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**Diagnostic Journeys in Prostate Cancer: In what ways can the accounts of men with prostate cancer increase understanding and improve care in Wales? A qualitative study of men with prostate cancer**

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**Diagnostic Journeys in Prostate Cancer: In what ways can the accounts of men with prostate cancer increase understanding and improve care in Wales? A qualitative study of men with prostate cancer**

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Masters in Research

School of Health Sciences

## Declaration

'Yr wyf drwy hyn yn datgan mai canlyniad fy ymchwil fy hun yw'r thesis hwn, ac eithrio lle nodir yn wahanol. Caiff ffynonellau eraill eu cydnabod gan droednodiadau yn rhoi cyfeiriadau eglur. Nid yw sylwedd y gwaith hwn wedi cael ei dderbyn o'r blaen ar gyfer unrhyw radd, ac nid yw'n cael ei gyflwyno ar yr un pryd mewn ymgeisiaeth am unrhyw radd oni bai ei fod, fel y cytunwyd gan y Brifysgol, am gymwysterau deuol cymeradwy.'

Rwy'n cadarnhau fy mod yn cyflwyno'r gwaith gyda chytundeb fy Ngrichwyliwr (Goruchwylwyr)'

'I hereby declare that this thesis is the results of my own investigations, except where otherwise stated. All other sources are acknowledged by bibliographic references. This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree unless, as agreed by the University, for approved dual awards.'

I confirm that I am submitting the work with the agreement of my Supervisor(s)'

## **Acknowledgements page**

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## List of Abbreviations

CASP- Critical appraisal skills programme
CRW- Cancer Research Wales
DRE- Digital rectal examination
GDPR- General data protection regulation
GP- General Practitioner
HCP- Health care professional
LOA- Letter of access
LUTS- Lower urinary tract symptoms
mpMRI- Multi parametric magnetic resonance imaging
MRI- Magnetic resonance imaging
NICE- National Institute for Health and Care Excellence
REC- Research ethics committee
PSA- Prostate specific antigen

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# Summary

## Background

Prostate cancer is the most commonly diagnosed cancer in men in the UK. Over 47,500 men are diagnosed every year with more than 2,500 diagnoses made in Wales. Earlier detection improves outcomes as it can provide extended treatment options, increasing the rate of survival and potentially saving costs to the National Health Service (NHS). The Welsh government has affirmed its commitment to tackling cancer and finding ways to improve early diagnosis. The diagnostic pathway to a prostate cancer diagnosis can be influenced by varying social, contextual and behavioural factors and these have the potential to hasten or lengthen a journey. Exploring these factors in detail and from the view of the men themselves can help illuminate this pathway and support potential interventions that could reduce delays for men in the future.

## Methods

This study utilised a qualitative methodology designed to explore the journeys of men to a prostate cancer diagnosis. A comprehensive narrative literature review comprising of a literature search to determine relevant papers, followed by an in-depth critical appraisal was first completed to understand what is already known in this field of research. The data collection comprised of 21 qualitative semi structured interviews with a purposive sample of men from across Wales with a recent prostate cancer diagnosis and who had experienced either a prompt, late or asymptomatic journey. All interviews were professionally transcribed, and data analysis was conducted using the Framework approach.

## Findings

Several factors were reported as influencing a man's decision-making along his journey. Symptoms that can be associated with prostate cancer were often interpreted by the men in this study as part of 'getting old' and as such dismissed by many or not investigated until they became troublesome. The influence of family was often seen as a pressure to seek help whereas friends offered guidance along the journey. The media played an important part in prostate cancer awareness and was the catalyst in seeking help for many men, along with observing other men going

through a cancer diagnosis, as this propelled them into considering their own health status. Awareness and views of the investigations undertaken were varied. Prostate Specific Antigen (PSA) blood tests were either requested, offered by the GP or conducted without the men's knowledge and impacted further investigations or help seeking. Within secondary care, inequities were highlighted around access to mpMRI scans and rapid diagnostic centres. Being able to have an mpMRI scan had the potential to influence the length of the pathway and brought confusion and disappointment to some men who were not offered it. Rapid diagnostic centres were also available to only a minority of the men and praised for their efficiency, producing positive accounts whilst also ensuring all investigations were completed promptly. The way men perceived their relationship with their health care provider influenced their help seeking behaviour, communication, and capacity to trust. Men recounted their journeys as either confusing or worrying, or with acceptance and feelings of assurance dependant on how they felt their journey had gone.

## **Conclusion**

This qualitative study has explored the ways in which interactions and experiences can influence the diagnostic journey of men newly diagnosed with prostate cancer in Wales. Through a robust methodological process, it has displayed the factors that can potentially influence a timelier diagnosis, and highlighted interventions or points along the pathway that could support the reduction of delays. Further research may be required to design and test such interventions.

# **Chapter One**

## **Introduction**

## **Introduction**

This research project has been taken from the Diagnostic Journeys in Prostate Cancer (DJIIP) study. A larger, mixed methods four phase study currently being conducted by the student exploring the diagnostic journeys of men newly diagnosed with prostate cancer in Wales. A mixed methods approach employs both quantitative and qualitative data collection and more than one style of analysis to explore a research question and can produce a robust study method when combined for investigative purposes in research (Letters, Curry & Creswell, 2013). It was decided this overall study would be too vast to be presented in adequate detail within a master's in research thesis. A decision was made to focus this thesis on phase two of the larger study which is the qualitative component. The qualitative study in phase two further supports the researchers career goal of becoming an established qualitative researcher in health sciences. The overall objective of phase two is to undertake semi structured interviews with men who have been through a prostate cancer diagnosis and to explore factors associated with their journey. A small sample of men who reported experiencing either a prompt, late or asymptomatic journey to diagnosis have been chosen. It was felt this sample would offer a good representation of the different journeys and starting points men experience. The step of obtaining data from three different sample categories increases the studies' rigour and validity, allowing the factors, interactions and perceptions of the men who have experienced these journeys to be captured and explored.

This chapter will take the reader through the aims and objectives of this thesis, providing a background to the topic and concluding in why this study is needed. The prevalence of prostate cancer will be explored, with information provided about the prostate and a breakdown of the key terms and investigations that will be discussed throughout. Prostate cancer risk factors will be provided along with an explanation of current national and Welsh guidelines. This will lead onto describing the various intervals that are found within the patient pathway to a prostate cancer diagnosis and conclude with reasons to why this study is needed.

## **Research questions**

In what ways can the accounts of men with prostate cancer increase understanding and improve care in Wales?

In what ways do interactions and experiences influence the diagnostic journeys of men newly diagnosed with prostate cancer in Wales?

## **Aims and objectives of thesis**

### **Aims**

To describe the accounts of the diagnostic journeys of men in Wales with a new diagnosis of prostate cancer with the intention of identifying factors which may influence a timelier diagnosis and reduce unnecessary delays.

### **Objectives**

To review the literature surrounding prostate cancer journeys to diagnosis in order to understand the context in which the study will be delivered.

To recruit and interview men who have experienced either a prompt/late or asymptomatic journey to a prostate cancer diagnosis to gain their views, perspectives, and experiences.

To discuss and develop ideas for potential interventions that could be utilised to reduce unnecessary delays and facilitate a timelier diagnosis.

To identify points along the diagnostic pathway at which these potential interventions could be implemented to help reduce unnecessary delays and promote a timelier diagnosis.

### **Background**

In the UK, prostate cancer is currently the most common cancer in men and around 'one in eight men will get prostate cancer in their lifetime' (Prostate Cancer UK, 2019). Worldwide figures show prostate cancer is the second most common cancer in males with nearly 1.3 million new cases reported in 2018, and this difference could be due to the varied screening and investigative procedures undertaken in different countries. It is also the fourth most reported cancer out of the 36 cancer types currently defined and published (Bray et al, 2018). Around 47,500 men are diagnosed every year with a surge in this number being observed between 2018 and 2019 (Prostate Cancer UK, 2019; Cancer Research UK, 2019). This surge has been explained due to the media awareness of two celebrities who spoke about their prostate cancer diagnosis in the UK around this time. This was seen to prompt more

men to seek help and make enquiries about the health of their prostate (National Prostate Cancer Audit, 2020). These numbers equate to around 129 men being diagnosed every day and in Wales these figures liken to around 2,500 men every year being diagnosed.

The disease is seen the most in older men, affecting men predominantly over the age of 50. The most common age for diagnosis is between 65-69, however around 35% of new cases are seen in men aged 75 or over (Prostate Cancer UK, 2019; Cancer Research UK, 2019). A man's chances of developing this cancer further increases with age (Prostate Cancer UK, 2019). Prostate cancer incidence is also increasing worldwide (Hamilton et al, 2018), although in comparisons to other cancers it has a high survival rate, with a 5-year survival rate of over 95% when diagnosed at stage 1-3 (Prostate Cancer UK, 2019). For some men this cancer will be low grade and slow growing, never becoming a problem and monitored through active surveillance or watchful waiting (Macmillan, 2019).

For others, diagnosis will be made of clinically significant prostate cancer, and this will be treated (after clarification of stage, which is determined from the primary classification, nodal involvement and whether metastatic disease found) and successfully cured or contained. However, for many men, this cancer will be caught late, resulting in advanced disease at diagnosis and subsequent mortality (Roberts et al, 2019). In 2018, 17.9% of men (535) were diagnosed at stage 4 in Wales and 19.9% (7457) in England (Cancer Research UK, 2022). The five-year survival rate drops to 49% for men diagnosed at stage 4 so it is extremely important that diagnosis at this stage is reduced (NICE Impact report, 2020). Deaths pertaining to prostate cancer equate to around 11,500 men every year in the UK and around 600 for men living in Wales (Prostate Cancer UK, 2019).

### **The DJiP study**

The Diagnostic Journeys in Prostate Cancer study (DJiP) is a four-phase project which aims to describe in detail the diagnostic journeys of men newly diagnosed with prostate cancer in Wales. It utilises a prospective, mixed methods approach obtaining data through questionnaires with patients, their GPs and diagnosing clinicians, semi structured interviews with patients, focus groups with GP practices and a stakeholder workshop. Phase 1 involves recruiting newly diagnosed patients



through the support of research nurses based within various hospitals around Wales. Consenting patients are asked to complete a postal questionnaire describing their journey to diagnosis. Due to missing data from sites, it is not known exactly how many men were initially approached, however 279 men completed the postal questionnaire. Upon receipt of the patient questionnaire, the patient's GP and urologist were also sent questionnaires to complete from the perspective of the primary and secondary care pathway. The responses patients provide in their questionnaire identify men with different starting points, symptom or asymptomatic presentation and overall prompt, late or asymptomatic journeys. Phase 2 of the study takes a small purposive sample from each of these categories for representation, to explore the men's experiences and perspectives of their journey in greater detail. Phase 3's data collection consists of focus groups with 4 GP practises to understand the management of potential prostate cancer patients within primary care. Phase 4 brings together the previous 3 phases and presents the findings in a workshop to aid further analysis and gain the views of prominent stakeholders. This thesis focuses solely on phase 2 of the study.

### **About the prostate**

The prostate is a gland within the male reproductive system and its main function is in making semen by producing a fluid that mixes with sperm. It is around the size of a walnut, sits under the bladder and surrounds the urethra. Understanding more about a man's knowledge of the prostate, its function and prostate cancer can be beneficial in helping researchers comprehend more about the patient journey, health beliefs and awareness (Grogan, Parlane & Buckley, 2017; Ogunsanya et al, 2017). Conditions related to the prostate, such as Benign Prostatic Hypertrophy (BPH), prostatitis or a benign growth can cause lower urinary tract symptoms which have been shown to affect 50% of men over the age of 50 and impact their sexual function (Hamilton, 2018; Macmillan, 2018; Prostate cancer UK, 2019; Public Health England, 2020). Lower urinary tract symptoms and changes in sexual function can also be an indication of possible symptoms related to prostate cancer, however this is normally when the cancer is more advanced, as localised or early cancer can, but does not usually cause symptoms (National Institute for Health and Care Excellence (NICE), 2017; Public Health England, 2019; Prostate Cancer UK, 2019). This potential cross over with symptoms can cause confusion for men and health care professionals

tasked with investigating prostate symptoms and possible prostate cancer (Merriell et al, 2018). Men can live with these symptoms for weeks, months or years before going to see their GP due to this confusion with possible symptom recognition and crossover. It is also important to note that prostate cancer can often be asymptomatic, especially at the early stages, with some men never experiencing any symptoms before diagnosis.

### **An understanding of key terms and investigations**

To allow a deeper understanding and add context to the study, it is beneficial to understand terms used when discussing investigations and results. There are several investigations that can be performed along the diagnostic journey within primary and secondary care to explore potential prostate issues, such as prostatitis, an enlarged prostate or prostate cancer. A health check that is described by the participants in these findings as either a 'well man check' or 'MOT', is an overall health check and can be offered annually in certain GP surgeries or requested by the patient. These checks are looked at as preventative screening and will monitor the risk of developing certain disease and comorbidities such as heart disease, diabetes, or a stroke. They will often involve blood tests, urine tests, a blood pressure and weight check, lifestyle discussions and exploration of relevant family history.

More specific tests for suspected prostate issues are required and involve a urine test which will look for possible infections and inflammation, whilst a Prostate Specific Antigen test (PSA) will look for a precise protein that is produced by the prostate and released into the blood. A physical digital rectal examination (DRE) is often performed alongside a PSA blood test, and this is where the prostate is felt for abnormalities through the wall of the back passage (Prostate Cancer UK, 2020). Normal PSA levels are classed within a range of zero to four and a GP is advised to use clinical judgement to consider other factors such as family history, presence of symptoms or an abnormal DRE result (The National Institute for Health and Care Excellence (NICE) guidelines, 2020). A raised PSA result can also be due to dynamic exercise, a urine infection, the use of medicines or ejaculation 48 hours before a test. A PSA test can however produce a false negative or false positive with figures showing that around 15% of men may have a false negative and around 75% of men with a positive PSA will go on to have a negative prostate biopsy (NICE,

2020). NICE further recommend a man aged between 50-69 with a PSA level of 3.0 nanograms/mL or higher, be considered along with a GP's clinical judgement, for an urgent referral along the suspected cancer pathway for further investigations within secondary care.

Secondary care will conduct a range of investigations to help confirm a prostate cancer diagnosis as well as repeating investigations undertaken in primary care. Procedural investigations include a biopsy and a magnetic resonance imaging (MRI) scan or multi parametric magnetic imaging (mpMRI) scan. A biopsy is a medical procedure used to take a sample or tiny samples of body tissue or cells from a patient using a needle or needles. These samples are then examined under a microscope to check for disease. There are two types of biopsies that are conducted in the investigation of prostate cancer - these are the trans rectal (TRUS) biopsy and the trans perineal biopsy. The transrectal takes small samples through the wall of the back passage and the trans perineal takes samples through the skin between the testicles and the back passage. The mpMRI is a multi-parametric magnetic resonance imaging procedure that takes 4 types of images. This specific scan often used with prostate investigations can produce pictures with added features in comparisons with a standard MRI. The National Institute for Care Excellence (NICE) guidelines (2019) currently state an mpMRI should be offered as the first investigation for prostate cancer. In Wales during the time of the interviews, there was no uniformity to the timing of these investigations, with different health boards offering either the mpMRI or standard MRI and at different times along the diagnostic journey. This difference was discussed by some of the men in the interviews and is included within the findings chapter.

### **Prostate cancer risk**

There are symptoms that can be associated with potential prostate cancer, and there are also factors associated with the disease that are important to look out for and consider alongside when considering risk. Risk factors include age, ethnicity, family history and genetics (Merriel et al 2018, Prostate Cancer UK, 2019). As previously mentioned, men over the age of 50 are at a greater risk of being diagnosed with prostate cancer and this risk increases with increasing age. A black man's risk age for diagnosis is reduced to 45, along with a 1 in 4 chance of getting prostate cancer

(Prostate Cancer UK, 2019). A family history such as a brother or father with prostate cancer can increase the likelihood of diagnosis by two and a half times and research also suggests a man's risk is increased if a mother or sister has had breast cancer (Prostate Cancer UK, 2019).

## **Current guidance**

There are several documents and national guidance pertinent to the diagnosis of cancer and prostate cancer. As this study is focussed on men in Wales, an exploration of documents relevant to the country have been explored to provide a background and to underpin the study.

NICE have developed guidelines for health care professionals (HCP), providers of prostate cancer services and people and their families with prostate cancer on the diagnosis and management of prostate cancer (Prostate Cancer: diagnosis and management NG131, 2019). This includes best practice, diagnostic and follow up guidance. It includes information on decision support for patients, assessment, risk stratification, treatment options and support for GPs with suggestions on investigations and symptom awareness.

The Cancer Delivery Plan for Wales 2016-2020 (Wales Cancer Network, 2016) is a document written to affirm the Welsh government's commitment to tackling cancer in Wales. It has recently been replaced by The Quality Statement for Cancer (Welsh Government 2021), however due to its detail, it is important to discuss. The visionary document is aimed at supporting collaboration between stakeholders, providers of services and commissioners to deliver a joined-up approach to improve cancer services in Wales. The Welsh government admit to having a long and challenging time ahead, with cancer diagnoses increasing and as such a subsequent demand on services (Wales Cancer Network, 2016) The Welsh vision is for Welsh services to match that of Europe who has improved rates of early diagnosis in comparison. The Cancer Delivery Plan (Wales Cancer Network, 2016) acknowledged the need for Welsh services to improve to ensure pathways last no longer than 62 days from when cancer is suspected to start of treatment, detecting cancer earlier. The plan further recognised the need to understand the contextual and behavioural situations of people who may have cancer and how the interactions between patient and

primary care and patient and secondary care are pertinent, along with greater and equal access to services.

The Quality Statement for Cancer (Welsh Government, 2021) policy, and strategy document has now built on the 2016 Cancer Delivery Plan (Wales Cancer Network, 2016) and provides a further five-year projection for Wales and the improvement of cancer services. It has underlined several attributes the Welsh government need to work towards, and states cancer services need to be equitable, safe, effective, efficient, person centred and timely.

The Welsh Cancer Alliance is a third sector alliance of 20 charities including Cancer Research Wales and Prostate Cancer UK. Their aim is to work in tandem to find ways to prevent cancer, improve care, fund research, and inform policy. They have written strategic documents including workforce strategies, manifestos for a cancer voice and early diagnosis policy papers (Wales Cancer Alliance, 2017). The Earlier Diagnosis (Wales Cancer Alliance, 2017) policy paper highlights the lack of diagnostic tools for prostate cancer and issues with recognition of vague symptoms, along with the need for greater awareness of alarm symptoms and hitting the 62-day referral target.

There are several charities that focus on prostate cancer, such as Prostate Cancer UK, Prostate Cymru, Tackle Prostate Cancer, along with cancer charities that incorporate this cancer into their research, guidance and support such as Cancer Research Wales and Cancer Research UK. These charities offer support, guidance and advice with many running research studies and investing in innovation and science aimed at tackling improved diagnosis and earlier diagnosis. These charities also have the ability to challenge guidance and emphasise improvements that can be made to improve a man's journey to a diagnosis of prostate cancer. This study will be able to add new data to relevant research in the field of prostate cancer diagnosis and provide further evidence to support current guidance and charity work.

### **The prostate cancer pathway**

A journey to a cancer diagnosis varies from patient to patient and can often be complicated due to events such as: individual patient appraisal and self-management; the initial decision to see a HCP; the referral and investigation process and the planning of treatment after diagnosis. Scott et al (2013) have created a

Pathways to Treatment model which highlights these intervals and is a valid model for researchers to use when exploring cancer pathways. The model highlights various pathways which can have no definitive starting point and a plethora of factors that impact. Understanding more about this pathway and its various components whilst in the health care system can help optimise future pathways and improve survival rates (Hiom, 2015; Coxon et al, 2018). It is important to learn more about these intervals within the pathways as mortality rates have been shown to be greater in men with prostate cancer who have experienced a longer pathway (Torrington et al, 2013). This research study has used guidance from other academic papers to support the categorisation of men into either experiencing an early, late, or asymptomatic journey. This is explained in further detail within the methods chapter.

If we understand more about men's experiences, worries, influences on decision making and priorities along their diagnostic journey, services can offer greater targeted support and improve their patient journey to diagnosis and subsequent outcomes (James et al, 2017). It is important to remember that not all journeys are linear and some men in this study may not fit neatly into the patient, primary or secondary care interval, with their presentation following a different route.

Understanding more about the appraisal and help-seeking intervals could help shed a light on this. Increased research in this field could also support the survivorship of men with prostate cancer and increase the evidence for future support (Naragen et al, 2019). Having a clearer understanding of these intervals, along with the contextual, behavioural, and social factors experienced by men can add to the body of literature that can help influence policy makers and highlights the first of many reasons, why the study is important (Swann et al, 2020). This study will provide an opportunity for men to divulge these experiences and the factors behind their decision making, allowing a more in depth understanding and adding to the research base to help inform and improve patient outcomes.

### **Why is this study needed?**

Understanding more about men's personal journeys to diagnosis and investigations undertaken can help illuminate any potential areas for intervention or improvement along the cancer pathway (Whitaker, 2020). Reason for delays in cancer diagnosis as we have already established can be complex and confusing. The work of

screening in early cancer diagnosis is widely discussed and there are specific screening tests for some cancers and not others (Neal et al, 2015). There is currently no specific national screening programme for prostate cancer (Cancer Research UK, 2019). Instead, several investigations are used by primary and secondary care to confirm this diagnosis. These investigations may not be delivered in the same order for each man and not everyone will need or be offered them all. A Prostate Specific Antigen (PSA) blood test is the closest thing the medical community currently has to a screening test for prostate cancer but due to its issues with specificity and reliability, it is normally used along with a digital rectal examination (DRE) in primary care and a biopsy and MRI and sometimes a CT or bone scan in secondary care (Cancer Research UK, 2019). Understanding more about a man's experiences of these investigations, perceptions and views during this journey holds even more importance due to these screening issues. It has the opportunity to promote best practice or highlight areas for improvement when it comes to time intervals and equity. These investigations and their order will be explored within this study, helping highlight any potential areas for further research or improvement.

The strength of understanding the patient's journey through various perspectives and in greater depth can allow for a deeper understanding of how patients perceive their symptoms (Keeble et al, 2014). Possible delays along the journey can start before a patient goes to see their GP and then further delays can be seen during the primary and secondary pathway interval. Recognising potential symptoms that could be relatable to more advance stage prostate cancer is imperative for both the men and primary care HCPs in facilitating an early diagnosis and many characteristics can influence this (Keeble et al, 2014).

Men have been shown to access health and wellbeing services less frequently than women and can be reluctant to see their GP or seek initial help until symptoms impact their life (Schlichthorst et al, 2016). This can be further complicated as prostate cancer can be asymptomatic or present the same as non-cancer prostate problems in older men - adding to the challenge. Understanding more about a man's reason for initial presentation, symptom awareness and the different routes men take when they present to primary care, could offer valuable data to support this area (Brookes et al, 2012). This study will allow men to recount the beginning of their journey adding to the current evidence base.

Behavioural science is imperative when it comes to understanding patient factors such as barriers and facilitators to initial help seeking and perspectives on health and wellbeing (Whitaker, 2020). The lead up to a cancer diagnosis can affect emotional wellbeing and these changes in wellbeing have the potential to impact the different parts of the diagnostic pathway. Anxiety and stress have also been known to increase during this time (Dillard et al, 2017; Groarke et al, 2018). The opportunity to understand men's emotional responses and also their perceived view of their HCP during their prostate cancer journey can provide further data on how to offer greater support to a man's emotional wellbeing (Harju et al, 2017). This study will explore these emotional responses from the reflections of the men involved.

Understanding more about the barriers faced when it comes to help seeking and decision making can be important in learning more about how to promote and support early cancer diagnosis (Moffat et al, 2016). Understanding these barriers through the different routes men take and how they present to primary care can further support work on early diagnosis and improve survival rates (Brookes et al, 2012). If these barriers throughout the journey are better understood, then national campaigns and health promotion could be better structured and targeted to focus on improving impact on the public (Whitaker, 2020). Previous recommendations to develop public health initiatives to support the raising of awareness for patients during the patient interval stage have been noted as important (Lyrtatzopoulos et al, 2015) so knowing more about a patient's perspective can help define and support these initiatives.

Equity in access to health care services can be affected by social inequalities, geographical and financial constraints. Being able to understand more about how men from all over Wales are able to access services along their journey to diagnosis can help illuminate further barriers that could influence delays in diagnosis. Certain areas in Wales have access to rapid diagnostic centres and mpMRI, whilst others do not. This study will collate data through interviews with the men that relate to these areas and could provide valuable information to direct future services.

Early diagnosis will continue to be one of the main topics of interest for policy makers and charities and the challenges faced are multi-dimensional and complicated (Whitaker, 2020). Results from this study highlight the interactions and experiences



that influence a man's journey to a diagnosis of prostate cancer in Wales. It produces data that supports the work of the Wales Cancer Alliance early diagnosis plan. It further highlights a greater awareness of the delays along the pathway to provide valuable insight to help develop future initiatives to support The Quality Statement for Cancer policy and strategy plan (Welsh Government, 2021) and their early diagnosis focus. The next section will provide an overview of the approach the study has taken and a breakdown on the structure of the thesis.

## **Approach**

A qualitative, exploratory approach was used to conduct this study and a comprehensive breakdown of the study methods will be provided within the methods chapter. This scientific method of research is appropriate as it helps us to understand more about a participant's view of the world and their why and how, through exploring their background, experiences, perspectives, and beliefs. This is imperative within this study to capture and learn more about the men's views of their pathway to diagnosis. Semi structured interviews were conducted with 21 men from Wales newly diagnosed with prostate cancer, who had experienced either a prompt, asymptomatic or late diagnosis. Framework analysis was chosen to manage the data for analysis. The Framework Method created by Ritchie and Spencer (1994) was used to provide a structure through familiarisation with the data, development of a coding framework, coding of transcripts, comparison and mapping of data and interpretation. The findings are displayed in thematic sections with a further discussion to combine the literature review and findings.

## **Thesis structure**

This thesis is separated into individual chapters to provide the reader with a logical pathway through the study and to follow a traditional narrative research paper format. An introduction chapter has already been provided describing the background for the study. It includes a breakdown of key terms, current statistics, national and Welsh guidance and concluded as to why the study is needed. A reflective piece exploring the art of reflection and an overall reflexive view of the student will follow this section. The next chapter will provide the literature review. This will display the methodology, search strategy, inclusion and exclusion criteria and the critical appraisal undertaken for each academic paper chosen. The narrative

review process will be explained, followed by a thematic presentation of the findings, concluding with a short reflexive piece. The following chapter will explain the study methods. Study design, data collection methods, the approval and ethics process, recruitment, and conduction of the interviews will all be described. A detailed explanation of the Framework method process will conclude the chapter. The next chapter presents the study findings in a thematic structure, detailing key themes and interpretations. A reflexive piece and diary extract will be added to this chapter to support the conduction of the interviews and analytic process. A discussion chapter will bring together the key findings from the literature and interviews using thematic headings derived from the interview findings chapter for structure. Finally, the thesis will be brought together with a concluding chapter providing an overview of the study, a summary of key findings and consideration of strengths and limitations. This chapter will close with further reflection and discussion of the overall study to provide examples of possible implications for policy, practice, and research.

### **Reflexivity - learning the art of reflection**

Reflexivity is a skill that takes time to build (Cottrell, 2015) and can enable a researcher to make sense of their experiences and decisions throughout their role within a study. As a qualitative researcher it is also important to recognise that reflexivity is imperative in helping evaluate your own research. Reflexivity identifies that a qualitative researcher does not come to any situation without bias, and recognises how one's background, life experiences and view on the world will impact the study and influence reflection. Researcher reflection can also increase the robustness of a study, adding clarity and understanding for the reader (Cottrell, 2015). Reflection can be unstructured in the form of note taking, verbal recordings and mind maps or take on a more structured approach using developmental prompts such as questions or models (Kolb, 2015). It offers a chance to be critical, to stimulate thought processes and evaluate work (Cottrell, 2015). I have taken on both an unstructured and structured approach to support my reflective journey during this masters in research (MRes). Notes, diary entries and verbal recordings have been made, along with a personal structured model of reflection to provide a structure when needed.

I have created an individual model of reflection tool (figure 1) to provide a personal approach that supports my style of learning and I have used it throughout the MRes process in my development and understanding, by reflecting on the stages after specific events. It is shaped through the careful consideration and examination of other reflexive models (Schon, 1983; Gibbs, 1998; Driscoll, 2007; Kolb 2015) and subsequently the adaptation of Cottrell's (2015) core model of reflection. I have devised each of the five stages shown in figure 1 to aid further reflection, exploration, depth and support good practice. I have structured the model with starting points - however it has fluidity and was adapted dependant on the situation I was exploring. This individually made model will also offer further use in my own future research work and support the habit of important qualitative reflections aiding to the reliability, validity and rigour of a study.

**Figure one. my personal individual model for reflection**

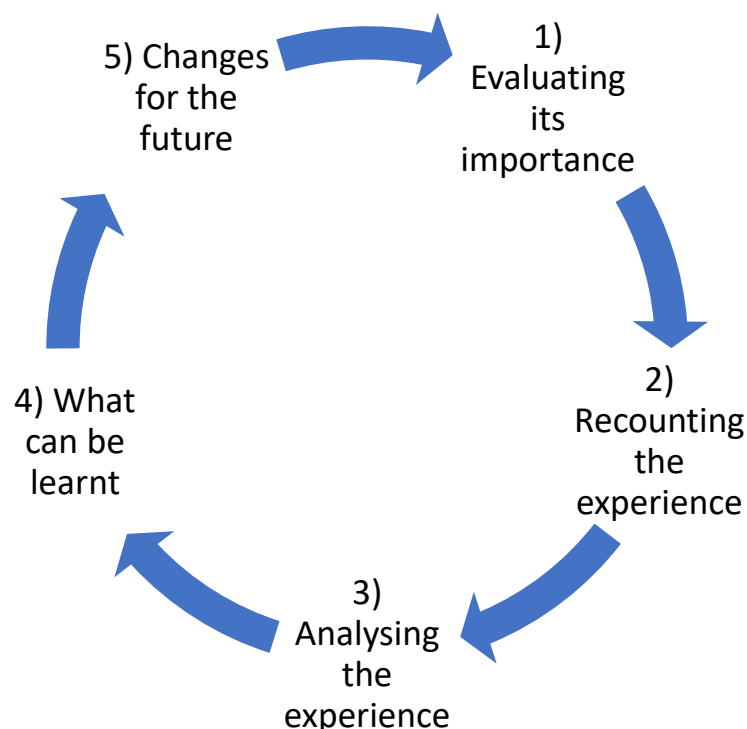


Figure 1- Adaptation of Core Model of Reflection from Cottrell, S (2015). *Skills for Success: Personal Development and Employability*. London: Palgrave Macmillan.

## **Stages of reflection model**

**Evaluating its importance** is the first stage of the model and this allowed me to consider if working through an event would help me understand things better or alleviate some concerns I might have had. It helped me reflect upon whether it was important enough to spend time on and would it help my work as a student, improve my professional practice or evaluate how my beliefs may have influenced my work. An example of this was when I needed to consider my own bias from my personal view of prostate cancer due to seeing two family members go through a diagnosis. This was important to reflect on in relation to my interview skills and the way I interpreted the data. If I deemed the event to be important enough, I would go onto stage two, **Recounting the experience**. During this process, I would consider the most relevant points and break these down in writing if needed. Sometimes a mind map would help to remember the experience and any emotions attached. I would then be able to see if I could have done anything differently or would do in the future.

**Analysing the experience** and considering whether any theory, explanation or event may explain the outcome would then be considered. Upon reflection I am aware that Covid restrictions and being isolated impacted my emotional responses.

**What can be learnt** is the next important process in the reflection model and allowed me to recognise my skills and qualities, future training that would be beneficial and any triggers I may need to be aware of in the future. Using the model has brought to my attention the need for support with literature searching and using my people skills as a strength in a future research career. The plan finishes with thoughts of **Changes for the future** - this has allowed me to make notes on future study I would like to conduct, structured on reflexivity within qualitative work and future plans.

## **My reflexive journey**

This thesis will firstly have an overall reflective account, encompassing my thoughts and feelings from undertaking the study. Following this, there will be a small section within the literature review chapter and a diary entry sample log and a longer reflective passage within the methods chapter. It will conclude with a small closing paragraph embodied within the conclusion. These smaller sections will provide the reader with greater clarity on the steps taken and the learning processes throughout.

## **An overall view**

This master's in research thesis has stemmed from a larger piece of research work I am completing through my role as a research project support officer (RPSO) within the North Wales Centre for Primary Care Research at Bangor University. The larger study is exploring the diagnostic journeys of men with prostate cancer through a four-phase mixed method approach. This is my first role in research due to coming to academia late and completing my degree four years ago in a Bachelor of Science with honours in Health, Wellbeing and Community at the age of 40. This thesis is based on Phase II of the overall study, which consists of qualitative methodological work. One of the main reasons for using this phase in qualitative research is the academic pathway I would like to travel along, to allow progression into becoming an established qualitative researcher and social scientist.

This work role has provided me with an opportunity to gain valuable knowledge and further experience, and as a novice researcher fresh out of university I recognised the need to obtain a post graduate qualification to further my career progression. As such, I made the decision to apply for a post graduate masters qualification part time alongside my work. My love of qualitative research is stemmed from my curiosity and interest in others, their values and beliefs and my desire to help and facilitate. I am also used to discussing emotionally charged topics due to previous roles.

Thoughts of undertaking this study initially brought feelings of trepidation due to the work ahead, but also a sense of eagerness and passion to understand more. Now on completion of this study I can stand back from my work and observe the challenges I faced, along with the successes. Time management has been a dominant factor as finding time to complete the work alongside my other role as a RPSO and a wellbeing coach for a charity was challenging. Add to the mix a pandemic, a house relocation and working from home with no dedicated office space, it has created many moments of stress, isolation and a lack of motivation. Successes have come in the shape of managing to conduct my interviews just before the pandemic hit, support from the Health and Care Research Wales (HCRW) nurses and having the resources to complete the analysis from home. It has taught me the value of believing in your own ability (as coming into this role later in life I often experience imposter syndrome) and to appreciate the often-steep learning

curve this master's in research study has provided. A further challenge has been trying to keep my role as a staff member and student separate, however this duo also has had its advantages as both revolve around research and complement each other.

I have been extremely lucky in the support I have been given from my supervisors who are experienced in the field of research and have provided inspiration, along with guidance and support / What have I learnt:

- A research study takes time, dedication, and patience
- Be prepared for issues throughout that can prolong the process
- Be ok with having the occasional meltdown
- Learn to adapt to changes and your resilience will increase

Undertaking a qualification of this kind has also enabled me to experience every part of a study, providing a building block for future understanding and work. The time spent to reflect during the study and within the writing up process has allowed me to recognise areas of work and academia I can improve on in the future. Without the process of using my personal reflection model and taking time out to pull apart my thoughts and actions, I feel I would not have documented these important points, and this just reiterates the power of reflexivity for personal growth and professional practice. I feel this completed thesis, especially with the reflexive elements within, will provide the reader with a full account of my journey and work and is written in the style of a narrative methodological paper for structure and clarity.

## **Chapter 2**

### **The Literature Review**

# Literature Review

## Literature review methodology

The purpose and importance of a literature review in establishing a stable foundation within research has been widely discussed and its role stated (Ridley, 2012; Saltikov, 2012; Aveyard, 2019; Snyder, 2019). A literature review is a wide-ranging, comprehensive study of specifically relevant literature that aims to explore a topic relating to a research question or topic of interest. It most often takes shape in the form of a piece of academic writing that surveys an existing body of literature, helping understand what is already known and where knowledge is sparse. Therefore, it can support the researcher in gaining clarity on where their work fits within their field of research, adding to existing data (O’Gorman & Macintosh, 2015). It further aids the researcher in bringing context into their work, whilst improving their skill set and improving professional practice.

A literature review can be a study or a paper in its own right or part of a larger project or chapter within a thesis. There is an ever-growing plethora of literature emerging within all academic areas including health sciences and it is important for researchers within their field to keep up to date and build on this research, whilst understanding its value (Pontis et al, 2015). Conducting a literature review can also support a researcher in aiding context and clarity to their academic and professional field. A review of current literature is often utilised by government and policy makers in aiding their decision making and can influence adaptations to professional practice in the workplace (Boaz et al, 2009; Menter & Hulm, 2012; Gough et al, 2013; Kristensen et al, 2016).

A review can take shape in various forms and has evolved over the years from the generic two types of standard review to over 35 varying types, each having their own structured pattern and degrees of detail (Aveyard and Bradbury, 2019; Sutton et al, 2019). The two standard review models have been highlighted as systematic and narrative. A systematic review is often looked at as the gold standard within the field and focuses on a defined, structured review of the literature using a priori and explicit methods (Uman, 2011; Pare & Kitsiou, 2017). Despite this, Garg et al (2008) argue that systematic reviews can be open to researcher bias. A narrative review is often looked at as more traditional, summarising published articles using appraisal and



debate, with potential limitations focussing on lack of description of methodology making replication an issue (Lau & Kuziemy, 2016; Booth et al, 2016). Both methods if conducted rigorously can offer a comprehensive overview of the literature. Upon exploring both options I made the decision as it was a more feasible approach as a lone student to follow a narrative structure as this complimented the qualitative nature of the study. Aveyard (2019) offers practical guidelines for this method with a clear and well-defined process for clarification and understanding. This narrative structure can support certain learning styles and was deemed appropriate for this reason.

### **Formation of literature review research question**

The focus of this literature review has evolved from the dissection of an area of interest within a larger study currently being researched, as part of a working role on the topic of early diagnosis in men with prostate cancer. Undertaking a review of the literature would support professional practice and career progression for a qualitative researcher, whilst complementing current ongoing work. The formation of a research question to aid the review was the first step in the process. The aim of the question was to be a simple guide to focus on throughout, whilst being interrogative. A clear research question should enable a researcher to gain greater clarity of the area to be explored and support future practice (Aveyard, 2019).

To help define the research question and channel the exploration of literature, various methods were applied. Firstly, a mind map was created to allow free thinking and to shower thoughts onto paper. This style of working can support ways of visually displaying reams of information through a visual process that can help solidify thought processes (Jones et al, 2012). Secondly, specific research tools were used as a guide. The first tool was created by Fineout and Johnston (2005) and is used as an acronym to prompt thinking. The tool systematically follows a list of prompts which include population, intervention, comparison or context, outcome and time or types of study (PICOT) (figure 2). The second tool used to advance thought processes was by Cooke et al (2012). This tool similarly provides prompts which include sample, phenomena, interest, design, evaluation and research (SPIDER) (figure 3). These specific tools are widely used and appropriate for qualitative

studies. They guide a structured thinking approach and add a crucial support mechanism to the methodological processes used.

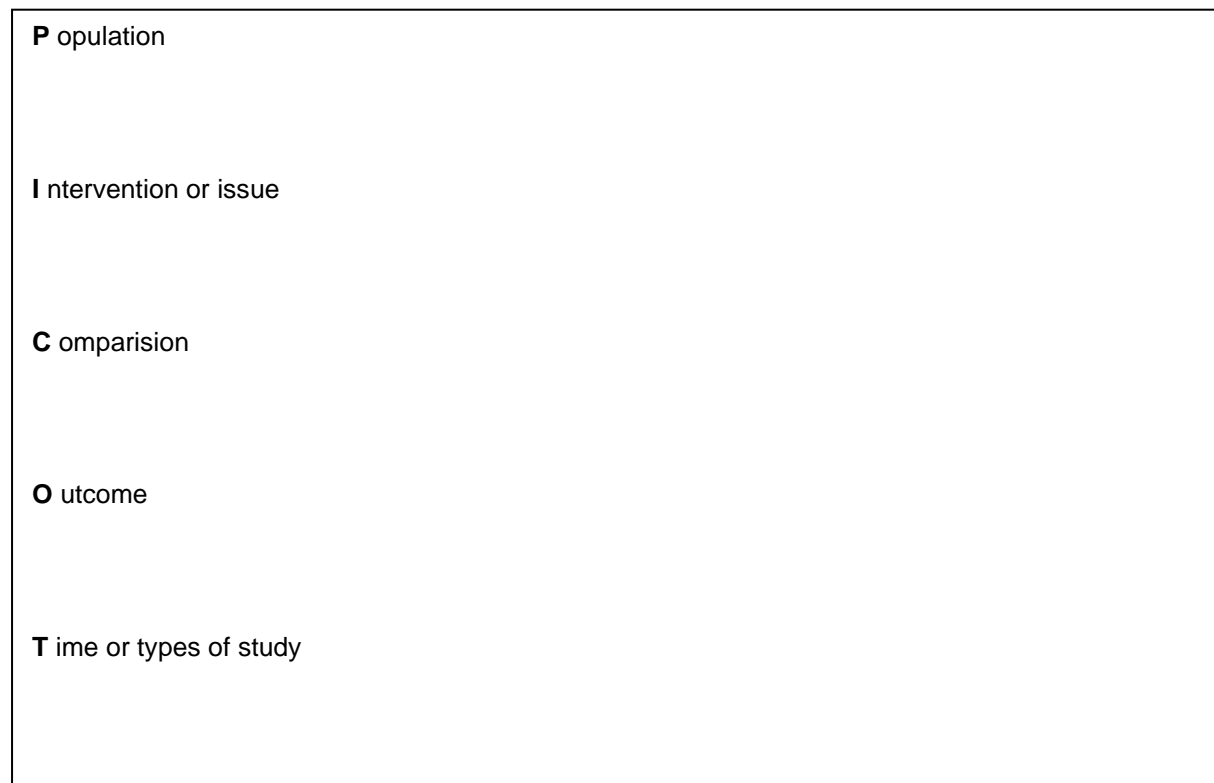


Figure 2- PICOT tool by Fineout & Johnson (2005)

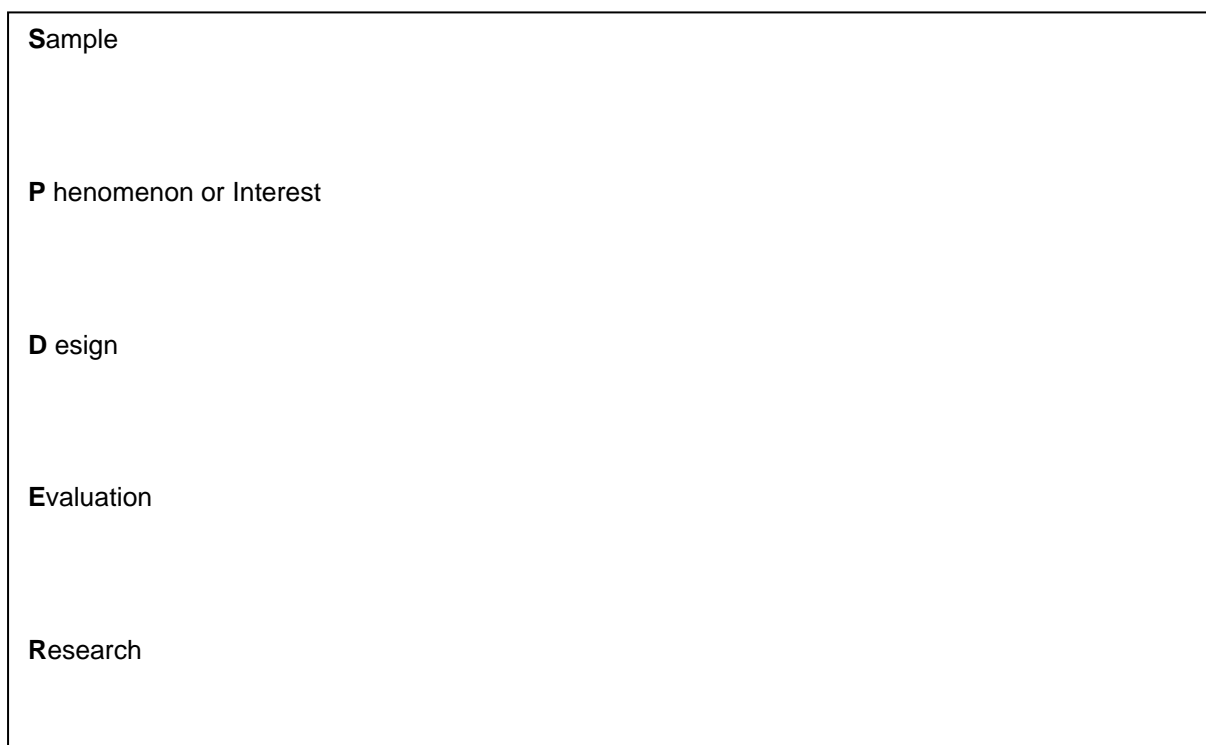


Figure 3- SPIDER tool by Cooke et al (2012)

### **What literature will be needed?**

Understanding the range of literature that will be needed for a review is another important part of the process. Wallace and Grey (2016) compiled a breakdown of such literature into themes: theoretical; research; practice and policy. The decision was made after background reading (Aveyard, 2019) to utilise research literature within the search strategy incorporating policy, practice and theory within the discussion and introduction sections if deemed relevant. This style of research literature can be broken down into more tangible areas such as systematic reviews, quantitative, qualitative and mixed method studies. To further support a researcher in understanding what studies are relevant, Hierarchy of Evidence strategies (Woolf et al, 1990; Cook et al, 1992; Sackett et al, 1997) have been created to help understand their validity. These would normally place systematic reviews and randomised control trials at the top of the list within a health or social care setting. However, due to the research question being exploratory, a more appropriate hierarchy of evidence table was developed to suit the research questions of the study (figure 4), placing qualitative research at the forefront.

<u>Hierarchy of Evidence</u>
<ul style="list-style-type: none"><li>• Qualitative studies of men's experiences/perceptions</li><li>• Systematic reviews of qualitative studies of men's perceptions or experiences</li><li>• Quantitative/mixed method studies of patient experiences/perceptions</li><li>• Expert opinion</li><li>• Anecdotal opinion</li></ul>

Figure 4 - Hierarchy of Evidence table

## Development of Inclusion/exclusion criteria

To provide focus within the search, an inclusion and exclusion criteria table (Table 1) was created. This provided a parameter and highlighted the most pertinent literature relevant to the review (Smith & Noble, 2016). The criteria within the table were selected for several reasons. The research question was used to make sure the literature included men's views on the prostate cancer journey to diagnosis and omitted any other cancer and any views other than from men. It also stipulated the exploration of the route to diagnosis and not treatment or post diagnosis.

Inclusion criteria	Exclusion criteria
Last 10 years	Pre 2010
Peer reviewed	Not peer reviewed
English Language	Not in English
Abstract available	No abstract
Exploring prostate cancer	Any other cancer
Men's views	Opinions from health care professionals
Studies that explore men's perspectives and experiences of pathway up to diagnosis	Studies that explore men's perspectives and experiences of prostate cancer treatment and post diagnosis

Table one - Inclusion and Exclusion criteria table

The literature needs to be up to date and relevant (Fink, 2020) so the date search criteria for this study was set to the last 10 years. It is imperative within health and social care to be aware of emerging work, and it was felt appropriate as this was an exploratory study that updated views would be advantageous. However, any seminal work that may be prevalent from background research of the overall topic was also

considered as recent literature should itself be built on robust earlier research. The papers for this review were also peer reviewed as this provided assurance that a process of evaluation from other research experts had occurred, increasing the likelihood the papers were of high quality (Kiron et al, 2018). Although it is best practice to include papers written in other languages, there was no budget for translation, so only papers written in English were included in this study. Finally, each paper needed to have an abstract readily available as this supported a smoother search strategy and supported time management.

### **Search strategy**

The next step after the creation of the research question and deciding on what research to prioritise was to implement a systematic search strategy. Conducting a search in a methodical recorded way leaves the reader with a sense of confidence in the work (Bramer et al, 2018; Cooper et al, 2018; Aveyard, 2019) and provides a definitive process to undertake. The process started with another thought shower and mind map session which resulted with a list of keywords. This task was spread out over several days to ensure a comprehensive list was created and various thought paths were exhausted. The synonym strategy was utilised, and background material was read to support this (Aromataris & Riitano, 2014). The decision was made to use four databases after an initial familiarisation search on the internet, a session with the university librarian and a discussion with colleagues: The Comprehensive Index to Nurses and Allied Health Literature (CINAHL) database was chosen as it related to nursing and health care; The Applied Social Sciences Index and Abstracts (ASSIA) database as it held social science literature; The Medical Literature Analysis and Retrieval System Online (MEDLINE) database as it is populated with biomedical literature and the psychological information (PsycINFO) database as it holds psychology literature relating to behavioural and social sciences. These four databases were also accessible through the support of Bangor University library services unlike some others.

To ensure the most comprehensive list of literature was produced, firstly a general search within the databases was conducted to increase familiarity with the specific terms and search strategies for each. Specific search facilities such as a databases' thesaurus and MESH terms were utilised as this helped reduce the number of results

(Atkinson & Cipriani, 2018). The written search strategy (table 2) also involved the use of the wildcard and truncation symbols and Boolean operators were utilised to create a more advanced search (Ecker and Skelly, 2010).

<u>Search Strategy</u>
<ul style="list-style-type: none"> <li>- Abstract available</li> <li>- English</li> <li>- Last 10 years</li> <li>- Peer reviewed</li> </ul>
<ul style="list-style-type: none"> <li>• Prostate cancer or prostate neoplasms or prostate carcinoma</li> </ul>
AND
<ul style="list-style-type: none"> <li>• Diag* or assess* or identify* or test or examination or screening</li> </ul>
AND
<ul style="list-style-type: none"> <li>• Views or opinion* or perceptions or belief* or attitude* or experience or qualitative or fact* or behavior* or contextual or social</li> </ul>
AND
<ul style="list-style-type: none"> <li>• Time or addition or length or route or interval or pathway</li> </ul>
AND
<ul style="list-style-type: none"> <li>• Symptom* or signs or character* or present* or perceive or bodily changes</li> </ul>

Table two- Search strategy chart

Keywords as highlighted in Table 2 were used to look for relevant titles, abstracts or within all text. This helped condense the search and provided the most relevant results. To try and balance the chance of not identifying all literature pertinent to the topic within the database searches, literature was further identified by using the simple syndication (RSS) content news feeds from Mendeley, reference searching of articles and author searching if specific researchers were highlighted within the field of expertise.

The search results are displayed in a literature search flowchart strategy diagram (appendix 1) adapted from Moher et al (2009) PRISMA flow diagram. The diagram offers structured support for researchers by following a flow pattern between different

phases of a review. These phases include identification, screening, eligibility and subsequent papers chosen. All papers highlighted were first screened by reading the title, and then potentially relevant articles were further screened again by reading the abstract. This depleted the numbers considerably. Out of the chosen 117, the decision was made upon discussion with supervisors to adapt the inclusion criteria and omit all papers that were not qualitative. This decision was made as the study was qualitative in nature. This condensed down results and ensured the remaining literature would pertain to the exploratory, qualitative nature of the study. The other papers were stored and if viable would be used within other areas of the thesis. After the omittance of another ten papers due to inclusion criteria, 19 qualitative papers were selected for the review. A summarised overview of the studies can be seen in table three. These were managed through printing a hard copy, saving an electronic version and the use of Ref Works reference manager.

**Table three- Summary of studies**

<b>Author, year, location</b>	<b>Study type</b>	<b>Study aim</b>	<b>Setting</b>	<b>Sample/Population</b>	<b>Data collection methods</b>	<b>Key findings</b>
Mathers et al (2011): UK/Scotland	Qualitative	To explore the experiences of people with a diagnosis of cancer whilst attending imaging procedures	Cancer support groups in Scotland through independent charity	8 men from cancer support groups	Qualitative semi structured interviews	Participants reported different routes to diagnosis and diagnostic procedures indicated a personal journey
Driedher et al (2017): Canada	Qualitative	To explore affective factors that interplay in public/laypersons decision making about cancer screening	Toronto	93 people – 46 women (not used) 47 men without prostate cancer	5 Qualitative Focus groups	Older men felt prostate cancer screening should be expanded. Fear of cancer, inspired by stories from family and friends and unreliable test is better than nothing.
Partin et al (2016): USA	Qualitative	To inform educational materials addressing patient concerns and	Minneapolis Veteran Affairs Health Care System centre	26 male veterans	Qualitative semi structured interviews	Most men expressed perceptions on the benefits of screening and had



		questions surrounding prostate cancer screening guidelines, harms, and benefits				difficulty identifying the possible harms. Recommendations about screening differed but most would accept recommendations from their provider
Kirkman et al (2017): Australia	Qualitative	Explore perceptions and experiences of prostate cancer diagnosis, treatment, and care	Regional and metropolitan areas of Melbourne	21 men recruited through the Prostate Cancer Outcome Registry	Telephone semi structured interviews	Every aspect of prostate cancer care would benefit from attention. Media publicity was important, case findings differed across regions, the process of diagnosis impacted perspective and time to diagnosis
Forbat et al (2014): Scotland	Qualitative	To better understand the features which influence the timely access to diagnostic services through men's accounts	Glasgow	30 men who have received a prostate cancer diagnosis and some partners	Semi structured interviews, mostly face to face but a few by telephone	Interpersonal relationships are pivotal in informing men's help seeking behaviour and diagnosed men would often encourage others to seek help
Yu Ko et al (2018): Canada	Qualitative	To explore the linkages between	Western Canadian City	24 Western Canadian men from prostate	Semi structured interviews	Work is central to men's identities.

		men's, work and their experiences of prostate cancer		cancer support groups and a urology clinic		Men knew little about implications of prostate cancer screening, but a prostate cancer diagnosis strengthened family networks
Shaw et al (2013): USA	Qualitative	Examining the role of family ties on prostate cancer decisions relating to screening, diagnosis, and treatment	New Jersey	64 men and 4 of these included joint husband/wife interviews	Semi structured interviews	Men's relational dynamics with family members is important to consider when it comes to shared decision making. Reaction to family pressure and open communication important.
Schildmeijer et al (2019): Sweden	Qualitative	To explore how prostate cancer patients experience their journey through the healthcare system	Hospital in Southwest Sweden	14 men who were prostate cancer patients	Semi structured interviews	Waiting for diagnosis was seen to be the worst part of the experience and lack of information was common.
King-Okoye et al (2018):UK but setting in Trinidad and Tobago	Qualitative	To explore men's pre diagnosis experiences of prostate cancer	4 Trinidad and Tobago urology and oncology centres	51 men diagnosed with prostate cancer	Semi structured interviews	Barriers to help seeking were seen as lack of knowledge and awareness. Fear of investigations, masculinity norms,

						cultural and religious beliefs all contributed towards delays
Conde et al (2011): Hawaii	Qualitative	To examine perceptions, attitudes and beliefs regarding barriers and facilitators to prostate cancer screening and identify potential intervention strategies	Community based settings in Hawaii	20 Filipino men aged 40 years and over without prostate cancer	5 Focus groups	Perceptions included hopelessness with misconceptions of prostate cancer causes. Barriers included lack of awareness and facilitators included urinary symptoms and family and friends
Grogan et al (2017):UK	Qualitative	Explore young British men's understandings of prostate cancer and health	UK homes	16 men aged 30-55 without a history of prostate cancer	Semi structured interviews face to face, VoIP and through email	Limited knowledge about the prostate and the screening process. Mixed views on investigative procedures
Ferrante et al (2011): USA	Qualitative	To explore the reasons behind why men chose to get or not get prostate screening	Northern New Jersey in community-based settings	64 men aged 50 and over never screened or screened abnormal	Semi structured interviews	Screening was due to family history or routine examination. Men never screened due to perceived low risk or healthy behaviour beliefs

Appleton et al (2019):UK	Qualitative	To investigate patient and primary care-based perspectives of what constitutes good care for men with prostate cancer	Participant's homes or GP practice in the UK	10 men with a diagnosis of prostate cancer 12 healthcare professionals (not used)	Semi structured interviews	Good care was noted as communication, information giving, active participation and context.
Appleton et al (2014):UK	Qualitative	To highlight how men cope with the disease of prostate cancer and manage their diagnosis	Outpatient clinic	27 men who had a diagnosis of prostate cancer and were receiving EBRT	Semi structured interviews	Many men did not understand consequences of a high PSA reading, investigations were viewed as painful and the worst part of the disease
Nanton et al (2010):UK	Qualitative	To investigate the perceptions and experiences of treatment and care of African American men with prostate cancer	Central England in men's own homes	16 first generation men with a confirmed diagnosis of prostate cancer	Semi structured interviews	Migration, culture, and historical contexts influenced responses. Medical treatment highly valued but lack of coordination between services
Matthew et al (2011): Canada	Qualitative	To explore the factors that influence the formulation of risk perception among men with a family history of prostate cancer	Prostate Cancer screening clinic	15 men who were currently engaged with screening/testing at the clinic	Semi structured interviews	Influencing factors included risk pathways, experience with other prostate disease, exposure to relatives or screening, illness beliefs and lifestyle

Anderson et al (2013):UK	Qualitative	To gain insight from men of African and African Caribbean (AAC) ethnicity on their perspectives of prostate cancer and to ascertain whether further research and health promotion is needed	Hospital trust premises	7 AAC men recruited from hospital trust patient list with diagnosed prostate cancer	Semi structured interviews	Level of awareness to prostate cancer and decision to seek help was influenced by socioeconomic status. Disease prompted awareness, personal beliefs and factors influencing screening uptake all deemed important
Torishima et al (2020): Japan	Qualitative	To explore negative recollections of prostate cancer patients regarding delivery of diagnosis	Medical institutions, patient associations and media advertisements	51 men with a diagnosis of prostate cancer	Secondary analysis of semi structured interviews	Negative recollections included direct and abrupt disclosure, negative communication, distrust in diagnosis and delays
Jones et al (2010): USA	Qualitative	To examine how African American men decide whether to have prostate cancer screening	Rural central Virginia in homes and library setting	17 rural African American men and not diagnosed with prostate cancer	Individual interviews	Family and friend involvement is important in decision making, trust in doctor and knowing others with prostate cancer impacts decision

## Critical appraisal of literature

The importance of immersion in the literature being reviewed is paramount within the appraisal process (Thomas & Hodges, 2010; Aveyard, 2019). The papers were read through firstly with notes added and sections highlighted. Each paper was then critically appraised using the Critical Appraisal Skills Programme (CASP) checklist tool for qualitative studies (2018). CASP offer eight different checklists as an educational resource in reading research and are compiled by experts. The decision was made to use the CASP qualitative checklist appraisal tool in comparison to others, as it can provide structure to an early career researcher and enable each paper to be appraised following the same format (Long et al, 2020). The qualitative tool allows the researcher to systematically make their way through the chosen article, assessing its rigour to cover the broad issues of validity, results and value. Ten questions are used to delve deeper into each paper along with a checklist. The checklist directs a fair and structured process of examining the aims, methodology, design, ethics, researcher bias and results of each paper. Each completed CASP paper was populated, printed and attached to the paper copy of the journal article. Having both the CASP completed paper and the journal article together aided any further future analysis and preparation for the narrative review. The questionnaire format was also a valuable instrument in the appraisal, and results were then added to a specific data summary chart to aid clarity.

A quality appraisal summary chart was created (table four) and a further data summary chart made to store the critical appraisal of each paper in depth and researcher notes. A small sample of the second chart is provided in table five. Populating the tables was a time intensive and worthwhile process. It was felt a positive use of time as it outlined a summary of each paper, helped absorb the data and information within and provided preparation for the next logical stage within the review

Table four- CASP checklist

<b>CASP checklist/ Author/Year</b>	<b>(Section A) Are the results valid?</b>	<b>Is a qualitative methodology appropriate?</b>	<b>Is it worth continuing?</b>	<b>Was the recruitment strategy appropriate to the aims of the research?</b>	<b>Was the data collected in a way that addressed the research issue?</b>	<b>Has the relationship between researcher and participant been adequately considered?</b>	<b>(Section B) Have the ethical issues been taken into consideration?</b>	<b>Was the data analysis sufficiently rigorous?</b>	<b>Is there a clear statement of findings?</b>	<b>(Section C) Will the results help locally?</b>
Mathers et al (2011)	yes	yes	yes	yes	yes	Can't tell	yes	yes	yes	yes
Driedher et al (2017)	yes	yes	yes	yes	yes	Can't tell	yes	yes	yes	yes
Partin et al (2016)	yes	yes	yes	yes	yes	Can't tell	yes	yes	yes	yes
Kirkman et al (2017)	yes	yes	yes	yes	yes	Can't tell	yes	yes	yes	yes
Forbat et al (2014)	yes	yes	yes	yes	yes	Can't tell	yes	yes	yes	yes
Yu Ko et al (2018)	yes	yes	yes	yes	yes	Can't tell	yes	yes	yes	yes
Shaw et al (2013)	yes	yes	yes	yes	yes	Can't tell	yes	yes	yes	yes
Schildmeijer et al (2019)	yes	yes	yes	yes	yes	Can't tell	yes	yes	yes	yes

King-Okoye et al (2018)	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes
Conde et al (2011)	yes	yes	yes	yes	yes	Can't tell	yes	yes	yes	yes
Grogan et al (2017)	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes
Ferrante et al (2011)	yes	yes	yes	yes	yes	Can't tell	yes	yes	yes	yes
Appleton et al (2019)	yes	yes	yes	yes	yes	Can't tell	yes	yes	yes	yes
Appleton et al (2014)	yes	yes	yes	yes	yes	Can't tell	yes	yes	yes	yes
Nanton et al (2010)	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes
Matthew et al (2011)	yes	yes	yes	yes	yes	Can't tell	yes	yes	yes	yes
Anderson et al (2013)	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes
Torishima et al (2020)	yes	yes	yes	yes	yes	Can't tell	yes	yes	yes	yes
Jones et al (2010)	yes	yes	yes	yes	yes	Can't tell	yes	yes	yes	yes



Table five (Further extracts can be found within appendix 3) prostate cancer=pca

Title of paper/type of literature	Main findings	Notes to use for critical appraisal
<p>A necessary evil: The experiences of men with prostate cancer undergoing imaging procedures.</p> <p>Mathers S, McKenzie G, Robertson E (2011): United Kingdom</p> <p>Primary research Qualitative research Exploratory and retrospective study design using semi structured interviews. Analysed using Miles and Huberman (1994).</p>	<p>Study sought to explore experience of patients with diagnosis of pca attending imaging procedures. Study states it provides a unique insight into experiences of men with pca relating to attendance for imaging. It states health professionals need to listen to patients and learn to deliver better service. Patients reported different routes to diagnosis, showing a personal journey. Imaging procedures were seen as part of the whole story and experience explained as a necessary evil, complex and chaotic. THEMES- Range of imaging procedures, importance given to imaging procedures, provision of information, understandings of procedure, feeling of discomfort and anxiety and receiving results.</p>	<p>Clear aims of research with goal and relevance as explained. Qualitative methodology appropriate as seeks to provide insight into experiences of pca investigations. Adequate to explore retrospective views. Research design appropriate and justified as little being known on topic and allows patient to tell story. Recruitment strategy appropriate and selection explained in detail and why study only focussed on one type of cancer. Also explains recruitment strategy. Data setting justified although participants are recruited through support groups so could show limitation. Data collection clear with semi structured interviews and full breakdown of process showing rigour. Did use patient respondent validity and patients could take away parts of interview if felt needed. Benefit due to using patient representation although potential issues with data being impacted if participants requested changes in data or removal. No discussion on saturation. Cannot tell if relationship between researcher and participants is considered as researcher role is not mentioned. Bias of sample however is mentioned in limitations. Ethics was obtained and study explained in detail to participants, consent and confidentiality. Data analysis was sufficient with a brief breakdown of thematic analysis and how it derived from the researchers examining the data. There is a clear statement of findings and in conjunction with the original question. Adequate discussion for and against results. Research has potential value from the point of offering recommendations for practice in bullet</p>

		points and how it can be transferred to other cancers. Previous research brought in for comparison.
<p>Can you un-ring the bell? A qualitative study of how affect influences cancer screening decisions</p> <p>Driedher S, Annable G, Brouwers M, Turner D, Maier R (2017): Canada</p> <p>Primary research</p>	<p>The study explores whether you can un-ring the bell of early detection awareness and whether this is your best protection. Findings state it is a mixture of yes and no. It states policy makers need to be more aware of early detection message in the role of a layperson's decision making and anticipate how messages will be shaped. Major factors that influence decision making are participant's family and friends. Older men felt pca screening should be expanded beyond its current usage. Younger men displayed less attachment to early detection messages and had more concern about harms of screening. They were also more receptive to messages if they were informed by evidence. Men stated they deserve pca screening and unreliable test better is than nothing. The small section which was relatable was the prostate cancer section.</p>	<p>After printing off appendix material the appraisal was easier and more thorough. Original paper didn't hold a large amount of information. There was a clear statement of intended aims of the research. Important however to note that study was also exploring breast cancer and conducted on men who did not have pca. Qualitative methodology was appropriate due to exploration of men's perceptions and understanding of PSA screening. Paper was also part of a larger study examining cancer control scenarios so was not predominantly focussed on pca or this specific aim. This is a potential limitation. No mention on why focus groups were chosen to research this topic but does state research was part of wider study again on decision making in cancer. Five groups however were conducted with different aged men helping improve demographics. Recruitment strategy was appropriate with an extra file as an appendix that could be read for further explanation. This information was not explicit on the paper itself. Strategy was to use survey companies so does this does question rigour, however states companies recruited through phone calls using existing databases and participants were then screened using a questionnaire designed by the team. For consideration, if participants were already in a database the sample might already be happy to talk about a variety of topics. Sample was socio demographically sampled for diversity. Data collected through five focus groups with established protocols in place and all participants gave consent. Strength that pilot group was conducted first, however limitation that after second group a new publication was published against use of psa so could have influenced answers. Audio recorded and transcribed with verification on recording</p>

		<p>to check for errors. No mention of researcher bias, however, does highlight researcher qualified and design of study was monitored throughout. Ethical approval and rigorous data analysis explaining how codes and themes were derived. No researcher role examination though. Clear statement of findings and adequate discussion using triangulation of other studies for support. Also, respondent validation used in checking interviews transcribed. findings discussed in relation to original question. Limitations of study as valuable locally as not generalised to population, a diverse mix though! Canada may also have different screening policies than the UK so this could impact comparisons. Does offer perceptions of what could influence a layperson's screening decision and aims to understand complex interplay of factors which could be transferred.</p>
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## Identification of themes

The identification of themes deriving from the data summary chart supported the first stage of creating an individual literature review to help bring a deeper meaning and understanding to the literature chosen. There is a plethora of methods that can be used to analyse literature and approaches consist of methods such as meta-analysis, meta-ethnography, integrated reviews and thematic analysis. Meta-analysis allows the combination of quantitative studies relevant to one topic to be statistically analysed (Field & Gillett, 2010). Specific software can be used for this style of analysis, though can be viewed as a complicated process. Meta-ethnography (Noblit & Hare, 1988) brings together qualitative papers and although was created to focus more on ethnographic literature, can be used with other qualitative methodology. It involves the use of comparing specific words, phrases and notions in specific papers on a topic and highlighting regularities and inconsistencies. An integrative review developed by Whittemore and Knafl (2005) is looked at as a broader style of review which can also encompass a range of methodological research papers.

Thematic analysis is another method often used in qualitative research for identifying themes derived from papers and if conducted well, can produce rigorous and robust findings (Braun and Clarke, 2013; Nowell et al, 2017). Common themes are derived from the literature and these themes are then used to provide the literature review findings in a structured, narrative manner. Upon understanding each approach and a discussion with supervisors, the decision was made to use thematic analysis. This analytic method works well with qualitative papers and can help an early career researcher with their understanding of how to present their findings whilst adding to their academic skill set.

Further background work was completed to allow the themes to emerge from the literature. The data summary chart was used to read over the main findings from each of the 19 papers and each paper was read again. The main themes that derived from each of the papers were subsequently tabulated into a new chart along with the authors to display the various themes that had emerged from the literature (appendix 4). The chart comprised of 21 themes or categories and these included barriers to seeking help, the importance of imaging procedures and receiving results and diagnosis to name a few. Each theme was then cross referenced and compared with the other papers to see how the results merged together. This allowed for each theme to be explored adequately and showed the weight of evidence relating to each. This way of moving between themes to find the best connections allows the researcher to gain assurance in their decision making and immerse themselves more within the findings (Lincoln and Guba, 1985).

Seven overarching themes were derived from the literature with sub themes or categories merged within. These were:

- Influences on family and friends on decision making
- Screening investigations- harms and benefits
- Provision of information and services
- Relationships and communication between patient and HCP
- Understanding procedures along the diagnostic pathway
- Barriers to seeking help
- Self-awareness and motivation.

Each theme was used for the literature findings chapter, with the findings from each paper being populated into the relevant sections. The following chapter will

encompass the literature review findings and will be written as a narrative review moving seamlessly between each theme. The narrative review will later be merged with the findings from the interviews to produce an in-depth discussion chapter comparing and contrasting both chapters.

### **Literature narrative review**

The findings of the papers derived from the methodological literature review process are presented in this chapter through a narrative review. This review aims to convey a story with the findings, after conducting a comprehensive analytical review in an easy-to-follow structure with a clear presentation of the themes. This style of review is comprehensive and often looked at as an appropriate method for qualitative papers (Aveyard, 2019). A narrative review also helps provide the researcher and the reader with a greater understanding of the current literature pertinent to the topic of interest.

The seven overarching themes presented in this chapter are a result of examining the commonalities and differences found in the literature. This was conducted through the creation of an identification of themes chart (appendix 5) which produced 21 categories and an important visual aid in the formation of the themes. These themes aim to flow seamlessly into the next. A thorough, in depth critical appraisal process was undertaken to evaluate each paper and provide an overall judgement. The paper appraisals are not presented within this narrative review so as not to take focus from the overall findings and are as previously highlighted, presented in a separate chart shown as table two and appendix 3.

The findings in this review will demonstrate what is already known in this field of research. They help illuminate the varied experiences, factors and interactions that influence a man's prostate cancer journey, in different countries around the world. Due to the complex nature of a diagnostic journey and the impact it can have on patients, several papers are relevant to more than one theme and hence some authors will be referenced several times and intertwined throughout.

### **Overview of the papers**

Nineteen qualitative papers were reviewed and examining the specific qualities of the papers produced several observations. Studies were conducted all over the

world- seven from the UK, four from the USA, three from Canada and then single studies from Australia, Sweden, Hawaii, Trinidad and Tobago and Japan. As the papers were qualitative, they explored the experiences, perceptions, beliefs, barriers and facilitators of men who had experienced prostate cancer or taken part in screening. Four studies focused on African American or African Caribbean men with one study exploring their experiences within the UK. Sample sizes ranged from seven to 64 with the average being 27. One study utilised secondary data from another larger prostate cancer study, whilst focus groups were the chosen method of data gathering for two of the studies with the remaining 16 gathering data from interviews. The relevance of the findings within the papers varied as results from numerous papers also reported treatment and post diagnosis issues or other variables such as work and other cancers which were not pertinent to the research question.

## **Overview of themes**

### **Barriers to seeking help**

Barriers to seeking help were reported as involving factors related to health education, historical and cultural context and men's attitudes towards their own health. African and African Caribbean men felt their prostate problems were private, especially if they related to a sexual aspect and openly discussing these described as unthinkable (Anderson et al, 2013; King Okoye et al, 2019). An extra barrier was reported if the doctor was female (Anderson et al, 2013). King Okoye (2019) described how the invasiveness of some procedures evoked feelings of homosexuality for one man, with this fear affecting his help seeking. Men's views towards their health were shown to be influenced by stoic attitudes such as black men were strong (King Okoye, 2019). Some men took over the counter medication or home remedies to deal with their symptoms instead of help seeking (King Okoye et al, 2019). The older African Caribbean and African generation were also less likely to discuss their own symptoms, perpetuating the reluctance to seek help if they did experience prostate issues or recognise the seriousness of the symptom (Anderson et al, 2013; King Okoye et al, 2019).

For others, an absence or confusion of symptoms could prevent any connection of possible prostate cancer being made within their own bodies (Ferrante et al, 2011).

A man's view on his own healthy behaviours was also pertinent when assessing barriers. Health behaviours such as exercising, not smoking and healthy eating made some men believe that these protective factors prevent prostate cancer (Ferrante et al, 2011). An absence of physical symptoms could also create a barrier due to lack of connection to possible prostate cancer as men did not feel ill (Ferrante et al, 2011). Relationships with health care providers and a sense of lack of trust in their ability or honesty was also given as a reason to not seek help (Anderson et al, 2013). Minimal health education, or education in general, also created a barrier, along with a limited knowledge of prostate cancer (Nanton et al, 2011; Anderson et al, 2013; King Okoye et al, 2019).

### **Communication and relationships with health care professionals**

Communication and relationships with health care professionals (HCP) were valued when discussed in relation to diagnostic journeys experienced from participant's accounts within various papers. The value men gave to communication and relationships however differed within the research papers (Anderson et al, 2013; Jones et al, 2013; Kirkman et al, 2017; Schidmeijer et al, 2019). When discussing their general practitioner (GP) or doctor, attributes such as being a good listener and showing care were relayed as positive values. Some stayed with the same GP or doctor over the years as building that relationship and feeling of trust was important to them (Jones et al, 2013; Kirkman et al, 2017). This long-term relationship allowed a rapport to build which some men stated influenced their decision making when it came to their health and possible screening decisions (Jones et al, 2013; Kirkman et al, 2013). A feeling of trust in their HCP often came with feelings that conversations about their health and care were real and honest (Jones et al, 2013; Kirkman et al, 2013). Overall, a good relationship with a HCP made men feel more relaxed about their health care experience especially when it came to the more intimidating conversations, appointments, investigations or tests (Kirkman et al, 2017).

Opinions on communication varied when it came to which HCP was seen during an appointment. Schidmeijer et al (2019) argue that certain types of HCPs were often seen as accessible and agreeable such as nurses, however diagnosing doctors or physicians were not and often looked at as inaccessible. Dissatisfaction was also noted during medical appointments for various reasons. Feelings of not being heard

and listened to during a consultation resulted in a breakdown of communication between a patient and their HCP (Torishima et al, 2020). Patients often left an appointment feeling their questions had not been answered in relation to their health concerns (Schidmeijer et al, 2019). The use of medical terms instead of lay language was also noted as a barrier to communication (Schidmeijer et al, 2019; Torishima et al, 2020).

### **Provision of information and services**

The way information and services are provided within the journey to diagnosis for men with prostate cancer can be intertwined within the theme of communication and relationships due to the way they integrate with each other. Having access to the right information at the right point along the diagnostic journey was imperative for informed decision making (Appleton et al, 2014; Kirkman et al, 2017; Torishima et al, 2020). Issues in providing that information were often seen as common, with reports of the information exchange being inadequate, when the right information would have provided mental security along the diagnostic pathway (Schildmeijer et al, 2019). Men felt that being given a diagnosis of prostate cancer without having a family or friend invited to be present in the room for moral support as bad practice (Torishima et al, 2000). This support was looked upon as important and valuable when absorbing information and retaining specific points in a consultation as family members often remembered different things to the patient (Schildmeijer et al, 2019; Torishima et al, 2020). When recalling conversations about diagnosis, men reported feeling unhappy about the way they were told they had prostate cancer with some reports of an almost casual reference to the diagnosis. Terminology used by the diagnosing clinicians was again reported as confusing and often without warmth and further explanation (Schildmeijer et al, 2019; Torisima et al, 2020).

There were varied responses in the way information was given when it came to imaging procedures and investigations (Mathers et al, 2011). When exploring information from health care, leaflets were looked upon as a good source of information to explain procedures, although not all were read, with reasons of complacency and forgetfulness as the reason (Mathers et al, 2011; Kirkman et al, 2017; Appleton et al, 2019). Information was also provided by family or friends who had already gone through the same journey and welcomed due to its personal touch.



Reading materials were not always understood and a combination of materials and a conversation with a HCP was looked upon as more beneficial when making decisions (Mathers et al, 2011; Kirkman et al, 2017; Appleton et al, 2019).

The importance of providing information related to a prostate cancer journey to men in a variety of ways was deemed advantageous along their pathways to a prostate cancer diagnosis (Mathers et al, 2011; Kirkman et al, 2017). Other avenues such as the media and advertising showed positive reactions even if sometimes seen as sparse and insufficient (Kirkman et al, 2017). All agreed a plethora of approaches to providing information would be beneficial as not all men are computer literate with added signposting using fundraising events and educational sessions a bonus (Kirkman et al, 2017). The way information was relayed from a health care provider was looked at as important when managing mental wellbeing conditions such as anxiety, worry and stress (Appleton et al, 2019). Some participants reported how they were thankful when a clinician provided them with information or sought it on their request in a calm and understanding manner (Appleton et al, 2019). Cultural and historical influences have also been noted as a barrier to retaining and understanding health care information. Nanton & Dale (2011) explored the views of African Caribbean men from a cultural and historical context. The men interviewed reported not being given much information regarding prostate health or prostate cancer awareness but explained how seeking answers and asking questions were not seen as the norm in their culture. A man's feeling of dignity was seen as culturally important and this feeling could influence how men would not seek answers to health care concerns due to not wanting to discuss private matters. Men who had spent their younger years living in Jamaica reported a limited knowledge due to health education and awareness in the country. Prostate matters were not generally discussed, so on arriving at the UK, knowledge was sparse. African Caribbean men were also looked upon to have a fear of cancer in general potentially impacting their uptake of provision and services (Nanton & Dale, 2011).

### **The influence of family and friends**

Family and friends were looked at as an important factor in the diagnostic journey of men in several areas. Family and friend recommendations for prostate cancer screening were often the catalyst for seeking help and subsequent testing (Ferrante

et al, 2011; Jones et al, 2013). Conversations with a friend or family member were also described as a catalyst in making some men interpret their symptoms as possible prostate cancer and act (Ferrante et al, 2011; Jones et al, 2013). These opinions were valued as important as the bond or relationship that had already formed signified to the men; they had their best interests in mind. When exploring family influences in more detail, several studies highlighted wives were pivotal in the decision-making process, pushing participants into making that first appointment with their doctor (Ferrante et al, 2011; Nanton & Dale, 2011; Shaw et al, 2013; Forbat et al, 2014). Wives were also seen to be influential in the uptake of screening and decision making along the pathway (Ferrante et al, 2011; Nanton & Shaw, 2011; Shaw et al, 2013; Forbat et al, 2014).

Conversely, not all men felt the pressure from family and friends affected them, reporting not wanting to give into it and even interpreting it as an irritation (Shaw et al, 2013). Symptoms were not discussed with anyone, and decisions were made alone (Forbat et al, 2014). However, pressure was sometimes given into, especially if due to an initial screening decision (Shaw et al, 2013). Men reported feeling they were in control of the final decision made regarding their health; nevertheless, they would consider a friend's guidance when it came to a primary care visit (Shaw et al, 2013). Observing other family and friends who had personally experienced prostate cancer, or another cancer was seen to affect a man's decision to seek help. This observation generated further awareness and often an inner connection due to experiencing the same affliction (Jones et al, 2013; Shaw et al, 2013; Forbat et al, 2014). Observing these experiences or chatting to family and friends about their experiences with procedures, diagnosis and personal journeys often interacted with their decision making to seek help. Whilst others highlighted, they did not discuss their symptoms with anyone and made their own decision.

### **Screening investigations: harms and benefits**

There is currently no specific screening test used for prostate cancer in the UK. That is because the PSA test has been deemed to have a high sensitivity and a low specificity, so can produce false positives and false negatives (Lojanapiwat et al, 2014). It is used within the UK along with other investigations. This is not however the case in other countries in the world and due to the literature within this review

pertaining to other countries, views may differ. Awareness of overall screening investigations and their potential harms and benefits was a popular theme prevailing from the literature. The perception of the potential harms and benefits of having a PSA test were varied and a range of responses presented themselves. The use of education for increasing a man's understanding of PSA screening was important for men. It was a tool to help promote awareness and informed decision making (Matthew et al, 2011; Anderson et al, 2013; Grogan et al, 2017; Partine et al, 2017; Yu Ko et al, 2018).

A conversation with a doctor or recommendation was often a driving factor for many in their decision to have a PSA screening test, even if the potential harms or benefits were not discussed first (Ferrante et al, 2011; Anderson et al, 2013; Yu Ko et al, 2018). Views however varied and doctors were also looked upon as an emergency option with some patients only making an appointment to see their doctor when they felt ill and were experiencing many symptoms (Conde et al, 2011). Participating in screening through the use of a PSA test evoked many emotions and could impact wellbeing. For some it was seen as a benefit, offering a sense of control, along with a greater feeling of security and peace of mind (Mathew et al, 2011; Anderson et al, 2013; Dreidger et al, 2017). An alternative view showed how the screening test could increase harm on mental health by increasing anxiety and worry before, during and after which would cause men to postpone their PSA test or delay having another (Conde et al, 2011).

When exploring the risks of a PSA test views represented in the literature were also diverse. An acceptance of risk was seen as beneficial over doing nothing at all even if displaying no symptoms (Mathew et al, 2011; Anderson et al, 2013; Dreidger et al, 2017). The PSA test was referred to as a 'value added item' by some men, whilst other men looked at it as a responsible way of taking care of themselves (Yu Ko et al, 2018). Screening by choice also brought other screening benefits as diagnosing prostate cancer at an earlier stage meant it could be treated quicker, enabling a longer life expectancy (Anderson et al, 2013; Partine et al, 2017). There were however several risks noted which could increase harm physically and mentally. Feelings of anxiety and worry especially when it came to waiting for appointments or results could lead to stress which could affect other comorbidities and impact daily life (Mathew et al, 2011; Dreidger et al, 2017). Test results also evoked discussion

as false positives were a possibility. A false positive could result in unnecessary further investigations or tests increasing chances of further health complications and health issues (Ferrante et al, 2011; Partine et al, 2017; Dreidger et al, 2017). Alternatively, a false positive test and the unnecessary further diagnostic tests that might prevail from the result still outweighed the overall further fear of a prostate cancer diagnosis for some (Dreidger et al, 2017).

### **Understanding and effect of procedures**

There are specific procedures used when undergoing the process of diagnosing prostate cancer and tend to be specific to primary and secondary care. A prostate specific antigen (PSA) test and digital rectal examination (DRE) examination are most used during the first part of the diagnostic journey along with urine tests and physical examinations. In secondary care, a biopsy and magnetic resonance imaging scan (MRI) along with bone scans and blood tests in varying orders tend to be the investigative procedures. Ways in which men coped with impending procedures and tests were mostly with acceptance (Mathers et al, 2011), however for a few men, these views were hazy, and they were unable to recall the order of their procedures or even the procedure name itself whilst being interviewed for a study (Mathers et al, 2011). There were however a range of reactions in relation to the procedures themselves.

The biopsy and DRE were noted as the tests that evoked the most emotion with reactions from feelings of anxiety, distress, unease and embarrassment (Mathers et al, 2011; Appleton et al, 2015; Grogan et al, 2017). The intrusive nature of some of the procedures caused awkwardness towards the HCP from the view of the patient, with one man moving to another general practice after the DRE procedure (Grogan et al, 2017). Physical effects of the biopsy and DRE were described as painful and invasive. The biopsy was reported as the worst part of the investigative process, with urinary retention, infection and discomfort being cited as post effects (Appleton et al, 2019). Other reactions to the investigations from men interviewed included the need to build up for the tests psychologically, although reiterating they would still have had the test conducted again if needed (Mathers et al, 2011). An alternative view saw men reporting feelings of nonchalance towards testing and procedures, stating they

were a necessary process, where important diagnostic information would be obtained in connection to their health (Mathers et al, 2011; Grogan et al, 2017).

### **Self-awareness and wellbeing**

A man's personal disposition often influenced their self-awareness and perception of their health and wellbeing (Matthew et al, 2011). Responses were varied and covered a wide variety of emotional reactions. Some men on their prostate cancer diagnostic journey felt vulnerable, uncertain and confused by their time under primary and second care resulting in withdrawing from others (Matthew et al, 2011; Appleton et al, 2015; Appleton et al, 2019). For others, the use of humour, wellbeing strategies and a positive mindset helped move their mentality to a brighter outlook (Matthew et al, 2011; Appleton, 2014; Yu Ko et al, 2018). Prostate cancer was even noted as not the worst cancer you could get (Matthew et al, 2011).

Talking to others about their diagnostic journey or emotional reactions was not always an option. Not wanting to feel a burden to others or unnecessarily worry a loved one was noted (Appleton et al, 2019; King Okoye et al, 2019). Views on a possible diagnosis pushed some men into not pursuing appointments or investigations as not wanting to know the answer (Ferrante et al, 2011; Shaw et al, 2013) or conjured thoughts of being irresponsible about not going to see a doctor with prostate health concerns especially with a family history of prostate cancer (Jones et al, 2013). Healthy behaviours were looked upon as protective factors (Conde et al, 2011; Ferrante et al, 2011; Matthew et al, 2011; Yu Ko et al, 2018). And this healthy outlook was even more important if there was a family history or a genetic risk of prostate cancer (Matthew et al, 2011). Alternatively, there were also views on behaviours that increased risk. A study of Latino men highlighted how a lack of sex or sexual promiscuity was believed to increase your risk of getting prostate cancer (Conde et al, 2011) whilst other suggestions included an increased risk with stress, smoking, alcohol and drug use (Matthew et al, 2011).

### **Summary**

Conducting and writing this literature narrative findings chapter has provided a greater understanding of the current literature in circulation relating to the specific topic of interest. It has supported the research question by adding depth and produced pertinent themes which are all relevant. Interestingly, each theme

interweaved seamlessly with others and helped illuminate the findings in other sections. A variety of factors were deemed influential when exploring **barriers that impacted help seeking**. A man's attitude towards wellbeing, health education, culture and history all created potential barriers. Healthy behaviours implemented by men looking after their wellbeing could be construed as a barrier as this could deter help seeking due to being viewed as a protective factor. Talking to HCPs or family and friends on matters that involved a man's pelvic anatomy or perineum were also regarded as demeaning and one that should be kept private.

**Relationships and communication** with HCPs were deemed as important. A good relationship with a HCP improved communication, increased feelings of being heard and listened too, which then promoted trust. The communication between a patient and HCP was impacted by the way information was provided and services offered. Having access to the right information and an understanding of the services along the diagnostic pathway was seen as a facilitator in influencing a man's decision making. A plethora of approaches towards the provision of **information and services** highlighted the importance of lay language to allow information to be understood and absorbed. The way information and services were offered also had the potential to impact a man's diagnostic journey. The significance of culture and history when exploring African and African Caribbean men's views was brought into the discussion when aiding how information was sought, understood and retained. Accompaniment by a family or friend to important appointments was highlighted as good practice, allowing a support mechanism to be put in place and increasing the chances of retaining pertinent information.

**Friends and family** were deemed to influence many parts of a man's pathway to diagnosis, however not all men discussed their journey with others. Decisions on screening, seeking health advice and recognising symptoms were all discussed, but not all men succumbed to pressure. Observing family and friends who had been through cancer journeys of their own propelled some men into thoughts on their own pathway of screening and investigations. **Screening investigations and their harms and benefits** were prevalent in numerous papers. The decision on whether to seek a PSA blood test was explored through the context of using educational resources and discussions with HCPs as decision aids. Benefits of screening were heralded as preventative and seen as a responsible way of taking control of one's

health. The risk of a false positive resulting in further unnecessary investigations was noted as a harm and a benefit. Harms to screening as alluded to include a decrease in wellbeing, exasperating worry and stress and possible health complications.

**Investigative procedures** were overall seen as a necessary process in the diagnostic journey with some accounts being vague on detail, the investigations undertaken and their order. A general consensus of acceptance and need were noted when describing their understanding of why the tests were being conducted. The biopsy and DRE produced evocative accounts, with recall of mental and physical repercussions due to the nature of the invasiveness of the procedures. Views of a **man's self-awareness and well-being** were intertwined throughout all parts of the diagnostic journey. Thoughts, emotions, and beliefs varied amongst the papers and changed dependant on intervals along the pathway or thoughts on taking the journey. Emotional responses ranged from a positive outlook to one of fear of the unknown. An importance was placed upon taking charge of your own health, especially if there was a history of prostate cancer in the family.

This review has provided evidence that exploring the factors, interactions and experiences that may influence a man's pathway to a diagnosis of prostate cancer will be beneficial. This study has the potential to add knowledge to the current body of literature and offer or build on previous insights and findings of other papers exploring the topic in a similar manner. There is a gap within the literature from UK and Welsh studies focussing on men's views on their prostate cancer journey. This is important to collate, as health services and screening differ between countries. Data from this study has the potential to influence policies and procedures related to not only a prostate cancer diagnosis, but also awareness on early diagnosis and factors associated.

A reflection of some of the processes undertaken to produce the literature review will now be provided to allow the reader an opportunity to understand more about the researcher's mindset. Following the reflection, a new chapter will commence dedicated to the methodology undertaken for this study.

### **Literature review reflection**

Evaluating my literature review process with reflection in action, along with reflection on action was an important process. I have only conducted a literature review once

before, whilst as an undergraduate student, so I was very aware from the offset that this would be a learning curve and a chance to hone and improve my skills. I am aware that my personality appreciates structure and planning, so initially finding a book I could utilise in the same way as an instruction manual was the best decision I made. It helped provide focus and reigned in my thought processes when I felt my own negative self-belief system turn on or felt overwhelmed with the task in hand. My mind can often catastrophise if faced with a vast number of tasks, so finding ways to break tasks down into tangible chunks, supports my work and wellbeing.

The most time intensive section of the literature review process was identifying my search strategy. These experiences were reflected in how many diary notes I felt compelled to write during that phase of the review. I debated my decisions, resulting in several strategy amendments and spent hours deliberating my work. Each database search strategy was executed differently and changing one small aspect, yielded wildly varying results, often resulting in the literature search being inadequate. Balancing the decision to settle on a specific search criterion and not change any other aspects was an uncomfortable one. As a novice researcher, I felt my implementation needed improvement, however from insight I think I may never have been happy with it. My confidence grew when the searches undertaken started revealing informative literature. I debated the sparseness of this literature due to a preconceived idea of being inundated with fulfilling results, however I told myself this was a positive development as it showed research was needed in this area.

I was aware that reading and absorbing the chosen papers would help me understand the topic I was going to be immersed in for the next two years and provide a background. Reading the papers was also a time intensive and pertinent part of the review and I found myself having to re-read several sections many times relating to methodology or findings to grasp the context. Content was thought provoking but also confusing at times. The CASP evaluation tool was extremely helpful in providing structure and I found systematically going through each paper and recording my observation in my summary chart pivotal. My aim was to provide an unbiased and balanced view of the literature but on reflection I feel my personal insight will have influenced my perspective. It did however cement the decision I had made to conduct a qualitative study, giving me some peace of mind.



Writing the narrative review was made a lot easier due to the amount of time I had put into the critical evaluation of each paper, however my estimation of the hard work and focus required for this was warranted. Once the narrative themes were derived, they provided me with structure, and I made the decision to colour code each theme and systematically make my way through each paper highlighting text relevant. Following this process, the writing stage was a lot more straightforward. Looking back, it probably would have made more sense to immerse myself in each paper and cover all themes before moving onto the next. However, from an overall reflection on writing this thesis, I seem to make tasks a lot harder than they need to be.

The decision to anchor my literature review learning journey to a specific book, created a rewarding and instructive experience. Advice from other academics provided further insight and a critical viewpoint, however confusion often arose from the various opinions given, resulting in me questioning my decisions on several occasions.

I felt a sense of accomplishment and satisfaction when I had completed the literature review and written the findings, however the process has illuminated the importance of practice and experience. I feel my organisational skills helped with the review, as I could implement timelines to adhere to, however these timelines also allowed procrastination in certain areas such as creating the charts, when time could have been better spent in other areas. In an obscure way, I look forward to undertaking another literature review and learning from past mistakes. From my perspective, there are many things I could have done differently to improve the process; however, I feel this learning process was a rewarding one. Developing a greater understanding on various search strategies within different databases will be a topic I endeavour to spend future time on. Future experience will illuminate search strategies that will offer key results and practice will allow simplification of processes. Further background reading of other literature reviews, future training opportunities and support and guidance from more experienced members of staff or peers will also help implement these improvements and this is something I hope to put into practice in the future.

## **Chapter Three**

### **Methodology and Study Design**

## **Methods**

As a result of the gap in research, identified by the literature review exploring men's views and accounts of their prostate cancer journey within the UK and Wales, the method proposed was qualitative and exploratory. The preparation to conduct this study will now be presented. The preparation process within a studies' method supports a researcher and provides a structured approach that can be catalogued, verified and described to others (Nowell et al, 2017). This methods chapter aims to demonstrate credibility, transferability, dependability and confirmability, all signs of a robust research study (Bengtsson, 2016; Nowell et al, 2017). The chapter will be broken down into easy-to-read sections and in chronological order to highlight the preparation and processes undertaken to conduct the study. It will provide transparency on the methodology followed throughout, as a clear rationale can support the justification behind the methodological processes followed, enhancing its robustness (Austin & Sutton, 2014). The chapter will commence with an explanation of the research methods and the creation of the research question and finish with the identification of themes from the study findings. Supplementary documentation will be highlighted throughout and can be found within the appendix to show processes, resulting in a clear audit trail explaining the rationale for decisions made (Gale et al, 2013; Nowell et al, 2017).

### **What is qualitative research?**

Qualitative research can be used as a scientific method when undertaking research and evaluation (Sale & Thiellke, 2018). It can also be looked upon as a holistic approach, placing importance in the participant and their view of the world and life experiences (Morse, 1991). Defining qualitative research is important, as it is pertinent in providing the researcher with the foundations of the method to be used and the practicalities and theory that underpin it. This is imperative for the novice or early career researcher and several text-based books were read to establish the research fundamentals behind this method and to add rigour to the study (Ritchie & Lewis, 2003; Polgar & Thomas, 2008; Braun & Clarke, 2013). Defining qualitative research is not an easy task due to either the methodological, ontological, or epistemological assumption it is founded upon (Spencer et al, 2003). Under these assumptions you will find varying characteristics such as techniques, schools of

thought, data collection methods, approaches or paradigms. To aid understanding, it can be beneficial to see qualitative research as an overarching consolidation of varying views with researchers and writers forming their own definitions or amalgamating from specific key elements (Ritchie & Lewis, 2003). Van Tassel & Novotny (2013) sees qualitative research as a method of understanding the social world we live in by learning about the factors, experiences, background and perspectives of participants being studied. Nowell et al (2017) describe it as a style of investigation which uses rigorous approaches to investigate human experiences. Whereas Braun & Clarke (2013) explain it in a simplistic form, involving a style of research using words as a quantitative researcher would use numbers. These words are further analysed in various ways, whereas numbers would be analysed following statistical methods.

Qualitative research data can be obtained through various means and place great focus on understanding the natural setting. Methods employed for understanding what, how and why can include focus groups, interviews, conversations, artifacts and observation (Ritchie & Lewis, 2003; Braun & Clarke, 2013). Data collection for this study will be conducted through interviews and explained further within the data collection paragraph. From the above definitions, it could be concluded that qualitative research was the most appropriate method to use within this study when trying to address the aims and objectives of this study and understand the why and how, due to the exploration of meaning. The words spoken by the participants within this study would share their experiences and views of their journey and this was imperative in answering the research questions, in comparison to collating quantitative data. Qualitative methods offer an opportunity to not just gather statistical data or a single answer from quantitative structured questionnaires but allow for conversations and exchanges. These exchanges can enable a researcher to gather meaningful data by exploring a participant's personal experience or view using not only spoken language, but written, drawn images and body language within a specific setting (Korstjens et al, 2017).

## **Study design**

The world view of a researcher will inevitably affect the overall research study design, from how the question is shaped, the collection of data, analysis and

reporting of findings (Austin & Sutton, 2014; Korstjens & Moser, 2017). The practical elements of this study are underpinned by methodology. The research questions for this study have aimed to understand how men have experienced their prostate cancer journey by hearing the accounts of their interactions, experiences, and perspectives. To do this, an interpretivist approach was required as men's personal accounts were needed to be heard through semi structured interviews to gain richness. Interpretivism looks for meanings and behaviours in social interactions and recognises that a person's knowledge and their reality of the world is socially constructed (Eliaeson, 2002; Chowdhury, 2014).

The study consisted of a qualitative, exploratory design often seen in qualitative research (Korstjens & Moser, 2017), utilising a sample of participants that had been previously identified in the survey of the larger overarching study. The research question was formulated using visual mapping techniques to thought shower the topic and refined through the use of the PICOT and SPIDER tool as explained within the literature methods chapter. These tools helped provide focus and fine tuning. The research question and its aim and objectives were kept in the forefront of the researcher's mind throughout the methodological process to help ensure the question is answered to the best of the researcher's ability (Doody & Bailey, 2016). To support this strategy, the research question was highlighted in prominent places within the written work, throughout the methodological process and used as a reminder prompt. The part time, two-year time frame for the conduction and write up of the study was discussed with supervisors and deemed feasible.

### **Data collection methods**

There are several data collection methods within qualitative research, and these can include various interview techniques and focus groups. There are advantages and disadvantages to these methods, and these were taken into consideration when looking at the participant sample and topic of this study. Deciding on the choice of qualitative method to use for this study was considered. Due to the sensitive nature of the topic, men may not wish to divulge these personal matters in front of others and the geographical nature of Wales may have meant some men had far to travel. For these reasons, focus groups were not deemed appropriate and interviews were chosen as the data gathering method. Interviews can be structured, semi structured

or unstructured in nature. A structured interview will often have precise questions with pre-determined responses allowing for consistency but also rigidity (Austin & Sutton, 2014). An unstructured approach is predominantly led by the participant; however, the interviewer may have some overarching topics they would like discussed (Braun and Clarke, 2013). These two approaches would not have been appropriate for this study as to answer the research questions, some structure was needed, but not enough as to lead the participant in only one direction. Semi structured interviews can allow a researcher some flexibility in comparison. Often starting with a more specific question but allowing for participant accounts to adapt the flow of the interview (Austin & Sutton, 2014). This study needed that flexibility to allow the men from each of the three categories to be able to share all aspects of their journey to diagnosis and focus on the elements that impacted them the most. Interviews can also be delivered in person, by telephone, email or online. Due to the age demographic of the sample, it was important to take into consideration, barriers such as online accessibility and hearing. For this reason, semi structured interviews were chosen and would be delivered in person at a location of the participant's choosing.

Due to the sensitive topic of prostate cancer explored in this study, it was felt that this method could further encourage the men to talk in more depth about their experience, divulging more detail. However, the empathy of the interviewer and the rapport created between researcher and the men interviewed was paramount as issues can result in participant distress or withholding experiences and this was something important to remember within this study. Semi structured interviews offer an opportunity to gather rich data through understandings, experiences, beliefs and perspectives. From a methodological perspective however, they can also be time consuming in terms of preparatory processes, delivery and transcription and these elements will be further explored.

## **Approvals**

Initial patient recruitment procedures were facilitated by utilising the health and care research workforce (HCRW). This process was enabled by following the rigorous process set out by HCRW which included the completion of schedule of events and

activities forms, research and development approval for individual sites and ethics approval.

## **Research and development**

A research passport was obtained to follow protocol requirements for research delivery by the National Health Service (NHS) and subsequent hospital research and development (R&D) departments. The passport allows honorary access to NHS sites through a letter of access (LOA) which is created by each health board upon receipt of the research passport. A research passport (appendix 6) is a stringent requirement by research and development departments to ensure a set of checks are conducted into the researcher's background to allow them to deliver their research (NHS, 2019). Good Clinical Practice training is a further prerequisite for research delivery within clinical and non-clinical research and was also completed. It ensures an internationally ethical and scientific standard towards research is delivered (NIHR, 2021).

## **Ethics**

Before the study could commence, ethical approval was required. Stringent ethical processes are put into place for the preparation, conduction and delivery of research and follow the principles of beneficence, non-maleficence, autonomy and justice (Silverman, 2016). A researcher should always aim to act professionally throughout a study and follow all ethical standards and processes (Green et al, 2007). It is important to note that ethical standards within a study do not stop upon approval, and as such, ethical integrity should and was followed throughout the research process. Due to the study being part of a larger research project, Bangor University school ethics had already been sought and granted. Ethical approval from the Leicester Central Research Ethics Committee (REC) was the next step in the process. The REC helps safeguard participants who may take part in a research study and the committee that monitors and approves studies consists of a range of professionals and lay personnel (Health Research Authority, 2021). Participants need full awareness that they are part of a research study and what that study entails, along with their rights (Edwards & Holland, 2013; Silverman, 2016) and a researcher has an obligation to protect a participant's identifying information even if the participant does not feel there is a need to do this. All patient facing

documentation for the interviews was sent to the committee for their perusal and feedback. The creation of the documentation was time intensive, and several versions were created before submission to the ethics board. Upon submission, the ethics board required further amendments, and these included adding a patient advisory and liaison service list to the patient information sheet, along with data security clarity. Once REC approved, these documents were further sent to the Health Research Authority (HRA) for final approval. To ensure any participant identifying information is secure, any information obtained from the interviews was kept following general data protection regulations (GDPR) and on a Bangor secured laptop and locked cabinets.

Upon successful completion of all documentation, access was granted for the study to commence. Meetings were held either remotely through online conferencing tools or face to face with the HCRW research nursing teams that were recruiting the men to complete any relevant documentation, explain the interview phase and answer any queries. These meetings provided further opportunity to facilitate open dialogue and build rapport with the nurses which proved advantageous when needing to make initial contact with the participants.

## **Recruitment**

Before recruitment could take place, a sampling strategy was determined. All participants within phase one of the larger overall study were recruited due to their eligibility. Each participant had to be over the age of 18 years of age, diagnosed with prostate cancer within the last six months and able and willing to consent and reside in Wales. For the purpose of this study (phase two), the criteria needed to be specific, with participants purposively chosen. Purposive sampling is a common concept used within qualitative research and can help a study gain access to the richest and most pertinent data relating to the study question, ensuring participants are appropriate for the research study (Richie and Lewis, 2003; Emmel, 2013; Plainikas et al, 2015).

From the participant's questionnaire responses in the survey, a sample of men who had reported either an asymptomatic, prompt, or late diagnosis were identified for interviews. This strategy was used in order to ensure a sample of men from each group within the interview data. These categories were originally decided upon to



provide a sample that reflected different starting points in the prostate cancer journey, and to create an opportunity to capture asymptomatic men with positive PSA results. This was based on the understanding that both a prompt and late diagnosis could potentially be symptomatic or asymptomatic at first. Men were not excluded from the interviews on the basis of these groups, rather the groups were used to ensure a representative sample of men from across Wales who reported differing diagnostic intervals. However, these groups proved to be too simplistic during the analysis stage as the complexity of men's accounts was not accounted for within these categories. The criterion for these three-time interval brackets were derived from two sources. The Aarhus statement (Weller et al, 2012) created a checklist to support researchers in their accuracy and transparency in work relating to early diagnosis and intervals and this was discussed within the supervisory team. Further work from Hansen et al (2011) brought recognition, data, and subsequent understanding about the specific time intervals for prostate cancer through patient and system delays and was also discussed. Guidance for researchers on how to measure specific diagnostic intervals and key time points has the ability to support further research and provide consistency for evaluations (Coxon et al, 2018). These three diagnostic criteria groupings were chosen, along with the aim of a sample geographically representative of Wales and used as headings for the sample matrix, with further variables added to inform the decision making. Matrices can be used to organise, display and help make sense of various types of data along the methodological process and can be beneficial when considering samples. They are used within qualitative studies but also commonly seen within quantitative research (Verdimelli & Scagnoli, 2013).

An adequate sample size was next to be considered. Sample sizes are often smaller than what would be seen within a quantitative research study sample due to the richness of the data (Dworkin, 2012; Priori & Adamson, 2014), however sizes are often debated. Miles and Huberman (2009) discuss how more than 15 participants can complicate the analysis process, whilst Bertraux (1981) states 15 should be the smallest sample. Creswell (2006) offers a wider range of between five to twenty-five being acceptable. Size can also be determined by various other considerations. Data saturation can be seen as a prerequisite of when to complete data collection (Austin & Sutton, 2014; Fusch et al, 2015; Saunders et al, 2018) and this is often considered

when the research team observe no new data coming from the sample. Originally upon discussion with the supervisory team, it was envisaged the sample size would consist of 20-30 participants, allowing for consideration of data saturation and time. Constraints such as time can influence a sample size (Edwards and Holland, 2013) and on commencement of the interviews, it was deemed unobtainable to recruit and interview 30 patients in the time frame allocated. A further supervisory feasibility discussion changed the total to 20. Subsequently 21 participants were recruited to the study through the support of the HCRW nursing team. This provided an opportunity to capture a wide range of recollections of different men's journeys and was still considered an appropriate sample size.

A matrix table was created to display the sample of participants that would be approached for recruitment, populated with the sample and utilised to monitor issues with recruitment. Variables within the sample table were displayed in horizontal and vertical subject lines (appendix 7). The two most important variables were their diagnostic journey grouping and the health board they were treated under. These would indicate whether they lived in North or South Wales, ensuring a representative sample and a journey classification of prompt, late or asymptomatic. Further demographics such as age, family history of prostate cancer, work status, home life and comorbidities were added, to provide an in-depth profile. When the sample table was populated, it became apparent a large proportion of participants were from Betsi Cadwaladr University Health Board (BCUHB) in North Wales, in comparison to the other health boards. This was envisaged due to barriers with travel and BCUHB questionnaire returns far outweighed other health boards in terms of numbers on phase one of the overall study. Before patients could be approached and invited to interview a wellbeing check needed to take place. This was supported by the research nurse who initially recruited the participant to phase one of the larger study. A phone call was made to discuss the patient's wellbeing and ascertain whether they were well enough to be contacted. Two potential participants were found to be unwell due to an advanced stage diagnosis and ineligible. A further two potential participants were then chosen.

The next step was to post out the information pack to the selected participant's home address. These patient facing documents were made into a pack and consisted of an invitation letter, a patient information sheet, a reply slip, and self-addressed envelope

(appendix 8). The reply slip was only to be sent back if the participant did not want to be contacted for a further discussion on the interview process. Two consent forms (appendix 9) were also created to go into the pack and these consisted of one for the participant and one for an additional contributor just in case another family member was present. During a supervisory discussion, it was decided that these two forms would be left out of the posting pack and completed on the day where consent could be decided upon a detailed breakdown of the study and an opportunity to ask questions. A two-week time lapse was put into place between the posting out of the pack and further contact, to allow the reply slip to be returned. During the two weeks wait, there were no reply slip returns indicating all participants were happy to be contacted. The chosen men were then contacted by telephone. No contact was made with three participants, so a further three were subsequently added to the sample. Phone calls consisted of introductions, a study breakdown and what to expect if a decision was made to take part. All further 21 participants approached, agreed to take part in the study and the sample table was subsequently adapted and a final version created. During the recruitment process, steps were being put into place to plan the practicalities of the interview process and complete the final documentation needed to conduct the interviews.

### **Creation of topic guide**

The topic guide was the last part of the documentation needed for the interview process for this study to help with the semi structured approach and one that was given careful consideration and time. A topic or interview guide is an integral component of the qualitative process, and often deemed essential when interviewing participants (Ritchie & Lewis, 2003). It helps aid the direction of the interview, ensuring the overall aims and objectives of the study are kept to the forefront of the interviewer's mind and contributes towards the trustworthiness of a study (Richie & Lewis, 2003; Kalio et al, 2016). It further provides transparency as a document, highlighting the research process, and supporting ethical validity (Edwards & Holland, 2013). A topic guide can also support the interviewer by creating a basic format to follow for each interview, providing uniformity in opening questions (Kalio et al, 2016). This supports the principle that each participant will be interviewed similarly, however still allowing flexibility if needed (Braun & Clarke, 2013). It was important that this study provided this conformity to ensure responses from the men

came from the same format. From an early researcher perspective, the topic guide was also a crucial memory aid within this study, especially during the beginning of the interview process where nerves were rife. It provided assurance and allowed greater attention to be given to the interview responses from the men.

There were several things to consider when undertaking the creation of the topic guide and the format was achieved through supervision meetings and reading appropriate qualitative research books (Ritchie & Lewis, 2003; Braun & Clarke, 2013). The study aims and objectives were added to the top of the guide to aid clarity and reiterate the focus of the research (Kalio et al, 2013). Next, an introductory section was written, ensuring appropriate introductions would be made, the outline of the study provided and the purpose of the interview. This section further explained what was to happen during the interview, timing, confidentiality and participatory rights. It was important this section was uniform for all interviews, as it covered vital information pertaining to the interview structure and patient autonomy. The researcher made sure the information sheets had been read and understood with questions invited and written consent taken. Before the interview began focusing on key sections, an ice breaker question was used first to generate conversation and build rapport. These types of questions can allow a participant to relax and conversation to flow easier. For the majority of interviews this was a successful tactic, however for a minority, the conversation veered off track, resulting in longer interviews and on the spot thinking to steer interviews back to the topic.

The main topic guide's structure (appendix 10) consisted of three key sections, each separated into sub-topics displayed as bullet points. These bullet points were further broken into headings, with the aim of these headings to be covered within the interview. The order of the key sections was discussed in a supervisory meeting, and it was decided they would follow the natural journey most men would follow on their route to diagnosis, consisting of first symptom or no symptom, the primary care journey, the secondary care journey and then overall experience. The topic guide concluded by exploring the participants overall experience of their journey to diagnosis, along with the positive and negative experiences and their ideas for improvement (appendix 11). This question helped to bring the recorded interview to a natural close and allowed the participant to add anything they had not considered earlier. These types of closing questions have been noted to facilitate further

discussion and can produce information rich data not previously discussed within the interview (Ritchie & Lewis, 2003; Braun & Clarke, 2013). The data process would then be explained, and a welfare check completed to monitor the participant's mental wellbeing, due to the sensitivity of the topic. If any medical questions arose, the participants were advised to speak to their specialist nurse and further signposting was given if necessary. Two participants became upset during their interviews, so extra time was spent with these men after the interviews to support their wellbeing and ensure they were well enough to be left alone. After the first interview had been conducted, a supervisory meeting was held to listen to the recorded interview and allow for reflection and feedback. This process resulted in some extra words being added to the topic guide (appendix 12) to serve as tips for further probing into answers. Probes can facilitate a deeper exploration into participant answers and generate further discussion beneficial in addressing the research question (Braun and Clarke, 2013).

### **Interview practicalities**

Preparation for fieldwork involved not just practical, but also wellbeing elements. From a practical standpoint due to long journeys, a vehicle with business insurance was needed. From a pragmatic perspective, thought was given for travel dates, route planning and timing between interviews. Possible travel disruptions and longer interviews also needed to be considered. It was imperative that a long journey was logistically thought out to make the best use of time. From a wellbeing perspective, rest and mental resilience needed to be factored in between interviews. This was to allow mental and physical rest time and nourishment. Braun & Clarke (2013) recommend not conducting more than one interview a day to protect a researcher's wellbeing and keep interviewing standards high. Due to geographical and financial constraints, this was not always able to happen due to some interviews needing to be in block bookings and a specific order. Travel in South Wales and rural North Wales resulted in three interviews needing to be completed in one day on two occasions.

The choice of interview location was left to the participant, to make interviews less intrusive and more comfortable for the participant. Twenty of the interviews took place at the participant's home and one at a hospital after a patient's appointment.

The Bangor university lone worker assessment documents were discussed and subsequently to help control risk, all interviews were conducted during work hours to enhance safety and support monitoring. Addresses, contact details and times of each interview were provided to supervisors, along with whereabouts and researcher status before and after each interview. Due to the participant sample being predominantly sixty years and over, the majority of men were retired, allowing interviews to be conducted during the day instead of an evening.

### **Interview technique**

An interviewer and participant will interact socially, and these interactions need to be considered carefully and with sensitivity (Green et al, 2007; Korstjens & Moser, 2017). To help with the aim of creating a sensitive interview technique within this study and a relaxed interview environment, mock interviews were first conducted. These sessions provided an opportunity to iron out any problems with the topic guide, pre-empt unanticipated answers and to make adjustments if needed. It further allowed practical issues such as managing the audio recorder, active listening and reading of the materials to be tested. Pilot testing can be conducted internally and within the field (Kalio et al, 2013) and this can include peers and patient and public involvement (PPI). Interviews were practiced with a colleague and two family members who had been through a prostate cancer diagnosis, as time constraints did not allow PPI to be involved. The interaction between the researcher and participant will not only consist of verbal cues but body language, facial expression and active listening; with all shaping the data (Edwards & Holland, 2013; Bengtsson, 2016). For this reason, it is advised to practice interview techniques with peers or others to help improve the interview process and allow observations to be made (Ritchie & Lewis, 2003; Braun & Clarke, 2013; Edwards & Holland, 2013; Kalio et al, 2013).

Memorising the introduction through practicing the mock interviews, provided added security and allowed further focus to be placed on building rapport by increasing eye contact and relaxed body language. An interviewer will have their own personal outward style, bringing in empathy and personal values into an interview, inadvertently influence a participant's response (Braun & Clarke, 2013; Korstjens & Moser, 2017). For these reasons, clothing was also considered, and a smart, casual attire adhered too, to show professionalism and approachability. When considering

empathy and personal values, awareness was given to the many years' experience of another work role as a life coach. This experience was deemed an asset, as both roles concentrate on the participant, hearing their views and take on a holistic approach. The supervisory meeting that explored any adjustments needed for the topic guide after the first interview, also focused on the interview style. This provided valuable reflexive time and resulted in adjustments being made with timbre, active listening and body language. These reflections are provided in further detail within the reflexive chapter.

### **Analysing the data**

There are various ways to conduct data analysis when undertaking qualitative research and these include Interpretative Phenomenological Analysis, Grounded Theory, Discourse Analysis, Thematic Analysis and Framework Analysis. It was decided that Thematic analysis would be appropriate for this study, using the framework method as an organising tool. Thematic analysis is suitable for an early career researcher due to its flexible nature and clear structure, helping build valuable experience in data handling and coding (Green et al, 2007; Nowell et al, 2017). It also helps derive answers from various data sets and identify themes (Braun & Clarke, 2013). The specific Framework method (Figure 5) created by Ritchie and Spenser (1994) and framed into a figure by Johnson et al (2017) was used to manage and analyse the data yielded from the 21 interviews. This method was originally created to support the implementation and development of social practice and policy but is now commonly used in many types of health research (Gale et al, 2013). It can also transform large quantities of data into an organised summary, providing clarity for the researcher (Erlingsson & Brysiewicz, 2017).

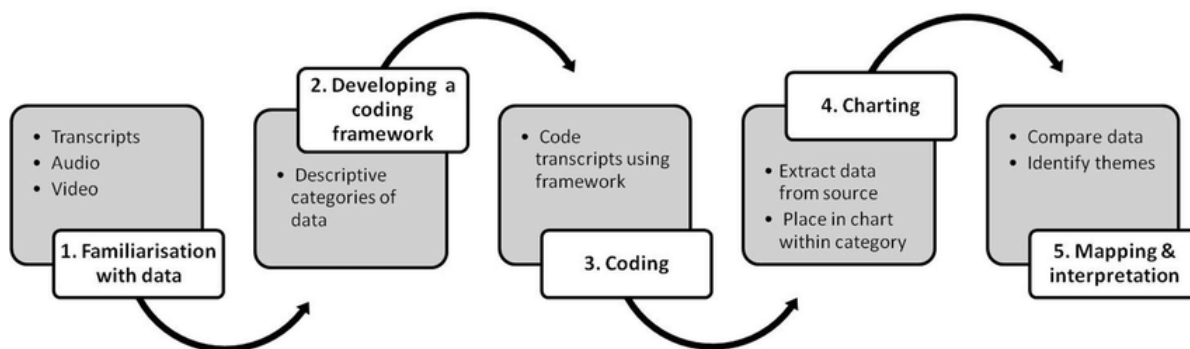


Figure 5- Five-step process in Framework Analysis, based on Ritchie and Spencer (1994) and adapted by Johnson et al (2017)

## The framework approach

To support the methodological process undertaken when using the framework approach, notes were taken during and after each supervisory meeting along with reflective writing pieces that interrelate with the steps. These have been used to inform the method write up and are expressed within the reflexive piece. The following paragraphs will provide a breakdown of the data analysis using the five steps outlined in the figure as headings for clarity.

### Stage one- familiarisation with the data

Before data analysis could commence, the 21 interviews were transcribed by a professional transcriber (appendix 13). Qualitative analysis is often conducted using transcripts (Braun & Clarke, 2013) and due to the study having a budget for professional transcription, it was deemed important to improve quality and consistency. Upon further discussion of the interview data, it was decided to not use any of the information collated from the additional contributors recorded within 8 of the interviews. It was felt this would take the focus away from the research study's aim of understanding the experience and interactions of men and their personal prostate cancer journey. To support accuracy, a sample of the transcripts were read



over to check for transcriber discrepancies and a random transcript re checked by listening to the original audio recording. The benefit of re listening to interviews is their accessibility post interview and can highlight subtle changes in the tone or timbre of a participant's voice, supporting the analytic process (Edwards & Holland, 2013). To further support the familiarisation with the transcripts, which is often considered a prerequisite of the analytic process (Green et al, 2007; Gale et al, 2013; Braun & Clarke, 2013; Erlingsson & Brysiewicz, 2017), the transcripts were read through along with notes made during the interview process itself.

The next step in the familiarisation process was to systematically read each transcript again and write down observations on post it notes relating to any factors, interactions, behaviours, thoughts or feelings described by the men. This lengthy process can help nurture ideas (Green et al, 2007) and resulted in the creation of over 200 written notes (appendix 14) and provided the initial information from which subsequent ideas were formed. The analytic end process of identifying themes from data within transcripts can be an intimidating prospect (Austin & Sutton, 2014), however one that needs to be done methodically and rigorously. This large selection of coloured post it notes were next collated into groups (appendix 15), highlighting repetitive observations and similar factors and points of interest. From a conceptual perception, the post it notes were looked upon as sheets and the process of sorting, as populating a filing cabinet. This process allowed the raw data to be seen from an alternative perspective and ensured the analytic process was kept grounded in the data. During this process it became apparent that the three categories assigned for the purposive sample were not as useful as they were originally thought to be as they did not account for the complexity of the men's own accounts of their journeys. The accounts were found to be too intricate and personal in nature to be classified in this manner.

## **Stage two- developing a coding framework**

The next step was to record these observations and produce new groups through written mind maps (appendix 16). Real life health stories can be emotional, complicated and messy (Gale et al, 2013), so the visual mapping helped simplify the data interrogation task by highlighting ideas, patterns and irregularities within the data that may be important when considering the research question. Supervisory

reflection meetings supported this initial process and the subsequent stages along the framework method by providing valuable feedback, allowing for reflection and reflexivity throughout. Reflexivity should be considered not only individually, but also collectively and throughout all stages of the research process (Barrett et al, 2020). Due to two family members going through a prostate cancer diagnosis and observing their journey, careful recognition was given to potential researcher bias and how this may impact how the data was viewed. A researcher's in-depth role within a qualitative study is looked upon as a fundamental part of the research process and not one that is expected to be split (Galdas, 2017). However, a researcher's own recognition of their values, background, opinions or potential bias can help provide transparency and is an important aspect to consider along with other study variables (Austin & Sutton, 2014). There were no preconceptions made regarding the data and a reflexive diary and notes (appendix 17) were written throughout the methodological process to support this. It was important to note that the descriptive categorisation of the data from the transcripts is where the coding would be derived from, however researcher observations and reflections were a supportive element.

Coding helps a researcher organise their data by labels, condensing into a more tangible size, with codes being matched to create groupings of similar ideas or concepts (Gale et al, 2013; Erlingsson & Brysiewicz, 2017). To ensure the coding process was focused on the research question and its aims and objectives, these sentences were written on A3 paper and placed in a prominent position throughout the framework analysis process. Immersion was supported by regular supervisory meetings to monitor progress and during this process, extra time was given to dwell with the mind maps, the topic guide and any other information deemed pertinent. This process is looked upon as part of conceptual scaffolding (Veale & Keane, 1992) as it can provide a base in which further interpretation can be teased out over time.

Coding often pushes the researcher to start making decisions with the data they have (Green et al, 2007) and further supervisory meetings were held, to support these decisions and create the coding framework. Headings for each potential framework section were an important element to consider and these were created ensuring they allowed the content of the data groupings to be organised, described and shared. Consideration was given to observations that were not regularly shown within the data as these less popular ideas may still have been pertinent within the

research (Buetow, 2010; Erlingsson & Brysiewicz, 2017). Several versions of the coding framework were created and adapted before the final product was produced (appendix 18). A small sample of transcripts were used when testing the second version to check for discrepancies and gaps in the data noted. Further changes were made to headings when clarity was needed. Version 3 resulted in some coding labels being moved or changed. To test the veracity of the framework, nine transcripts were mock coded, and a tally taken to observe popular and unpopular codes. Some coding headings were collapsed after this process and the final fourth version was subsequently created.

### **Stage three- coding**

The coding framework was created and consisted of seven main headings; symptom awareness, decision to seek help, route through primary care, PSA testing and relevance, route through secondary care, external influences on decision making and potential help, support and services. Under each of these headings, five to seven codes were added, resulting in the 32 overall codes within the framework. An 'any other issues' code was supplemented under each heading to allow for unanticipated observations to be noted. Each transcript was coded in full before starting the next, systematically reading through each page. Each sentence was given its own code dependent on content and if queried, were given two with a question mark to allow for further consideration during the charting process. Comparisons of the data with the codes and vice versa is an imperative part of the coding process (Maher et al, 2018) and one that took time and focus. A tagging process to support the charting was also put into place with a Q, QQ or QQQ written on important lines of speech that could be prominent in highlighting the code or used for quotes further into the analytic process and writing stage. This time intensive process lasted several weeks to ensure each line was carefully considered and labelled correctly.

### **Stage four- charting**

The process of charting the data into the coding framework described above involves the creation of thematic charts and is deemed a significant feature of the framework method. It utilises rows to display cases, columns for codes and cells to populate the data in a summarised format. The charts (appendix 19) were created in Microsoft

excel to provide a structural matrix format and allow data to be inputted efficiently. This matrix chart structure also provides an easy way to display data for visual purposes (Gale et al, 2013). The chart's creation had no hierarchical structure, however the coding process observed that some codes were highlighted more than others, creating larger amounts of text within certain cells. A demographic page was added to the charts, as this would be used to further support the interpretation process (appendix 20). To ensure general data protection regulation (GDPR) compliance and participant anonymity, names of participants were removed during the creation of the transcripts and the men were allocated numbers instead. These numbers were used for the chart rows with further demographic information populated, including age, ethnicity, diagnostic category, health board, location, additional contributor present, interview location, work, Welsh index multiple deprivation score, household living status and any comorbidity recorded.

The seven charts mirrored the coding framework and overall consisted of 21 horizontal lines per page and 5-7 columns. Overall, 39 columns were created, and each column was methodically populated over several weeks. The 'any other issues' column was further used to add any observations noted when charting. Each transcript was read through from cover to end, one by one, populating the cells dependent on the code shown. The charting procedure requires balancing the need for maintaining the original data's meaning, whilst reducing the size, so it fits neatly within the cells (Gale et al, 2013). Recognising the depth of data needed for the charts was troublesome and under or over summarising found to be a balancing act. The tagging process which is often used when charting (Gale et al, 2013) was utilised within this study and is also displayed within the cells, using the Q labelling previously discussed and page number. This allows the researcher to go back to a specific page within a transcript with ease and highlights a pertinent quote. Words were also shortened, and abbreviations used to create shorthand. Populating the charts took time and was completed over several weeks. This process was also found to illuminate potential concepts, ideas and connections that would be looked at during the mapping and interpretation stage. The populated charts were then sent off to be printed in A3 to allow the mapping and interpretation process to begin.

## **Stage five- mapping and interpretation**

The mapping and interpretation stage allows the researcher to make their way systematically through descriptive and explanatory stages to help provide accounts of the data. Once the mapping has been completed, the interpretation process then takes the data beyond the descriptive elements and into a richer interpretation process (Ritchie & Lewis, 2003). To complete the descriptive account, you must first take the step of detection, then categorisation and if deemed relevant the creation of typologies (Ritchie & Lewis, 2003). Upon completion of the descriptive account, explanations are then sought where patterns, links and associations in the data are examined. To allow for in depth interpretation, large chunks of time were allocated to the descriptive and explanatory stages, allowing for immersion in the data and time to reflect. It is imperative that a researcher immerses themselves within their data to support pattern identification, however distance is also needed to be able to observe the bigger picture and allow further concepts to grow (Braun & Clarke, 2013). The research question, aims and objectives were again written and displayed prominently to support the process.

To begin the detection process, a chart was read and skimmed for observations. Next, each column within a chart was read through in depth, allowing each participant cell to be considered in conjunction with others. This helped detect elements that may be relevant, such as perceptions, views, attitudes, experiences or behaviours of the men interviewed. These similar elements were highlighted in specific colours, allowing any patterns to be initially observed within each column. Written notes were also made within margins to tag points of interest or researcher thoughts. This detection process was then re-created until each chart had been analysed and a mind map created to transfer these observations into an easier to display format. This mapping phase offered further opportunities to reflect on the data, supporting the next stage. The mind maps were then used to enable further thought showers and start the categorisation process. Labels were added to the mind maps, noting potential categories, abstract opinions, and observations. Participant details were added to these notes to allow for future observations to be made and to utilise quotes and background information. All elements were given consideration and categories re organised several times.

Once the categorisation process was complete, links and associations were sought to aid explanation. Notes were made on possible connections or where categories or men intertwined or differed with their thoughts, views, perceptions, and experiences with analysis moving thoughts towards becoming more abstract and conceptual. Specific quotes were examined in detail, alongside possible explanations for these thoughts. Patterns or puzzles pertaining from the data were written down for further thought and supervisory discussion (appendix 21). Rows within certain charts were examined again to pursue these possible puzzles within the dataset and previous literature linked to the emerging findings.

Upon completion of this stage, a mind map was created with possible identifying themes and connections between the data (Appendix 22). Certain transcripts were interrogated further to deepen understanding and quotes added which helped highlight the emergent ideas. This mind map was used again along with any notes and reflections from the interview process to generate possible explanations. This worthwhile, labour-intensive process provided an in depth and rigorous method in seeking patterns within the three diagnostic categories the men were allocated to and any other linkages or cases that stood out. Further supervisory meetings provided an opportunity to discuss emerging ideas and puzzles and connections within the data set, resulting in provisional themes that were considered candidates. Seven themes were identified from the mapping and interrogation stage of the framework method and were felt to encompass the findings and provide the future structure required.

This methodological process has been described in detail to provide transparency in the methods used to prepare, conduct and analyse the study. It describes in great detail the processes and follows a structured format to show the robustness of the study and the detail. The Framework method has been used to analyse the data produced by the interviews and further described in detail to aid clarity and validity. The next chapter will provide the findings derived from the analysis of the interviews. The seven themes will now be used to catalogue and describe the findings in a logical and structured process. Certain themes will also have sub themes, as an aid to capture and organise smaller concepts.

## **Chapter 4**

### **Study Findings**

## **Thematic presentation of study findings**

This thematic, narrative presentation of the study findings will display the key findings of the study using themed paragraphs. A logical, structured layout to display the themes revealed through the analysis of data can provide a clear story to the reader and aid a natural flow through each theme (Rubin & Rubin, 1995). The findings will provide a narrative of the participant's recollection of their individual diagnostic journeys from first symptom or no symptom to subsequent appointments, investigations, and diagnosis. Six thematic sections are provided with added sub themes embedded within certain sections were deemed appropriate, to enhance the narrative.

Contradictory verbal accounts were observed from some men when comparing their written record of first awareness of possible symptoms or bodily changes in the questionnaire responses. Fethers et al (2013) explores how qualitative data can be an important tool when exploring the validity or supporting the findings of quantitative data within a mixed methods study. This has the potential to move some men into different categories and resulted in classifications that were not ideal for analysis and should be considered by the reader whilst absorbing the reporting process.

Interviews were conducted by request at the participant's home address, with only one taking place in a hospital setting to correspond with a participant's medical appointment. Nine of the 21 interviews were also attended by a spouse, with some contributing to the interviews. These additional contributions as previously explained within the methods chapter, were transcribed for interview purposes but have not been included in the findings as the study's aim was to explore the accounts of men that had experienced a recent diagnosis of prostate cancer and not their families. All participants have been given pseudonyms to provide participant anonymity and used to support the narrative, as it was felt the use of names provide depth to the findings chapter. Quotes have further been added to aid richness with identifiers consisting of pseudonym name, journey grouping, age and geographical location used to provide further context. It is important to note the findings within the themed sections could be relatable and intertwined into other themed sections and as such should be looked at with a broader perspective.



**Characteristics of interview study sample- table 6**

Health Board	ABUHB	BCUHB	CVUHB	CTUHB	HDUHB <sup>1</sup>	TOTAL
<b>Total breakdown</b>	3	13	1	2	2	21
Asymptomatic		4	1	2		7
Early	1	4			1	6
Late	2	5			1	8
<b>Age</b>						
50's				1		1
60's	1	4	1		1	7
70's	2	9		1	1	13
80's and above						
<b>Working status</b>						
Retired	3	11	1	1	2	18
Working		2		1		3
<b>Home life</b>						
Lives alone		2				2
Lives with partner	3	11	1	1	2	18
Lives with partner and children				1		1
<b>Comorbidity present</b>	2	6	1			9
<b>Family history of prostate cancer</b>	1	1	1	1		4
<b>Work status</b>						
Work/semi ret		2		1		3
retired	3	11	1	1	2	18

## **'I had to google it' Understanding testing and symptom recognition**

### **Symptom awareness and seeking help**

Understanding a man's awareness of symptoms or bodily changes they were experiencing and the possible connection to prostate cancer is an important factor in documenting their diagnostic journey and looking further into potential reasons for delays in diagnosis. There were varied responses in relation to a man's awareness of the reasons he was experiencing bodily changes. Due to the breakdown of

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<sup>1</sup> ABUHB-Aneurin Bevan University Health Board, BCUHB-Betsi Cadwaladr University Health Board. CVUHB- Cardiff and Vale University Health Board, CTUHB-Cwm Taf University Health Board, HDUHB-Hywel Dda University Health Board

participants in the study it is important to note several of the men taking part in the study classed themselves as asymptomatic, describing the beginning of their journeys as symptomless. Although men in the prompt and late diagnosis categories also reported an absence of symptoms and feeling 'normal'. The interviews however proved this to be a more complicated process with several recollecting during interview physical indications and bodily changes they experienced before starting their diagnostic journey. These had not been mentioned earlier and subsequently they did not connect them to the possibility of prostate cancer. Gerald talked about feeling unusually tired which effected his day-to-day activities, however even feeling 'different' he did not give it more thought. This could be due to fatigue being a universal ailment that is often accompanied after exertion. Keith classed himself as 'perfect' and 'without a worry' nevertheless talked about getting up to go to the toilet frequently at night. This was looked at as part of getting old and to be expected. Lower urinary tract symptoms (LUTS) such as frequent urination, nocturia, dribbling and urgency were recurrent in each category, and looked at as a normal part of the ageing process and as such were dismissed by the men.

*'I had no symptoms, except I was getting up during the night, not just once but two or three times. I didn't think anything- I thought it was just me getting old'*

Keith, prompt journey, 60s, South Wales

Ted however spoke about how frequent urination at night had raised concern and approached his GP with these symptoms and was told it was part of the ageing process. This interaction resulted in a two-year wait before seeking further help whilst the same symptoms were progressing. Anthony however was concerned about his occasional erectile dysfunction and poor urinary stream and looked online to seek out an explanation of his symptoms in relation to prostate cancer. This internet search reassured Anthony that his symptoms were related to old age and this also resulted in him not going to see his GP with his concerns for 11 months. The correlation of potential symptoms with old age, was a commonly held view and could have had an impact on the decision of when the men decided to go and see their GP or nurse. This should also be taken into consideration when exploring the length of the men's overall journey to diagnosis and the patient pathway.

Not all men related their symptoms to old age. Andrew noted that having haematuria along with other urinary problems were the catalyst in propelling him to see his GP within a week of experiencing changes. Blood in urine can be quite an alarming symptom and one that could be a cause for concern in comparison to other urinary issues. Reduced quality of life due to bothersome or painful symptoms were also a catalyst for seeking help after several years of symptoms for Albert. He had attributed these physical changes to over exertion from working hard, exercising and the possibility of a reaction to an old illness. Albert went onto receive an advanced stage prostate cancer diagnosis in which the cancer had left the prostate and spread to other parts of the body. There were varied levels of awareness of the possible symptoms of prostate cancer, and physical signs were dealt with in different ways. This variance also seems to account for differing journeys and a factor in seeking help.

Confusing possible symptoms with old age was not the only issue spoken about during the interviews. Having comorbidities such as a previous cancer, a heart issue or neurological diagnoses were also apparent in each category with varying awareness of how these other health problems or symptoms created by these health issues could impact a prostate cancer diagnosis. Connecting physical changes to other comorbidities was a factor in symptom recognition and seeking help. It also aided confusion in category placement as symptoms may have been due to another ailment, the natural ageing process or as a result of prostate cancer. Henry suffered with nocturia for several years and only after gaining a diagnosis of Parkinson's disease which led to mobility issues had he sought help which resulted in his prostate cancer diagnosis. It should be noted that nocturia can also be a side effect from Parkinson disease, however this symptom did propel further tests by the GP. Oscar who received a late diagnosis described feeling confused with the long-term symptoms he had been experiencing, associating them with the possibility of a flare up from a previous cancer in which his physical reactions were similar. There are a variety of symptom awareness discussions throughout the men's interviews, and the importance of recognising the impact another comorbidity may have on a prostate cancer diagnosis should be discussed further.

## Primary care investigations and understanding

Varied procedures and investigations are used in the process of confirming a prostate cancer diagnosis as there is currently no specific screening tool. The PSA is one of the first investigations conducted whilst under primary care and was discussed by the men during their interviews. There were varied responses when it came to the men recounting their awareness of a PSA test and these were spread out within the three diagnostic groups. Few men had requested a PSA test during a routine appointment, either due to being concerned about possible symptoms or having an awareness of prostate cancer. Several men spread out into each group interviewed stated they had no awareness or understanding of a PSA test and the test was conducted without their knowledge. These tests were undertaken at a GP or nurse appointment during either a yearly well man or MOT check or at the GP's request. A family history of prostate symptoms offered a greater awareness for some due to previous conversations had with family members and observing others go through the diagnostic journey and subsequent prostate cancer treatment.

*'I knew about it, it's talked about ..... I've been aware of the prostate thing since I was a teenager, so I thought I'd have it checked'*

Henry, prompt journey, 70s, North Wales.

PSA tests can be used as a monitoring or surveillance method, along with being part of the diagnostic process. Albert had awareness of the PSA blood test being used as an investigative tool as had been having PSA tests for over 20 years through either work or on occasion his GP. He had observed his PSA levels going up and down 'from 7 to 9 to 6 to 10' however made the decision to not seek further investigations when he felt fit and healthy. This only changed upon the presence of problematic symptoms such as bone pain and severe fatigue as they were impacting his day to day living. Sydney was not concerned about his test result. He compared his 5.8ng/ml result with his fathers of 478ng/mL and felt it was nothing to be worried about due to the vast difference in result numbers. This lack of concern led to him forgetting to attend a further GP appt to monitor his PSA levels and consequently a delay in additional investigations. His awareness consisted of the reason why a PSA was undertaken but not what the readings indicated.

PSA awareness was brought about to some by the offering of a free test by a charity, or by being a member of a club or society. Gerald was offered a PSA test at a discounted price through the society he was a member of, paying £10.00. The test results were relayed using a traffic light system with his result written in red indicating the need to see a GP. Gerald made the decision to seek further assistance from his GP due to this results system. Wilfred's understanding of the implications of a PSA reading were varied. This was due to his experience of knowing other men who had been given high PSA readings but had no symptoms and subsequently no diagnosis of prostate cancer. The consideration that PSA testing could produce false positives or false negatives was not discussed during any of the interviews. The observation of others especially friends or family has the potential to impact perceived levels of health awareness or understanding.

### **'If I hadn't seen the programme!' influences on decision making along the diagnostic journey**

There were several notions of facilitators and barriers to help seeking, decision making and support along the primary and secondary pathways to a prostate cancer diagnosis from the men. The following paragraphs will separate these concepts into sub themes entitled, Influences from family and friends, the media and the observation of others. These subtopics will provide a structured format to the narrative.

#### **Friends and family**

The influence a family member or friend exerted over men in the interviews was a common thread throughout the interviews. When relating to family, the concept of pressure was discussed more, whilst when talking about friends, advice was often the term used. The pressure from a family member had various effects. Richard was having regular blood tests due to a comorbidity and a conversation with his wife sparked by local cancer publicity propelled her to speak to their medical practice receptionist. Richard felt he had enough going on; however, his wife had concerns and took the decision into her own hands securing him a PSA test. Wilfred's wife had picked up on his nocturia and spoke about her concerns of possible prostate cancer. This prompted a casual conversation with his doctor which encouraged him into having a test. Pressure from family didn't always have a positive effect however

when it came to healthcare seeking. A few men delayed seeing their GP even when being pushed, reporting reasons such as they would rather not know, or they were too busy.

The benefits of having a friend to talk too proved a common theme in the interviews and one which offered support, a listening ear and guidance. The bonds of friendship were spoke about in many ways. Wilfred had kept his cancer journey to himself not informing family, however he felt secretly talking to one friend who had been through his own diagnosis of prostate cancer helped greatly. Gerald had also been talking to a friend who had recommended going for a PSA test. This conversation influenced his decision to accompany other friends to a prostate screening event even though he was not experiencing any symptoms. Victor approached his GP and requested a health MOT test after a friend spoke about his own cancer experiences and the benefits of regular testing. Friends were shown to be influential with support and advice throughout the diagnostic journey and not just initial health care seeking. After talking to a friend, Lawrence and Victor made the decision to request specific investigations during their secondary care journey when they had queries about their care. Due to an overlap of themes, this will be explored further within the understanding procedures section.

## **The media**

The media is a form of communication and for this section involves the internet, reading materials, television and radio. It can have a wide-ranging influential effect on a role in decision making when it comes to health care and was spoken about by several men throughout the interview process. There were varied responses in relation to its influence, however most were directed towards the first reason to seek healthcare advice. Oscar credits an article he read in a national newspaper as being the push needed to seek advice for the symptoms he had been experiencing. The article had a list of possible prostate cancer symptoms to be aware of and he ticked everyone. Richard explained how watching a television programme aimed at prostate cancer awareness set off a chain of events. This started with talking to his wife and friend, seeking more information through reading relevant materials and accumulating in a conversation with the nurse at his next medical appointment. Keith described himself as extremely lucky after watching a news programme on prostate

cancer by chance, and credits it to his decision to seek help which resulted in a prompt diagnosis.

*'If I hadn't seen that programme I'd have been totally eaten and it would've been developing inside me and it could have been too late by the time I developed any other symptoms'*

Keith, prompt journey, 60s, North Wales.

Media awareness was not always discussed as a positive connotation. Lawrence had read about prostate cancer, yet despite this did not make any connections to himself. George credits his prostate cancer awareness from attending an educational well man seminar provided through work, nonetheless, due to being asymptomatic felt it made no difference to his initial journey as he also made no self-comparison. Media awareness was also looked upon by some as a catalyst to needless worry, and over concern for one's health and sometimes it can be better to be kept in the dark over potential impeding health matters. Several men stated they felt there was enough media awareness on prostate cancer even saying there seemed to be more than ever. However, as these interviews took place after diagnosis, this could be due to an over sensitivity to the topic which was not as apparent beforehand.

### **Observing others**

Conversations with family and friends or media awareness were not the only reported influences on decision making. The observation of other men going through the same or similar journey was also a primer in making the decision to seek further health care for some. Harold had recently found out that an old friend had passed away from prostate cancer and this triggered a thought process which resulted in him researching the symptoms.

*'A friend of mine, ... he's just died of prostate cancer, I thought, gosh, why didn't I think of it, So I looked it up'*

Harold, late journey, 70s, South Wales

Recognising his own symptoms with what was displayed on screen was the push to seek help straight away. Henry recalled observing the diagnostic journey his brother had taken and how the decisions he made, and investigations undertaken had

affected him. This made Henry anticipate his own upcoming journey differently, basing some of his future choices on these observations. Andrew also directed some of his decisions and thought processes throughout his journey on the success of a neighbour's diagnostic pathway, explaining how he was doing well now so it must have worked. Fred gave credit to his observation of a friend's journey to be tested, as what helped him make the connection and supported him on the different parts of the journey he had to go on.

The observation of others did not always have a positive effect on decision making. Conversations over procedures put some off with explanations of biopsies and invasive tests. The graphic detail reiterated concern of being prodded and poked and resulted in asking for one referral to secondary care to be delayed for 6 months. This was felt justified due to the absence of symptoms apart from a raised PSA level. David was asymptomatic and offered a PSA test through a check-up with the doctor. He spoke about although he had witnessed his father and brother go through a prostate cancer diagnosis and treatment for prostate cancer, he had not made any connections to himself or thought about the possibility. The influences discussed throughout this chapter could all be seen as informal networks

### **‘Sometimes they give you lots of info without actually doing anything’. The provision of information along the diagnostic pathway**

The provision of information throughout the diagnostic journey was a topic spoken about during the interviews. How information was given, sought, made use of and displayed were all discussed. These will now be discussed using the primary and secondary care pathway intervals as subtopics as experienced by the men. It should be noted that the pathways were not all linear, with two men utilising private health care within different pathway intervals. No men within this study presented as an emergency to secondary care, missing out primary care completely, however this can happen and should also be noted.

#### **The primary care pathway**

The GP surgery was predominantly where most men interviewed started their diagnostic pathway. One man was seen at a private clinic for a health check-up. Several participants had initial conversations with either a GP or nurse practitioner during their first appointment. After the initial appointment, some men recounted how



they were relayed information about prostate issues and possible prostate cancer. Several recalled being kept informed through further appointments and on occasion information sheets. George and Arthur recount their experience of being given information over the telephone by their GPs. George recalls the confusion he felt from the information he received, however accepting the process as the nature of how things are. A phone call from his GP first alerted him to being referred to the hospital for further tests. After a secondary care appointment and biopsy, he was called again by his GP relaying he had received a letter from the hospital to say he did not have cancer. This phone call was then superseded by a letter he received over 12 months later requesting George come in for second biopsy resulting in a prostate cancer diagnosis. Arthur recalls being told about possible prostate cancer over the phone and at a subsequent appointment. He recalled feeling like it was a 'shock out of the blue'. He had been to see his GP several days earlier with what he assumed was a kidney infection and believed the blood test that was undertaken was to check on this. After being informed of their referral by their GP, several men talked about having to chase up further appointments after not receiving any information.

### **The secondary care pathway**

The provision of information was discussed in the most detail within the secondary care pathway in relation to appointments and results. Sydney and David were the only participants in the study to have their investigations completed in one day at a rapid diagnostic centre. They both described feeling pleased with the information they were given and felt staff 'couldn't have done anything better'. Interestingly both participants also had a positive overview of their journey as a whole and made no suggestions for change. The potential influence these diagnostic centres could have in positively influencing a patient's perception of their journey and providing a swifter route to diagnosis will be explored further in the discussion chapter. Keith described his journey as being 'mapped out in front of him' with a clear understanding of what was going to happen and with the information needed. Many men in the study reiterated this, reporting being given all the information needed when under secondary care. Fred talked about having all the information you could want after conversations with his doctor and information sheets. He was also provided with a phone number to call if in need of any more information or support. Malcolm also felt

he was given a plethora of information by asking the right questions, however questioned its format. He explained how sometimes if the information you are given is just to read, you may struggle to take it all in and a spoken explanation could offer more context.

*‘Sometimes you’re just dreaming when you’re reading; you’re not taking it in, So I won’t say it’s not there, but it’s different when someone actually takes you aside and says. ‘This could happen, that could happen.’*

Malcolm, asymptomatic journey, 70s, South Wales

Health literacy was a concept spoken about by several men and encompasses an individual’s capability to understand information often in written form and related to one’s health. George described how linguistics was a barrier to understanding the information he was given being a Welsh speaker. He felt being able to have conversations and reading material in Welsh would have translated the correct terms for the Welsh language. Providing more lay orientated information would also have helped some of the men with feelings that the information provided was not suitable for them to digest with certain words being used they did not understand. It was not always about the presentation of the information. Henry discussed how being given information relating to his appointments could have been more organised. He turned up at hospital to be told the specialist with whom he had an appointment with was off on leave and a substitution had not been put in place. After a wait, the diagnosis was given by another doctor who had been ‘pulled off his ward rounds’. Seeing more than one consultant along the diagnostic journey was spoken about as an added confusion in the delivery of information and brought up by others. Anthony explained how it helped to see the same nurse and sit and talk to one individual throughout. This familiarity can influence the communication and forming of relationships between an HCP and patient and its connection considered when reading the next theme.

**‘If I wanted to speak to someone, I could!’ The importance of communication and relationships with healthcare providers.**

**Feeling heard**

The importance of feeling heard was a theme that ran through the interviews in relation to the men's relationships with health care professionals. This was mainly focussed on the primary care journey when men were expressing their concerns about symptoms or just starting their diagnostic journey. Several men reported feeling they were listened too during their medical appointments. GPs were quick to pick up on symptoms being described and concerns were heard, with PSA blood tests being offered consequently. Whilst one man reported a straightforward appointment of requesting a PSA test with little conversation, others spoke about having more than one appointment with their GP to discuss concerns before being referred. Sydney expressed his appreciation of feeling heard after voicing his concerns over the next steps that needed to be taken after a high PSA reading result. He was assured by his GP that 'they do things differently and monitor it better'. There was no further explanation if this meant at the surgery itself or the health board.

Dismissal by their general practitioner (GP) was a feeling conveyed by some when it came to voicing concerning health matters. Men reported wanting to feel reassured by their GP when they talked about prostate concerns and to be monitored. Samuel felt he was not taken seriously when he spoke to his GP about his worries during an appointment. He wanted the GP to listen and understand the anxiety he felt with an offer of a future monitoring appointment which was not offered. The appointment left him feeling it was a waste of his time and he had been a nuisance. Samuel consequently decided to do nothing further about his concerns for 18 months. The decision was then made to go back to the GP practice but to see another GP. Samuel reported the second appointment was a different experience, feeling heard and at ease. Leo explained how he felt his doctor did not believe him when he explained his symptoms, and this heightened his anxiety and cause him to feel uncertain about his health. The scepticism he felt created a barrier to seeing his GP and impacted the professional relationship.

### **Forming relationships**

The importance of forming a relationship with the various health care professionals the men saw along their diagnostic journey was noted throughout the interviews. Within primary care, many men spoke about their preference to see the same GP

within their practice as they felt getting to know their GP over the years helped both parties. This was due to the building of trust, feeling more open to talk and the GP knowing their medical history. A few men also spoke about thinking nothing of seeing their GP out and about in the community and mentioning their health concerns before making an appointment. The geographical landmass of Wales supports cities, towns but also small often tight knit communities. Oscar spoke about being happy to wait longer for an appointment as he only wanted to see a specific GP who was popular in the practice. Albert talked about having several appointments with his GP to discuss his raised PSA results over the years. He was always involved in his future steps and was consulted in what next steps he would like to take when it impacted his health. He made the decision on several occasions to not take up the offer of a referral to secondary care until he felt a deterioration in his health. Relationships in primary care however were not always noted as a positive experience. Men reported being put off at the thought of going back for a further appointment if they did not feel they 'got on' with the GP or nurse practitioner often resulting in delays along the journey.

Within secondary care, the effect of seeing different consultants along the journey was common when related to a thread of communication. The preference to have seen one consultant only was noted, with further explanation of understanding more about the consultant's speciality or the reasons they were seen as advantageous. Nursing staff were described as amazing and helpful by some, offering advice and consistency and showing clinical expertise. This was especially the case when talking through an aspect of care as it was felt nurses often talked about things in a different way to a consultant. Relationship facilitators involved being spoken to so the men would understand what was being said and on their level. This aided a connection with their consultant. Relationship barriers were described as feeling that staff did not have the time to sit and talk to the men, a lack of interest in giving advice and staff showing signs of being overworked. Some men talked about seeing up to four different consultants, Men felt their own barriers to forming a relationship with their consultant or nurse involved factors such as being unused to going to hospital and feeling ignorant due to not understanding what was being said. Others reported 'muddling' through their journey and a feeling of being disconnected to their consultant. Harold had to visit four different hospitals, seeing four different

consultants before he was given his diagnosis. He recounted this experience as stressful and felt communication was especially confusing when it came to keeping track of results.

### **Mixed messages in communication**

A sample of participants spoke about how they perceived conversations they had with either their GP or the practice nurse. A few recounted how they left their appointments with the understanding they did not really have anything to worry about and it probably wasn't prostate cancer. Men recalled being told by their GP or nurse that they didn't think it was anything serious, they did not need to worry, or they were being referred or checked just to be on the safe side.

*'The doctor at the hospital, he was sort of talking it down, so I didn't really connect. It was a slow process connecting with what they were talking about. I was not unduly worried because I didn't notice there was any reason for doing so'.*

John, late journey, 60s, South Wales

Conversations such as these led to feelings of disappointment on diagnosis for Anthony who reflected that he felt he should have been told more but debated whether the doctor was trying to avoid worrying him at the time. He left the appointment with a false sense of security. Some men spoke about being confused with mixed messages from seeing different HCPs within their practice. Ted recounted how his conversation about his concerns with a nurse felt negative. After enquiring about a PSA test, he was informed they do not offer PSA testing for specific symptoms. The explanation given was the test was not reliable and it could produce a false reading and lead to unpleasant investigations. On pursuing this matter with his GP, he was offered a PSA test on discussion of symptoms. Other barriers to communication included being put off attending the practice initially, due to feeling it was not a friendly place and Welsh language barriers.

### **I had the 'click click'; procedures and their Impact.**

There was a range of responses during the interviews to investigations undertaken during secondary care. These were predominantly in relation to having a biopsy and an MRI. The biopsy procedure recounted emotion and physical reactions, whilst the

MRI produced the most queries, generating conversations between the men and their urologist. The following section is split up into two sub themes to aid explanation on how procedures were understood and the physical and emotional effects resulting from the biopsy.

### **Understanding procedures**

There were varied views when participants described their understanding of the procedures they had experienced and their timings. Victor and Andrew reported feeling fully informed about the procedures undertaken, with tests being explained in detail during every appointment. Others reported feeling able to probe further with concerns or questions as staff were helpful. Several men in South Wales had their investigations completed over a day at a specialist unit or over several days, finding them quick and efficient. Others however didn't feel the procedures were explained well and longer waiting times in between appointments impacted their understanding. Samuel had an x-ray on his pelvis along with a biopsy and MRI and questioned why. He felt the nurse did not give a true explanation for the reason behind it, building feelings of mistrust. Others reported not feeling the need to understand the reasoning behind procedures, trusting in the process, whilst others came to their own conclusions.

*'I'd seen about four doctors by now, so I knew it wasn't good. You don't have to ask questions, you're seeing four doctors and they've all had their thumb up your bum, you know that's something's not right, don't you? I just assumed'*

Gerald, asymptomatic journey, 70s, North Wales

Investigative procedures were conducted in various orders, and this order was dependant on the health board providing the healthcare. There were differences in the order of the procedures given dependant on which health board care was provided under. Men in South East Wales were the only men offered an MRI before a biopsy, with these often being performed at a day centre. Others were given a biopsy before their MRI. David relayed how pleased he was with his secondary care journey. Attending a day centre, he was given an MRI in the morning, followed by an appointment with a consultant and a biopsy in the afternoon.

Many participants discussed how they enquired to see if they could have an MRI before their biopsy, through speaking to their urologist and showing preparatory paperwork they had compiled displaying potential benefits. Reasons included conducting background reading beforehand to understand risk and an awareness that the procedures were offered in this order in other areas. Richard had been advised by a friend to ask for a scan before a biopsy due to having other health complications. Upon asking, he was told it was not on offer at the hospital. Due to family pressure, he pursued the matter again at his next appointment but was told the same. Lawrence also requested to have an MRI scan before he had his biopsy. Feeling it made sense to have a scan first to pinpoint the problematic areas. Recounting the conversation, he explained the doctor said he did not need an MRI scan and the biopsy would prove it. Lawrence exclaimed he would have been happy to pay private for peace of mind and to reduce anguish. Others were also told they could pay privately if they wanted the MRI first as it was not an option under the NHS at that hospital. Due to reasons of expense, this was not taken up by any men interviewed. This response brought about feelings of acceptance in some due to not having the capital to fund the investigation and a refusal response. The relevance of the staging of these procedures and whether a biopsy or MRI were performed first, could impact the view they had of their biopsy.

### **Effect of biopsy**

Emotional states and physical response were vocalised when expressing experiences of the biopsy investigation and these were varied in response. The men overall were vocal when it came to expressing how they felt about their emotional state and the physical effects resulting from their biopsy and these responses varied. Interestingly, sounds produced from the procedure itself resonated in some of the men's recollections when describing the event, using the words click, click. These sounds were produced when the biopsy samples were taken. Responses included the apprehension of having the procedure, due to samples being taken from either the perineum or back passage and the embarrassment due to the nature of the procedure itself. Anthony expressed his initial concern about going for the procedure due to having his back passage probed again and the nature of the procedure. Afterwards however, he recalled the procedure being painless and felt supported by the nurse and doctor. Gerald also spoke about feeling embarrassed

about having the procedure performed in front of female nurses but felt the procedure went well and suffered no aftereffects. Many men felt the worry and thought of the procedure was worse than the procedure itself. The biopsy was also described as revolting, aggressive and invasive with participants describing varying physical effects.

*'Then they moved to the biopsy, which was the most unpleasant thing of the whole experience. It takes about 20 minutes and its quite invasive'*

Keith, prompt journey, 60s, South Wales

Some men felt no pain during or after, whilst others experienced pain and discomfort during and post procedure. The procedure however was accepted as an important investigative tool in the diagnostic process even with queries relating to the timing when looked at along with the MRI

### **'Being a man, a typical man'. self-awareness and perspective along the journey to diagnosis.**

Thoughts, feelings and beliefs felt during these personal journeys to diagnosis were sprinkled into all parts of the interview transcripts. Participants spoke about thoughts they were experiencing throughout their journey, along with feelings that were evoked and how these may have been influenced by their belief system. When describing the beginning of their journey many men used words such as feeling normal or perfectly fine. These men were either asymptomatic or associated the symptoms they were experiencing such as frequent urination or nocturia as just a normal part of getting older. These feelings of normality coincided with a lack of worry regarding their health and wellbeing as a lack of symptoms was congruent with a lack of concern. For many of these men a subsequent prostate cancer diagnosis brought about feelings of confusion, which may have been a result of a lack of connection at the beginning of the diagnostic journey.

Feelings of 'something just not feeling right' were descriptions some men used when recalling the beginning of their journey, however feeling they couldn't quite put their finger on what the issue was. Gerald, Andrew and George felt looking back they were feeling more lethargic than usual, however did not give it further thought. When it came to receiving the results of the PSA blood test, there were varying accounts of



how this made the men feel. Victor felt shocked and confused about his high result. When recounting his experience, he felt with hindsight he should have been aware of the possibility of prostate cancer. This was due to his father also being diagnosed and the three years of urinary changes he had experienced and dismissed. Feelings of shock were also felt by others when told by their GP they were being referred to secondary care after their PSA result. This was due to either a lack of concern regarding their own health status or a false sense of security, recounting the PSA reading wasn't high enough to be concerned about. Oscar spoke about how his PSA reading of 221 ng/ml did not cause him further anguish as he knew that meant he probably had prostate cancer and acceptance was quicker. A lack of surprise or worry was also expressed by other men when presented with a high PSA reading. Reasons included having other family or life issues to worry about or avoiding worry by holding back on seeking further medical assistance until they felt it was needed.

Various emotions were evoked from the referral from primary to secondary care. The referral itself caused worry for some, anticipating what was to come and the possibility of a diagnosis of prostate cancer. Others however felt assurance from the referral feeling they were no longer burying their face in the sand and taking action. For others the waiting time from referral to first appointment in secondary care was the catalyst in rising anxiety. These feelings were dependant on how long the patients had to wait to be seen, with some feeling it felt like forever and others happily surprised with the wait.

Encounters with various health care professionals involved in these important diagnostic journeys were described by some. The word trust was regularly spoken, when discussing both the primary and secondary care parts of these journeys. Men overall listened to the advice of their health care providers along the journey as they were deemed the professionals. Malcolm had nothing but praise for the care he received when under secondary care. Pressing the importance in placing trust in the care given and the assurance that his diagnostic journey was mapped out for him. Men reacted differently to thoughts on their diagnosis. Gerald felt he had lived a good life and it didn't matter if he was given a prostate cancer diagnosis. Albert recounted how he felt at the time, with his own resilience beliefs being tested.

*'I thought, Okay, I'm pretty hard. I can take this. I didn't think about it. He said, 'you've got cancer, it's bone cancer, it's secondary, we think it's your prostate'. I was starting to feel a bit fed up with that'.*

Albert, late journey, 70s, North Wales

Men with other comorbidities either reacted to the thought of the new diagnosis adding to their worries or as just another health problem. When discussing the time to diagnosis through secondary care, men thought staff in general were over worked and stressed with beliefs that the NHS was under strain due to lack of funding and facilities. This belief resulted in a feeling of acceptance for some on the length of their journey and their appointment schedule. Men also expressed how staff showed clinical expertise when under their care, resulting in feeling looked after and positive remarks when amalgamating thoughts of their overall journey. Some delays in the diagnostic pathway were put down to the men themselves. This was due to having holidays booked, family issues or for the younger men work priorities.

Towards the end of the interviews, men also spoke about how the journey had affected their thoughts on general health and the wellbeing of themselves and others. The journey had caused stress in many, with descriptions of feeling shunted all over the place and impeding worry. Lawrence also voiced concern about how his complicated journey with added health complications could reduce his resilience in the future and potentially cause mental health issues. Throughout the interviews the men spoke about the importance of having someone to share their journey with, whether it be a family member or a friend. These relationships and confidants shifted the way some of the participants felt about speaking to others and sharing their journey. Several men spoke about how their journey had propelled them to speak to other friends and family members about their health and wellbeing. Others had offered advice to men to get checked for prostate cancer and shared their symptoms.

This findings chapter has provided an in-depth account of the 21 interviews conducted with men newly diagnosed with prostate cancer in Wales. Themed sections exploring various primary and secondary care intervals within the diagnostic journey have helped structure content and unravelled individual journeys to diagnosis through recollections, thoughts, feelings, and perceptions. Due to the

integral importance of the interviews, a reflexive diary was kept supporting data analysis and personal reflection. The following paragraphs will provide a reflexive account of the interviews along with several diary extracts to add context. The succeeding chapter will bring together the narrative review findings from the literature review, alongside the study findings above to provide an in depth, critical discussion focussing on the study's aims and objectives.

### **Reflexive account for interview process**

The interview process has been an illuminating experience and cemented my desire to be a qualitative researcher. Each completed interview taught me something about my own interview style and how to make improvements or changes. I felt honoured to be invited into the participant's homes and to hear their often emotional and personal journeys. I observed different attitudes, thoughts and feelings and every interview provided an important contribution to my study. I have been a neuro linguistic programming coach for six years in another role which involves spending a lot of time listening to others in a non-judgemental and holistic way. I feel this role made the decision to focus on qualitative interviews a natural one and contributed towards feeling comfortable with the process early on. This role however also influenced my own interactions as a researcher within the study and being aware of this potential bias was important to consider when undertaking the analysis.

Before undertaking the interviews with participants, I was advised to complete some mock interviews if possible. These would provide insight into how the topic guide would work, help familiarise myself with the topic guide and allow me to rehearse my interview style. Due to a lack of confidence and time constraints, I completed several mock interviews but with my peers and two family members who had both gone through a prostate cancer diagnosis. I felt disappointed with myself after this process as I did not utilise the public and patient involvement (PPI) team at Health and Care Research Wales. Interviews with impartial people would have added richness to my preparation. The mock interviews however were rewarding and significant and provided insight into the topics that may be spoken about and the interactions I may expect from additional contributors, which I had not envisaged. An important observation arose from the way the additional contributors seemed to have alternate versions of certain parts of the prostate cancer journey. This made me contemplate

as to whether this would be a recurrent aspect and to ensure I focussed on the views and perspectives of the men as this was the aim of the study. In future studies, I will ensure I factor in enough time for mock interviews with relevant PPI to gain a richer experience, valuable feedback and improve my professional practice.

The flow of the interviews was affected by many things, from my own interview style to the environment. Where we sat, who was present, animals, phone calls, interruptions, refreshments and more were all factors. Some of these things cannot be controlled and cannot be prepared for, however others can and not having a dog jump all over you when you are interviewing or the phone ringing were aspects, I could have had some control over. These are things I will consider when I conduct any other interviews and try to prepare the area before the interviews commence. Throughout the interviews, I was aware on the impact of how I was feeling that day and how my own wellbeing could affect the interviews and tried to ensure a professional and positive demeanour throughout. From past experience I feel that Initial impressions can make all the difference when being welcomed into a home and building rapport, so I decided to start each introduction with a positive interaction. This would often come from observations of aspects such as their house, garden, pets or family, generating easy conversations which would hopefully make the participants feel more relaxed. Being able to offer the interviews in a place of the participant's choosing was also a useful aid in creating a relaxed environment. I felt these small factors helped implement good preparation, however along with having positive implications they also provided some pitfalls. For some men, it provided an opportunity to talk about topics that were evocative or that interested them and at times, they weaved their way into the recorded interviews and took the interview off topic, in which I sometimes found difficult to bring back on track.

These conversations were conflicting to my values as I appreciate how important it can be for people to open up about their lives, however these off topic tangents also wasted valuable interview time and transcribing resources. Over the course of the interviews, I did adapt my style, making sure I was clear on the purpose of the recorded interview, stating I may reiterate the topic that needed to be discussed throughout to ensure the interviews focussed on the research aim. Through insight, I also learnt to observe when conversations were veering off topic and would instruct that I would love to hear more about it, but after the interview had finished. The

changes made to my interview style had occurred due to reflecting throughout the process and having regular supervision meeting. I feel these observations will help me develop my interview technique for future studies.

I am aware that my personality propels me to help people and has caused me work stress in other roles due to taking on more than my work role dictated. On several occasions during the interviews, I had to make a conscious decision to not become involved in some other issues' participants had and stick to the interview process at hand. Due to the topic, some interviews were also emotionally charged, and I felt it was my duty during and after to monitor each participant's wellbeing and make sure each man or additional contributor were well before I left. During one interview both the man and his wife started crying when they recounted the journey they had been on due to another condition and even though it extended the interview time, I felt it was important for them to express this before they could focus on the prostate cancer diagnosis. I turned the voice recorder off for them to tell their story. I was also aware that this cancer only effected men and an area of the body often felt as private and as such this may have affected the openness of the answers I was given. I feel my response to emotion will not always be beneficial to a career as a qualitative interviewer and I may need to adapt my reactions, however this will come with practice.

Thinking back on practicalities, there are several things I will remember. I need to make sure I factor in enough time for the journey and rest in between appointments. Due to time and financial constraints I had to undertake three interviews in one day with travel between and I felt drained emotionally and physically. This was not good practice and I feel the last interview did not present me at my best. Travelling also heightened pre anxiety, especially if I did not know where I was going, and these anxious feelings effected my first presentation to the participants on one or two occasions. In the future I will make sure time management is a priority to this stage and factor in enough time for travel and time out to re-focus before interviews start.

Time brought experience but also on occasion complacency. Listening back to Interviews, especially early on in the process with my supervisor allowed me to monitor my technique. Constructive feedback helped me recognise how initially I was recounting what the men had said at time back to them and this could have negative

effects on the flow of the interview and data. Adding notes to the topic guide until this habit was squashed helped enormously, along with extra words to support probing and prompting. After I had many interviews, I found myself not needing to use the topic guide as much, my anxiety reduced, and my interview technique improved. I further found changing the tone and tempo of my voice a positive interview technique, along with leaning towards the participants and nodding. I also became more comfortable with awkward silences, allowing the participant time to think and respond. On occasion I lost focus or forgot to focus on an important point but overall, I feel my first experience of semi structured interviewing was a successful one. The process has been rewarding and has illuminated possible issues I may come across in the future and ways to improve my practice. From a positive perspective, it has helped me recognise my strengths and the important contribution qualitative research has to offer.

To provide a deeper understanding on how the interviews were conducted and the processes taken, an extract has been provided from the diary written to support the learning and methodological process.

### **Interview diary extracts**

ENTRY- My first interview! I felt very stressed due to the issues with the traffic and delays getting there. The interview lasted for an hour and 20 minutes overall. On reflection, I do not think I put the tape recorder in the best place to capture the speaking and I may have asked some leading questions and repeated back some of what he said for clarity (will need to listen back to check). I did have to steer the interview a few times to keep it on track and I think this will be a problem I keep getting. I managed to follow all procedures and get everything signed. A small win and a big learning curve.

ENTRY- Today I had a meeting with my supervisor to listen to the first interview. I did not enjoy hearing myself back, however it was a good reflection tool. My supervisor agreed I did ask some leading questions in an attempt to get richer answers and interrupted the flow of the conversation a few times. The positives were, I did probe to gain further understanding and I feel I may need to add some extra details on the topic guide to remind me of these things.

ENTRY- Struggling juggling my MRes and other aspects of my job. I am experiencing lots of firsts and find my project management is helping keep me on track. I'm on my 4<sup>th</sup> interview and I forgot to start with the introductory piece. I think this was because I chatted a lot before the interview started due to feeling the participant was emotionally charged. I had to go back after the initial ice breaker and go through it. I am still struggling to not ask leading questions at times, but it is getting easier. The participant got upset halfway through the interview and this stopped me from probing further on some questions as I did not want to cause more upset. This resulted in a quicker interview than the others. The participant's journey was also a prompt one and asymptomatic, so this seems to shorten the responses. I think before the other interviews I will remind myself whether the participant had either a prompt, late or asymptomatic journey as this may influence the way I prompt.

ENTRY- I am really enjoying making connections with the men being interviewed and feel quite at ease with the process. I have noticed that making general conversation about the house, weather, area etc also helps build rapport before the interview starts.

ENTRY- A successful interview from the standpoint of gaining information. The gentleman was receptive and descriptive with his thoughts and experiences. I struggled at times to keep him on track with the topic as his journey to diagnosis was very long. Good eye contact and body language is helping with the rapport and today I was taken on a tour of his garden after the interview which made me think that he felt comfortable with me, which made my day.

ENTRY- First interview in a hospital setting. The setting made it feel more formal but did help focus the topic. There were also fewer outside interruptions and I found myself actively thinking about not interrupting the conversation or repeating. I am now starting to use body language instead of replies so leaning forward and nodding and this seems to be making a positive difference. It was nice because I also got to meet with the research nurse that recruited the patient after.

## **Chapter 5**

### **The Discussion**



## Discussion

This discussion chapter will bring together the findings that have emerged from the analysis of the interview data and interpret and discuss these in conjunction with the findings from the narrative literature review. The six major themes derived from the interpretation of the interview findings will be embodied and intertwined with the seven major themes from the literature narrative review. Similarities and differences between both chapters will be explored. Presentation of the study findings and the literature narrative review were thematic in nature, with headings deriving from interpretation, aiding the synthesis. This chapter will outline any similarities and features and interpret and dissect, whilst considering the results from the previous chapters. These evaluations will be made whilst ensuring the research question and the aims and objectives are explored and addressed. Interaction and experiences of men will be noted, along with contributing factors that may have influenced the prostate cancer journey, as these are pivotal in helping understand potential delays in diagnosis (Scott et al, 2013). Ideas for potential intervention points will also be observed to support the target of detecting cancer earlier (Scott et al, 2013). To note, the literature did not reference or explore directly the different diagnostic pathway intervals as the interview study findings have, so this is pertinent only to the interviews. On further exploration of the wider literature, these diagnostic pathway intervals are highlighted more within papers exploring cancer in general and explained in detail in Scott et al's (2013) Pathways to Treatment model as noted within the introduction chapter.

A comparison of the interview findings and literature narrative review revealed the findings from the interviews aligned with the majority of the identified themes from the literature explored. There was a plethora of similar thought processes from the men in the interviews and the literature. The themes discussed in this discussion chapter will be made clear at the beginning of each section to provide further clarity and connection. Interview findings will be upheld using pseudonyms allocated earlier in the study and literature studies referenced to highlight discussion points. The six themed chapter headings used within the interview findings chapter will be utilised again for this discussion chapter to aid structure, clarity and richness. Each theme will be highlighted by a heading before moving onto the next.

## **Symptom awareness and seeking help**

Symptom awareness as a topic, plays a vital role when aiming to understand the length of a man's journey and the time points and intervals within. It can provide rich information which can support the work of early diagnosis, which is often complicated (Whitaker, 2020) and at times poorly described (Lyratzpoulos et al, 2015). The men's awareness of symptoms further supported the allocation of men in this study to either the asymptomatic, early or prompt journey category. Data collection from phase 1 and the findings from other academic papers as explained within the introduction chapter were used to establish these time points and intervals and then categorise each man into one of three diagnostic journeys. It became clear through analysing the findings that a small sample of men interviewed, recalled differing accounts of their symptoms or bodily changes in comparison to the accounts they first provided in the survey which was used to collate the study sample. The accurate measuring of symptom onset can be a challenge within research due to patient recall (Keeble et al, 2014). This would have potentially placed the men within a different category to what they were placed for this study as this had the potential to impact the patient interval. These observations suggest there are complications with determining the length of the patient pathway or appraisal interval (Scott et al, 2013) for men with prostate cancer as recognising symptoms that could be attributed can be confusing and subsequently influence help seeking. These interesting findings also question how a mixed method strategy used to elicit responses can produce different replies from the same participant, dependant on the method used and further research on this would be beneficial.

An absence of awareness or recognition over symptoms or bodily changes men experienced during the beginning of their journey has the ability to cause confusion towards a possible connection to prostate cancer and was confirmed within the interviews and the literature (Ferrante et al ,2011). In this study, Keith spoke about having no symptoms at all, yet he was getting up every night with nocturia. The consensus from most men reporting lower urinary tract symptoms (LUTS) and the association of these being just part of old age suggests these symptoms can cause confusion in the older man, even though early prostate cancer does not normally

cause symptoms. The beginning interval or patient pathway within the diagnostic journey before initial help seeking is an important aspect to explore further. A deeper understanding of symptoms experienced and a person's response, can support earlier diagnosis as these can vary (Whitaker et al, 2020; Hannaford et al 2020). Research further shows that 50% of patients diagnosed with cancer, present with non-specific but concerning symptoms (Erridge et al, 2021). These findings could pose the question of how increased awareness of the possible symptoms of prostate cancer could propel an earlier diagnosis, due to men going to see their GP earlier. The problem is, some of the classic symptoms of prostate cancer including hesitancy, frequent urination, nocturia or a weak flow are also a normal part of the ageing process for older men due to prostate changes. Further symptoms such as back or hip pain, erectile dysfunction, fatigue or blood in the urine can provide a greater connection, however these can also indicate the cancer has left the prostate area and travelled, resulting in an advanced stage diagnosis. The interview data has showed how confusing this connection can be and added to the literature.

Being able to differentiate between LUTS as a cause for concern or part of getting older poses issues for not just the patient, but also the health care provider. Within the interviews Ted had concerns about his LUTS and approached his GP. He was told his symptoms were just part of the ageing process and this resulted in him being reluctant to go back again for some time with the same problem. Delays in the diagnostic journey after symptom awareness can be during the appraisal interval and within primary care (Keeble et al, 2014). This hesitancy could have the potential to increase the length of the patient pathway and the overall diagnostic pathway. Within the literature, Conde et al (2011) found men would often only make an appointment to see their health care provider when they felt very ill and symptomatic. The findings of this study concur. Albert had ignored how he was feeling, until the issues were affecting his daily life and causing pain. Albert was given an advanced stage diagnosis which may have been caught earlier, reducing his treatment options. It could be inferred that unless symptoms are alarming such as blood in urine or extreme pain, the correlation between old age and specific symptoms can delay help seeking in primary care.

Symptoms or bodily changes were not apparent in all the men in the interviews or literature, suggesting asymptomatic presentations for some men. Ferrante et al

(2011) found that an absence of symptoms could create a barrier to seeking help as feeling well or normal equalled no health problems and as such no chance of cancer and study findings agreed with this data. It is hard however to establish whether a PSA test, which is one of the investigative tools used to aid a prostate cancer diagnosis would be beneficial for asymptomatic patients. This concept was not discussed within the interviews or highlighted within the literature, suggesting an area for further research. Offering or having this blood test could create the 'worried well man' who subsequently could end up having needless investigations, increasing anxiety and a resulting negative diagnosis. Other factors such as a family history of prostate cancer were an important propellant for seeking help for Sydney whose father had had prostate cancer. He was not experiencing any symptoms, however his awareness of an increased risk due to hereditary factors drove him into making an appointment. Interviews also noted that other comorbidities could impact a man's symptom connection to prostate cancer. Salika et al (2018) state co morbidities at an older age are more common, along with a greater risk of cancer. Examining the correlation between these and how chronic disease can impact cancer diagnosis could support initial help seeking for symptoms attributable to cancer (Renzi et al, 2019). Associations however were often linked to comorbidity pairs, and this was not explored within this study. Henry and Oscar had other comorbidities and these health issues caused some confusion in relation to the new symptoms they were experiencing. They were initially accepted as part of their current comorbidity and not questioned, resulting in delayed help seeking. This calls into question whether having another comorbidity is a barrier to seeking help as it could aid confusion due to associating the symptom with the current disease (Salika et al, 2018). It could however conversely be looked upon as a facilitator to seeking help due to an already established relationship with a HCP. Open communication, more opportunities and encouragement for dialogue on reporting any new symptoms (Salika et al, 2018) could facilitate the ability of a HCP to establish possible health issues that could be related to prostate cancer, aiding a swifter diagnosis.

Interestingly, the literature highlights data not found within the interviews, underlining other attributing factors that could affect seeking help. Healthy behaviours reported by men interviewed were believed to be protective factors and helped protect men against developing prostate cancer (Ferrante et al, 2011).

Several men within the interview study described themselves as feeling normal or healthy before being diagnosed and these men unremarkably also commented on not seeing their GP often. This could corroborate the literature, in the sense of feeling healthy equals less inclination to access primary care. Findings derived from Anderson et al (2013) and King Okoye et al (2019) and their research with African and African Caribbean men spoke about the challenges of speaking about these matters due to the prostate being a private matter and relatable to sexual health. These points did not concur with the study interviews; however, this could have been due to a number of factors, including the sample being predominately white with only one mixed race African Caribbean man within the sample, so it lacked cultural diversity.

It has become vividly apparent from examining the interview and literature findings that the possible symptoms attributed to prostate cancer and their similarity with natural processes of old age side or other comorbidities can create many complications in help seeking. A clearer symptom awareness campaign for men or educational awareness of prostate health from an earlier age could offer benefits, as it is suggested from this discussion that various levels of symptoms awareness can account for possible differing journeys along the diagnostic pathway. It could also however create a pool of worried well men, who had previously perceived themselves to be fit and healthy, resulting in heightening anxieties and a disproportionate use of health services. Finding the balance will not be easy and there seems no direct answer.

### **Testing awareness and understanding**

There were various accounts of how men interviewed in the study looked upon testing and their understanding of the process. They were predominantly focussed on the PSA test, although other investigative tools within primary care were described. Patient interval data relating to the PSA test when a patient is asymptomatic can be missed (Keeble et al, 2014) so capturing this awareness and understanding is beneficial. These accounts however appeared to be sparse in comparison to discussions related to other parts of the diagnostic journey. Opinions on PSA testing, varied within each of the three categories, suggesting varied levels of awareness. A few men described having no awareness that they had had a PSA

test, or that it was discussed with them or any understanding of what it was. These accounts could question the importance of the need for a thorough PSA discussion during a medical appointment to help increase awareness for a man possibly starting his route to diagnosis.

The PSA test was often referred to as a screening tool within the literature and noted as a more prevalent topic than within the interviews. Multiple studies (Mather et al, 2011; Anderson et al, 2013; Grogan et al, 2016; Partine et al, 2017; King Okoye et al, 2019) all illustrated screening awareness through harms and benefits, along with understanding. The literature further commented on negative emotional connections such as worry when having a PSA test, whereas men in the interviews referred to the test by only the benefits it could provide. The literature came from various countries where different healthcare systems and screening programmes are available. These differences could account for the importance and awareness described within the literature and the different pre-conceptions described.

Extracts from the interview findings provided evidence of feelings of confusion in relation to a PSA reading and what number constituted a cause for concern. Sydney and Albert recalled slightly high readings with both being over 5ng/ml but under 10ng/ml. NICE guidelines stipulate a normal PSA reading is between 0-4 ng/ml, however interpretation is asked to be taken by the HCP they are under with consideration to be given to other factors such as age, ethnicity, family history and symptoms. Sydney's PSA result was vastly lower than that of his father who had prostate cancer, causing him to not worry about the reading and subsequently miss his next monitoring appointment. Albert had experienced a raised PSA level for a number of years, however never felt the need to worry also causing delays in returning for appointments. Greater clarity and understanding on what a PSA reading could indicate, could have resulted in Albert and Sydney attending their appointments earlier, aiding the possibility of a swifter diagnosis.

False negative and false positive readings, coupled with a man's understanding of a PSA number were prominent within the literature (Ferrante et al, 2011; Partine et al, 2017; Dreidger et al, 2017) along with educational awareness but this did not correlate with the interview findings. This suggests men within the literature had a deeper understanding in what constituted a worrying PSA reading and how a PSA

test can also lead to other investigations. This calls into question the different awareness campaigns, referral criteria and conversations had between HCP and patients around the world and whether these campaigns are seizing attention and making a difference (Whitaker et al, 2020). It may be beneficial to further explore the educational awareness within other countries when relating to a PSA test, to monitor best practice and support a greater awareness for men in Wales, which could possibly reduce unnecessary delays or needless investigations.

### **The Importance of communication and relationships with health care providers**

The literature confirmed the interview findings in that good communication and valued relationships with HCPs were deemed important along the diagnostic pathway. The formation of a relationship with a health care provider whether this be a GP, diagnosing clinician or nurse was spoken about in both the interviews and literature. Men in the interviews in this study spoke about the relevance of trust with their GP along with a sense of openness, with some happy to wait longer to see the GP they felt most comfortable with. This relationship building was also noted by Kirkman et al (2017) and Jones et al (2013) in which trust with a HCP was shown to increase the building of a rapport. Concerns regarding a HCPs ability to perform their role was noted as a barrier to communication, resulting in a negative experience, however this was not reported within the interview findings. Instead, the experience of a previous primary care appointment was shown to be influential to future help seeking. Men would delay going back to see their GP if they had encountered a bad experience such as a negative interaction. Capturing this information can support an increased understanding of the issues faced along the pathway that can result in delays (Scott et al, 2013).

This plethora of factors that can influence a positive relationship between a patient and a HCP, increasing feelings of trust and feeling heard, brings into question the importance of these conversations within healthcare. Appropriate and adequate training in communication with a patient could be beneficial for HCPs, equipping them with strategies such as active listening, the use of body language, timbre and tone. Conversations about possible cancer worries will often already be emotionally charged from a patient perspective, so the importance of these conversations and their subsequent effect should not be overlooked. When it comes to discussion on

the possibilities of prostate cancer investigations, then a counselling style conversation could almost be considered appropriate to allow for informed decision making from a patient perspective.

Findings from this study and the literature review (Conde et al, 2011) concur that only when symptoms became problematic, causing issues such as pain or malaise which resulted in day-to-day living being impacted, would some men then seek help. Feelings of pain or severe unwellness have the potential to impact the communication between a patient and HCP as communication can be hindered. This can be due to the patient's illness impacting their emotional response, their ability to retain information or it can affect future help seeking as a negative thought process can be connected to these appointments. Visiting the GP or nurse equals pain or illness instead of a possible preventative strategy supporting good health.

The topic of prostate cancer can be a sensitive one, due to the prostate being part of the male reproductive system. Good communication and trust with a HCP has the ability to make these conversations easier to approach and discuss (Kirkman et al, 2017). Regular conversations relating to the prostate and its functional health could be embedded within a man's yearly MOT or health check which are often performed when a man gets to a certain age. These checks would provide an opportunity for men to feel more at ease within a medical environment, approach taboo topics easier and improve HCP relationships over time. To further enable positive connotations towards a GP practice, practices could explore potential avenues to make buildings look more inviting, have information open days or establish protocols that work on communication that start from the time you approach the reception desk. Time constraints within a health care environment are inevitable though when it comes to appointments, and these can often hinder communication and relationship building for both patient and HCP.

Language is an important part of the communication process and communication can be hindered when the patient does not understand or is not able to express themselves in their native language. Wales has Welsh as a national language, and the importance of bilingualism was noted by one man in the interviews, feeling the lack of communication in Welsh hindered his understanding and created a disconnect when discussing health matters. Ensuring all GP practices and



secondary care departments have a Welsh speaking professional in their team could help alleviate some of these issues. Language implications were absent in the narrative literature review adding a different element, however barriers relating to health education often due to cultural norms were noted when exploring African and African Caribbean men's help seeking (Nanton et al, 2011; Anderson et al, 2013; King Okoye et al, 2019). The interview sample in this study was predominantly white, with only one man of mixed race, so cultural values were not a topic of conversation. Awareness of how culture and heritage can affect communication and relationship building should be further explored and more diverse samples involving men with different ethnicities would support this.

Communication and relationship building facilitators and barriers were apparent within the secondary care pathways. A consensus was observed within the literature and study findings when it came to opinions on support from a nurse. Men within the interviews felt conversations were positive, using words that were easy to understand. This opinion was echoed through Schildmeijer et al's (2019) study where nurses were also seen as approachable, whereas a consultant not so. The lay language used by a nurse or diagnosing clinician may differ and this could influence how conversational communication influences positive relationship building. A breakdown in communication was shown to evoke interactions in which men felt they were not listened too. Feelings of not being heard or understood were shown to cause communication breakdowns in all three diagnostic groups in the interviews and the literature (Schildmeijer et al, 2019; Torishima et al, 2020). Interview findings further expanded on communication barriers with secondary care which were not noted within the literature, notably, a lack of continuity of consultants for appointments, along with a general perceived feeling of lack of interest or time to talk. The factor of continuity could be explored within appointments, with the potential of hospitals aiming to ensure men see can the same consultant if viable. Consultant continuity offers the opportunity for both patient and clinician to build rapport and improve further one to one appointments.

The addition of providing supplementary information during an appointment to aid clarity and understanding or having a friend or family member attend the appointment was harmonised in both the interviews and the literature. Torishima et al (2020) found men felt the often casual way a diagnosis was given was unkind and

attendance with a family member or friend could help alleviate this upset. Having a companion also improved the relay of important information and decreased feelings of dismissal. The concept of a family or friend as a mechanism for support during an emotive appointment offers opportunities to support a man's desire to feel heard by having an advocate and aid clarity on what was said during reflection. There could however be negative connotations connected with this additional support. Men may feel unable to fully disclose how they are feeling or the family member or friend could be the dominant speaker, not allowing concerns to be heard. Problems such as these can be guided by the HCP who could ensure the patient's voice is at the forefront of the conversation.

Travelling along a cancer diagnosis pathway is an emotional time, often heightening senses of anxiety and confusion, so support in aiding clarity would be beneficial. Safety netting procedures or the production of guidelines for staff to follow when approached by a concerned patient with potential prostate cancer symptoms could be an option in reducing experiences such as these. Facilitators in improving communication and relationships involved feeling heard and listened too. Positive recollections of appointments and HCPs were given in the interviews and literature when appointments resulted in men feeling their concerns were considered and they felt cared for (Kirkman et al, 2017; Jones et al 2013).

### **Influences in decision making**

Influences from family members and friends on decision making were a common thread within both the interviews and literature. Influences were seen with initial health care seeking, PSA testing decisions, and querying secondary care investigation processes. Recommendations or conversations with friends and family members often propelled a man in seeking initial help, although reasons for this differed in nature. The literature (Ferrante et al, 2011; Nanton et al ,2011; Shaw et al, 2013 & Forbat et al, 2014) and interviews highlighted family members were often pivotal in influencing a man to take the first steps in seeking help or when coming to a decision on whether to have PSA test, with this being more often from a spouse or partner. Pressure placed on some men from family highlighted within the literature (Shaw et al, 2013) was confirmed by the interviews and created an opposite effect,

stalling initial help seeking and causing some men's self-awareness and attitudes to change.

A man's stoic attitude towards help seeking was shown within the interviews and literature with some men not discussing their symptoms or feelings with anyone and making decisions alone. Talking to a male friend could be seen as easier due to being able to open up more about private male issues and the benefit of this was observed within the literature and confirmed within the interview findings. Friends were seen to be supportive in the literature (Ferrante et al, 2011; Jones et al, 2013). And again, the interview findings confirmed this. In the interviews, Gerald attended a PSA testing event with a group of friends for camaraderie and Wilfred chose to confide in a friend about his journey and his family. There are still however barriers, when it comes to perceived societal norms and men expressing their thoughts and feelings, with these often being more apparent within the older man due to generational norms. There are now media campaigns encouraging men to speak more about their health and seek help. Continued awareness should help change these perceived societal norms over time, benefitting the younger generation and educational support through health campaigns starting in schools could support a wider family awareness, allowing the younger generation to inform the older.

Watching another man go through a prostate cancer journey could initiate thoughts on health belief systems and provide an alternative view. Watching a friend or family member go through an illness was shown to initiate an evaluation of one's own health and health beliefs (Jones et al, 2013; Shaw et al, 2013; Forbat et al, 2014) and also observed within the study findings. These observations could generate internal dialogue, propelling possible symptom connections or a thought process concerning a man's health belief system. Interview data showed how observations of other health journeys were not always positive and this was not observed within the literature. Men felt put off after watching others go through an invasive test or a lack of disconnect when related to family history. This brings again into question the benefit of raising awareness of prostate cancer when there are risk factors, such as a family history.

The media played a prominent factor for some men in this study when it came to the initial decision to seek help, yet this was sparsely mentioned within the literature.

Oscar spoke about how a newspaper article highlighting the possible symptoms of prostate cancer propelled him into seeking help after he ticked every box in the 'all that apply' questionnaire. Whereas Keith credited watching a television programme as his reason to seek due to making a symptom connection. For others in the study, a media influence was not spoken about, and some men declared there was more than enough media awareness on prostate cancer. It is important to reflect on the timing of these interviews as they were conducted after the men had received a diagnosis. Due to this diagnosis, a heightened sense of awareness to the topic may have been experienced, whilst before or during the start of these journeys, this may not have been the case. Friends and family influences, observing others and the media could all be considered as informal networks that have the potential to influence the primary and secondary pathways to diagnosis. These informal networks all have the capacity to expedite the decision for that first help seeking appointment. They can also help create a deeper internal monologue on health, resulting in possible swifter journeys to diagnosis. The media has the potential to not only influence a man's decision to seek help but also create a domino effect, in which it influences a friend or family decision to start a conversation. As such, it would be beneficial to explore these influences and their potential further through other studies.

### **The provision of information along the diagnostic pathway**

The provision of information along the diagnostic pathway was spoken about in connection to the emotional and physical responses it evoked. Responses were noted within the primary and secondary pathway within the interviews, adding to the literature, which focussed more on information provision within the secondary pathway, involving procedures, investigations and diagnosis.

Within the primary pathway, men in this study reported a variety of experiences. Some appointments were described as informative, with regular updates on the referral process given by either the GP or nurse. Others reported having to chase up appointment information and receiving mixed messages. This disparity could be linked to communication differences or formed relationships as previously discussed between HCPs and the men and adds to the literature. George's confusing route to diagnosis may have been exacerbated by the way information was relayed during

one of his appointments, over the telephone or by the letters he was sent. People retain and absorb information differently, dependant on their health literacy. Looking at various ways to ensure updates or information are adequately understood would be beneficial. The literature (Appleton et al, 2019; Kirkman et al,2017) and interviews also found that the way information was relayed by an HCP was pivotal when it came to wellbeing. Kirkman et al, (2017) found access to a plethora of approaches beneficial when it came to providing information, although this is not always achievable. Further consideration into ways of providing information whether it be over the telephone, face to face, a written information sheet or educational awareness could foster a more resilient wellbeing. The introduction of supported written materials were shown to help reduce anxiety and improve feelings of security for some men (Mathers et al, 2011; Kirkman et al, 2017; Appleton et al, 2019).

The provision of information was shown to impact the overall reflection of the journey to diagnosis for men and agreed in both the interviews and the literature (Appleton et al,2014; Kirkman et al, 2017; Torishima et al, 2020) with not all wanting to be kept regularly informed (Nanton & Dale, 2011). The majority of men felt they were given adequate information during the secondary pathway in their journey. However, some men questioned its format as again, a preference was given to the relay of information in person and not just reading materials. These observations again correlate a link to the benefit of providing information within robust communication methods. Utilising these along with counselling style conversations could offer greater opportunities for more open dialogue. Seeing more than one or several consultants along the secondary pathway seemed to further impact the provision of information with some being lost in translation. The interview findings data found that men that attended the rapid diagnostic clinic provided positive accounts of their secondary journey. These rapid diagnostic clinics are in place with the aim of providing a more streamlined pathway to support earlier diagnoses and offer an opportunity to expedite cancer diagnosis within the UK (Erridge et al, 2021). Rapid diagnostic clinics could be highly beneficial in improving both a men's prostate cancer journey experience and a reduction in time to diagnosis. These clinics were not discussed in the literature adding new data to the overall topic. Providing more rapid diagnostic clinics in expanded areas of Wales further has the opportunity to

improve the way information is relayed, reduce anxiety, stress, support a timelier diagnosis and increase equity in health services.

### **Procedures and their impact**

The interviews in this study provided various responses in relation to having a procedure and its impact. It is important to note that due to the geographical spread of the participants, types of procedures and timings were varied. Responses in relation to how the men in the study felt they understood these procedures and their impact ranged from feeling fully informed, ill-informed or the need to not understand. Again, the men who attended the rapid diagnostic centre and had all investigations and procedures conducted in one day, reported a good understanding of their procedures and were happy with the process. There was no literature pertaining to the use of rapid diagnostic clinics or access to procedures. Men experiencing longer waiting times overall reported less understanding of the procedures they experienced, along with a lack of a sufficient explanation. Again, trust in an HCP was imperative, impacting how procedural information was absorbed or discussed and this was often due to good communication.

Rapid diagnostic centres again provided positive feedback from the men who attended them. These centres further ensured an mpMRI was conducted before a biopsy, whereas men under other health boards treated in a hospital were given a biopsy before their MRI. The interviews provoked the most discussion on this topic and due to previous studies and supporting information, some men requested an MRI before a biopsy but were refused. These procedural differences between health boards in Wales pave the way for further discussion as these differences seemed to evoke emotion within the men. Offering the same procedural journey within all health boards in Wales would help build trust and feelings of inclusion, instead of further questions and resentment. The prominence of this discussion within the interviews and not the literature may be due to the literature pertaining from various countries and not just the UK. These countries offer different screening programmes and procedural pathways to diagnosis.

The biopsy evoked the most discussion and was concurred within the interviews and literature with emotional reactions resulting in stress, worry and unease (Mathers et al, 2011; Appleton et al, 2015; Grogan et al, 2017). These emotional attachments

were often related to the invasiveness of the procedure and the embarrassment felt whilst the procedure was being conducted. This invasive style of procedure can often increase worry and anxiety. Men often admitted to an understanding that the procedures were intimate, however apprehension still followed. The literature (Appleton et al, 2015; Grogan et al, 2017) and interviews both found that the biopsy was looked upon as revolting, aggressive, painful, invasive and embarrassing. The literature further reported a number of physical reactions to the procedure including infection and discomfort. Open communication and information could help alleviate some worry and embarrassment, however due to the nature of the procedure these types of emotions will almost always be attached to these types of investigations.

### **Self-awareness and perception**

Self-awareness throughout the journey to diagnosis was notable within the literature and interview findings, and prevalent within both the primary and secondary care pathways and the three different diagnostic journeys. Self-awareness can be a contributing psychological patient factor that can impact all areas of the pathway to treatment (Scott et al, 2013) along with social and cultural factors. Within the literature (Mathers et al, 2011; Appleton et al, 2015; Appleton et al, 2019) journeys were often described as confusing resulting in feelings of vulnerability and uncertainty. Interview findings found journeys would often turn into feelings of confusion especially when men had described feeling fine or normal when first visiting the doctor or GP. These feelings would be described when men considered themselves asymptomatic or were experiencing mild symptoms that they put down to a process connected with old age. These mild symptoms would sometimes evoke thoughts of feeling 'not quite right' but men would struggle to pinpoint the reason.

This casual awareness often later connected to feelings of confusion but also shock or surprise when told of their referral to secondary care. Again, a lack of symptoms or painful or worrying symptoms seems to correlate with levels of concern. Symptom awareness as discussed in a previous chapter seems to correlate with a man's perception of his own health and this brings into question how a physical symptom can often change someone's perception or awareness of illness or its possibility. Campaigns focussed more on men with a previous immediate family history of prostate cancer or black men who have a one in four chance of getting prostate

cancer in comparison with a one in eight for the rest of the population (Prostate Cancer UK) could be more beneficial, however these need to be created from robust evidence, and in the consideration of behavioural science relating to help seeking behaviour (Whitaker, 2020; Hannaford et al, 2020). The 'Be Clear on Cancer' campaigns led by Public Health England focus on different types of cancer and have been found to impact help seeking and referral rates (Lai et al, 2021), however an evaluation of a previous prostate cancer campaign found it was successful in raising awareness but provided a lack of evidence on improving outcomes for men subsequently diagnosed.

Interestingly, the literature only highlighted how the pursuit of certain behaviours could either provide a protective factor or increase the prevalence of getting prostate cancer (Conde et al, 2011; Ferrante et al, 2011; Mathew et al, 2011; Yu Ko et al, 2018). These perceptions contributed towards feelings of good health and a decreased likelihood of getting prostate cancer. These studies however were not conducted within the UK so health campaigns or health messages may be focussed more on these aspects of preventative good health measures within the other countries and health education may differ.

Trusting in a HCP was spoken about when it came to feelings of wellbeing along the journey to diagnosis in this study and the literature. A lack of trust created a barrier, whilst increased trust seemed to improve feelings of assurance and care. For men in the interviews and the literature, a referral evoked feeling of assurance for some and worry for others. This assurance was felt as men were taking charge of their health, however the worry that could be generated from a referral delayed initial help seeking for some, for fear of the possible outcome (Jones et al, 2013; Ferrante et al, 2011; Shaw et al, 2013).

Diagnosis itself also evoked various emotional perceptions within this study. Feelings of optimism were spoken about by some men in the interviews and Gerald felt he had lived a good life up until the point of diagnosis. For others however, resilience was tested, and it became another health issue to worry about. Interestingly, many men spoke about how their journey to diagnosis had propelled them to speak to other friends and family members, highlighting the possible symptoms and risks of prostate cancer, along with wellbeing advice. There is an opportunity here for men



who have experienced a prostate cancer diagnosis to support other men going through a diagnosis as peer support or become a tool in helping increase local awareness through community champions or national awareness.

## **Summary**

This chapter has provided an opportunity to amalgamate both the literature review findings and the study findings to allow for a thorough discussion. The themed headings have provided a structured approach and allowed the research question and the aims and objectives of the overall study to be explored. The interactions and experience of the men in the study and the literature have been compared, critiqued and contrasted. Possible points along the diagnostic pathway have been noted, along with possible interventions to promote a timelier diagnosis and reduce unnecessary delays further described within each section. These identifying factors will now be further discussed in the resulting conclusion chapter. The chapter will provide an overview of the study and a summary of the key findings, along with its strengths and limitations, and concluding with ideas on implications for future practice, policy, and research.

## **Chapter 6**

### **The Conclusion**

## Conclusion

This qualitative study's overall aim has been to explore the ways in which the accounts of men newly diagnosed with prostate cancer in Wales, can increase understanding, improve care, and inform possible interventions that could reduce unnecessary delays to diagnosis. The research question aimed to explore how the interactions, experiences and influences of 21 men living in Wales who experienced either an early, late or asymptomatic pathway influenced their journey to a prostate cancer diagnosis. The study has highlighted factors which can influence the time to diagnosis and illuminated points along the pathway in which improvements or changes could be made. Discussions on potential interventions that could be implemented have also been provided.

The thesis has been divided and presented in sequential chapters. Chapter one provided an introduction to the research, outlining the background on prostate cancer, facts and figures, current policy and recommendations. Research aims and objectives are introduced and further clarified. Chapter one also provided an introduction to the methods used for reviewing the literature, collecting and analysing the data. Chapter two consists of a comprehensive narrative literature review. Models are provided for clarity on the formation of the research question, the literature inclusion and exclusion criteria, along with the search strategy. All included papers were critically appraised, and the findings of the review are presented thematically. The literature narrative review centres around seven key themes that evolved from the analytic process: Barriers to seeking help, Communication and relationships with HCPs, Provision of information and services, Investigation awareness- harms and benefits, Understanding and effects of procedures and Self-awareness and wellbeing.

Chapter three provides the methodology for the study, demonstrating the robust study design. This chapter also details the processes taken to ensure ethical standards were met and approvals granted. The recruitment process and data collection methods are defined and detailed, along with the framework data analysis method, mapping, and interpretation. Chapter four presents the study findings. They are displayed through six identified key themes and further sub-themes derived from the data analysis process to provide structure and focus.

Chapter five is the discussion chapter and brings together the interview findings and narrative literature review findings and again takes a thematic structure, utilising the themes and sub-themes that were presented within the study findings. This chapter discusses the aims and objectives of the study, comparing both the literature and study findings. Points on further exploratory ideas, areas of interest and possible interventions are also generated. This concluding chapter will summarise the key findings from the study, consider strengths and limitations and outline possible policy, practice and further research implications.

## **Summary of lay findings**

### **Theme one-understanding testing and symptom awareness**

Sub theme one explored men's symptom awareness and the ways in which they seek help. Lower urinary tract symptoms were experienced in all three journey categories and looked upon by most as a normal part of the ageing process. This confusion between symptoms of old age or potential signs of prostate cancer impacted the uptake of help seeking in primary care for some. Living with a comorbidity was another key factor within the interviews. Physical changes and symptoms associated with other conditions had the potential to impact the connection with possible prostate cancer and help seeking.

The second sub theme focussed on primary care investigations and understanding. When it came to the various investigations used to initiate a referral to secondary care, the PSA test was widely discussed. There were varied responses in the awareness and understanding of this blood test and its implications. A greater awareness for some was due to a family history, observing others, media campaigns and local health initiatives. Whilst others recounted not being aware they had a test or the reason why it was undertaken.

### **Theme two- influences on decision making along the diagnostic pathway**

Within this major theme, one sub theme explored how friends and family can influence a man's decision-making thought process. Family advice was seen more as pressure and propelled some men into open conversations and seeking help, whilst initiating a delay in others. Friends were reported as being used as a support network. Conversations with friends influenced decisions to request PSA tests and

seek help at a primary care level, along with generating discussion on further investigations whilst under secondary care.

The influence of the media was another sub-theme and was spoken about by many as the catalyst to first seeking help. Newspaper articles and television programmes were heralded as influential. However, for some, media awareness did not have an effect due to a lack of personal connection.

The observation of others was the third and final sub theme and propelled some men into making the first appointment with their GP. Observing a friend, neighbour or family member go through a prostate cancer or other cancer diagnosis initiated a new thinking process and a possible self-connection. For others these observations actually delayed help seeking with negative recollections, putting some men off going to see their GP. A few recollected observing others go through a similar journey but made no connection to themselves.

### **Theme three -provision of information along the diagnostic pathway**

A sub-theme associated with provision of information along the primary pathway was found here, but few men spoke about this in detail. Information was relayed to the men through conversations at appointments, over the telephone or by post. Further supplementary Information was given during these conversations, with some men reporting this offered clarity, but for others caused confusion.

A second, related Sub theme explored information provided during the secondary pathway and provided plentiful accounts from the men with detailed responses on information provided during appointments and results. Emotionally, accounts varied; Men who received their diagnosis in one day due to attending a rapid diagnostic clinic reported positive experiences all information needed. Men who experienced a different pathway to diagnosis, overall reported feeling their journey was mapped out for them. Provision varied however and opportunities for more consistent and relevant communication along with the information given between men and their HCP was noted as a beneficial aspect. The way information was interpreted varied, highlighting the importance of lay information in a range of formats.

### **Theme four- communication and relationships with health care providers**

Theme four was a pertinent theme and was found to be intertwined throughout many others. Men wanted to feel heard and have their concerns listened to and many reported GP conversations where active listening took place. Others felt dismissed and attending several appointments with different HCPs was shown to impact this.

The formation of relationships was noted as important, with a pre-established connection shown to be a positive factor, especially at the beginning of the journey and initial help seeking. Men preferred to see a GP they already knew and felt comfortable with as it evoked feelings of trust and reduced initial anxieties. Without these reported relationships, men often felt barriers to communication were apparent, impacting further appointments. During the secondary care interval, men found relationships were impacted by the ability to see the same consultant or HCP. Nurses were described as helpful and approachable with consultants referred to as harder to understand and often aloof. Men also felt their own issues hindered the patient and HCP relationship if they did not like hospitals or felt the experience stressful and confusing.

A third Sub theme described men's perceptions of mixed messages received from communicating with HCPs, especially when the information was regarding a possible referral. Interviewees recalled feeling confused after a conversation with a GP, particularly when given different advice from two HCPs within the same practice.

### **Theme five - procedures and their impact**

When discussing medical procedures and their impact, participants recounted their understanding of procedures they had in secondary care. Most men described feeling informed, with an understanding of their upcoming procedures. Again, the rapid diagnostic centres where all procedures were undertaken in one day produced positive recollections. For others, longer waiting times and lack of explanations left feelings of distrust and a lack of understanding. Issues with procedure impact many, with some men being offered an MRI before their biopsy and others after.

Another sub theme was the accounts men gave of having their biopsies. The effect of the biopsy produced a variety of reactions. Reports of not feeling anything and an easy acceptance of procedures was contrasted with other accounts of invasive, revolting procedures which brought worry and embarrassment and post investigation discomfort.

## **Theme six- self-awareness and perspectives**

Men's sense of self awareness and perspectives of their journeys were woven throughout the interview data, but predominantly spoken about when discussing the beginning of the journey and diagnosis. Assurance, anxiety, resilience and worry were all emotions reported by participants. A lack of symptoms resulted in an absence of concern or worry at the start of the journey. This absence evolved into shock upon referral and subsequent diagnosis. Men experiencing bodily changes were often ascribing them to old age and they were further dismissed unless symptoms were alarming or impacting day to day life. Perspectives changed if family members had been diagnosed or men had a greater understanding of PSA results and risk. Referral brought anguish and worry for some whilst assurance for others with a perspective on the transience of life. Men reported increased resilience and appreciation of the life they had or, conversely, feeling an increase in worry and distress. Trust was imperative for the patient and HCP relationship, with many making allowances for experiences such as late appointments or long waiting times due to stresses and strains put upon the NHS.

This exploratory study has added to the body of evidence relating to the experiences, interactions and perspectives of men who have experienced a prostate cancer diagnosis. It has highlighted the ways men navigate their journeys and has made an impactful and important contribution towards the evidence base.

### **Strengths and limitations**

The strengths and limitations of this study have been considered to support reflection, improve professional practice, and allow a deeper interpretation of the data to be considered.

#### **Strengths**

This study is a piece of original research which will enable a new contribution to what is already known on the topic. It has been rigorously undertaken with reflexivity explored and intertwined. A comprehensive narrative literature review of the current qualitative literature on the topic has been provided and the study was carried out ethically and adhering to all approvals. The study was supported by the Health and Care Research Wales workforce to support the initial survey through to sample

method eligibility for recruitment. The recruitment sample was taken from five different health boards within North and South Wales to provide breadth of perspective across Wales. Interviews were delivered at the place of the participant's choosing, enabling participants to feel more at ease and supporting their wellbeing. A comprehensive methodological structure was utilised and documented, using the framework method for analysis and the study was funded by Cancer Research Wales and links in with another larger study enabling further analysis of the findings.

## **Limitations**

The interview study sample was self-selected due to the sample being taken from the existing DJiP study. The socioeconomic status of participants was not considered within the sample and it lacked racial and ethnic diversity as all but one of the men were white British. The perspectives of gay men have also not been considered within the literature review and the interview sample. The three categories used to initially group the sample together proved to be unsuitable as the nature of the accounts was too complex to allow for such categorisation. The overall sample was able to recruit more participants from Betsi Cadwaladr University Health Board and would have benefitted from larger samples from the other health boards to provide a broader perspective. Restrictions due to time and travel constraints also influenced interviews with men from certain health boards. Covid-19 influenced many areas of the study, preventing accessibility to the university campus, face to face meetings and access to certain materials and paperwork.

## **Policy implications**

There are several implications for policy that could be explored due to the findings from this study. Enabling a more established and uniformed pathway for all men in Wales no matter what health board they are under, could offer greater stability and less confusion in the future. Health promotion campaigns improving awareness of all elements of prostate cancer at a national level would be beneficial. Aiming these campaigns at not just men but also their influencers would offer further opportunities to increase awareness and support men in their decision making along the diagnostic pathway. Educational message should focus on publicising the importance of that first conversation with a GP or health care provider over any concerns with prostate health or possible prostate cancer symptoms.



Provision of a primary care tool kit full of resources such as decision aids and up to date information on prostate cancer to support a consensus on advice given. These kits could be disseminated out to all practices in Wales to correspond with the public health campaign. Consideration should also be given to how these campaigns are implemented and displayed, with information being provided in various formats to support clarity and understanding

### **Practice implications**

An increase in more open and in-depth conversations with patients in primary care over prostate health could facilitate a timelier diagnosis and potentially reduce unnecessary delays for some men. Yearly health checks could be used to engage in more open conversations over prostate health, with posters in waiting rooms displaying the importance for men to start these conversations. Support for health care providers on how to have these counselling style conversations, along with using the tool kit should be offered. If these resource packs are utilised as standard and given with training, safety netting procedures could be improved. Delivering both a policy and practice intervention in parallel offers a robust opportunity for both policy and practice intervention to be successful.

### **Implications for further research**

This study has indicated how further research focussing on the ways improved education for both patient and health care provider could influence a prostate cancer diagnosis and would be beneficial. A deep dive exploration of current 'decision aid' literature in circulation would help improve patient and HCP communication and inform policy and practice implications. Further research on the impact of informal influencers such as friends and family on a patient's initial decision making, the effect of support through the attendance of appointments or communication with HCPs, could all be avenues for exploration. Further ideas for research could be focussed on men with other comorbidities who have received a diagnosis of prostate cancer; Do comorbidities create a barrier to seeking help due to symptom confusion or can they be a facilitatory factor in opening up conversations.

Rapid diagnostic clinics produced positive recollections for men in this study and seemingly a quicker diagnosis whilst under secondary care. Further research on men's experiences of using these clinics could offer evidence to support further

clinics opening within Wales. Several men spoke about the importance of sharing their journey with others for wellbeing support and to provide advice to others. Research into the benefit of utilising men who have been through a prostate cancer diagnosis in supporting others, could shed further light on new ways informal networks may influence men and their wellbeing.

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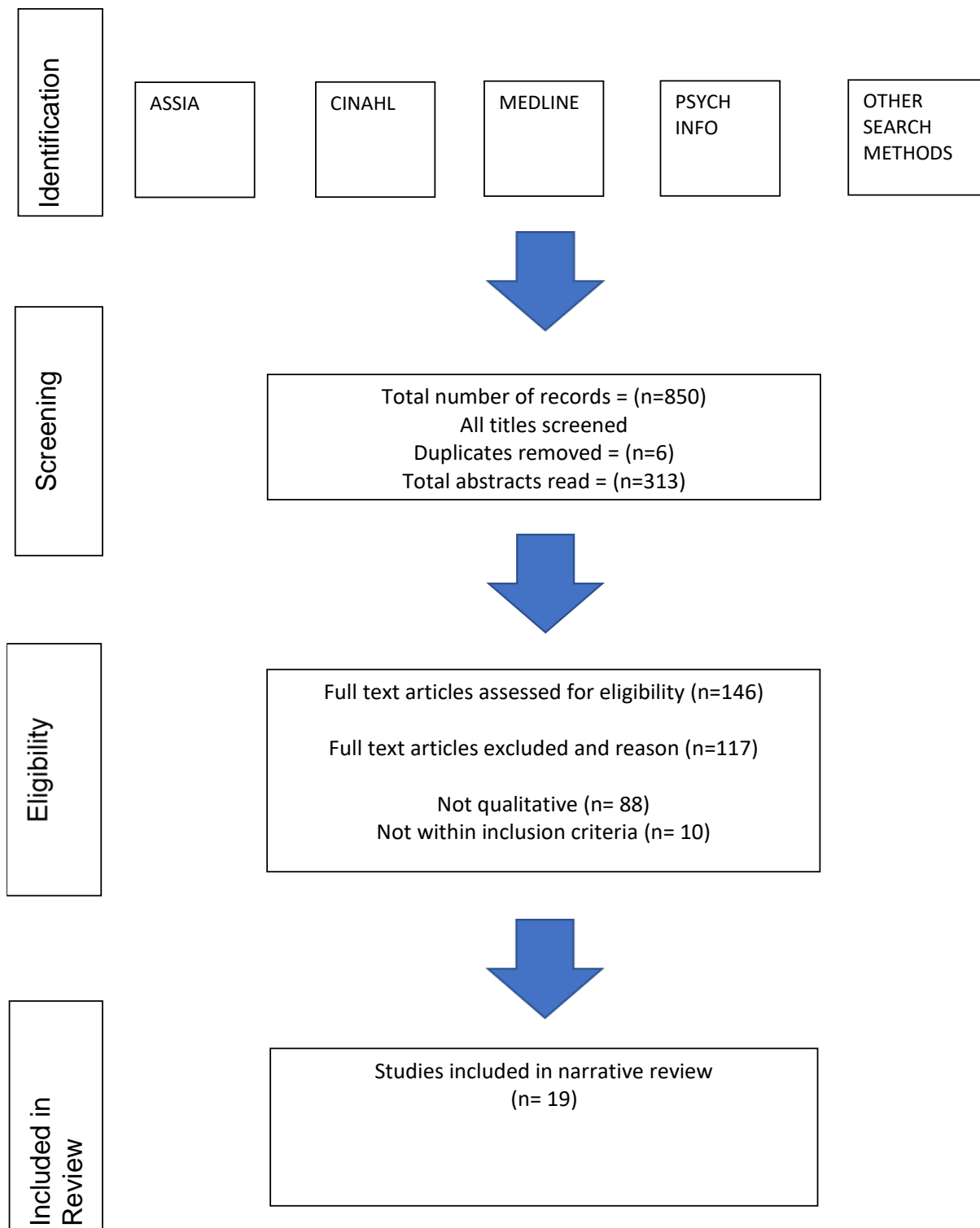
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# Appendix

Literature Search Flowchart Strategy Diagram





**CASP Checklist:** 10 questions to help you make sense of a **Qualitative** research

**How to use this appraisal tool:** Three broad issues need to be considered when appraising a qualitative study:

- ▶ Are the results of the study valid? (Section A)
- ▶ What are the results? (Section B)
- ▶ Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

**About:** These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

**Referencing:** we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

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Paper for appraisal and reference: Examining risk perception among men with a family history

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes	<input checked="" type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

- HINT: Consider
- what was the goal of the research
  - why it was thought important
  - its relevance

Comments: The introduction paragraph breaks down the relevance and importance of the study in detail and then there is a small sentence at the end talking about the goal. Relevance/Importance: little is known about relevance of additional factors that influence risk perceptions in men with a family history of p.c.a. relevance of exploring this is risk perception is associated with an individual's intention to participate in screening and with psychological distress. Backs up relevance of research with other studies. Not just inheritance for risk perception, but also environmental and behavioural factors. Importance explained as current research is sparse. Goal of research: To explore factors that influence formulation of risk perception among men with family history of p.c.a who have initiated p.c.a screening. Understanding this contributors could help reduce risk distortion and increase adherence to screening programmes and reduce psychological distress.

2. Is a qualitative methodology appropriate?

Yes	<input checked="" type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

- HINT: Consider
- 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

Comments: Qualitative research seems to be the best way to address goal as the need to understand participants conceptualisation of their risk of developing prostate cancer due to family history. Sample size, saturation, eligibility were explained.

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes	<input type="checkbox"/>
Can't Tell	<input checked="" type="checkbox"/>
No	<input type="checkbox"/>

- HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments: Researcher does not justify why they chose the design

4. Was the recruitment strategy appropriate to the aims of the research?

Yes	<input checked="" type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- 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
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments: Yes researcher explained how participants were selected and why they were most appropriate. It was also discussed the reasons why some participants chose not to take part. A prostate centre at a hospital was used for recruitment. Sample criteria; men deemed to be high risk, date they were approached, eligibility, sample size, demographics.

5. Was the data collected in a way that addressed the research issue?

Yes	<input checked="" type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If the setting for the 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 are 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

Comments: Setting justified as patient's preference as either telephone or face to face and collected by semi structured interviews. No justification for why this method was chosen though. Explanation on how questions were created due to pooled knowledge and clinical expertise of investigative team and modified after 7 interviews due to analysis but no great explanation on the changes. Form is clear and audio taped. Saturation discussed clearly as no new information was emerging regarding a theme and all were established.

6. Has the relationship between researcher and participants been adequately considered?

Yes	<input type="checkbox"/>
Can't Tell	<input checked="" type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- 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

Comments: No examination of own role of researcher or potential bias during formulation of research question or choice of sample and location. It does however discuss in conclusion how limitation was the sample was highly educated and high socio-economic and meaningful purposive sampling was unavailable due to time frame. It was highlighted how the sample was unlikely to reflect men from different backgrounds, limits generalisation. Implications to research design were highlighted and adapted.

#### Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes	<input type="checkbox"/>
Can't Tell	<input checked="" type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- 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)
- If approval has been sought from the ethics committee

Comments: No reporting of how research was explained to participants but ethics was approved. No discussions on consent, confidentiality only discussed in relation to changing of names for report. No discussion on how participants were after study or how this was dealt with.

8. Was the data analysis sufficiently rigorous?

Yes	<input checked="" type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- 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

Comments: Paragraph on data analysis, interpretive thematic analysis used and how themes were created. Text was broken down into meaningful units followed by clustering. Data is presented to support themes and findings and direct quotes are also used. No discussion. Analysis performed by 5 researchers, if no agreement on theme reached, it was explained how investigator met to review and came to agreement. Discussed unexpected findings and gave potential reasoning for this.

9. Is there a clear statement of findings?

Yes	<input checked="" type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider whether

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's 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

Comments: Clear statement of findings, through a discussion and conclusion section. Some discussion findings are attributed to other psychology literature theory. Some credibility given by association with other theory and themes. Findings are discussed in relation to original research question.

Section C: Will the results help locally?

10. How valuable is the research?




HINT: Consider

- 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
- 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

Comments: Results are discussed in relation to supporting influencing future screening and strategies and supporting and expanding theoretical framework already established. No new areas identified but added how results could be used to improve.

**CASP Checklist:** 10 questions to help you make sense of a **Qualitative** research

**How to use this appraisal tool:** Three broad issues need to be considered when appraising a qualitative study:

-  Are the results of the study valid? (Section A)
-  What are the results? (Section B)
-  Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

**About:** These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA ‘Users’ guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

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Paper for appraisal and reference: Men's perceptions of pca diagnosis and care: insights from

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes	<input checked="" type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

- HINT: Consider
- what was the goal of the research
  - why it was thought important
  - its relevance

Comments: Goal was to contribute to evidence from which can be built continuing improvements in prostate health care. Sought to explore perceptions and experiences of pca diagnosis, treatment and care. Clear statement of aims and relevance. In Australia interviewing pca patients and also men who hadn't been diagnosed. 21 men qualitative interviews over phone.  
THEMES- CASE FINDING, DIAGNOSIS,( TREATMENT AND CARE mostly not relevant but some sections are), SPREADING THE WORD.

2. Is a qualitative methodology appropriate?

Yes	<input checked="" type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

- HINT: Consider
- 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

Comments: Researcher aims to seek explanation and meaning, so states qualitative study design most appropriate.

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes	<input checked="" type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

- HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments: Discussion on what method used and how this was undertaken. Justification as highlighted above and explained.

4. Was the recruitment strategy appropriate to the aims of the research?

Yes	<input checked="" type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- 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
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments: Explanation on how participants were recruited and the reasons for different participant inclusion criteria. Men who didn't complete the paperwork were not included. Participants were sought from local community advertising and through the prostate cancer registry.

5. Was the data collected in a way that addressed the research issue?

Yes	<input checked="" type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If the setting for the 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 are 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

Comments: Setting explained as telephone interviews but no justification as to why these were chosen. Semi structured in design with topic guide description and opportunity to access it as separate document. No discussion on data saturation, but clear breakdown of recruitment method.



6. Has the relationship between researcher and participants been adequately considered?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input checked="" type="checkbox"/>

HINT: Consider

- 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

Comments: The researcher's adequate background is highlighted for the reason they conducted the interviews but no bias or potential influence from the researcher or implications on changes of research design.

#### Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes	<input checked="" type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- 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)
- If approval has been sought from the ethics committee

Comments: States ethical approval granted by ethics committee, however should be noted that each participant was given \$20 to participate. Pseudonyms were used and identifying details deleted before transcription

8. Was the data analysis sufficiently rigorous?

Yes	<input checked="" type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- 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

Comments: Clear description of data analysis and how themes were derived and 4 researchers finalised the emerging themes. Themes are broken down with supporting quotes.

9. Is there a clear statement of findings?

Yes	<input checked="" type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider whether

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's 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

Comments: A clear statement of findings through thematic presentation. Findings are discussed in relation to original question and credibility added by supporting studies.

Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider

- 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
- 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

Comments: Research is valuable to support aims of study, however there is no section that talks about strengths or limitations of study to show reflexivity and evaluation.

### Data Summary Chart

pca= prostate cancer    Part= participants    HCP- health care professional

Author/date: Location of author	Title of paper	Type of literature	Method of research	Main findings	Notes to use for critical appraisal
Mathers S, McKenzie G, Robertson E (2011): United Kingdom	A necessary evil: The experiences of men with prostate cancer undergoing imaging procedures	Primary research	Qualitative research Exploratory and retrospective study design using semi structured interviews. Analysed using Miles and Huberman (1994).	Study sought to explore experience of patients with diagnosis of pca attending imaging procedures. Study states it provides a unique insight into experiences of men with pca relating to attendance for imaging. States health professionals need to listen to patients and learn to deliver better service. Patients reported different routes to diagnosis, showing a personal journey. Imaging procedures were seen as part of the whole story and experience explained as a necessary evil, complex and chaotic. THEMES- Range of imaging procedures, importance given to imaging procedures, provision of information, understandings of procedure, feeling of discomfort and anxiety and receiving results.	Clear aims of research with goal and relevance as explained. Qualitative methodology appropriate as seeks to provide insight into experiences of pca investigations. Adequate to explore retrospective views. Research design appropriate and justified as little being known on topic and allows patient to tell story. Recruitment strategy appropriate and selection explained in detail and why study only focussed on one type of cancer. Also explains recruitment strategy. Data setting justified although participants are recruited through support groups so could show limitation. Data collection clear with semi structured interviews and full breakdown of process showing rigour. Did use patient respondent validity and patients were allowed to take away parts of interview if felt needed. Benefit due to using patient representation although potential issues with data being impacted if participants requested changes in data or removal. No discussion on saturation. Cannot tell if relationship between researcher and participant is considered as researcher role is not mentioned. Bias of sample however is mentioned in limitations. Ethics was obtained and study explained in detail to

### Data Summary Chart

					participants, consent and confidentiality. Data analysis was sufficient with a brief breakdown of thematic analysis and how it derived from the researchers examining the data. There is a clear statement of findings and in conjunction with the original question. Adequate discussion for and against results. Research have potential value from the point of offering recommendations for practice in bullet points and how it can be transferred to other cancers. Previous research brought in for comparison.
<del>Diederich</del> S, <del>Annabek</del> G, Brouwers M, Turner D, Maier R (2017): Canada	Can you un-ring the bell? A qualitative study of how affect influences cancer screening decisions	Primary research	Qualitative research. Focus groups comprising of 93 people looking at prostate cancer and breast cancer screening. 43 men with pca in 5 focus groups.	The study explores whether you can un ring the bell of early detection awareness and whether this is your best protection. Findings state it is a mixture of yes and no. States policy makers need to be more aware of early detection message in the role of a layperson's decision making and anticipate how messages will be shaped. Major factors that influence decision making are participant's family and friends. Older men felt <del>pca</del> screening should be expanded beyond its current usage. Younger men displayed less attachment to early detection messages and had more concern about harms of screening. They were also more receptive to messages if they were informed by	After printing off appendix material the appraisal was easier and more thorough. Original paper didn't hold a large amount of information. There was a clear statement of intended aims of the research. Important however to note that study was also exploring breast cancer and conducted on men who did not have <del>pca</del> . Qualitative methodology was appropriate due to exploration of men's perceptions and understanding of PSA screening. Paper was also part of a larger study examining cancer control scenarios so was not predominantly focused on pca or this specific aim. This is a potential limitation. No mention on why focus groups were chosen to research this topic but does state research was part of wider study again on decision making in cancer. Five groups however were conducted with different aged men helping improve demographics. Recruitment strategy was appropriate with an extra file as an

## Data Summary Chart

			<p>evidence. Men stated they deserve <del>psa</del> screening and un reliable test better is than nothing.</p> <p>The small section which was relatable was the prostate cancer section.</p>	<p>appendix that could be read for further explanation. This information was not explicit on the paper itself. Strategy was to use survey companies so does this does question rigour, however states companies recruited through phone calls using existing databases and participants were then screened using a questionnaire designed by the team. For consideration, if participants were already in a database the sample might already be happy to talk about a variety of topics. Sample was socio demographically sampled for diversity. Data collected through five focus groups with established protocols in place and all participants gave consent. Strength that pilot group was conducted first, however limitation that after second group a new publication was published against use of psa so could have influenced answers. Audio recorded and transcribed with verification on recording to check for errors. No mention of researcher bias, however does highlight researcher qualified and design of study was monitored throughout. Ethical approval and rigorous data analysis explaining how codes and themes were derived. No researcher role examination though. Clear statement of findings and adequate discussion using triangulation of other studies for support. Also, respondent validation used in checking interviews transcribed. findings discussed in relation to original question.</p>
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## Data Summary Chart

				Limitations of study as valuable locally as not generalised to population, a diverse mix though! Canada may also have different screening policies than the UK so this could impact comparisons. Does offer perceptions of what could influence a layperson's screening decision and aims to understand complex interplay of factors which could be transferred.
Partin M, Lillie S, White <del>K.Wilt</del> <del>T.Chrousos</del> <del>K.Taylor</del> <del>B.Burgess</del> D ( 2016): USA	Similar perspectives on prostate cancer screening value and new guidelines across patient demographic and PSA level sub groups: A qualitative study	Primary research	Qualitative research Interviews with 26 men from veterans' healthcare system exploring screening using inductive approach informed by grounded theory	Findings are in relation to new guidelines from USA task force recommending against PSA screening for all men. This is not the same as UK so findings may not be transferrable, however some elements may be useful. Veterans were used as a sample and findings were most men expressed misconceptions about benefits of pca screening and had difficulty identifying harms with it. States due to results that targeted educational materials by race, age or psa level may not be necessary and efforts to inform psa screening decision making should address the misconceptions. THEMES- perceptions about beliefs of PSA, harms, reactions to screening and motivations for decisions.
				Study conducted in USA with veterans and examining usptf recommendations about not screening using psa so does not align with views of UK or sample. Methodology appropriate as exploring perceptions. Research design appropriate as reason given to explore older men and subgroups as lack of information on their views. However, sample was from veterans so this could skew data but their recommendations support not screening. Participants were recruited through medical records and without diagnosis of <del>psa</del> with a large age range. Purposive sampling used and stratified by race. 150 randomly recruited from over 11,000 but this was not explained. A letter was sent out and part who didn't return the letter to say they were not interested were contacted. They also received \$40 which wasn't explained if this was mentioned before or after interview. Data setting justified and consistent. Topic guide provided and interviewed by two staff. No saturation of data due to sample size a

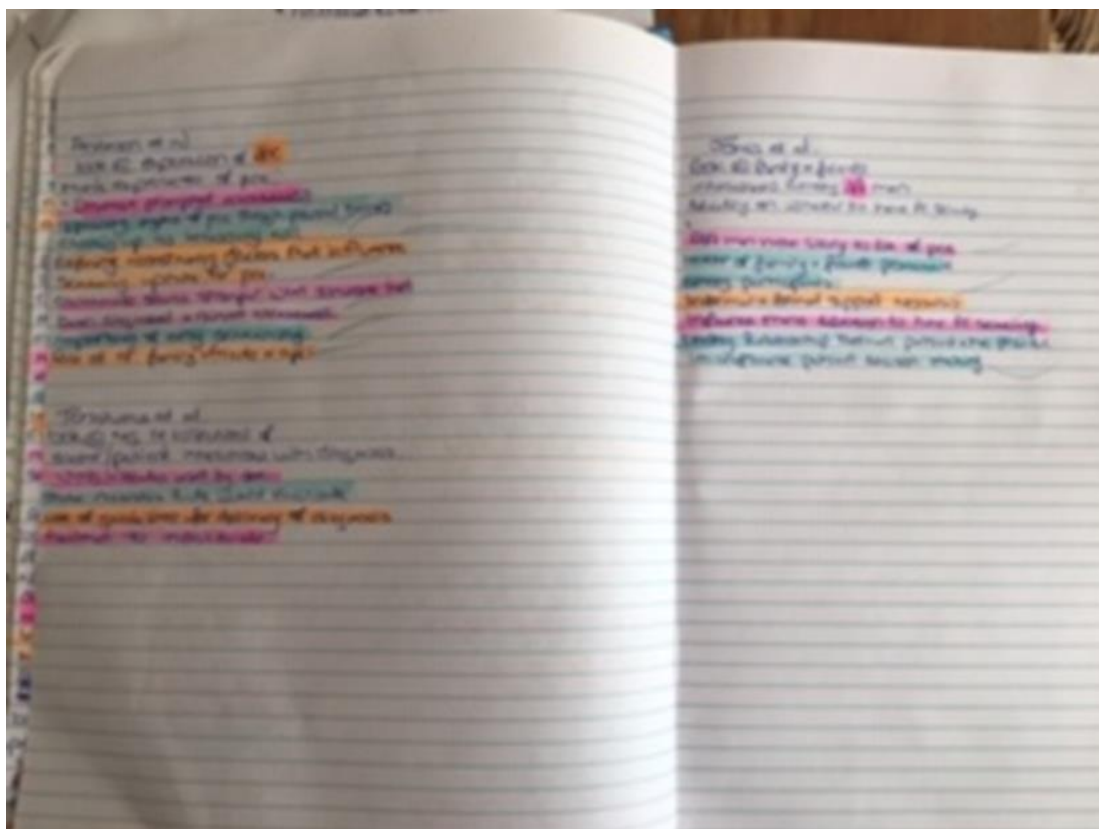
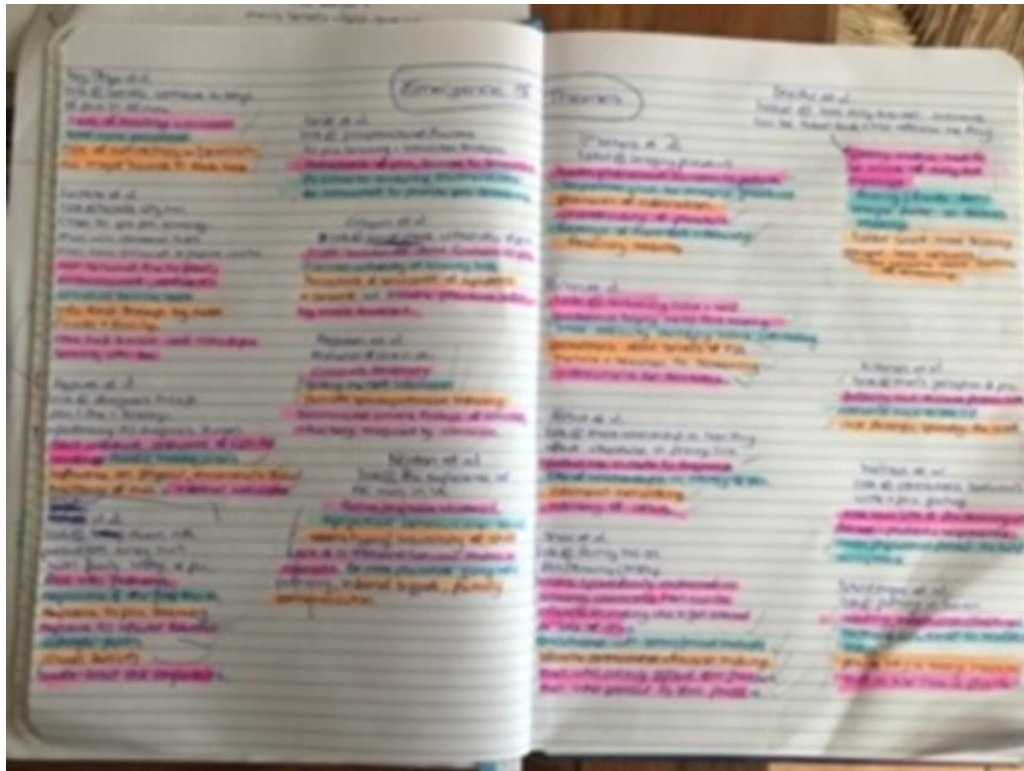
					<p>priori. Does not show relationship between researcher and participant was adequately considered and no mention of researcher bias awareness or influence. States ethical approval through review board. Data analysis showed rigour and discussed using inductive approach with grounded theory due to topic not being widely known. Objective to characterise perceptions to inform hypothesis to test in future quantitative study but not reason why. Clear statement of findings using quotes and broken into themes. Discussion brings in triangulation from other evidence and in response to original question. Unsure how valuable findings are for comparison with my study but offers awareness in context of USA and demographics. It contributes to existing knowledge but also challenges screening programme perception and consideration for future practice guidelines.</p>
<p>Kirkman M, Young K, Evans S, Millar J, Fisher J, Mazza D, Ruseckaite R (2017): Australia</p>	<p>Men's perceptions of prostate cancer diagnosis and care: insights from qualitative interview in Victoria, Australia</p>	<p>Primary research</p>	<p>Qualitative Research In depth interviews with 21 men to explore men's experiences and perceptions of prostate cancer. Transcripts analysed thematically.</p>	<p>To note conducted in Australia and interviewed 21 men with and without pca diagnosis over phone. Will have different healthcare system aims and objectives - States evident from findings that every aspect of pca care would benefit from attention: publicising the need to check prostate health and with treatment and after care (not relevant to my lit review). States a weak link within any part would</p>	<p>Clear aims of research stated to contribute evidence from which can be built continuing improvements in pca health care. Findings could be transferrable to UK. Qualitative methodology appropriate as study aims to seek explanation and meaning. Justification of method as most appropriate due to seeking above. Recruitment strategy was explained and participants sought by recruitment through local community advertising and through pca registry. Men who did not complete paperwork were not used in the</p>



### Data Summary Chart

				<p>undermine the rest. Programme to publicise and normalise need to see GP to diagnose pca at more curable phase, wouldn't be beneficial without offering support and advice and range of treatments. Proposes health data registries would benefit from incorporating qual research in programmes and how qual data can inform quant data and what pca means to the people who experience it. THEMES- case finding, diagnosis, spreading the word (relevant to this review)</p>	<p>study. Limitation of sample due to using local community and mode of advertising as limits sample uptake. Data collected through telephone interviews but no justification as to why this was used instead of face to face. Semi structured interview structure and topic guide offered as separate attachment. Breakdown of demographics for recruitment but no mention of saturation. Study indicates researcher background as adequate for the study interviews, however does not divulge their potential bias throughout study or any implications to research design. Ethic approval received with identifying details deleted before transcription and pseudonyms used. Each participant was given \$20 to participate so this may have influenced some. Adequate data analysis with description of how themes were derived and 4 researchers finalised these. Themes are used to show results with quotes in study. No examination of researcher role throughout this process though. Clear statement of findings through themes and discussion section. It supports original question and other supporting studies brought in for discussion. Research supports aims of study, however no section on limitations. Results are also transferable to other countries in relation to awareness and spreading the word. Proposes study results can be used to inform health data registries and further investigations into people who experience pca.</p>
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## Appendices four



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[illegible]

## Appendices six


### Research Passport Application Form – Version 3 01/09/2012

Please refer to the guidance notes before completing the form.

<b>Section 1 - Details of Researcher</b> To be completed by Researcher			
1. Surname: Forby	Prof <input type="checkbox"/> Dr <input type="checkbox"/> M <input type="checkbox"/> Ms <input checked="" type="checkbox"/>		
Forename(s): Lisa	Miss <input type="checkbox"/> M <input type="checkbox"/> Other <input type="checkbox"/>		
Home Address: 11 Florid Bryn Esyn, Wod, Flintshire, CH7 1TJ			
Work Tel: 01248393621	Mobile: 07800728626	Email: lforby@bangor.ac.uk	
2. Date of birth: 30/04/1977	Gender: Male <input type="checkbox"/> Female <input checked="" type="checkbox"/>	National Insurance number: JLA48039D	
3. Professional registration details, if applicable (Doctors undertaking any form of medical practice should confirm they have a licence to practice).	N/A <input type="checkbox"/>		
4. Employer: North Wales Centre for Primary Care Research, Bangor University. or place of study: Work Address/Place of Study: Cambrian 2, Wrexham Technology park, Wrexham, LL13 7YF. Post or status held: Research Project Support Officer			
<b>Section 2 - Details of Research</b> To be completed by Researcher			
5. What type of Research Passport do you need? Project-specific <input checked="" type="checkbox"/> Multi-project <input type="checkbox"/> If you will be conducting one project only please complete the details below. If you anticipate that you will be undertaking more than one project at any one time, please give details in the Appendix.			
Project Title: D.J.P. Diagnostic journeys in Prostate Cancer.			
Project Start Date: June 2017 End Date: Jun 2021			
Proposed start and end-date of 3-year Research Passport Start Date: Jan 2019 End Date: Jan 2021			
NHS organisation(s):	Dept(s):	Proposed research activities:	Manager in NHS organisation:
Cam Taf University Health Board	Prtyce Charles hospital research team, Royal Glamorgan hospital research team	questionnaires and small selection of interviews	Jane French
Hywel Dda Health Board	Glanwill Hospital, Willybush and Bronglais hospital research teams.	questionnaires and small selection of interviews	Sarah Moore
Betsi Cadwaladr University health Board	Wrexham major, Ysbyty Gwynedd and Glen Clynid research teams.	as above	Nikola Cornen
Aneurin Bevan University health Board	Royal Gwent and Neill Hall research teams	as above	Janet Marry

The Research Passport Version 3

Page 1 of 8

Cardiff and Vale University health Board	RN University Hospital of Wales research team	as above	Kathryn Newell
<b>Section 3 - Declaration by Researcher</b> To be completed by Researcher			
6. Have you ever been refused an honorary research contract? Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>			
Have you ever had an honorary research contract revoked? Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>			
If yes to either question, please give details:			
I consent to the information provided as part of this Research Passport and attached documents being used, recorded and stored by authorised staff of the NHS organisations where I will be conducting research.			
Signed: 		Date: 14/3/19.	
When Sections 1, 2 and 3 have been completed, the researcher should forward the form to the appropriate person to complete Section 4			

The Research Passport Version 3

Page 2 of 8

## **Diagnostic Journeys in Prostate Cancer: Interview study**

Dear

Thank you for participating in the first phase of our research study.

In the first phase of the study you kindly completed a questionnaire for us.

We are now writing to you with further information about the interview phase of our study.

By interviewing some of the men who participated in the first phase of the study, we hope to understand more about the personal experiences of being diagnosed with prostate cancer.

We would like to invite you to an interview. The interview can be conducted in your home, at the research centre or a place of your choice. It will last around an hour.

We enclose information that outlines the reasons for doing this study and what would be involved for you if you take part.

If you would like to participate in the interview, the study researcher will contact you in about two weeks. If you decide you would not like to participate, please return the reply slip at the end of the information sheet. You will not be contacted again.

If you have any queries and wish to talk to someone before you decide whether to take part you can contact me by email [l.formby@bangor.ac.uk](mailto:l.formby@bangor.ac.uk) or telephone 01248 383517

.

Thank you once again for your time.

*Lisa*

*Lisa Formby*, Study Researcher

On behalf of the DJiP study team

North Wales Centre for Primary Care Research

## **Diagnostic Journeys in Prostate Cancer: Why are they so long and what may facilitate earlier diagnosis? Interview study**

I do not wish to participate in the interview phase of this study and do not wish to be contacted for an interview.

Name:

---

Contact details:

---

---

Signature:

---



North Wales Centre for Primary  
Care Research  
Canolfan Gogledd Cymru ar gyfer  
Ymchwil Gofal Cychwynnol



# Diagnostic Journeys in Prostate Cancer.

## Patient information sheet: Interview study

Thank you for participating in the first part of our research study.

We are sending you details of the second phase of the research as we would like to conduct an interview with you.

This information is intended to help you understand the reason we are doing this interview study and what it will mean to you personally if you choose to take part.

Please feel free to contact the study researcher for any additional information:

**Lisa Formby Study team contact:**

**Tel: 01248 383517**

You have been given this information because you took part in the first phase of our research study, and agreed to receive further information about an interview. We would like you to consider being interviewed by the study researcher.

### **Aim of the interview study:**

The overall aim of this study is to describe the diagnostic journeys of men with prostate cancer. This has involved collecting information to measure and describe the diagnostic journeys of men in Wales who have had a recent diagnosis. In this part of the study we wish to interview men who took part in the first phase to gain more understanding of their individual journey. The study will, therefore, collect very detailed information about “how and why” the journeys occurred in the way they did. This information may help us understand more fully the reasons why some journeys to diagnosis are quicker or longer.

### **Why have I been asked to participate?**

You have been diagnosed with prostate cancer and participated in the questionnaire study (first phase). You have been selected for an interview from the information you gave in your questionnaire.

### **Do I have to participate in the study?**

No. Taking part in the study is entirely voluntary. Should you decide to take part, information you provide regarding your diagnosis or treatment will remain confidential. The information you give us will not be shared or given to your clinical team or GP.

Should you decide not to participate your choice will be respected. Your decision will not affect your medical treatment or care in any way.

### **What will participating involve for me?**

If you take part you will be asked to

- Complete a consent form  
You will be required to sign a consent form. This consent form will be signed in the presence of the researcher before the interview. You will be given a copy of the consent form.
- Give consent for us to use your data should you become mentally incapacitated and unable to make your own decisions during the course of the study. Giving this permission means that we will be able to use the information you have provided and your journey to diagnosis in our analysis of all the evidence we collate, once all the participants have been recruited.



- Have an interview with the study researcher

An interview will be offered to you at a time convenient to you, but within normal working hours. The interview can be undertaken at either your home or at the hospital where you receive treatment for your prostate cancer. The interview will be with the study researcher and involve answering some questions about your experiences and the events that led to your diagnosis. You are welcome to bring a person of your choice along to the interview with you.

It is always hard to say exactly how long interviews will take but it is likely that interviews will be about 60 minutes long.

Interviews will, with your permission, be recorded and then transcribed (written up) by the study team. Transcriptions will have your identify protected through the use of a unique study identification number. Place names and GP/hospital names will also be removed from transcripts. Audio tapes, which contain identifiable information, will be transferred to a secured database under the custodianship of Bangor University.

### **Are there any risks associated with me taking part?**

There are no anticipated risks with your taking part in this study. However, it is possible that you may find recalling your pathway to diagnosis upsetting. The questions in the interview have been reviewed by previous patients to help reduce any distress. Previous studies that have included interviews where people discuss their experiences of a cancer diagnostic journey have not led to long term distress and we have generally found that people find it therapeutic to discuss their journeys and experiences. However, we acknowledge there is a possibility this may upset you and if during the interview you become distressed the researcher will suspend the interview and give you time to consider whether you wish to continue. As you remain under the care of your clinical team the researcher may discuss with you how you can obtain advice and support within this team and offer to ask the team to get in contact with you.

### **What are the advantages of me taking part?**

The NHS is committed to improving outcomes in cancer. This study will help us understand how men with prostate cancer get diagnosed and how, and if, this may be improved. This is likely to help future men who may be diagnosed with prostate cancer.

### **What if something goes wrong?**

As this part of the study involves only taking part in an interview there is little to go wrong. However, if you have concerns you may contact the local study team researcher (details on the front cover of the information sheet).

## **Data security:**

**Bangor University is the sponsor for this study based in Wales. We will be using information from you and your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Bangor University will keep identifiable information about you for 5 years after the study has finished.**

**Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.**

**You can find out more about how we use your information by contacting the compliance and records assistant; Lynette Hunter on 01248 388530 or by email: [l.d.williams@bangor.ac.uk](mailto:l.d.williams@bangor.ac.uk)**

**Bangor University will collect information from you and your medical records for this research study in accordance with our instructions.**

**Your NHS health board will use your name and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from your NHS health board and regulatory organisations may look at your medical and research records to check the accuracy of the research study. Your hospital will pass these details to Bangor University along with the information collected from you and your medical records. The only people in Bangor University who will have access to information that identifies you will be people who need to contact you to ask for more information or audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name, NHS number or contact details.**

**You will be assigned a unique trial number and this trial number will be used throughout the interview and research data analysis. Information collected during interviews will be anonymised for names, places and critical events e.g. family, staff and GP practice or hospital.**

**Bangor University will keep identifiable information about you from this study for 5 years after the study has finished.**

### **What if I decide to withdraw?**

You are free to withdraw your consent to participate in this study at any time. The data collected up to the point of your withdrawal will remain available for analysis. No further data will be collected following your withdrawal and you will not be approached again.

### **Who is sponsoring this study?**

Bangor University are sponsoring this study and provide indemnity for the conduct of the research.

The study researcher is funded by Cancer Research Wales.

This study steering committee is led by Professor Clare Wilkinson (Director, North Wales Centre for Primary Care Research, Bangor University) and includes Professor Richard Neal (Academic Unit of Primary Care, Leeds Institute of Health Sciences, University of Leeds), and John Staffurth (Velindre Cancer Centre, Cardiff University).

### **Has the study received ethical approval?**

This study has been reviewed and received ethical approval from Bangor University and the NHS Health Research Authority; Leicester Central Ethics Committee.

### **If you have any concerns:**

You can contact a patient advisory and liaison service connected to your health board who can offer you independent advice.

### **Betsi Cadwaladr University Health Board (BCUHB) concerns team.**

Tel- (01248) 384194, Email - concernsTeam.bcu@wales.nhs.uk

### **Cwm Taf University Health Board (PALS) service.**

Tel- (01685) 724468, (01443) 443039, Email - CTUHB\_PALS@wales.nhs.uk

### **Cardiff and Vale University Health Board (CVUHB) PALS service.**

Tel- 029 20743301, 02920744095, Email - concerns@wales.nhs.uk

### **Aneurin Bevan University Health Board (ABUHB) Community health Council service.**

Tel- (01633) 838516, Email - enquiries.aneurinbevanchc@wales.chc.org.uk

**Hywel Dda University Health Board (H DUHB) PALS service.**

Tel- 03000200159 Email - [hdhb.patientsupportservices@wales.nhs.uk](mailto:hdhb.patientsupportservices@wales.nhs.uk)

If you require further information about this study please contact either the study researcher Tania Seale or your diagnosing urologist

**Thank you for reading the information and considering participating in this study**

*Lisa*

Lisa Formby on behalf of the DJiP study team

## Diagnostic Journeys DJiP Prostate Cancer.

Consent form interview study:

Name:

DOB:

Study Number:

**Please read through the consent form.**

**Confirm you agree to the sentences listed below by adding your initials to each box.**

Please also sign your name and date the end of this form

Please initial  
each box below



I confirm that I have read the attached information sheet Version ..... I understand why the research is being done.	
I am willing to be interviewed by the study team researcher.	
I give permission for the interview to be recorded.	
I give permission for the use of my anonymised data to be used in publications.	
I agree for the information collected to be stored securely under the custodianship of Bangor University.	
I consent for use of my data if I become mentally incapacitated during the course of this project.	
I am aware I may withdraw my consent to be a part of the project at any point. I am aware any information I have given up to the point I withdraw my consent may be used in analysis.	

Name (please print):

Signature:

Date:



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Care Research  
Canolfan Gogledd Cymru ar gyfer  
Ymchwil Gofal Cychwynnol



## Diagnostic Journeys in Prostate Cancer.

Consent form for an additional contributor to accompany a participant in an interview:

Name:

DOB:

---

**Please read through the consent form.**

**Confirm you agree to the sentences listed below by adding **your initials to each box.****

Please sign your name and give the date of your signature at the end on the form.

**Please initial**

I confirm that I have read the attached lay person information sheet Version .....	
I am aware I will be attending an interview which is being recorded and freely give my consent for anything I say within this interview to be used in analysis.	
I am aware that my conversation may be used as quotes within published scientific articles but am aware these would be anonymised to me and my place of residence.	
I agree for the information collected to be stored securely under the custodianship of Bangor University.	
I am aware I may withdraw my consent to be a part of the project at any point. I am aware any information I have given up to the point I withdraw my consent may be used in analysis.	

Name (please print):

---

Signature:

Date:

---

## OBJECTIVES

- To explore the patients account of their diagnostic journey
- To interview patients who have experienced either a prompt, longer or asymptomatic diagnostic pathway.
- To determine the experiences the patient had with in the three parts of the pathway
  - First symptom/No symptom
  - GP interactions
  - Specialist interactions
- To make sure the patients views are captured in relation to supporting future prostate cancer patients.

## INTRODUCTION

- Introduce myself, the study and its purpose
- Thank the participant for their time under the circumstances
- Explain what is going to happen (questions/times/cofficiality/ recording)
- Make sure patient understands rights (stop or cancel interview at anytime)
- Read through patient facing documents if needed and gain consent.
- If attended by by person, also make sure consent is completed.

## PATIENT INTERVIEW

- Set the scene before they were diagnosed (family, geographical daily activities, social, cultural, co morbidities etc)??
- How were they feeling, detection of bodily changes? [Self management](#)
- Did they have any symptoms
- Did they talk to family/friends about them
- What made them decide to contact a GCP

## PRIMARY CARE INTERVIEW

- How did they make first contact (walk in, phone call, emergency apt, routine)
- How long did they have to wait?
- Feeling of how the apt went? [Interview too, rushed, ??](#)
- What happened next? [Investigations, a ppts,](#)
- Waiting times
- What went well? What didn't?
- Referral to secondary care?

## SECONDARY CARE INTERVIEW

- How long did they have to wait?
- Talk me through that day? Support offered, voice heard,
- Tests undertaken? Invasive, supported and processes explained? (planning and scheduling of a ppts)
- Interactions with secondary care?
- Diagnosis and treatments offered?

## OVERALL EXPERIENCE OF THE JOURNEY

Could anything have been done differently?

What would have helped?

Do you feel more awareness of symptoms would have benefited?

What went well?

If you could offer advice for future prostate cancer patients, what would it be?

???????

## THANK YOU AND EXPLAIN DATA COLLECTION

SIGNPOST AND WELFARE CHECK IF NECESSARY

## **DJiP Topic Guide**

### **OBJECTIVES**

- To explore the patients account of their diagnostic journey
- To determine experiences throughout the three parts of the pathway

\*Use active listening\*

### **1) INTRODUCTION**

- Give thanks
- Introductions, study outline and purpose of interview
- Explain what will happen (questions/times/confidentiality/audio recording)
- Explain rights to cancel or pause at any time
- Take consent

### **2) PATIENT INTERVAL**

- Background circumstances
  - All about you
  - Family (emotional, stability, economic)
- Any symptoms/detection of bodily changes



- Looking back
- Connection to cancer?
- Waiting game
- Talking
- Reason for contacting HCP/GP

- Worries
- Family pressure
- Routine apt
- Systems of support
- 

### **3) ROUTE TO DIAGNOSIS**

- Access and systems of support
  - Specialist nurse
  - Cancer facilitator
  - Family and friends
- Waiting times
  - Short/long
  - Kept informed
- Tests/appts
  - Explained well
  - Invasive
  - Apt schedule
  - Treatments offered
- Patients voice
  - Felt heard

### **4) OVERALL EXPERIENCE OF THE JOURNEY**

- Negative experiences
- Positive experiences
- What would have helped
- Ways to improve
- Thoughts for the future

### **5) THANK YOU AND EXPLAIN DATA COLLECTION**

### **6) SIGNPOST AND WELFARE CHECK IF NECESSARY**

### **DJiP Topic Guide (asymptomatic)**

#### **AIM**

- **To determine potential interventions to prevent unnecessary delays in diagnosis.**

\*Use active listening\*

#### **2) INTRODUCTION**

- Give thanks
- Introductions, study outline and purpose of interview
  - Cancer Research Wales as funder
  - Explain aim and objective
- Explain what will happen
  - Time up to an hour
  - Questions to prompt journey
  - Audio recording
  - Confidentiality- no names/GP's/Hospitals
  - ID is a code
- Explain rights to cancel or pause at any time
- Check information sheet is understood
- Take consent for additional contributor if relevant

- Can you tell me a little more about?
- How did you respond when?
- What was it about?
- In what way?

#### **2) BEFORE ENGAGEMENT**

- Background circumstances

- All about you All about you (age, current activity, Work retired, geographical, social life)
- Family and friends (composition, emotional, stability, economic)
- Asymptomatic
  - Looking back
  - General health
  - Connection to cancer
  - Routine tests/offered through charity/private
- 
- Reason for contacting HCP/GP
  - Routine appt
  - Test outcome
  - Other illness/tests
  - Cancer awareness
  - Family history
  - advice

### 3) ROUTE TO DIAGNOSIS

- Waiting times
  - Referral times
  - Appt schedule
  - Long/short
- Tests
  - How many
  - Invasive
- Treatments offered/started
- HCP/specialists seen
  - How many
  - Apt schedule
- Access and systems of support

- Can you tell me a little more about?
- How did you respond when?
- What was it about?
- In what way?
- Could you just explain
- What effect did?

- Specialist nurse, cancer facilitator, family and friends

**4) OVERALL EXPERIENCE OF THE JOURNEY**

- 
- What would have helped
- Ways to improve services

Is there anything else you would like to tell me before we bring this interview to a close?

**5) GIVE THANKS AND EXPLAIN WHAT WILL HAPPEN TO THE DATA**

- Offer lay summary
- Are they interested in taking part in any other aspects of study in the future?

**6) SIGNPOST AND WELFARE CHECK IF NECESSARY**

## DJiP Topic Guide (early/late diagnosis)

### AIM

- To determine potential interventions to prevent unnecessary delays in diagnosis.

### OBJECTIVES

- To explore the patients account of their diagnostic journey
- To capture views in relation to supporting future prostate cancer patients.

\*Use active listening\*

### 3) INTRODUCTION

- Give thanks
- Introductions, study outline and purpose of interview
  - Cancer Research Wales as funder/
  - Explain aim and objective
- Explain what will happen
  - Time up to an hour
  - Questions to prompt journey
  - Audio recording
  - Confidentiality, no names/GP/hospitals recorded.
  - Your ID is a code /name not used.
- Explain rights to cancel or pause at any time
- Check information sheet is understood
- Take consent for additional contributor if relevant

- Can you tell me a little more about?
- How did you respond when?
- What was it about?
- In what way?
- Could you just explain
- What effect did?

## 2) BEFORE ENGAGEMENT

- Present circumstances
  - All about you (age, current activity, Work retired, geographical, social life)
  - Family and friends (composition, emotional, stability, economic)
- Any symptoms/changes
  - Looking back- symptoms
  - Connection to cancer
  - Waiting game/reasons if delayed
  - Talking to others
- Reason for contacting HCP/GP
  - Worries
  - Family pressure
  - Routine appt
  - Systems of support

## 7) ROUTE TO DIAGNOSIS

- Waiting times
  - Referral times
  - Appt schedule
  - Long/short
- Tests
  - How many
  - Invasive
- Treatments offered/started
- HCP/specialists seen
  - How many

- Can you tell me a little more about?
- How did you respond when?
- What was it about?
- In what way?
- Could you just explain
- What effect did?

- Apt schedule
- Access and systems of support
- Specialist nurse, cancer facilitator, family and friends

## **8) OVERALL EXPERIENCE OF THE JOURNEY**

- What would have helped
- Ways to improve services

Is there anything else you would like to tell me before we bring this interview to a close?

## **9) GIVE THANKS AND EXPLAIN WHAT WILL HAPPEN TO THE DATA**

- Offer lay summary
- Are they interested in taking part in any other aspects of the study in the future?

## **10) SIGNPOST AND WELFARE CHECK IF NECESSARY**

Notes

Appendices twelve

**Interview 1 MS COLWYN BAY - Audio Transcript**

Duration: 54:10 minutes

Speakers: 2

Interview Date:

Transcription Date: 3<sup>rd</sup> November 2019

Researcher: Lisa Formby



**R: Researcher**

**P: Participant**

**R: So, I told you a little bit about the study itself, briefly, and you very kindly completed the questionnaire for me, which is fantastic. So, before we get into your journey, I was just wondering if you could tell me a little bit about you, yourself. So, I can see that you live in a lovely house in a lovely area, so a little bit about your background.**

**P: Yeah. Well I was born in South Wales, I've lived up here for, how long have I lived here for, 35 years now.**

**R: Wow, you've still got an accent though, yeah.**

**P: [Laughs] I was married but my wife died 30 years ago now. Got three children.**

**R: Okay, do they live close by to you?**

**P: Yeah. One lives [Location D 0:00:59.9], one lives on [Location C 0:01:00.6] and the other one lives in [Location B 0:01:02.5] in [Country A 0:01:04.5].**

**R: Wow. Do you get to see them quite often?**

**P: I've been there about four, five times. They want me to go for Christmas but I'm not sure about that. [Laughs]**

**R: It's a long journey, isn't it?**

P: Oh I don't mind that. Usually when I've gone before I've flown there and back twice non-stop, but I'll just go. You know I've been all round sort of, I've done sort of [Location P 0:01:32.1], [Location S 0:01:34.5], [Location B], [Location A 0:01:36.8], [Location N 0:01:37.2] -.

R: **You enjoy your travelling.**

P: Yeah. I went to Singapore, I've been all over the place, Hong Kong, without the troubles. I've been where they're having all the trouble but I digress [Inaudible 0:01:51.8]. [Both laugh]

R: **No problem. So I take it you're retired?**

P: Oh yes. I've been retired for, eleven years now. I'm 71, by the way, I'm nearly 72.

R: **Nearly 72, great. So what did you do for a living?**

P: Well the last 30-odd years, I was in local government. I was a county transport officer, when I finished, I'd done that for seven years, but I used to sort out problems that used to crop up with various departments.

R: **Okay. Did you enjoy that job then?**

P: Yeah, it was good. Yeah, it was interesting.

**R: So would you class yourself, obviously your house is beautiful, would you class yourself as economically stable?**

P: Yeah. Yeah.

**R: Yeah? So there's no worries or anything that way? Okay, and I take it where you live at the moment, [Location C 0:02:50.7], would you say geographically-wise that it's a good place to live? Do you feel like you're close to resources and medical services?**

P: Yeah. Oh yeah, you're not far from, you know you've got [Location O 0:03:01.4]. This is actually [Location L 0:03:04.8], which is just, the route you've just come up, [Road Name 0:03:11.4], which turns up there which is [Location L] Village, but this is [Location L] here. There, [Location O], [Location C], [Location LI 0:03:21.1], where all the trouble is at the moment, and all that.

**R: At the moment.**

P: Yeah, they're not massive communities but sort of all put together -.

**R: Close community. Have you got a doctors' surgery close by here?**

P: Have I got?

**R: Doctors' surgery, is that close by?**

P: Yeah, [GP Surgery 0:03:36.0]. Well, five-minute drive.

**R: Have you been there? Have you been with them for a long time?**

P: Oh ever since I've been up here.

**R: Have you?**

P: Yeah.

**R: A lot of people like stick to their GP surgeries don't they. And I take it your nearest hospital -?**

P: Is [Location Bo 0:03:50.1]. Well no actually, [Location O], but they don't do this sort of thing there. It's, I'm not sure, you know you get blood tests, you get x-rays -.

**R: For the smaller things, like a more community hospital.**

P: Yeah.

**R: Yeah. So [Hospital G 0:04:08.3] is the one that you go to for your bigger hospital appointments etc. Righty ho, okay, so now we'll take it to the -. What we're trying to understand is, when you first either had a symptom, or when you first had those feelings that maybe something was wrong. I**

**don't know how far back that was, if you could start to talk to me about that?**

P: Oh it would be over a year about now.

**R: A year -?**

P: Yeah, but I, you know, because I'm previous -. I was paralysed from the waist down when I had the non-Hodgkin's lymphoma. I couldn't walk, couldn't stand up for 18 months.

**R: Wow, what a recovery you've made.**

P: I know. I'm a miracle. [Laughs]

**R: Amazing. Strong man. [Both laugh]**

P: Yeah, I was a bit younger then mind, so. And, I say, it took me 18 months, and I'm still, I'll walk down to the pub or whatever, it's a good mile away about 20 minutes, something like that. I do that twice a week. Yes, only for the exercise though. [Laughs]

**R: Of course, not for any social reasons, or a pint.**

P: Get a taxi back. [Both laugh]

**R: I don't blame you. So, you think then about a year ago?**

P: Oh at least a year ago.

**R: At least, so it could be longer?**

P: Yeah. Well it could be, yeah. Because, that's [inaudible 0:05:33.6] because my innards they got affected as well, it wasn't just my legs, you know, so. And so I wasn't too certain about things and then at the beginning of this year, my lady friend, she wanted me to drop a sample, she had to take [laughs] to the, she was in the same -.

**R: Okay, so tell me a bit about that then, your lady friend wanted you to -.**

P: No, no, she had a sample, her sample, to be dropped off for the doctor. And I dropped it off for her and I just said to the girl, I said, "I think I've got all the symptoms of -.", you know, this is receptionist, "Of prostate cancer." And she said, "Oh, do you want an appointment for the doctor?" I said, "Well, yeah." But I thought, "Oh here we go, two, three weeks." But as it happened, I said, "When will it be?", she said "Oh about ten minutes."

**R: What? Oh wow! That's probably the quickest appointment I've heard of.**

P: Yeah, somebody had just rung in to cancel an appointment.

**R: And you got the cancellation?**

P: Yeah, ten minutes.

**R: That's brilliant. So can you tell me what you thought were the possible symptoms that you might have had that you connected -?**

P: Well, a couple of weeks previous, in the newspaper it had an article about it. So I'd read the article and it had the symptoms. Well I ticked every box, so I thought, "I need to go and see somebody about this." And as it happened, she asked me to take a sample. She lives the other side of the doctors and I sort of had to pass it, so I said yeah, and then when I was there, I just thought I'll just ask.

**R: Can you tell me what the symptoms were? Do you mind talking about them?**

P: Oh well, you know, sort of going to the toilet a couple of times at night and, you know, sort of dribbling, and not starting when you're busting to go, and then not stopping. You name it, I had it. So when I read this I thought, "Oh dear."

**R: So that was a newspaper, that was just an article that you -?**

P: Yes an article in the newspaper, with you didn't actually tick it, but just listed the, there was about seven, eight, nine symptoms.

**R: Do you know where the article was from? Do you know, was it a charity, or -?**

P: It would have been in the Daily Express because that's the only newspaper I -.  
[Laughs]

R: **Right. Oh don't worry -.**

P: I might even have the tick list.

R: **Oh, well, I tell you what, show it me if you want at the end because that would be really interesting for me to find out what sort of -.**

P: I'm pretty certain it was in the Daily Express. It would have been the Daily Express or the Sunday Express. That's the only thing, yeah.

R: **Okay. So you looked at these symptoms, and you recognised that, "Yeah, I've actually been having those." So you think you were probably having those for about 12 months, did you say? Maybe more, progressively -?**

P: Yeah, getting worse and worse, yeah.

R: **Okay. If your lady friend hadn't asked you to pop to the doctors to drop off a sample, what do you think you would have done about those symptoms?**

P: I might not have asked. It was only I was there, you know because when -. The only thing I could go to the doctors and try to make an appointment. I think there's two or three weeks, something like that.



**R: It is, isn't it? There are long delays, aren't there, for doctor's appointments.**

P: But because I was there, I just thought, "I'll ask." And, as it happened, it literally, within ten minutes, I was seeing the doctor.

**R: So, you sort of saying to me, you may not have gone to the doctors, would you have -? Had you told anybody else that you were having any of these symptoms?**

P: No.

**R: No, you kept it to yourself?**

P: Pretty much.

**R: Do you think that if you hadn't have got this doctor's appointment, do you think you would have sat on them for a while longer?**

P: Well I suspect I would, yeah. Once I saw all the symptoms there, it did really make me think then.

**R: So do you feel that that article was beneficial to you going and approaching the doctor for the first appointment?**

P: Oh, yeah, yeah. Yeah because I would have just dropped off, there's only a box that you drop off the samples, up in the surgery. Then I might have just dropped it in and then gone. But I thought, "I'm here, and having read that, I'll ask."

R: **Okay. So that worked out well for you then, in regards to that. Because I do understand what you mean, it can be really hard when you know that you've got to wait weeks, often for a doctor's appointment. People can put things off, can't they?**

P: Yeah. But also, I was thinking, it could still be a throwback to when I had the paralysis and all that. Because it did affect other parts of me, you know.

R: **Right. So you weren't sure whether it could have been connected to the cancer in the past?**

P: Yeah. Well the biggest pain that I had with it was I couldn't go to the flipping toilet. [Laughs] Just everything was paralysed, so. But that's sorted and all now, but then in the end it's -. Well especially if I went for a drink, be alright 'til I have one drink and then back and forth.

R: **If you look back now, when you first had symptoms, do you think that it would have been beneficial for you to approach the doctor sooner?**

P: Oh yeah, yeah. Because, when I went to the doctor and he checked my prostate, and he said, "There's something there." And then he give me, to go and get a blood test, appointment to go and get a blood test, in [Hospital O 0:11:32.8]. And, I got that the next day, and then the day after the blood test, I got a call from the doctor to go and see him.

**R: Right. Is this a doctor that's been your, is it a regular doctor that you see? Or do you have a set of doctors that you just -?**

P: Well, he's been there a while but I used to see [Doctor R 0:11:56.2], but you know, everybody wanted to see [Doctor R]. So if you wanted [inaudible 0:12:03.6] -.

**R: Often do, don't they, when it's a good doctor? [Laughs]**

P: So if you want to get in to, you know, within a reasonable time -. But I can't remember his name now.

**R: Oh don't worry about names.**

P: But, no, he was very good, good at being honest.

**R: Did you feel when you first went for the appointment, can you talk me through what happened during that appointment?**

P: Well I just went into the doctors' and he said, "What's the problem?" And I said, "Well I think that I've got all the symptoms of prostate cancer.", and all that. And he asked me to go and have a sample of my pee like. So I just went in the toilet. And came back and he put a bit of litmus paper, or something like that. And he looked, and then did, you know, with up the backside.

**R: The examination, yeah [participant laughs], that no one seems to like.**

P: Well, no. And, then he give me the, to go and get a blood sample, well that was the next day.

**R: Did he tell you at the time, what the blood sample was, or were you aware why you were getting asked -?**

P: I knew what it was for.

**R: You did?**

P: Yeah. And it came, he called me, well he didn't call me, the lady there, she said, "Doctor wants to see you [inaudible 0:13:20.5]."

**R: So was that a receptionist, do you think?**

P: Receptionist, yeah. So, I went there about two days later, and -.

**R: Wow. So around three, two, three days from originally going to -.**

P: Well, four. There might have been a weekend in between.

**R: And then getting a call back.**

P: Yeah but within a week, it was -. You know, I knew when he was making an appointment for me to go and see the consultant.

**R: So did he call you in, or did he speak to you over the phone?**

P: No he called me in, no.

**R: Can you talk me through that appointment and what happened?**

P: Went in and he said about the PSA, he said, "The norm's about five, six, or seven.", something like that, he said, "And yours is 221." So, he said -.

**R: Two hundred and twenty-one? [Participant laughs]**

P: Yeah but apparently, they get some, they're in the thousands.

**R: Yeah, you do. You get a wide variety of levels, yeah.**

P: Like I had, well I had a PSA test, about a week or so ago, ten days. Because I'm going for the radiation, radio therapy, on Thursday, start on Thursday. And they took a blood sample, so I'll be interested to know what the PSA is now. But I'm expecting it to go down quite a bit because I've been on hormones. Well, we'll get to that I suppose.

**R: Yeah, don't worry, we will move along to that along the journey. No but it's great, it's great that you're telling me, I really appreciate it.**

P: So that was it. And he referred me to -.

**R: Did he tell you then that he thought -?**

P: Well he said to me, "It should be softer and it's hard." And he said, "And the likelihood -." And I'd also read that anything over a hundred is likely to be cancerous anyway. And I was 221, so I'm not a dull guy. [Laughs]

**R: So how did that make you feel when you left that appointment?**

P: Well to be honest everybody thinks I'm odd, because it didn't worry me at all. [Both laugh] And even my lady friend now, and she said, "You'd laugh if he said you were dying tomorrow". I said, "Well, that's not going to change anything is it?" And so even with my kids, I didn't tell them until about three weeks ago. I've known for six months.

**R: And what was the reason? Why have you not -?**

P: I didn't want to worry them.

**R: So you felt that you were happy to have that diagnosis. When did you tell your lady friend?**

P: Well, about, sort of, within a week or two of it and all. Thought better tell her because I'm going up and down the hospital and all this sort of thing and she, well she's not dull either. [Laughs]

R: **She'd sense something.**

P: And the kids didn't know anything, and they had a bit of a shock, about three, four weeks ago.

R: **It's not surprising is it?**

P: Yeah but my lad in [Location A 0:16:22.6], and he rang my daughter saying, "He never told me about it, he's had it six months." And she said, "Well he never told anybody."

R: **Everyone deals with things differently, don't they? And it sounds like, the process that you went through with the GP, you came out of that feeling okay.**

P: Yeah. Well even when I went in there, he said to me, "Well you were right, you self-diagnosed yourself." [Laughs] So, and once we get down to [Location Bo], the doctor thought I was odd, so -.

R: **I don't think you're odd. [Both laugh] So you've been to this GP appointment, he has told you about your PSA and explained about that your prostate didn't feel normal, and he was going to refer you to [Hospital**

**G 0:17:11.8]. How long was it between that referral, and you getting your first appointment, any ideas?**

**P:** I'm trying to think, three or four weeks and I was down there.

**R:** Yeah, that's fine. Don't put yourself out and look through paperwork, honestly.

**P:** Oh it's there, I've got it.

**R:** You're nice and organised, it's always good to have everything in a folder. I'm a bit like that. [Laughs]

**P:** Well this is what I used to do for a living, so I -. Here we go.

**R:** Did you speak to anyone in the meantime, before that, in that interim of when you'd finished seeing the GP, up until the secondary care? Did you see anybody else in the surgery, or -?

**P:** No. It's -. [Shuffling paper] Oh I tell you what, I'll tell -. No that was when I went down to there -. This one, I, we'll get to this.

**R:** Yes, we'll get to that don't worry. You can talk to me all about that. It only makes more sense if we go through it in a structure.



P: Oh yeah.

**R: But it's fantastic that you've got so much information.**

P: So, no I, the next thing was I went to [Location Bo], on Tuesday the 26<sup>th</sup> of February.

**R: Okay so that's about three to four weeks from your GP diagnosing you.**

P: Yeah, in the January that would have been.

**R: How did you feel about that first part of the journey? So from firstly going in to see your GP to getting referred, did you think that that was a good waiting time for you?**

P: Yeah, quite happy with it.

**R: That was quite swift?**

P: Oh god, yeah, yeah. Mind you when read about other parts of the country -. When I tell people in South Wales about how quick things happen up here, because South Wales is terrible compared to here. They're quite good up here.

**R: Health boards are different aren't they, the way that they -.**

P: Oh, no end. I'm not happy about, what is it [Local Health Board 0:19:16.3] and all that, you know. But I wouldn't have a go at them, even try and go on about all of them because they need sorting out.

**R: There's lots of things isn't there?**

P: But the [inaudible 0:19:26.3] itself, yeah, no problem at all.

**R: So did you get the letter through the post with the appointment?**

P: Yep.

**R: Okay, and can you talk me through that first appointment when you went in to see the urologist, and what actually happened then?**

P: Yeah. He, the first one, he went from the same as the younger doctor had told me and all this sort of thing.

**R: So what was that?**

P: About my PSA, and what was going to happen in the future and all -. Well he said, you know -. I had to agree to it and that.

**R: What did you agree to?**

P: Well, just progressing it as he said. You know, sort of going for a biopsy and -.

R: **Right, so he explained -.**

P: And I went and had a CT scan.

R: **Okay. Was that the first stop for you then? So was the first appointment just telling you what was going to happen?**

P: Pretty much, yeah.

R: **So you didn't have any tests on that day?**

P: Yeah, oh I had the backside -. [Laughs]

R: **Again. [Both laugh] Lovely. [Laughs]**

P: [Inaudible 0:20:38.2] something about that. [Laughs]

R: **It's one of those things, unfortunately, tests like that.**

P: And he explained it all to me and all that. And then -.

**R: Was there a nurse with you at all, as well?**

P: Sorry?

**R: Was there a nurse there at all?**

P: Yeah. I've got, yeah well she gave me all this. And I tell you what her name is now, it's on here -.

**R: So on this first appointment, when you went in to see the urologist and there was a nurse there with you, so talk me through -. You were saying that they discussed the tests that you were going to have, what else did they chat about?**

P: Well, all the support and all that, that was available. But to be honest I don't need that.

**R: Is that what you've got there in your folder? The support? So what was it, a pack?**

P: It was a pack, yeah. It's all here telling you all about it, research, and all that. You know, what's going to happen -.

**R: So, did you read that pack?**

P: Oh yeah.

R: **Yeah? Did you read that, was that -?**

P: My woman, she read more of it. [Laughs]

R: **Okay, so was that one of the first things that you did, when you came home?**

P: Oh yeah. Diagnostic journeys in prostate cancer, do [Inaudible 0:22:02.1] -.

R: **That's me, yeah. That's probably me. So, right, we'll touch on that again in a minute. So you had this first appointment, you had your DRE tests, the one that no one really likes. And then what other tests did you have in your first appointment?**

P: Well I had two scans.

R: **On that same day?**

P: No, no. This went on for a couple of weeks.

R: **Right, so in the first appointment, you just met the urologist and nurse?**

P: Yeah, that was 26<sup>th</sup> of February, that would have been that one.

R: **Okay. Had that DRE, and did you have blood tests on the first appointment again?**

P: Might have, can't remember to be honest.

R: **Okay. Given that information -.**

P: Yeah.

R: **And then told the -. Can you tell me what happened then? Did they say that they were going to book you in again?**

P: Yeah he said, you know, sort of, he told me how it could be treated, or would be treated and all that.

R: **And can you remember what he said, how you were treated?**

P: Yeah, first part we'd go on hormone treatment, which I'm on now. I took these tablets for 28 days. Now I have Decapeptyl stuck in me backside every 12 weeks. Turning me into a woman. [Both laugh]

R: **I've heard that a lot from the gentlemen that I speak to.**

P: And said, make absolutely certain, just to check how far the cancer, had it gone or where it was contained? Well I had a bone scan, nothing in my bones. CT scan, nothing in the rest of the body so it's all contained in the prostate.

**R: Did you say to me that you had a biopsy?**

P: Yeah and then I had a biopsy.

**R: Okay, and how did that feel? How did that go?**

P: Well, wouldn't want another one in a hurry but [laughs] it's got to be done, so.

**R: You understood the process of why you were having these tests.**

P: Oh yeah, yeah. It wasn't that bad really. Thinking about it first of all was worse than the act.

**R: Yeah. So how many appointments did you have altogether with the consultant, or going into [Hospital G], would you say, before you had your diagnosis?**

P: And, just with the consultant, or actually going for the scans?

**R: Ooh, tell me, if you can remember, you can tell me them all, that would be great.**

P: Yeah, I had, one with, I had one which was this first one, that was when we went through it all. Been through but not in as much detail, with the doctor. Then, he said about getting the scans and the biopsy, so I had those three done. Three separate events.

**R: Three separate times visiting back, yeah -?**

P: Yeah. And then, I met another consultant, who told me [inaudible 0:25:19.3]. He was a bit, he, because of my attitude, he said I was laughing at it, and all that. And I said, "Well, you know, I'm not mad, I don't think it's funny." I said, "But I'm not going to, it's there, it's got to be sorted and, you know, people die from flipping worrying about things. So, I'm going to die of cancer, I'm not going to die from worrying about that." I didn't think I was going to die anyway.

**R: Would you say that that was a good thing that you saw two different urologists? or would you have preferred to have just seen one?**

P: I was a bit surprised when I saw two, because I did actually prefer the first one to be honest.

**R: And do you think sometimes when you prefer a urologist, does that make you feel better in going for your appointments? Or chatting to someone to find out more details about things?**

P: I've been through it again with another one in the cancer treatment centre, as well so. [Laughs] He's got all the details and telling me what's going to happen with the radiotherapy. So I've done one with that as well, you know I've seen



^-.

**R: So that was more to do with the treatment side?**

P: Yeah, yeah.

**R: So how many appointments do you think, from the first time you saw the urologist to your diagnosis, would you on average?**

P: Including scans?

**R: Yes, yeah.**

P: I've had three scans now, because I had to go one to have the tattoos put on me, to line me up for it. There's three scans, one, two, there's three consultants, I think that's it.

**R: Yeah? And that was from the point of first appointment to diagnosis?**

P: Yeah.

**R: So, the timeframe, have you got any ideas what you think that would be?**

P: Well, I say, that first one was 26<sup>th</sup> of February, so you can say the end of February. [Shuffling paper] The last one, was the 13<sup>th</sup> of June, so you've got, let's see, March, April, May, mid-June, three and a half months. And then -.

**R: Right. Yeah for your diagnosis.**

P: Yeah but I had the hormone treatment in between as well.

**R: In between that as well?**

P: Yeah, oh yeah.

**R: So I suppose then, the diagnosis was probably have been a bit earlier if you'd started on the hormone treatment, would you say? Or when did you feel that you were told that you had prostate cancer, would you say?**

P: When I was told or -?

**R: Yeah, when do you feel that you were -?**

P: Well I think when the doctor told me, to be honest, yeah. And, well [laughs], as I say, I didn't really bother me that much. You know I didn't want it, obviously, just looking at this -. [Both laugh] But, you know -.

**R: So why do you think then, tell me more about why you think it didn't bother you too much.**

P: It's just the person I am. And it didn't bother me when I had -. They actually got a psychiatrist to me when I had the lymphoma. Because I wanted to come out of hospital, I'd been there three weeks and it was just before Christmas. And they weren't going to start a treatment until, well, they said early January, I said, "Oh can we make it after the 8<sup>th</sup> of January because it's my birthday." So they started on the 10<sup>th</sup> of January. And well, more social services and said, "Oh well you can't go home, you've got no one to -." I said, "I can get myself around and all that."

**R: So do you feel very -?**

P: Independent?

**R: Yes. So that's the word you'd use for yourself at the moment, independent?**

P: Yeah, yeah.

**R: And I take it you've got quite good, well you have your lady friend, and I take it you've got friends when you go down to the pub and things? So you've got -.**

P: Yeah, when I was going back and forth, and my daughter to have my first grandson, he was only about eight weeks old when I went down with it. But, oh

no, my son actually lived here, so I don't know what, I didn't see a problem with it to be honest. I have a bed down here -.

**R: Everyone deals with things differently don't they, everyone's got a completely different reaction.**

P: Yeah.

**R: Do you feel that, in relation to when you first went to see the GP, up until your diagnosis, so if we forget the treatment bit just for a second. Can you tell me how you feel about that whole process, in your opinion?**

P: Yeah I'm quite happy with the way it's gone. You know, it's, well, where are we now, what is it six months, something like that? And, if it'd been a worse cancer, well I can't imagine it would have, I'd still be having this, they'd be treating it. I know the first one, literally within six weeks, I had radiotherapy then for five days on the trot, and that sort of ate the cancer. But then I went on the chemotherapy for, six times over three, eighteen, about four, five months, something like that. And -.

**R: Yeah. Do you think if you hadn't have gone to the doctors' that day through coincidence really, that you got that appointment, do you think you still maybe now would be sitting on those symptoms? Or do you think due to the article -?**

P: When I read the article it did really -.

**R: If you hadn't have read the article, do you -?**

P: Well most probably I wouldn't have bothered. But, although, difficult to say, I would say, I might have put it off for a bit longer. But I think I knew in the end, you know, I was going to have to go. And once I read that, and I was there, I didn't hesitate, I just said, well I said to them, I said, "I believe I've got prostate cancer." Saw the doc and I told him and, well as I said, and he called me back [inaudible 0:32:09.3], and he said, "Well you diagnosed it yourself." I said, "Well I didn't diagnose it, I just said I had all the symptoms." [Laughs]

**R: Yeah. Well, no, definitely sounds like the article made a big difference.**

P: You'll have to excuse me because I need to go to the toilet. [Laughs]

**R: You go to the toilet, not a problem.**

P: No, I, you know, I have to say, I'm happy with the way it's all coming together.

**R: Yeah. [Shuffling] (.)**

P: [Door closing] Yeah, well, I say I've no problems with how it's all progressed.

**R: So you're quite happy. Oh that's off my pen I think, thank you. [Both laugh]  
So you're quite happy with the -? What would you say, is happy the word  
that you'd use, for the process?**

P: Yeah, oh definitely, yeah. It's -.

**R: Do you want to talk to me about the treatments then? Tell me about what's happened since, so the treatments that you're now on.**

P: Well, I say, the hormone therapy, I've been on that, I know when I first, I can't remember exactly when I had it. I know, about two weeks ago I had my second shot, of Decapeptyl. And it would have been 12 weeks before that, so three months. Say about four months ago I started, and it's, you know, other than feeling a bit tired and all that, it hadn't really affected me, you know. I'm assuming, it's knocking the old cancer back [coughs] because me testosterone's going. [Laughs]

**R: One of the side effects, isn't it, yeah.**

P: But I can live with that.

**R: So you told me that you'd been visiting [Hospital G]? Did you say that you -?**

P: Oh, well yeah, well a couple of my, it's after I seen, I got referred to the out patient department, [cancer treatment centre 0:35:42.6]. And the chappy there, consultant, oncologist, I'm not too, yeah he would have been oncologist being in there. And he did, he really went through it all with me.

**R: So, when you mean went through it -?**

P: About the radiotherapy treatment and all that. And, you know, didn't do any tests on me or anything. He just, he had all that information there and he even told me that, you know my previous cancer 14 years ago, which I didn't realise, I didn't think it was that long ago. But, and he told me that, and of course, my lady friend, I had to take her into the exam with me.

R: **Of course, that's 'cause she cares about you. [Both laugh] Us women like to know what's going on. [Laughs]**

P: I know. She'd be upset with me. I haven't told her you're here this morning. [Laughs]

R: **Oh she could have come and joined us, couldn't she?**

P: And she's there and she's asking more questions than I do, I just listen really. [Laughs] And she's read all this.

R: **Has she?**

P: Oh yeah.

R: **Do you feel that she's a good support network for you?**

P: Oh god yeah. Well she was the only one, I could really talk about it, you know for the first couple of months. My mate in the pub, he's had it, so I could speak to him, you know he was sworn to secrecy and all. And he, you know all the

lads in the pub I've been going there and they were all shocked when I -. You know once I'd told the kids and all that, because I didn't tell anyone because I thought it would get back to the kids, and they'll say, "Why didn't you tell us first?" So I didn't tell anybody.

**R: And they all know now.**

P: Oh they all know now, yeah.

**R: Does that make you feel better that they know?**

P: Well it's easier because [laughs], I don't have to -. You know sometimes I go to say things and I say, "Oh going to the hospital." And they say, "What you going to the hospital for?" "Just for a check-up."

**R: So you felt that your lady friend offered you all the support that you needed in that time?**

P: Oh yeah, yeah.

**R: And do you think that definitely made a difference for you then?**

P: Oh yeah, oh yeah. Didn't [Inaudible 0:37:59.8] or anything like. But it was all like [Nurse 0:38:03.0] and all. They -.



**R: Is [Nurse] the -?**

P: She's the nurse.

**R: The nurse, the one you met on the first visit.**

P: Yeah. And she, you know I said she'd been in touch a couple of times and all that.

**R: Has she?**

P: Yeah.

**R: How does she get in touch?**

P: She's phoned me, she's emailed me, sent me, you can go on these, with Macmillan nurse and all that. And I haven't been to be honest, but -.

**R: So is that just like a wellbeing check that she calls to see how you're doing?**

P: Yeah, yeah. And say, you know what you can do, what you're entitled to and all this sort of thing.

**R: And did you like that? Have you felt that that's been beneficial for you in your journey?**

P: Well, yeah, I haven't been, but somebody who needed more support than me, I could see it work for them. And going to meetings, coffee meetings and all that.

**R: Yes, some people do enjoy that don't they?**

P: Well they do yeah, but as I say, it -. But you know, I didn't feel I needed it then. She got in contact with me and said about it and I just said back to her that I didn't feel the need for it but if I was ever bothered by anything, I said, "I'll be straight on to you."

**R: So you knew you had someone that you could contact straight away? And by the looks of your folder that you've got, you've been given, brilliant that you're keeping all your papers, but you've been given plenty of information in relation to your journey, and helping you understand what's happening.**

P: Oh yeah. Well that's what all this is about really, well mainly.

**R: That's great to have it all in a folder, that's really good. I'm very impressed.**

P: [Laughs] Well they gave me the folder at the start.

**R: Oh did they?**

P: Yeah, it's all this, well you know, some of it I've put in.

**R: Oh you're a lot more organised than my stepdad, because I tell you, I don't think he kept hold of a lot of his stuff from when he was there.**

P: And well, she gave me all, you know -.

**R: The details?**

P: Yes. And here's a list of questions you can ask people and all that sort of -.

**R: That's great.**

P: Well, here it is, I've got a telephone number there, [Nurse].

**R: Brilliant, so you have everything that you need for contact in that folder.**

P: I do, yeah. And, well, various, tips for asking questions, even. But it's all, everything that's happened is in here and they even give me that book but it's all repeated there, so.

**R: Do you feel that you have any questions in relation to the journey that you've had from your first symptom all the way to your diagnosis? Is there anything left unanswered for you?**

P: Not really, it's all been pretty straight forward. All of the various stages have not been that far apart. I say, I went to, it's only about ten days ago, I went and had another scan, just to pinpoint where they're going to hit the radiation and that. Actually showed me where my tattoo was from, because I've never known where it was. Obviously when I had the previous, I couldn't see it, and -.

**R: So that was pointed out to you as well.**

P: They circled it for me. [Laughs]

**R: So now you know.**

P: I know where it was now. Or is, it's still there but it's only tiny, these ones are bigger than that one. They're only like that tapping, but this one they broke the skin. Well they'd obviously that broke the skin for them to, but it's nothing really. And, I just go there now on Thursday morning. And, just start 20 shots of that over the next, well it's four weeks but it's two a week, I suppose. They'll do two this week and then I'll have a break of two days, and then five, five, five. Five and three then.

**R: So it's quite intensive isn't it?**

P: And that again -. So it's all there. It'll make you tired and all that so. That's why we went this weekend. Had a long weekend.

R: **Oh and enjoyed Liverpool beforehand, yeah, don't blame you. Why not? Yeah 'cause you need to look after yourself in between don't you?**

P: Oh yeah. Well just wait and see really, how it goes. People say, "Oh well are you going to be coming down?" I said, "I hope to but I don't know how badly it's going to affect me with the radiation. So we'll just, as they say, play it by ear." So, that's about it and then hopefully that's sorted. But of course, once that's done I'll still be on the hormone treatment for about another two and a half years after.

R: **Yeah, it's quite long isn't it? Do you feel that, it sounds like from what you're talking to me you've not had to wait too long between your appointments?**

P: No, no, it seems as though every couple of weeks I've been going down for something or the other.

R: **So if you had to describe or say how you feel that your journey's gone, is there any particular -?**

P: Well nothing really bothered me about it or thought they could have done better or anything like that. I say, if it had been I different cancer, well then it most probably would have moved on quite a bit quicker. But it's all happened, I am being treated anyway, I've been being treated for four months really, with the

hormone treatment. So it's just the radiotherapy now just to kill it off and then take it from there.

**R: See how it goes. Do you think there's anything, or could you suggest anything that you think could improve the service or the journey that you've had?**

P: Not really. As I say, I've been pretty happy, like with the scans, obviously, I can, have been going there, you'd say oh one, two, three, in a row while you're there. I don't think you can with radiation and all that, you obviously can have too much of it. And the different machines, so the bone scanner was one machine, I've had two CT scans, just you know check my body first of all. And then another one to -. But the other one was actually, I didn't realise that they had in the cancer treatment, they've got a radio, a CT scanner in there. Yeah, because I went to the other place I thought they only had the CT, I didn't read it properly.

**R: Yeah, well quite a lot they do, yeah, it does depend doesn't it, different places have different equipment.**

P: But, no, they just said, "Oh you're in, it's the CT scanner in the cancer treatment -." "Oh" So I just went to the one I'd been to before. [Laughs]

**R: It does sound like your journey has, from what you're telling me, your journey has gone along at a steady pace.**

P: It has, yeah.

**R: Before we finish, we'll pull everything together, I'm interested in, by chance, you read this article in the newspaper, which had the symptoms listed. Do you think that being more aware of the symptoms, or is there any way that you think that men could be made more aware of their symptoms?**

P: I'm just thinking, might even be in here, [shuffling paper] no, wouldn't be that simple would it? [Both laugh]

**R: Don't worry.**

P: No, as I say, I'm pretty certain it must have been in the Daily Express. Would have been, I know I cut it out.

**R: Would you have been aware of the symptoms if you hadn't have read that article, do you think as much?**

P: I wouldn't have known them all, no. But I had an inkling, that it could be a problem. But when I read that I thought, "Yeah I've got a problem here." And, I say, being there, and I did say to them, I said, "I think I've got prostate cancer."

**R: When you had your first appointment. Do you think that -?**

P: Well when I went in to the receptionist.

**R:** Do you think that made a difference for you getting, because obviously there was that cancellation, do you think that maybe made a difference for you getting that cancellation appointment because that's what you said?

**P:** Possibly.

**R:** Or you would have been given it anyway?

**P:** Oh yeah, you don't want to mess about with cancer. [Laughs]

**R:** Yeah, like you say, receptionists and things as well, will react differently.

**P:** Yeah because sometimes some of these receptionists and, some of them are not the brightest people I've ever met, I've got to be honest. [Both laugh] I had something on my back, what's it called, keratoma, keratoma is it, something like that?

**R:** Oh carcinoma?

**P:** No keratoma, it wasn't carcinoma. That would be -.

**R:** Oh, okay.



P: I thought it might have been a carcinoma. And, I took my t-shirt off one time and it was a bit sweaty and all that. And I pulled the top off this and it was bleeding and all that. And so I went to the doctors, because I know, if you've got moles and all, if they start bleeding and that -.

R: **Get them checked, yeah.**

P: It would have, that could have been cancerous. It was dark, crusty and then started bleeding, but apparently, and I said to this and she said, "Oh we'll make an appointment for about three weeks' time." I said, "Listen, I've had cancer and that is bleeding.", and it looked as though it could be cancerous. And I said, "I need to see the doctor quickly." And she said, "Oh [mumbling]", so suddenly she found one. And I just went in to see him and to be fair, he said, "No, it's a keratoma and you've just pulled it." Which I'm quite happy really because it not very nice-looking thing, and I pulled it off taking my shirt off and I disappeared after that.

R: **It sound like you're quite aware though, of looking after yourself and looking out for keeping an eye on your wellbeing, which is really positive.**

P: Well, I read a lot. And I read these things, and I think, "Oh", and I log it away.

R: **Yeah. Often that's how a lot of people recognise that there's things going on.**

P: Yeah, so. I didn't know that was a keratoma but he said it was a -.

**R: I'll have to look it up myself, and figure out what that is. We've chatted about everything at the moment now, do you think there's anything else that you want to tell me about your journey?**

P: No, as I say, I'm quite happy with the way it's gone and all that. I don't sit here thinking they could have done this or they could have done that. Well, if I'd let them they would have done even more, going to these meeting and -. I know enough about it to think, I don't need somebody else to tell me. But for other people, they're the sort of people who, like I don't sit home here normally and all, I go on out.

**R: Yeah, you're out and about. I'm stopping you from moving around today.  
[Laughs]**

P: Well I'm out, well it'll be this afternoon now, but I'll be out. And, when you phoned, because you phoned here, was it Friday or something like that?

**R: I can't remember when we originally spoke, yeah.**

P: And, you know the landline, I've said to [Nurse]] and whatever, better to ring my mobile phone than the landline, because first of all, I very rarely answer it, I've got to be honest.

**R: I'm exactly the same, I don't bother because normally it's phone calls off people isn't it?**

P: I nearly cut my sister in law off in Spain yesterday because it started 03 something, I thought, "That's not right." It's Spain isn't it, 034. So, there we go.

R: **Well, I think I'll stop the recorder in a minute so we can carry on chatting about anything. But what I'm hoping to do at the end of this study is, I'll be pulling all this information together, and then we'll be delivering workshops to prominent people with the prostate cancer remit. Are you interested, would you like me to keep you updated on how the study goes? We can create a summary for anybody that's interested that's taken part in the study, is that something you would like to read?**

P: Yeah, if you send me the summary, if there's anything in there, you know I'll get back to you and comment, because I'm that sort of person like. I say, I used to be what they used to call the trouble-shooter for the authority if things went wrong and all that and -.

R: **Well we will be pulling together some other, if we do some stakeholder groups and things like that we'll be wanting to invite some gentlemen that have taken part in the study to give their feedback. Is that something that you might be interested in in the future?**

P: Well I might be, it all depends if -.

R: **Yeah? Shall I keep your name -?**

P: Yeah you can put me down as a maybe. [Laughs] It all depends where it is.

**R: We're talking in a year's time, probably. So I could maybe contact you closer to the time then?**

**P: Yeah, no problem.**

**R: Okay, and we can see if there's anything that if you're interested.**

**P: On my mobile.**

**R: On your mobile, not on your landline. [Laughs] Or by post which is quite an old-fashioned thing as well these days. Right well I think, that's it really. I'm so grateful that you've taken time out this morning, to talk to me, thank you very much.**

**P: Possibly, why it's taken a little bit longer, you know I'm happy with how long it's taken, but when I found out about this, and I said to my lady, I said, "We'll go away for a holiday." So in March, we went to Egypt for two weeks I think, before I start having all these things and all. We'll go away, because we like going away and all that, funny places, yeah.**

**R: Why not? I like going away as well, yeah. [Both laugh]**

**P: Like Africa we've been to, sort of Morocco and Marrakesh, Gambia. And try to get up, well go to Australia because she's not happy about that, [laughs] she doesn't like the idea of flying all the way there. There's a good stop-off [inaudible 0:53:34.9] places.**

**R: Yeah. So did you mean that that might have, that's altered the -?**

P: Well it might have extended it a little while, because that was my request really.

**R: Yeah of course, that's what you decided to do.**

P: So, that was it. that's how worried I was about it. [Both laugh]

**R: Not that worried at all. [Laughs] Right, I'll stop this tape recorder now and then that will be us covered.**

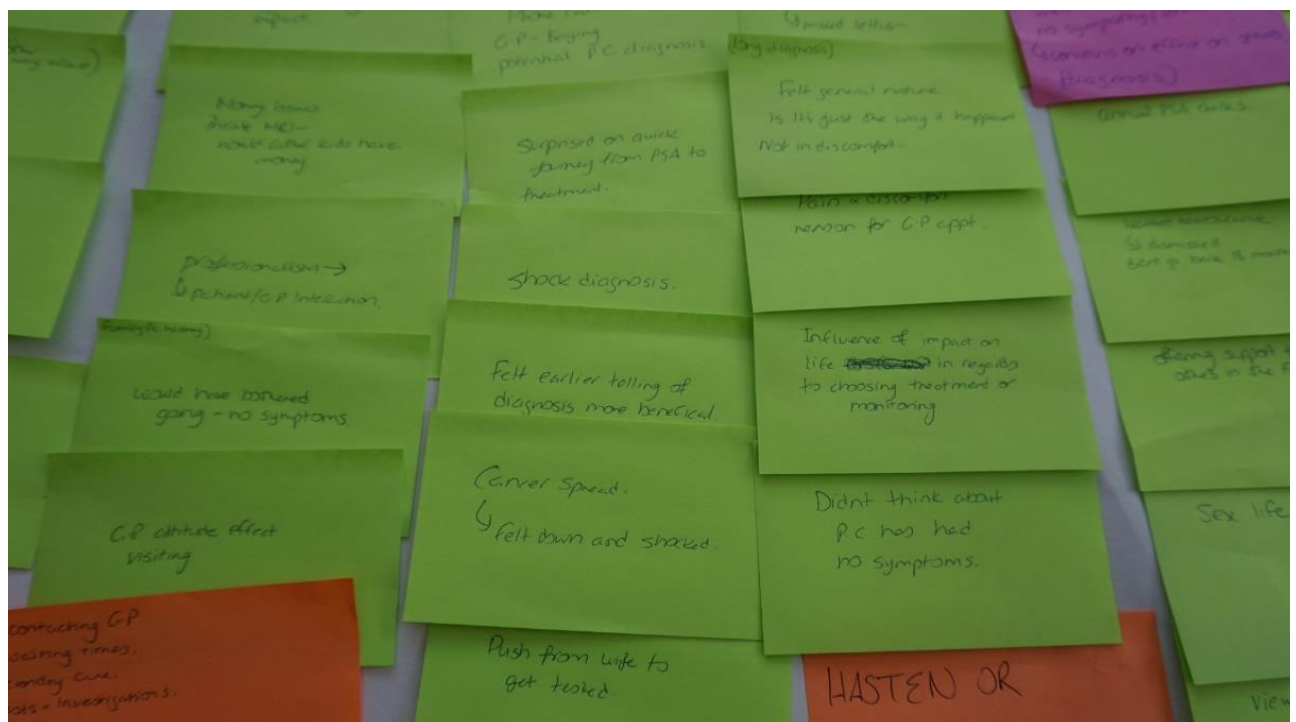
P: Okey-doke.

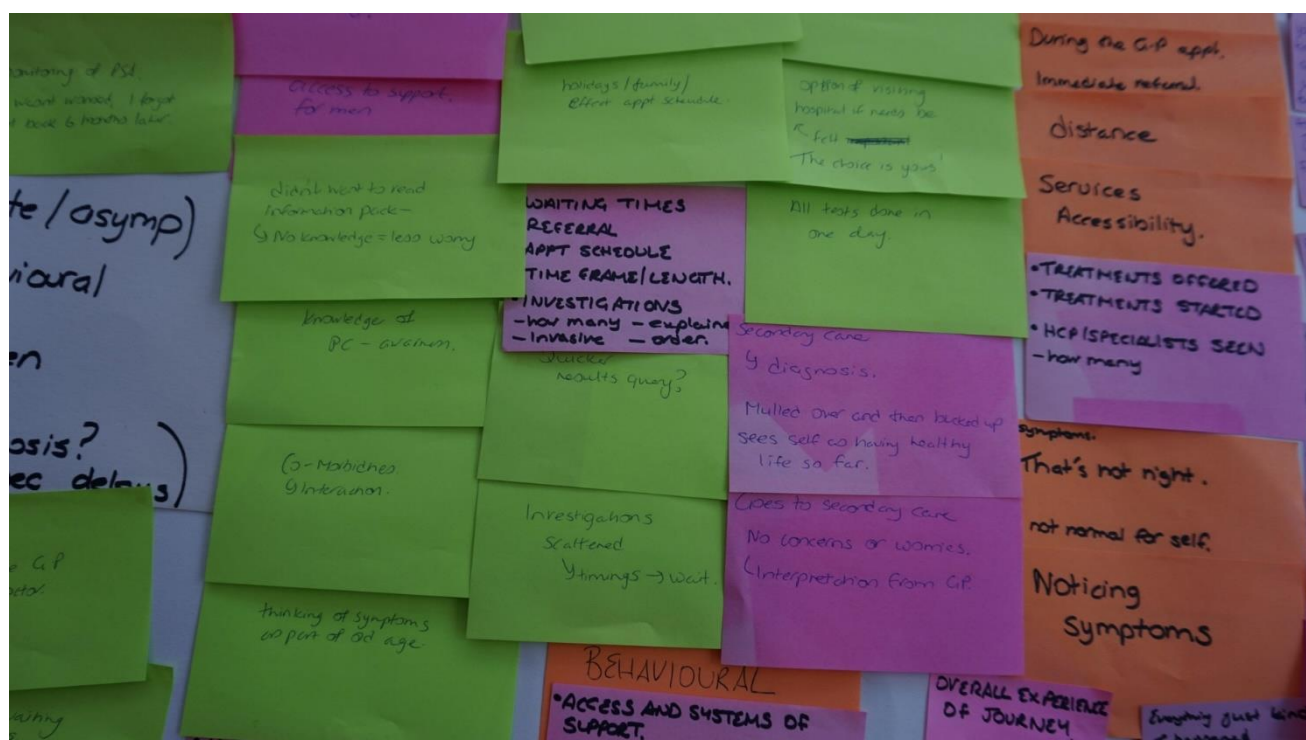
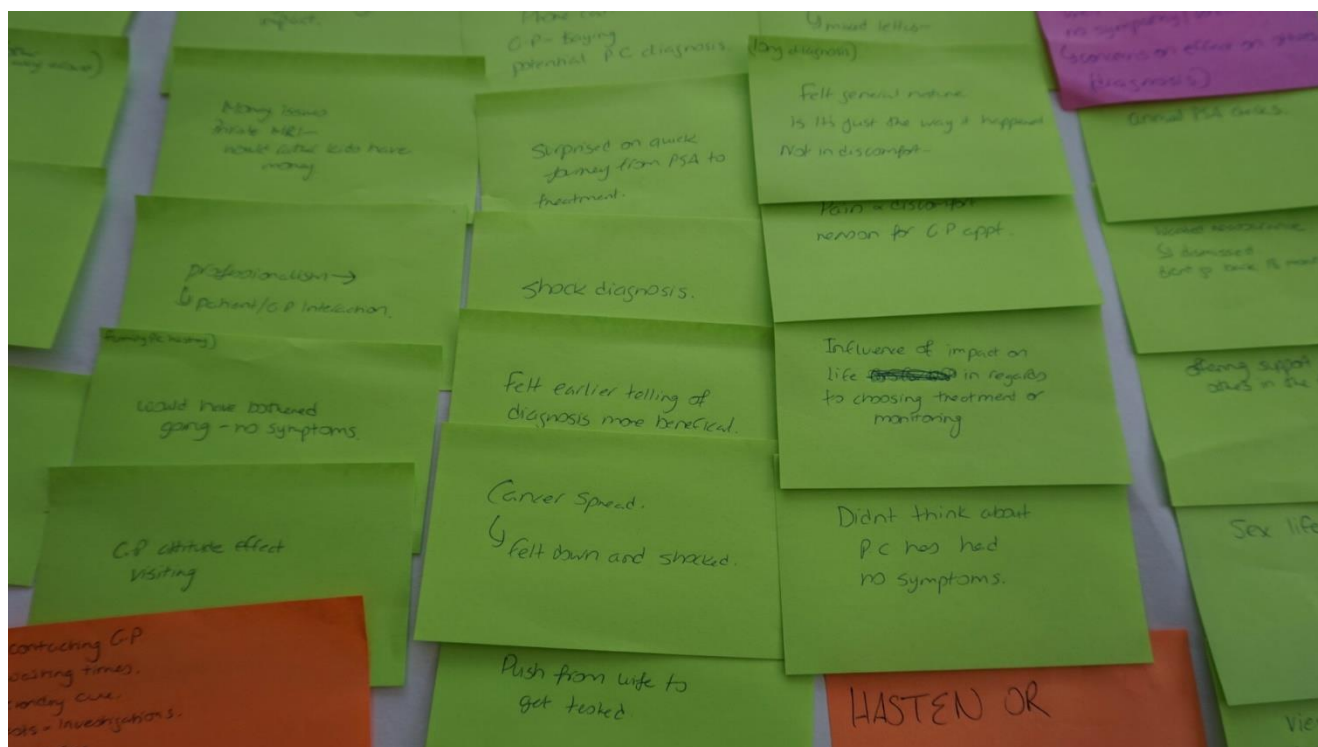
**R: Fantastic.**

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\* End of Interview \*

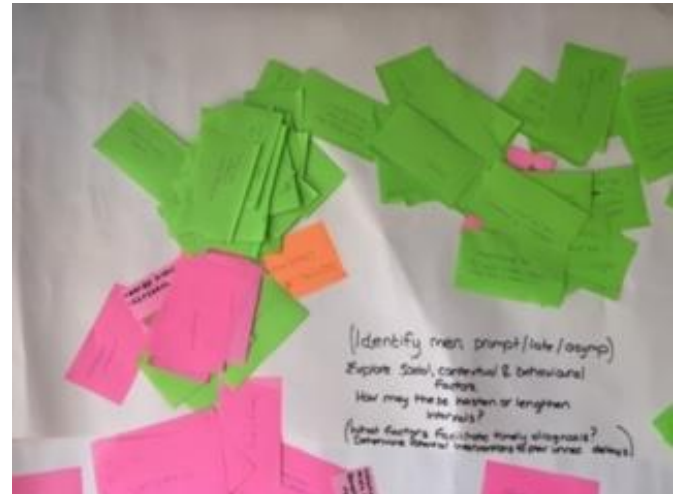
## Appendices thirteen





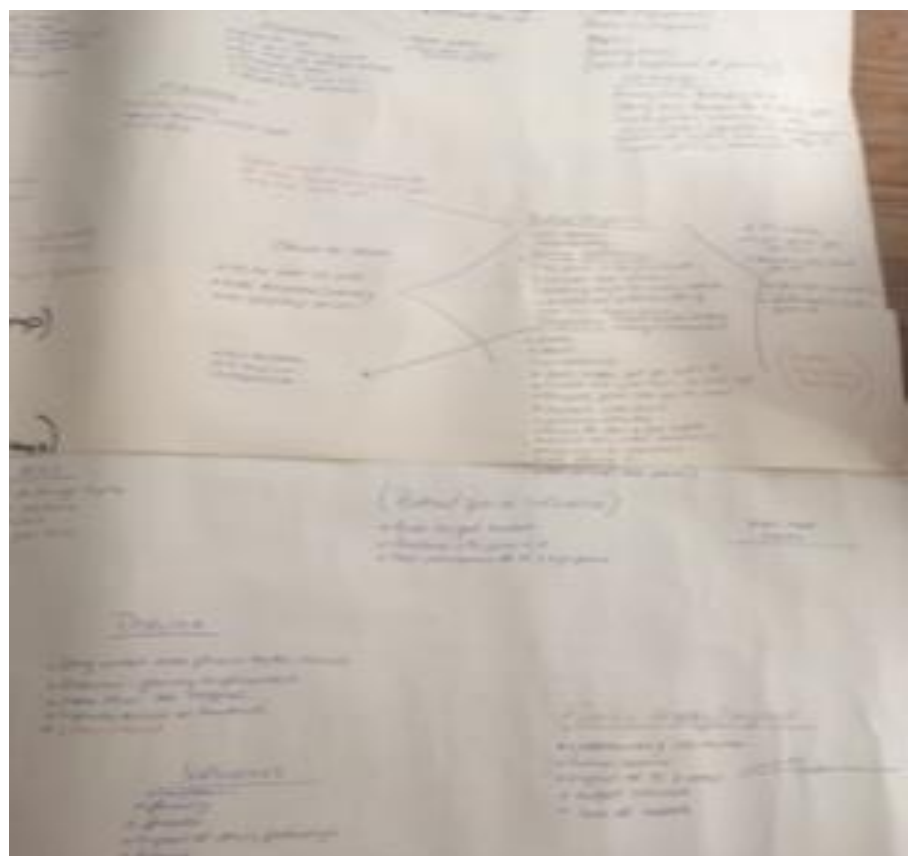
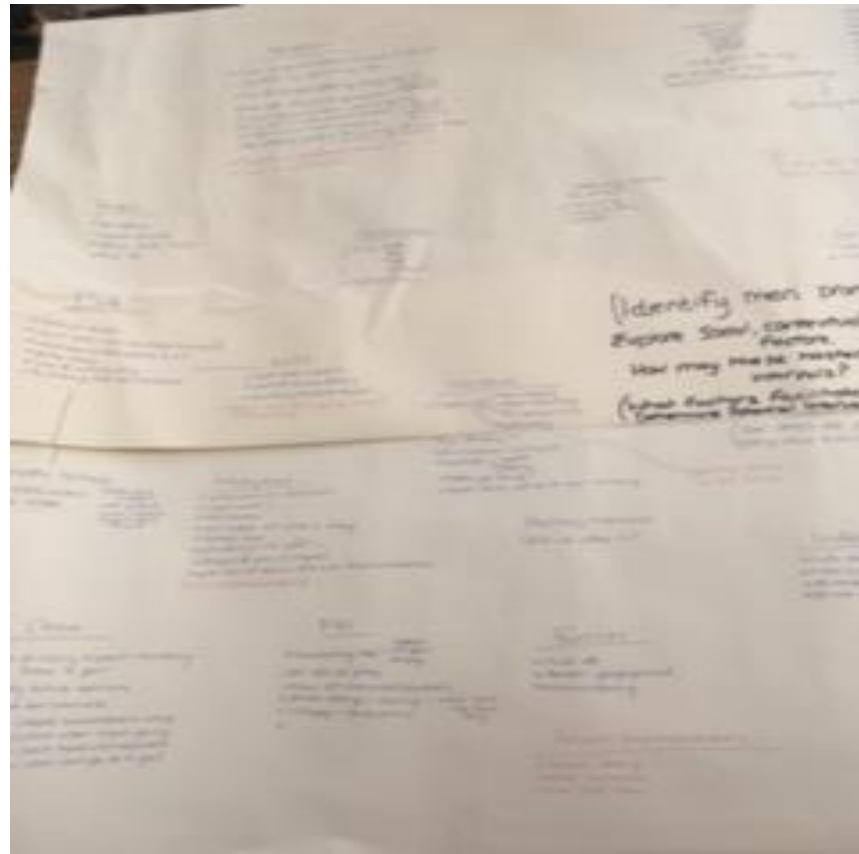


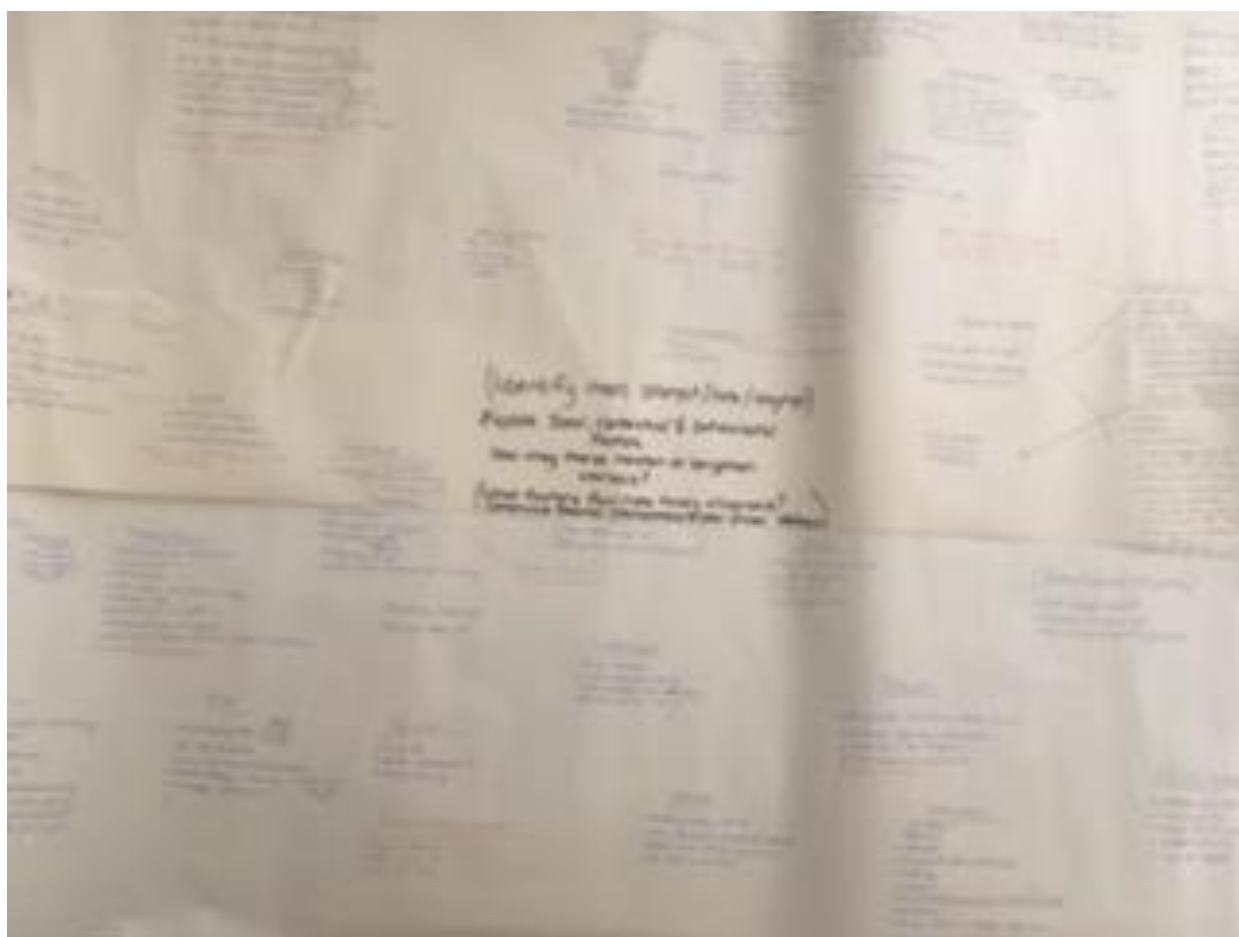
## Appendices fourteen





Appendices  
fifteen





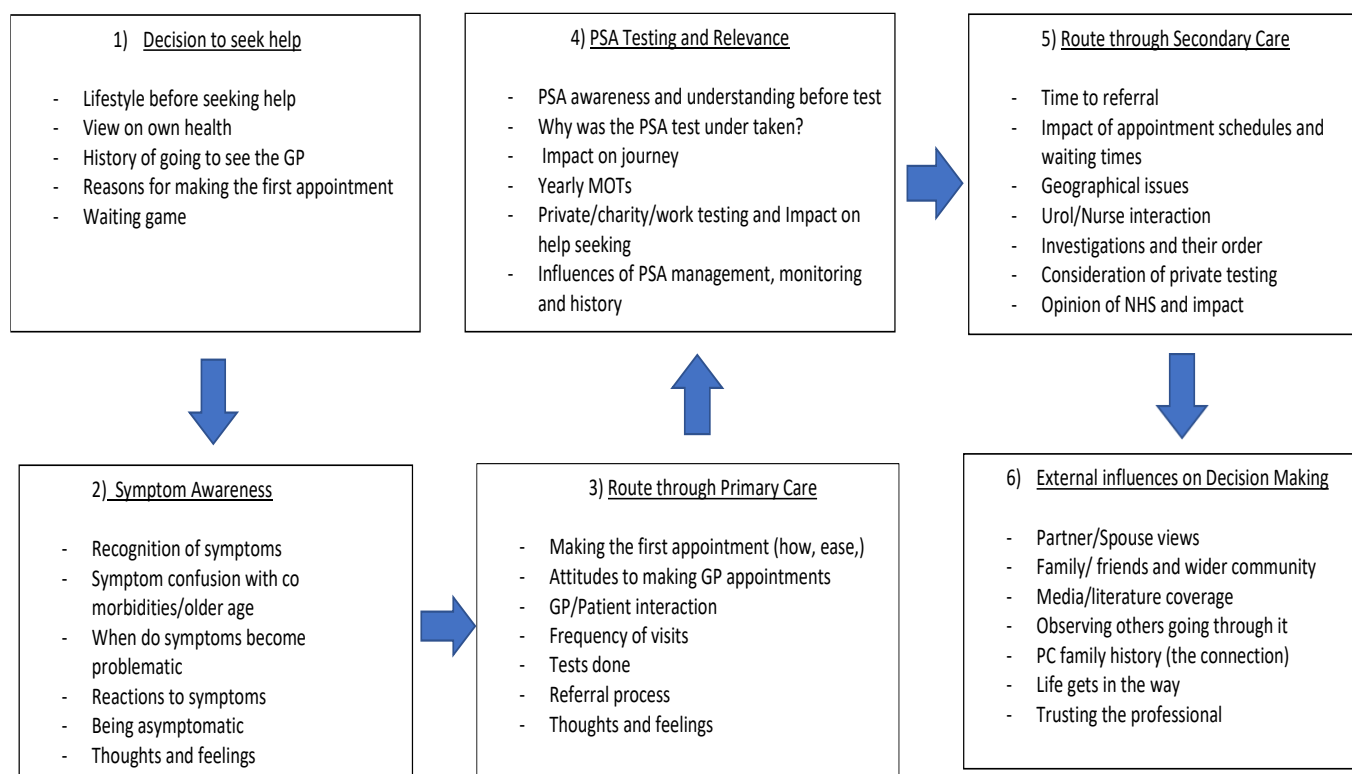
## Appendices sixteen



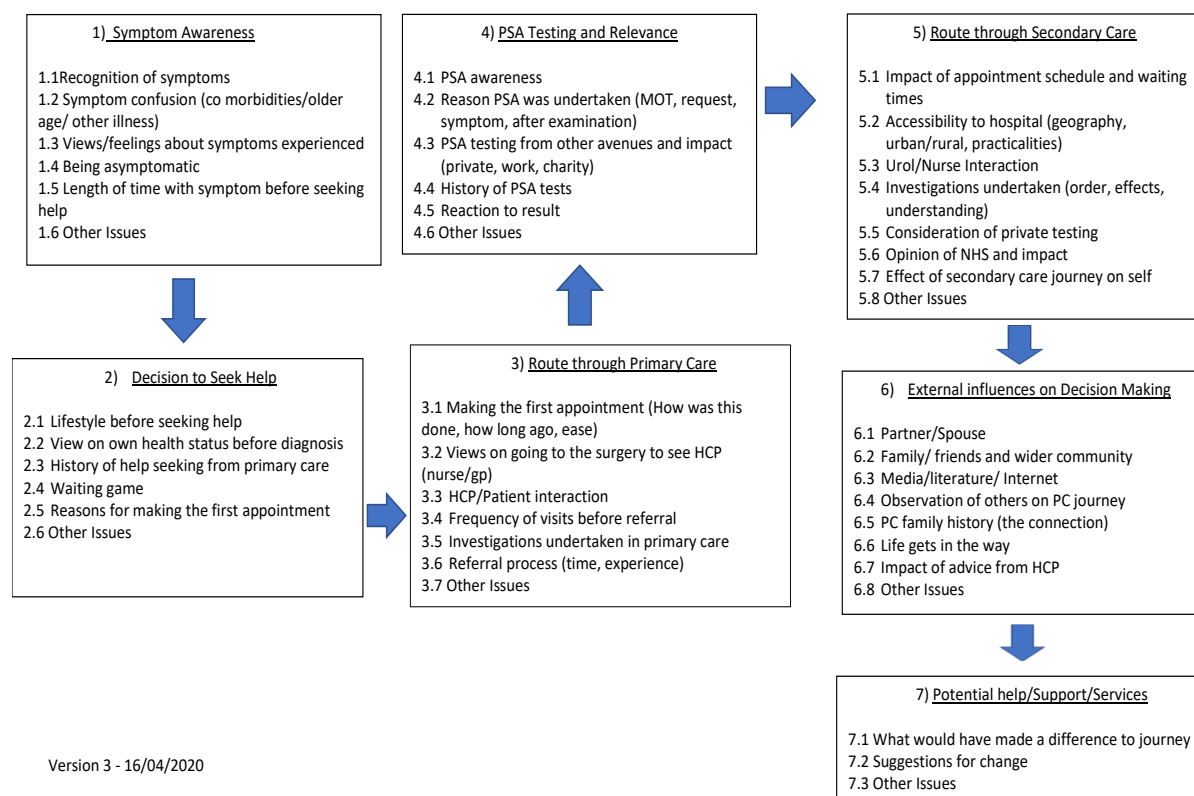
## Appendices seventeen

<p><u>Investigations/tests</u></p> <ul style="list-style-type: none"> <li>- The order of the tests, does it matter.</li> <li>- Thoughts and feelings (anxiety, embarrassment, apprehension)</li> <li>- Implications of private testing on money and time</li> <li>- Does explaining and understanding help.</li> <li>- Hcp/patient interaction</li> <li>- Impact of appt schedule and waiting times</li> <li>- Could break it down for primary and secondary care?</li> </ul>	<p><u>Literature/Media impact</u> ( this could potentially be amalgamated in impact of listening to others?</p> <ul style="list-style-type: none"> <li>- Different media awareness before and during journey</li> <li>- The impact on this awareness and decision making</li> <li>- Views on the importance of media/literature awareness</li> <li>- Information overload/underload</li> </ul>	<p><u>PSA testing</u></p> <ul style="list-style-type: none"> <li>- PSA awareness and understanding before test</li> <li>- Why was the PSA test done?</li> <li>- Hcp/patient interaction. Impact on journey</li> <li>- Yearly MOT's</li> <li>- Private/charity/work testing and their impact on help seeking</li> <li>- Influences of PSA management, monitoring and history.</li> </ul>
<p><u>Impact of Listening to others on decision making</u></p> <ul style="list-style-type: none"> <li>- Partner/spouse views</li> <li>- Family/ friends and the wider community</li> <li>- Media coverage</li> <li>- Observing others going through it</li> <li>- PC family history ( the connection)</li> <li>- The power of talking</li> <li>- Trusting the professional</li> </ul>	<p><u>Geographical issues</u></p> <ul style="list-style-type: none"> <li>- distance- journeys to access care</li> <li>- the impact on decision making for tests and treatment</li> <li>- how many hospitals visited?</li> <li>- urban/rural differences</li> </ul>	<p>Views, thoughts and feelings throughout journey</p> <ul style="list-style-type: none"> <li>- Before diagnosis, health, views on life</li> <li>- Journey through primary care</li> <li>- Journey through secondary care</li> <li>- On diagnosis</li> <li>- Did these thoughts impact decision making</li> <li>- letting others know, does it matter</li> <li>- Life gets in the way ( holidays, illness, deaths etc)</li> </ul>
<p><u>Making the first appt and seeing the GP.</u></p> <ul style="list-style-type: none"> <li>- Reasons for making the appt</li> <li>- How are appts made at the surgery</li> <li>- Frequency of past visits to the GP</li> <li>- Attitudes to appointment making</li> <li>- Attitude to health status on seeing GP.</li> <li>- GP interaction</li> <li>- Fpoc,</li> </ul>	<p><u>Symptom awareness</u></p> <ul style="list-style-type: none"> <li>- Recognition of symptoms</li> <li>- Symptom confusion with co morbidities/older age</li> <li>- When do symptoms become problematic</li> <li>- Catalyst to seek help</li> <li>- Reactions to symptoms</li> <li>- Being asymptomatic</li> </ul>	<p>Others points to think about</p> <ul style="list-style-type: none"> <li>- Monitoring concerns</li> <li>- Choice- having options</li> <li>- Systems of support</li> <li>- Health before pc.</li> <li>- Offering advice to others ( looking back)</li> <li>- Continuity</li> <li>- nurses</li> </ul>

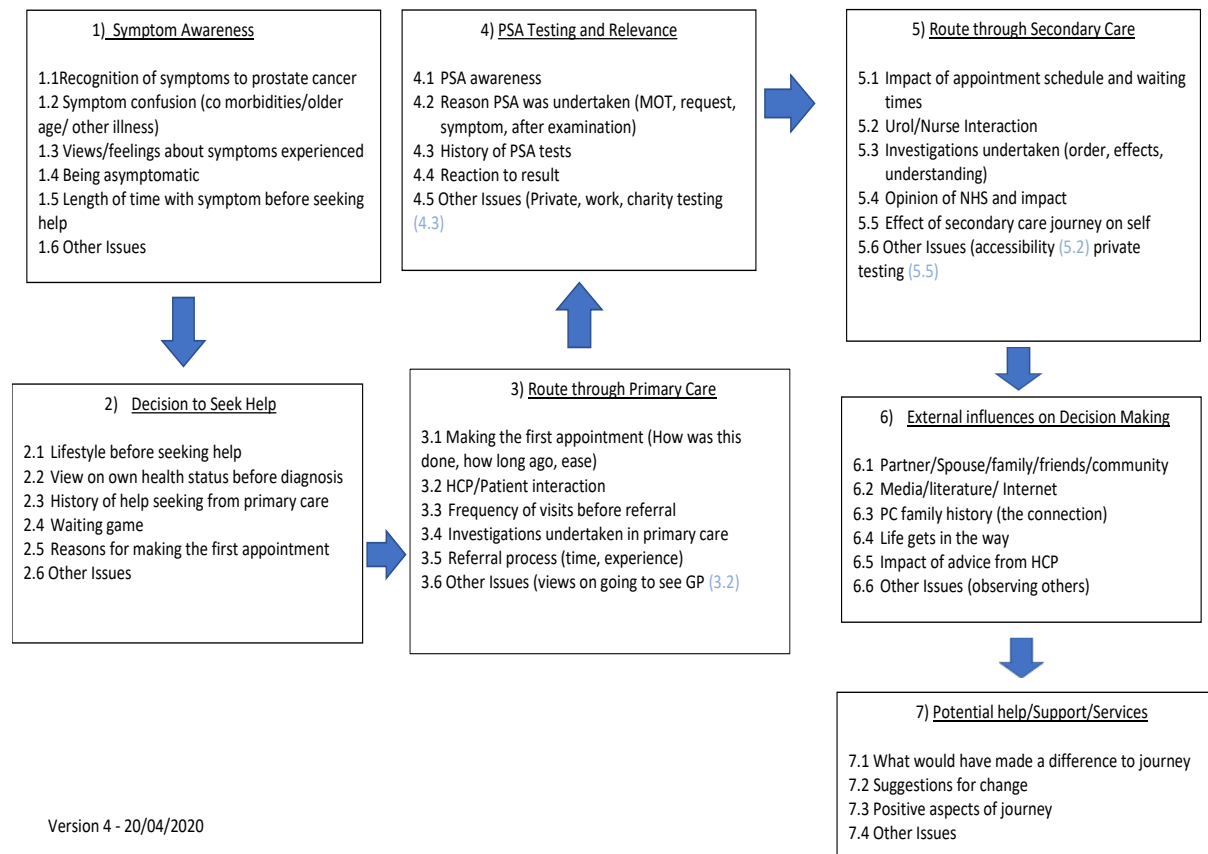
Version 1



Version 2



Version 3 - 16/04/2020



Version 4 - 20/04/2020

## Appendix eighteen- samples from excel charts

PARTICIPANT	1.1 RECOGNITION OF SYMPTOMS TO PC	1.2 SYMPTOM CONFUSION CO MORB/OLDER AGE/ILLNESS	1.3 VIEWS/FEELINGS ABOUT SYMPTOMS EXPERIENCED	1.4 BEING ASYMPTOMATIC	1.5 LENGTH OF TIME BEFORE HELP SEEKING	1.6 OTHER ISSUES
P8, age 69, prompt, BCUH8	if that episode hadn't happened, wouldn't have known anything was wrong with mw Q0 p3 made no connection to pca just thought infection p3	n/a	feeling really tired, news eve had blood in urine... it never happened again and i thought, that's not right p2 Q0	n/a	went to see doc within a week of blood in urine and delay due to christmas year	
P9, age 70, prompt, ABUH8	Ac- he hadn't been getting up much in the night, that's the one thing we always worry about with me, don't we? Getting up in the night, I mean Q0p4	n/a	n/a	doesn't think had any symptoms before blood test was done. Ac- said he never complains p4.	n/a	RN- prompt journey but also asymptomatic.
P10, age 69, prompt, HDUH8	I looked up these things on the internet, so when i read there was symptoms, had none of it. P1 Q0Q	experienced occasional erectile dysfunction, bit concerned as never had before, also peeing a bit slower, looked up on internet, there was other things about pca, all i had was slow peeing and that was it, looked online so thought, ok, i haven't got it', it basically said what it was, old age, i then didn't do anything about it. Q0Q P1 full quote in transcript. i do read up about things and i had none of major symptoms, and other types of illness quite normal, old age Q0, p10	looked online and thought all i had was slow peeing, thought ok, haven't got pc, it comes with old age p1	n/a even though didn't associate symptoms with pca.	stayed with symptoms for 11 months, maybe longer, before doing anything about it p1 Q	RN- down as prompt diagnosis but did have symptoms for nearly 11 months but did not associate these at all with pca ? Potential change group ng!!
P11, age 64, prompt, BCUH8	after seeing more publicity on tv about pca, approached GP at appt and asked for jss p1	was told by gp getting up to go to toilet at night, prostate gets bigger, one of those things, an age thing p1	had concerns, just problems, back and to the toilet at night. That kind of thing, getting up two or three times. P1	n/a	had symptoms for some time, maybe progressively, over two years now. Had visited GP and spoke, they said, just an age thing' Q	RN- written as prompt from database but conflicting interview as says symptoms over 2 years

PARTICIPANT	2.1 LIFESTYLE BEFORE SEEK HELP	2.2 VIEW ON HEALTH BEEF DIAG	2.3 HISTORY OF HELP SEEK PRIOR CARE	2.4 WAITING GAME	2.5) REASONS FOR MAKING FIRST APPT	2.6) OTHER ISSUES
P1, age 75 asymptomatic, BCUHB	belong to a group for retired people, do activities every month p1	pretty good as goes to gym three times a week, goes walking p1. see self as reasonably fit p2. sees self as healthy QQ, p10.	felt it used to be best surgery, but not anymore QQ, p3. used to have 5 excel docs but all left.	Chrismas caused delay in getting appt P2.	Reply from masons after psa test was a red letter saying PSA 10 and recommending to see GP p2.	CN-sees self as healthy but maybe catalyst to appt was both psa and also comparison to others
P2, age 76 asymptomatic BCUHB	retired since 60 with illness,	has regular blood tests for rheumatoid osteo and medication they are on . lots going on health wise last 16 years,	had various experiences with hospitals , lots of history for various health issues Qp9 , feel beneficial having same doc for 45 years. Knows history	delays with tests due to other health problems AC- disappointed with wait between some appts ( 6-8 weeks)	AC- I spoke to receptionist during blood appt as felt he wouldn't have done it otherwise	CN-emotional re count of journey as intertwined with other health issues and scares.
P3, age 70 asymptomatic, BCUHB	enjoys a drink, watching rugby, holidays p1	felt fit and healthy in general but had cough p2	na	na	went to gp over cough and GP did PSA without him knowing . 'She never told me, whether they do it auto or not or if she had a spare QQ, p2.	
P4, age 79, asymptomatic, CTUHB	Always been very active, all my life, playing golf for 30 yrs. p1 Q	healthy, rarely got ill	its all new to me going to hospital, im not. P4 Q	no delay	decided to have health check 8 years ago privately as could afford it. p1 Q	
P5, age 56, asymptomatic, CTUHB	currently works as a train driver p1	na	na	It was probably my fault it was left before going to docs. Could have gone 2 mths earlier	my father had pca and he kept on me to go and have my prostate checked. P1 QQ	
P6, age 69, asymptomatic, BCUHB	I was doing fine , was looking after wife who had cancer p1	had issues with blood pressure and just before diagnosed with polymyalgia rheumatic p1	n/a	n/a	was just having a blood pressure blood test check up so didn't make appt for pca	
P7, age 69, asymptomatic, CUUHB	After the tongue cancer was back to feeling fit and healthy again p1	two years previous had just recovered from tongue cancer, so just got over that P1	condition and handy as just across road. feels GP surgery are good as can get urgent appt if want one on same day, when you need them. They don't argue, if you need an urgent appt, they give you one, they're really good QQ, p7	n/a	happened to watch a tv programme that featured pca and mentioned if you are getting up to go to toilet at night, if so get checked QQQ. p1 . if I hadn't seen programme, would have been eaten and it would have been developing inside me and	
P8, age 69, prompt, BCUHB	home birds p1	never had anything wrong with me p2	I don't go there often. Its something rare for me to go to the doctor anyway p2 QQ probably been 3 times in 23 years Q, p2	had to wait to see doc as it was christmas and new year.	after blood in urine felt it wasn't right so went to doc on first day it was open after new year. P2	



PARTICIPANT	3.1 MAKING THE FIRST APPOINTMENT	3.2 HOP-PATIENT INTERACTION	3.3 FREQUENCY OF VISITS BEFORE REFERRAL	3.4 INVESTIGATIONS UNDERTAKEN IN PRIMARY CARE	3.5 REFERRAL PROCESS (TIME EXPERIENCE)	3.6 OTHER ISSUES (NEWS ETC)
P15, age 78, late BCUHB	4 yrs ago it took about a week to get appt, now its 3-4 weeks unless its an emergency. Q p4	Had appt with doc 25 yrs so, high psa then and checked twice. doc said- 'dont think much to worry about, keep an eye on it, but then moved. p5 first appt with doc was given painkillers for pain, went back second time and had blood test. Went back week 1tr told no pain indic in blood, given steroids. P4, worked well for a yr, then had well man every 12 mths. P5, called in to see gp, concern it was 12, gp asked what pt wanted to do about it, pt asked gp advice and was left for 3 mths. p6 psa had gone up, pt was asked opinion of what wanted to do so decided to wait another 6 mths. QQQ p6. ** (carried on in other issues)	numerous visits over the yrs to see locum and normal doctor. He count goes back in time at points	PSA tests, DRE, examination.	gp referral on agreement with pt after they had returned with symptoms, referral for bone scan and urology P7.	interaction carried on here due to extremely long journey re cap. ** doc said, its gone up what do you want to do?, well dont really want a biopsy, ive got no other symptoms let it role for 6 mths QQQ. to note check 6.1 as pt put off by recount of another journey so impacted decision to not go for further tests. Went back to GP after having urinary problems and also pains in bones. GP referred, then recount of going to see locum with blood in urine, recommended referral but pt decided didnt need it, felt nothing going on, psa wasnt overly concerning. RC- complicated journey spanning over 25 yrs of high PSA tests and symptoms. Important to note GPhpt reactions to results and conversations had. Check QQ ** HCPGP
P16, age 78, late BCUHB	had message to say needed to go and see doctor, he didnt know why, just sent for p2, felt didnt know what doc to see as original doc saw was 25 yrs ago, so just picked one out of the 3. Q p2	On first appt asked to take stains, then was 'bugged again about having to see doctor' p2. Had another appt with doc, was told needed to see specialist because PSA is too high, much too high. P1 felt. Why bother'. Q p3. pt asked what could be done, was told by doc thats why he was being sent to hosp. p3. Felt in 2 yrs time going to be 80, cant be much time left anyway? QQQ p3. was explained by doc it was about quality of life, so need treatment, he felt that was a good point so agreed to it. p3	on second visit, referral made	na	pt didnt think referral time was that long, couple of months maybe. P3	
P17, age 62, late, RTH HR	when chatting to doc in his workplace explained about feeling tired, doc got out scrap of paper and was told to give it to nurse in surgery and tell her you want these checks done Q p1	after bloods came back to say issue with PSA and to see doc. Had examination and he said was happy with prostate, wasnt enlarged but referred to hospital for further tests. P2	1 phone, 1 doc visit and referred then	PSA Aand DRE	ended up going private as panicked and was seen straightaway. P3	

PARTICIPANT	4.1) PSA AWARENESS	4.2) REASON PSA WAS UNDERTAKEN	4.3) HISTORY OF PSA TESTS	4.4) REACTION TO RESULT	4.5) OTHER ISSUES (PRIVATE, CHARITY, WORK)
P16, age 78, late BCuHB	just awareness that on time blood test was done, nurse said they had to test for everything that's conven for them to test p2. That's the first time he had heard of it, know its something similar to having your tyres blown up on car but that's about it Q p3.	PSA test was taken with yrly blood test, usually have it and go away, that's the end of it p1	Had no reason to think the docs was going to find anything wrong with blood test p1. had test over a yr ago. P1	was told by doc PSA was too high. That's the first time he had heard of it, know its something similar to having your tyres blown up on car but that's about it Q p3. felt why bother about seeing specialist p3	
P17, age 62, late, BCuHB	didn't really have awareness of what PSA test was, was told by doc, believe it is hit or miss, known men with very high readings and nothing wrong with them p3 Q	pt had asked doc about feeling tired on chance encounter. Was sent to surgery for bloods. P1	after first raised blood test, was referred to hospital. Biopsy was clear was told to continue to have PSA tests to monitor and it was still rising, doc not happy so managed to get an MRI scan.p4	everyone panicked and wife then made appt for him to go private p2	feels docs more aware of it and more tests being done, things are on the up and improving by looks of it p6 Q
P18, age 71, late, HDuHB	awareness of pca from media	prof ass ordered blood test after DRE examination and enlarged prostate with ridges p1.	n/a	n/a	
P19, age 71, late BCuHB	knew what the blood test was for p6  feels PSA awareness is still a guide p11 Q. AC- felt didn't know what it was, knew it was a test for blood but didn't know what PSA was. Had to google it Q p11.	PSA undertaken after first appt with GP and DRE showed something p5	n/a	was told PSA was 2.21 but had heard some can be in thousands p7. 'id also read anything over 100 likely ot be cancerous anyway so not a dull guy' QQ p7. People think hi m as odd as it didn't worry him at all. P7.	even lady friend says to him 'you'd laugh if they told you you were dying tomorrow', feels its not going to change anything, so didn't tell kids p7 Q didn't want to worry them. P7.
P20, age 66, late ABuHB		due to going to docs with blood in urine	n/a	was told PSA result was fine. But felt that even when asked surgeon 'tr what it was, was told, 'that's a good question, no one mentioned PSA p5	AC- feels should go for a blood test, just go and have your blood done p11
P21 could be late or asymp?	awareness through family history	due to family hisotry and brothr in law feeling him to, has been having tests for yrs. P1	been having annual checks for pca for quite a few yrs, due to brother having it p1. Previous 4 yrs had annually PSA which gradually went up. When went up to 4, told borderline and sent for other check to make sure p2	n/a	

PARTICIPANT	5.1) IMPACT OF APPT SCHED AND WAITING TIMES	5.2) UPGRADE INTERACTION	5.3) INVESTIGATION (INCIDENT) (sides, effects, understanding)	5.4) OPINION OF NHS AND IMPACT	5.5) EFFECT OF SECONDARY CARE JOURNEY ON SELF	5.6) OTHER ISSUES (accessibility, feeling)
P8, age 68, prompt, BCJHB	felt long winded, but on other side, lots of people going through it and can't see everyone at once, so have to bear that in mind. P10 Q9	go to urology first appt, uni, says something doesn't seem right, p8 told don't drink enough water and to come back for another scan. P8, of went with knowledge prostate didn't feel right and in need of other scan Q10 p8, after tests go and see coos, told had pcs, wasn't surprised then, felt wife more upset P8.	check urine, bloods, cbs, DfE on first appt p8, also camera in bladder, ultrasound on stomach all same day. P8, then another bladder scan, biopsy and ps-test. Didn't feel much, a bit from biopsy, wasn't all that uncomfortable, that was end of that P7 Q.	felt hos were informative, look after you when go to appts and can ask questions and get answer Q10. Lack of facilities at hospital, wales second class to england, if you want anything serious done have to cross border. P12.	felt. This is it, got to find out what's wrong with me, kind of thing P8 Q10. Feeling after biopsy that something not right, hoping results are going to say your ok. Q10 P7 AC- hoping but in back of mind because of way he was, having it confirmed some things not right, you know really Q10 P7	P10- first appt in van and diag in march but felt it seemed to drag on even though classed as prompt journey p11
P9, age 70, prompt, ABJHB	very quick to first appt. P2. AC- We were told to be prepared to be there all day and we thought that was fantastic because we went in there at 7, had things done and were out at 4, all done in one day Q10 p5	I saw the consultant chap after MRI scan and he said he wanted to do a biopsy. P2. They did the biops and said not to worry too much, the biops are up, were taken bits from biopsy, with your age we don't usually operate, we'll monitor, asked if happy with that. P2 Q10	went to a day centre, went in the morning about 7 and they gave me a MRI scan. Was then told I needed to see consultant P2 Q, saw consultant and had biopsy P2, all tests done in one day p5 MRI in the morning, come out of there and then she looked at charts and went back in for biopsy Q10 P5 I was told I would have gone back and forth a couple of times, but it was all in one day, p5	we were very pleased with journey, they are a fantastic unit, we got to be fair, absolutely brilliant Q10	I was feeling a bit worried about it then, to be honest, as I say, my father and brother had it so it did worry me a bit Q10 P2. marvelous quick journey p8, thought it was the best way to do, get it over and done with Q10	P10- Being monitored so account of going back and forth to hospital but hasn't been added to here as just going up until diagnosis
P10, age 68, prompt, HJHB	p4 quick journey and quick appts p5	At first appt had DfE and then he really spelt it out for me, he said it was quite bad, prostate swollen and had need to do something urgently Q10 p4. Nurse and doc amazing during biopsy p8, was told diagnosis by original nurse and felt it helped to sit and talk to one individual p7, told her bottom line, we had 68 bloody good years, and happy days if I go tomorrow p6 Q	first appt, another DfE, second appt, another biopsy and was very concerned about again the embarrassment, my back passage being entered for the third time p5. Q. Procedure was painless, procedure explained. P8	sheer clinical expertise of people who dealt with me, it's been brilliant p11	felt referral was due to them just checking our high reading and nothing there so nothing really going through mind on first appt p4 AC- after examination you could tell he was devastated. Bottom line, sat in car after appt and mullied over info, thought what is to be is to be. We had 68 bloody good years Q10 p4	he didn't want anyone to know in the family, don't want sympathy and don't want anyone concerned or worried about me, no one knows p6 Q
P11, age 64, prompt, BCJHB	had private appt within 3 days of GP- appt. p3, strangely had phone call from hosp saying also had cancellation with NHS, decided to stay with private healthcare p3. Was told 3/4 mths waiting list on phone call enquiring p4, waited and phoned again to see if could get cancellation, was fitted in week later, p4 wondered if he hadn't phoned, what would have happened Q10 p4, felt it was almost like the phone call got me the appt. Q	during private healthcare, first appt had examination and told needed MRI, they're not available on NHS. P3. Also told psa was slightly high P3. Saw consultant after MRI result, he did explain fairly good, said felt I should have biopsy P3, just a slight concern, he couldn't explain it, but felt biopsy would benefit p4, results of biopsy given through NHS by same spec seen when went private p4, felt he was very good, much the same, can't criticise him and explained low grade cancer found Q10	psa examination, private healthcare paid £800 for MRI, waited couple of weeks for results. P3 priv healthcare wouldn't cover biopsy, so went back to NHS.	made some enquiries about biopsy on NHS and told 3/4 mths waiting list p4, felt as it happened had cancellation through NHS so could have seen specialist just as quickly as private, but maybe next time it wouldn't happen P8 Q. It was luck, probably can't understand why NHS in Eng and Wales work differently.	felt quite concerned after discussion with coos after MRI, not knowing how long would take. P4	went private as already had healthcare cover, limit of £2,000 to cover diagnosis P3. Wonders if had not had priv healthcare to fall back on, whether it would have been months for appts and tests p6.

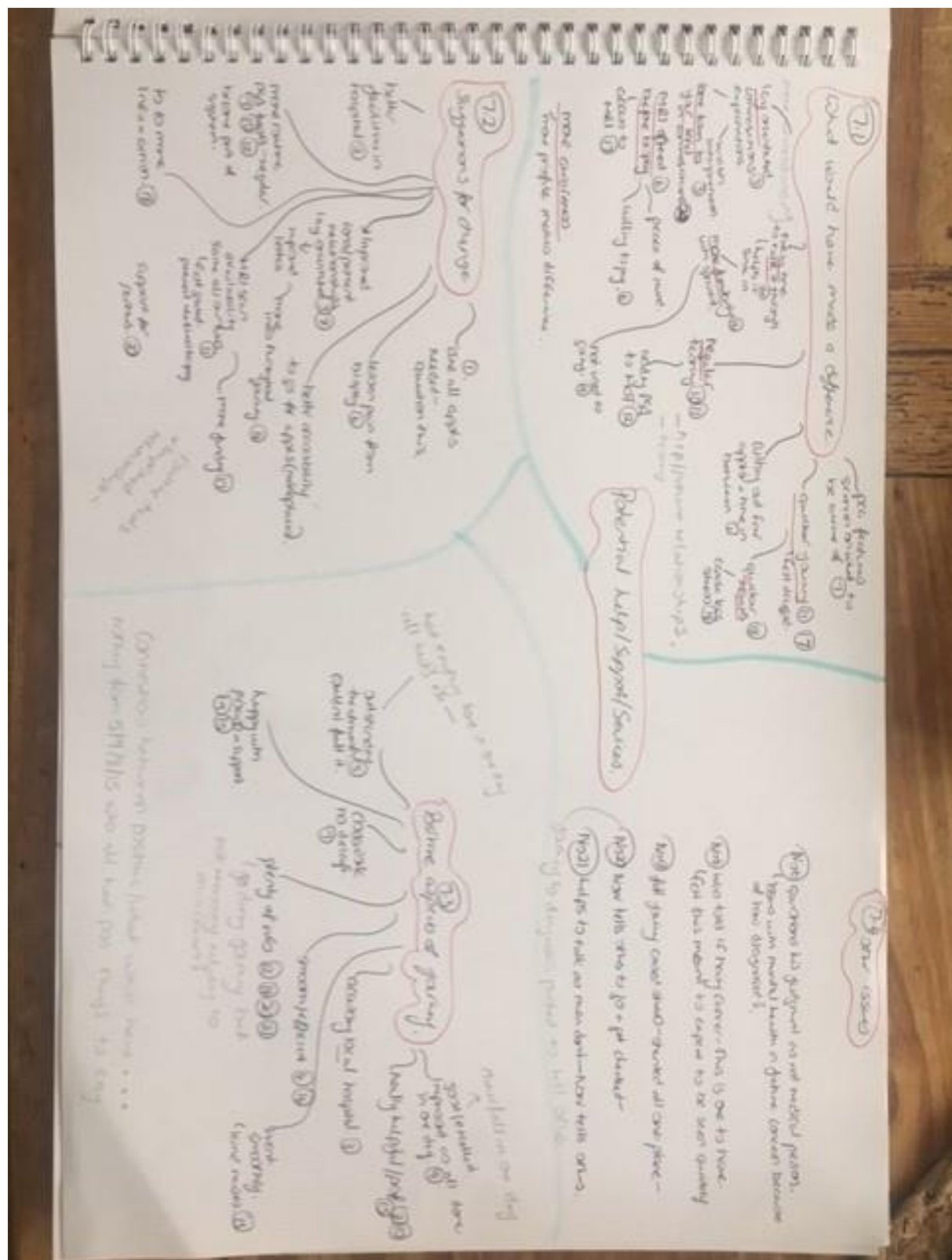
PARTICIPANT	6.1) PARTNER/FAMILY/FRIENDS/COMMUNITY	6.2) MEDIA/LITERATURE/INTERNET	6.3) PC FAMILY HISTORY	6.4) LIFE GETS IN THE WAY	6.5) IMPACT OF ADVICE FROM HCP	6.6) OTHER ISSUES
	wife had picked up on weeing in night and stop starting, she had heard something, she told him it was a prostate problem. p2. Felt wife talking to him started him thinning p2. Went private due to spking to someone who said their husband waited weeks to see someone. p3. ive spoken to one or two friends whove gone through it, helped to chat p8				was expecting more professional from urol who told him to go home and read up on inter what he wanted to do. 'I was trusting him, I wanted him to say' Q. p4	
p17, age 62, late, BCUHB	push to go to docs was friend had recently died of pca, he'd just died of pca. 'I thought, gosh, prostate cancer of course.. Why didn't I think of that? So I looked it up and immediately saw frewuent urination, that's it, off we go. That's why I went strightaway	before going to docs he had looked it all up ( all about pca) on internet and seen quite a lot so didn't ask questions at appt. p1. Had also causally been reading about S. Fry and Turnbull and it was on tele, saying go and get yourself tested. QQ p2. couldn't even watch programme about bill turnbull p3. had read some of his blog and how awful it was. Q. p3. .	Hadn't realised father had pca at stage of going to docs, found out later when talking to family p3. he didn't die of pca though p7. compares self with borther who he feels is unhealthy but he has no issues. 'im quite healthy I think, what is it about me and my dad but not my borther' Q. p11.	was due to go on holiday before biopsy and was offered yo wit until back from holiday but felt 'id rather have it now, this very moment' QQ p3.	n/a	opinion of comparison to someone who had all tests and scans done in one day for another issue. 'Felt very happy for him, 'but I thought, hes had both scans, all tests and all took one day, hes not dying from that, prostate cancer is the biggest killer of men in this country and you can't even get a scan, you can't even get scanned in two months, this is a strnage world' QQ. p5
p18, age 71, late, HDUHB	QQ. p1					

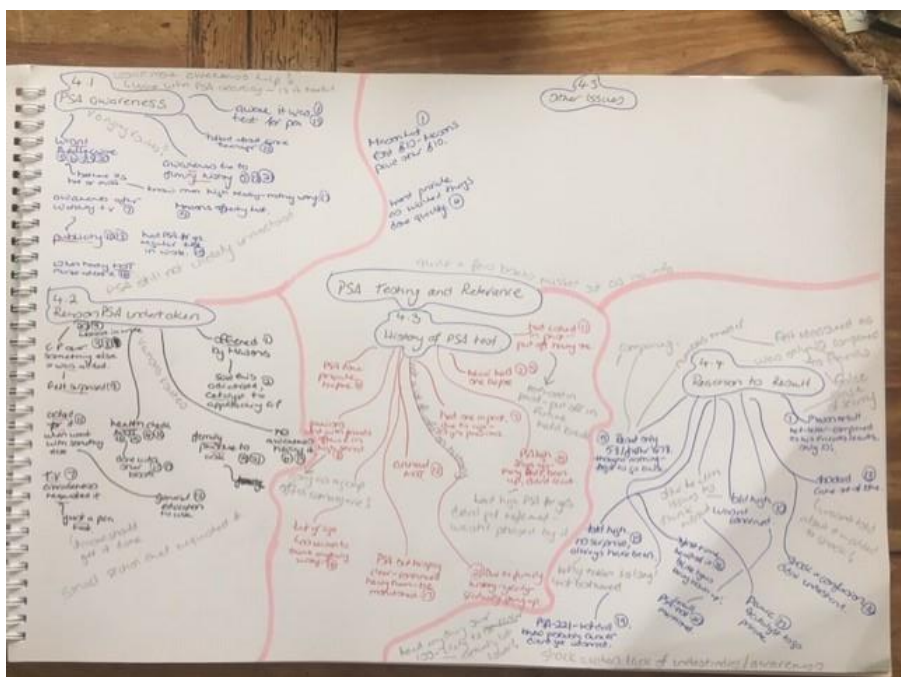
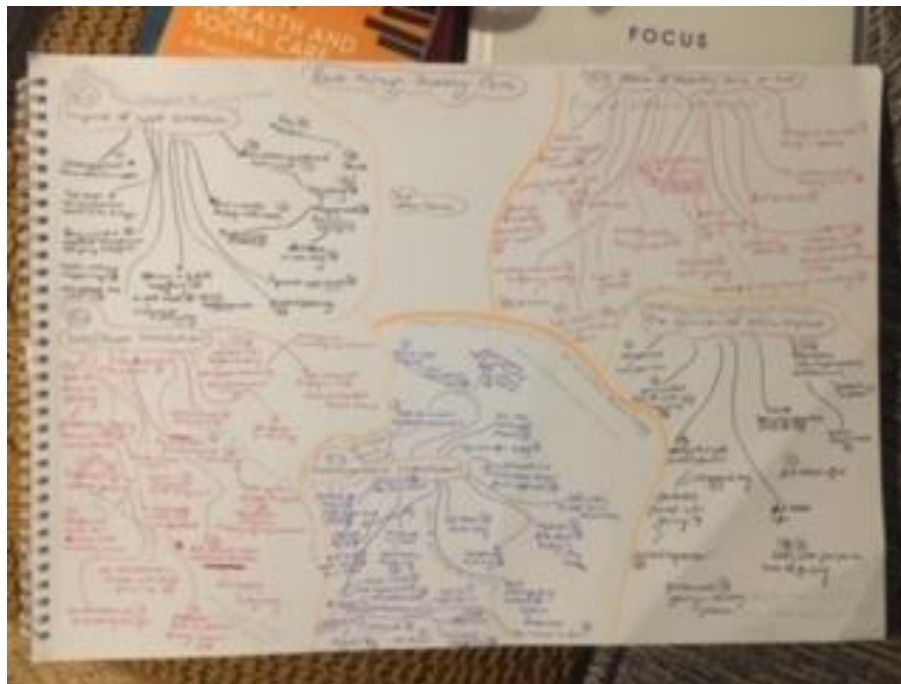
PARTICIPANT	7.1) WHAT WOULD HAVE MADE A DIFFERENCE	7.2) SUGGESTIONS FOR CHANGE	7.3) POSITIVE ASPECTS OF JOURNEY	7.4) OTHER ISSUES
P1, age 75 asymptomatic, BCUHB	cutting out a few appts and time in between as some could be cut out, results quicker Q. p8	questioning whether it is needed to do all appts, investigations and wait, why need 2 MRI's, p10.	N/A	
P2, age 76 asymptomatic BCUHB	n/a	facilities in the hospital the way they give out information on your condition and system. Consultant not in same world.	AD- felt staff were amazing, talked about things, really helpful , really good, no fault	wife emotional on talking about journey
P3, age 70 asymptomatic, BCUHB	more lay orientated interpretation , issues with welsh interpretation as well p15	QQ p14.	going to local hosp is good.	lingusitic issues, being able to talk in welsh
P4, age 79, asymptomatic, CTUHB	things are written down for you but different when someone takes time to talk to you , can be dremaing and not taking it in when written down	N/A	smooth and efficient	
P5, age 56, asymptomatic, CTUHB	N/A	N/A	felt treatment was outstanding , felt if they treat others same way, couldn't do anything better Q. p4 couldn't fault anything	CN- swift jouney and during interview, very upbeat and pleased with time o f jouney
P6, age 69, asymptomatic , BCUHB	being able to have an MRI before biopsy. Would have given peace of mind and was willing to pay. No jumping of queue QQ. p2	felt biopsy was aggressive and again talked about doing something to lessen pain for others	N/A	questions his judgements as feels not a medical person QQ. p3. questions how at time of diagnosis if it affects him physically in future, may also affect mental health , now feels ok.
P7, age 69, asymptomatic, CVUHB	features on pca, when they do them are very useful and I think the more regularly they do the features QQ. p6 a little section on pca and what to look out for.	surprised that GP's don't as matter of course have PSA tests done regularly. Seems to be long gap and it was only because I went there, I was tested. Simple and straightforward thing to do, only take two minutes and routine, can save lives QQ. p5 .	it was like clockwork, amazing, there were no delays QQ. p3	

## Appendices nineteen

A	B	C	D	E	F	G	H	I	J	K	L
P1, age 75 asymptomatic, BCuHB											
P2, age 76 asymptomatic											
P3, age 70 BCuHB	76 WHITE UK		asymptomatic	BCuHB,Glan Clwyd	Flint	yes	home	retired store manager	50% least deprived	with wife	rheumatoid osteoarthritis/ various hospital visits, intensive care previous
P3, age 70 asymptomatic, BCuHB	70 WHITE UK/welsh sp		asymptomatic	BCuHB,Ysbyty Gwyn	Caernarfon	no	home	retired gov worker	50% least deprived	with wife	
P4, age 79, asymptomatic, CTuHB			asymptomatic	ABuHB, Royal Gwent	Caerphilly	no	home	retired FE principal	50% least deprived	with wife	
P5, age 56, asymptomatic, CTuHB	56 WHITE UK		asymptomatic	CTuHB, Royal Glam	Pontypridd	no	home	train driver	30-50% most deprived	wife and kids	
P6, age 69, asymptomatic, BCuHB				BCuHB,Glan Clwyd	Wrexham	yes but didn't speak	home	retired engineer	50% least deprived	wife	recovered from tongue cancer
P7, age 79, prompt, BCuHB	69 WHITE UK		prompt	CUHB, Un hos of Wales	Cardiff	no	home	retired insurance underwriter	10-20% most deprived	wife	
P8, age 69, prompt, BCuHB	69 WHITE UK		prompt	BCuHB,Glan Clwyd	Holwell	yes but didn't speak	home	semi retired/engineer	50% least deprived	wife	heart issues, on tablets
P9, age 70, prompt, ABuHB	70 WHITE UK		prompt	ABuHB, Royal Gwent	Newport	yes	home	retired gas engineer	30-50% most deprived	wife	
P10, age 69, prompt, HDuHB	69 WHITE UK		prompt	HDuHB,Glangwili	Tenby	no	home	retired gas engineer	30-50% most deprived	wife	
P11, age 64, prompt, BCuHB	64 WHITE UK		prompt in quest but then in interview over two yrs symptoms	BCuHB,Wrexham	Wrexham	no	home	retired police officer	50 % least deprived	wife	raynauds
P12, age 70, prompt, BCuHB	70 WHITE UK		prompt on sheet but would say long diag due to co morbidity down as prompt due to extremely quick diagnosis from 1st appt but on interview said had back pain for over 2 yrs	BCuHB,Ysbyty Gwynedd	Bethesda	yes	home	retired interpreter	50 % least deprived	wife	Parkinsons
P13, age 74, prompt, BCuHB	74 WHITE UK			BCuHB,Wrexham	Flint	no	home	retired	10-20% most deprived	on own	new hip a few yrs ago and on diagnosis, had spread to bones.













## Appendices twenty-one

### Potential ideas for Themes

#### 'I had to google it' Understanding screening and symptom recognition.

- Exploring the awareness of screening and symptoms
- Comorbidity confusion
- relating it to old age
- symptom awareness
- screening understanding

#### 'Sometimes they give you lots of information without actually doing anything' The provision of Information along the diagnostic pathway

- The primary pathway
- The secondary pathway
- The presentation of literature

Could have another on the decision to seek help?

#### 'If I wanted to speak to someone, I could' The Importance of communication and relationships with HCP.

Exploring the communication between patients and HCP throughout the diagnostic journey up until diagnosis.

- Importance
- Feeling heard
- Impact of knowing your HCP.
- Influence on making decisions
- Potential barriers to communication

#### 'I had the click, click'. Procedures and their impact.

- Participants understanding of procedures
- Effect of biopsy and implications
- Confusion between MRI and biopsy, which comes first/impact

#### 'If I hadn't seen the programme, it would have eaten away at me'. Influences on decision making

- Friends and family
- Media/internet/campaigns

#### 'Being a man, a typical man'. Self-awareness in response to their personal diagnostic journey.

- Thoughts and feelings
- Reactions
- Beliefs

Could have another on what would have made a difference?

### Explanatory Ideas

getting up to go to the toilet at night or urinating more (7,10,11,14,21) = an acceptance of just getting older= potential delay in seeing GP.

When symptoms become bothersome, effect daily life/pain= Then seek help (12,15,20)

Urinary symptoms but still late diagnosis (15 down to pain,18 friend had pca and recognition of symp,19 article in paper,21 family history),

Asymptomatic= sees self as healthy (1,3,4,5). Does symptoms or pain effect view on health perception?

Relationship issues with GP= delay in going back to seek help = later diagnosis (11,20,21)

If have **comorbidity** = Report better relationship with GP (2,7,12)

People who see self as healthy= less likely to see GP (4,8,10,17,18)

Association of symptoms with other things and not possible pca= potential delay (12,15,19,20,13 **comorbidity**) (working hard 17,15)

Down as asymptomatic but in interview talk about symptoms just lack of awareness (1,7,9) 9 states if made more aware would have gone sooner

Down as prompt but in interview talks about longer symptoms (10,11)

Awareness brought about by media- (10,18 internet- 11 tv, 19 article) 2 of these classes as prompt but interview shows symptoms were longer so potential late diagnosis) 7 as asymptomatic but tv programme highlighted possible issue= Does this type of awareness support help seeking behaviour (Fry and Turnbull effect on news?) (Implications of celebrity endorsement of prostate cancer awareness in a tertiary referral unit – the ‘Fry-Turnbull’ effect- Lovegrove et al 2020)

Does choice impact late diagnosis (15)

Secondary journey appts in one day = positive opinion of NHS=positive recount of journey=no suggestions for change ( 5,9)

Didn't want to bother doctor= late diagnosis ( 14,17) attitude impact time to diagnosis?

Asked for MRI before biopsy= all refused= BCUHB=f & f impact this decision (1,2,6)

Asymptomatic- reasons for having PSA-

CHARITY TEST 1,2

GP REQUEST 3

HEALTH CHECK 4,7

FAMILY PRESSURE-5

UN AWARE- 6

Prompt- reasons for having PSA-

SYMPTOMS 8,10,12

GP REQUEST 9

PATIENT REQUEST 11

UNAWARE 13

HEALTH CHECK 14

Late – reasons for having PSA

HEALTH CHECK 15,16

GP REQUEST 17

MEDIA AWARENESS/F&F 18,19,21

SYMTPOMS 20

Approached a pharmacist before seeing GP (3,20)

Are informal networks ( F&F) or observing others important along the diagnostic pathway?

1- Had test with friend support

2- Push from friend to ask for test

3- Support from friend

8- observed neighbour go through it

9- friend mentioned and prompted action

12- saw friend go through it

14- advice from friend

18- observed friend go through it- recognised symptoms

21- observed friend go through it.

Could informal networks promote earlier diagnosis as a tool? (literature from review shows this

Impact of reading about possible symptoms

(1,2,11,19) prompted symptoms awareness, however 1 and 2 didn't have symptoms as asymptomatic

Read about symptoms but didn't connect to self (6 had no symptoms, 10 symptoms didn't fit list even though are recognised as symptom according to study)

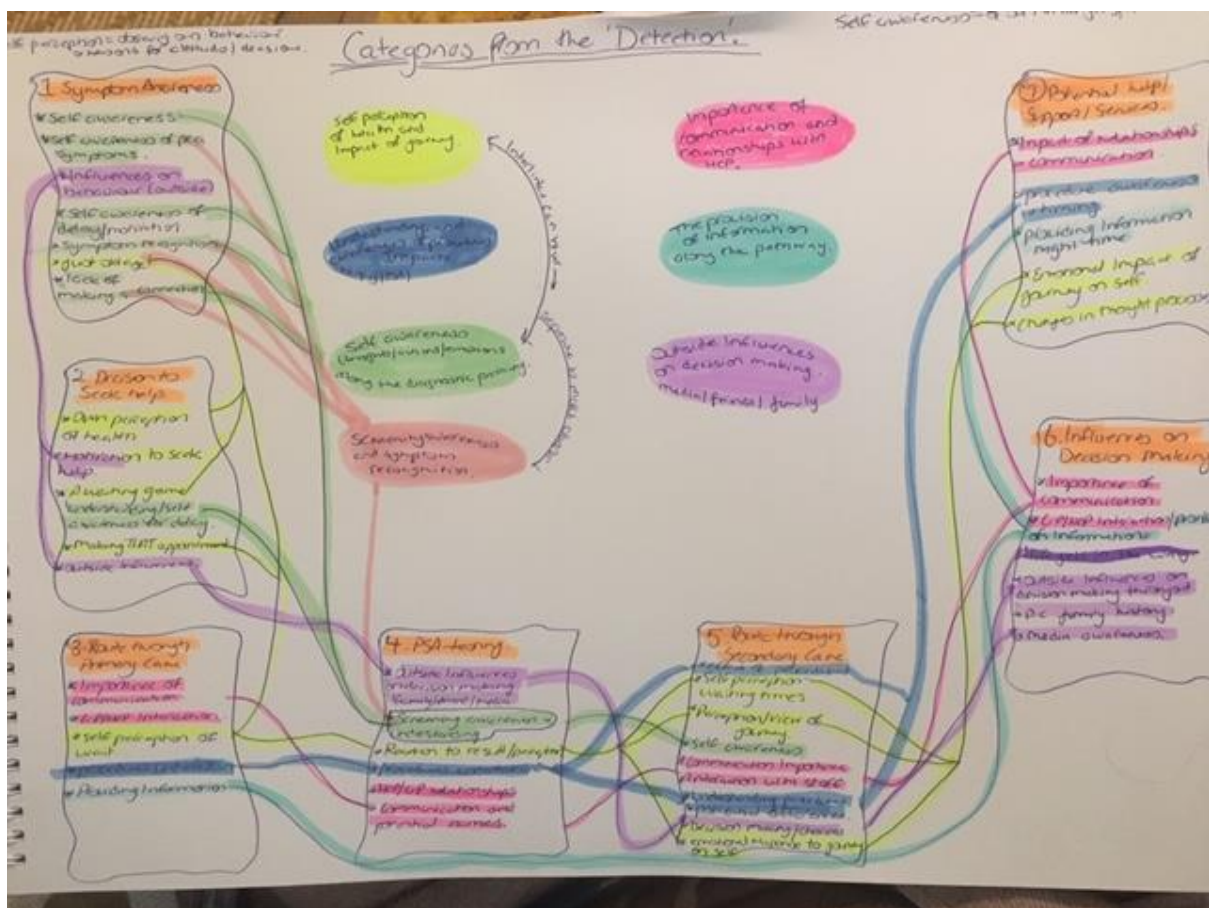
Info overload 1,4 –

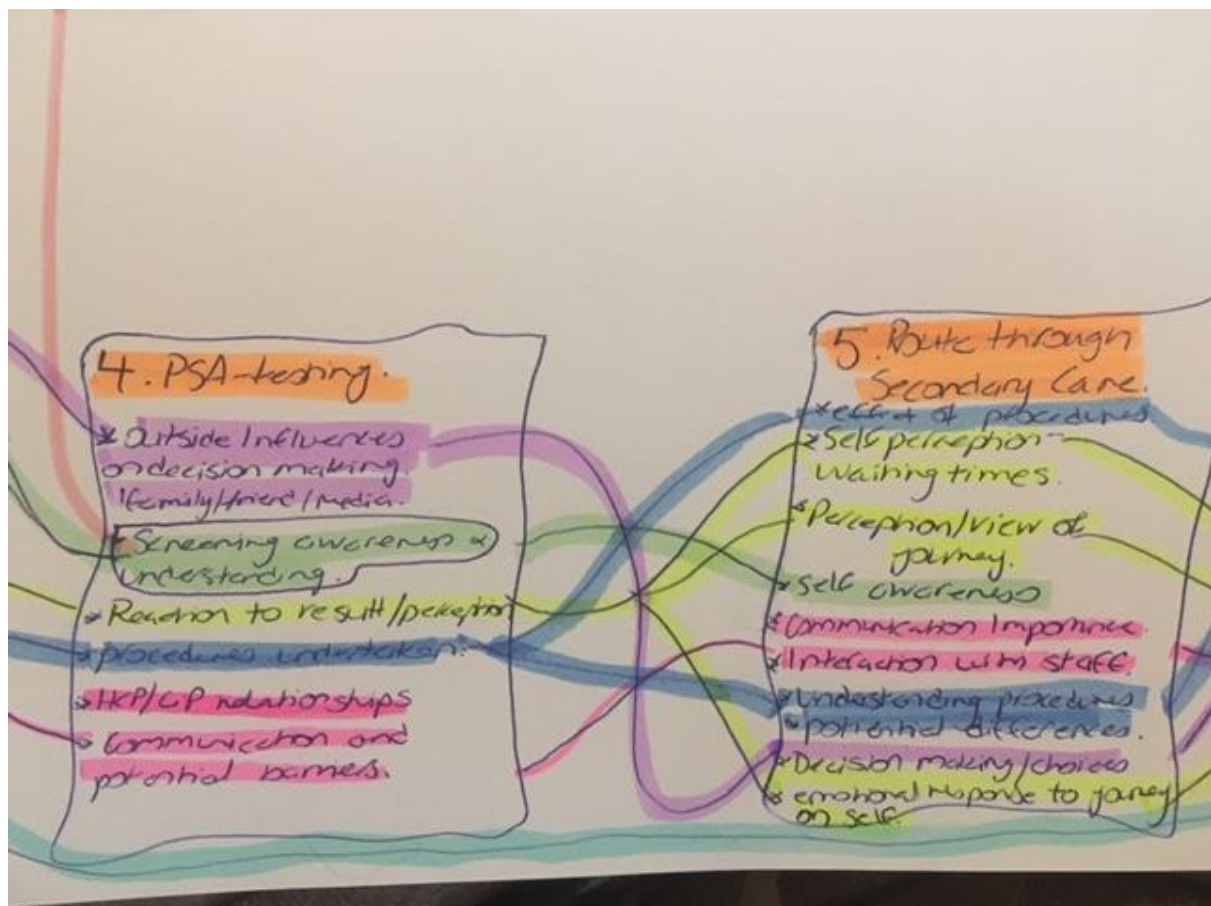


Impact of pressure from f&f

Family pressure but still delayed 9,5 = down to attitude, didn't want to know 9 and no connection as didn't have symptom.

So, does family pressure help or hinder? Is the absence of symptoms a cause of lack of connection to pca?





Self-perception = observing one's behaviour  
or reasons for attitude / decisions.

## Categories from the 'Detection'

### 1 Symptom Awareness

- \* Self awareness
- \* Self awareness of physical symptoms.
- \* Influences on behaviour (outside)
- \* Self awareness of delay / motivation
- \* Symptom recognition
- \* Lack of delay
- \* Lack of making a connection

### 2 Decision to Seek help

- \* Own perception of health
- \* Motivation to seek help
- \* Playing game / understanding / self awareness for delay
- \* Making that appointment
- \* Outside influences

Self perception  
of location and  
impact of journey.

Understanding and  
awareness of physical  
impacts  
(e.g. PSA)

Self awareness  
(diagnosis / emotions)  
along the diagnostic pathway.

Screening awareness  
and symptoms  
recognition.

Interlinked categories

Separate & still change

Importance of  
communication &  
relationships w/  
HCP.

The provision  
of information  
along the pathway

Outside influences  
on decision making  
medical / friends / family