but we're also getting older, so I suppose things like that happen anyway. But, you know, there is a problem on that side and sort of the medication he has and things, so it's something that – maybe – I don't know, maybe it would help if we talked to some other people about it. I don't think we've reached that point yet. I: And do you talk about that with him? P: Not very often. I suppose that, again, is something that perhaps we should do a little bit more, but it sort of – feels as though you're making matters more difficult by talking about it, rather than clearing the air, which is the wrong thing to do, I know, but I don't know. There's been so much upheaval in the last sort of 18 months or so, that	sexual problems that have arisen due to the PCa. Adam does not mention this issue.

			trying to sort of settle this – the move and everything else down and sort of see how we go on from here. But I think, you know, it is – not an issue for me but I think it is an issue between us, if you know what I mean. And I think it's probably an issue for D, as well. I can just sort of accept the situation but I think he feels uncomfortable and, again, we really should talk about it, but maybe after he's spoken to you, and he thinks about it, perhaps we'll sit down and talk a bit more, ourselves. Maybe that's where – if you were in a group – you might feel – if somebody else brought the subject up, you would sort of join in, I don't know; I think sort of – it's just one of those difficult parts, I feel.	
	Supportive care needs	I felt okay – doing my own sort of research reading, but that's just my approach and that wouldn't necessarily suit other people. So it suits me; I've not needed to chat to someone to make informed decisions as to whether we go down the surgery route or chemo or radiotherapy. It's never – that's never been particularly high on our sort of – list,	if somebody else brought the subject up, you would sort of join in, I don't know; I think sort of – it's just one of those difficult parts, I feel. I: Yes, if somebody else brought up - even in a consultation, you know, just asked the question? P: Yes, yes. So that is a possibility in a consultation, if it was brought up, but then – I think	**Sensitive topics need addressing more directly** Alice feels the impact PCa can have on a couple's sex life should be discussed in a consultation, and that may open the lines of

		really (I: Okay) But if I was in that position, then maybe I would feel that it would be really useful to have a chat with someone, but I've never felt that I've been in that position of having to get further support.	trying to sort of just keep things ticking over at the moment. I don't know; it is sort of one of the issues, I suppose, that needs to get resolved as best it can be and I think it is resolved as best can be, but I'm not sure D does.	communication on the topic. **No extra support needed** Adam feels confident in conducting his own research and has not needed anything extra. If there was more of a need to make some treatment decisions it would be useful to have someone to contact to discuss options.
Dyad 4 2535822 & SIG009 Sophie & Alex		Well, course, these days it's seems it's so difficult to get the consultant to actually advise you what to do, at all. So – which actually I found a little bit frustrating, because the pros and cons of the different options are obviously very significantly different, but I did find it very difficult to try and compare. But in the end it was good that I got to see a consultant at [hospital] and I saw a chap up there		**Frustration with patient-led care** Alex found it frustrating that the clinician was reluctant to provide clear advice about the best way forward.

		and his advice was – probably going on active surveillance was a sensible way forward. So the first consultant I saw xxx told me that I'd got the cancer xxx gave me really no guidance at all, so, you know, it's much more just – this is a situation, these are your choices, which are – several choices xxx active surveillance, to radiotherapy, to a full xxx options and I think there was a couple of other options as well, which they don't push quite so actively because – whether they are – is it xxx or something, I think, is one of them, where it still sort of considered, in the UK, xxx as a – not a completely normal treatment, whereas in some other countries I think that's quite a normal treatment. So they didn't – they gave me – here's a leaflet, here's your options, let us know what you want to do.		
		I think when I originally saw the people in xxx, they xxx sent me leaflets from the – Prostate UK or	have you had any leaflets, anything like that?	**Wanted information to help compare treatments**

		whatever xxx, lots of leaflets, I think. So xxx leaflets which, again, are quite good but xxx try to compare, I found the most difficult thing. So I also had a chat with the Prostate UK people, but, to be honest, I didn't really get a lot from them because I don't think there was much more xxx already got it from the leaflets from them, in any case, at that point.	P: I haven't; T has got a whole bunch which I have gone through, I've looked through some of them and he's pulled out some for me to read, but none have come to me personally.	Alex received leaflets, but wanted something to help him compare different treatment pathways. **SO has looked at leaflets given to patient** Sophie did not receive any leaflets or information herself, but has looked at the leaflets given to Alex.
	Reaction to diagnosis	Well I suppose, particularly with all the other things, it felt like, in the scheme of things, it was actually – I wouldn't say trivial, but relatively minor compared with the other things and it seems that [at this early stage] that it was an early catch and therefore, you know, the prognosis was good. So from the beginning, didn't feel too bad, in the scheme of things, too bad.	That I wondered whether they should do something straightway – well – more – straightaway, the – you know – cut out all that – but it was explained to me that it isn't that far advanced and you can live with prostate cancer, which you can't with some others, that other cancers are more aggressive. Well obviously I was upset for him. I tried to support him best I could and tried to show that I wasn't – you know – too worried; tried to support him. But again,	**Differing reactions to diagnosis** Alex felt the diagnosis was relatively minor compared to his other health issues. Sophie felt worried they should be operating to remove the cancer straight away.

			you know, I mean it's hard isn't it, because you don't know if it's going to flare up or get worse or whether it's going to go on like that for years. So it's always hanging over you, isn't it?	**SO putting on a brave face** Sophie was worried, but tried not to show it and tried to support Alex.
	Reaction to AS	Well, to be honest, I don't think I really know a heck a lot about the treatment plan yet. As I say – I think I'm already on active surveillance. It's on the basis that, you know, just double checking xxx, so – but actually I don't totally know what my plan is.	I probably – it's hard when it's not you; I mean I probably would have wanted it out of me but – he wants that and he's happy with that and it's not that far advanced, so I'm happy to support him and I'm okay with it.	**Differing reactions to AS** Sophie feels in a similar situation she'd rather have the cancer removed, but will support Alex. Alex understands he's being monitored but seems unclear about the AS plan.
	Hoping for new treatments	I suppose partly my age, I'm not all that old, hopefully xxx, at 60, so – you know – that who knows what other treatments might be coming along in the next 5 or 10 years, that may be easier, better, whatever, have better outcomes, or even better outcomes, shall we say and – so there just doesn't seem to be		**Hoping for new treatments** Alex is hopeful that new appropriate treatments will emerge.

		any need to rush towards one of the other treatments, at this stage.		
	Current feelings about AS	how do you feel about it now that some time has gone by? P: This at this stage I'm hoping that the template biopsy will confirm nothing worse than what we know already, either that it is only the 3+3 on the Gleason and – and that there is no reason why active surveillance shouldn't be appropriate, as long as it's coming back with that, that I think, is almost certainly what I want to do.	how do you feel about the diagnosis and about active surveillance now? P: Well better now because he's been to see the xxx, we've had xxx and he's being kept informed on what's going on; so, yes, better than I was first of all, yes.	**Dyad content with AS at the moment** Alex is hopeful he can stay on AS. Sophie feels better about AS than she did initially.
	PCa related communication	I think she's okay with it. I don't think she has any particular – problem with it, yes. I suppose, I don't know, obviously she'll tell you. In truth, we haven't discussed it a heck of a lot but, you know, I don't think there's a heck of a lot to discuss. Some of the information we've got, it seems that is appropriate at this time; it's not impacting on our lives obviously, because – there's no xxx, from doing nothing, there's	He doesn't talk much about it; he's quite a strong man but, yes, I think he's fine with it. His friend had it and had it really badly and had to have the operation, so he knows all about that, as well. So I think he's happy as it is at the moment.	**SO would like communication to be different** Sophie explains that Alex does not talk about the cancer and is a strong man. She would like him to start conversations about it. Alex

		no side-effects, apart from the psychological thing that you know you've got a cancer which you're not doing anything about. I don't find that a huge problem, psychologically. So you mentioned that you don't talk about it that much? P: Not really. I don't think it's particularly avoided; it's more that there isn't a heck of a lot to say, probably. We talk enough to understand that (a) xxx. I don't know how much she has or hasn't read the leaflets [Inaudible dialogue] if she wanted to. She hasn't particularly asked me a heck of a lot about it xxx, but – xxx because it doesn't appear to be anything that needs to be done, in the shorter term, and maybe never, who knows.	I try to talk to him more than he talks to me; he doesn't talk that much about it, but he does answer questions if I ask him. I: Okay. And would you like that to be different in any way? P: Yes, it would be nice if he could start the conversation off.	also says they do not discuss it, mostly because there is not much to discuss.
	Perceptions of each other's feelings and reactions	I think she's okay with it. I don't think she has any particular – problem with it, yes. I suppose, I don't know, obviously she'll tell you. In truth, we haven't discussed it a heck of a lot but, you know, I don't think	He doesn't talk much about it; he's quite a strong man but, yes, I think he's fine with it. His friend had it and had it really badly and had to have the	**Uncertainty around So feelings** Sophie views Alex as very strong and believes he took

		there's a heck of a lot to discuss. Some of the information we've got, it seems that is appropriate at this time; it's not impacting on our lives obviously, because – there's no xxx, from doing nothing, there's no side-effects, apart from the psychological thing that you know you've got a cancer which you're not doing anything about. I don't find that a huge problem, psychologically. I suppose it was – it really was much more of just a relief because of that; the other issues seemed much more potentially to be focussed on, so it was almost – oh well, it's only a little bit of prostate cancer. Xxx it really didn't seem quite so bad, in the context. I: So it sounds like A responded quite similarly to yourself? P: I think so. She'll tell you. Yes, you'll see what she says; she'll tell you what she says. But, yes.	operation, so he knows all about that, as well. So I think he's happy as it is at the moment. how did he respond to the diagnosis and treatment plan, from your perspective? P: He's very strong and he seemed to take it all in his stride. Obviously he went a bit quiet. It's hard to say. I mean – he lost his brother from cancer, a different sort of cancer xxx, so I think he's had to reassess what's going on and think about it in great detail before you move forward with what is done. So, yes, I think it had quite a big impact on it because, as I say, his brother died of cancer. He was a smoker and it was more of lung cancer and that, but at one time T thought he might have had lung cancer. So, yes, I think he went through quite a bad stage at that point.	the diagnosis in his stride. Alex seems unsure how Sophie feels about AS, but thinks she's okay with it. Alex believes Sophie felt the same as him at diagnosis. **Miss-match between SO and patient accounts** Sophie explains that Alex had a tough time for a while with the diagnosis. Alex does not mention this.

	Changes due to PCa or AS	I don't think there's been anything much, to be honest; life carries on pretty much. So normal, I think.	No, not really. I mean obviously at the beginning he was thinking about – what's going on, what's going to happen to me and how long have I got, and that sort of thing, but I think once he'd gone through and see all the consultants, he's carrying on as he would have done.	**No changes due to PCa or AS** Alex does not feel his life has changed due to PCa or AS. Now the initial diagnosis stage has passed Sophie also feels not much has changed.
	AS uncertainty	there's no side-effects, apart from the psychological thing that you know you've got a cancer which you're not doing anything about. I don't find that a huge problem, psychologically.	Well obviously I was upset for him. I tried to support him best I could and tried to show that I wasn't – you know – too worried; tried to support him. But again, you know, I mean it's hard isn't it, because you don't know if it's going to flare up or get worse or whether it's going to go on like that for years. So it's always hanging over you, isn't it? The worst part would be [going there] and being told that it had suddenly progressed and, you know, it was getting really bad – which is why, you know, if you're having active surveillance, hopefully it would be caught before it got to that.	**AS uncertainty not an issue for patient, but is for SO** Alex does not find the uncertainty associated with AS a problem psychologically. Sophie feels differently and feels it is always hanging over them.

	SO involvement - appointments	how important do you think it is that your significant other is involved in the clinical consultations? P: Xxx but actually I think is important. Having said that, I think – I think, you know, xxx, normally I think there would be a reasonable amount of involvement, but I think it's – the main thing is – is normally, understanding (a) what the problem is and what the options are. I mean that's really – what it comes down to.	how important do you think it is that you, as the significant other, are involved the – in those consultations? P: He likes to do it on his own. I will go if he wants me to, I'd be happy to go, but he likes to go on his own. And I take him in the car if he needs to be driven, but usually I wait outside. (I: Okay) I think if it was worse, he'd let me in with him, but he goes on his own. I: And how do you feel about that? P: Again, I'd quite like to be in there with him but it's his choice.	**SO would like to be more involved in consultations** Sophie would like to be included in consultations, but explains that Alex likes to do it alone. Alex believes it's most important the SO understands the situation and options more than being involved in appointments.
	SO involvement - decisions	how important do you think it is that significant others are involved in the treatment decision-making? P: Again, I guess they should be, yes. I think it is reasonably important.	When it comes to the treatment decision-making, how important do you think it is that wives and partners are involved in that process? P: I think it's quite important. I: Can you expand on that, at all, to me.	**Important that SOs involved in decisions** Sophie feels it is important that SOs are involved in treatment decisions. Alex

			P: Well, if it’s going to affect your life, then really, you need to discuss it, don’t you, before you do anything. But obviously the final decision [falls to] the person with the cancer.	feels it’s reasonably important. **Decisions have to be the patient’s** Sophie believes the final decision has to be Alex’s.
	Supportive care needs	Yes it’s xxx really to have had much more – a better discussion on the options, in a comparative sort of way xxx, option A xxx option B, but it’s impossible for me to compare a xxx. I: Yes. Did you have somebody that you could – like a clinical nurse specialist – you could go back to and ask questions? P: Well, I did and – I think she was okay, but, again, it did rather feel like it had to be very much driven by me, rather than – I just would have expected the system to – have been able to – because, you know, they’re dealing with people like me all the time, so they know the questions I should be asking, because – I don’t even know the questions to ask, to some	is there anything extra that you might have liked, that you didn’t get? P: No, because he gives me – if he didn’t share his leaflets with me, then, yes. But they are here for me to read, so I don’t [inaudible dialogue] xxx because it’s just more expense, post-wise and paper-wise, isn’t it?	**Needed more guidance with treatment options** Alex felt he needed more expert guidance to explain and compare treatment options. Sophie was satisfied with the leaflets and information given.

		extent, in the first place. So – yes. So, because of that comparison, so because – I suppose – it listed different treatments, the pros and cons are quite different, it is difficult and it will probably vary from person to person and depending on their age and their health and various other aspects, I guess as to – so – it's not easy probably to do that comparison. But that's definitely the one area where I would liked to have seen something more.		
Dyad 5 2537358 & SIG016 Betty & Ben	Information received	did you receive any kind of information or support, like leaflets or were you signposted to any groups or anything at all? P: Bags of it, absolutely bags of it, yes. one of the other issues you asked about information – in some ways you get the point where you get information overload and also – one of the problems with information is that you read it and you pick out the negative bits and you concentrate on the	He may well disagree on that score but my thoughts are that initially there wasn't any information about it. I felt quite lost, actually, when we came out there was no leaflets; there was no number to phone, there was nothing. And I think, over the next couple of days, I think I perhaps started looking for things online, more than A did; I can't quite remember.	**Differing opinions on information received** Ben reports receiving 'bags' of leaflets and information. Betty does not report this and instead says she felt quite lost with the lack of information. **Negative aspects of information**

		negative bits and the negative bits are the ones that cause you most problems.		Ben explained that sometimes you can have information overload and it can make you overly focus on the negative parts.
	PCa support	in this area, they make – there is a connection between Macmillan charity and the local council, [name] and they have – now what is it – I guess the support is both in issuing information, but also in every public library within the city boundaries, there is a dedicated area for cancer support, not just prostate cancer, but cancer support and that is staffed on a sort of – not a daily basis, but certainly on a weekly basis, that is staffed by trained volunteers through Macmillan, where you have – you can go along simply for a cup of tea or chat or you can go along and ask questions that are more detailed.	maybe a couple of weeks later, A got a phone call from a very nice specialist nurse at the hospital where he was diagnosed and I think it was just a blip at that time, because she had been on holiday. So otherwise she said he would have been given her name right away and I think that would be helpful. After that she was very, very helpful and that was open to me, if I wanted to speak to her. I haven't done and didn't need to but I think more information at the time would have been very helpful.	**Informed about available support** Ben is very informed about the various charities and support available. He also spent some time volunteering for PCUK. **CNS beneficial** After initially being away at the time of diagnosis, Betty found the CNS very helpful.

	PCa Support Groups	I did for some, others I found were just a bit – a bit raw for me, like – men's support groups for prostate cancer, in particular. I was not inclined to go along to a session with other men and talk about prostate cancer in detail. you didn't want to go to prostate cancer specific groups; what was it about it, what put you off, what didn't you like? P: I didn't – I said to the nurse that – was saying that this group was available and they met on a weekly basis; I said I don't want to sit there with a bunch of men who are all talking about their prostate cancer, I want to think about other things. And she said – quite rightly – she said, well, that's what some men need to do. And – she was right in that, but it was – at the time it was wrong for me because my – my past has always been – if there was something difficult to handle, then I'll put my head in the sand. And that's the way I will cope with it. Now that was still the way I wanted to cope with it, but as I got over		**Disliked idea of support group** Ben disliked the idea of attending a PCa support group. Instead he focussed on providing telephone support to those newly diagnosed.

		the anxiety part of it, I decided, no, I did want to put something back, but because I was volunteering for Prostate Cancer UK, it meant that I wasn't – I wasn't sitting with a group of men, talking about prostate cancer; I was supporting people who had recently been diagnosed or were in the process of going through the pre-diagnosis stage. So I was doing telephone support for people who were being offered the option of active surveillance and I was also doing telephone support for those who had been on it but just wanted to talk a bit more about it and I found that okay.		
	PCa anxiety and depression	once the initial couple of years passed, I did start volunteering for Prostate Cancer UK and I stopped volunteering – I took a break back in November. I made contact with them and said – I'm not coping very well at the moment, emotionally; I'm getting myself anxious and stressed – because it's a bit like the willing horse. The more you do, the more that you're invited to do and I was – I was quite happy to		**Patient suffering PCa related anxiety and depression** Ben took medication for anxiety and depression from the point of diagnosis.

		do things. But at the same time I was also on ... drugs for anxiety and depression. I'd been on that from the point of diagnosis for, I think, a year		
	Volunteering for charities	I was also doing – manning, along with my wife, we were manning information stands at different things like motor shows and things like that and at the local hospital, on the day that the urology department was doing prostate cancer checks, that sort of thing. And then it all became too much – because I didn't – the way that I see it is – I no longer had the support of the antidepressant and I was having to face things – and I have to say – the charity were very supportive. They didn't just sort of say, well – yes – okay, if you don't want to work with us any more, that's fine, goodbye. They were actually very supportive in saying – if you're finding it tough, if you're needing any support, we have specialist nurses available to talk to, that sort of thing. So I have no – I have no bugs with them, at all.	we've done a little bit of volunteering and we know other people and I think they had much better initial support than we did.	**Dyad volunteering to help other PCa patients** Both Ben and Betty volunteered for PCa charities to help others. **PCa charities supportive** When Ben needed support from the PCa charities he found them very supportive.

	Treatment decision making	What did you feel about that? P: I played no part in it; I was just told. well I wasn't involved at all; I was just told, well, we think you're suitable for active surveillance. I mean – that decision, okay, clinically it may have been very obvious. From my age, my PSA results, the results of the biopsy; for a clinician, that may have been very clear and it was probably, probably it was, and is, still the right decision, but I played no part in it.	taken into account with other medical issues, age and everything else, that the multidisciplinary group at the time thought that was the best way to go forward. And, again, that wasn't a discussion, it was just a statement to A, was my understanding, that's what you should go on.	**Clinician led decisions** Ben and Betty explain the clinician made the decision for Ben to go on AS.
	Reaction to diagnosis	Immediate reaction was one of coming out of the clinic – and giving my wife the thumbs up in that everything was good because I only had localised prostate cancer and we went and we had lunch to celebrate. Now I find that looking back on that, that seems totally illogical, but it was almost as if – I wasn't – because I had to impart the information to	After lunch, we came home and I think we were both shattered and I think – I think maybe at that point, I started thinking – so does that mean that all his trips to the loo during the night were not attributed to – digestive problems	**Initial reaction to diagnosis illogical** Ben explains that initially he felt elated that it was not more severe. He now feels his reaction was illogical and the reality set in a little

		her, I wasn’t able to stick my head in the sand. So the next best thing was to put an illogical, positive spin on it all, because it could have been much worse. It hadn’t occurred to me that it could have been a lot better if the results had been negative. So that – that was the – that was the response; it was almost one of – not quite elation, but not far from it. And it was only later on that I suppose the reality, once you start reading and digesting and take time to digest, it was only from that point on that the reality came home Once I stuck my nose into books and leaflets and internet, it very quickly became no longer elation but a real reality and the outcomes that were possible and the consequences that were possible … So it became – it became all very raw … I came back down to ground pretty quickly.	So there was a lot of questions about that. And then it was also – so how are they going to get rid of it, because it didn’t sink into me – active surveillance meant that it wasn’t going to be fixed; it was a jumble about it all. Is he going to need an operation; how suitable would that be? So a real mix of feelings about it. And how he was going to feel about it. And also I thought - he’s a nice guy and he doesn’t deserve it. So, yes.	later. Betty had a lot of questions and felt the unfairness of the diagnosis.

	Initial feelings about AS	What did you think about it; what did you think about that treatment plan? P: It seemed good because it was – it was, in effect, crossing your fingers and hoping for the best.	on the one hand, I was very happy with that, that he wasn't having to go down the road of operations, because we know two people; one, it worked very well, the other it didn't work well. So I was happy that he wasn't being subjected to that.	**Mixed feelings about AS** Betty felt mixed about the idea of AS, and that living with the cancer untreated was worrying. Ben felt ok about AS.
	AS uncertainty and anxiety	the one thing I think that is not addressed – is the – the mental impact that it has on someone who's been – who is on active surveillance – because, in effect, nothing is happening – except – your fingers are being crossed. (I: Yes, absolutely) And that – yes, that can be quite difficult, so it almost warrants being something that you put out of your mind, to be able to handle it adequately and properly. You have the option of – as some people seem to want to do – go into it in enormous detail and be absolutely – have a cast-iron guarantee that that is the right decision. I could probably still feel of that mind if I thought about it too much. But I think that the – for guys	I was happy he was suitable for active surveillance, although sometimes it's difficult to – accept that he's living with the cancer; it's not something that's being fixed. It's there all the time, but if it can stay at that acceptable level, then I think that's something that he and I need to just accept and try and make life as good as we can with it. So I suppose I was a bit concerned about the way he was – he was dealing with it and I would make suggestions about trying to get some help, some support, whatever, but, no, that wasn't going to be for him. Yes, a bad time.	**AS uncertainty difficult** Betty finds living with the untreated cancer difficult. Ben also explains it is hard for those on AS. **SO concerned about how man was coping** Betty was concerned for a while about Ben and how he was coping.

		who are having treatment, be it hormone, be it surgery, be it whatever, radiotherapy – they are having something done, and whilst I'm not suggesting that they don't worry about it, of course they worry about it, but they are having something done. It's the point that you're not having anything done; you're being reassured that there will be plenty of time to do anything if things change, but at the same time, you're being told that – well – all of the current tests that we have for diagnosis and prognosis, are all a bit uncertain and – not definitive. Then, you know, you really are – you really are in lots of ways, you are just crossing your fingers.	I think the uncertainty of it all is a big thing and also a way of living with this cancer.	
	Current feelings about AS	how do you feel about your diagnosis and about active surveillance now? P: Oh, it's like everything; you just get used to it. It doesn't really – I don't think it causes me any undue concern these days, no. No, I would say that	I think much the same in some way; I feel we're both settled into it and – yes – I think I would still be happy. I'm still happy that he's been able to remain on active surveillance, yes.	**Happy with AS now** Betty is happy with the AS pathway at present. **PCa not causing worry**

		it doesn’t, because I’ve now turned 78 and I’m feeling fine.		Ben does not feel his PCa or AS is causing him any concern at the moment.
	Perceptions of each other’s feelings	I’m not sure how she feels about active surveillance. I would say that my – my mental – one of the major causes for me giving up Prostate Cancer UK volunteering, it was – I was having a negative impact on her. It was not good for her. She was becoming - she was becoming quite anxious, I think mostly about me and I was causing her a lot of emotional distress and that is the last thing in the world that I would want. So I could see that it was having a real negative impact on her and that was the point at which I said no, no, this has got to stop. she could see how I was handling or not handling it mentally and – that was causing – she was concerned and worrying about me and I was concerned and worrying about her. And we have an uncanny ability to transfer our emotions on to each other and sometimes, well sometimes it really is	how do you think A feels about active surveillance? P: Well I think also he’s happy too, that he doesn’t require an operation, but I know he does struggle sometimes, about the uncertainty of living with it. And a few weeks before the next check-up with the nurse, he does start getting a little nervous, anxious about it. And I suppose we both do and you’re just hoping that the results of the PSA and the examination and everything, will be okay. I would say that he – I think he does find it difficult sometimes, yes, but would prefer to be able to stay on that route, rather than operation, I think; well that’s what I think he thinks. He was quite – upbeat is too strong a word, but he was okay and then other times he would get quite low about it. And he’s someone who, if there is an issue, he prefers to bury his head in the sand and I	**Cyclical anxiety** Both Betty and Ben describe how the anxiety builds before a check-up. **SO accurately describes man’s feelings** Betty’s perceptions of Ben’s feelings about the diagnosis match Ben’s description. **Man worried about SO anxiety** Ben explains he’s unsure how Betty feels about AS, but could see the volunteering was making

		uncanny about how one can impact on the other. No, it had to stop. how did C respond to the diagnosis and to the treatment plan of active surveillance? P: I'm not sure; I think – I think she was happy that – because of my cousin's husband's experience, I think she was happy that we could cross our fingers and hope for the best and that I didn't need invasive surgery or any other treatment. I think that's – yes: maybe I never asked her how she felt. I became quite reclusive. I worried, maybe about a month before my clinic appointment, I would start to get quite concerned and then go along, get a good result, come away quite happy and at the point at which I was in three monthly visits. Then I had that to worry about in two months' time.	think he did that for a while. I'm kind of getting mixed up because it's a few years now, but I think he buried his head in the sand. He went from that, to being a bit elated and, oh yes, it's fine and – you know – I'll beat this, but I think mostly it was head in the sand and he got quite low at times about it. I would say that – it's about – it's about the uncertainty, and difficult for me, seeing when he does get anxious about it or upset about it.	her anxious and worried about him. **Man believes SO happy with AS when presented** Ben voices that he might not have asked Betty how she felt about AS, but believes she was happy with the plan. **SO struggles to see man feeling anxious or upset about PCa** Betty finds it hard to see Ben in distress about his PCa.

		Probably the active surveillance is – is less of an impact on her than my general mental well-being; I think that was the thing that was taking its toll.		
	Changes due to PCa	I don't feel – I don't feel much different and I don't look much different.		**No changes due to PCa** Ben reports no changes in his life due to PCa.
	PCa related communication	I would tend not to talk about the sort of negative sides of things. No, I don't think we talk. She may give you a different answer and that's fine, because during the process of my anxiety depression, I think the GP was – I think he was starting to get the impression that perhaps I was not being totally honest or totally – revealing all, so he actually asked if I would mind if [wife] joined the appointment. And I said, no, that's fine, so she joined the appointment. And when he asked her a question about how she thought I was handling life in general, although he asked her the question, he watched me the whole time, to see what my reaction was. And she's fairly astute and fairly straightforward with things and that was – that was	do you talk about it, do you feel able to talk about it? P: Yes, I would say we are, yes, I would say we're pretty open with each other and also because we've been doing, A much more than me, volunteering, you know, we've been to quite a lot of meetings and different activities that he was doing. He was doing 1 to 1 telephone support and things, but, yes, we would chat quite openly about it, yes.	**Differing opinions about communication** Betty feels they communicate openly about PCa and AS. Ben feels they do not really talk about it. **Protection of SO** Ben explains he might not talk about things with Betty if he thinks it might cause distress.

		the key, I think, to the treatment. He was satisfied that he had a total picture of what was going on, rather than my version of it. Do you feel able to talk to [wife] about it, if you needed to, if you wanted to? P: Oh yes, yes. (I: Okay) But then, if it was going to cause her any anxiety or any distress, then I wouldn't want to; I would want to keep it to myself and think about it myself.		
	SO involvement	She came to every clinic with me, she insisted that any time, even though I said to her, look, you don't need to come, she insisted in supporting me and coming to every – every clinic. She joined me in the – I think – probably against her best idea – she joined me in the prostate cancer support. And she read all the booklets, she read all the information	I think it depends on the couple themselves. We've always been a pair that – we go along with each other for appointments, but we don't go in. I think only once I've gone in, when the GP suggested it and A agreed, because he was feeling very low at that time. But, no, I think it really depends; I think the option should certainly be there, to be part of – because – when you're living with someone, it affects both of you; so I definitely think the opportunity should be there and then it's up to the	**SO involvement in appointments depends on the couple** Both Ben and Betty explain that SO involvement in appointments is good if it suits the couple.

		I think – if they want to be and if they can cope with it, I think it's – it's a great support to be able to do things as a pair rather than do it on your own, yes. I think xxx, but I mean if you're in a – if you are a significant other and you're in a stable relationship where you do support each other through love and caring, then it's absolutely essential that they are part of it. Yes.	couple themselves whether they want to do that or not. how important do you think is that you or the significant other would be involved in that treatment decision-making process? P: I think it would be important and I think – A was the sort of – well, they decided that. And, again, that wasn't, that's not derogatory, because he's very supportive of the NHS and volunteers, but, you know, the decision was made without any discussion and I think it may have been helpful to have more discussion and also the partner as well. Now, whether that was the xxx one or in an ideal world maybe the person, like A, would have the diagnosis and then maybe a follow-up appointment, not with the consultant necessarily, but perhaps even a week later or two weeks later. I think in an ideal world but I don't see there's anything wrong to aim for an ideal world really. I think that would have been quite helpful because we had an awful lot of	**SO involvement important in treatment decision making** Both Ben and Betty agree it is important to involve SOs in treatment decisions.

			questions at that time and if there had been something like that, then I would certainly have been in the room with him at that time, as well, with my list of questions. I'm a great one for having things written down. So, yes, I think it's very important.	
	Supportive care needs	It might have been helpful to have been offered counselling at some point. But the problem with counselling, it's like everything else; you can get a good counsellor or a not so good counsellor. I do think you have – you have a responsibility for your own health, for your own self and that's probably –. Yes, we've managed okay.	I think, you know, as I was saying, we didn't get the telephone number of the specialist nurse; I think that would have been helpful at the very beginning, just to know that and perhaps even a telephone call. The telephone call that A got – in fact – no – it was longer, it might have been 3 ½ weeks or something, that would have been helpful a few days after it. Perhaps also some information, some leaflets: I know you can look things up online but it's also still helpful, I think, just to have something in your hand that you can just casually pick up.	**SO desired more support and information** Betty would have liked contact from the CNS at the point of diagnosis and some extra written information. **Patient feels counselling may have been beneficial** Ben feels being offered counselling at the point of diagnosis might have been helpful.

	The future	Do you think it will remain the same? P: Yes. (I: Okay) Yes, I do.		**Man believes he will stay on AS** Ben believes he will stay on AS and things will continue as they are.
Dyad 6 2549868 & SIG021 Bridget & Max	Initial reaction to diagnosis	When I was diagnosed – you sort of obsess about it initially till you find out a bit more about it. My wife came in when I was given the diagnosis and obviously she took in more than I did, but after about a month, I decided to be a bit more proactive. I contacted Prostate Cancer UK, first of all to get a bit of information from them and then also I decided to volunteer my services	Well, you know when you're going to get the results, it's either going to be a good one or a bad one and I thought – well it is a bad one, but, you know, I hadn't wanted anything, of course, but that would be the one to go for, that there was slight signs, but it wasn't malignant, so it wasn't aggressive, that's the word I'm looking for. So, you know, I thought that was – not too bad, at all, or it did seem to be liveable with, you know, resolving, before it needed – went into the bones and all this lot. So I was quite relieved, really	**Pt obsessed after diagnosis** Max describes obsessing at the point of diagnosis until he'd learnt more about the condition. **SO relieved at diagnosis** Bridget felt the diagnosis could have been worse, so felt relieved.
	Information received / seeking	When I was diagnosed – you sort of obsess about it initially till you find out a bit more about it. My wife came in when I was given the diagnosis and obviously she took in more than I did, but after about a month, I decided to be a bit more proactive.	So he knew exactly what was what and all the options and the more people he speaks to, support groups and all this, the more information there is. So it's pretty good, I have to say.	**Self-initiated research** Max contacted PCUK for information.

		I contacted Prostate Cancer UK, first of all to get a bit of information from them and then also I decided to volunteer my services, sort of, whatever I could do as a volunteer.		**Volunteering for PCa charities** After contacting charities for information Max became a volunteer to help others with PCa. **SO felt they were well informed** Bridget feels that between the CNS and PCUK they knew all of the options and understood what was going on.
	Support received	Certainly the specialist nurses at Prostate Cancer were very, very helpful; I phoned them on a few occasions and they've been excellent. And they’ve got urology nurses that the hospital who, again, has been very good in basically answering any questions and any concerns. Also in my fundraising, I contacted local prostate cancer support groups and	He spoke immediately to the specialist nurses, the urology specialist nurses at the [hospital] and they were absolutely brilliant. They put all my fears to rest and made him feel very reassured and that he wasn’t on his own, that there was always help.	**CNS helpful** Max and Bridget found the CNS very helpful. **PCa charities helpful**

		I found one which is a little way away, which is in [town] and they were very supportive in sponsoring me and what have you. So I went to some of their meetings and they had visits from a couple of the consultant specialists at the hospital and I found that very interesting, what they had to say, to such an extent, I'm not sure whether you're going to cover this somewhere else or not, but I actually transferred my care from the hospital I was initially at to [hospital]. (I: Oh, interesting) So that was supportive and also a very interesting learning process from the consultants there and certainly the specialist nurses at the hospital and at the charity, have been excellent. Can I just ask – that support group, was it for men on active surveillance specifically? P: No, no, it was men – I think most of the men there had been through different procedures and treatments. I think I was a little bit sort of on my own there, on the active surveillance, because I	Then they suggested he contact Prostate Cancer UK and had a good chat with some of their people who had experienced the same thing. And then he decided he wanted to get involved himself.	Max found the PCa charities very supportive. **Support group not aimed at AS** Max explains the support group was for men with PCa, but he was the only one on AS.

		think what happened was that they had a contact with the hospital and men then, who had gone through various treatments and so on, were given the support group details for them to join if they wanted to and get help that way.		
	SO involvement		since he was the age of 60, he's always had an annual PSA test; his doctor suggested it as part of his well man thing that they instigated 10 years or so ago. And obviously I keep a note; he always tells me what it is and he keeps a record, so I can see whether it's up or down. And if it's up, I know the reason why, if he's run the odd marathon or whatever.	**SO keeps track of PSA** Bridget describes how she kept track of Max's PSA results since he started having the tests.
	Reaction to diagnosis	Initial reaction was – surprise, because I knew I had an issue with my prostate but I just thought it would be an enlarged prostate, problems with urinating. And the cancer aspect, I hadn't really considered, so that was a bit of a surprise. As I say, that's really all	And then it did go up and they said, you must have the biopsy, that's all good really, isn't it, because whatever it is, if you catch it early enough, at least you've got more of a chance and the statistics being 1 in 3 will get it, cancer of some sort, then – you	**SO practical** Bridget describes being practical and not alarmed about diagnosis.

		that occupied my mind for about a month afterwards and then I made a conscious decision, rather than just keep thinking about it, to go and do something positive. I think that's probably – a little bit in my nature; I thought, well, that way, at least, I can get out and learn more and it would help me, if you like, to be a bit more accepting of it.	know – it just seems sensible, to me, it's no good getting emotional about it all. So, you know, and then obviously the first biopsy – well you carry on and ask the questions. I: That's okay. P: I wasn't alarmed because – I – this is life, isn't it; you have to expect something. I'm very practical and – you can't just bury your head in the sand and hope it will all go away. Well he was shocked and that was a bit of a mystery to me, because obviously we're on this route; I wasn't shocked, I was sort of half expecting it.	**Differing reactions to diagnosis** While Bridget describes not being alarmed and feeling practical about the diagnosis, Max describes feeling shocked and occupied by the news. **Being proactive as a coping mechanism** Max describes being proactive to help him become more accepting.
	Perceptions of each other's feelings	how do you think L feels about active surveillance? P: Well I think she's quite happy about it. She probably knows – almost as much as I do about – the condition and all the associated aspects, because she helps out with the volunteering for the charity as well, so she's become fairly	I mean he was a little shocked, but I was of the opinion, well, it could have been a whole lot worse; it could have been a lot of aggressive stuff, but at least he said – well it isn't aggressive and there are only about three or four tiny little spots.	**Accurate description of each other's feelings at diagnosis** Max and Bridget accurately describe each other's feelings about the diagnosis.

		knowledgeable about it. I think she's fairly relaxed about it. I think she was okay, I think she was fairly calm, because she was actually able to recall more of what happened with the initial visit with the consultant than maybe I was. But she seemed to be quite together with it all, I think, probably some concern, obviously, because we didn't know where this is going to take us. But apart from that, she's been – I don't know – fairly level-headed about it all and, yes, positive. I think it was positive, yes. I mean thinking of different scenarios, she could have fallen apart I suppose, which wouldn't have been very supportive at all, but no, she was – yes – she was supportive and positive about it	Well he was shocked and that was a bit of a mystery to me, because obviously we're on this route; I wasn't shocked, I was sort of half expecting it. And how do you think he felt about active surveillance? P: Yes, he's quite pleased he's got that and he has chased up when he knows it's time for the next check. I mean the hospital have been a bit tardy on some instances but he's sorted it out himself; he hasn't just buried his head and hope it will go away, which I suppose is what a lot of men do, I know. I was surprised, yes, I wasn't shocked, but I was surprised that he wasn't quite as philosophical as I am, that was all. But then I'm very straightforward and, you know, a fact is a fact and that's it.	**Supportive SO** Max feels Bridget has been very supportive. Bridget accurately describes Max's initial feelings towards AS. **SO surprise at pt reaction** Bridget was surprised that Max was so shocked by diagnosis.

	Reaction to AS	Yes, it was okay. I mean after seeing the consultant, I was fairly quickly taken out into another room, with a specialist nurse, and she explained it all to me and she actually went into the extent of all the other treatments, but that wasn't really applicable at the time. So she explained what the active surveillance was and so I thought, well, at least this is going to keep a check on things, so, yes, I was more than happy with that.	I mean I would have said, well probably it's best removed, but I know that causes a lot of problems and J would do anything to have that avoided, because he's heard so many stories and it wouldn't bother me either way, but then – So – I thought the active surveillance was fine and he's very good with the PSA test, having them done regularly and always – follows them up and tells me. So – yes. if the prostate was removed altogether, he wouldn't have to keep dashing to the loo, but then – that's the only problem; suddenly he is fine and then it's desperately urgent, but that's because it's enlarged. But most men have to go through that. So if they took it out, he wouldn't have that, but then he may become incontinent, I understand that – and all the sort of sexual parts of it. I don't know whether you've had children, but once you've had children,	**SO would have preferred to remove the cancer** Bridget explains she thought it would probably be best to remove the cancer, but understood Max's decision and was fine with AS. **SO less bothered by side effects of treatment** Bridget explains Max was worried about the side effects that might come with intervention, but she is less concerned about these. **Pt content with AS**

			you've lost all sort of sense of modesty, it's just a slab of meat on a butcher's slab, isn't it? [Slight laughter from both] I can't get excited about that. [More laughter] People are so funny about it, but – you know, it doesn't bother me.	Max describes feeling happy with the AS plan.
	Current feelings about PCa/AS	I'm due to have a bi-annual visit, either with the specialist nurses or with the consultant, to talk things through further, as to whether we carry on with this or not. But I'm fairly happy to carry on with it.	I'm very sort of philosophical about it. I mean he's lucky to get to 70 and I'm nearly catching up with him and we've had very little other problems, so I think, you know, we have to be thankful.	**Happy with AS** Max and Bridget are happy on AS at the moment.
	Treatment decision making	well, it was put to me because – I discovered later on that the cancer cells they'd found were – there was a fairly small percentage and it was low grade, so they didn't think there was a necessity for any		**Clinician led decision** Max explains the clinician presented AS as the obvious choice.

		further treatment and so it was put to me as the obvious route. And I thought, yes, okay, that sounds fine.		
	Changes	I think the main issue I have is – because of the enlarged prostate – that I've become accepting of the situation and the route that I'm taking and feel positive about it, carried on my work with the charity.	How has your life changed? P: It's got busier. Well, nothing's changed really, other than – you know – he's taking up lots of new interests and so am I; we're making the most of our retirement and that's entirely what we do all the time. So – not with a view that it's not going to last long, but just life generally; you've got to enjoy each moment, haven't you. You can't be wondering about – what if or what might happen; it doesn't matter does it, just live for the moment and enjoy everything.	**Pt acceptance increased** Max describes how his acceptance of the situation has increased over time. **Making the most of life** Bridget describes making the most of life.

	SO involvement	I think she's very happy to – if I want to do anything like – seek any different views or treatment or whatever, to come along with me on that; she usually accompanies me to the hospital when I have a check-up or whatever. how important do you think it is that the significant other is involved in the clinical consultations? P: I think it's very important, yes, very important. I think the visits I've had to hospitals, more often than not, I think the men have had their partner with them; so that seems to be fairly common. It's rare to see a man on his own. So, yes, it's important. I think, for men, we're not always that good at coping in these situations, with health issues. I mean if it was something like sorting out the fence in the garden or whatever, we'd be fine, but personal health issues, men aren't always really up to it that well. And quite often it's the woman who's the one	how important do you think it is that they're involved in clinical consultations? P: Oh, very important. I think they need to get behind the man and find out information, do you think it's important that you're involved in that as well? P: Yes, oh yes, he always discusses everything with me.	**So involvement in consultations important** Max and Bridget agree it is important for the SO to be involved in consultations. **So involvement in treatment decisions important** Max and Bridget agree it is important for the SO to be involved in treatment decision making. **Final treatment decision is the Pt's** Max feels the final treatment decision needs to be his own.

		who – has maybe got the sensible head on and is there to – well to listen to what’s being said and maybe sometimes reinterpret it to the man afterwards. Yes, I think it’s important that they’re maybe there with the consultant, to listen. At the end of the day, I think it’s down to the man to make the decision, but certainly it’s good to have their views or opinion on it, because if there was going to be treatment, some of the treatments are quite drastic for this condition and they are maybe going to have to deal with the consequences of it – or share them, anyway.		

	Clinician interaction		the doctor was a little abrupt, telling him that – I was of the feeling that, if he had got it, they said, you know, if you're going to have a bad outcome, that was the best of the bad outcome So it sounds like he was a bit more shocked than you were? P: Well he was. He said, oh, I didn't like the way he came out with it. I mean he could have just said, you know, we do have the tests results back and – you know – it's not entirely good, something like that. But, no, he just said – oh we've had the results back, and yes, you've got cancer. And that was it; we were somewhat stunned. I mean he got the message across but he could have done it a little bit softer, I think.	**Clinician was blunt** Bridget describes how the clinician was blunt in delivering the diagnosis.

	AS & PCa related communication	I mean I don't have any issues about it at all; whether I'm talking to L or whether I'm talking to somebody else about it, because my main – idea is just to get the message across. So, yes, I'm happy to talk to her about – I mean I show her the – I tell her what the PSA readings are and so on and she knows if I've got another appointment fixed up. So, yes, I mean I don't hold anything back, keep any secrets or anything; I just share it all with her and she normally says, oh, okay, yes, right.	how do you and J communicate with each other when it comes to talking about active surveillance; do you feel like you can talk about it? P: Oh yes, we talk about it all the time.	**Good dyad communication** Max and Bridget feel they communicate well about the PCa.
	Supportive care needs	anything else at all, that would have been good? P: Yes, yes, much more information from the consultant. The initial consultant I had – it was really – okay, so telling me what he thought I needed to know, or the minimal what I needed to know, which, quite often left me, initially for the first year or two, in just wondering – exactly what the condition was, what it might progress to and so on.	is there anything else, at all, that would have been useful? P: I don't think so, because there's so much information online and – you know – that is all good, because you've got so many experiences, if you choose to go and look for them, that you can assess everything that there is available.	**Pt desired more information from the consultant** Max wanted more information and explanation from the consultant. **AS specific support group would be helpful**

		That was really less than what I would have hoped or expected earlier, when you mentioned that you found that support group, that you were kind of – the only one on active surveillance; how about anything like that, that was more active surveillance specific, would that have been helpful? P: Yes, I think it would have been, certainly earlier on, yes, it would have been helpful. Active surveillance tends to be a little bit glossed over, in other words it's summed up in a few words, in the sense that you're given a blood test every 3 - 6 months and then we're just keeping an eye on you. But I think – the reason was why you're under active surveillance and little bit more about – you know – the underlying condition, sort of how it could change and so on, would be better, because essentially you're just launching yourself on this program, thinking that, okay, well that's the lesser	You need to get a support group, which is the most important thing, I think, because then they don't feel alone and wives go along, some of the wives go along and they can see that it's just – it's just a medical thing; it's not personal, it's not sexual and all this business, it's just a thing that people have information to share. And it becomes a much more manageable thing, if you like and it's seen as, you know, commonplace almost, rather than something people get all embarrassed about talking about. I mean I collar all sorts of strange men and say – have you had had a PSA test?	Max explains how the PCa support group he attended was not specific to AS, and that this would have been beneficial. **Support group is the most important thing** Bridget believes going to a support group is the most important thing to do.

		of many other evils, but I’m not quite sure where it’s going to end up taking me. There isn’t really, I suppose, a group that I’m aware of – of people that are on active surveillance, so although there are support groups, and the support group, I think, was really set up for men who have gone through maybe medical treatment, to help them through the consequences of that, there isn’t really anything, a group of men who are on active surveillance, who might want to get together and talk about it, because what I’ve picked up on, certainly from the – Prostate Cancer website and Facebook pages – is the anxiety that can come up every time that you’re going for your PSA test, waiting for the results and the stress that that can cause. I suppose that’s – that’s generally always there and some men, I think, actually go for treatment, and maybe a radical prospect to me, so they no longer have to go through that stress – which is – I don’t know. Sometimes the treatments aren’t necessary and there is no real support to help		

		you through maybe the ongoing anxiety. I mean I always – when I’ve had my blood test – I will always phone up the surgery a few days later to get the result; that way I know and it’s done. But – yes – that is the main downside to it, I suspect.		
	The future	for the time being, it will be carrying on with the active surveillance. I have the next appointment coming up in May, so we’ll see what it is then. I’m having further tests, but as far as I can see, unless anything changes, any of the readings get worse, then it will carry on like that – short to medium term, I guess. But I am always listening out for any – further developments in the treatment, should it be necessary in the future. As I say, I think my main issue, really, certainly medium-term, can be – the enlargement of the prostate and how to deal with that. But that’s sort of slightly aside from the cancer. But the cancer issue, I mean I think it was a broadcast last week – nationally – that it’s been greatly underfunded, this disease, and I think a lot		**Will continue on AS until something changes** Max will be guided by the test results and remain on AS unless something changes.

		of the time we're sort of shooting a bit in the dark. So unless there's anything better, then we'll stay on the active surveillance.		
Dyad 7 2611660 & 2613712 Mike & Sue	Uninformed throughout diagnostic procedures	I went to the consultant with the absolute minimum of information. I found out that I was in a one stop – prostate biopsy clinic. I wasn't forewarned or anything, other than on a compliment slip, of some incomplete information about prostate. I say incomplete because I checked it out afterwards. I found myself in a room with three women and it was all set out for a biopsy. I had a little bit of knowledge beforehand and I didn't want the biopsy and I was going to leave the room, but I crumbled to the expertise of the nurse that was leading this. So I had the biopsy, ill informed, and then – it would have been a week later I got the result which was given by – a nurse that they'd found cancer in the prostate.	And we were very, very surprised when he had letter inviting him to a clinic of an unknown woman, not his usual consultant, somebody he'd never heard of, there was no title. There was a tiny compliment slip hinting that he might be offered a biopsy on the day, it is possible. Again, the clinic wasn't named; there was no contact number, just a name and no title and, you know, he seemed quite shocked, well, surprised; a biopsy, why do they want to refer me for a biopsy? Maybe two pages, very badly photocopied, of information for Prostate Cancer UK, but leaving out all the side-effects, there was only two pages.	**Healthcare provider communication breakdown** Mike went to his consultant appointment unaware and unprepared for a biopsy.
	Information received	The support and information has come, really, from – my own enquiry which has been prompted by my	There were Prostate Cancer UK leaflets for men newly diagnosed, which the clinical nurse specialist	**Lack of information**

		partner; she's given me links and things to read. So a lot of it is self-gleaned. When I got the results on 30th of March, I was given a prostate cancer charity booklet and until recently my lifelong – family doctor, GP, gave me information. No, I haven't been signposted to any other support.	who gave us results had partially filled in; she'd put the Gleason grade tumour stage, which is interesting, because without visual imaging, again, I find it quite hard to believe that you could put down a tumour stage just on the grounds of one random biopsy. She put on her name and contact number and also informed us that she was a key worker. She put down the name of the nurse consultant who had done the biopsy, but no contact number and no consultant and that was pretty much it. And it took us months to find out whether she had a consultant and, if so, who it was. I still wasn't clear.	Sue and Mike both felt the need for more information, and that what they received was unsatisfactory, and they did not receive signposting.
	SO involvement	I think it – only in rare exceptions should they not be involved, yes. I: And why do you think it's kind of helpful? P: Well purely for – well various reasons: one of them is because the patient will only probably take in a small percentage of what's happening, particularly if they've just received what might be perceived as a shock, being told they've got cancer.	And I was not entirely sure, you know, whether I had to come along or not, but, you know, we talked about it and I was quite happy with him going to gain a bit more information, just to find out why and, you know, why they considered necessary – or as I said, ask about an MRI first because from what I understand, transrectal – xxx guided biopsies are pretty much playing battleships. Without any prior imaging it just seems madness to stick a needle	**SO anger about lack of inclusion by healthcare providers** Sue explains the appointment information did not advise to take someone along to the biopsy, and she is upset it happened without her

		So there's a second pair of ears; there's also a voice, where the patient might not, at that consultation, be saying what they've said in private, plus – you know – in a partnership you go through health issues together. There might be a patient, unless it were a carer, but you know, it's hard for me to think that the two are not hand-in-hand. I: How about in terms of the treatment decision-making; how important do you think it is that they're involved in that as well? P: Oh, absolutely; yes, absolutely. I mean if I had have gone for the – well – any of the options, then it would have been life changing in our relationship; it would be life changing for her as well. So, yes, I think, you know, as it were – my illness, I think it's shared because of the significant effects on the partner.	several times into a nicely contained organ, through someone's rectum, which is full of all sorts of things. Yes. Within 20 minutes from what I knew the appointment time to be, I had a text saying – I wish you'd been there, they've done it. ... I'm still struggling for words to actually describe what I felt – absolutely outraged is somewhere near it. He never should have gone by himself; there was no mention on the letter, either bring somebody along xxx no [consideration for any partner] Yes. It was absolutely atrocious. And he arrived home with nothing, bar antibiotics not even in a packet, no package; there was no discharge letter, no contact numbers, no info, and he is in a complete state of shock, as was I, plus the antibiotics he had been given – do carry a warning on them that they might impair cognitive ability. And given that he faced a 90 minute drive home, he should never have been driving by himself. He was in pain; he was in shock, he couldn't remember even signing a consent form.	there. She is angry about her lack of inclusion in all appointments. **SO as advocate** Sue has had to be an advocate for Mike, and it has been hard to speak to the right people and gain information. **SO involvement in appointments and treatment decision making crucial** Both Sue and Mike agree SO involvement is very important.

			I don’t know how familiar you are with PTSD, but it can manifest in all sorts of ways; he’s somebody who acquiesces very easily, because it’s the path of least resistance and he almost disappears sometimes, as an individual, when put under pressure. So I think that’s what happened, largely and, yes, he needs an advocate; he needs somebody to sit and he would just establish what it is he might like and want and that wasn’t offered, that wasn’t there. I’ve had to fill that role and it’s been bloody hard, every step of the way has been a battle, even just getting to speak to relevant people, establishing who is in charge, establishing how we can talk to them. Yes, I’m his advocate, if anything. I was never asked, I was never even considered, he was never even asked – have you got a partner, I was not asked my name at the results appointment; I was not asked who I was, I wasn’t offered a chair and, yes, xxx.	

			That’s not how people should treat each other, let alone medics to vulnerable patients. So 120% crucial. in terms of the treatment decision-making as well? P: Absolutely, yes, yes, it’s supposed to be joint, not just between medic and patient, which clearly hasn’t been, but also, you know, wider support networks, partner, friends, family and it’s just not happening or it hasn’t happened to us. And from what I hear from other people, very, very similar, if not worse.	
	Dissatisfaction with care		Yes and it got - it got more and more interesting, the results appointment. Oh yes and – three people in the room at the time, from what he did remember, bit by bit, were not even introduced. The door opened halfway through the procedure, to hand over paperwork, which we found out afterwards was his urine test results, without which they should never have started. Antibiotics were given minutes before. ... The risks – and if it’s uncertainties and	**Dissatisfied with care throughout diagnosis period** Sue explains a number of short fallings on the side of the healthcare provider.

			alternatives were not discussed. I mean 20 minutes does not give time for any discussion and, from what I understand, he basically was coerced into it, through fear. The signature on the consent form, which I finally got to see, was his. The date next to it was filled in by somebody else, not signed and clearly stated at the bottom - you will be offered a copy of this – which he never was, the copy was still attached to it. Yes, the results appointment, again, at least half an hour late. It was made with the nurse consultant who conducted the biopsy, who never turned up, no explanation given. Again, there was another woman in the room, never referred to, not introduced and had I had my wits about me, I would have said – and who are you and can you leave please. The nurse carried on reading through the options. I then asked to see the consent form, the PSA graph the path results, which – was met with surprise. The	

			woman said – have you got a medical background? I said no, but I'd still like to see them. Yes – at which point I had a look at the consent from and – yes – also a quick look at his notes; there was no time stated as to start; it was not stated who was present. There was not stated which – if any antibiotics had been given, nothing, which was interesting	
	GP experiences		We went to see his GP about two weeks later and not only had she not been informed that he'd been referred, nor that a biopsy had taken place, nor of the results, still hadn't had a letter. And she then received a letter not long after we'd seen her saying he'd stated very clearly he'd opted for active surveillance – which is a treatment in itself – and needed his consent, which he clearly had not given	**GP uninformed by hospital** Sue explains the GP had not received up to date information from the hospital.

	Supportive care needs	But, yes, I would say it affected her more than myself. I do think there is a lack of care for the partners of people with the illness. anything extra that would have been good? P: Yes, I think full disclosure from the – the nurse, consultant-led [team]. I think far better information, which is balanced and not just with perhaps a vested interest of individuals or departments or whatever. Yes, I think there needs to be a far greater open discussion about it. we rather laughingly had a key support worker and, in all fairness to her, we later found out she had 650 patients; so, you know, even when we were able to get hold of her, which might take days and subsequently trying to get hold of consultants, not for myself, but my dad's got cancer, trying to get what is termed a key worker, someone who knows you and knows your case, isn't working; it just seems to be window-dressing. So that would be	So, yes, going round in circles and no contact numbers and the clinical nurse specialist exceedingly difficult to contact. When we did contact her, she did not seem to take on board that G has got both memory and hearing trouble, as well as suffering PTSD, which was down on his referral letter, which was marked non-urgent and refused to, first of all, conduct any further communication by email, said, no, we can't do that; refused to send us the pathology report of the PSA graph. She did retract that eventually and then it was, oh, of course we'll – we can email you but, yes, unhappy story, a very unhappy story. We did put in a concern informally and that didn't get us anywhere; we put in a concern officially, that didn't get us anywhere and the matter is now with the ombudsman. I work in cancer support myself, so I've got a little bit more overview and I've done hours and hours and hours and hours of research over the last year;	**CNS not helpful** Sue describes the CNS as hard to get hold of and has not been helpful **SO initiated research** Sue has conducted a lot of her own research to better understand the situation. **Pt believes lack of support for partners** Mike believes there is a lack of support for partners in illness. **Need for emotional support** Mike and Sue believe there is a need for emotional support for those who are diagnosed.

		good. I think, for some people, there might be a need for some sort of emotional, psychological or ... support from that side of things. It's all very well to look at a medical illness, but there's the mind involved in any illness.	so, yes, that's become not secondary, but less alarming. And, you know, looking further, emotional or practical or financial signposting: nothing. And people find themselves dropped, falling through cracks. So, yes. And I think that's already been pointed out by so many different bodies, you know, Prostate Cancer UK and Macmillan; they all know, everybody knows and it doesn't get done.	
	Reaction to diagnosis	So thinking back now to your diagnosis; what was your initial reaction? P: Well I was still – I was still in a distressed state.	Outraged, not so much over the diagnosis but in the way it was presented, which was about as badly as could be. I: And how did you feel about the actual diagnosis? P: The actual diagnosis? ... I didn't know half as much as I know now, so, yes, it was alarming but it's becoming less so. I work in cancer support myself, so I've got a little bit more overview and I've done hours and hours and hours and hours of research over the last year; so, yes, that's become not secondary, but less alarming.	**Distress at diagnosis** Sue felt alarmed and Mike felt distressed at the point of diagnosis. Both feel this was added to by the way the news was delivered.

	Reaction to AS	Well I think active surveillance – I had my issue with the biopsy but, yes, I think – I think – to remove my prostate and then life changing conditions just on one – one little test, would seem absurd; I think rushing into anything without information is probably near on stupidity.		**Agreed with AS** Mike explains that although he did not want biopsies, he agreed that AS seemed sensible.
	Treatment decision making	Well on the 30th, the nurse that gave me the results, she said – I've got – it's shown I've got cancer and I have got options. The first option is to remove, then there was radiation and then there was hormonal treatment. I think there were about four – four options that I had. And I said well the option I want is to wait and see, as I called it, or what you would say is active surveillance. So I stated that on the day. And so it was made, on the day, my partner was with me and now fully backed me in that. So that's how it was decided. So it wasn't with any – as I say – it was nurse-led, not even the nurse that led the prostate biopsy, but just a support nurse and that's how I made my decision.	Had it been properly explained, had time been taken to say, look, you know, there are all these options; there's also the option of doing absolutely nothing right now and going home and talking it over with your partner. That would have been fine. As it was, it was incomplete information, it was very badly presented and it was not something G would have chosen and didn't at the time, and still doesn't. Again, care is supposed to be patient-centred and empowered and ultimately, you know, no decision about me, without me; that was completely and utterly ignored. He might have come to a fear-based decision, had he been by himself but – yes – it was very, very badly done and not suitable for him, as an individual. It didn't take into consideration what he	**Clinician-led decisions** Sue does not feel they received patient centred care, and the clinician did not take Mike's feelings or thoughts into consideration.

			might like or be happy with; so it was a box which he didn't fit in and that box wasn't even explained prior to being offered.	
	Current feelings about AS & PCs	how do you feel about your diagnosis now? P: I'm kind of fine with it. As I've got my health issues with the PTSD, cancer seems quite easy. And yes, I'm getting more information. I've had two mpMRIs and the second one says comparison with the first one, shows that there hasn't been any change in the shadow areas where they say – they assume the cancers are, so I think time is good. I know enough to know that prostate – cancer, by and large, as with a lot of other cancers, are very slow-growing; that's not saying that there aren't highly aggressive prostate cancers, but, by percentage, the data experience shows that taking a step back and giving it time, is really the most sensible way of going forward.	Now we've made a bit of a fuss, it is offered and I think it's a good way forward, for now, visual imaging.	**Pt is not worried about PCa** Mike explains that at the moment he has other things to worry about and he's fine about the cancer. **AS is sensible** SO explains they needed to ask for mpMRI scans as Mike did not want biopsies. They were successful and now feel content with AS.

	Perceptions of each other's reactions	Oh I think E is – without the biopsy she's really, yes, together, but she's encouraging me because of information. But, yes, I wouldn't think of any other way. how did she respond to the diagnosis, in the beginning? P: I know she was more shocked by it than I was; that's because of our own personal – her own story. But, yes, I would say it affected her more than myself. I do think there is a lack of care for the partners of people with the illness.	He's somebody who doesn't show – an awful lot of emotion; he tends to shutdown or hide or not even feel, sometimes. I don't know how familiar you are with PTSD, but it can manifest in all sorts of ways; So, yes, confused is another one, very confused, I guess, being given conflicting information or none or misleading and concerned about me, because, yes I was very upset. how do you feel about the way that he responded? P: ... That's a really difficult one. Again, I hate to see somebody not listened to; I hate to see somebody disempowered, whether that's through their own condition or through outside lack of awareness or taking advantage. Yes, I guess protective, very protective – sums it up. At no point, from what I see or understand, was he even considered as disabled, even though it's clearly stated in his notes or any [provision] made or asked – is there anything we could do to support you or,	**SO feels protective over Pt** Sue feels Mike was very confused and did not have the right information. Sue felt protective over Mike and felt he was not treated fairly. **Pt believes SO more shocked** Mike believes Sue was more shocked by the diagnosis than himself.

			you know, do you normally wear a hearing aid, have you bought your glasses? I couldn't read the consent form without my glasses, so I don't know whether he wore his.	
	Changes since diagnosis	Positive: I was already healthy eater but I've become even more aware of what I'm eating. So I think there's a healthy side to that. There's a side to be in control of, you know, my own condition is meant to be patient-led and I feel I am being in control by getting information	On the positive side, we've researched extensively into the more holistic picture and getting to the core of why what's happened, happened, because Western medicine just seems to be incredibly symptom focused: this is happening, let's medicate, let's operate, let's radiate, rather than – what's made it unhappy in the first place and what can we do about it and how can we support. So we've been looking into that and we're doing that and so far, from the best information that is available to us, it seems to be not having an adverse effect; if anything, it seems to be having a positive effect, plus I eat better than I have done. Yes, and it's led to some really interesting conversations and two folders worth of info on any and all aspects of prostate cancer and so-called care and actual care.	**Positive changes** Mike maintains a healthy lifestyle to help manage his cancer. Sue has also improved her diet. Sue explains they have been looking into holistic approaches.

	PCa communication	Yes, we're very open about, yes, yes; it's absolutely easy and that makes it easier for me, well for both of us, I guess.	So do you feel able to talk to him as much as you want to? (P: Yes) Yes? Is there anything at all you would like to be different in that kind of way? P: No, absolutely fine.	**Open communication** Both Sue and Mike feel they are open and communication well about the PCa and AS.
	Impact of diagnosis		So, yes, I've been – I've been obsessing a little bit about it. It's stopped me working, it's stopped me socialising.	**SO obsessing** Sue has stopped working and socialising because she has been obsessing, trying to get hold of the right information relating to Mike's PCa.
Dyad 8 2606632 & SIG024 Alan & Jan	Cancer nurse specialist	I'm now in contact with a cancer nurse, which I wasn't for the first 8 years, xxx under the specialist. You said, oh, why are you phoning me to get an appointment, you should get on to your cancer nurse. I said I haven't got cancer nurse, I don't know	it wasn't until later that I realised we'd not been given a cancer care nurse and whether that was – well I don't know why – but we didn't get one, so I felt we were sort of dealing with it a bit on our own.	**Delay in being given CNS** Alan was not given details of a CNS until 4 years after diagnosis. Jan felt they were

		what he's talking about. So I've got one now who S actually taught her children. So she's fine	that's helped because you're just talking to somebody without having to go to hospital to discuss things; that's much better.	a bit on their own with the diagnosis. **CNS helpful** Jan feels the CNS is helpful because she can discuss things by phone.
	Diagnosis delivery	We were told on the phone – or I knew – xxx – don't worry about it, just tell me yes or no, I want the result, I don't care who knows, I'm not interested, because everybody's got their own life. It's not a bother to me, I don't care if anybody knows. So he phoned us up and told us.		**Diagnosis given by phone** Alan received the diagnosis by phone as requested.
	Breakdown in communication with healthcare provider	And there was a nurse in there. I said so what is it you want; why have we come here? And it was a right hike, it's 25 miles away. So he said, well, we've got the results of the biopsy. I said, yes, I know, I've got cancer. Oh, you know? I said, yes, I know. Oh, he said, that makes it a lot easier for me, which I can understand because, you know, it's a horrible thing		**Healthcare provider communication breakdown** Alan went to the hospital for an appointment to be told what he had already been

		to tell somebody they've got cancer. Yes I know, but I've had no more tests since then, so you're not actually telling me anything, are you? No, and they've done this a few times, called us down there, and it can be done on the phone.		told by phone. This was not an isolated incident.
	Reaction to diagnosis	no, it didn't – it didn't upset me – well it didn't ruin my day at the donkey sanctuary. [Laughter from both] That was quite a hoot, really; I thought, well at least I remember where I was when I heard, you know.	I was really upset, really upset, yes. I mean – it was the actual – it was the chap who had done the biopsy phoned us and he's very matter-of-fact, he's very good, and he's been very – you know – definite about that it will be, you know, J won't die from it. He has always put our minds at rest and I think you need somebody like him.	**Differing reactions to diagnosis** While Jan felt very upset about the diagnosis, Alan felt ok.
	Supportive care needs	did they offer you any support at all, any kind of –? P: No, not really. (I: Okay) My older brother, he did; he said Macmillan or – what's the other one? He said there was a Macmillan nurse and I think the same with [other brother], that was down in [county]. I've never really been offered anything and I'm not that bothered.	– it was the chap who had done the biopsy phoned us and he's very matter-of-fact, he's very good, and he's been very – you know – definite about that it will be, you know, J won't die from it. He has always put our minds at rest and I think you need somebody like him.	**Clinician manner important** Jan found the clinician's confidence and manner reassuring. **No support offered**

		they could have told me about the nurse earlier; that was a bit xxx. I don’t know what you’re talking about, we looked at each other. And he was surprised. He said, well when you got cancer, you was given – assigned a nurse. No we weren’t assigned a nurse, we were assigned – nobody.	We should have had the cancer nurse sooner, you know, but blips happen, it wasn’t done intentionally; it’s not as if it was malice, you know. We should have had [name] sooner. I think the whole biopsy thing needs to be explained more clearly to you as to what actually happens, because I’m still even a bit befuddled about it now and that’s with reading about it, but I think that could be fear. ... No, I mean – I know when I went to the – I went up to the ward with him when he was going to have the biopsy and they said, oh right, off you go, you’re not needed here now. And that I didn’t like; I wouldn’t – I would like to have been able to stay in that area and read, rather than feel – I better go shopping and – you know; that’s not nice. But, again, they can’t have everybody hanging around, I suppose. how long do you think it took until he felt reassured and –?	Alan does not recall being offered any support, but also does not feel like it was needed. **Needed CNS earlier** Having the CNS at the point of diagnosis would have been helpful. **More information for biopsy preparation needed** Jan feels they could have done with more information about the biopsy procedure. **Need to discuss things with knowledgeable person** Jan explains that to be able to cope with diagnosis she needed to talk to somebody

			P: I suppose it took a little while, because I couldn't speak to anybody then other than [name] and J had phoned [name] first and they were chatting and she said do you think Aunty [name of participant] wants to speak? And he said, yes, I think she does. And that was good that she felt - she knew I needed to talk about it, so – I think – until you've actually spoken to somebody knowledgeable, it takes a long time for you to be feeling you can cope with it.	knowledgeable, and she was lucky to have such people within her family.
	Reaction to AS		I thought it was a very good idea; I thought it was, you know – there's no point in jumping too soon, but you need to make sure everything's being looked at.	**Agreed with AS** Both Alan and Jan felt pleased with the AS plan.
	Present feelings about AS & PCa	if you're ill, you're ill, but I'm not ill, I've not been ill, I've not had any – symptoms at all. But it doesn't – it doesn't keep me awake at night; I don't even think about it unless somebody says – and how are you And I'm like, oh, I'm fine. And then somebody last	I'm not as worried about his – the diagnosis – because so many people have said to me it's such a slow-moving cancer and as long as it stays in the prostate you don't have any worries; that has made things a lot easier to cope with. And also now,	**Pt forgets about diagnosis** Alan does not feel ill and does not think or worry about PCa. Now some time as passed Jan feels less

		night, sitting on the front xxx xxx I forget about it, really.	having the cancer nurse, that I know we can phone her whenever we want. Well it is something that you can never actually escape from; like the other night he was saying, when was the last blood test, when have we got to organise the next one? So it's always in your head; every three months, it comes up very quickly. And it's silly things like thinking – well don't do too much – a couple of days before the blood test in case that makes anything spike; take it easy, don't go if you've got a cold, just things like that, just being aware all the time that it's hanging over you. And the fact that we probably will have to do something one day.	concerned about the diagnosis. **PCa hangs over them** Jan explains that she feels the PCa hangs over them and the 3 monthly checks come around quickly.
	Treatment decision making	So you said that the consultant's given you the choice of having some treatment, (P: Yes); so active		**Unclear treatment decision making**

		surveillance, did you decide on that with the consultant or –? P: No, they just – with active surveillance, I suppose I was on it before anybody mentioned active surveillance, because they were doing it every three months, they've been doing it every three months for quite a few years now, before I retired, I think; it must have been going on for about six years now.		Alan was given the option of active treatment. He was already being monitored in a way similar to the AS protocol before diagnosis.
	Feelings about diagnostic tests		I don't like the biopsies; I get very, very worried when he has to have a biopsy, I don't like that at all.	**Anxiety before biopsies** Jan feels worried before each biopsy.
	Changes	No, I wouldn't say it's had any effect whatsoever. I mean – no, I can't really think of anything. It's in the back of your mind because you think you've got to do something about it, but you might not.		**No changes** Alan does not feel the diagnosis has changed his life in any way, even though it is in the back of his mind.

	Perceptions of each other's feelings	Yes, she was upset, but she's a worrier. how do you think she feels about active surveillance? P: She's quite pleased. Yes, she's - I'd say she's quite – [delighted] with it. I mean the treatment I've had, you know.	I think he's really pleased with it; he isn't the least bit – he's probably more – well he's a very matter-of-fact person anyway and he, again, says, yes, fine, keep an eye on me. They've more or less said to him, he could go for treatment at any time, so he's just monitoring his numbers. I know the PSA isn't – the best indicator in the world, but it's the only indicator we have, as such, and his number is creeping up. I think he feels in control of the situation, which is good. how did he respond to the diagnosis? P: You really need to know J [slight laughter from both]; he was just – oh right, okay. Shall we go and have a cup of coffee now; do you want to go and see these donkeys? And I'm there, you know, weeping away into my hanky. how did you feel about the way he responded?	**Accurate description of each other's feelings around the diagnosis and AS** Alan and Jan both agree that while Jan was very upset at the diagnosis, Alan was more matter of fact. Both are happy with AS plan. **SO unsurprised by Pt reaction** Jan did not feel surprised about how Alan responded to the diagnosis.

			P: I wasn't the least bit surprised because that is him. When you've been married to somebody that long, you know what they're going to be like anyway. I think if he'd responded any other way, I probably would have panicked.	
	PCa related communication	how do you and S communicate with each other about – about prostate cancer and about active surveillance? P: I want to say semaphore, but I won't. We are able to talk about it – just talk about it, you know, it doesn't – I: So you talk about it as much as you want to? P: Yes, talk about it in front of anybody, whatever, it doesn't really – we'll talk about anything. We've got no secrets and, you know, we don't xxx people are different, I suppose, everybody's different, but it don't bother me. I tell people my business.	It's something that's there all the time; it's something we're quite happy to talk about. We're quite happy to talk about it to other people Do you feel like you can talk as much as you want to? P: Oh yes, as much as we want to, yes. And it doesn't get to the point where you think, oh shut up. If he wants to talk, that's fine, and if I want to talk, that's fine too.	**Open communication** Jan and Alan both feel they communicate well about the PCa.

	SO involvement	how important do you think it is that they are involved in the consultations? P: Oh yes, I think – yes, very important, very, very important. I: Why do you think it's important? P: Well, because then they know what's going on – and – obviously – you know – people who are having it done are generally older people, so when they tell you something, I mean, you get home and – oh, I wonder what was that. Well there's two of you, if it's two of you, you've got more chance of remembering it, haven't you. That's the main way. Some people are very private and they don't talk to each other, which is – that's how they carry on, but, you know, I'm of the opinion that the more people who know, the more chance you've got of remembering – not forgetting something important.	how important do you think it is that they are involved in the clinical consultations? P: Very important. I don't think anybody should go through something like this on their own. I think when you go to the consultations, you hear what you want to hear; you might not hear everything that's been said, so if you have somebody else there and they say, no this was actually what he said, you think, oh, right, and you can discuss things. I think it's very important that [you're] there, yes. how about in terms of the treatment decision-making, as well? P: You can put your point of view forward, but it has to be his decision. I think the whole biopsy thing needs to be explained more clearly to you as to what actually happens, because I'm still even a bit befuddled about it now	**SO involvement in consultations important** Dyad agree SO involvement in consultations is important. **SO involvement in treatment decision making important** While the dyad agree SO involvement in treatment decisions is important, Jan says the final decision has to be the patient's. **SO told to leave while Pt went for biopsy** Jan was told not to stay on the ward when Alan was

		how about in terms of the treatment decision-making; how important do you think it is that they are involved in that too? P: Yes, absolutely, yes, yes. Well I mean they know you, they know what you're going to say anyway. S knows exactly what I'm thinking, so, you know, we've been together 40 years	and that's with reading about it, but I think that could be fear. ... No, I mean – I know when I went to the – I went up to the ward with him when he was going to have the biopsy and they said, oh right, off you go, you're not needed here now. And that I didn't like; I wouldn't – I would like to have been able to stay in that area and read, rather than feel – I better go shopping and – you know; that's not nice. But, again, they can't have everybody hanging around, I suppose.	going for his biopsy, and she felt upset about that.
	PCa uncertainty		what do you think the worst part is about living with somebody on active surveillance? P: Just the worry that the next blood test is going to be such a high number that it might be too late, that it might have actually got out of the prostate.	**Anxiety about missing opportunity to treat** Jan feels the worst thing about being on AS is the worry they might miss the opportunity to treat.
	The future	Well I'm thinking the number will probably go up and I'm thinking I'll probably have to go and get some treatment done this year; that's the awful truth.	I think, you know, we're expecting the number to rise and when it gets to a number that's obviously in J's head, then he will say – I want something done about it now.	**AS is temporary** The dyad both feel the PSA number will probably rise to

				a point where treatment will be necessary.
Dyad 9 2881908 & SIG036 Dan & Emma	Clinician experiences	I've been back to talk to the surgical urologist. He was very careful and thorough and I'm impressed. He's my port of call; I think he's very good, so I'm very happy with him.		**Positive clinician experiences** Dan is very pleased with the care he received from the urologist.
	Treatment decision making	He was helpful – because he offered me everything really from radical surgery through to radiotherapy, through to – referral, whatever it is; he offered me the range of stuff. But there, lurking at the end of the range of stuff, was the active surveillance and he's aware of the dangers of other treatment; I'm aware of the dangers of other treatment and – sorry – you were talking about support. (I: That's okay) Yes, so the oncologist radio therapist, she was nice and informative, but overall I got the message from this urologist that active surveillance is my best bet, given what I've got. you know, he didn't recommend anything; he laid me out the spectrum of treatment that he reckoned		**Patient-centred treatment decision making** Dan was presented with all of the options and the decision for AS was made together with the clinician.

		I was eligible for and active surveillance was there at the end.		
	Information seeking	I have used the prostate cancer website and I sent them some money and sent off for their material. I think their material is absolutely excellent; it's clear, it's informative, possibly my only criticism is there's almost too much of it. And I rang them up once and spoke to a very helpful nurse about travel insurance; so they've been supportive. I: Was this PC UK? P: PC UK, yes. So, you know, I'm very glad that they are around and they've been very good, but I don't sort of hover on their website.	Well P immediately logged on to the prostate cancer support website.	**Self-initiated information seeking** Dan sought information himself from PCUK.
	CNS experiences	The bit of support that hasn't worked, not that I want it, but it clearly hasn't – is – what do they call it – key worker Technically I haven't met him; there's a nurse at [city] who is supposed to be my first port of call and know all about me, but he doesn't know me from Adam. He's dealing with iller		**Unsatisfactory CNS experiences** Dan feels their CNS is dealing with iller people and is not on his radar.

		people, I'm sure, than I and actually I think I feel slightly embarrassed ringing him up because he'd have to wrack his brains to try and work out who I was, or pretend to remember. I: So that's your cancer nurse specialist? (P: Yes) Yes, okay.		
	Supportive care needs	Nothing like support groups, but I'm sure if I wanted one, I could have had it. But actually, quite honestly, the idea of sitting around with a load of other old blokes with prostate cancer, talking about it – frankly almost repels me, at the moment, anyway. That's not to diss them; I think they are enormously helpful or can be helpful for people, but that's not where I am. is there anything else that you think may have been helpful for you or for M, throughout the whole process; anything extra? P: Probably – a better or closer relationship with the so-called key worker; either you have a key	I mean in terms of support for me, we're very open as a family and – once the diagnosis was made, we let the – we have three grown-up kids and – I mean – and also siblings and he was very open with them, I mean in a very non-dramatic sort of way. He just sort of told them that this is what the situation was. So they were aware of that, too and a huge amount of – I'm thinking of you and all that sort of stuff; so lots of family support. I mean nothing – nothing more than that. So, yes, support, lots of it, really, but not professional, not that I wanted professional support, but from friends and family and especially family, I think, yes, and friends, yes.	**Dislike for support groups** Dan does not like the idea of attending a PCa support group. **Social support important for SO** Emma sought support from family and describes their PCa communication as 'open'.

		worker that works or you don't have one at all. So I think in a way – and that's probably [hospital] and, you know, they need to sort out quite what they mean by this character. I'm perfectly content that I can probably get access to my surgeon. I mean eventually, when I want to – I mean in a sense that I can ring up his secretary and say, look, I really would like to talk about X, Y and Z and will probably get an appointment.	would you have liked any extra support, anything that would have helped or did you get everything that you felt you needed? P: No, I don't think so. I mean, you know, we still feel as if we're kind of at the beginning of the journey. I mean as things develop and – if symptoms occur or he has an operation or – whatever, then, you know, I will probably – I'll be in a different position and might well require a bit more support.	**No need for professional support** Emma did not feel the need for professional support. **Improvements in support** Emma does not feel like she needed any extra support. Dan feels a better relationship with the CNS would have been helpful.
	Reaction to diagnosis	Dismay. ... This is – this is not what I wanted, thank you, and frankly, you know, they said – you've got benign, prostatic enlargement, but actually the surgeon – both my GP, when he referred me and my surgeon, on rectal examination, both of them had found an enlarged right lobe. So I thought to myself, I wonder. But I was sorry to get – to receive it, so	I was concerned and I just felt that, you know, we needed to be guided by the professionals and just take each step and consider it and – and go with what we were advised and we thought best. So, yes, you know, I was – I was concerned, because I love him to bits, but ... not to the extent that I was sort of, you know, full of angst and didn't sleep at night and all that kind of stuff.	**Dismay and concern at diagnosis** Dan describes feeling dismay at the diagnosis. While Emma was concerned, she was measured in her reaction.

		dismay at that and reasonable less dismay on finding what stage it was at.		
	Perceptions of each other’s feelings / reactions	I think she’s content with it, largely because I am. I mean we talked about it; it’s not a unilateral decision, we talked about it together. I’d say to the diagnosis – she was probably dismayed at it. Yes, I don’t think she was rapturous. Treatment plan: I’d say – I’d use the word – content with, again. She’s a palliative care nurse; she’s seen people die, she’s dealt with lots of cancer. She’s very realistic about it; she knows I’m not ill, if you see what I mean. So we’re both happy to go with the flow. I think she responded entirely appropriately. I think there was just one episode I remember saying to her – well I’m not dead yet and she said – don’t speak like that – or I don’t like you speaking like that. And I suppose I was probably being flippant or – I certainly wasn’t being overdramatic and I	P, his approach, right from the start was – I really don’t mind dying with it, I don’t want to die of it. he responded in his usual rational ... almost – objective way; he is not somebody to get het up over things, he’s incredibly broad shouldered and has dealt with all sorts of different crises, mainly affecting other people, but – I mean – I think he responded – I felt he responded to this in his characteristic way, just with – without getting, you know, over – overly worked up about it. Well I wasn’t expecting anything else, really. We’ve been married for 44 years and – he’s – he’s just like that; he’s – he’s very – sort of level-headed and sort of pragmatic. I mean he wouldn’t ignore it and pretend it wasn’t there – ever; there’s no denial.	**Mismatch in perceptions and descriptions** Dan feels Emma was dismayed at the diagnosis. This does not fit with her own description of her reaction. Emma feels Dan was level headed and pragmatic, whereas he describes himself as feeling dismay. **Dyad found each other’s reactions appropriate** Both Emma and Dan describe each other’s reactions and handling of the diagnosis as appropriate.

		realised that, you know, no, of course I shouldn't speak like that, not even flippantly.		**SO does not like Pt being flippant about PCa** Dan describes a time he upset Emma by being flippant about the diagnosis and agrees he should not talk like that.
	Reaction to AS	I thought, well, fine, that all sounds wonderful, we'll deal with it I think that's good and I find it an entirely acceptable way of dealing with it, because my philosophy on this [death] is that I'm very happy to die with it, I do not want to die of it. And it strikes me that active surveillance is probably the best way of ensuring that. I get the impression that we're both roughly singing from the same hymn sheet, that we are both roughly content that we're under very good care, I'm under very good care and that we're content to	Well I kind of looked to P and – I mean – again, having worked in palliative care where so many of our patients had been through so many different – operations, manoeuvres, interventions, to try and stave off the evil hour, it struck me that, as I think it struck him, that the very best approach was to wait and see and – and so active surveillance seemed to be the most rational sort of way of approaching it, to me. I totally agreed with P's reaction, which was, yes, hands off unless absolutely necessary, sort of thing.	**Dyad content with AS** Both Emma and Dan agreed with the idea of AS when it was first introduced.

		go with it and see what happens, because active surveillance is very much, it strikes me, a case of seeing what happens – or seeing what is happening.		
	Present feelings about PCa & AS	Well, I'd rather not have it. I have got it; I feel completely accepting of it and the next bit of excitement is next month when I get another PSA done and another MRI done and, in a way, possibly I should talk to you sort of after that, because I guess if that shows it's static, I will be very happy. And if it shows it isn't static, I will be looking at other treatment options. I suppose 99% of the time I just put it to one side; it's just one of those things that is and I don't actively think about it. That's not denial, that's just – there's life to be got on with and life is for living now.	how do you feel about the diagnosis and active surveillance now? P: Fine. I mean we're kind of in the middle of it. He hasn't had anything, any intervention, anything done for about a year I'm completely on board with this. I mean I'm slightly kind of – not anxious exactly, but I do hope that when they do the next thing – the next PSA test – and then they will possibly follow it up with a scan, I think, and then if the scan shows anything, they'll biopsy it. So, you know, I'm hoping that it'll be in its box and not [spread any]. As long as it sticks in its box, it'll be alright, but we don't know that; we just have to wait and see and I suppose eventually – it will, and that will mean more radical sort of treatment and we'll have to really think hard about what the options are then.	**Dyad accepting of diagnosis** Both Emma and Dan are accepting of the situation and content on AS. **AS uncertainty** Both Emma and Dan talk about the next set of tests and what the results might mean. **Dyad agree they do not think about the PCa much** Both Emma and Dan say that 99% of the time they do not think about PCa and the situation.

			he says 99% of the time he's not thinking about it, which is very reassuring to me. I suppose 99% of my time I don't think about it, because there's no point, really. If things showed up, then, you know, we'd be in a different position. I'm completely happy with the way in which it's being treated or not treated and I shall be, you know, alongside, all the way. I don't know what the ultimate outcome of it will be, but – I think – I have a great confidence, along with him, in the – in the care he's being given and the support that we will have all along the way.	
	Changes	It has focused my mind – slightly more – on mortality and finitude. So I have thought about that a little more than I would have otherwise. I don't brood on it, but it's part of my – I'm about to be 71. I mean I know that nothing; 70 is the new 50 etc, but I've got to come to terms now with – well there's a verse in the Psalms about threescore years	What impact has active surveillance had on P? ... Not a great impact. I mean he has full confidence, having been – explained in detail what is involved, the impact has been really – sort of – unremarkable; it hasn't had a great impact on him, I would say.	**Increased awareness of mortality** Both Emma and Dan feel the diagnosis has given them both an increased awareness of their mortality.

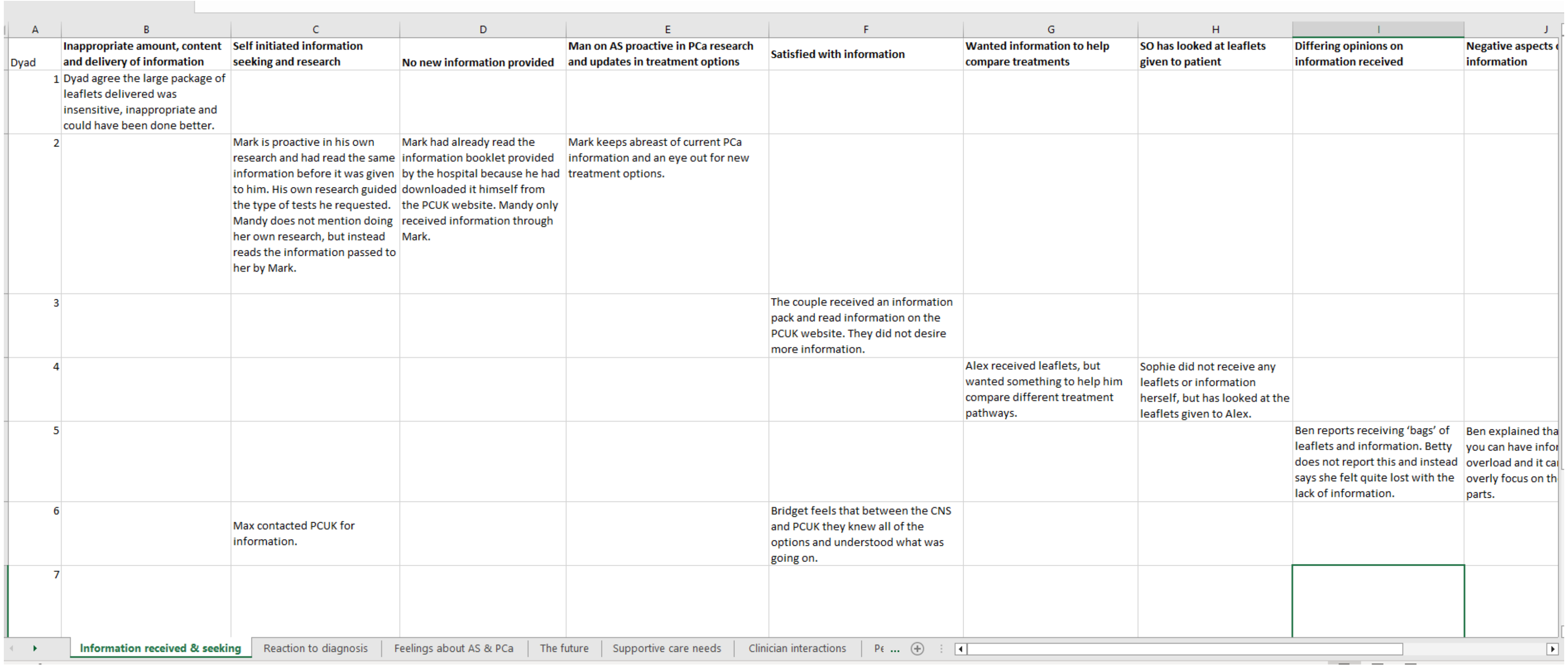
		and 10 and, you know, so I've done those threescore years and 10. Great. I now need to start thinking about the end of my life, a bit, and this has, you know, this has focused me thinking about the end of my life, a bit. But I'm not – I haven't gone into terminal decline or morbid fantasies or anything like that. So I call that positive, rather than negative; it has just accentuated that sense that, well, you know, none of us are infinite.	Well I suppose, you know, when you're faced with something that speaks of mortality, ultimately – you know – either frightens you or brings you closer together or – and I think, on balance, it's sort of brought us closer together I think, on balance, it's brought us closer together.	**Become closer as a couple** Emma feels the diagnosis has brought them closer as a couple.
	PCa related communication	I feel perfectly happy and content that I could talk to M about it if I wanted to anymore and I think I could do it without alarming her or scaring her or making her feel I was being self pitiful. I think I could do it without any of the negative things, yes.	He's open and we communicate well between us and with the family	**Good PCa related communication** Both Dan and Emma agree they are open and communicate well about the diagnosis.
	SO involvement	how important do you think it is that the significant other is involved in clinical consultations? P: Enormously important, for me. We have a good – I would say and I hope M may say, but I won't listen in - we have a good relationship. We trust	Oh, very important, yes, very important. And [consultant] is really good at that. I mean we've only seen him really – we went for a biopsy somewhere, but I was alongside and I didn't feel as if I had to leave the room and P wouldn't have wanted that; so	**Dyad feel SO involvement is important** Emma and Dan agree SO involvement in clinical consultations and treatment

		each other and talk about stuff; I don't think either of us is frightened of illness or death, though we don't welcome either, particularly, but we are aware that we're finite. Sorry, what was your question? I: How important do you think it is that they are involved in the consultation? P: Oh, yes. So I think it's really important they're involved. I'm not going to go off and make decisions or do stuff on my own, because I think that would be irresponsible. We work life as a unit, as a duo; we are a unit. do you feel she was included enough in the process? P: Yes, very well. When I went to see my GP and my PSA was up a bit, he said – what do you want to do? I'm sorry, I know I'm interrupting (I: That's okay) and I said – what do you suggest? And he said, well, I suppose I could do another PSA in a year's time or I could to a rectal now or – I guess that's it. So I said, well, let's do	we share – we always go together and that's important too, for any sort of subsequent discussion or, you know, questions and things. I mean he knows a lot about it anyway because he's medical, so ... we can talk on a certain level, which is – you know – which has a history of sort of expertise to it. Yes, no, but – any – any sharing, I feel, has to be done. Then we decide who we share those sorts of clinical ... clinical discussions with, outside of the clinic.	decision making is important. **SO encouraged Pt to get tests** Dan explains he was going to leave further investigations for another year, but Emma encouraged him to return and have them sooner.

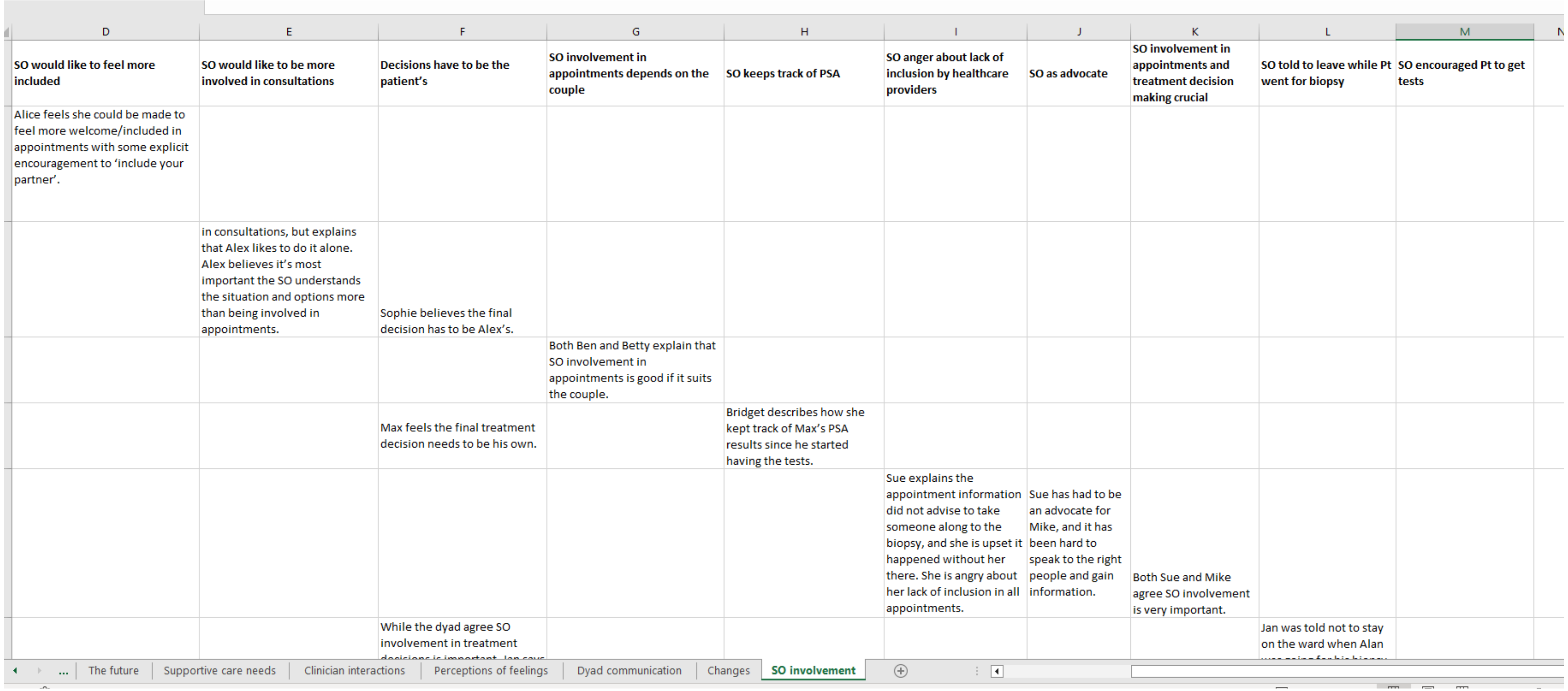
		another PSA in a year's time. And I came back home and I told M what he'd said and she said – go back down there and get him to do a rectal – straightaway. [Laughter from both] So she was a bit proactive and that was really helpful. Yes, okay.		

Appendix C The Framework Matrix

Figure 16: Screenshots of the Framework Matrix



A	B	C	D	E	F	G	H	I	J
Dyad	**Inappropriate amount, content and delivery of information**	**Self initiated information seeking and research**	**No new information provided**	**Man on AS proactive in PCa research and updates in treatment options**	**Satisfied with information**	**Wanted information to help compare treatments**	**SO has looked at leaflets given to patient**	**Differing opinions on information received**	**Negative aspects information**
1	Dyad agree the large package of leaflets delivered was insensitive, inappropriate and could have been done better.								
2		Mark is proactive in his own research and had read the same information before it was given to him. His own research guided the type of tests he requested. Mandy does not mention doing her own research, but instead reads the information passed to her by Mark.	Mark had already read the information booklet provided by the hospital because he had downloaded it himself from the PCUK website. Mandy only received information through Mark.	Mark keeps abreast of current PCa information and an eye out for new treatment options.					
3					The couple received an information pack and read information on the PCUK website. They did not desire more information.				
4						Alex received leaflets, but wanted something to help him compare different treatment pathways.	Sophie did not receive any leaflets or information herself, but has looked at the leaflets given to Alex.		
5								Ben reports receiving 'bags' of leaflets and information. Betty does not report this and instead says she felt quite lost with the lack of information.	Ben explained tha you can have infor overload and it ca overly focus on th parts.
6		Max contacted PCUK for information.			Bridget feels that between the CNS and PCUK they knew all of the options and understood what was going on.				
7									



D	E	F	G	H	I	J	K	L	M
SO would like to feel more included	**SO would like to be more involved in consultations**	**Decisions have to be the patient's**	**SO involvement in appointments depends on the couple**	**SO keeps track of PSA**	**SO anger about lack of inclusion by healthcare providers**	**SO as advocate**	**SO involvement in appointments and treatment decision making crucial**	**SO told to leave while Pt went for biopsy**	**SO encouraged Pt to get tests**
Alice feels she could be made to feel more welcome/included in appointments with some explicit encouragement to 'include your partner'.									
	in consultations, but explains that Alex likes to do it alone. Alex believes it's most important the SO understands the situation and options more than being involved in appointments.	Sophie believes the final decision has to be Alex's.							
			Both Ben and Betty explain that SO involvement in appointments is good if it suits the couple.						
		Max feels the final treatment decision needs to be his own.		Bridget describes how she kept track of Max's PSA results since he started having the tests.					
					Sue explains the appointment information did not advise to take someone along to the biopsy, and she is upset it happened without her there. She is angry about her lack of inclusion in all appointments.	Sue has had to be an advocate for Mike, and it has been hard to speak to the right people and gain information.	Both Sue and Mike agree SO involvement is very important.		
		While the dyad agree SO involvement in treatment						Jan was told not to stay on the ward when Alan	

Appendix D Subthemes and subcodes

Framework Matrix to refine subthemes and subcodes

Information received & Information seeking

Sub themes	**Subcodes**
Dissatisfaction with information received	• Inappropriate amount, content and delivery of information • Lack of information in general • Lack of information to compare treatment options • Information overload leads to a focus on negative parts of information • Lack of information directly from consultant
Self-initiated information seeking / research	• Man on AS proactive in PCa research and updates in treatment options • SO self-initiated research
Differing opinions on information received	• Man on AS and SO felt differently about the information received
Satisfied with information	• Couple felt well informed

Possible themes:

- Dissatisfaction with information received
- Self-initiated research

Reaction to diagnosis

Sub themes	**Subcodes**
Feelings about diagnosis	• Dyad felt differently about diagnosis • Distress, dismay and concern about diagnosis • Shock and anxiety • Relief about diagnosis
Reaction to diagnosis	• SO putting on a brave face • Pt obsessing over diagnosis • SO guilt about own feelings • Feelings initial reaction was illogical • SO being practical • Staying proactive as a coping mechanism

Possible themes:

- PCa diagnosis reactions are complex

- Differing reactions to the diagnosis

Feelings about AS & PCa

Sub themes	**Subcodes**
Uncertainty and anxiety	• AS is a rollercoaster • Living with AS uncertainty is hard • Mixed feelings about AS • Anxiety before biopsies • Painful side effects of biopsies increase anxiety • Pt suffering PCa related anxiety and depression
Differing dyad feelings	• Differing feelings about AS and/or PCa • Man more concerned about active treatment side effects than SO
Contentment with AS	• Dyad does not think about the PCa much • Dyad accepting of diagnosis • Pt forgets about diagnosis • Pt is not worried about PCa • Hoping to stay on AS in the future • AS is a safety net • Happy with AS
The future	• Hoping for new treatments • AS is temporary

Possible themes:

- Living with uncertainty
- Worry about missing the opportunity to treat
- Differing concerns and priorities

Supportive care needs

Sub themes	**Subcodes**
Dissatisfactory support	• Left out on a limb • No support offered
More support needed	• Need more support from a professional • Sensitive topics need addressing more directly • More guidance needed with treatment options and decisions • More support needed generally • More information for biopsy preparation needed • Need for emotional support • Mixture of feelings around the idea of a support group • Counselling may be beneficial
Cancer nurse specialist	• Not needed CNS • CNS beneficial • CNS not helpful • Needed CNS earlier

	- Delay in being informed about CNS
Positive support experiences	Informed about available support PCa charities supportive Supportive SO Social support valuable Volunteering to help other PCa patients

Possible themes:

- Inadequate access to CNS
- PCa charities provided valuable support
- What would help?

Clinician interactions

Sub themes	**Subcodes**
Dissatisfaction with clinician	Clinician conflict Clinician was blunt Healthcare provider communication breakdown Dissatisfied with care throughout diagnosis period GP uninformed by hospital
Patient-centred care	Decision made with clinician Clinician led decisions Clinician manner important Frustration with patient-led care

Possible themes:

- Treatment decision making: patient-centred or clinician-led?

Dyad perceptions of feelings

Sub themes	**Subcodes**
General perceptions of each other's feelings	Dyad accurately describe the other's feelings Mismatch in perceptions and descriptions of each other's feelings SO surprise at pt reaction Dyad found each other's reactions appropriate Uncertainty around SO feelings Pt believes SO more shocked than themselves
Caring for each other	Man on AS a support to SO SO concern over pt coping Man on AS worried about SO anxiety SO struggles to see man on AS feeling anxious or upset about PCa

Possible themes:

- Concern for each other
- Putting on a brave face for each other
- Support two directional
- Mismatch in perceptions or saving face?

Dyad communication

Sub themes	**Subcodes**
Tensions in communication	Difficult to discuss PCa related sex problems Differing opinions about communication Communication hindered by desire to protect each other
Good communication	Dyads communicate openly and effectively

Possible themes:

- Tensions in communication

Changes since the diagnosis

Sub themes	**Subcodes**
Positive changes	Attitude to life has changed for the better Acceptance of situation gradually increased over time Become closer as a couple
Other changes	No changes Increased awareness of mortality

- Diagnosis has inspired attitudinal changes

SO involvement

Sub themes	**Subcodes**
SO involvement in appointments	SO would like to feel more included Involvement in appointments depends on the couple SO anger about lack of inclusion by healthcare providers Crucial SOs are involved in appointments
SO involvement in treatment decision making	SO involvement most important for treatment decision making Decisions have to be the patient’s
General SO involvement	Consensus that SOs should be involved SO keeps track of PSA SO as advocate SO encouraged pt to get tests

Possible themes:

- Significant other involvement is crucial
- Discontent with level of SO inclusion

Appendix E Synthesis searches

E.1 Qualitative Synthesis Search 1 Search Terms and results from February 2018

Table 35: Search terms used in Medline, EMBASE, PsychINFO, CINAHL and Cochrane Library: Search 1, February 2018

Ovid Medline ® Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Ovid MEDLINE 1946 to Present on 1st February 2018	**EMBASE 1980 – 2018 week 05 on 1st February 2018**	**PsycINFO on 1st February 2018**	**CINAHL on 1st February 2018**	**Cochrane Library searched on 8th February 2018** **(These figures include all Cochrane Reviews, Other Reviews, Trials, Methods Studies, Technology Assessments, Economic Evaluations and Cochrane Groups. All were imported into Endnote apart from Cochrane Groups.)**
1. (prostat* adj3 cancer*).tw. (107481) 2. exp Prostatic Neoplasms/ (111874)	1. (prostat* adj3 cancer*).tw. (156080) 2. Prostate Cancer.tw. (149468)	1. TI prostat* N3 cancer* OR AB prostat* N3 cancer* (2816)	1. TI prostat* N3 cancer* OR AB prostat* N3 cancer* (2816) 2. Prostatic neoplasms (22886)	1. prostat* cancer* (10807) 2. prostat* tumor* or prostat* tumour* (3426) 3. prostat* malignan* (797)

3. (prostat* adj3 tumo?r*).tw. (11520) 4. (prostat* adj3 neoplas*).tw. (3460) 5. (malignan* adj3 prostat*).tw. (3380) 6. 1 or 2 or 3 or 4 or 5 (142141) 7. exp Watchful Waiting/ (2574) 8. (watchful adj wait*).tw. (2196) 9. active surveillance.tw. (5668) 10. (active* adj monitor*).tw. (640) 11. 7 or 8 or 9 or 10 or 11 (10009) 12. spouse*.tw. (15234) 13. wife.tw. (5069) 14. partner.tw. (60709)	3. (prostat* adj3 tumo?r*).tw. (13965) 4. (prostat* adj3 neoplas*).tw. (4348) 5. (malignan* adj3 prostat*).tw. (4420) 6. 1 or 2 or 3 or 4 or 5 (197115) 7. Watchful Waiting/ (3186) 8. (watchful adj wait*).tw. (3180) 9. active surveillance.tw. (9233) 10. (active* adj monitor*).tw. (965) 11. 8 or 9 or 10 or 11 (14578) 12. spouse*.tw. (18413) 13. wife.tw. (5937) 14. partner.tw. (78231)	2. TI prostat* N3 neoplas* OR AB prostat* N3 neoplas* (13) 3. TI prostat* N3 tumo?r* OR AB prostat* N3 tumo?r* (2) 4. TI malignan* n3 prostat* OR AB malignan* n3 prostat* (18) 5. 1 or 2 or 3 or 4 (2837) 6. TI watchful waiting OR AB watchful waiting (152) 7. TI watchful N wait* OR AB watchful N wait* (30) 8. TI active surveillance OR AB active surveillance (523) 9. TI active N monitor* OR AB active N monitor* (310) 10. 6 or 7 or 8 or 9 (965) 11. TI spouse* OR AB spouse* (17517) 12. TI wife* OR AB wife* (7769)	2. TI prostat* N3 neoplas* OR AB prostat* N3 neoplas* (13) 3. TI prostat* N3 tumo?r* OR AB prostat* N3 tumo?r* (2) 4. TI malignan* n3 prostat* OR AB malignan* n3 prostat* (18) 5. 1 or 2 or 3 or 4 or 5 (28015) 6. TI watchful waiting OR AB watchful waiting (152) 7. TI watchful N wait* OR AB watchful N wait* (30) 8. TI active surveillance OR AB active surveillance (523) 9. TI active N monitor* OR AB active N monitor* (310) 10. 6 or 7 or 8 or 9 (965) 11. TI spouse* OR AB spouse* (17517) 12. TI wife* OR AB wife* (7769) 13. TI partner* OR AB partner* (90402)	4. prostat* neoplas* (6832) 5. MeSH descriptor: [Prostatic Neoplasms, Castration-Resistant] explode all trees (4338) 6. #1 or #2 or #3 or #4 (11405) 7. watchful wait* (783) 8. active surveillance (1408) 9. active monitor* (6966) 10. MeSH descriptor: [Watchful Waiting] explode all trees (286) 11. #7 or #8 or #9 or #10 (8434) 12. spouse* (1438) 13. wife* or wive* (324) 14. partner* (9250) 15. significant other* (84594) 16. husband* (603) 17. family* (28021) 18. relationship* (71808) 19. couple* (6327) 20. relative* (74291) 21. dyad* (1667)

15. significant other*.tw. (3479) 16. husband.tw. (5394) 17. family.tw. (685360) 18. relationship*.tw. (1111878) 19. couple*.tw. (307461) 20. relative*.tw. (1217100) 21. dyad*.tw. (16868) 22. support network.tw. (1108) 23. 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 (3119480) 24. 6 and 11 and 23 (335) 25. limit 24 to (English language and yr="1990 - Current") (321)	15. significant other*.tw. (4342) 16. husband.tw. (6303) 17. family.tw. (828805) 18. relationship*.tw. (1322712) 19. couple*.tw. (327874) 20. relative*.tw. (1407801) 21. dyad*.tw. (18151) 22. support network.tw. (1497) 23. 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 (3651084) 24. 6 and 11 and 23 (689) 25. limit 24 to (english language and yr="1990 - Current") (672)	13. TI partner* OR AB partner* (90402) 14. TI significant other* OR AB significant other* (127431) 15. TI husband OR AB husband (12534) 16. TI family OR AB (335851) 17. TI relationship OR AB relationship (626732) 18. TI couple* OR AB couple* (54341) 19. TI relative* OR AB relative* (258844) 20. TI dyad* OR AB dyad* (28914) 21. TI support network OR AB support network (20839) 22. 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 (1261490) 23. 5 and 10 and 22 (29)	14. TI significant other* OR AB significant other* (127431) 15. TI husband OR AB husband (12534) 16. TI family OR AB (335851) 17. TI relationship OR AB relationship (626732) 18. TI couple* OR AB couple* (54341) 19. TI relative* OR AB relative* (258844) 20. TI dyad* OR AB dyad* (28914) 21. TI support network OR AB support network (20839) 22. 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 (1261490) 23. 5 and 10 and 22 (115)	22. support* network* (7458) 23. MeSH descriptor: [Family] explode all trees (8104) 24. #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 (234569) 25. #6 and #11 and #24 (278) (6 of these were ‘groups’ and not imported into Endnote)

E.2 Qualitative Synthesis Search 2 Search Terms and results from May 2018

Table 36: Search terms used in Medline, EMBASE, PsychINFO, CINAHL and Cochrane Library: Search 2, May 2018

Ovid Medline ® Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Ovid MEDLINE 1946 to Present on 24th May 2018	**EMBASE 1980 – 2018 week 05 on 24th May 2018**	**PsycINFO on 24th May 2018**	**CINAHL on 24th May 2018**	**Cochrane Library searched on 24th May 2018** **(These figures include all Cochrane Reviews, Other Reviews, Trials, Methods Studies, Technology Assessments, Economic Evaluations and Cochrane Groups. All were imported into Endnote apart from Cochrane Groups.)**

1. (prostat* adj3 cancer*).tw. (95934) 2. exp Prostatic Neoplasms/ (114402) 3. (prostat* adj3 tumo?r*).tw. (10635) 4. (prostat* adj3 neoplas*).tw. (3254) 5. (malignan* adj3 prostat*).tw. (3092) 6. 1 or 2 or 3 or 4 or 5 (130541) 7. exp Watchful Waiting/ (2723) 8. (watchful adj wait*).tw. (1954) 9. active surveillance.tw. (4943) 10. (active* adj monitor*).tw. (548)	1. (prostat* adj3 cancer*).tw. (162044) 2. Prostate Cancer.tw. (154966) 3. (prostat* adj3 tumo?r*).tw. (14381) 4. (prostat* adj3 neoplas*).tw. (4424) 5. (malignan* adj3 prostat*).tw. (4551) 6. 1 or 2 or 3 or 4 or 5 (204336) 7. Watchful Waiting/ (3369) 8. (watchful adj wait*).tw. (3306) 9. active surveillance.tw. (9838) 10. (active* adj monitor*).tw. (1020) 11. 8 or 9 or 10 or 11 (15428)	1. TI prostat* N3 cancer* OR AB prostat* N3 cancer* (2866) 2. TI prostat* N3 neoplas* OR AB prostat* N3 neoplas* (13) 3. TI prostat* N3 tumo?r* OR AB prostat* N3 tumo?r* (2) 4. TI malignan* n3 prostat* OR AB malignan* n3 prostat* (18) 5. 1 or 2 or 3 or 4 (2887) 6. TI watchful waiting OR AB watchful waiting (154) 7. TI watchful N wait* OR AB watchful N wait* (31) 8. TI active surveillance OR AB active surveillance (534) 9. TI active N monitor* OR AB active N monitor* (319)	1. TI prostat* N3 cancer* OR AB prostat* N3 cancer* (20944) 2. TI prostat* N3 neoplas* OR AB prostat* N3 neoplas* (182) 3. TI prostat* N3 tumo?r* OR AB prostat* N3 tumo?r* (159) 4. TI malignan* n3 prostat* OR AB malignan* n3 prostat* (285) 5. 1 or 2 or 3 or 4 (21117) 6. TI watchful waiting OR AB watchful waiting (623) 7. TI watchful N wait* OR AB watchful N wait* (60) 8. TI active surveillance OR AB active surveillance (2738) 9. TI active N monitor* OR AB active N monitor* (507)	1. prostat* cancer* (12288) 2. prostat* tumor* or prostat* tumour* (3729) 3. prostat* malignan* (834) 4. prostat* neoplas* (7807) 5. MeSH descriptor: [Prostatic Neoplasms, Castration-Resistant] explode all trees (5382) 6. #1 or #2 or #3 or #4 (12962) 7. watchful wait* (832) 8. active surveillance (1525) 9. active monitor* (7442) 10. MeSH descriptor: [Watchful Waiting] explode all trees (277) 11. #7 or #8 or #9 or #10 (9054) 12. spouse* (1577) 13. wife* or wive* (339) 14. partner* (10485) 15. significant other* (88238) 16. husband* (638) 17. family* (30577)

11. 7 or 8 or 9 or 10 (9055) 12. spouse*.tw. (13923) 13. wife.tw. (4681) 14. partner.tw. (54449) 15. significant other*.tw. (3136) 16. husband.tw. (4899) 17. family.tw. (623320) 18. relationship*.tw. (998938) 19. couple*.tw. (249158) 20. relative*.tw. (1074761) 21. dyad*.tw. (13778) 22. support network.tw. (993) 23. 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 (2765162)	12. spouse*.tw. (19106) 13. wife.tw. (6111) 14. partner.tw. (81165) 15. significant other*.tw. (4461) 16. husband.tw. (6488) 17. family.tw. (854204) 18. relationship*.tw. (1365607) 19. couple*.tw. (337697) 20. relative*.tw. (1448515) 21. dyad*.tw. (19087) 22. support network.tw. (1581) 23. 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 (3762490) 24. 6 and 11 and 23 (731) 25. 6 and 11 (5286) 26. 25 not 24 (4555)	10. 6 or 7 or 8 or 9 (987) 11. TI spouse* OR AB spouse* (17718) 12. TI wife* OR AB wife* (7817) 13. TI partner* OR AB partner* (92294) 14. TI significant other* OR AB significant other* (129958) 15. TI husband OR AB husband (12653) 16. TI family OR AB (340801) 17. TI relationship OR AB relationship (638015) 18. TI couple* OR AB couple* (55264) 19. TI relative* OR AB relative* (263120) 20. TI dyad* OR AB dyad* (29566)	10. 6 or 7 or 8 or 9 (3783) 11. TI spouse* OR AB spouse* (6876) 12. TI wife* OR AB wife* (1799) 13. TI partner* OR AB partner* (57531) 14. TI significant other* OR AB significant other* (93750) 15. TI husband OR AB husband (3731) 16. TI family OR AB (168286) 17. TI relationship OR AB relationship (232668) 18. TI couple* OR AB couple* (20837) 19. TI relative* OR AB relative* (145849) 20. TI dyad* OR AB dyad* (7063)	18. relationship* (75607) 19. couple* (7042) 20. relative* (79707) 21. dyad* (1896) 22. support* network* (7914) 23. MeSH descriptor: [Family] explode all trees (8354) 24. #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 (250445) 25. #6 and #11 and #24 (285) 26. #6 and #11 (596) 27. #26 not #25 (357) 28. interview* or experience* or qualitative* (106552) 29. #27 and #28 (69)

24. 6 and 11 and 23 (301) 25. 6 and 11 (2402) 26. 25 not 24 (2101) 27. (interview: or experience:).mp. or qualitative.tw. (1140882) 28. 26 and 27 (200) 29. limit 28 to (English language and yr=”1990-Current”) (186)	27. (interview: or experience:).mp. or qualitative.tw. (1714010) 28. 26 and 27 (618) 29. limit 28 to (English language and yr=”1990-Current”) (597)	21. TI support network OR AB support network (21404) 22. 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 (1282968) 23. 5 and 10 and 22 (29) 24. 5 and 10 (88) 25. 24 NOT 23 (59) 26. interview* OR experience* OR TI qualitative OR AB qualitative (913317) 27. 25 and 26 (17)	21. TI support network OR AB support network (9200) 22. 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 (626623) 23. 5 and 10 and 22 (122) 24. 5 and 10 (668) 25. 24 NOT 23 (546) 26. interview* OR experience* OR TI qualitative OR AB qualitative (525798) 27. 25 and 26 (58)	

E.3 Qualitative Synthesis Search 1 Search Terms and results from November 2022

Table 37: Search terms used in Medline, EMBASE, PsychINFO, CINAHL and Cochrane Library: Search 1, November 2022

Ovid Medline ® Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Ovid MEDLINE 2018 – 8th November 2022	**EMBASE 2018 – 8th November 2022**	**PsycINFO on 2018 – 9th November 2022**	**CINAHL 2018 – 9th November 2022**	**Cochrane Library searched on 9th November 2022**
1. (prostat* adj3 cancer*).tw. (147060) 2. exp Prostatic Neoplasms/ (144960) 3. (prostat* adj3 tumo?r*).tw. (14424) 4. (prostat* adj3 neoplas*).tw. (3838) 5. (malignan* adj3 prostat*).tw. (4126)	1. (prostat* adj3 cancer*).tw. (221242) 2. Prostate Cancer.tw. (208592) 3. (prostat* adj3 tumo?r*).tw. (18005) 4. (prostat* adj3 neoplas*).tw. (4905) 5. (malignan* adj3 prostat*).tw. (5627)	1. TI prostat* N3 cancer* OR AB prostat* N3 cancer* (3597) 2. TI prostat* N3 neoplas* OR AB prostat* N3 neoplas* (13) 3. TI prostat* N3 tumo?r* OR AB prostat* N3 tumo?r* (3) 4. TI malignan* n3 prostat* OR AB	1. TI prostat* N3 cancer* OR AB prostat* N3 cancer* (34868) 2. TI prostat* N3 neoplas* OR AB prostat* N3 neoplas* (295) 3. TI prostat* N3 tumo?r* OR AB prostat* N3 tumo?r* (285) 4. TI malignan* n3 prostat* OR AB	1. prostat* cancer* (17862) 2. prostat* tumor* or prostat* tumour* (5215) 3. prostat* malignan* (1401) 4. prostat* neoplas* (9186) 5. MeSH descriptor: [Prostatic Neoplasms, Castration-Resistant] explode all trees (6248) 6. #1 or #2 or #3 or #4 or #5 (18636)

6. 1 or 2 or 3 or 4 or 5 (186502) 7. exp Watchful Waiting/ (5013) 8. (watchful adj wait*).tw. (3016) 9. active surveillance.tw. (9422) 10. (active* adj monitor*).tw. (1146) 11. 7 or 8 or 9 or 10 or 11 (16166) 12. spouse*.tw. (19374) 13. wife.tw. (6011) 14. partner.tw. (85974) 15. significant other*.tw. (4597) 16. husband.tw. (6771) 17. family.tw. (902070)	6. 1 or 2 or 3 or 4 or 5 (277157) 7. Watchful Waiting/ (5305) 8. (watchful adj wait*).tw. (4590) 9. active surveillance.tw. (15530) 10. (active* adj monitor*).tw. (1727) 11. 8 or 9 or 10 or 11 (23760) 12. spouse*.tw. (24867) 13. wife.tw. (7557) 14. partner.tw. (113430) 15. significant other*.tw. (5861) 16. husband.tw. (8335) 17. family.tw. (1118789)	malignan* n3 prostat* (21) 5. 1 or 2 or 3 or 4 (3618) 6. TI watchful waiting OR AB watchful waiting (192) 7. TI watchful N wait* OR AB watchful N wait* (41) 8. TI active surveillance OR AB active surveillance (736) 9. TI active N monitor* OR AB active N monitor* (498) 10. 6 or 7 or 8 or 9 (1396) 11. TI spouse* OR AB spouse* (20438) 12. TI wife* OR AB wife* (8414) 13. TI partner* OR AB partner* (119182)	malignan* n3 prostat* (508) 5. 1 or 2 or 3 or 4 (35149) 6. TI watchful waiting OR AB watchful waiting (980) 7. TI watchful N wait* OR AB watchful N wait* (102) 8. TI active surveillance OR AB active surveillance (4618) 9. TI active N monitor* OR AB active N monitor* (929) 10. 6 or 7 or 8 or 9 (6356) 11. TI spouse* OR AB spouse* (10423) 12. TI wife* OR AB wife* (2965)	7. watchful wait* (1059) 8. active surveillance (2025) 9. active monitor* (12332) 10. MeSH descriptor: [Watchful Waiting] explode all trees (370) 11. #7 or #8 or #9 or #10 (14561) 12. spouse* (2596) 13. wife* or wive* (596) 14. partner* (18126) 15. significant other* (110836) 16. husband* (1188) 17. family* (48174) 18. relationship* (98740) 19. couple* (10754) 20. relative* (107390) 21. dyad* (4094) 22. support* network* (8051)

18. relationship*.tw. (1536647) 19. couple*.tw. (417799) 20. relative*.tw. (1598590) 21. dyad*.tw. (27939) 22. support network.tw. (1673) 23. 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 (4182979) 24. 6 and 11 and 23 (491) 25. limit 24 to (English language and yr="2018 -Current") (165)	18. relationship*.tw. (1856253) 19. couple*.tw. (460061) 20. relative*.tw. (1898692) 21. dyad*.tw. (31236) 22. support network.tw. (2352) 23. 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 (5007714) 24. 6 and 11 and 23 (1061) 25. limit 24 to (english language and yr="2018 - Current") (368)	14. TI significant other* OR AB significant other* (162951) 15. TI husband OR AB husband (13376) 16. TI family OR AB (144339) 17. TI relationship OR AB relationship (786709) 18. TI couple* OR AB couple* (66924) 19. TI relative* OR AB relative* (316346) 20. TI dyad* OR AB dyad* (38888) 21. TI support network OR AB support network (29250) 22. 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 (1406436)	13. TI partner* OR AB partner* (96159) 14. TI significant other* OR AB significant other* (159749) 15. TI husband OR AB husband (6059) 16. TI family OR AB (109738) 17. TI relationship OR AB relationship (389670) 18. TI couple* OR AB couple* (36841) 19. TI relative* OR AB relative* (243033) 20. TI dyad* OR AB dyad* (13503) 21. TI support network OR AB support network (17987)	23. MeSH descriptor: [Family] explode all trees (10804) 24. #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 (341512) 25. #6 and #11 and #24 (281) (6 of these were 'groups' and not imported into Endnote) 26. Limit 2018 – 2022 (119) (8 of these were protocols, 1 special collection and 1 clinical answer and not exported, giving a total of 109)

		23. 5 and 10 and 22 (40) 24. limit 23 to yr=2018-current (14)	22. 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 (939979) 23. 5 and 10 and 22 (188) 24. limit 23 to yr=2018-current (70)	

E.4 Qualitative Synthesis Search 2 Search Terms and results from November 2022

Table 38: Search terms used in Medline, EMBASE, PsychINFO, CINAHL and Cochrane Library: Search 2, November 2022

Ovid Medline ® Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Ovid MEDLINE 2018 – 8th November 2022	**EMBASE 2018 – 8th November 2022**	**PsycINFO on 2018 – 9th November 2022**	**CINAHL 2018 – 9th November 2022**	**Cochrane Library searched on 9th November 2022**
1. (prostat* adj3 cancer*).tw. (147060) 2. exp Prostatic Neoplasms/ (144960)	1. (prostat* adj3 cancer*).tw. (221242) 2. Prostate Cancer.tw. (208592)	1. TI prostat* N3 cancer* OR AB prostat* N3 cancer* (3597)	1. TI prostat* N3 cancer* OR AB prostat* N3 cancer* (34868)	1. prostat* cancer* (17862)

3. (prostat* adj3 tumo?r*).tw. (14424) 4. (prostat* adj3 neoplas*).tw. (3838) 5. (malignan* adj3 prostat*).tw. (4126) 6. 1 or 2 or 3 or 4 or 5 (186502) 7. exp Watchful Waiting/ (5013) 8. (watchful adj wait*).tw. (3016) 9. active surveillance.tw. (9422) 10. (active* adj monitor*).tw. (1146) 11. 7 or 8 or 9 or 10 or 11 (16166) 12. spouse*.tw. (19374) 13. wife.tw. (6011) 14. partner.tw. (85974)	3. (prostat* adj3 tumo?r*).tw. (18005) 4. (prostat* adj3 neoplas*).tw. (4905) 5. (malignan* adj3 prostat*).tw. (5627) 6. 1 or 2 or 3 or 4 or 5 (277157) 7. Watchful Waiting/ (5305) 8. (watchful adj wait*).tw. (4590) 9. active surveillance.tw. (15530) 10. (active* adj monitor*).tw. (1727) 11. 7 or 8 or 9 or 10 (23402) 12. spouse*.tw. (21189) 13. wife.tw. (6213) 14. partner.tw. (113430)	2. TI prostat* N3 neoplas* OR AB prostat* N3 neoplas* (13) 3. TI prostat* N3 tumo?r* OR AB prostat* N3 tumo?r* (3) 4. TI malignan* n3 prostat* OR AB malignan* n3 prostat* (21) 5. 1 or 2 or 3 or 4 (3618) 6. TI watchful waiting OR AB watchful waiting (192) 7. TI watchful N wait* OR AB watchful N wait* (41) 8. TI active surveillance OR AB active surveillance (736) 9. TI active N monitor* OR AB active N monitor* (498) 10. 6 or 7 or 8 or 9 (1396) 11. TI spouse* OR AB spouse* (20438)	2. TI prostat* N3 neoplas* OR AB prostat* N3 neoplas* (295) 3. TI prostat* N3 tumo?r* OR AB prostat* N3 tumo?r* (285) 4. TI malignan* n3 prostat* OR AB malignan* n3 prostat* (508) 5. 1 or 2 or 3 or 4 (35149) 6. TI watchful waiting OR AB watchful waiting (980) 7. TI watchful N wait* OR AB watchful N wait* (102) 8. TI active surveillance OR AB active surveillance (4618) 9. TI active N monitor* OR AB active N monitor* (929) 10. 6 or 7 or 8 or 9 (6356)	2. prostat* tumor* or prostat* tumour* (5215) 3. prostat* malignan* (1401) 4. prostat* neoplas* (9186) 5. MeSH descriptor: [Prostatic Neoplasms, Castration-Resistant] explode all trees (6248) 6. #1 or #2 or #3 or #4 or #5 (18636) 7. watchful wait* (1059) 8. active surveillance (2025) 9. active monitor* (12332) 10. MeSH descriptor: [Watchful Waiting] explode all trees (370)

15. significant other*.tw. (4597) 16. husband.tw. (6771) 17. family.tw. (902070) 18. relationship*.tw. (1536647) 19. couple*.tw. (417799) 20. relative*.tw. (1598590) 21. dyad*.tw. (27939) 22. support network.tw. (1673) 23. 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 (4182979) 24. 6 and 11 and 23 (491) 25. limit 24 to (English language and yr="2018 - Current") (165) 26. 6 and 11 (4215) 27. 24 not 23 (3724)	15. significant other*.tw. (5861) 16. husband.tw. (8335) 17. family.tw. (1118789) 18. relationship*.tw. (1856253) 19. couple*.tw. (460061) 20. relative*.tw. (1898692) 21. dyad*.tw. (31236) 22. support network.tw. (2352) 23. 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 (5007714) 24. 6 and 11 and 23 (1056) 25. limit 24 to (English language and yr="2018 - Current") (368) 26. 6 and 11 (7637) 27. 26 not 24 (6581)	12. TI wife* OR AB wife* (8414) 13. TI partner* OR AB partner* (119182) 14. TI significant other* OR AB significant other* (162951) 15. TI husband OR AB husband (13376) 16. TI family OR AB (144339) 17. TI relationship OR AB relationship (786709) 18. TI couple* OR AB couple* (66924) 19. TI relative* OR AB relative* (316346) 20. TI dyad* OR AB dyad* (38888) 21. TI support network OR AB support network (29250)	11. TI spouse* OR AB spouse* (10423) 12. TI wife* OR AB wife* (2965) 13. TI partner* OR AB partner* (96159) 14. TI significant other* OR AB significant other* (159749) 15. TI husband OR AB husband (6059) 16. TI family OR AB (109738) 17. TI relationship OR AB relationship (389670) 18. TI couple* OR AB couple* (36841) 19. TI relative* OR AB relative* (243033) 20. TI dyad* OR AB dyad* (13503)	11. #7 or #8 or #9 or #10 (14561) 12. spouse* (2596) 13. wife* or wive* (596) 14. partner* (18126) 15. significant other* (110836) 16. husband* (1188) 17. family* (48174) 18. relationship* (98740) 19. couple* (10754) 20. relative* (107390) 21. dyad* (4094) 22. support* network* (8051) 23. MeSH descriptor: [Family] explode all trees (10804)

28. (interview: or experience:).mp. or qualitative.tw. (1794458) 29. 27 and 28 (385) 30. limit 24 to (English language and yr="2018 - Current") (160)	28. (interview: or experience:).mp. or qualitative.tw. (2192578) 29. 27 and 28 (923) 29. limit 24 to (English language and yr="2018 - Current") (352)	22. 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 (1406436) 23. 5 and 10 and 22 (40) 24. limit 23 to yr=2018-current (14) 25. 5 and 10 (128) 26. 25 NOT 23 (88) 27. interview* OR experience* OR TI qualitative OR AB qualitative (1160455) 28. 26 and 27 (30) 29. limit 28 to yr=2018-current (12)	21. TI support network OR AB support network (17987) 22. 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 (939979) 23. 5 and 10 and 22 (188) 24. 5 and 10 (1160) 25. 24 NOT 23 (927) 26. interview* OR experience* OR TI qualitative OR AB qualitative (847929) 27. 25 and 26 (111) 28. limit 23 to yr=2018-current (46)	24. #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 (341512) 25. #6 and #11 and #24 (281) 26. #6 and #11 (789) 27. #26 not #25 (508) 28. interview* or experience* or qualitative* (172779) 29. #27 and #28 (64) 30. Limit 2018 – 2022 (34)

E.5 Qualitative Synthesis Inclusion and exclusion criteria

Table 39: Inclusion Criteria for both searches

Criteria	**Justification/further notes**
Men (over 18) diagnosed with prostate cancer being managed using active surveillance	The study must be about men on AS for PCa. Studies about men having alternative treatment for prostate cancer will not be included.
Examines experiences of AS diagnosis and treatment plan (for either patients or significant others, or both)	Experiences and needs surrounding AS for PCa must be a primary aim of each study.
Articles published in English	Due to limited resources translation of studies in other languages will not be possible.
Articles published after 1990	AS was not common practice before 1990
Study must have a qualitative component	For synthesis

Table 40: Exclusion criteria for both searches

	Reason	**Further explanation**
1	Study not specifically about AS	Sample may include men on AS, but not focussed on AS. Topic may be about AS, but study sample are not on AS (e.g., may be about treatment decision making).
2	Study does not look at experiences of AS	Papers may look at experiences of other things, e.g., using a decision aid, but would still be ineligible if experiences of AS are not explored.
3	No qualitative component in the study	
4	Article is not published in English	
5	Article published before 1990	
6	Other	

E.6 Qualitative synthesis included papers characteristics

Table 41: Papers from 2018 searches

Authors	**Year**	**Sample description**	**Country of Origin**	**Design**	**Analysis**	**Recruitment site**
Mallapareddi et al(86)	2017	12 men on AS and 6 partners	USA	Focus groups	Thematic analysis	Local cancer registry & academic urology office
Rossen et al(149)	2016	8 spouses of patients on AS	Denmark	Semi structured interviews, which turned into an open dialogue	Constant comparative analysis	Participants in the NILS study (Department of Urology at Aarhus University Hospital, Denmark)
Yen-Chi et al(84)	2016	15 couples given all information about treatment options	USA	Semi structured interviews	Thematic analysis	Multidisciplinary Prostate Cancer Clinic (MPCC) at The University of Texas MD Anderson Cancer Center
Bailey et al(80)	2005	10 men on AS	USA	Semi structured interviews	Fundamental qualitative description	The urology clinic of a tertiary care medical centre located in a south-eastern state
Berger et al(90)	2014	14 men who self-elected to leave AS	USA	Semi structured interviews	Modified grounded theory	Brady Urological Institute at Johns Hopkins School of Medicine

Davison et al(91)	2009	25 men on AS*	Canada	Semi structured interviews	Thematic analysis	Vancouver Prostate Centre and the British Columbia Cancer Agency
Fitch et al(102)	2017	52 men eligible for AS	Canada	Semi structured interviews & focus groups	Qualitative description analysis	PCa programs in Montreal, Toronto, Winnipeg, Vancouver, and Thunder Bay
Hedestig et al(83)	2003	7 men on AS	Northern Sweden	Semi structured interviews	A phenomenologic-hermeneutic approach	Database containing registration of prostate cancer in northern Sweden
Kayser et al(311)	2015	8 couples where the men were on AS	Denmark	Other (mixed methods using HLQ as a framework)	Thematic analysis	Participants in the NILS study (Department of Urology at Aarhus University Hospital, Denmark)
Kazer et al(310)	2012	6 men who had undergone AS for a minimum of 6 months before converting to radical treatment	USA	Structured interviews	Fundamental qualitative methodology	Identified from the clinic schedule by participating urologists in the eastern United States
Kazer et al(309)	2011	7 men on AS	USA	Focus groups	Fundamental qualitative methodology	Identified from the clinic schedule by participating urologists in the eastern United States

Loeb et al(92)	2018	37 men on AS	USA	Focus groups	Thematic analysis	Men identified through 2 'clinical sites'
Lyons et al(82)	2017	19 men eligible for AS or treatment (&16 practitioners)**	USA	Semi structured interviews	Thematic analysis	Academic medical centres
Mader et al(85)	2017	15 men on AS**	USA	Semi structured interviews	Thematic analysis	2 academic centres
Mroz et al(93)	2013	25 men on AS*	Canada	Semi structured interviews	Thematic analysis	Vancouver Prostate Centre and the British Columbia Cancer Agency
O’Callaghan et al(142)	2014	21 men and 14 partners	Australia	Semi structured interviews	Thematic analysis	A private urology practice, an integrative cancer centre, and a public hospital’s oncology service
Oliffe et al(308)	2009	25 men on AS*	Canada	Semi structured interviews	Interpretive description	Vancouver Prostate Centre and the British Columbia Cancer Agency
Pietila et al(312)	2016	10 men on AS (and 10 having RT)	Finland	Semi structured interviews & focus groups	Unclear	Tampere University Hospital & 3 volunteers from advert in a magazine

Volk et al(87)	2014	15 men on AS (and 15 having RT)	USA	Semi structured interviews	Thematic analysis	Multidisciplinary Prostate Cancer Clinic (MPCC) at The University of Texas MD Anderson Cancer Center

* Potentially same sample　　** Potential sample overlap

Table 42: Papers from 2022 search

Authors	**Year**	**Sample description**	**Country of Origin**	**Design**	**Analysis**	**Recruitment site**
Beckmann et al(316)	2021	14 men on AS	UK	Semi-structured interviews (face-to-face)	Inductive thematic analysis	The Royal Marsden Urology department
Donachie et al(111)	2020	17 men on AS	The Netherlands	Semi-structured interviews (face-to-face)	Thematic analysis	Two Dutch Urology Clinics
Eymech et al(81)	2022	13 men on AS	UK	Semi-structured interviews	Thematic analysis	One London clinic

Hughes et al(313)	2019	13 men on AS	UK	Semi-structured interviews (telephone)	Thematic analysis	Two clinics (Southampton and London)
Matheson et al(314)	2019	24 men on AS or WW	UK	Semi-structured interviews (telephone)	Thematic analysis	Men identified through cancer registries in Scotland
McIntosh et al(110)	2022	33 men (10 on AS, 23 left AS)	Australia	Semi-structured interviews (telephone)	Thematic analysis	Men identified through Australian cancer registries
Merriel et al(315)	2019	20 interviews with stakeholders including men with and without PCa	UK	Unclear	Unclear	Unclear
Seaman et al(88)	2019	16 men on AS and 5 who had left AS	USA	Semi-structured interviews	Iterative content-driven approach	Two academic medical centres
Wade et al(101)	2020	20 men on AS	UK	Longitudinal serial in-depth qualitative interviews	Thematic analysis	4 centres in the PROTECT Trial

Appendix F CASP

F.1 The CASP Framework

Table 43: The CASP Framework

Question	**Hint: consider**	Possible responses
Was there a clear statement of the aims of the research?	What was the goal of the research? Why it was thought important? Its relevance	Yes Can’t tell No
Is a qualitative methodology appropriate?	If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants Is qualitative research the right methodology for addressing the research goal?	Yes Can’t tell No
Was the research design appropriate to address the aims of the research?	If the researcher has justified the research design (E.g., have they discussed how they decided which method to use)?	Yes Can’t tell No
Was the recruitment strategy appropriate to the aims of the research?	If the researcher has explained how the participants were selected If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study	Yes Can’t tell No

	If there are any discussions around recruitment (e.g., why some people chose not to take part)	
Was the data collected in a way that addressed the research issue?	If the setting for data collection was justified If it is clear how data were collected (e.g., focus group, semi-structured interview etc.) If the researcher has justified the methods chosen If the researcher has made the methods explicit (e.g., for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)? If methods were modified during the study. If so, has the researcher explained how and why? If the form of data is clear (e.g., tape recordings, video material, notes etc) If the researcher has discussed saturation of data	Yes Can't tell No
Has the relationship between researcher and participants been adequately considered?	If the researcher critically examined their own role, potential bias and influence during (a) Formulation of the research questions (b) Data collection, including sample recruitment and choice of location How the researcher responded to events during the study and whether they considered the implications of any changes in the research design	Yes Can't tell No
Have ethical issues been taken into consideration?	If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained If the researcher has discussed issues raised by the study (e.g., issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)	Yes Can't tell No

	If approval has been sought from the ethics committee	
Was the data analysis sufficiently rigorous?	If there is an in-depth description of the analysis process If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data? Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process If sufficient data are presented to support the findings To what extent contradictory data are taken into account Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation	Yes Can't tell No
Is there a clear statement of findings?	If the findings are explicit If there is adequate discussion of the evidence both for and against the researchers arguments If the researcher has discussed the credibility of their findings (e.g., triangulation, respondent validation, more than one analyst) If the findings are discussed in relation to the original research question	Yes Can't tell No
How valuable is the research?	If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy?, or relevant research-based literature? If they identify new areas where research is necessary	Free text

	If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used	

F.2 CASP Results

F.2.1 Are the results valid?

Table 44: CASP Section A: Are the results valid?

Paper	**1. Was there a clear statement of the aims of the research?**	**2. Is a qualitative methodology appropriate?**	**3. Was the research design appropriate to address the aims of the research?**	**4. Was the recruitment strategy appropriate to the aims of the research?**	**5. Was the data collected in a way that addressed the research issue?**	**6. Has the relationship between researcher and participants been adequately considered?**	**Comments**
Mallapareddi et al (2017)	Yes	Yes	Yes	Yes	Yes	Partly	They did not discuss how they decided which method to use. Relationship between researcher and participants: Perhaps did not 'critically examine' their own role but considered it - used same Black male facilitator for all patient focus groups, and Black female facilitator for partner groups. Did not go into detail

							about why this person was chosen.
Rossen et al (2016)	Yes	Yes	Yes	Yes	Yes	Yes	
Yen-Chi et al (2016)	Yes	Yes	Yes	Yes	Yes	Yes	
Bailey et al (2005)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants.
Berger et al (2014)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants.
Davison et al (2009)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants.
Fitch et al (2017)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants.

Hedestig et al (2003)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants.
Kayser et al (2015)	Yes	Yes	Yes	Can’t tell	Yes	Yes	
Kazer et al (2012)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants.
Kazer et al (2011)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Authors explained the facilitator was male, but no further information.
Loeb et al (2018)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants.
Lyons et al (2017)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Authors describe job role of each interviewer, but did not comment on relationship to participants.

Mader et al (2017)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Authors describe job role of each interviewer, but did not comment on relationship to participants.
Mroz et al (2013)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants.
O’Callaghan et al (2014)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants.
Oliffe et al (2009)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants.
Pietila et al (2016)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants.
Volk et al (2014)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants.

Beckmann et al., (2021)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants.
Donachie et al., (2020)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants.
Eymech et al., (2022)	Yes	Yes	Yes	Yes	Yes	Yes	
Hughes et al., (2019)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants.
Matheson et al., (2019)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants.
McIntosh et al., (2022)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants.

Merriel et al., (2019)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants.
Seaman et al., (2019)	Yes	Yes	Yes	Yes	Yes	Yes	
Wade et al., (2020)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants.

F.2.3 What are the results?

Table 45: CASP Section B: What are the results?

Paper	**7. Have ethical issues been taken into consideration?**	**8. Was the data analysis sufficiently rigorous?**	**9. Is there a clear statement of findings?**	**Comments**
Mallapareddi et al (2017)	Yes	Yes	Yes	States ethical approval. Does not detail how study was explained to participants, just that it was done by telephone. 1-3 quotes for each theme and an adequate description of each theme.
Rossen et al (2016)	Yes	Yes	Yes	Explained informed consent process and ethics committee approval.
Yen-Chi et al (2016)	Yes	Yes	Yes	
Bailey et al (2005)	Yes	Yes	Yes	
Berger et al (2014)	Cannot tell	Yes	Yes	
Davison et al (2009)	Yes	Yes	Yes	Stated that ethical approval was granted, but has not discussed further.

Fitch et al (2017)	Yes	Yes	Yes	Stated that ethical approval was granted, but has not discussed further.
Hedestig et al (2003)	Yes	Yes	Unclear	Stated that ethical approval was granted, but has not discussed further. Findings quite long winded and absorbed into the conclusions/discussion section.
Kayser et al (2015)	Yes	Yes	Yes	
Kazer et al (2012)	Yes	Yes	Yes	Stated that ethical approval was granted, but has not discussed further.
Kazer et al (2011)	Yes	Yes	Yes	Discussed possible distress in focus groups and procedures in place.
Loeb et al (2018)	Yes	Yes	Yes	Stated that ethical approval was granted, but has not discussed further.
Lyons et al (2017)	Yes	Yes	Yes	Stated that ethical approval was granted, but has not discussed further.
Mader et al (2017)	Yes	Yes	Yes	Stated that ethical approval was granted, but has not discussed further.
Mroz et al (2013)	Yes	Yes	Yes	Stated that ethical approval was granted, but has not discussed further.

O’Callaghan et al (2014)	Yes	Yes	Yes	Stated that ethical approval was granted, but has not discussed further.
Oliffe et al (2009)	Yes	Yes	Yes	Stated that ethical approval was granted, but has not discussed further. Figure to show findings good.
Pietila et al (2016)	Yes	Cannot tell	Unclear	Stated that ethical approval was granted, but has not discussed further. Statement of findings quite hard to pick out, absorbed into discussion.
Volk et al (2014)	Yes	Yes	Yes	Stated that ethical approval was granted, but has not discussed further.
Beckmann et al., (2021)	Yes	Yes	Yes	Stated that ethical approval was granted, but has not discussed further.
Donachie et al., (2020)	Yes	Yes	Yes	Stated that ethical approval was granted. Describes informed consent process.
Eymech et al., (2022)	Yes	Yes	Yes	
Hughes et al., (2019)	Yes	Yes	Yes	Stated that ethical approval was granted. Describes informed consent process.

Matheson et al., (2019)	Yes	Yes	Yes	Stated that ethical approval was granted, but does not provide further information about ethical considerations.
McIntosh et al., (2022)	Yes	Yes	Yes	Stated that ethical approval was granted, but does not provide further information about ethical considerations.
Merriel et al.,	Yes	Cannot tell	Unclear	Analysis process for interview data not described. Findings are absorbed into results and discussion with no clear statement of findings.
Seaman et al., (2019)	Yes	Yes	Yes	
Wade et al., (2020)	Yes	Yes	Yes	Stated that ethical approval was granted, but does not provide further information about ethical considerations.

F.2.4 How will the results help locally?

Table 46: CASP Section C: How will the results help locally?

Paper	**10. How valuable is the research?**

Mallapareddi et al (2017)	Researcher states new contribution to existing findings, states where further research is needed, consider the findings in relation to current practice (e.g., that the term AS needs to be standardised, and recognised as a management plan).
Rossen et al (2016)	Statement of 'nursing implications' helpful for future practice. Discusses the findings in relation to previous literature. Suggestions for future research made.
Yen-Chi et al (2016)	Authors make suggestions where changes to future practice could be beneficial.
Bailey et al (2005)	Statement of 'relevance to clinical practice' and suggestions for use of the findings.
Berger et al (2014)	Authors make suggestions for clinical practice change.
Davison et al (2009)	Researcher states relatively new topic and further research to be done as next steps.
Fitch et al (2017)	Not all of the sample was on AS, but still valuable in understanding how/why men choose AS.
Hedestig et al (2003)	Authors do not make suggestions for clinical practice implications; they also do not make suggestions for future research. They claim their study is just a snapshot of experience.
Kayser et al (2015)	Future research suggestions, and implications for clinical practice discussed.
Kazer et al (2012)	Suggestions made for future interventions supporting men on AS.

Kazer et al (2011)	Suggestions made for future interventions supporting men on AS, and for future clinical practice.
Loeb et al (2018)	Suggestions made for future clinical practice.
Lyons et al (2017)	Suggestions made for future clinical practice.
Mader et al (2017)	Suggestions made for future research.
Mroz et al (2013)	Suggestions made for future clinical practice.
O'Callaghan et al (2014)	Suggestions made for future clinical practice.
Oliffe et al (2009)	Suggestions made for both future research and future clinical practice.
Pietila et al (2016)	Hard to tell - although interesting, they authors do not provide suggestions about what to do with the information.
Volk et al (2014)	Suggestions made for future clinical practice.
Beckmann et al., (2021)	Suggestions made for future clinical practice.
Donachie et al., (2020)	Suggestions made for both future research and future clinical practice.
Eymech et al., (2022)	Suggestions made for future research.
Hughes et al., (2019)	Suggestions made for future research.
Matheson et al., (2019)	Suggestions made for both future research and future clinical practice.

McIntosh et al., (2022)	Suggestions made for both future research and future clinical practice.
Merriel et al., (2019)	Unclear.
Seaman et al., (2019)	Suggestions made for both future research and future clinical practice.
Wade et al., (2020)	Suggestions made for both future research and future clinical practice.

Appendix G Study Protocol

SO ACTIVE Protocol

Exploring significant other experiences of undergoing ACTIVE surveillance for prostate cancer: an exploratory study.

Protocol Version 1.0, 18th September 2017

ERGO 29805

Version Number	Author	Effective Date	Reasons for Change
1.0	Stephanie Hughes	01/09/2017	New
1.1	Stephanie Hughes	18/09/2017	PPI feedback

CONTENTS

1. GENERAL INFORMATION

1.1. Protocol authorisation and amendments

The final protocol for the SO ACTIVE study and any subsequent amendments will be authorised by the Chief Investigator (Stephanie Hughes), and the Principal Investigator (Dr Hazel Everitt). Any changes made to the protocol will be sent to and approved by the University of Southampton Ethics Committee.

1.2. Compliance

All aspects of this study will be undertaken in full compliance with the protocol and in keeping with Good Clinical Practice (GCP) guidelines and the Data Protection Act (1998).

1.3. Sponsorship

The University of Southampton will act as the sponsor for this study.

Sponsor's contact: Research and Development Office

E Level, Southampton Centre for Biomedical Research
Laboratory and pathology block, mail point 138
Southampton General Hospital
Tremona Road
Southampton
SO16 6YD

Telephone: 023 8120 8215

Email: R&Doffice@uhs.nhs.uk

1.4. Funder

This study is funded in full by the charity Prostate Cancer Support Organisation (PCaSO).

Funder's contact:

PCaSO Prostate Cancer Support Organisation
PO Box 66
Emsworth
Hants
PO10 7ZP

info@pcaso.org

1.5. Ethical Governance

This study has received full ethical approval from The University of Southampton Ethics Committee.

REC's contact:

University of Southampton
University Road
Southampton
SO17 1BJ
United Kingdom

Email: researchintegrity@soton.ac.uk

2. RESEARCH TEAM

Chief Investigator	**Mrs Stephanie Hughes** Senior Research Assistant in Primary Care & PhD Student Primary Care and Population Sciences Aldermoor Health Centre Aldermoor Close Southampton SO16 5ST Telephone: 02380 522286 Email: sh3r11@soton.ac.uk
Principle Investigator	**Dr Hazel Everitt** Associate Professor in General Practice Primary Care and Population Sciences Aldermoor Health Centre Aldermoor Close Southampton SO16 5ST Telephone: 02380 241052 Email: h.a.everitt.ac.uk
Co-Investigators	**Dr Sam Watts** – PhD Supervisor of Stephanie Hughes, Post-doctoral Research Fellow, University of Southampton **Dr Rebecca Band** – PhD Supervisor of Stephanie Hughes, Research Fellow, University of Southampton
Additional Study Team	**Beth Reed** – Medical Student, University of Southampton

3. LAY SUMMARY

Background:

Localised prostate cancer sometimes grows very slowly, and some men may never need treatment for it. For this reason, 'active surveillance' may be recommended; this means the cancer is monitored closely without radical intervention such as surgery or radiotherapy. Active surveillance (AS) comes without the unwanted side effects of radical intervention, such as urinary incontinence and erectile dysfunction; however, research has shown there may be psychological consequences such as heightened levels of anxiety, concern and distress.

Previous research suggests that men with higher levels of anxiety and depression are more likely to choose surgery when there is no clinical reason, which may lead to unnecessary complications.

The SO ACTIVE study was previously part of PROACTIVE (PROstate cancer support intervention for ACTIVE surveillance, funded by Prostate Cancer UK).

PROACTIVE aimed to support men on AS for prostate cancer. It involved 3 group workshops (led by prostate cancer nurse specialists) and 6 interactive internet sessions that provided further support, information and self-management techniques. In the third group workshop the participants had the option to bring their significant other (e.g., partner, relative, and friend). PROACTIVE was piloted with a group of 7 men and the results were encouraging, suggesting that the intervention helped to lower distress and improve quality of life related survivorship issues.

In qualitative interviews with PROACTIVE participants a recurring theme around the involvement of partners or significant others was present. They felt the way in which their significant other understands their diagnosis and AS a treatment plan is of great importance, and that it would be beneficial for them to be involved. SO ACTIVE will further explore and begin to address this.

SO ACTIVE: Exploring Significant Other experiences of undergoing ACTIVE surveillance for prostate cancer: an exploratory study

SO ACTIVE will focus on the significant others of men undergoing active surveillance for prostate cancer. This may be their wife, husband, partner, close relative or friend. Participating men with prostate cancer and their significant others will be asked to complete a questionnaire, and a subset of participants will be asked to take part in a telephone interview.

The men with prostate cancer and their significant others will be given separate questionnaires which will differ slightly. These questionnaires will look at levels of anxiety and depression, quality of life, couple communication, relationship quality and illness perceptions. The significant other questionnaires will also measure the same variables to explore their responses to the illness.

These measures will be used to explore how couple communication, relationship quality and illness perceptions may relate to anxiety, depression and quality of life.

A subset of participants will be asked to take part in a telephone interview. All participants will be asked to take part in the interview independently (without the presence of their significant other). The interviews (for both the men with prostate cancer and their significant others) will further explore their reactions to the prostate cancer diagnosis and AS treatment plan, perceptions about their significant other's feelings, responses and reactions to the diagnosis and treatment plan, and the way they see their illness being managed in the future. The interviews will help us to gain an understanding about how significant other responses impact on the men with a diagnosis of prostate cancer.

This project will help us understand how to better support both men on active surveillance and their significant others.

4. BACKGROUND

4.1 Introduction

Due to increased PSA testing and an aging population, incidences of prostate cancer (PCa) diagnosis have risen dramatically over the last two decades.[1] The treatment options for prostate cancer are radiotherapy, surgery or active surveillance (AS). AS involves closely monitoring the cancer using blood tests, biopsies and ideally MRI scans with a view to delaying or avoiding radical intervention and the associated side effects. Where prostate cancer is localised and slow growing, choosing surgery over AS has not been shown to significantly improve 12 year survival.[2] For this reason, AS may be recommended for this type of PCa. Radiotherapy and surgery carry risks such as erectile dysfunction and urinary incontinence. AS avoids these risks, but research has shown that men on AS may have heightened levels of anxiety[3],[4], concern and distress[5] due to living with an untreated cancer. The PROACTIVE study aimed to address these issues.

PROACTIVE was an intervention designed to support men undergoing AS for PCa. The intervention consisted of 3 group workshops run in parallel with 6 online sessions. The group workshops and the online sessions were designed to complement each other and cover topics such a relaxation and resilience techniques, healthy lifestyle advice (specifically diet and exercise), dealing with emotions and talking to others. The sessions also provided reliable information about PCa, AS and PSA testing, and signpost participants to further reliable sources. PROACTIVE was piloted with 7 men on AS at University College London Hospital in 2013. The results were promising and indicated that PROACTIVE might be a useful tool in supporting this population. Qualitative interviews with the men who took part in the pilot indicated that partners/significant others are key to the way in which their PCa is managed both practically and emotionally and having them involved in the intervention would be beneficial. This finding sparked the initial idea for SO ACTIVE, and a review of the literature related to partners in active surveillance and PCa was carried out.

The literature around partners of PCa patients supports the findings from the PROACTIVE pilot qualitative interviews and strengthens the case for partner involvement in treatment and care. Gorin et al., (2011)[6] found that for men who chose AS a treatment plan “family members being supportive of this alternative” was the fourth out of 12 most important factors, and was ranked ahead of concerns about impotence or incontinence. A review by Couper et al., (2006)[7] found that the partners of men with prostate cancer report higher levels of anxiety than the men themselves, however, they perceive their male partners to have higher levels of anxiety than themselves, and went on to state that ‘future research into psychosocial ramifications of prostate cancer should incorporate the partner as well as the patient’.

SO ACTIVE is an exploratory study focusing on both men undergoing AS for prostate cancer and their significant others. More specifically the study aims to explore how significant other responses to, perceptions of and anxiety about the prostate cancer diagnosis and the AS treatment plan impact on the anxiety levels of the patient themselves. Dyadic relationship quality, and illness-related communication will also be examined in relation to patient anxiety.

4.2 Population to be studied

Men with a biopsy confirmed diagnosis of prostate cancer who are being managed with active surveillance, and their significant others. The ‘significant other’ may be a partner or other close relative or friend.

5. AIMS, OBJECTIVES AND HYPOTHESES

5.1 Aims

Aims for the quantitative study:

1. To explore the relationship between significant other responses to, and perceptions of, active surveillance and patient anxiety.

2. To explore the relationship between relationship quality and illness related dyadic communication, and patient anxiety.

3. To explore the relationship between significant other prostate cancer related anxiety, and patient anxiety, depression and quality of life.

Aims for the qualitative study:

1. To explore how the significant other responses to the PCa diagnosis and AS treatment plan impact on the PCa patient.

2. To explore the way in which the dyads perceive each other’s AS related feelings and reactions.

3. To explore the feelings of both the patient and the SO around being managed with AS.

4. To explore the way in which both the patient and the SO see the PCa treatment plan longer term.

5.2 Hypotheses

This exploratory study aims to explore the potential influence of the significant other on the prostate cancer patient being managed by active surveillance. Therefore, the hypotheses below include both prostate cancer patient outcomes, and significant other outcomes.

The proposed hypotheses are:

Primary hypotheses:

1. There is a relationship between significant other responses to the PCa diagnosis and AS treatment plan, and patient anxiety.

2. There is a relationship between relationship quality and illness related dyadic communication and patient anxiety.

3. There is a relationship between significant other prostate cancer related anxiety and patient anxiety, depression and quality of life.

Secondary hypotheses:

1. There is a relationship between prostate cancer patients' beliefs about prostate cancer, and their own levels of anxiety and depression.

2. There is a relationship between the way in which significant others perceive the prostate cancer diagnosis, and their own levels of anxiety and depression.

The qualitative data gathered in this study will be broad and mostly participant led with a semi-structured interview guide to ensure important areas are covered. Data analysis will be approached initially using an inductive thematic approach. Therefore, no explicit theoretical hypotheses will be tested, but the thematic data will be used to generate a model of partner concerns and behaviour in this context.

6. STUDY DESIGN

A mixed methods study to explore significant other responses and the impact they may have on men undergoing active surveillance for prostate cancer. The study will ask men and their SO to complete a set of questionnaires, with a nested qualitative study for a purposively sampled subset of participants.

7. TIMELINE

Please see the Gantt chart (Appendix 1) for a detailed breakdown of the timeline for this investigation

8. SO ACTIVE study overview

SO ACTIVE focusses on men undergoing active surveillance for prostate cancer and their partners/significant others.

Participants will be recruited through the following channels:

1.) Via the PCaSO charity with mail outs (by post and email), and recruitment adverts placed in the charity newsletter and in PCaSO centres.

2. Via adverts placed on the social media sites (Facebook and twitter) of Prostate Cancer UK and Tackle Prostate Cancer.

Participants will complete a questionnaire either online or by post and a subsection of participants will complete a qualitative interview by telephone.

9. METHODOLOGY

9.1 Recruitment

Participants will be recruited through adverts placed in the following places (see appendices 16.8, 16.9 and 16.10:

- PCaSO newsletter
- PCaSO email circulation
- PCUK newsletter
- PCUK Facebook and twitter
- Tackle Prostate cancer newsletter
- Tackle Facebook and Twitter

Both the men on AS for PCa, and their significant others can opt to either receive the study information, consent form and questionnaire by post, or view and complete it online. This will be up to the participant.

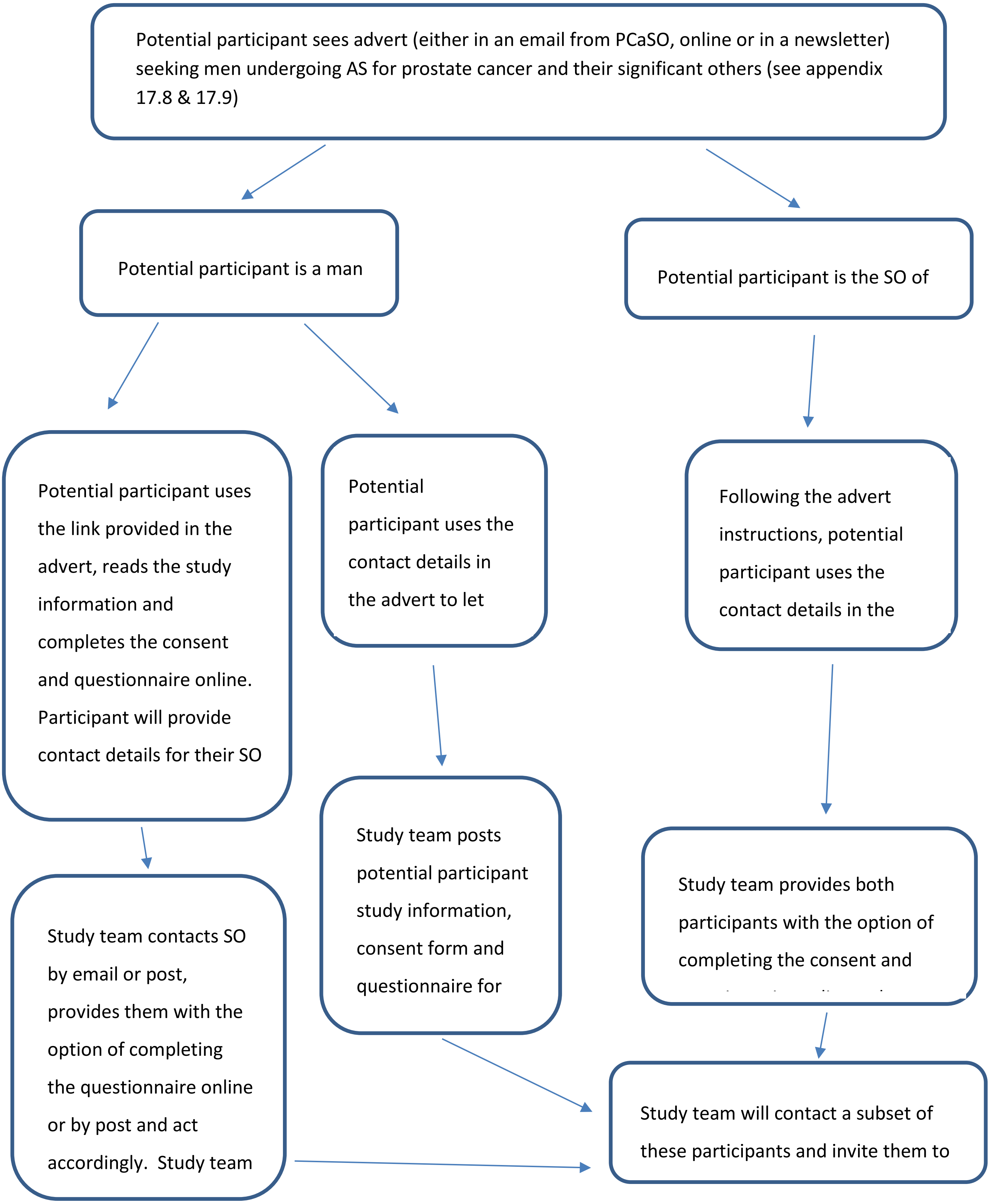
The advert will ask men on AS for PCa to either follow a link to view the study information, consent form and questionnaire online; or to get in touch with the study team to express their interest and be posted a study pack. The study pack will contain a study invite letter, participant information sheet, reply slip, consent form and questionnaire (see appendices 16.2, 16.4, 16.5). The men will also be posted a study pack to pass to their significant other containing an invite letter, participant information sheet, reply slip, consent form and questionnaire (see appendices 16.3, 16.4, 16.6).

In case the advert is seen by the significant others of men on AS, the advert (appendices 16.8, 16.9, 16.10) will ask them to get in touch with the study team to express their interest. The study team will then provide the dyad with the option to complete the study online or by post and act accordingly.

See figure 1 for the recruitment flow chart.

9. METHODOLOGY

9.2 Figure 1: Recruitment flow chart:



9.3 The Recruitment Advert

The questionnaire for the PCa patient, and the significant other differ slightly. To avoid confusion, the adverts will contain only the link to the PCa patient questionnaire, and the information will clearly state that it is to be completed only by these participants. See advert in appendix 16.8 & 16.9.

9.4 Managing Dyads in Recruitment

The following processes will be followed to ensure dyad data can be matched:

1. If a participant uses the link from an advert to complete the questionnaire online, the questionnaire will gather the details of their significant other (name, contact details). The study team will allocate this participant and their SO an ID, before sending out the information and questionnaire to the SO. The study team will be able to link the IDs for analysis.

2. If a dyad request the information and questionnaires by post, they will each be allocated an ID, which the study team can link.

9.5 Sample Size and Power Calculation

It is intended that 404 dyads will be recruited, 808 participants in total. We anticipate that there will be a moderate correlation between each of the key measures of significant other anxiety/distress and patient anxiety/distress. Based on a 95% confidence interval, a sample size of 404 completed pairs of questionnaires would allow us to estimate a correlation coefficient of 0.70 within a confidence interval of (0.65-0.75).

9.6 Quantitative Study Measures

The questionnaire for the prostate cancer patient, and the questionnaire for their significant other will differ slightly.

The questionnaire for the patient will include:

- **Demographics**
- **Your significant other** This section will gather information such as the SO relationship type, and length of relationship.
- **Your prostate cancer** This section will gather information about PCa history, e.g., time since diagnosis and previous treatments.
- **The Hospital Anxiety and Depression Scale** (HADS; Zigmond & Snaith, 1983) 14-item questionnaire assessing anxiety and depression. Items are rated on a 4-point scale from 0-3 (not present – substantial), and a total score on each subscale is calculated.

- **SF-12** (Ware, Kosinski, & Keller, 1996) Assesses general health and well-being/quality of life in 12 items.
- **The Memorial Anxiety Scale for Prostate Cancer** (MAX-PC; Roth et al, 2003) 18-item questionnaire designed to gain an insight into prostate cancer related anxiety.
- **The Couples' Illness Communication Scale** (CICs; Arden-Close et al, 2010) adapted to include significant others that are not partners. Questionnaire contains 4 items designed to gain insight into patient and partner illness communication.
- **Revised Dyadic Adjustment Scale** (RDAS; Busby et al, 1995) contains 14 items measuring couple consensus, satisfaction and cohesion.
- **The Illness Perception Questionnaire** (IPQ-R; Weinman et al, 1996) provides questions across 5 components (identity, cause, timeline, consequences and cure/control) to gather an understanding of patient illness perception.

The questionnaire for the significant others will include:

- **Demographics**
- **Your significant other**
- **The Hospital Anxiety and Depression Scale** (HADS)
- **SF-12** (Quality of Life)
- **The Memorial Anxiety Scale for Prostate Cancer** (MAX-PC) adapted for significant others
- **The Couples' Illness Communication Scale** (CICS), adapted to include significant others that are not partners.
- **Revised Dyadic Adjustment Scale**
- **The Family Response Questionnaire** (FRQ; Cordingley et al, 2001) assesses responding style of family members, based on 25 items rated on a 5-point scale from never-very often. Responding styles can be classified as sympathetic-empathic; active engagement; rejecting-hostile and concern with self.
- **The Illness Perception Questionnaire for significant others** (IPQ-R-SO; Lobban et al, 2005), adapted to be appropriate for significant others.

9.7 Qualitative Methodology

Participants will be contacted by email or telephone to arrange a suitable time for the interview to take place. All interviews will be conducted by telephone, audio-recorded and transcribed verbatim. Transcripts will be anonymised by removing all identifiable data, such as names. The participant will be made aware of this process and understand that their data will remain anonymous throughout. In order to obtain the most honest, accurate data, participants will be asked to take part in the interview alone. If for any reason this is not possible, or the participant is not comfortable being alone for the interview, the presence of the other person will be noted and taken into account in analysis.

It is expected that around 40 participants will be interviewed, but this number may be adjusted if saturation is reached and no new themes are emerging with fewer interviews. 20 of these will be men with prostate cancer and 20 will be their significant others.

The Interview guides will be developed by a team of qualitative experts and cover topics such as:

- Involvement in the study and expectations
- Reaction to diagnosis and active surveillance treatment plan
- The significant other (i.e., questions around how they communicate with each other, and how their significant other reacted to the diagnosis and treatment plan)
- Further thoughts and anything to add

The interview guide may be adjusted and changed iteratively as the study develops.

9.8 Duration of study participation

The questionnaires will be completed at a single time point. The interviews will take place no longer than 12 months after questionnaire completion. Therefore, study participation will last a maximum of 12 months.

9.9 Inclusion criteria

- Prostate cancer patient must be undergoing active surveillance
- Willing to participate/provide informed consent
- Fluent English (written and oral)

9.10 Exclusion criteria

- Under the age of 18
- Unable to take part in telephone interviews
- Not fluent in English

9.11 Withdrawal Criteria

Participants will be withdrawn from the study if there are any concerns regarding informed consent. Participant can also withdraw if they choose without giving a reason. The information on the event will be collected in the Drop-out Report Form.

10. DATA ANALYSIS

10.1 Quantitative Analysis

Descriptive statistics and graphical representations of the quantitative data will be used to explore:

1. Patient relationships between PROMS (anxiety, depression, wellbeing, communication and illness perception).

2. Significant other relationships between PROMS (anxiety, depression, wellbeing, communication and illness perception).

3. Relationships between patient responses and significant other responses.

Correlation, partial-correlation and regression analyses will be the primary methods of statistical analysis.

10.2 Qualitative Analysis

Qualitative interviews will be digitally recorded, anonymised and transcribed. Data will be analysed using a thematic approach. Thematic analysis (TA) will allow for an inductive process of analysis, enable both similarities and differences across the data to be explored, and allow for the generation of unanticipated insights[8]. Using the Braun and Clarke (2006) method, TA involves 6 stages:

1. Familiarisation with the data: Listening to the recorded interviews, reading and re-reading the data, taking notes of any initial ideas.

2. Generating initial codes: Identifying and highlighting sections of the data that are interesting, or relevant to the research questions.

3. Searching for themes: Collating the initial codes into broader initial themes.

4. Reviewing themes: Generating a thematic ‘map’ of analysis and re-checking the codes fit under each proposed theme.

5. Defining and naming themes: Refining the themes to allow for the generation of initial results. Giving each theme a clear definition.

6. Producing the report: Final analysis, selecting extract examples, relating the results back to the research questions.

11. ETHICAL CONSIDERATIONS

Participants recruited into this study will either have cancer themselves, or have a significant other living with cancer, and may therefore be regarded as being a potentially vulnerable group. Consequently, participants will only be recruited into this study if they have the full capacity to make an informed decision to participate.

It is also possible that participants recruited into this study may experience an increase in emotional distress and uncertainty as a result of discussing and analysing their problems relevant to their own or their significant other's prostate cancer and active surveillance. This will be managed as part of the study and any participant displaying elevated distress or anxiety will be correctly managed and referred to relevant support services as required. In additional, the Participant Information Sheet and Participant Information Letter will list the name and contact details of the study manager should the participant have any questions, queries or concerns.

12. DATA PROTECTION AND STORAGE

Data will be collected and retained in accordance with the Data Protection Act 1998.

The Data Protection policy of the School of Medicine, Southampton University, will be complied with.

Anonymised paper questionnaires will be stored in a locked filing cabinet at Primary Medical Care – University of Southampton.

Study documents (paper and electronic) will be retained in a secure location during and after the study has finished. All source documents will be retained for a period of 15 years following the end of the study.

13. RESEARCH GOVERNANCE

This study will be conducted in accordance with the International Conference for Harmonisation of Good Clinical Practice (ICH GCP) guidelines, and the Research Governance Framework for Health and Social Care. The University of Southampton has agreed to be the Sponsor for this study.

Regular updates and meetings will ensure good communication. Each team member will consult the other team members immediately by email and/or phone on any issues that arise.

14. PATIENT PUBLIC INVOLVEMENT

Patient Public representatives were recruited from the charity Prostate Cancer Support Organisation (PCaSO).

Two PPI representatives were given the study questionnaires and interview schedules to view. They were given the opportunity to provide comments and feedback. The feedback has been used to amend the documents as necessary.

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Appendix H Questionnaires

H.1 Questionnaire for men on AS

SO ACTIVE

Exploring Significant Other experiences of undergoing ACTIVE surveillance for prostate cancer: an exploratory study

Questionnaire for man on AS

Thank you for your participation and support for the SO ACTIVE Study. This questionnaire is completely confidential and will only be seen by the researchers involved in the study.

Please try to complete all the questions even if they seem similar or repetitive as this will help us to collect the most reliable information for the study. Please enter the date completed below.

If you have any study related questions please get in touch by email: sh3r11@soton.ac.uk

Study ID	

Date Completed (ddmmyyyy)								

Demographics

For each question please tick the box most relevant to you.

1. Employment:

Full time employment	
Part time employment	
Retired	
Unemployed	

2. Relationship status:

Married/Civil Partnership	
Co-habiting	
Divorced	
Widowed	
Single	

3. Ethnicity:

White British	
White Other	
Black African	
Black Caribbean	
Asian	
Other, please specify: ____________________________	

4. Education:

Left school before 15	
Completed secondary education	
College / specialised training	
University	
Unknown	

Your significant other

By ‘significant other’ we mean the person you are closest to and are most likely to talk to about your prostate cancer and treatment plan.

The following questions are designed to help us understand a little more about this relationship.

1. Type of relationship:

Partner by marriage	
Partner unmarried	
Close relative, please specify: ______________________	
Close friend	
Other, please specify: ______________________	

2. How long have you had a close personal relationship with this person?

Less than 1 year	
1-5 years	
6-10 years	
11-15 years	
16-20 years	
More than 20 years	

Your Prostate Cancer

1. How long ago were you diagnosed with prostate cancer?

Less than 1 year	
1-5 years	
6-10 years	
11-15 years	
More than 15 years	

2. How many MRI scans have you had? _______

3. When did you have these MRI scan(s)? (MM/YYYY)

1. _ _ / _ _ _ _ 2. _ _ / _ _ _ _ 3. _ _ / _ _ _ _

4. _ _ / _ _ _ _ 5. _ _ / _ _ _ _ 6. _ _ / _ _ _ _

4. How many biopsies have you had? _______

5. When did you have these biopsies? (MM/YYYY)

1. _ _ / _ _ _ _ 2. _ _ / _ _ _ _ 3. _ _ / _ _ _ _

4. _ _ / _ _ _ _ 5. _ _ / _ _ _ _ 6. _ _ / _ _ _ _

6. Since diagnosis, what treatment have you received for your prostate cancer? (Tick all that apply)

	Y/N	Approximate start/finish date	Any further information on treatment
Active surveillance			
Watchful waiting			
Surgery			
Radiation therapy			
Cryotherapy (cryosurgery)			

Hormone therapy			
Chemotherapy			
High intensity focussed ultrasound			

7. What treatment are you currently undergoing for your prostate cancer?

	Y/N	Approximate start/finish date	Any further information on treatment
Active surveillance			
Watchful waiting			
Awaiting surgery			
Radiation therapy			
Cryotherapy (cryosurgery)			
Hormone therapy			
Chemotherapy			
High intensity focussed ultrasound			

8. a.) Are you currently seeing a hospital specialist / going to clinic at the hospital for your prostate cancer?

Yes	
No	

b.) If yes, how often?

Monthly	
Every 3 months	
Every 6 months	
Yearly	
Other, please specify: ______________________ ______________________	

9. a.) Do you consult with your GP about your prostate cancer?

Yes	
No	

b.) If yes, how often?

Monthly	
Every 3 months	
Every 6 months	
Yearly	
Other, please specify: ________________________	

10. Since your diagnosis what sources of information have you used? (Tick all that apply)

Leaflet given to you in clinic	
Internet searches	
Prostate Cancer charities	
Prostate Cancer support group	
Other, please specify:	

11. Are you a member of a prostate cancer support group?

Yes	
No	

12. If you had a prostate cancer related query, where would you seek advice? (Tick all that apply)

GP	
Specialist nurse	
Internet search	
Others with prostate cancer	
Prostate Cancer charities	
Prostate Cancer support group	
Other, please specify:	

13. Please add any additional information about your prostate cancer and the treatment and information you have received in the box below:

For the following questions, please indicate (tick) the response that best applies to how you have felt in the past week:

1. I feel tense or 'wound up'.

Most of the time	A lot of the time	From time to time, occasionally	Not at all

2. I still enjoy the things I used to enjoy.

Definitely as much	Not quite so much	Only a little	Hardly at all

3. I get a sort of frightened feeling as if something awful is about to happen.

Very definitely and quite badly	Yes, but not too badly	A little, but it doesn't worry me	Not at all

4. I can laugh and see the funny side of things.

As much as I always could	Not quite so much now	Definitely not so much now	Not at all

5. Worrying thoughts go through my mind.

A great deal of the time	A lot of the time	Not too often	Very little

6. I feel cheerful.

Never	Not often	Sometimes	Most of the time

7. I can sit at ease and feel relaxed.

Definitely	Usually	Not often	Not at all

8. I feel as if I am slowed down.

Nearly all the time	Very often	Sometimes	Not at all

9. I get a sort of frightened feeling like ‘butterflies’ in the stomach.

Not at all	Occasionally	Quite often	Very often

10. I have lost interest in my appearance.

Definitely	I don’t take as much care as I should	I may not take quite as much care	I take just as much care as ever

11. I feel restless as if I have to be on the move.

Very much indeed	Quite a lot	Not very much	Not at all

12. I look forward with enjoyment to things.

As much as I ever did	Rather less than I used to	Definitely less than I used to	Hardly at all

13. I get sudden feelings of panic.

Very often indeed	Quite often	Not very often	Not at all

14. I can enjoy a good book, or radio or television programme.

Often	Sometimes	Not often	Very seldom

Twelve-Item Short-Form Health Survey: SF-12

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Answer each question by choosing just one answer. If you are unsure how to answer a question, please give the best answer you can.

1. In general, would you say your health is:

Excellent	Very good	Good	Fair	Poor

The following questions are about activities you might do during a typical day. Does <u>your health now limit you</u> in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
2. Moderate activities such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.			
3. Climbing several flights of stairs.			

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	Yes	No
4. Accomplished less than you would like.		
5. Were limited in the kind of work or other activities.		

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	Yes	No
6. Accomplished less than you would like.		
7. Did work or activities less carefully than usual.		

8. During the past 4 weeks, how much did pain interfere with your normal work (including work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely

These questions are about how you have been feeling during the past 4 weeks.

For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks…

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
9. Have you felt calm & peaceful?						
10. Did you have a lot of energy?						
11. Have you felt down-hearted and blue?						

12. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time

The Memorial Anxiety Scale for Prostate Cancer (MAX-PC)

Your feelings about prostate cancer and prostate specific antigen (PSA) tests.

We would like to better understand how prostate cancer patients cope with aspects of their treatment for prostate cancer and the medical tests frequently involved in their care.

Below is a list of comments made by men with prostate cancer. Please indicate by ticking the boxes below how frequently these comments were true for you during the past week.

	Not at all	Rarely	Sometimes	Often
1. Any reference to prostate cancer brought up strong feelings in me.				
2. Even though it's a good idea, getting a PSA test scared me.				
3. Whenever I heard about a friend or public figure with prostate cancer I got more anxious about having prostate cancer.				
4. When I thought about having a PSA test, I got more anxious about having prostate cancer.				
5. Other things kept making me think about prostate cancer.				
6. I felt kind of numb when I thought about prostate cancer.				
7. I thought about prostate cancer even though I didn't mean to.				
8. I had lots of feelings about prostate cancer, but I didn't want to deal with them.				

9. I had more trouble falling asleep because I couldn’t get thoughts of prostate cancer out of my mind.				
10. I was afraid that the results from my PSA test would show that the disease was getting worse.				
11. Just hearing the words ‘prostate cancer’ scared me.				

For the next three questions, please indicate how frequently these situations have EVER been true for you.

	Not at all	Rarely	Sometimes	Often
12. I have been so anxious about my PSA test that I have thought about delaying it.				
13. I have been so worried about my PSA test result that I have thought about asking my doctor to repeat it.				
14. I have been so concerned about my PSA test result that I have thought about having the test repeated at another lab to make sure it was accurate.				

Listed below are a number of statements concerning a person’s beliefs about their own health. In thinking about the past week, please indicate how much you agree or disagree with each statement.

	Strongly agree	Agree	Disagree	Strongly disagree
15. Because cancer is unpredictable, I feel I cannot plan for the future.				
16. My fear of my cancer getting worse gets in the way of my enjoying life.				
17. I am afraid of my cancer getting worse.				
18. I am more nervous since I was diagnosed with prostate cancer.				

Couples' Illness Communication Scale

The following questions ask about your relationship with your significant other.

Each question should be answered on the scale shown below.

1	2	3	4	5
Disagree strongly	Disagree	Undecided	Agree	Agree strongly

1. It is hard for me to express feelings about my illness to my significant other. ______

2. I feel comfortable discussing issues related to my illness with my significant other.______

3. My significant other is reluctant to talk about my illness. ______

4. My significant other is willing to share his/her feelings about my illness with me. ______

Revised Dyadic Adjustment Scale

Most persons have disagreements in their relationships. Please indicate below the approximate extent of agreement or disagreement between you and your significant other for each item on the following list.

	Always agree	Almost always agree	Occasionally agree	Frequently disagree	Almost always disagree	Always disagree
1. Religious matters						
2. Demonstrations of affection						
3. Making major decisions						
4. Sex relations						
5. Conventionality (correct or proper behaviour)						
6. Career decisions						

	All the time	Most of the time	More often than not	Occasionally	Rarely	Never
7. How often do you discuss or have you considered divorce, separation, or terminating your relationship?						
8. How often do you and your SO quarrel?						

9. Do you ever regret that you married (or lived together)?						
10. How often do you and your SO 'get on each other's nerves'?						

	Everyday	Almost everyday	Occasionally	Rarely	Never
11. Do you and your SO engage in outside interests together?					

How often would you say the following events occur between you and your mate?

	Never	Less than once a month	Once or twice a month	Once or twice a week	Once a day	More often
12. Have a stimulating exchange of ideas						
13. Work together on a project						
14. Calmly discuss something						

Illness Perception Questionnaire (IPQ-R): Your views about your prostate cancer

We are interested in your own personal views of how you now see your prostate cancer.

Please indicate how much you agree or disagree with the following statements about your prostate cancer by ticking the appropriate box.

	VIEWS ABOUT YOUR ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER DISAGREE NOR AGREE	AGREE	STRONGLY AGREE
IP1	My illness will last a short time					
IP2	My illness is likely to be permanent rather than temporary					
IP3	My illness will last for a long time					
IP4	My illness will pass quickly					
IP5	I expect to have this illness for the rest of my life					
IP6	My illness is a serious condition					
IP7	My illness has major consequences on my life					
IP8	My illness does not have much effect on my life					
IP9	My illness strongly affects the way others see me					

IP10	My illness has serious financial consequences for me					
IP11	My illness causes difficulties for those who are close to me					
IP12	There are some things I can do to control my symptoms					

	VIEWS ABOUT YOUR ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER DISAGREE NOR AGREE	AGREE	STRONGLY AGREE
IP13	To some extent what I do can determine whether my illness gets better or worse					
IP14	The course of my illness depends on me					
IP15	Nothing I do will affect my illness					
IP16	I have the power to influence my illness					
IP17	My actions will have no effect on the outcome of my illness					
IP18	My illness will improve in time					
IP19	There is very little that can be done to improve my illness					
IP20	My treatment will be effective in curing my illness					
IP21	The negative effects of my illness can be prevented or avoided by my treatment					
IP22	My treatment can control my illness					
IP23	There is nothing which can help my condition					
IP24	The symptoms of my condition are puzzling to me					

IP25	My illness is a mystery to me					
IP26	I don’ t understand my illness					

	VIEWS ABOUT YOUR ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER DISAGREE NOR AGREE	AGREE	STRONGLY AGREE
IP27	My illness doesn’t make any sense to me					
IP28	I have a clear picture or understanding of my illness					
IP29	The symptoms of my illness change a great deal from day to day					
IP30	My symptoms come and go in cycles					
IP31	My illness is very unpredictable					
IP32	I go through cycles in which my illness gets better and worse.					
IP33	I get depressed when I think about my illness					
IP34	When I think about my illness I feel upset					
IP35	My illness makes me feel angry					
IP36	My illness does not worry me					
IP37	My illness makes me feel anxious					
IP38	My illness makes me feel afraid					

We are interested in what you consider may have been the cause of your illness. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your illness rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your illness. Please indicate how much you agree or disagree that they were causes for your illness by ticking the appropriate box.

	POSSIBLE CAUSES	**STRONGLY DISGREE**	**DISAGREE**	**NEITHER DISAGREE NOR AGREE**	**AGREE**	**SRONGLY AGREE**
C1	Stress or worry					
C2	Heredity - it runs in the family					
C3	A germ or virus					
C4	Diet or eating habits					
C5	Chance or bad luck					
C6	Poor medical care in the past					
C7	Pollution in the environment					
C8	My own behaviour					
C9	My mental attitude e.g., thinking about life negatively					
C10	Family problems or worries					
C11	Overwork					

C12	My emotional state e.g., feeling down, lonely, anxious, empty					
C13	Ageing					
C14	Alcohol					
C15	Smoking					
C16	Accident or injury					
C17	My personality					
C18	Altered immunity					

In the table below, please list in rank-order the three most important factors that you now believe caused your illness. You may use any of the items from the previous question, or you may have additional ideas of your own.

The most important causes for my illness:

1. ____

2. ____

3. ____

If there is anything else you would like to share with us, please write it in the box below:

H.2 Questionnaire for Significant Others

SO ACTIVE

Exploring Significant Other experiences of undergoing ACTIVE surveillance for prostate cancer: an exploratory study

Questionnaire for Significant Other

Thank you for your participation and support for the SO ACTIVE Study. This questionnaire is completely confidential and will only be seen by the researchers involved in the study.

Please try to complete all the questions even if they seem similar or repetitive as this will help us to collect the most reliable information for the study. Please enter the date completed below.

If you have any study related questions please get in touch by email: sh3r11@soton.ac.uk

Study ID								
Date Completed ddmmyyyy								

Demographics

For each question please tick the box most relevant to you.

1. Employment:

Full time employment	
Part time employment	
Retired	
Unemployed	

2. Relationship status:

Married/Civil Partnership	
Co-habiting	
Divorced	
Widowed	
Single	

3. Ethnicity:

White British	
White Other	
Black African	
Black Caribbean	
Asian	
Other, please specify: _______________________________	

4. Education:

Left school before 15	
Completed secondary education	
College / specialised training	
University	
Unknown	

Your significant other

A man with prostate cancer has identified you as their significant other.

By ‘significant other’ we mean the person they are closest to and are most likely to talk to about their prostate cancer and treatment plan.

The following questions are designed to help us understand a little more about this relationship.

1. Type of relationship:

Partner by marriage	
Partner unmarried	
Close relative, please specify: ______________________	
Close friend	
Other, please specify: ______________________ ______________________	

2. How long have you had a close personal relationship with this person?

Less than 1 year	
1-5 years	
6-10 years	
11-15 years	
16-20 years	
More than 20 years	

Your significant other's Prostate Cancer

How long ago was your significant other diagnosed with prostate cancer?

Less than 1 year	
1-5 years	
6-10 years	
11-15 years	
More than 15 years	

For the following questions, please indicate (tick) the response that best applies to how you have felt <u>in the past week:</u>

1. I feel tense or ‘wound up’.

Most of the time	A lot of the time	From time to time, occasionally	Not at all

2. I still enjoy the things I used to enjoy.

Definitely as much	Not quite so much	Only a little	Hardly at all

3. I get a sort of frightened feeling as if something awful is about to happen.

Very definitely and quite badly	Yes, but not too badly	A little, but it doesn’t worry me	Not at all

4. I can laugh and see the funny side of things.

As much as I always could	Not quite so much now	Definitely not so much now	Not at all

5. Worrying thoughts go through my mind.

A great deal of the time	A lot of the time	Not too often	Very little

6. I feel cheerful.

Never	Not often	Sometimes	Most of the time

7. I can sit at ease and feel relaxed.

Definitely	Usually	Not often	Not at all

8. I feel as if I am slowed down.

Nearly all the time	Very often	Sometimes	Not at all

9. I get a sort of frightened feeling like ‘butterflies’ in the stomach.

Not at all	Occasionally	Quite often	Very often

10. I have lost interest in my appearance.

Definitely	I don’t take as much care as I should	I may not take quite as much care	I take just as much care as ever

11. I feel restless as if I have to be on the move.

Very much indeed	Quite a lot	Not very much	Not at all

12. I look forward with enjoyment to things.

As much as I ever did	Rather less than I used to	Definitely less than I used to	Hardly at all

13. I get sudden feelings of panic.

Very often indeed	Quite often	Not very often	Not at all

14. I can enjoy a good book, or radio or television programme.

Often	Sometimes	Not often	Very seldom

Twelve-Item Short-Form Health Survey: SF-12

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Answer each question by choosing just one answer. If you are unsure how to answer a question, please give the best answer you can.

1. In general, would you say your health is:

Excellent	Very good	Good	Fair	Poor

The following questions are about activities you might do during a typical day. Does <u>your health now limit you</u> in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
2. Moderate activities such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.			
3. Climbing several flights of stairs.			

During the <u>past 4 weeks</u>, have you had any of the following problems with your work or other regular daily activities <u>as a result of your physical health</u>?

	Yes	No
4. Accomplished less than you would like.		
5. Were limited in the kind of work or other activities.		

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	Yes	No
6. Accomplished less than you would like.		
7. Did work or activities less carefully than usual.		

8. During the past 4 weeks, how much did pain interfere with your normal work (including work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely

These questions are about how you have been feeling during the past 4 weeks.

For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks…

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
9. Have you felt calm & peaceful?						
10. Did you have a lot of energy?						
11. Have you felt down-hearted and blue?						

12. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time

The Memorial Anxiety Scale for Prostate Cancer (MAX-PC, adapted for SO)

Your feelings about prostate cancer and prostate specific antigen (PSA) tests.

We would like to better understand how the significant others of prostate cancer patients cope with aspects of their treatment for prostate cancer and the medical tests frequently involved in their care.

Below is a list of comments made by significant others of men with prostate cancer. Please indicate by ticking the boxes below how frequently these comments were true for you <u>during the past week.</u>

SO = Significant Other

	Not at all	Rarely	Sometimes	Often
1. Any reference to prostate cancer brought up strong feelings in me.				
2. Even though it's a good idea, my SO getting a PSA test scared me.				
3. Whenever I heard about a friend or public figure with prostate cancer I got more anxious about my SO having prostate cancer.				
4. When I thought about my SO having a PSA test, I got more anxious about him having prostate cancer.				
5. Other things kept making me think about prostate cancer.				
6. I felt kind of numb when I thought about prostate cancer.				
7. I thought about prostate cancer even though I didn't mean to.				

8. I had lots of feelings about prostate cancer, but I didn’t want to deal with them.				
9. I had more trouble falling asleep because I couldn’t get thoughts of prostate cancer out of my mind.				
10. I was afraid that the results from my SO’s PSA test would show that his disease was getting worse.				
11. Just hearing the words ‘prostate cancer’ scared me.				

For the next three questions, please indicate how frequently these situations have EVER been true for you.

	Not at all	Rarely	Sometimes	Often
12. I have been so anxious about my SO’s PSA test that I have thought about asking him to delay it.				
13. I have been so worried about my SO’s PSA test result that I have thought about asking him to have it repeated.				
14. I have been so concerned about my SO’s PSA test result that I have thought about asking him to have the test repeated at another lab to make sure it was accurate.				

Listed below are a number of statements concerning a person's beliefs about their significant other's health. In thinking about the past week, please indicate how much you agree or disagree with each statement.

	Strongly agree	Agree	Disagree	Strongly disagree
15. Because cancer is unpredictable, I feel I cannot plan for the future.				
16. My fear of my SO's cancer getting worse gets in the way of my enjoying life.				
17. I am afraid of my SO's cancer getting worse.				
18. I am more nervous since my SO was diagnosed with prostate cancer.				

Couples' Illness Communication Scale

The following questions ask about your relationship with your significant other.

Each question should be answered on the scale shown below.

1	2	3	4	5
Disagree strongly	Disagree	Undecided	Agree	Agree strongly

1. It is hard for me to express feelings about his illness to my significant other. ______

2. I feel comfortable discussing issues related to his illness with my significant other.______

3. My significant other is reluctant to talk about his illness. ______

4. My significant other is willing to share his feelings about his illness with me. ______

Revised Dyadic Adjustment Scale

Most persons have disagreements in their relationships. Please indicate below the approximate extent of agreement or disagreement between you and your significant other for each item on the following list.

	Always agree	Almost always agree	Occasionally agree	Frequently disagree	Almost always disagree	Always disagree
1. Religious matters						
2. Demonstrations of affection						
3. Making major decisions						
4. Sex relations						
5. Conventionality (correct or proper behaviour)						
6. Career decisions						

	All the time	Most of the time	More often than not	Occasionally	Rarely	Never
7. How often do you discuss or have you considered divorce, separation, or terminating your relationship?						
8. How often do you and your SO quarrel?						

9. Do you ever regret that you married (or lived together)?						
10. How often do you and your SO 'get on each other's nerves'?						

	Everyday	Almost everyday	Occasionally	Rarely	Never
11. Do you and your SO engage in outside interests together?					

How often would you say the following events occur between you and your mate?

	Never	Less than once a month	Once or twice a month	Once or twice a week	Once a day	More often
12. Have a stimulating exchange of ideas						
13. Work together on a project						
14. Calmly discuss something						

Family Response Questionnaire (FRQ)

When a person suffers from an illness for a long time, it is likely to affect his/her family. There are a number of different ways in which family members cope with the problems of a person's illness. This form is designed to assess those ways of coping.

Below, there is a series of questions about your feelings and reactions to the person in your family who is ill. We have called the ill person ''X.'' Please read the questions and mark the reply which comes closest to describing how you have felt or acted **over the past 3 months**.

	Never	Rarely	Occasion-ally	Often	Very often
1. Thought about how X must be feeling?					
2. Worried about X's illness?					
3. Felt frustrated about the practical limitations that X's illness has on your life?					
4. Felt that there is nothing really wrong with X?					
5. Wished that you could get some of the attention that X gets?					
6. Tried to work out what you would do in X's position?					
7. Felt that your own health might be suffering because of X's illness?					
8. Felt that X's illness has drawn you together?					
9. Reminded X to slow down?					

10. Felt that X has used his/her illness to get you to do things you did not really want to do?					
11. Felt that X may be exaggerating his/her symptoms?					
12. Been angry with X because he/she cannot do what he/she used to do?					
13. Tried to find out more about X's illness by reading, talking to others, etc.?					
14. Made allowances for X when he/she has been irritable or unreasonable?					
15. Felt let down by X?					
16. Felt that X is using his/her illness to avoid doing things he/she usually does?					

	Never	Rarely	Occasion-ally	Often	Very often
17. Tried to cheer X up, e.g., by bringing treats or presents or arranging entertainment?					
18. Thought that X should make more of an effort to do things?					
19. Felt that attending to X’s illness has caused you to neglect the needs of other family members?					
20. Felt that you could not cope any longer with X’s illness?					
21. Insisted that X rest?					
22. Felt that X does not understand the impact that his/her illness has on your life?					
23. Protected X from seeing other people?					
24. Spent time discussing X’s illness with him or her?					
25. Encouraged X to get support from other people?					

Illness Perception Questionnaire (IPQ-R-SO): Your views about your significant other's prostate cancer

We are interested in your own personal views of how you now see your significant other's current prostate cancer.

Please indicate how much you agree or disagree with the following statements about your significant other's prostate cancer by ticking the appropriate box.

	VIEWS ABOUT THEIR ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER DISAGREE NOR AGREE	AGREE	STRONGLY AGREE
IP1	Their illness will last a short time					
IP2	Their illness is likely to be permanent rather than temporary					
IP3	Their illness will last for a long time					
IP4	Their illness will pass quickly					
IP5	I expect them to have this illness for the rest of their life					
IP6	Their illness is a serious condition					
IP7	Their illness has major consequences on their life					
IP8	Their illness does not have much effect on their life					

IP9	Their illness strongly affects the way others see them					
IP10	Their illness has serious financial consequences for them					
IP11	Their illness causes difficulties for those who are close to them					
IP12	There are some things they can do to control their symptoms					

	VIEWS ABOUT THEIR ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER DISAGREE NOR AGREE	AGREE	STRONGLY AGREE
IP13	To some extent what they do can determine whether their illness gets better or worse					
IP14	The course of their illness depends on them					
IP15	Nothing they do will affect their illness					
IP16	They have the power to influence their illness					
IP17	Their actions will have no effect on the outcome of their illness					
IP18	Their illness will improve in time					
IP19	There is very little that can be done to improve my significant other's illness					
IP20	Their treatment will be effective in curing their illness					
IP21	The negative effects of their illness can be prevented or avoided by their treatment					
IP22	Their treatment can control their illness					
IP23	There is nothing which can help their condition					

IP24	The symptoms of their condition are puzzling to me					
IP25	Their illness is a mystery to me					
IP26	I don’ t understand their illness					

	VIEWS ABOUT THEIR ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER DISAGREE NOR AGREE	AGREE	STRONGLY AGREE
IP27	Their illness doesn't make any sense to me					
IP28	I have a clear picture or understanding of their illness					
IP29	The symptoms of their illness change a great deal from day to day					
IP30	Their symptoms come and go in cycles					
IP31	Their illness is very unpredictable					
IP32	They go through cycles in which their illness gets better and worse.					
IP33	I get depressed when I think about their illness					
IP34	When I think about their illness I feel upset					
IP35	Their illness makes me feel angry					
IP36	Their illness does not worry me					
IP37	Their illness makes me feel anxious					
IP38	Their illness makes me feel afraid					

We are interested in what you consider may have been the cause of your significant other's illness. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your significant other's illness rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your illness. Please indicate how much you agree or disagree that they were causes for your significant other's illness by ticking the appropriate box.

	POSSIBLE CAUSES	**STRONGLY DISAGREE**	**DISAGREE**	**NEITHER DISAGREE NOR AGREE**	**AGREE**	**SRONGLY AGREE**
C1	Stress or worry					
C2	Heredity - it runs in the family					
C3	A germ or virus					
C4	Diet or eating habits					
C5	Chance or bad luck					
C6	Poor medical care in the past					
C7	Pollution in the environment					
C8	Their own behaviour					
C9	Their mental attitude e.g., thinking about life negatively					
C10	Family problems or worries					
C11	Overwork					
C12	Their emotional state e.g., feeling down, lonely, anxious, empty					
C13	Ageing					
C14	Alcohol					
C15	Smoking					
C16	Accident or injury					
C17	Their personality					
C18	Altered immunity					

In the table below, please list in rank-order the three most important factors that you now believe caused YOUR SIGNIFICANT OTHER'S illness. You may use any of the items from the previous question, or you may have additional ideas of your own.

The most important causes for my significant other's illness:

1. ____

2. ____

3. ____

If there is anything else you would like to add, please do so in the box below:

Appendix I Interview Schedules

I.1 Semi-structured interview guide for men on AS

Introduction

- Thank you for agreeing to take part in this interview [short hello].
- I would like to record the conversation we have today so that I can refer back to it at a later date. It enables me to listen to you better, is that ok?
- Before we start there are a few things I'd just like to mention.
- What we talk about will be used as part of the study, but anything said will remain anonymous. We're going to ensure this by not using your real name when we type up the interview. Is that ok?
- If I ask a question that you don't want to answer that is absolutely fine, just say so and I'll ask you a different question. If at any point you would like to stop participating then please just tell me and we will stop the interview.
- Anything you can tell me about your experiences including good and bad points would be useful.
- Do you have any questions before we start? Are you happy to continue?

SO ACTIVE PC Patient Questions

1. Involvement in the study and expectations

- Could you tell me about how you first knew that you had a problem with your prostate and what then happened?
- Could you tell me about any support and/or information you have received since your diagnosis?
    - For example, has the hospital signposted any support services?
    - If so, have you used utilised any of these services?
    - Were you given written information about prostate cancer and any support that may be available to you?
    - Is there anything you particularly value about the support and information you have received so far?
    - Is there anything you have found less helpful, or disliked about the support and information you have received so far?
- Can you describe your understanding of what active surveillance is and how it works?
- Can you tell me how you became involved in the SO ACTIVE study?
- What was your motivation for taking part, why did you decide to become involved?

- Can you tell me about any expectations you may have of taking part in the SO ACTIVE study?
    - Is there anything you are hoping to gain from participating?
- Do you have any reservations about taking part, and if so, can you tell me a bit about them?

2. Reaction to diagnosis and AS treatment plan

- What was your initial reaction to your diagnosis?
- What was your initial reaction to the treatment plan of AS?
- How was Active Surveillance decided upon as a treatment plan?
    - Did the consultant give you a choice?
    - Did you agree this is the best route for you?
- How do you feel about your diagnosis now?
- How do you feel about the AS treatment plan now?
- Can you tell me about any changes that have occurred, either positive or negative, since the diagnosis and treatment plan of AS?

3. The Significant Other

- How do you think your partner/SO feels about AS?
- How did your partner/SO respond to the diagnosis and treatment plan of AS?
- What impact has AS had on your partner/SO?
- How do you feel about the way your partner responded to the diagnosis and treatment plan of AS?
- Can you tell me a bit about how you and your partner/SO communicate with each other when it comes to your thoughts and feelings about AS?
    - Are you able to talk to your partner/SO about AS?
    - Would you like it to be different? If so, how?
- How does your partner/SO feel about your participation in the SO ACTIVE study?
    - Did they play a part in your decision to take part?

4. SO involvement

- How important do you think it is that your significant other is involved in the clinical consultations?
    - Can you tell me a bit about why you feel this way?
- How important do you think it is that your significant other is involved in the treatment decision making?
    - Can you tell me a bit about why you feel this way?

5. The future

- How do you see the future management of your prostate cancer?
    - Do you see your treatment remaining the same/changing?
    - What do you think will happen?

<u>6. Further thoughts and anything to add</u>

- Can you think of anything that may have been helpful for you or your partner/SO when you were first given the treatment plan of AS?
- Is there anything else you would like to share with me about your experiences so far?

I.2 Semi-structured interview guide for significant others

Introduction

- Thank you for agreeing to take part in this interview [short hello].
- I would like to record the conversation we have today so that I can refer back to it at a later date. It enables me to listen to you better, is that ok?
- Before we start there are a few things I'd just like to mention.
- What we talk about will be used as part of the study, but anything said will remain anonymous. We're going to ensure this by not using your real name when we type up the interview. Is that ok?
- If I ask a question that you don't want to answer that is absolutely fine, just say so and I'll ask you a different question. If at any point you would like to stop participating then please just tell me and we will stop the interview.
- Anything you can tell me about your experiences including good and bad points would be useful.
- Do you have any questions before we start? Are you happy to continue?

SO ACTIVE Significant Other Questions

<u>1. Involvement in the study and expectations</u>

- Could you tell me, about how you first knew that your partner/significant other had a problem with his prostate and what then happened?
- Could you tell me about any support and/or information you and/or your SO have received since the diagnosis?
    - For example, has the hospital signposted any support services?
    - If so, have you used utilised any of these services?

    - Were either of you given written information about prostate cancer and any support that may be available to you?
    - Is there anything you particularly value about the support and information you have received so far?
    - Is there anything you have found less helpful, or disliked about the support and information you have received so far?
- Can you describe your understanding of what active surveillance is and how it works?
- Can you tell me a bit about how you became involved in the SO ACTIVE study?
- What was your motivation for taking part, why did you decide to become involved?
- Can you tell me about any ideas or concerns you had you may have had of taking part in the SO ACTIVE study?
    - Is there anything you were hoping to gain from participating?
- Did you have any reservations about taking part, and if so, can you tell me a bit about them?

2. Reaction to diagnosis and AS treatment plan

- Can you tell me a bit about your SO's diagnosis – when did they get the diagnosis, and what happened?
- What was your initial reaction to your SO's diagnosis?
- How did you feel about the idea of AS when it was introduced as a treatment plan?
- How do you feel about your SO's diagnosis now?
- How do you feel about your SO's AS treatment plan now?

3. The significant other

- How do you think your partner/SO feels about AS?
- How did your partner/SO respond to the diagnosis and treatment plan of AS?
- What impact has AS had on your partner/SO?
- How do you feel about the way your partner responded to the diagnosis and treatment plan of AS?
- Can you tell me a bit about how you and your partner/SO communicate with each other when it comes to your thoughts and feelings about AS?
    - Are you able to talk to your partner/SO about AS?
    - Would you like it to be different? If so, how?
- Can you tell me what you think the worst part of living with a partner/SO undergoing AS for prostate cancer is?
- Can you tell me about any changes that have occurred, either positive or negative, since the diagnosis and treatment plan of AS?
- How does your partner/SO feel about your participation in the SO ACTIVE study?
    - Did they play a part in your decision to take part?

4. SO involvement

- How important do you think it is that you, as the significant other, are involved in the clinical consultations?
    - Can you tell me a bit about why you feel this way?
- How important do you think it is that you, as the significant other, are involved in the treatment decision making?
    - Can you tell me a bit about why you feel this way?

5. The future

- How do you see the future management of your significant other's prostate cancer?
    - Do you see his treatment remaining the same/changing?
    - What do you think will happen?

6. Further thoughts and anything to add

- Can you think of anything that may have been helpful for you or your partner/SO when the diagnosis and treatment plan of AS were /given?
- Is there anything else you would like to share with me about your experiences so far?

Appendix J Recruitment adverts

J.1 SO ACTIVE Advert for email circulation

Dear XXXX

SO ACTIVE

Exploring significant other experiences of undergoing ACTIVE surveillance for prostate cancer: an exploratory study (REC Ref: 29805)

Are you on Active Surveillance for Prostate Cancer?

The University of Southampton is undertaking a research study to explore the experiences of men undergoing Active Surveillance for Prostate Cancer, and the experiences of their significant others (wife, partner, other relative or close friend).

Please note, to take part in this study your significant other must also be willing to take part.

The study involves completing a questionnaire, and possibly taking part in a telephone interview.

If you are a man on active surveillance go to the following link online to read more and complete the questionnaire:

iSurvey link

OR, if you would rather complete the questionnaire on paper, we'd be happy to post you one out. Let us know using our contact details below.

If you are the significant other of a man on active surveillance and you are interested in taking part, please get in touch using the contact details below.

Contact details:

Email: sh3r11@soton.ac.uk
Tel: 023 8059 1787 (Please leave a voicemail if there’s no answer)
Address: SO ACTIVE Study
C/O Stephanie Hughes
University of Southampton, 1st Floor Aldermoor Health Centre, Aldermoor Close, Southampton, SO16 5ST

J.2 SO ACTIVE Advert for Newsletter

Are you on Active Surveillance for Prostate Cancer?

SO ACTIVE: Exploring significant other experiences of undergoing ACTIVE surveillance for prostate cancer: an exploratory study

The University of Southampton is undertaking a research study to explore the experiences of men undergoing Active Surveillance for Prostate Cancer, and the experiences of their significant others (wife, partner, other relative or close friend).

Please note, to take part in this study your significant other must also be willing to take part.

The study involves completing a questionnaire, and possibly taking part in a telephone interview.

If you are a man on active surveillance go to the following link online to read more and complete the questionnaire:

www.isurvey.soton.ac.uk/25011

OR, if you would rather complete the questionnaire on paper, we’d be happy to post you one out. Let us know using our contact details.

If you are the significant other of a man on active surveillance and you are interested in taking part, please get in touch using the contact details below.

Email: sh3r11@soton.ac.uk **Tel:** 023 8059 1787 (leave voicemail)
Address: SO ACTIVE Study, C/O Stephanie Hughes, University of Southampton, 1st Floor Aldermoor Health Centre, Aldermoor Close, Southampton, SO16 5ST

J.3 SO ACTIVE Advert for social media

Text used on Twitter and Facebook:

On active surveillance for prostate cancer? SO ACTIVE want to hear about your experiences to help others: isurvey.soton.ac.uk/25011

Appendix K Study invite letters

K.1 Invite letter for man on AS

Study ID:

Dear Potential Participant,

SO ACTIVE: Exploring significant other experiences of undergoing ACTIVE surveillance for prostate cancer.

Thank you for expressing your interest in the SO ACTIVE study. This study is being led by researchers at the University of Southampton.

To take part in this study your significant other must also be willing to take part. Your significant other can be your partner, or a close relative or friend, but needs to be the person in whom you are most likely to confide about your prostate cancer.

Your participation in the study is purely voluntary and you may decide not to take part without affecting your patient care.

We have enclosed an information sheet outlining the study, telling you more about it and what you would be asked to do should you decide to take part. This contains contact details if you require any further information.

If you would like to take part, please complete the **enclosed questionnaire** along with **page 2 and 3** of this letter, and return them directly in the FREEPOST envelope enclosed.

If after reading this information you do not want to participate please complete **page 4** of this letter and return it directly in the FREEPOST envelope enclosed.

Thank you very much for taking the time to read this letter and the attached information sheet.

With best wishes,

SHughes

Stephanie Hughes
Senior Research Assistant in Primary Care & Population Sciences
University of Southampton, Aldermoor Health Centre, Southampton, SO16 5ST
Email: sh3r11@soton.ac.uk

K.2 Invite letter for significant other

Study ID:

Dear Potential Participant,

SO ACTIVE: Exploring significant other experiences of undergoing ACTIVE surveillance for prostate cancer.

Thank you for expressing your interest in the SO ACTIVE study. This study is being led by researchers at the University of Southampton.

To take part in this study both yourself (as the significant other), and the man undergoing active surveillance for prostate cancer must be willing to take part.

Your participation in the study is purely voluntary and you may decide not to take part without affecting your significant other's patient care.

We have enclosed an information sheet outlining the study, telling you more about it and what you would be asked to do should you decide to take part. This contains contact details if you require any further information.

If you would like to take part, please complete the **enclosed questionnaire** along with **page 2 and 3** of this letter, and return them directly in the FREEPOST envelope enclosed.

If after reading this information you do not want to participate please complete **page 4** of this letter and return it directly in the FREEPOST envelope enclosed.

Thank you very much for taking the time to read this letter and the attached information sheet.

With best wishes,

SHughes

Stephanie Hughes

Senior Research Assistant in Primary Care & Population Sciences

University of Southampton, Aldermoor Health Centre, Southampton, SO16 5ST

Email: sh3r11@soton.ac.uk

Appendix L SO ACTIVE Participant information sheets

L.1 SO ACTIVE Participant information sheet for man on AS

Participant Information Sheet

SO ACTIVE: Exploring significant other experiences of undergoing ACTIVE surveillance for prostate cancer.

To take part in this study your significant other must also be willing to take part. Your significant other can be your partner, or a close relative or friend, but needs to be the person in whom you are most likely to confide about your prostate cancer.

Who is running this study?

SO ACTIVE is being run by a team of researchers at The University of Southampton. The Chief Investigator is Stephanie Hughes, a Researcher at The University of Southampton.

Do I have to take part?

Participation in the project is entirely voluntary. It is up to you to decide whether to take part. You are able to withdraw at any time without giving a reason. If you decide to withdraw or not to take part in this study this will not affect the standard of care you or your significant other receive.

Why is this study being done?

We currently have very little understanding of the role that close interpersonal relationships might have for people undergoing active surveillance for prostate cancer. We are interested in how you and your significant other feel about this diagnosis and treatment plan, and how it impacts on your life. We hope this will give us an understanding of what might be helpful for others in this situation in the future.

What is the background to SO ACTIVE?

The same group of researchers previously carried out a study called PRO-ACTIVE (PROstate cancer support intervention for ACTIVE surveillance). PRO-ACTIVE was a study designed to test a support programme specifically for prostate cancer patients being managed with active surveillance. Results from this study highlighted the importance of the significant other whilst undergoing active surveillance. SO ACTIVE will explore this further.

What will happen to me if I take part?

If you decide you would like to take part you have two options:

1. Use the following link to complete your consent form and questionnaire online.

www.isurvey.soton.ac.uk/25011

2. Return the reply slip at the bottom of the attached letter to the study team, along with the consent form and the completed questionnaire.

A sub-section of participants will be contacted and asked to take part in a telephone interview.

If you are asked, and agree to take part in the interview, we would prefer you to be alone, and able to speak freely to the interviewer on the telephone. This is because we would like you to be able to talk as openly and freely as possible. If for any reason this is not possible, we would ask you to inform the person conducting the interview that somebody is with you, and who that person is.

Are there any risks involved in participating?

There exists a potential risk that private information gathered during the interview process may be identifiable. To minimize the risk of releasing sensitive personal or family information, we have developed strict guidelines to protect privacy of medical and personal information.

Sometimes talking about your experiences during the interview process may bring about feelings of sadness, anger, or anxiety. If talking or thinking about your experiences makes you unusually anxious, or if any part of the study process causes any bad feelings for you, you will be offered a referral to your GP who will be able to help you manage your distress. You will also be signposted to charities which offer support, such as Macmillan and Prostate Cancer UK. However, if at any time you find the interview distressing, you are free to decline to answer any questions or to terminate the interview immediately and indefinitely.

What are the possible disadvantages of taking part?

There are no known disadvantages in taking part in this study.

What are the possible benefits of taking part?

If you agree to take part in this study there may or may not be direct benefits to you. However, we hope that the information learnt through this study will benefit other prostate cancer patients and their significant others' in the future.

What if something goes wrong?

If you have any concerns or complaints about any aspects of how this research has been conducted by the researcher then please contact the Research Integrity and Governance Office, Room 4079, Highfield, Southampton, SO17 1BJ. Telephone: 023 8059 8848/9 or email: rgoinfo@soton.ac.uk

Will my participation be confidential?

All information that you provide will be strictly confidential. You will be identified by an ID number and the information you provide will be stored in locked filing cabinets or a password protected computer. The study will fully comply with the Data Protection Act and University policy on conducting research studies. All data will be stored in accordance with research governance for 10 years.

What will happen to the results of the research study?

The results of the research will be published in a medical book or journal and used for teaching purposes. When the study is completed, there will be copies of the published results available from Stephanie Hughes (sh3r11@soton.ac.uk). Please note that neither your name nor any identifying information will be used in any publication or teaching materials without your specific permission.

Who is organising and funding the research?

The research is being funded and organised by the University of Southampton and University Hospital Southampton (UHS).

Who has reviewed this study?

This research has been reviewed and given a favourable ethical opinion for conduct by The Faculty of Medicine Ethics Committee.

Contact for further information

If you have any questions regarding your rights as a participant in the SO ACTIVE study and/or concerns about the study, or if you feel under any pressure to enrol or continue to participate in this study, you may contact the study team at any time:

SO ACTIVE Chief Investigator: sh3r11@soton.ac.uk / 023 8059 1787 (Stephanie Hughes)

SO ACTIVE Principal Investigator: h.a.everitt@soton.ac.uk / 02380 241 052 (Dr Hazel Everitt)

Thank you again for reading this information and for considering participation in this study.

L.2 SO ACTIVE Participant information sheet for the SO

Participant Information Sheet

SO ACTIVE: Exploring significant other experiences of undergoing ACTIVE surveillance for prostate cancer.

To take part in this study both yourself (as the significant other), and the man undergoing active surveillance for prostate cancer must be willing to take part.

Who is running this study?

SO ACTIVE is being run by a team of researchers at The University of Southampton. The Chief Investigator is Stephanie Hughes, a Researcher at The University of Southampton.

Do I have to take part?

Participation in the project is entirely voluntary. It is up to you to decide whether to take part. You are able to withdraw at any time without giving a reason. If you decide to withdraw or not to take part in this study this will not affect the standard of care you or your significant other receive.

Why is this study being done?

We currently have very little understanding of the role that close interpersonal relationships might have for people undergoing active surveillance for prostate cancer. We are interested in how you and your significant other feel about this diagnosis and treatment plan, and how it impacts on your life. We hope this will give us an understanding of what might be helpful for others in this situation in the future.

What is the background to SO ACTIVE?

The same group of researchers previously carried out a study called PRO-ACTIVE (PROstate cancer support intervention for ACTIVE surveillance). PRO-ACTIVE was a study designed to test a support programme specifically for prostate cancer patients being managed with active surveillance. Results from this study highlighted the importance of the significant other whilst undergoing active surveillance. SO ACTIVE will explore this further.

What will happen to me if I take part?

If you decide you would like to take part you have two options:

1. Use the following link to complete your consent form and questionnaire online.

www.isurvey.soton.ac.uk/25089

2. Return the reply slip at the bottom of the attached letter to the study team, along with the consent form and the completed questionnaire.

A sub-section of participants will be contacted and asked to take part in a telephone interview.

If you are asked, and agree to take part in the interview, we would prefer you to be alone, and able to speak freely to the interviewer on the telephone. This is because we would like you to be able to talk as openly and freely as possible. If for any reason this is not possible, we would ask you to inform the person conducting the interview that somebody is with you, and who that person is.

Are there any risks involved in participating?

There exists a potential risk that private information gathered during the interview process may be identifiable. To minimize the risk of releasing sensitive personal or family information, we have developed strict guidelines to protect privacy of medical and personal information.

Sometimes talking about your experiences during the interview process may bring about feelings of sadness, anger, or anxiety. If talking or thinking about your experiences makes you unusually anxious, or if any part of the study process causes any bad feelings for you, you will be offered a referral to your GP who will be able to help you manage your distress. You will also be signposted to charities which offer support, such as Macmillan and Prostate Cancer UK. However, if at any time you find the interview distressing, you are free to decline to answer any questions or to terminate the interview immediately and indefinitely.

What are the possible disadvantages of taking part?

There are no known disadvantages in taking part in this study.

What are the possible benefits of taking part?

If you agree to take part in this study there may or may not be direct benefits to you. However, we hope that the information learnt through this study will benefit other prostate cancer patients and their significant others' in the future.

What if something goes wrong?

If you have any concerns or complaints about any aspects of how this research has been conducted by the researcher then please contact the Research Integrity and Governance Office, Room 4079, Highfield, Southampton, SO17 1BJ. Telephone: 023 8059 8848/9 or email: rgoinfo@soton.ac.uk

Will my participation be confidential?

All information that you provide will be strictly confidential. You will be identified by an ID number and the information you provide will be stored in locked filing cabinets or a password protected computer. The study will fully comply with the Data Protection Act and University policy on conducting research studies. All data will be stored in accordance with research governance for 10 years.

What will happen to the results of the research study?

The results of the research will be published in a medical book or journal and used for teaching purposes. When the study is completed, there will be copies of the published results available from Stephanie Hughes (sh3r11@soton.ac.uk). Please note that neither your name nor any identifying information will be used in any publication or teaching materials without your specific permission.

Who is organising and funding the research?

The research is being funded and organised by the University of Southampton and University Hospital Southampton (UHS).

Who has reviewed this study?

This research has been reviewed and given a favourable ethical opinion for conduct by The Faculty of Medicine Ethics Committee.

Contact for further information

If you have any questions regarding your rights as a participant in the SO ACTIVE study and/or concerns about the study, or if you feel under any pressure to enrol or continue to participate in this study, you may contact the study team at any time:

SO ACTIVE Chief Investigator: sh3r11@soton.ac.uk / 023 8059 1787 (Stephanie Hughes)
SO ACTIVE Principal Investigator: h.a.everitt@soton.ac.uk / 02380 241 052 (Dr Hazel Everitt)

Thank you again for reading this information and for considering participation in this study.

Appendix M Reply slip and consent

M.1 Reply slip and consent form for all participants

STUDY ID:

If you wish to take part in our study please fill in this page and send it back to us in the FREEPOST envelope along with page 3 of this letter and your completed questionnaire.

I would like to take part in the study and am happy to complete the enclosed questionnaire ☐

Please tick

Your details

My name is: ____

My date of birth is: _________________________

My address is: _____________________________

____

Postcode: _________________________________

My contact telephone number is:

Home: ________________________

Mobile: _______________________

My email address is (if applicable): _______________________________

My GP is:

GP Name: __________________________________

GP Surgery Address: _________________________

____

____

Signature: _________________________________

Date: _____________________________________

Participant Consent Form

SO ACTIVE: Exploring significant other experiences of undergoing ACTIVE surveillance for prostate cancer.

PLEASE PUT YOUR INITIALS (NOT A TICK) IN EACH BOX IF YOU

1. I confirm that I have read and understand the information sheet dated 18/09/17 (version 1.1) for the above study and have had the opportunity to ask questions. ☐

2. I agree to take part in this research project and agree for my data to be used for the purpose of this study. ☐

3. I understand that I may be contacted to take part in an interview about my experiences of active surveillance for prostate cancer. ☐

4. I understand that the data I provide may be monitored by a regulatory authority such as the University of Southampton. ☐

5. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my own or my significant other's medical care being affected. ☐

6. I agree that all interviews conducted as part of this study will be audio taped in full. ☐

7. I agree that verbatim quotes from the interviews will be anonymously utilised in the write up and publication of the investigation. ☐

8. I agree to being contacted in the future for any studies related to this one. ☐

Signature: ______________________________ **Date:** ________________________________

If you wish to participate please post this page back to us in the FREEPOST envelope along with page 2 of this letter and your completed questionnaire.

ID

If you do not wish to take part in our study please fill in this page and send it back to us in the FREEPOST envelope. Your responses will help us in the planning and design of future research studies. We truly appreciate your time. Thank you.

I do not wish to take part in this study because: (tick all that apply)

1. I do not have time in my daily schedule ☐

2. I do not wish to complete the paper questionnaires ☐

3. I do not wish to take part in the interviews ☐

4. My significant other is not willing to take part ☐

5. Any of the previous options do not apply to me ☐

(Please specify your own reasons below)

____

____

____

____

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