Understanding capacity development needs within the NHS Scotland prostate cancer service: A Delphi study

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Abstract

Background: The NHS Scotland prostate cancer service has experienced capacity shortage, contributing to the Urological cancer service's missed government waiting time targets, which have been missed to a greater extent than any other cancer service. This study aims to gain understanding of the capacity development needs of the NHS Scotland prostate cancer service by answering the following research questions: How has usage of the NHS Scotland prostate cancer service changed and how is it predicted to change, (RQ1), Why has the NHS Scotland prostate cancer service been unable to meet demand (RQ2), and how should capacity be developed within the NHS Scotland prostate cancer service to meet demand (RQ3)?

Methodology and methods: Informed by ontological holism and epistemological and methodological pragmatism and pluralism, this Delphi study utilised the expertise of carefully selected participants to reach consensus on the capacity development needs of the NHS Scotland prostate cancer service. To do this, three phases of research were used. Firstly, national datasets were used to provide a descriptive analysis of trends in incidence and treatment usage (Phase 1). Then, interviews with healthcare professionals provided context for these trends, specifically to explain trends in treatment usage and predict how they would change, what impact this change would have on service delivery and organisation, and how this could be better planned for (Phase 2). Finally, consensus was facilitated over three rounds of online questionnaires to establish how capacity should be developed within the NHS Scotland prostate cancer service (Phase 3).

Results: Phase 1 established that incidence, active surveillance, radiotherapy and chemotherapy usage had increased, and surgery, hormone therapy and watchful waiting had decreased, generally uniformly across Scotland. Phase 2 established that though usage of some treatments had decreased, developments in treatment modalities had led to more lines of treatment. Therefore, capacity shortage was evident across all parts of prostate cancer services in Scotland. When discussing service developments, healthcare professionals dismissed government waiting time targets as a measure of quality care and were developing services in line with their own understanding of quality. And through analysis five issues were identified as hindering service development: lack of cohesion and leadership in prostate cancer care across Scotland, which would relieve capacity shortage at local levels; efficient training of nurse specialists to adopt further roles in prostate cancer care; and lack of clarity on the roles and responsibilities that patients and primary care can reasonably adopt to relieve capacity shortage throughout all parts of services. Finally, healthcare professionals reached consensus that development of national working groups to lead development of quality care and further development of Managed Cancer Networks to lead implementation of quality care, and the development of a multi-faceted specialist nurse training programme, and a national working group to guide development of specialist nurses and allied health professionals roles. Though moving some aspects of prostate cancer care to primary care and supporting patients to have further responsibilities in their own care would substantially reduce pressures within prostate cancer care in Scotland, healthcare professionals were not confident that capabilities existed to enable this.

Conclusion: These findings present a clear route forward for development within the NHS Scotland prostate cancer service, and though this study is specific to the NHS Scotland prostate cancer service, evidence indicates that the issues identified are not unique to this service.

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Abbreviations

EAU – European Association of Urology

eDRIS – electronic Data Research and Innovation Service

GMC – General Medical Council

GP – General Practitioner

GS – Gleason Score

ISD – Information Services Division Scotland

ISUP – International Society of Urological Pathology

MCN – Managed Cancer Network

NHS – Scottish National Health Service

NICE – National Institute for Health and Care Excellence

NoSCAN – North of Scotland Managed Cancer Network

OECD – Organisation for Economic Co-operation and Development

ONS – Office of National Statistics

PSA – Prostate specific antigen

R1 – Delphi consensus Round 1

R2 - Delphi consensus Round 2

R3 - Delphi consensus Round 3

RQ – Research question

SCAN – East of Scotland Managed Cancer Network

SMC – Scottish Medicine Consortium

The Service – The NHS Scotland prostate cancer service

UNDP – United Nations Development Programme

WoSCAN - West of Scotland Managed Cancer Network

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Introduction

1.1 Introduction

In this Chapter, I give a general introduction to this study. First, I give a brief summary of prostate cancer (1.2), prostate cancer within the Scottish context (1.3), and an account of the NHS Scotland prostate cancer service as a complex service (1.4) followed by the rationale for this study (1.5). I then introduce the research questions (1.6) before introducing the underpinning philosophy and study design used (1.7) and my personal position (1.8). Finally, the thesis structure (1.9) is given.

1.2 Prostate cancer

The prostate forms part of the male reproductive system. It is a donut shaped gland that sits below the bladder, which the urethra passes through. The prostate contributes a slightly alkaline solution to semen, and it is widely accepted that as men[1] age the prostate naturally enlarges. As the prostate enlarges, it may begin pressing against the urethra, leading to lower urinary tract symptoms like urinary frequency, nocturia, difficulty passing urine, urinary urgency, and blood or semen in the urine. When cancer develops in the prostate, depending on the location and size of the cancer, the cancer may or may not press on the urethra, leading to lower urinary tract symptoms. As a result, prostate cancer may be symptomatic or asymptomatic (Hamilton & Sharp, 2004). If the cancer metastasises and spreads to other parts of the body, men may be diagnosed as a result of investigations for symptoms related to the sites that the cancer has spread to, most prominently from bone pain as prostate cancer spreads to the bone.

Cancer forms when changes occur in the genetic material held within a cell, leading the cell to begin replicating uncontrollably. As all cells contains mechanisms that prevent changed cells affecting the body, it is thought that many changes to genetic material are required before cancer will occur. Changes can result from errors in the cells replication process, or damage to the genetic material. As the risk of developing prostate cancer relates to genetic material, the risk of developing prostate cancer is related to genetic factors such as having a family history of prostate cancer (Bratt et al., 2016; Randazzo et al., 2016; Stewart et al., 2017), particular variations of genes (Amin Al Olama, 2015; Pritchard et al., 2016; Schumacher et al., 2018), and ethnicity (Tan et al., 2016; Conti et al., 2017). In addition to genetic factors, lifestyle factors affecting cell replication or increasing chance of damage to genetic material are also risk factors, such as stress, diet and exercise. For example, risk of

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[1] Referring to people with prostate cancer as men is problematic as a small number of women will have a prostate, and a small number of men won't. Prostate cancer is referred to throughout this study as a male cancer for consistency with European Association of Urology (EAU), National Institute for Health and Care Excellence (NICE) guidelines and to align with current biological understanding of prostate cancer.

developing prostate cancer was found to change when a person moves from a low to a high-risk country and adopting new lifestyle habits (Whittemore et al., 1995; Brawley, Jani & Master, 2007; Giovannucci et al., 2007), alcohol use (Dickerman et al., 2016; Zhao et al., 2016), level of vitamin D within the body (Kristal et al., 2014; Nyame et al., 2016), past medical history of sexually transmitted infections (Lian et al., 2015; Russo et al., 2018), nightshift work (Rao et al., 2015), and smoking (Islami et al., 2014). As cancer develops as a result of a cumulation of genetic changes within a cell, age is also considered a risk factor for prostate cancer (Leitzmann & Rohrmann, 2012; EAU guidelines, 2019).

Finally, though it is unlikely that affluence is related to development of prostate cancer, affluence is related to likelihood of being diagnosed with prostate cancer (Haas et al., 2008; Bell et al., 2015). Firstly, men are more likely to be diagnosed with prostate cancer if they live in an affluent area, and secondly, men living in developed countries are more likely to receive a prostate cancer diagnosis (Dutta, Philip & Javle, 2005; Shafique, Oliphant & Morrison, 2012; Cancer Research UK and National Cancer Intelligence Network, 2014; NHS Services Scotland and Macmillan cancer support, 2017). These findings are attributed to increased awareness of, and availability of, testing for prostate cancer (Bray et al., 2012; Ferlay, 2015) and not thought to relate to increased likelihood of developing the disease.

1.3 Prostate cancer care within the Scottish context

In Scotland, more than 3000 men are diagnosed each year with prostate cancer and incidence is anticipated to increase (Deas, 2018). This increase is predicted to be the result of increased awareness of testing for prostate cancer and not increased likelihood of developing prostate cancer (Bray et al., 2012; Ferlay, 2015). Consistent with the understanding that most cancers are thought to occur as a result of an accumulation of genetic changes in a cell over time, most men are diagnosed with prostate cancer in Scotland over the age of 65 (Deas, 2018). Though prostate cancer is the most commonly diagnosed cancer in men, it is only the fourth most common cause of death from cancer in men in Scotland (Deas, 2018). This lower mortality rate when compared with incidence is likely due to increased awareness and testing for prostate cancer leading to earlier diagnosis (Bray et al., 2012; Ferlay, 2015) alongside improvements in treatment (European Association of Urology guidelines, 2019). Though trends in incidence across Scotland are generally consistent, there are key regional differences resulting from sociodemographic factors, which have been linked to inequality in prostate cancer incidence and mortality in men living in Scotland.

Particularly, Scotland is known to be geographically diverse and includes large urban areas such as major cities, and sparsely populated areas such as remote rural areas (National Records of Scotland, 2019a) each of which require a different approach to health service development to meet public need

(Godden, 2005). Anecdotally, it is said that those living in rural regions of Scotland experience poorer prostate cancer patient outcomes. However, the availability of robust data to understand whether differences in urban or rural service provision leads to inequality in patient outcomes for men with prostate cancer is sparse. For example, in a detailed study of diagnostic patterns, Laing (et al., 2014) identified poorer patient outcomes in men living with prostate cancer in NHS Highland, a region in Scotland with a high proportion of men living in rural areas, when compared with NHS Lothian, a region in Scotland with a high proportion of men living in urban areas. However, as only two regions were compared, it is unclear whether this finding is truly the result of poorer outcomes for men living in rural regions, or other factors evident between regions.

Additionally, as outlined in Section 1.2, there is clear evidence that socioeconomic factors such those affecting awareness of PSA testing and lifestyle factors, impact on likelihood of developing or being diagnosed with prostate cancer. The impact of socioeconomic factors on patient outcomes in those with prostate cancer in Scotland has been most evident in the West of Scotland, a region with a large proportion of Scotland's most deprived areas (Taulbut, 2014), where 1-, 3- and 5-year survival is lower than other regions of Scotland (UK Cancer Atlas, 2011). Scotland is thought to have wider socioeconomic disparity than any other European country (Taulbut, 2014), which has led to wide disparity in life expectancy across Scotland (National Records of Scotland, 2019b). Though there has been limited study to understand the effect of deprivation within the prostate cancer population in Scotland, studies have shown that men are more likely to be diagnosed with advanced prostate cancer if they are from a deprived area (Haas et al., 2008; Bell et al., 2015). And, people living in Glasgow (West of Scotland) have been found to have poor health behaviours, high levels of comorbidity and overall poor life expectancy (Gray, 2007; Cowley, Kiely & Collins, 2016).

The diverse geographic and demographic landscape in Scotland makes service development complex. As services within each region must meet local need (Scottish Government, 2013a; NHS Health Scotland, 2014), there is potential for inequity in service availability and lack of a cohesive national approach to prostate cancer care.

1.4 NHS Scotland prostate cancer service

Diagnosis and treatment of men with suspected prostate cancer requires a complex service that allows for multiple routes to diagnosis and treatment, and the involvement of multiple specialities and disciplines. In Scotland, there is no established national standard for prostate cancer treatment or pathways. As such, each Health Board in Scotland is guided by the NICE guideline for prostate cancer treatment, which set a minimum expectation of care for men with prostate cancer in the UK, and the European Association of Urology guidelines, which provide an annual review of the evidence available to inform prostate cancer diagnosis, treatment and care across Europe (EAU, 2019; NICE, 2019).

In Scotland, men are commonly diagnosed with prostate cancer through the opportunistic screening of asymptomatic men or investigations for bothersome lower urinary track symptoms, though men may also be diagnosed with prostate cancer following an incidental finding during investigations for another disease or an emergency admission to hospital (National Screening Committee Prostate Cancer Risk Management Programme, 2016; NICE, 2019). Following diagnosis, individual cases are then discussed at multidisciplinary team meetings to determine the treatment options available to each patient based on the patient's cancer staging, individual health and personal circumstances (EAU, 2019; NICE, 2019). Patients eligible for active treatment then talk with clinicians to determine which of the available treatment options from across the different specialities is best for them (EAU, 2019; NICE, 2019). However, some treatments are not available in all parts Scotland, for example brachytherapy is only available in a limited number of Health Boards. And some treatments are performed using different methods across Scotland, for example, during the course of this study, radical prostatectomy was being performed using open, laparoscopic and robotic methods as standard depending on Health Board. Patients who are not eligible for active treatment enter the palliative care part of the Service where patients generally move through lines of treatment in a fixed order, aimed at slowing the advancement of the cancer whilst managing the patients' symptom burden (NICE, 2019). Though the Service is largely urology-led, oncology specialists lead most treatments (NICE, 2019).

To enable this all to be possible, the NHS Scotland prostate cancer service consists of a range of healthcare professionals from different disciplines, including doctors registered with the General Medical Council (GMC), nurses and allied healthcare professionals including specialist physiotherapists and pharmacists, and the service supported particularly by healthcare professionals working in primary care and acute care. Each Health Board in Scotland has a different mix of disciplines working within prostate cancer care and different roles and remits for each discipline. For example, in one Health Board a nurse undertakes a particular role, whereas in another it is a doctor registered with the GMC, or a specialist pharmacist. Or in one Health Board a doctor registered with the GMC is responsible for the design and development of prostate cancer care, but in another it is a nurse. Additionally, some roles or services exist in one Health Board that do not exist in another. And there is a general lack of clarity on how each service was composed including the disciplines and roles present. Ultimately, this made the service challenging to study.

1.5 Rationale for this study

In Scotland, the quality of cancer care has been measured using waiting time targets (Scottish government, 2000; 2008a), and urological services have missed these waiting time targets to a greater extent than any other cancer care service (NHS National Services Scotland, 2019). Capacity shortage is thought to be the result of a combination of increased incidence of prostate cancer (Deas, 2018; Scottish Public Health Observatory, 2018), and substantial development of the prostate cancer treatment pathway leading to the integration of more specialities and more lines of treatment (EAU guidelines, 2019; NICE, 2019). Most recently, Scottish Government have also reported staffing issues within Urology services (Scottish government, 2018a), further hindering the ability of the NHS Scotland prostate cancer service (the Service) to meet demand. No publications were evident to understand how changes in incidence and the treatment pathway had impacted on the Service or whether capacity shortage was widespread throughout the Service or confined to some parts only. And no publications were also found to guide development of the Service to meet demand. Therefore, it was pertinent to gain understanding of the capacity needs of the NHS Scotland prostate cancer service to enable development of the Service to meet demand.

1.6 Research questions

This study aims to gain understanding of the capacity development needs within the NHS Scotland prostate cancer service. This aim was divided into specific research questions (RQs):

1. How has usage of the NHS Scotland prostate cancer service changed and how is it predicted to change?
2. Why has the NHS Scotland prostate cancer service been unable to meet demand?
3. How should capacity be developed within the NHS Scotland prostate cancer service to meet demand?

1.7 Research design

Informed by ontological holism, and epistemological and methodological pragmatism and pluralism, this Delphi study utilised the expertise of carefully selected participants to reach consensus on the capacity development needs of the NHS Scotland prostate cancer service. To do this, three phases of research were used. Firstly, national datasets were used to provide a descriptive analysis of changes in incidence and treatment usage (Phase 1) to understand how usage of the Service had changed (RQ1). Then, interviews with healthcare professionals provided context for these changes, specifically to explain changes in treatment usage and predict how they would change, what impact this change would have on service delivery and organisation, and how this could be better planned for (Phase 2) to further understand how usage of the Service is predicted to change (RQ1) and to understand why the Service has been unable to meet demand (RQ2). Finally, consensus was facilitated over three rounds of online questionnaires to establish how the Service should develop to meet demand (Phase 3): specifically, to understand how capacity should be developed within the Service to meet demand (RQ3).

1.8 Personal position

Throughout this thesis I have included reflective sections to ensure that my PhD journey is captured. This to ensures that I have considered and reported how my own experiences and actions guided this study considering arguments by Dewey (1910) and Morgan (2007; 2014) who emphasised the importance of reflective effort to inform and ensure transparency in scientific inquiry.

Whilst training as a nurse, I developed an interest in men’s health and oncology, and this interest, along with prior training in biochemistry and research methods, led me to apply for this PhD opportunity. Though when this study began I had limited knowledge of the NHS Scotland prostate cancer service, as this study progressed I found that my understanding of patient care and healthcare services without direct experience of the service enabled me to develop an understanding of service need without preconceived ideas of what this should be.

In the first half of this study, I interned one day per week with Prostate Scotland, who co-funded this PhD. I spent time with the team often helping at fundraising events, public engagement events, sitting on the charity’s patient education advisory panel, and working on other research projects. This experience enabled me to follow prominent narratives in prostate cancer care and related service development issues. This also enabled me to meet specialists working in prostate cancer care, and it was my perception that my affiliation with Prostate Scotland gave the research greater credibility amongst healthcare professionals.

Prostate Scotland acted in an advisory capacity throughout this study and though they did not seek to influence the study outside of this, I found that the collaboration with Prostate Scotland did influence my own decision-making within this study. Prostate Scotland is a small, but influential charity and are active in changing the healthcare landscape in Scotland to benefit men with prostate disease. Aware that research is not always as useful as we intend it to be (Cheetham et al., 2018), I was keen to produce a piece of research that would be useful in helping with this change. Though this did not influence the integrity of this study, it did provide the basis for decision-making throughout this study. Ultimately, I wanted to do research that would enable change in practice.

My drive to do impactful research that enabled change in practice complemented the motives of Prostate Scotland well. Specifically, Prostate Scotland had funded this research to inform government and thereby enable needed service developments. Though Prostate Scotland was aware of the increasing capacity shortage across the Service, like healthcare professionals working within the Service, they were unaware of how to develop capacity meet need within current financial and environmental constraints, such as budget, and availability of equipment and clinical spaces. Ultimately, this drive to inform government and produce practically useful results informed the direction of scientific inquiry that this research took.

1.9 Thesis structure

This thesis consists of eight chapters. Following introduction (Chapter 1), background literature is provided to contextualise the Service and refine the capacity problem (Chapter 2), followed by underpinning philosophy and study design (Chapter 3). Research findings are presented across three Chapters (Chapter 4, 5 and 6). Findings are then discussed and contextualised (Chapter 7), and finally, the thesis is concluded (Chapter 8).

The NHS Scotland prostate cancer service

2.1 Introduction

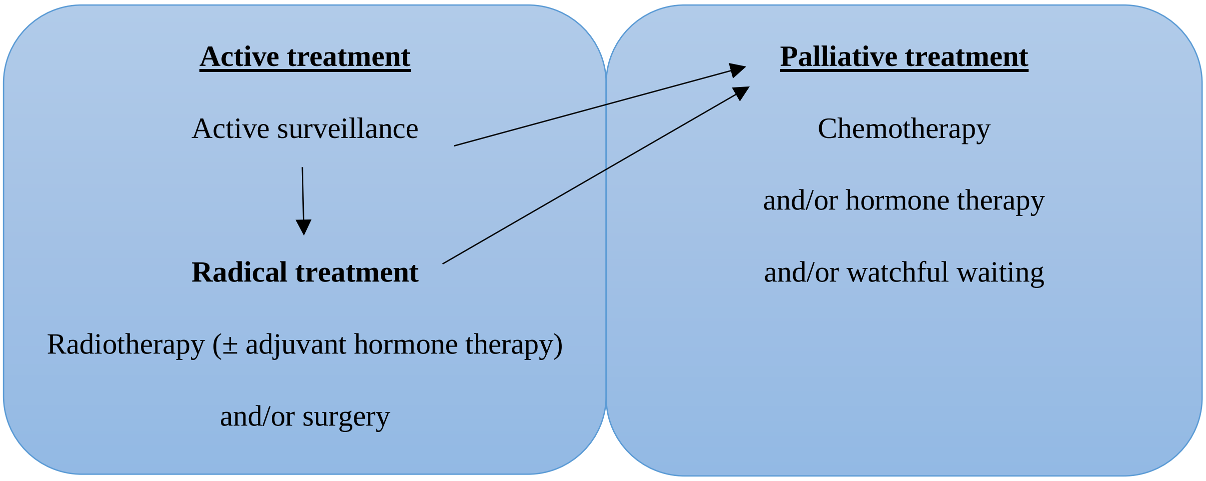
This study aimed to understand the capacities needed to develop the NHS Scotland prostate cancer service (the Service) to meet public demand. In this Chapter, I provide an account of the relevant background literature to contextualise this study and understand the capacity problem. Specifically, after this introduction (2.1), I describe the Service and how the capacity needs of the Service have changed, outlining evidence of capacity shortage within the Service (2.2), and review Scottish policy pertinent to cancer care (2.3). Then, I reflect on the development of the research problem (2.4), define capacity and capacity development (2.5), and identifying the capacities generally needed to develop capacity in healthcare services (2.6). Finally, I outline the aim and research questions guiding this study (2.7) and briefly summarise this Chapter (2.8).

2.2 Changing capacity needs of the NHS Scotland prostate cancer service

Evidence showed that the capacity needs of the Service had changed over time. This section describes the Service and increased demand within the Service beginning with increased incidence (2.2.1) and screening uptake (2.2.2), developments in biopsy (2.2.3) and diagnostic protocols (2.2.4), and developments in the prostate cancer treatment pathway, which is summarised in Figure 1. Developments in the treatment pathway include developments in active surveillance (2.2.5), radical treatment (2.2.6) and palliative treatment (2.2.7) protocols. And the Service had been unable to adapt to changed capacity need as shown by missed waiting time targets (2.2.8) and in Scottish Government policy documents (Scottish government, 2018a).

2.2.1 Incidence

Prostate cancer is now the most common cancer diagnosed in men in the developed world (Ferlay, 2015; Allemani et al., 2018; Culp et al., 2019) and the incidence of prostate cancer has increased across the developed world at a faster rate than most other cancers (Allemani et al., 2018). In Scotland, prostate cancer accounts for 20.8% of all cancer diagnoses in men (Deas, 2018; Scottish Public Health Observatory, 2018). Increased incidence is thought to be the result of improvements in diagnostic testing and protocols rather than an increase in likelihood of developing prostate cancer, as reflected in recent national projections and reports (Scottish Executive, 2006; Oduro, Black and Brewster, 2010; Deas, 2018; Scottish Public Health Observatory, 2018) and the European Association of Urology clinical guidelines (EAU guidelines, 2019).



Arrows represent patient decision-making, a change in patients' health status, and/or prostate cancer progression or recurrence

Figure 1: General structure of the NHS Scotland prostate cancer service treatment pathway

2.2.2 Screening

Currently, no screening test for prostate cancer exists (EAU guidelines, 2019). In the absence of a screening test, an opportunistic screening protocol operates throughout the UK. This protocol consists of patient counselling, then Prostate Specific Antigen (PSA) testing and a digital rectal exam, and further testing in secondary care if indicated (National Screening Committee Prostate Cancer Risk Management Programme, 2016; National Institute for Health and Care Excellence, 2019). Opportunistic screening is recommended by EAU to diagnose asymptomatic prostate cancer and is defined in guidelines as the individual case finding of prostate cancer initiated by the patient or the physician (EAU guidelines, 2019). In the UK, individual case findings rely on patient awareness of prostate cancer and PSA testing to initiate discussion with a General Practitioner (GP) (National Screening Committee Prostate Cancer Risk Management Programme, 2016). However, as PSA testing is not specific to prostate cancer, but rather indicates the size of the prostate, not all GPs are supportive of PSA testing and can dissuade men from being tested (Rai et al., 2007). As a result, prostate cancer incidence rates are generally attributed to usage of prostate cancer screening protocols (Ferlay, 2015; Allemani et al., 2018; Culp et al., 2019; EAU guidelines, 2019). It is expected that symptomatic men do receive PSA and a digital rectal exam testing where appropriate (National Screening Committee Prostate Cancer Risk Management Programme, 2016). Though the prostate cancer screening protocol used in the UK has progressed very little whilst undertaking this study, biopsy protocols have developed substantially.

2.2.3 Biopsy

All men eligible for prostate biopsy are required to have pre-biopsy counselling to discuss the pros and cons of having biopsy and determine appropriateness of further testing considering each man's history and likelihood of having clinically significant prostate cancer (National Institute for Health and Care Excellence, 2019). When this study began in 2013, prostate biopsies were associated with poor levels of accuracy. For example, 12-core biopsies were shown to have only 43% accuracy (Serefoglu et al., 2013). However, methods of targeting biopsies using MRI have recently been recommended for use in prostate cancer testing including pre-biopsy MRI and MRI-biopsy fusion, which enables healthcare professionals to compare a 3-dimensional MRI of a patient's prostate with real time ultrasound images (EAU guidelines, 2019). In the UK, pre-biopsy MRI were integrated into prostate biopsy treatment protocols as an additional step in 2019 (NICE, 2019), and although are not yet recommended as a screening tool for prostate cancer, they are recommended as part of a developed diagnostic protocol (EAU guidelines, 2019; NICE, 2019).

2.2.4 Diagnosis

Tissue samples collected at biopsy are graded by pathologists to describe both the primary and secondary cell patterns evident. Both cell patterns are scored between one and five to reflect how advanced the prostate cancer is, and added together to give a Gleason Score, as shown in Table 1. If only one cell pattern is evident, this score is doubled. A Gleason Score of ≤5 is not considered a prostate cancer, whereas higher Gleason Scores describe aggressive prostate cancers (Epstein et al., 2005; Epstein et al., 2016a; EAU guidelines, 2019). As Gleason Scores provide a measurement of how advanced a prostate cancer is, Gleason Scores can be used to stratify patients for treatment using International Society of Urological Pathology (ISUP) grading system (Epstein et al., 2005; Epstein et al., 2016a; Epstein et al., 2016b; Kane et al., 2017; EAU guidelines, 2019; NICE, 2019) also shown in Table 1, though it is clear that this is still a developing area (Srigley et al., 2019).

In addition to Gleason Scores, which seek to understand how advanced the cancer is within the prostate, the Tumour, Node, Metastasis (TNM) grading system is used to understand how advanced the cancer is within the body (Brierley et al., 2017; EAU guidelines, 2019; NICE, 2019). The primary tumour is graded from one to four to describe the size of the tumour and whether it is contained within the prostate (T1-2), has broken through the prostate capsule (T3) or has invaded adjacent structures (T4). Nodes and metastasis are graded zero or one to indicate whether cancer is present within lymph nodes or in other parts of the body, respectively. Only patients with cancers confined within the prostate are eligible for radical prostate cancer treatment (NICE, 2019). In low and low-intermediate risk prostate cancers, delayed radical treatment is also recommended as a treatment option to avoid morbidity from radical treatment for as long as possible (EAU guidelines, 2019; NICE, 2019).

Table 1: Gleason grading system and prognosis

Primary score	**Secondary score**	**Gleason score**	**ISUP grade**	**Interpretation of ISUP grade**
2	4	6	1	Low risk prostate cancer; patient may benefit from delayed treatment
3	3	6		
4	2	6		
3	4	7	2	Low-intermediate risk prostate cancer; patient may benefit from delayed treatment
4	3	7	3	High-intermediate risk prostate cancer; low risk of recurrence following radical treatment
3	5	8	4	High risk prostate cancer; intermediate risk of recurrence following radical treatment
4	4	8		
5	3	8		
4	5	9	5	High risk prostate cancer; high risk of recurrence following radical treatment
5	4	9		
5	5	10		

2.2.5 Active surveillance

As an opportunistic screening protocol is used to identify men with prostate cancer, men are at risk of being diagnosed and treated with an indolent cancer (National Screening Committee Prostate Cancer Risk Management Programme, 2016). An indolent cancer is a cancer that is will not progress without treatment and as such, treatment can be considered patient harm (National Screening Committee Prostate Cancer Risk Management Programme, 2016; Bordersen, et al., 2018). Though diagnosis of indolent prostate cancer is a developing area (Fraser et al., 2017; Faulkner et al., 2019), there are currently no accepted methods of differentiating indolent from clinically significant prostate cancer. To prevent patient harm, patients who are diagnosed with a low-risk, or low-intermediate risk localised prostate cancer are now offered treatment via an active surveillance pathway, to delay radical treatment and morbidity associated with radical treatment, or to avoid radical treatment altogether (EAU guidelines, 2019; NICE, 2019). Patients on an active surveillance pathway are followed-up using repeat PSA testing, digital rectal exam, biopsy and, more recently, MRI testing (EAU guidelines, 2019; NICE, 2019). As men on active surveillance protocols are never discharged and intensive follow-up will continue until treatment is indicated or until the patient is no longer eligible for radical treatment, this treatment is associated with a substantial demand on Service capacity.

2.2.6 Radical treatment

Radical treatments for prostate cancer include radical prostatectomy and external beam radiation therapy, though some men with low-grade, localised prostate cancer may be eligible for brachytherapy, another type of radiotherapy, which involves the insertion of radioactive beads into the prostate capsule (EAU guidelines, 2019). Radical prostatectomy is the traditional treatment for prostate cancer and aims to eradicate cancer through removal of the prostate and seminal vesicles while preserving continence and potency where possible (Adolfsson, 2008; EAU guidelines, 2019). During this study, robot assisted radical prostatectomy became established in Scotland, and the introduction of robotic surgery has redefined surgery in Scotland as a centralised (being provided in 3 tertiary hospitals) rather than local (being provided in regional secondary care hospitals) service. Additionally, in the last 10-20 years, developments in external beam radiotherapy has led radiotherapy to become an established treatment for prostate cancer and is widely considered to be equal to surgical treatment (Hamdy et al., 2016; Berg et al., 2019; EAU guidelines, 2019; NICE, 2019) and is available to a wider group of patients as it is considered safer than surgery (EAU guidelines, 2019). Different protocols for external beam radiation therapy exist and current evidence does not show a definitive best treatment (EAU guidelines, 2019; NICE, 2019), though use of neoadjuvant and adjuvant hormone therapy has led to improved patient outcomes (Bolla, et al., 2010; Denham et al., 2011; EAU guidelines, 2019). Irrespective of treatment modality chosen, radical treatments for prostate are considered morbid due to risk of incontinence, erectile dysfunction, bowel and bladder issues, and negative impact on overall quality of life (Donovan et al., 2016). Though European guidelines give limited steer on management of side effects following radical treatment (EAU guidelines, 2019), UK guidelines provide minimum expectations of side effect support (NICE, 2019).

2.2.7 Palliative treatment

Palliative care encompasses treatment and interventions aimed at symptom management and quality of life rather than cure (NICE, 2019). Within the Service, palliative treatment includes chemotherapy, hormone therapy and watchful waiting, and prior to the emergence of evidence indicating the effectiveness of chemotherapies in prostate cancer (EAU guidelines, 2019; NICE, 2019), most medical oncology departments had limited input into prostate cancer care and hormone therapy was generally prescribed by urologists when indicated. However, medical oncology is now, arguably, the fastest growing field of prostate cancer treatment. Though the EAU best practice guidelines make recommendations for practice (EAU guidelines, 2019), not all treatments have been made freely available for use by the Scottish Medical Consortium. This section begins by summarising current evidence and then giving an account of what is available in Scotland.

Hormone therapy or watchful waiting are generally accepted as the first treatments for patients entering a palliative care pathway (Pagliarulo et al., 2012; EAU guidelines, 2019; NICE, 2019), though more recently, both docetaxel or abiraterone (chemotherapies), and hormone therapy were recommended as a combined treatment for men presenting with metastatic disease (Gravis et al., 2013; Sweeney et al., 2015; James et al., 2016; Sydes et al., 2018; Wallis et al., 2018; Vale et al., 2018; EAU guidelines, 2019). Watchful waiting is recommended for patients who are suspected of having indolent cancer but are not fit for radical treatment, and patients with clinically significant disease and wish to avoid the side effects of chemotherapy and hormone therapy (EAU guidelines, 2019). Prostate cancer is hormone refractory when hormone therapy is not effective in slowing prostate cancer progression, and hormone-refractory prostate cancer is debilitating. Patients with hormone-refractory prostate cancer will require support from a large multi-disciplinary team, and follow-up consisting of regular review, 2-3 monthly bloodwork, and 6 monthly CT scans (Gillessen et al., 2015; EAU guidelines, 2019). A combination of docetaxel, abiraterone or enzalutamide (chemotherapy), with hormone therapy is recommended to treat hormone-refractory prostate cancer (Petrylak et al., 2004; Tannock et al., 2004; Small et al., 2006; Berthold et al., 2008; Kantoff et al., 2010; Ryan et al., 2013; Beer et al., 2014 Rathkopf et al., 2014; Ryan et al., 2015; EAU guidelines, 2019), though docetaxel is highly recommended as it provides the best evidence base for second line treatment (EAU guidelines, 2019), Cabazitaxel (chemotherapy) or Radium-223 (radiation injection).

In the UK, hormone therapy is recommended for patients presenting with non-metastatic disease, and in 2019, docetaxel was recommended for use in all patients within 12 weeks of starting hormone therapy for patients who have metastases only (NICE, 2019). Overall in Scotland, chemotherapies are only recommended for use in patients with metastatic prostate cancer (Scottish Medicines Consortium, 2012; Scottish Medicines Consortium, 2016a; Scottish Medicines Consortium, 2016b) and radium-223 is also only recommended if symptomatic bone metastases are present (Scottish Medicines Consortium, 2015).

2.2.8 Missed waiting time targets

In Scotland, the quality of cancer care is measured against adherence to waiting time targets (Scottish government, 2016a), and urological cancer services have missing these waiting time targets to a greater extent than any other cancer care service (NHS National Services Scotland, 2019). These targets build on Health improvement, Efficiency, Access and Treatment (HEAT) targets implemented as part of Our National Health action plan (Scottish government, 2000) and were further developed in the Better Cancer Care action plan (Scottish government, 2008a). These targets implement a 'minimum time to treatment' threshold for all cancer services. Specifically, it is expected that (i) treatment should begin within 62 days of referral for ≥95% of men with suspected cancer and (ii) treatment should begin within 31 days of making the decision to treat for ≥95% of men. Adherence to waiting time targets are collected for all urological cancers without specific reporting of prostate cancer (NHS National Services Scotland, 2019). As shown in Table 2, adherence with the 62-day treatment target has decreased steadily from 91.6% of patients with a urological cancer meeting the target in 2012 to 68.4% of patients meeting the target in 2019. However, the 31-day target has seen some improvement increasing from 85.0% of patients meeting the target in 2016 to 91.6% of patients meeting the target in 2019. And unmet capacity need within the NHS Scotland urological cancer service is recognised within the waiting times improvement plan (Scottish government, 2018a).

Though it is unclear whether other urological cancer services were struggling to meet waiting time targets, it is clear that the Service had a substantial impact on missed targets, specifically as a result of increased incidence (2.2.1) resulting from increased screening uptake (2.2.2), a complex diagnostic protocol (2.2.3), the development of active surveillance leading to some men not being discharged from the Service (2.2.5), the development of radiotherapy as a treatment (2.2.6) and the development of medical oncology in prostate cancer care (2.2.7). The complex prostate cancer diagnostic protocol may explain worsening adherence 62-day treatment time, while adherence to the 31-day treatment time targets shows some improvement in recent years (NHS National Services Scotland, 2019), and the integration of MRI scanning as an additional step in the protocol (EAU guidelines, 2019; NICE, 2019) could further hinder adherence to waiting time targets. Also, it was unclear whether increased incidence and developments in treatment modalities had led to capacity shortage across all parts of the Service or only some parts of the Service.

Table 2: Percentage of patients with urological cancers who met Scottish waiting time targets

YEAR	REFERRALS MEETING 62-DAY TREATMENT TARGET	REFERRALS MEETING 31-DAY TREATMENT TARGET
2012	91.6%	94.9%
2013	91.3%	94.4%
2014	86.3%	91.3%
2015	81.4%	89.0%
2016	77.0%	85.0%
2017	72.1%	85.2%
2018	68.8%	87.7%
2019[1]	68.4%	91.6%

[1] First two quarters of year only

Within the Better Cancer Care action plan (Scottish government, 2008a), in addition to further developing waiting time targets, the National Cancer Quality Steering Group was developed to oversee the implementation of improved quality indicators for cancer care in Scotland. In 2016, the Scottish government released Beating Cancer: Ambition and Action, which will act as a blueprint for Scottish cancer services until 2021-2025. In addition to waiting time targets, this document lays out National Cancer Quality Performance Indicators (QPIs) as additional measures of quality cancer care. The prostate cancer QPIs are as follows (Scottish Cancer Taskforce, 2016):

1. Pathology should receive a minimum of 10 cores (tissue samples) in ≥90% of patients with prostate cancer who undergo trans-rectal ultrasound guided prostate biopsy;
2. As part of the diagnostic process, ≥95% of patients diagnosed with intermediate risk prostate cancer eligible for radical treatment should have an MRI and ≥95% of patients diagnosed with high risk prostate cancer eligible for radical treatment have an MRI and isotope bone scan, or whole-body MRI to inform treatment decisions;
3. ≥90% of pathology reports following surgery should contain all data items
4. ≥95% of patients without metastatic prostate cancer should be discussed at MDT before definitive treatment is commenced, and ≥95% of patient should be discussed at MDT within four weeks of commencing treatment;
5. <20% of patients with stage T2 on TNM grading system (2.2.4) should have tumour present at the margin;
6. 100% of radical prostatectomy procedures should be performed in tertiary surgical centres (2.2.6) by surgeons who perform a minimum of 50 procedures per year;
7. ≥95% of patients presenting with metastatic prostate cancer should be treated with immediate hormone therapy and ≥70% of patients presenting with metastatic prostate cancer should be treated with immediate hormone therapy and docetaxel (chemotherapy);
8. <20% of patients with post-surgical incontinence are still incontinent one year following surgery and <10% of patients with post-surgical incontinence using more than one incontinence pad per day;

11. ≥95% of patients having active surveillance should undergo MRI within 6 months of diagnosis and ≥75% of patients having active surveillance undergo trans-rectal ultrasound guided prostate re-biopsy within 14 months of diagnosis;
12. <5% of patients who have chemotherapy die within 30 days of treatment;

13. ≥ 7.5% of patients diagnosed with prostate cancer are enrolled on an interventional clinical trial and ≥15% of patients diagnosed with prostate cancer are enrolled on translational research.

QPI 9 and 10 relate to post-radiotherapy toxicity and PSA relapse rate respectively and will not be released as QPIs until better quality or relevant routinely collected data is available.

Essentially, these quality indicators supplement waiting time targets to include adherence to prostate cancer specific protocols, and the first national report assessing the Service against these new measures is imminent.

In this Section, I described the Service, how the capacity needs of the Service have changed, and outlined evidence of capacity shortage within the Service. In the next section I define the concepts capacity and capacity development.

2.3 Scottish policy pertinent to prostate cancer

This section provides a concise review of Scottish policy to situate this study. In doing so, this Section provides a review of policy to illustrate how policy published by Scottish government sought to direct cancer care. I also draw on the wider literature to illustrate how this direction relates to prostate cancer care in Scotland.

To identify relevant policy, the Scottish government website was searched using the search function within the publications section to identify all health and social care policies. Specifically, strategies and plans were searched for as these documents guide the subsequent decision making of government and other relevant bodies, for example NHS Scotland. In doing so, these documents provide a context for the direction of change for healthcare services in Scotland, including service structure, priority setting and measures of quality healthcare. This method of searching meant that some influential policy papers were not directly captured as they were not categorised by Scottish government as strategies or plans. However, the *impact* of policies such as Realistic Medicine were captured within policies identified.

At the time of searching (August, 2020), the Scottish government listed 146 policies on their website. Documents titles were screened based on their fit with directing public health, or health and social care services. In total, 43 policies were identified as being potentially relevant. These policies were directed at (i) public health, (ii) health and social care, (iii) cancer care, and (iv) healthcare professionals. Table 3 summarises the names and focus of these publications.

Table 3: Timeline of health and social care publications that provide context to the NHS Scotland prostate cancer service

	PUBLIC HEALTH	**HEALTH AND SOCIAL CARE**	**CANCER CARE**	**HEALTHCARE PROFESSIONALS**
2004				
2005				• Modernising nursing careers: Setting the direction
2006				
2007		• Better health, better care: Action plan		• Better health, better care: Planning tomorrow's workforce today
2008	• Better health, better care: Action plan, what it means for you	• Equally well: Implementation plan	• Better cancer care, an action plan	
2009				• Delivering quality through leadership: NHSScotland leadership development strategy
2010		• The healthcare quality strategy for NHSScotland		• Delivering quality in primary care: National action plan
2011		• Living and dying well: Building on progress • NHSScotland efficiency and productivity: Framework for SR10		
2012		• The Scottish government's plan to integrate adult health and social care		• AHPs as agents of change in health and social care: The national delivery plan for the allied health professions in Scotland

2013				• Prescription for excellence: A vision and action plan for the right pharmaceutical care through integrated partnerships and innovation
2014	• Making it easy: A health literacy action plan for Scotland			• Everyone matters: 2020 workforce vision – implementation framework and plan 2014-15
2015				• Everyone matters: 2020 workforce vision – implementation framework and plan 2015-16 • A health and biomedical informatics research strategy for Scotland: Enhancing research capability in health informatics for patient and public benefit • Driving improvement, delivering results: The Scottish healthcare science national delivery plan
2016	• Fairer Scotland: Action plan	• Strategic framework for action on palliative and end of life care: Executive summary • A national clinical strategy for Scotland • Health and social care delivery plan	• Beating cancer: Ambition and action	• Everyone matters: 2020 workforce vision – implementation framework and plan 2016-17

2017	A nation with ambition: The government’s programme for Scotland Making it easier: A health literacy action plan for Scotland			Everyone matters: 2020 workforce vision – implementation framework and plan 2017-18 Executive level leadership and talent management in NHSScotland National health and social care workforce plan: Part 1, a framework for improving workforce planning across NHSScotland National health and social care workforce plan: Part 2, a framework for improving workforce planning across NHSScotland Nursing 2030 vision: Promoting confident, competent and collaborative nursing for Scotland’s future Achieving excellence in pharmaceutical care: A strategy for Scotland
2018	Delivering for today, investing for tomorrow: The government’s programme for Scotland	Waiting times improvement plan		Everyone matters: 2020 workforce vision – implementation framework and plan 2018-19 National health and social care workforce plan: Part 3,

				improving workforce planning for primary care in Scotland
2019		• Social care support: An investment in Scotland’s people, society and economy: Our shared vision for adult social care support, including support for carers • Social care support: An investment in Scotland’s people, society and economy: Programme framework		• The Scottish government national monitoring and evaluation strategy for primary care
2020	• Protecting Scotland’s future: The government’s programme for Scotland	• Self-directed support implementation plan	• Beating cancer: Ambition and action (2016): An update, achievements, new action, and testing change	

The following sections provide an overview of Scottish cancer policy (2.3.1), followed by the Scottish government's interpretation of quality healthcare and how this is measured (2.3.2), and then understanding of the key challenges in cancer care identified in policy: increasing incidence and prevalence (2.3.3); cancer prevention and genetics (2.3.4); diagnostics (2.3.5); availability of care (2.3.6), inequality (2.3.7). This review then translates these findings into the prostate cancer care context (2.3.8).

2.3.1 Overview of Scottish cancer policy

Scottish cancer policy is informed by the wider policy context illustrated in Table 3. Specifically, Scottish cancer policy takes the relevant directions identified in wider government policy and applies these to direct the delivery of cancer care, and resolve emergent issues in cancer care. Better Cancer Care, An Action Plan (Scottish government, 2008a) was the Scottish government's first cancer policy paper following devolution of healthcare, and translates the direction of change set by prior healthcare policy such as Better Health, Better Care, Action Plan (Scottish government, 2007a) to a cancer care context and introduces the challenges in cancer care within the Scottish context and how these should be overcome. Then, Beating Cancer: Ambition and Action builds on Better Cancer Care, An Action Plan (Scottish government, 2016a) and captures the latest challenges facing cancer care considering developments. Particularly, considering the organisational change resulting from the integration of health and social care (Scottish government, 2012a) this policy paper acknowledges to a greater extent the organisational factors that prevent quality healthcare. Finally, Beating Cancer: Ambition and Action – An update, provides direction for cancer care during and following the COVID-19 outbreak in lieu of the next full cancer strategy expected to be released in 2021 (Scottish government, 2020a). These policies will be drawn on within subsequent sections to illustrate how policy published by Scottish government sought to direct cancer care.

2.3.2 Definitions and measures of quality healthcare

A core issue running throughout relevant policy documents is the misalignment between ambitions of cancer services, how quality healthcare is defined and how good care is measured in cancer services. For example, in Beating Cancer: Ambition and Action, the Scottish government state that it is the ambition of Scottish government to develop cancer services "*to become one of the highest performing cancer healthcare systems internationally*" (Scottish government, 2016a, pp. 51). However, in Better Cancer Care, An Action Plan, to enable the development of internationally renowned care, the Scottish government defined quality healthcare to align with the United States Institute of Medicine goals where quality healthcare was understood to be patient-centred, safe, effective, efficient, equitable and timely (Scottish government, 2008a). Quality was then was then measured using waiting time targets, which were detailed in Section 2.2.8, though further national indicators of quality were also identified, these were not described in depth (Scottish government, 2008a).

Subsequently, understanding of quality was later refined to safe, effective and person-centred healthcare (Scottish government, 2010a) removing efficient, equitable and timely from definitions of quality, but waiting time targets continued as the measurement of quality care. However, understanding of quality in cancer services has now been devolved to the National Cancer Quality Performance Indicator (QPI) programme (Scottish government, 2016a) which provides a framework for measuring adherence to prostate cancer specific protocols and waiting time targets, but has otherwise not furthered understanding of quality in cancer care (Scottish government, 2016a). Interpretation or measurements of quality were not furthered in Beating Cancer: Ambition and Action – An update, and audits of existing measures were pledged to ensure adherence (Scottish government, 2020a).

2.3.3 Increasing incidence and prevalence of cancer

Scottish cancer policy identifies increasing incidence and prevalence as one of the biggest challenges facing cancer care in Scotland. In Better Cancer Care, An Action Plan (Scottish government, 2008a), the challenge faced as a result of increasing incidence and prevalence of cancer was addressed within two sections of the policy: *the challenge for Scotland* and *living with cancer.* In Beating Cancer: Ambition and Action (Scottish government, 2016a), these were also addressed within two sections of the policy: *Scotland is changing* and *living with, and, beyond cancer.* In Beating Cancer: Ambition and Action – An update (Scottish government, 2020a), the challenge faced as a result of increasing incidence and prevalence of cancer was addressed in one section only: *actions on best care and support for all people with and beyond cancer*.

In Better Cancer Care, An Action Plan, prostate cancer was identified as one of the most common cancers in men in Scotland and incidence of prostate cancer was anticipated to increase by 35.8% in Scotland between 2006-2010 and 2016-2020 due to the ageing population. Though an increase in the number of deaths from prostate cancer was predicted, this was likely to be due to increasing incidence as the relative survival rate of men with prostate cancer was 80.1% and has improved over time (Scottish government, 2008a). Though Beating Cancer: Ambition and Action makes limited reference to prostate cancer, this publication continues to attribute increasing incidence of cancer to the ageing population as well as improvements in mortality (Scottish government, 2016a). This means that more men are living with and beyond prostate cancer.

Due to the long-term physical and psychological effects of cancer treatment, as well a long follow-up periods and risk of recurrence, Scottish policy positions cancer as a long-term (Scottish government, 2008a) or chronic (Scottish government, 2016a) condition. The Better Cancer Care, An Action Plan also identifies other effects of living with and beyond cancer on a person's life including the financial and social effects, and seeks to support people mitigate these effects through improved communication, support with returning to work, increased support for and involvement of carers, and the development of protocols or pathways to ensure psychological support as part of routine care, and other initiatives. However, Better Cancer Care, An Action Plan also demonstrated awareness of a lack of understanding of all needs of people living with and beyond cancer and sought to rectify this through introduction of the Transforming Care After Treatment (TCAT) programme. Greater understanding of the complex needs of people living with and beyond cancer has led to the recommendation that healthcare professionals should use holistic needs assessments to ensure that all needs are met through follow-up (Scottish government, 2016a), with the subsequent adoption of link officers and key support workers to support people affected by cancer alongside disease-specific follow-up care protocols (Scottish government, 2020a).

2.3.4 Cancer prevention

In both Better Cancer Care, An Action Plan (Scottish government, 2008a) and Beating Cancer: Ambition and Action (Scottish government, 2016a) cancer prevention was addressed in one section only in each publication. All publications sought to prevent the development of cancers through promoting improved lifestyle factors and the life circumstances of the Scottish population. This approach fits with wider initiatives to improve the health and wellbeing of the Scottish population (Scottish government, 2016b; 2017a; 2018b; 2019a; 2019b; 2020b), and so, activities are generally not specific to cancer. From 2020, these activities will be guided by Public Health Scotland (Scottish government, 2020a).

2.3.5 Diagnosis

In Better Cancer Care, An Action Plan (Scottish government, 2008a) and Beating Cancer: Ambition and Action (Scottish government, 2016a), diagnosis was addressed in three sections of the policies: *early detection of cancer*, *referral and diagnosis* and *genetic and molecular testing;* and *early detection and diagnosis, improving survival* and *referral and diagnosis* respectively. In Beating Cancer: Ambition and Action – An update (Scottish government, 2020a), diagnosis was also addressed in two sections of the policy: *Actions on early detection* and *actions on smoother patient journeys.*

In Better Cancer Care, An Action Plan (Scottish government, 2008a), screening for prostate cancer was not recommended due to the limitations of the PSA test. Rather, to improve diagnosis, the Scottish government developed the capacity of genetic services, recommended increasing awareness of cancer symptoms in the general public and in primary care, promoting earlier diagnosis, tasked

Managed Cancer Networks and Health Boards with increasing the percentage of electronic referrals and adoption of standard templates for referrals to improve communication between primary and secondary care, and increased capacity for technological advances and investigations to be carried out locally. By 2016, the Scottish government had launched the Detect Cancer Early programme which aimed to oversee these actions with linked awareness campaigns such as the ‘wee C’, which sought to reduce fear of cancer in the general population, and promised further investment in technological advances. Further, there was greater awareness of the problematic primary and secondary care interface, which was thought to cause primary care professionals to be hesitant in referring people with suspected cancer.

In Beating Cancer: Ambition and Action – An update activities to promote awareness of cancer and early detection continued to be a focus in cancer policy with the launch of the Survivors campaign and the Effective Cancer Management Framework. These documents aimed to increase cancer health literacy within general public and amongst healthcare professionals, and improve monitoring of men with suspicion of cancer (Scottish government, 2020a). Consistent with preceding policy, Beating Cancer also pledges increased capacity for technological advances. Though waiting time targets are recommended throughout to measure quality of cancer care, recent policy provided recognition of the complexity of some diagnostic pathways, which can cause delays in cancer diagnosis (Scottish government, 2020a). To further improve waiting time targets, the Scottish government are exploring investment in rapid diagnostic test centres, and additional diagnostic and treatment centres.

2.3.6 Availability of care

Increased incidence and prevalence of cancer has meant greater demand on availability of care. However, the expectations of care delivery have also changed over time. In Better Cancer Care, An Action Plan (Scottish government, 2008a), availability of care was addressed in the section called *treatments* only. In Beating Cancer: Ambition and Action (Scottish government, 2016a) and Beating Cancer: Ambition and Action – An update (Scottish government, 2020a) availability of care was addressed in two sections of each policy: called *improving treatments* and *workforce; and actions on “prehabilitation”* and *actions on treatment,* respectively.

Better Cancer Care, An Action Plan directed services to deliver care locally. However, Beating Cancer: Ambition and Action recognised the patient benefits of high-volume treatment centres in some instances. In this change, services are encouraged, where these is clear benefit, to provide treatments like surgery in high volume centres, whilst pre- and post-treatment care should be delivered locally. Further, Beating Cancer: Ambition and Action tasked regional or national working groups, as relevant, in guiding the delivery of reliable and sustainable care across geographical boundaries. Beating Cancer: Ambition and Action – An update did not recognise a particular model of care delivery, but referred to national working groups to advise on the delivery of specialist care across Scotland.

As cancer policy developed, there was clear recognition of increased demand and the impact of technological advances in specialist treatment. In 2008, policy was focussed on surgery as the most common first line treatment for cancer. However, a marked shift in focus to radiotherapy has been noted in more recent cancer policy reflective of increased demand and the drive for local delivery of care (Scottish government, 2016a; 2020a). Throughout policy, there is a clear demonstration of Scottish government tasking healthcare professionals to guide or support capacity development including in surgery (Scottish government, 2008a) and radiotherapy (Scottish government, 2016a; 2020a). In 2008, Scottish government pledged investment in treatment services, (Scottish government, 2008a). However, though Beating Cancer: Ambition and Action acknowledges the need for continued investment to meet demand for treatment, particularly in urological surgery, no clear investment was pledged.

This lack of clear financial investment in treatment from 2016 is evident in chemotherapy also. Better Cancer Care, An Action Plan recognised increased chemotherapy use and the associated financial cost, and directed healthcare professionals to better consider the benefits vs. cost of drugs used. Beating Cancer: Ambition and Action and then, Beating Cancer: Ambition and Action – An update encouraged the re-purposing of off-patent drugs and cautioned that better understanding of the effects of chemotherapies was needed to fully appreciate the usefulness of currently prescribed treatments.

In the delivery of care, Better Cancer Care, An Action Plan predominantly guided care through directing the delivery of the treatment itself, whereas later policy recognised to a greater extent the demand created in the service when care is holistic and person-centred care. Particularly, Beating Cancer: Ambition and Action recognises specialist services as only part of the care that patients receive; patients receive care to manage their cancer from a range of generalists or healthcare professionals with non-cancer specialisms to ensure that all needs are met. As such, policy recognises that availability of care is not solely related to the number of healthcare professionals or number of specialists, but rather the diversity of healthcare professionals involved and the quality of multidisciplinary team working (Scottish government, 2016a). Following from this, the 2020 policy has greater focus on care surrounding treatment rather than on the specialist treatment itself.

2.3.7 Health inequality

As a government priority (Scottish government, 2016b; 2017a; 2018b; 2019a; 2019b; 2020b), reducing inequalities is embedded throughout cancer policy. Specifically, cancer policy recognises the impact of demographic inequality, i.e. poor patient outcomes associated with rural living and socioeconomic status. Further, cancer policy also recognises inequality in cancer treatment caused by differences in local demographics and care provision. Inequalities were addressed throughout policy. However, directions to services are inconsistent, with some policies directing equal service provision (Scottish government, 2008a; 2020a) and other policy directing equitable service provision (Scottish government, 2016a).

In addition to the activities undertaken by Scottish government to reduce widening inequality within the Scottish population, The Better Cancer Care, An Action Plan tasked Health Boards and Community Health Partnerships with reducing health inequality through improved relations with communities, targeting services in the most deprived areas, ensuring equal uptake of screening across groups with particular demographics characteristics, and reducing the geographic inequality in the quality of care caused by regional differences in service provision. Though Better Cancer Care, An Action Plan also directs services to reduce health inequalities through similar activities as those outlined in Better Cancer Care, An Action Plan, this policy recommends reducing health inequalities through equitable rather than equal care provision. Beating Cancer: Ambition and Action – An update does not refer to inequity and identifies further inequality; inequality in survival between cancers, and lack of focus on rarer cancers.

2.3.8 Impact of policy on the NHS Scotland prostate cancer service

Scottish cancer policy identifies challenges unique to the cancer care context, and directs resolutions to these guided by the wider Scottish policy context. Scottish cancer policy attributed increased incidence and prevalence to the ageing population (Scottish government, 2008a; 2016a; 2020a). However, within prostate cancer care, advancements in technologies have had a greater impact on service provision. For example, the introduction of PSA testing has led to large increases in incidence of prostate cancer in Scotland across all age groups (Deas, 2018; Scottish Public Health Observatory, 2018; EAU guidelines, 2019). As such, incidence of prostate cancer is more likely to correlate with PSA testing than the ageing population, which makes changes in incidence harder to predict and plan for.

Further, the changed expectations of care provision were also recognised within policy as having shifted the demand on care services. The Scottish government have directed changes in expectations of care delivery in three ways: (i) delivery of care locally (Scottish government, 2008a), but utilising high volume centres where appropriate (Scottish government, 2016a), (ii) greater focus on meeting all patient needs holistically (Scottish government, 2008a; 2016a; 2020a), and (iii) the delivery of equal or equitable cancer care. Policy recognised the impact of these shifts in service provision as impacting on services in many ways including on the training needs of the healthcare workforce, including the creation of new roles, and different models of working that encompassed the need for increased collaboration between regions, disciplines, specialities and with patients.

To facilitate the delivery of local care, the Scottish government asked for improved collaboration between primary and specialist care. However, it was evident throughout iterations of policy that this had proved problematic. Within prostate cancer care, this is likely due to the complexity and changeability of tests and treatment protocols for prostate cancer care and the resulting inadequate understanding of this in primary care (Rai et al., 2007; National Screening Committee Prostate Cancer Risk Management Programme, 2016), as well as increased burnout, poor job satisfaction and widespread recruitment concerns thought to result from this shift in expectations of care (British Medical Association, 2014; Royal College of General Practitioners, 2014). Though collaboration between primary and specialist care was a key policy objective of Scottish government when healthcare was devolved (Scottish Office, 1997; Scottish Executive, 1999; Woods, 2001), local delivery of care models are not always the best solution to service provision issues (Weir, 1999).

Further, the misalignment of definitions of quality of care with measures of quality care (2.3.2) problematises service provision. For example, diagnostic protocols can be complex, leading to delays in diagnosis and treatment in some cancers, as reflected in missed waiting time targets in urological cancer services (NHS National Services Scotland, 2019) and as recognised in Beating Cancer: Ambition and Action – An update (Scottish government, 2020a). Diagnosis of prostate cancer involves a complex, multi-step protocol, which includes discussion with patients prior to biopsy and treatment, as recommended in best practice guidelines (EAU guidelines, 2019; NICE, 2019). Within these discussions some patients may demonstrate an identifiable preference for biopsy or treatment (Bae, 2017). Regardless, decision making during appointments could be confounded by factors such as emotional responses to information given and poor health literacy (Power, Swartzman and Robinson, 2011; Brabers et al., 2017). Therefore, it is important to ensure that patients have adequate time to reflect on choices given. As such, waiting time targets apply pressure on the Service to ensure that patients move through the complex, multistep diagnostic and treatment decision-making processes in a timely manner, which can undermine shared decision-making processes and patient autonomy.

This section demonstrated a disconnect between policy and practice. To resolve this, there is a need for policy to better reflect the unique challenges of the cancer care context and for policy-makers to better support cancer services to respond to policy change, which can have substantial impact on service delivery and service capacity. This study sought to understand the needs of the Service, as reflected in the development of the research question.

2.4 Refining the research problem

With the understanding that prostate cancer incidence had increased and was due to increase further (Deas, 2018) and that as a result, capacity shortage already evident within the Service was expected to worsen (Scottish Public Health Observatory, 2018), Prostate Scotland funded this study to provide insight on how to better meet demand. Early in the PhD, my understanding of the research problem was gained from my understanding of the literature, networking with healthcare professionals and learnings from my supervisors and colleagues. When this study began, I did not intend to address capacity shortage within the entire NHS Scotland prostate cancer service, but through sequential phases of research, identify the areas of the Service most in need of development to meet demand. From this, I had an expectation that through phases of research, that the research problem would narrow.

Though some consider research questions to be fixed once a study begins, this is not always possible or considered good practice (Agee, 2009). Consistent with guidance in the literature (Janesick 2000), this study was driven by a fixed overarching goal or focus from which research questions developed. As research questions are developed to reflect the researchers understanding of the research problem and their position within the research (Charmaz, 2006; Creswell, 2013), initial research questions used in this study reflected my understanding of the research problem before data collection began. As such, they were generally exploratory and sought to make best use of potentially accessible data. As findings then emerged, my understanding of the research problem developed, allowing research questions to be refined to reflect my understanding of the research problem.

As my understanding developed through phases of research, I realised that findings reflected integral issues within the Service as a whole, and the solution to the research problem did not lie within individual parts of the Service, but was systemic. This understanding came towards the end of the study, and saw me shift the focus of the analysis and data interpretation from *understanding the design and delivery needs of parts of the Service* to *understanding capacity shortage within the Service as a whole.* Though arguably this is semantics, this subtle shift in focus represented an important development in my understanding of the problem. Specifically, I stopped searching for the solution to the capacity problem within the Service itself, but realised that the root of the problem existed between the Service and its environment. From this point, I sought to understand capacity as a concept and how capacity should be developed within healthcare services to inform the development of research questions to guide the study towards the most practically useful findings.

2.5 Defining capacity and capacity development

It was clear that the Service was lacking capacity to deliver quality prostate cancer care in line with NHS Scotland cancer policy (2008; 2016) and though the Scottish Government have pledged increased capacity across services to meet waiting time targets (Scottish government, 2018a), no clear understanding of capacity or capacity development was evident. The terms capacity and capacity development are often criticised for being poorly defined (Potter & Brough, 2004; Trostle, 1992), hence I wished to explicitly define them in this study. To identify definitions for capacity and capacity development, the literature was searched.

To identify relevant papers, BusinessSource, CINAHL, HealthSource, and SocIndex were searched for “health*” AND “capacity development” in the abstract only. The review included all quantitative and qualitative primary research papers, written in English, and published between January 2004 and May 2017. Primary research papers only were included and papers relating to university education were excluded. First the inclusion and exclusion criteria were applied to the titles, and then to abstracts. If the relevance of a paper was not clear from the abstract, the full text of the paper was assessed.

57 full papers were assessed, as shown in Figure 2. From these, 29 papers were excluded as they provided no information to understand how capacity had been conceptualized within the study. As most papers identified did not provide a definition for capacity or capacity development, and often did not provide enough information within the paper to understand fully how the terms had been used, the reference list of each paper was hand-searched to identify further relevant papers. These papers were selected if they helped to understand how capacity had been defined or conceptualised within each of the 28 remaining studies. A further 6 papers were excluded as the cited literature was not enough to support understanding of how capacity had been defined or conceptualised within the study. All 22 papers identified through database searching are summarised in Table 4 alongside the papers identified from hand-searching each reference list. Explicit definitions of capacity and capacity development extracted from the literature are given in Table 5 and Table 6.

Most papers identified sought to address capacity issues within low- to middle-income populations (Lembani et al., 2008; Mayhew, Doherty, & Pitayarangsarit, 2008; Perry et al., 2008; Gurinovic, et al., 2010; Gulzar, Mistry & Uphall, 2011; Holvoet & Inberg, 2014; Jessani et al., 2014; Kebede et al., 2014; Chanturidze et al., 2015; Bahraminejad et al., 2015; Park et al., 2015; Aidam & Sombie, 2016; Atkins et al., 2016; Lembani et al., 2016; Reinsma, Nkuoh, & Nshom, 2016). Though the capacity issues faced in low- to middle- income populations are likely to be different to those within high-income countries, the conceptualisation of capacity and capacity development within these papers was unlikely to be differ between populations. For example, conceptual and definitional papers such as Potter and Brough (2004), which was developed considering research in a low- to middle- income population, has demonstrated wide applicability (Peirson et al., 2012; Kislov et al., 2014; Bauman & Cabassa, 2020).

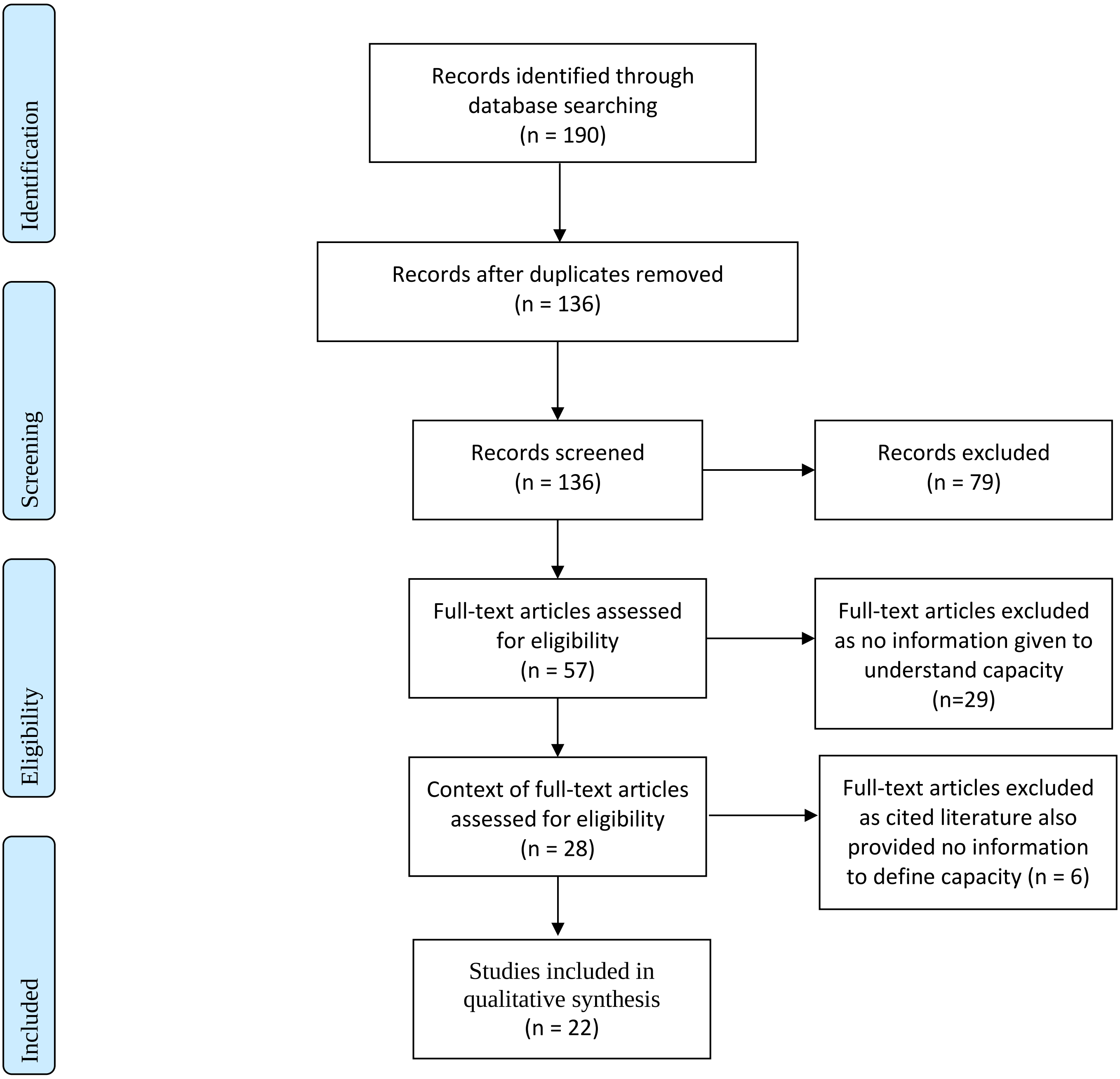


Figure 2: Adapted PRISMA diagram (Moher et al., 2009) summarising identification and selection of studies to conceptualise capacity and capacity development

Table 4: Summary of papers identified with the relevant cited literature

PAPER	*FURTHER RELEVANT PAPERS IDENTIFIED	**AIM(S)**	**DATA COLLECTION METHODS**	**ANALYTIC METHODS**
AIDAM & SOMBIE, 2016	Nchinda (2002), Lansang and Dennis (2004), Sawyer (2004), Bates, Akoto & Ansong (2006) and Minja (et al., 2011) informed by UNDP (1998)	To evaluate the programme and identify key experiences, strengths, weaknesses and challenges during implementation of research development programme	Triangulation of document analysis and field experiences • Document analysis of programme technical and financial reports of research activities and independent report • Field experience and exchanges between researchers and stakeholders And review of programme activities by independent consultant • Semi-structured interviews with key stakeholders • Review of documents analysed above	Framework analysis
ATKINS ET AL., 2016	Research group informed by Commission of the Social Determinants of Health (2008)	To gain understanding of how to increase postgraduate students' research capacity in Africa and Asia	Document analysis of project meetings and discussion minutes, project reports, and deliverables Group meeting with people involved	Unknown
BAHRAMINEJAD ET AL., 2015	None identified, but rich paper	To identify the factors concerning quality, quantity and sustainability of community participation in base health programmes	Key stakeholders purposively sampled from organisations at local and national levels Semi-structured interviews	Content analysis

		that influence policy-makers and managers		
CHANTURIDZE ET AL., 2015	OECD (2006) and UNDP (2009)	To understand the steps needed to build capacity	Case study approach • Key stakeholders identified through mapping according to engagement in policy cycle • Mapping of policy processes using institutional capability assessment model used by UK NHS • Institutional capability review instrument completed by stakeholders • Individual competency and skills assessment instrument completed by stakeholders • Delivery and evaluation of capacity building interventions	Unknown
COHEN ET AL., 2013	Norris (et al., 2008) informed by Goodman (et al, 1998)	To develop a tool to guide research, dialogue, reflection and action on public health capacity development to achieve health equity goals	Interviews with key informants ("health equity champions") identified purposively and then through snowball sampling Literature review (academic and grey literature) Meetings and conference calls to refine findings Key informants completed questionnaire to critique findings	Thematic analysis
DRESSENDORFER, 2005	Hawe et al., 1997; Goodman et al, 1998	To describe the derivation of a conceptual model of	Case study approach (4 cases)	Thematic analysis of qualitative data

		community capacity development through exploring the process of partnership formation and collaboration within communities as they planned for, organised, mobilised and attempted to sustain heart health promotion programmes	Qualitative: Individual and group interviews with site coordinators; focus groups; observations of staff meetings Document review: meeting minutes; media clippings; correspondence; annual reports; other background documents	Inductive analysis of data for each case
GERRISH & PIERCY, 2014	Crisp, Swerissen & Duckett (2000) and Department of Health (2006)	To evaluate the success of knowledge transfer capacity development secondments from the perspective of multiple stakeholders	Purposively sampled participants Focus groups with participants Group discussions with knowledge transfer teams Semi-structured interviews with managers of knowledge transfer teams	Framework analysis
GULZAR, MISTRY, & UPHALL, 2011	Global health workforce alliance (2008)	To address the perception of the role of the community health nurse assistant manager, with the goal of strengthening that role	Key informants purposively sampled In depth, semi-structured interviews Observation of clinical health nurses at work and informal discussions with range of staff within organisation used to provide additional data and verify statements made during interview	Content analysis
GURINOVIC ET AL., 2010	Lopes & Theisohn (2003 - 2013 edition reviewed), Pavlovic (et al., 2009) informed by UNDP (2007)	To increase the number of contracts with non-European Food Information Resource compilers in Middle Eastern and North African countries to complete an inventory of	Online questionnaires	Unknown

		food composition databases status To identify specific training needs as a basis for capacity development activities		
HOLVOET & INBERG, 2014	None identified, but rich paper	To develop understanding of application of monitoring and evaluation tool within Uganda's education sector	Academic and grey literature review including policy Semi-structured interviews with stakeholders	Unknown
JESSANI ET AL., 2014	Potter and Brough (2004), Bates, Akoto, & Ansong (2006), OECD (2006), Green & Bennett (2007), Mayhew, Doherty and Pitayarangsarit (2008), Kitua (et al., 2009), Bennett (et al., 2011), Minja (et al., 2011) and Mirzoev (et al., 2014)	To develop a clear picture of existing capacities for health systems research at the Higher Education Alliance for Leadership through Health (HEALTH) Alliance SPHs For each SPH, draft and build consensus around health systems research capacity development strategies and work plans for implementing them To make an initial and rapid assessment of health systems research priorities in the different countries involved in HEALTH Alliance	Grounded theory approach • Modified Canada's International Development Research Centre's organisational capacity tool for partner organisations • Tool revised and adapted at workshop with partner organisations • 5-8 semi-structured interviews per country and transcripts verified • Workshop to discuss and interpret emerging findings and reach agreement on strengths and weaknesses • Workshop to discuss and build capacity development plan • Attended meetings and teleconferences	Average score per item on capacity tool Thematic analysis

KEBEDE ET AL., 2014	Bates, Akoto & Ansong (2006) and WHO (2006)	To describe governance and stewardship of research in health research institutions in the World Health Organisation (WHO) African Region	Tool 6 from Health Research System Analysis (HRSA) Initiative Toolkit: Methods for Collecting Benchmarks and Systems Analysis Toolkit used to evaluate health research institutions in Africa identified by World Health Organisation (WHO). 847 of 1882 institutions across 42 countries responded	Responses weighting scheme to give composite rank of 1 to 5
LEMBANI ET AL., 2016	Block Gonzalez & Mills (2003), Bennett et al., (2010) and Mirzoev (et al., 2014)	To understand the contribution of the Collaboration for Health Systems Analysis and Innovation post-doctoral research fellowships in health policy and systems research	Case study approach • Meetings with key experts • Experts submitted reflective narrative guided by schedule • Group discussion to construct analytical themes	Thematic analysis
MAYHEW, DOHERTY, & PITAYARANGSARIT, 2008	Lansang and Dennis (2004)	To evaluate the partnerships developed between the Health Economics and Financing Programme of the London School of Hygiene and Tropical Medicine and three research partners in South Africa and Thailand to strengthen health economics-related research capacity	Quantitative document analysis of programme memoranda, annual reports, and other programme documentation. 25 semi-structured stakeholder interviews with purposively selected to be partners or policy-makers.	Descriptive statistics Framework analysis
NOORAIE ET AL., 2017	Maxwell, Adily & Ward (2007) and Pierson (et al., 2012)	To understand the role of social networks in evidence-informed decision making	Social network analysis	TAMS analyser used Framework analysis

			• Longitudinal analysis of the information-seeking networks and evidence-informed decision-making behaviours before and after intervention (purposive sample) • Focussed interviews (different purposive sample)	
PADWA ET AL., 2016	Aarons (et al., 2011)	To measure integrated behavioural care capacity using an evaluation tool among a small sample of primary care clinics, and to observe how measures of integrated care capacity shift over time among a subsample of clinics for which longitudinal data were available To describe how various outer and inner contextual factors promote or inhibit the development of integrated care capacity in primary care clinics	Behavioural health integration in medical care (BHIMC) evaluations conducted across 3 sites every 11-18 (average 14.7) months Qualitative analysis of: written policies, procedures and reports; team meetings, conversations with staff and email exchanges; annual surveys; and focus groups	Mean scores calculated across domains of Behavioural health integration in medical care (BHIMC) evaluations to evaluate change over time in each domain Content analysis of qualitative data informed by Conceptual Model of Evidence-Based Practice Implementation in Public Service Sectors
PARK, ET AL., 2015	None identified, but rich paper	To understand whether it would be appropriate to use the HPS concept in countries selected, and if so, what aspects of health	15 public schools in urban or semi-urban areas recruited by project partners: • Principals, teachers, parents and people from education and	Framework analysis using ATLAS.ti

		promoting schools should be the focus for future interventions	health authorities participated in semi-structured interviews • Group interviews were also conducted with participants • Observation of school environment	
PERRY ET AL., 2008	None identified, but rich paper	To assess stakeholders' perceptions of progress in relation to the objectives of research fellow posts	Questionnaires with people seeking support from research fellows Semi-structured interviews with senior managers	SPSS • Frequency counts • Percentages Content analysis • Member checked
REINSMA, NKUOH, & NSHOM, 2016	None identified, but rich paper	To determine the potential effectiveness of infant feeding counselling on exclusive breastfeeding rates in children between the age of 0-5 months To determine the potential effectiveness of infant feeding counselling on complementary feeding in children between the age of 6-8 months To determine the potential effectiveness for infant feeding counselling on wasting and/or stunting in children 0-8 months	Comparative cross-sectional evaluation • Caregivers between ages of 18-50 years and their infants between 0-8 months accessing care recruited from different sites (participants matched for demographics) • Participants selected by systematic random sampling • Adapted validated Infant and Young Child Feeding practices (IYCF) questionnaire (piloted beforehand) • Anthropomorphic measurements of children	G*Power used to determine sample size World Health Organisation Anthro Software 3.2.2 used to analyse anthropomorphic measurements of child (z-score) Chi-squared and binary logistic regression using SPSS to analyse IYCF data and z-score
SARRE & COOKE, 2009	Trostle (1992)	To provide practical support to primary care trusts	Nominal group technique	Attendees at workshops grouped indicators

		through the development of indicators against which to plan and measure progress of research capacity development at an organisational level	• Indicator generation at 5 workshops • Iterative questionnaire completion (purposively sampled experts) • Group discussion (purposively sampled experts)	Median score calculated from questionnaire Group consensus (85% or higher is consensus)
ZUKOWSKI, 2014	Norris (et al., 2008) informed by Goodman (et al, 1998)	To determine If relationship exists between the development of core capabilities at the community level and disaster response and recovery outcomes To measure the impact of adaptive capacity on disaster response and recovery within communities	Counties affected by major disaster targeted and stratified proportionate random sampling used Community demographic data from national census National cross-sectional survey (online and telephone)	Strata 12 SE used Descriptive and inferential statistics Factor analysis Cronbach’s alpha Multiple regression analysis Multilevel linear modelling

*For each paper identified through database searching, relevant papers were identified through hand searching of reference lists, and used to contextualise use of the terms capacity and capacity development within the literature

Table 5: Definitions of capacity extracted from cases

SOURCE	DEFINITION OF CAPACITY
GOODMAN ET AL., 1998	“Often [community] capacity is used interchangeably with other, similar concepts… For example, although empowerment shares characteristics with capacity, capacity seems to be a broader construct… Also, capacity may be distinguished from competence. We view capacity as a potential state and competence as an active state. That is, capacity reflects a community’s potential for addressing presenting health issues, whereas competence signified how skilfully capacity is applied. Capacity is most similar to readiness in that both are potential states that may lead to community action” (pp. 260)
MIRZOEV ET AL., 2014	“Capacity, which can be defined as the ability of individuals or groups to perform tasks in a sustainable manner, is a complex concept involving different related elements—including structures and staff expertise—at individual, organizational and wider systems levels.”
OECD/DAC, 2006 AS CITED IN GREEN & BENNETT, 2007	“[Capacity is] the ability of people, organisations and society as a whole to manage their affairs successfully” (pp 8)
OECD, 2006	“Capacity is not only about skills and procedures. It is also about incentives and governance.” (pp 3) “The concepts of capacity and capacity development are so all-encompassing that practitioners have often found it difficult to make operational sense of them. It is important for practitioners to begin by asking the question “capacity for what?” and focus on the specific capacities needed to accomplish clearly defined goals. The “best fit” approach to capacity development then calls for a systematic effort to think through what might work in the particular circumstances.” (pp 4) “The concepts of capacity and capacity development are so all-encompassing that practitioners have often found it difficult to make operational sense of them. It is important for practitioners to begin by asking the question “capacity for what?” and focus on the specific capacities needed to accomplish clearly defined goals. The

	"best fit" approach to capacity development then calls for a systematic effort to think through what might work in the particular circumstances." (pp 4)
UNDP, 1998	Capacity is defined as the ability of individuals and organisations or organisational units to perform functions effectively, efficiently and sustainably. This implies that capacity is not a passive state but part of a continuing process and that human resources are central to capacity development. The overall context within which organisations undertake their functions are also key considerations in capacity development. Capacity is the power of something (a system, an organisation, a person) to perform or to produce." (pp x)
UNDP, 2009	"Capacity – the ability of individuals, institutions and societies to perform functions, solve problems, and set and achieve objectives in a sustainable manner." (pp 53)
WARE ET AL., 2010	"Personal capacity refers to attributes of individuals that equip them to exercise agency. Capacities are both inherent and developed, meaning that a certain amount of capacity may "come naturally." Inherent capacities improve and new ones are acquired with learning and practice. Personal capacities constitute "agency potential." Capacities are not the same as skills. Though both suggest competence, we may think of skills as competencies acquired through practice, such as playing the piano or—in the context of mental health treatment—symptom management, emotion regulation, or stress reduction. Capacities, in contrast, are competencies acquired through developmental processes aimed at moral, social, cognitive, and emotional growth. Skills may be thought of as performative and capacities as generative."

Table 6: Definitions of capacity development extracted from cases

SOURCE	DEFINITION OF CAPACITY DEVELOPMENT
LOPES & THEISOHN, 2013	“Capacity development is an all-encompassing term… it is a broad goal achieved over time” (Ch1) “Capacity development… is voluntary… it takes time… is case specific… is based on existing capacity… is dynamic” (Ch1)
OECD/DAC, 2006 AS CITED IN GREEN & BENNETT, 2007	“[Capacity development is] the process whereby people, organisations and society as a whole unleash, strengthen, create, adapt and maintain capacity over time” (pp 9)
OECD, 2006	“Capacity development involves much more than enhancing the knowledge and skills of individuals. It depends crucially on the quality of the organisations in which they work. In turn, the operations of particular organisations are influenced by the enabling environment – the structures of power and influence and the institutions – in which they are embedded.” (pp 3) “The new consensus, articulated strongly in the 2005 Paris Declaration, sees capacity development as a necessarily endogenous process, strongly led from within a country, with donors playing a supporting role. According to this vision, political leadership and the prevailing political and governance system are critical factors in creating opportunities and setting limits for capacity development efforts. Country policy ownership is not a simple yes/no issue, however, but a matter of processes and trends. It is also not monolithic. The conditions may be right for donors to support locally-owned processes of improvement in certain organisational spheres even when the conditions in the wider system are suboptimal.” (pp 3) “The concepts of capacity and capacity development are so all-encompassing that practitioners have often found it difficult to make operational sense of them. It is important for practitioners to begin by asking the question “capacity for what?” and focus on the specific capacities needed to accomplish clearly defined goals. The “best fit” approach to

	capacity development then calls for a systematic effort to think through what might work in the particular circumstances.” (pp 4)
UNDP, 1998	Capacity development is a concept which is broader than organisational development since it includes an emphasis on the overall system, environment or context within which individuals, organisations and societies operate and interact (and not simply a single organisation). In the case of development programmes, it includes a consideration of all factors which impact upon its ability to be developed, implemented and the results to be sustained.” (pp x)
UNDP, 2007 AS CITED IN PAVLOVIC ET AL., 2009	“Capacity development gives primacy to national priorities, plans, policies and processes. It underpins a shift from a technical assistance supply driven approach to an endogenous led process of change, and gives tangible form to the principle of national ownership” (pp 1047).
UNDP, 2009	“[Capacity development is] the process through which individuals, organisations and societies obtain, strengthen and maintain the capabilities to set and achieve their own development objectives over time” (pp 2) “Capacity development [is] the organisation’s overarching service to programme countries” (pp 2) “Capacity development is not a one-off intervention, but an iterative process of design-application-learning adjustment” (pp 8)

However, it was clear that the conceptualisations of capacity and capacity development in research conducted in high-income countries, namely Canada (Dressendorfer, 2005; Cohen, et al., 2013; Nooraie et al., 2017), America (Zukowski, 2014; Padwa, et al., 2016), and England (Sarre & Cooke, 2009; Gerrish & Piercy, 2014) were informed by a different body of literature to research conducted in low- to middle- income countries. The conceptualisations of capacity in research focussing on low- to middle-income countries were generally informed by grey literature published by organisations such as UNDP and OECD, whereas the conceptualisations of capacity in research focussing on high-income countries were generally informed by other research papers. Particularly, in 3 of the 7 papers focussing on high-income countries conceptualisations of capacity were informed by Goodman's (et al., 1998) understanding of capacity.

Though grey literature has not undergone a robust peer review process (Lawrence et al., 2014), academics are often involved in the process of creating or informing much of this literature including peer reviewing prior to release (Lawrence et al., 2014; Bellefontaine & Lee, 2013; Briner & Denyer, 2012) and so they are often still of high quality (Gibbons et al., 1994; Grayson and Gomersall, 2003). The grey literature included in this review are publications from governmental organisations such as UNDP and OECD and so were considered high quality. Further, these publications were used extensively within the academic literature and provided detailed conceptualisations of the terms 'capacity' and 'capacity development'. As such, they added value to this review.

Additionally, papers covered a range of topics; papers covered education, training and research (Lembani et al., 2008; Sarre & Cooke, 2009; Gurinovic, et al., 2010; Jessani et al., 2014; Kebede et al., 2014; Aidam & Sombie, 2016; Atkins et al., 2016), communication and knowledge transfer (Mayhew, Doherty, & Pitayarangsarit, 2008; Perry et al., 2008; Gerrish & Piercy, 2014; Nooraie et al., 2017), community-based interventions (Dressendorfer, 2005; Gulzar, Mistry & Uphall, 2011), health service development (Padwa, et al., 2016; Reinsma, Nkuoh, & Nshom, 2016), policy, monitoring and evaluation systems (Holvoet & Inberg, 2014; Chanturidze et al., 2015), and public health (Cohen et al., 2013; Zukowski, 2014; Park et al., 2015). As this paper was not limited to one field of research, conceptualisations of capacity in different health-related fields were reviewed.

As this review did not seek to analyse study findings, but rather gain understanding of how capacity had been conceptualised, studies were not excluded based on quality. Rather, all studies that conveyed some understanding of how capacity was conceptualised were included in this review. However, clear variation in quality was evident between studies. Most evidently, several studies sought to consolidate large-scale capacity development programmes. These studies generally employed a case study approach, though this was not always explicit, and the analytic methods used were not always evident within the article. For example, Aidam and Somie (2016) employed independent consultants to evaluate the programme who conducted 180 interviews and completed a documentary analysis, whereas Atkins (et al., 2016) employed a simple, but critical, reflective exercise involving the core implementation and research group. Irrespective of the quality studies, each study contributed a distinct conceptualisation of capacity and/or capacity development.

Though few papers explicitly defined capacity, all papers identified (Table 4) used capacity to convey understanding of a *need* in relation to a phenomenon. For example, Mayhew, Doherty and Pitayarangsatir (2008) utilised the terms *individual capacity, institutional capacity, research capacity* and *national capacity* to convey understanding of *need* as related to individual, institution, national, and research activities or goals. And capacity was generally synonymous with *need*, for example, implicit in the use of the phrase *research capacity,* was the understanding that research capacity encompassed everything *needed* to facilitate research activity. Only one paper identified did not agree with this understanding of capacity as an all-encompassing need; Goodman (1998) defined capacity as a potential and not active state, where a potential state is something that might one day exist, and an active state is what is needed to reach a potential state. Though Goodman's (1998) understanding of capacity was well cited within the literature, this understanding of capacity was not consistent with how capacity was used in the literature and was also not consistent with other definitions of capacity identified. For example, United Nations Development Program (UNDP) (1998, pp. 9) define capacity as "*not a passive state*" implying that it is active "*and part of a continuing process*". In this study, it was useful to define capacity as 'everything that was needed', including capacities that were already present, and capacities that were not, to enable the Service to cope with demand and included current, potential and active capacities. Defining capacity in this way enabled consideration of all capacities needed by the Service, including capacities needed to develop capacity (active state) as well as existing capacity (current state) and desired capacity (potential state).

All papers identified (Table 4) used capacity development to describe the active state or "*a continuing process*" (UNDP, 1998, pp. 9) towards meeting a pre-defined goal. Specifically, capacity development was understood to be the bottom-up empowerment of individuals to develop capacity towards achieving a goal or for a purpose. Capacity development did not refer to a short-term goal or sole activity, but rather was a long-term strategy that was continually adjusted to reflect need and included maintaining capacity as well as obtaining capacity. For example, the development of research capacity is a long-term strategy and the goal or purpose of the strategy may change as research capacities become established, or in response to influence from the wider context. Additionally, within the richer descriptions of capacity or capacity development, such as those provided by United Nations publications (UNDP, 2006; 2008; Green & Bennett, 2007), it was advocated strongly that capacity development could only be considered successful where the capacities developed were *sustainable* or could be maintained, though no criteria for this measuring sustainability was identified.

Studies included conveyed understanding of capacity in different ways. Some studies were placed within the wider context of ongoing capacity development initiatives (for example, Reinsma, Nkuoh & Nshom, 2016), aimed to identify capacities (for example, Jessani et al., 2014), or aimed to build or develop capacities (for example, Chanturidze et al., 2015). This enabled conceptualisation of capacity to be studied from different perspectives. Implicit across all studies was the use of the terms capacity and capacity development within papers to convey understanding that something was lacking. No paper identified sought to identify or understand capacity excess or capacity imbalance, but rather sought only to identify where capacities were lacking and understand how to address lacking capacities, which were termed *capacity needs*. To develop capacity needs, existing capacities or *capacity assets* which could be mobilised to develop capacity towards achieving goals could also be identified. However, except for Mirzoev (et al., 2014) and Chanturidze (et al., 2015), papers identified generally focussed on reporting or discussing capacity needs.

Within this study, capacity was understood to be everything needed to enable the Service to meet demand including capacity assets and capacity needs. And capacity development was understood to be the bottom-up empowerment of healthcare professionals within the Service to develop and maintain capacity to meet and continue meeting demand.

2.6 Understanding the capacities needed to develop healthcare services

In this study, capacity was defined as everything needed to enable the Service to meet demand, including capacities needed to develop capacity (active state) towards meeting demand. As conceptual frameworks aim to identify all capacities needed to direct research and capacity development efforts (Rallis, 2018), conceptual frameworks were used to gain understanding of the capacities needed to develop other healthcare services. This understanding was then used to direct efforts to gain further understanding of Service capacity, including gaps in knowledge of the Service.

As no accepted tool exists to quality appraise conceptual frameworks, and philosophical stances or worldviews were likely to differ across frameworks, the scoping review method was used. Scoping reviews are often used where there are likely to be differences in the way that concepts are defined, or where papers utilise different worldviews that would be irreconcilable using different approaches (Arksey & O’Malley, 2005; Levac et al., 2010). To identify and analyse conceptual frameworks for capacity development, the scoping review method developed by Arksey & O’Malley (2005) and refined by Levac (et al., 2010) was used. This process occurs in five steps: (i) identification of research question, (ii) identification of relevant studies, (iii) selection of studies, (iv) data charting, and (v) collating, summarising and reporting results. This review sought to identify the capacities required to develop healthcare services. To do this, BusinessSource, CINAHL, HealthSource, and SocIndex were searched for “capacit*” AND “framework” in the title of the paper only. This review includes papers published between January 2004 and June 2017. Papers were then excluded if they were not directly related to healthcare service development i.e. they related to electronics, engineering, cognition, physiological, taxation/costing, lot management, vehicular transport, plant, legal, framework directives capacities, or if the paper did not provide a capacity framework. To ensure that frameworks reflected the full scope of capacity development efforts needed to develop healthcare services, frameworks relating to surge and absorptive capacities, and knowledge management capacities only were also excluded. The exclusion criteria were applied to the titles, and then to abstracts. Where papers did not present a conceptual framework for capacity development but identified a framework, this framework was identified from the reference list or by searching of the wider literature. Following the screening process, 9 frameworks were included in this review as summarized in Figure 3.

Unlike the prior review, capacity development frameworks did not focus predominantly on capacity issues in low- to middle- income populations, but addressed issues globally (n=4), in high-income countries (n=2), and in low- to middle- income populations (n=3), as shown in Table 7. This study also did not exclude frameworks focussing on low- to middle- income populations only as conceptualisations of capacity and capacity development are likely to be consistent across populations. Further, during analysis, no clear difference in the types of capacities identified was evident between high-income and low- to middle- income populations, as reflected in Table 8. Rather, the same types of capacities were needed.

Frameworks identified used literature reviews (n=6) or a mixed methods approach (n=3) to understand need. Though no critical appraisal tool exists to assess quality of conceptual frameworks, studies using mixed methods approaches are likely to provide the most complete understanding of need as they combined the existing literature with the expertise of key people and further analysis to establish gaps in need evident within the literature. Consistent with scoping review method, the quality of studies was not instrumental (Arksey & O’Malley, 2005; Levac et al., 2010), so no further consideration was given.

Within frameworks, needs identified were consistently attributed to different organisational or conceptual levels within frameworks, and the levels used differed between papers. Most frameworks recognised the individual and organisational level as the first and second level in some form. But frameworks were divided between recognising the governmental or policy level, inter-organisational networking, cultural, and values-based level as the third level. As this study did not define capacity or capacity development as level specific, all needs were collated, and overall, three types of capacities were identified: finite resources (2.6.1), collaborations (2.6.2) and capabilities (2.6.3), as shown in Table 7. Understanding of these capacities were then used to direct efforts to gain further understanding of Service capacity, including gaps in knowledge of the Service.

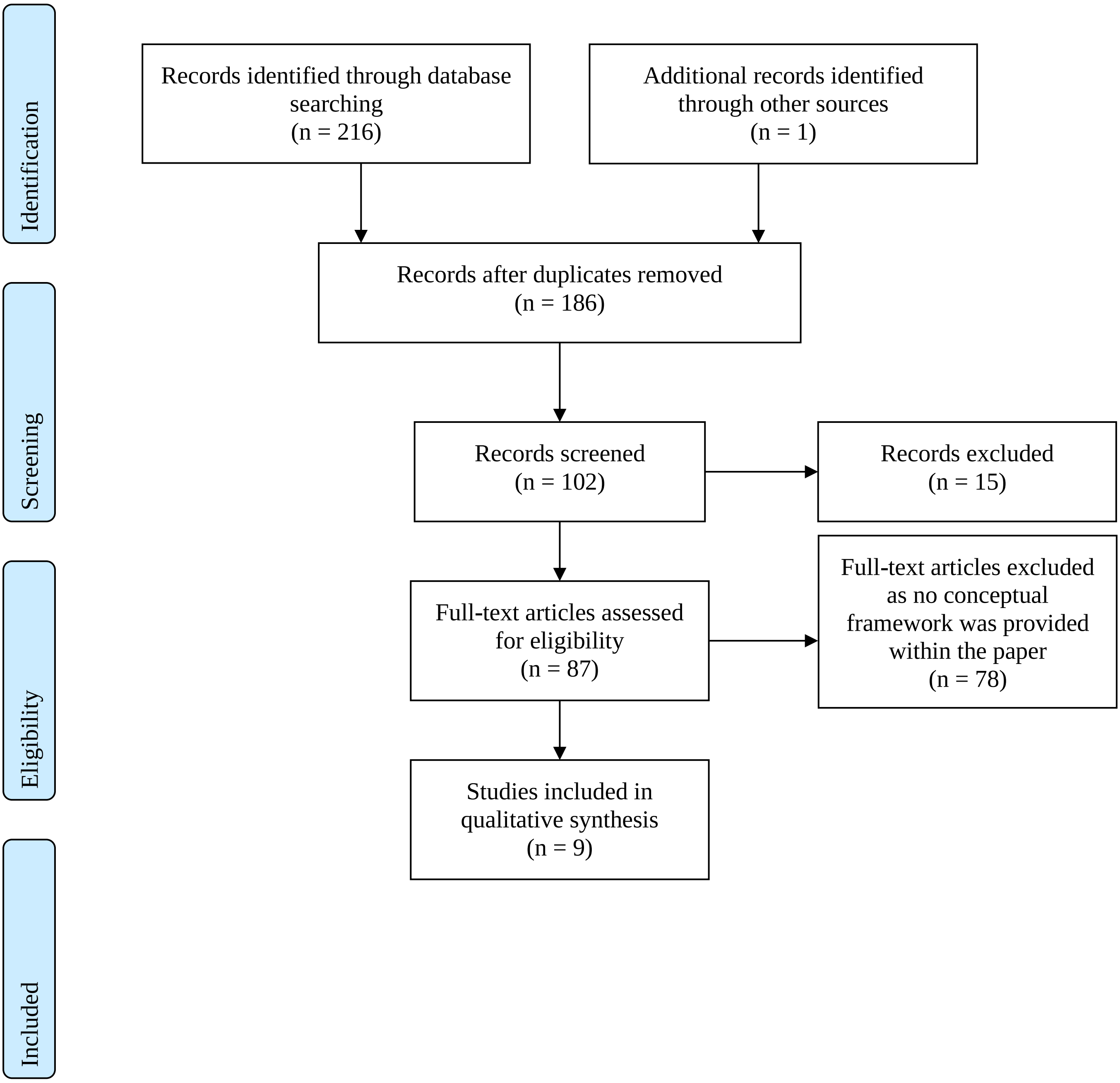


Figure 3: PRISMA diagram (Moher et al., 2009) summarising identification and selection of studies to develop understanding of the capacities needed to develop healthcare services

Table 7: Summary of capacity development frameworks

PAPER	TOPIC	LOCATION	METHOD
BAILLIE ET AL., 2007	Public health nutrition	Global	Literature review
BOBO, 2014	Public health (general)	Africa	Literature review
COHEN ET AL., 2013	Equity of public health services	Canada	Mixed methods • Literature review • Interviews with key people
LAFOND, BROWN & MACINTYRE, 2002	Health system	Low income countries	Literature review
MIRZOEV ET AL., 2014	Health policy processes	Tajikistan	Mixed methods • Interviews • Document reviews • Observations of policy events
PATTERSON, SMITH & BELLAMY, 2013	Environmental management (public health)	Global	Literature review
SCHELL ET AL., 2014	Public health programme	Global	Mixed methods • Literature review • Expert-informed concept-mapping
WALLAR ET AL., 2016	Public health (general)	Canada	Literature review Content analysis
WOLFRAM, 2016	Urban transformation (public health)	Global	Literature review Theoretical coding

Table 8: Needs of a capacity development programme

Collaboration	Within the organisation	Human resources (LaFond, Brown & MacIntyre, 2002; Baillie et al., 2007; Cohen et al., 2013; Patterson, Smith & Bellamy, 2013; Mirzoev et al., 2014; Wallar et al., 2016; Wolfram, 2016)
	With other organisations	Access to resources (Bobo, 2014; Mirzoev et al., 2014; Wolfram, 2016)
		Support (Schell et al., 2014; Wolfram, 2016)
		Contribution and responsibility (Baillie et al., 2007; Cohen et al., 2013; Patterson, Smith & Bellamy, 2013; Bobo, 2014)
		Empowerment and power (Cohen et al., 2013; Wolfram, 2016)
		Identity (Cohen et al., 2013; Bobo, 2014)
		Engagement (LaFond, Brown & MacIntyre, 2002; Baillie et al., 2007; Cohen et al., 2013; Patterson, Smith & Bellamy, 2013)
		Vision (Baillie et al., 2007; Wolfram, 2016)
		Diversity (LaFond, Brown & MacIntyre, 2002; Baillie et al., 2007; Cohen et al., 2013; Mirzoev et al., 2014; Wolfram, 2016)
Capability	Hard skills	Knowledge (LaFond, Brown & MacIntyre, 2002; Baillie et al., 2007; Patterson, Smith & Bellamy, 2013; Bobo, 2014; Mirzoev et al., 2014; Wallar et al., 2016; Wolfram, 2016)
		Project management and planning (LaFond, Brown & MacIntyre, 2002; Baillie et al., 2007; Patterson, Smith & Bellamy, 2013; Schell et al., 2014; Wallar et al., 2016)
		Learning, training and development (LaFond, Brown & MacIntyre, 2002; Baillie et al., 2007)
	Soft skills	People management (LaFond, Brown & MacIntyre, 2002; Baillie et al., 2007; Patterson, Smith & Bellamy, 2013)
		Transparency and clarity (LaFond, Brown & MacIntyre, 2002; Mirzoev et al., 2014)
		Communication and networking (Baillie et al., 2007; Cohen et al., 2013; Patterson, Smith & Bellamy, 2013; Bobo, 2014; Mirzoev et al., 2014; Wallar et al., 2016; Wolfram, 2016)

		Innovation and entrepreneurship (Baillie et al., 2007; Patterson, Smith & Bellamy, 2013; Wolfram, 2016)
		Transformation and reflexivity (Patterson, Smith & Bellamy, 2013; Wolfram, 2016)
		Motivation and purpose (LaFond, Brown & MacIntyre, 2002; Cohen et al., 2013; Wolfram, 2016)
		Leadership (LaFond, Brown & MacIntyre, 2002; Baillie et al., 2007; Cohen et al., 2013; Patterson, Smith & Bellamy, 2013; Mirzoev et al., 2014; Wallar et al., 2016; Wolfram, 2016)
		Ownership (Baillie et al., 2007)
		Autonomy and empowerment (LaFond, Brown & MacIntyre, 2002; Bobo, 2014; Wolfram, 2016)
		Identity (LaFond, Brown & MacIntyre, 2002; Cohen et al., 2013; Patterson, Smith & Bellamy, 2013)
Finite resources	Finances (LaFond, Brown & MacIntyre, 2002; Baillie et al., 2007; Bobo, 2014)	
	Stability (LaFond, Brown & MacIntyre, 2002; Cohen et al., 2013; Mirzoev et al., 2014)	
	Equipment and environment (LaFond, Brown & MacIntyre, 2002; Patterson, Smith & Bellamy, 2013; Bobo, 2014; Wallar et al., 2016)	

2.6.1 Finite resources

To enable services to function as intended, access is required to specific quantities of finite resources such as finances, equipment, workspaces, and staffing (LaFond, Brown & MacIntyre, 2002; Baillie et al., 2007; Cohen et al., 2013; Patterson, Smith & Bellamy, 2013; Bobo, 2014; Mirzoev et al., 2014; Wallar et al., 2016). And though financial requirements were not discussed in depth in any of the frameworks, it was acknowledged that finances were core to a successful capacity development programme. In Scotland, the Christie commission (2011) warned of the impact of an expected drop in funding in healthcare over an indefinite number of years, despite increasing expectations on services, though cancer services in Scotland are generally protected against budgetary constraints (Scottish government, 2008a; 2016a). To accommodate growing demand on healthcare services considering budgetary constraints, in response to the Christie commission, the Scottish government promised improved efficiency in the healthcare workforce (Scottish government, 2012a) and other finite resources such as equipment and workspaces (Scottish government, 2018a), to ensure saturation of resource usage across services. However, the clinical workforce has grown consecutively since 2012, though staffing in Urology services is a concern (Scottish government, 2018a).

2.6.2 Collaborations

Within organisation and between organisation collaborations were also required to enable capacity development. Within the Service, there were two main organisational structures that facilitated the delivery of care; Health Boards and Managed Cancer Networks (MCNs). 14 regional Health Boards managed patient care, which provided healthcare professionals with the ability to lead patient care to a greater extent than other UK regions (Greer, 2004), enabling bottom-up change to occur like the development of thee MCN regions; the North of Scotland MCN (NoSCAN), the East of Scotland MCN (SCAN), and the West of Scotland MCN (WoSCAN). MCNs were developed by healthcare professionals to enable the delivery of disease-specific, specialised care across multiple Health Boards, whilst being directly answerable to those Health Boards (Guthrie, et al., 2010). MCNs were considered vehicles for healthcare reform (Scottish Office, 1998; Scottish Executive Health Development Letter, 2001; 2007; Scottish government, 2008a) and were more recently used to audit care in the Service (Scottish government, 2016a). To enable capacity development, reliable support staff (LaFond, Brown & MacIntyre, 2002; Wallar et al., 2016), and a supportive infrastructure (LaFond, Brown & MacIntyre, 2002; Baillie et al., 2007; Cohen et al., 2013), concrete work plans (Wolfram, 2016), and policy, legislation, and regulations that reflected the needs of the capacity development programme (Cohen et al., 2013; Wolfram, 2016) were required. From the evidence available, it was unclear to what extent these capacities existed within the Service to enable capacity development.

In addition to capacities needed within the Service, frameworks also described networks, collaborations, partnerships, and coalitions between organisations. These collaborations were informal and formal (LaFond, Brown & MacIntyre, 2002), multi-sectoral (LaFond, Brown & MacIntyre, 2002; Baillie et al., 2007; Cohen et al., 2013), included media and lobbyists (LaFond, Brown & MacIntyre, 2002), and were centralized or decentralized (Wolfram, 2016) as required. Tying collaborations together was a shared vision (Baillie et al., 2007; Wolfram, 2016), power (Cohen et al., 2013), and responsibility (Cohen et al., 2013). Rather than one organisation providing capacity to meet demand, multiple organisations provided support (Schell et al., 2014; Wolfram, 2016), access to resources (Bobo, 2014; Mirzoev et al., 2014; Wolfram, 2016) and/or other contributions (Baillie et al., 2007; Patterson, Smith & Bellamy, 2013; Bobo, 2014) to facilitate capacity development. In Scotland, the delivery of healthcare services is closely entwined with Scottish Government. Specifically, the Scottish Government Directorate for Health and Social Care implement healthcare policy to direct healthcare development and are responsible for the administration of the NHS (Scottish Executive Health Development Letter, 2019). Regional responsibility of healthcare is devolved to Health Boards who deliver care in collaboration with 32 local authority areas across Scotland (Public Bodies (Joint Working) Act, 2014). And though Scottish government acknowledge the need for capacity development in Scottish healthcare services (Scottish government, 2008a; 2016a; 2018a) tensions generally exist between policy makers and healthcare professionals as a result of the top-down approach used by UK Governments to enact change in healthcare (Snell et al., 2011; Storey & Holti, 2012; Zachariadis et al., 2013; Braithwaite, 2018) and a lack of understanding of the respective roles (Braithwaite, 2018). In the last 15 years, Scottish Government have enacted two key policy changes to meet changing public need, most pertinently the decline of acute health events and the increase in chronic conditions. Firstly, Scottish Government are directing healthcare services to 'shift' care from secondary and tertiary care to community and primary care (National Planning Team, 2005) with the support of the third sector (Christie commission, 2011; Scottish Council for Voluntary Organisations, 2014). Secondly, Scottish Government have integrated health and social care services (Public Bodies (Joint Working) Act, 2014). And these policy changes have directed cancer care and related policy (Scottish government, 2008a; 2010a; 2012a; 2016a; 2018a). In addition to these collaborations, patients are also important in shaping healthcare development (National Planning Team, 2005; Scottish government, 2008a; 2010a; Christie commission, 2011; Scottish government, 2012a; 2016a; 2018a). Specifically, the Christie commission report (2011) advocated the development of services around "*the needs of people and communities, their needs, aspirations, capacities and skills, and work to build up their autonomy and resilience*" (pp. 26). Ideally, healthcare service developments should be co-produced with patients and members of the public (Loeffler & Hine-Hughes, 2013). However, it is unclear to what extent the Service is utilising capacities that may be available from other organisations or entities.

2.6.3 Capabilities

Capabilities are the skills required to complete a task, and capabilities can be considered hard or soft (Helfat & Peteraf, 2007; Lichtenthaler & Lichtenthaler, 2009). Within this study, hard skills included professional or academic training and knowledge, and soft skills included personal attributes. Though many capabilities were identified, two capabilities dominated frameworks; knowledge, and leadership. Firstly, though capacity development is a collaborative effort, and many skills were identified to nurture collaborations, the importance of leadership was emphasized over other skillsets, largely to ensure oversight and guidance of the capacity development programme. Secondly, knowledge was needed in three ways: different types of knowledge were needed including experiential (LaFond, Brown & MacIntyre, 2002; Baillie et al., 2007; Wolfram, 2016) and academic (Baillie et al., 2007) knowledge; secondly, as capacity development is usually a collaborative endeavour, knowledge is also required of all collaborators or partners (LaFond, Brown & MacIntyre, 2002; Baillie et al., 2007; Wolfram, 2016) and the wider context in which capacity is being developed (Mirzoev et al., 2014); finally, for the programme to be successful, organisations must know the resource requirements for the project (Baillie et al., 2007), deficits in need (Wolfram, 2016), and barriers to capacity development (Bobo, 2004). And it is unclear to what extent these capacities exist to support development of the Service. Development of the healthcare workforce is a primary focus for quality improvement in Scottish healthcare services (Scottish government, 2010a), and to reflect this, the Scottish government released the 2020 workforce vision for quality healthcare delivery in Scotland to focus explicitly on the development of the healthcare workforce to facilitate the delivery of quality healthcare (Scottish government, 2013a). However, limited information was provided on how capabilities would be developed within the workforce to facilitate service development. And interim learning from the Transforming Care After Treatment initiative suggests that capacity is lacking within cancer services to enable healthcare development (Edinburgh Napier University, 2016).

2.7 Aim and research questions

When searching the literature, no previous study addressing the capacity needs of the Service was identified. However, given that waiting time targets were missed to a greater extent than other services (NHS National Services Scotland, 2019), it was pertinent to gain understanding of how the Service can be supported to better meet demand. Therefore, this study aimed to gain understanding of the capacity needs of the NHS Scotland prostate cancer service. To gain this understanding, the following research questions were asked:

1. How has usage of the NHS Scotland prostate cancer service changed and how is it predicted to change?
2. Why has the NHS Scotland prostate cancer service been unable to meet demand?
3. How should capacity be developed within the NHS Scotland prostate cancer service to meet demand?

2.8 Summary

The capacity needs of the Service had changed due to increased incidence (2.2.1) resulting from increased screening uptake (2.2.2), a complex, multistep diagnostic protocol (2.2.3), the development of active surveillance leading to some men not being discharged from the Service (2.2.5), the development of radiotherapy as a treatment leading to the reconfiguration and increased complexity of the radical treatment pathway (2.2.6) and the development of a rapidly developing palliative pathway that now included multiple lines of treatment (2.2.7). And the Service had been unable to adapt to changed need as indicated in missed waiting time targets (NHS National Services Scotland, 2019).

Within this study, capacity was understood to be everything needed to enable the Service to meet demand including capacity assets and capacity needs. And capacity development was understood to be the bottom-up empowerment of healthcare professionals within the Service to obtain and maintain capacity to meet and continue meeting demand. To develop the Service to meet demand, finite resources, collaborations, and capabilities were likely to be needed, though it was unclear whether the Service was currently drawing on these capacities.

Considering capacity shortage, this study aimed to gain understanding of the capacity needs of the NHS Scotland prostate cancer service. To gain this understanding, the following research questions were asked:

1. How has usage of the NHS Scotland prostate cancer service changed and predicted to change?
2. Why has the NHS Scotland prostate cancer service been unable to meet demand?
3. How should capacity be developed within the NHS Scotland prostate cancer service to meet demand?

Methodology and methods

3.1 Introduction

Robust research requires considerable self-conscious, well-considered and reflective effort that guides the research in one direction rather than another (Morgan, 2007; 2014). Ultimately, there is no correct way to do research, and research may be guided by a range of beliefs, viewpoints, approaches and methods, some of which will fit the researcher or research better than others. There are a range of methodologies and methods that have been used to understand the needs of complex services such as grounded theory (for example, Schwarz & Nandhakmar, 2002; DuPraw, 2014; Rashid et al., 2017), realist evaluation (for example, Greenhalgh et al., 2009; Kwamie et al., 2014; Rycroft-Malone et al., 2015), co-production (for example, Dunston et al., 2009; Verma et al., 2012; Osborne, 2018) and service evaluation (for example, Hoefer, 2000; Eldbridge, Dawer & Gray, 2011; Parke et al., 2020). Four considerations contributed to the decision to choose the Delphi technique over other methodologies and methods.

1. At the beginning of this study there was very limited knowledge of the Service as outlined in Section 1.3 and Section 2.2; beyond increased incidence and the development of new treatment modalities, which had been adopted sporadically across Scotland, there was little systematically generated knowledge of how the NHS Scotland prostate cancer service operated. This included how the Service was composed regionally, why it was not meeting current demand, and how demand had changed with time. This meant that methodologies that relied on some level of prior understanding of the Service or the problem such as realist evaluation or service evaluation would be problematic. However, methodologies such as grounded theory and consensus techniques, like the Delphi technique, help to develop understanding where knowledge of phenomena is limited (Humphrey-Murto et al., 2017; Tie, Birks & Francis, 2019).
2. As stated in Section 1.8, this research was informed by my want to do impactful research that would inform service development. To be most useful in practice, the chosen method had to enable anticipation of future need as well as current need; it was clear from the literature and networking with healthcare professionals working within the Service that public need, prostate cancer care, and the Service itself were simultaneously developing rapidly. Therefore, it could not be assumed that if need in part of the Service had increased that it would continue to increase; there was a need to anticipate future developments and more importantly, the impact of the anticipated developments on the Service. Essentially, for this study to enable useful change in practice, the methods had to facilitate forecasting of future need.

Specifically, grounded theory generally seeks to develop a theory (Tie, Birks & Francis, 2019), whereas the Delphi technique generally seeks to determine consensus on a given topic (Humphrey-Murto et al., 2017). Though there were clear benefits to using grounded theory such as gaining a thorough understanding of the capacity problem, grounded theory was less likely to enable forecasting of future need in a way that would be useful; grounded theory is generally used to understand *what is*, not *what needs to be* (Timmonen, Foley & Conlon, 2019). Alternatively, consensus techniques, particularly the Delphi technique, are often used to forecast.

3. This research was also informed Prostate Scotland's motivations for funding this study, which was to support the development of a piece of research that would inform government. Government decision-making is generally guided by value judgements, where a value judgement is the judgement made when what is deemed to be in the best interest of society is integrated with the available evidence (Majone, 1989; Torjman, 2005). As such, public policy is not informed by evidence alone, and we have seen examples of this in today's healthcare crisis; each government has a unique method of integrating their values with the available evidence.

   As a result, evidence is best able to inform policy through the development of a persuasive interchange or rhetoric (Majone, 1989; Stone, 1997; Greenhalgh & Russell, 2006). Essentially, to inform public policy, it is not enough to do high quality research; research must also be persuasive to a person not trained in research methods (Greenhalgh & Russell, 2006). An inherent problem with this is that to be impactful, research findings must then also be palatable, i.e. findings must be deemed appropriate and desirable within the current socio-political climate (Greenhalgh & Russell, 2006). This is particularly problematic as it is not always possible to anticipate research findings, or how palatability will change over the course of a study. Therefore, armed with the understanding that the findings of this study may not be palatable at time of publication, the methods chosen must partly enable a persuasive interchange.

   As the Delphi technique utilises the expertise of carefully selected participants to reach consensus on a topic, usually through the iterative distribution, analysis and development of a questionnaire (James & Warren-Forward, 2015; Foth et al., 2016; McMillan, King & Tully, 2016; Waggoner, Carline & Dunning, 2016; Humphrey-Murto et al., 2017), the Delphi technique contributes to the development of a persuasive interchange. By drawing on existing experience of the Service, consensus techniques such as the Delphi technique, help to create a common sense narrative that a person not trained in research can be convinced by (Green & Timothy, 2000; Greenhalgh & Russell, 2006).

4. The research had to be feasible with the resources available. This study aimed to understand the capacity needs of the NHS Scotland prostate cancer service (the Service) to meet demand. And though many approaches exist to understand the capacity needs of healthcare services, the resources required to study all aspects of a national service would have been substantial using many of these. Therefore, many approaches would not have suited this study due to the limitations of the budget, available time and my own expertise as a novice researcher. As such, the Delphi technique was chosen over similar techniques for its ability to facilitate consensus remotely (James & Warren-Forward, 2015; Foth et al., 2016; McMillan, King & Tully, 2016; Waggoner, Carline & Dunning, 2016; Humphrey-Murto et al., 2017); facilitating a national consensus was unlikely to be feasible using face-to-face methods such as the nominal group technique.

In this Chapter, I first describe the underpinning philosophy that I used to understand the world during investigation, and then I describe the study design used detailing the procedures that were chosen a priori to investigation of the phenomenon. After this introduction (3.1), I describe how I used ontological holism to understand the existence of the Service and provide a rationale for not defining the nature of reality itself (3.2), I then describe how I used classical pragmatism and pluralism to understand what could be known of the Service (3.3). Building on understand of what could be known, I describe how this could be known and how I could utilise this knowledge through use of the Delphi technique (3.4). I then describe considerations made that latterly guided participant sampling to ensure a robust consensus, specifically, what I understood to be the robust individual inquiry (3.4.1), what I understood an expert to be within the context of this study (3.4.2), and the need to avoid coercion (3.4.3). Finally, I describe the approach to inquiry used in this study (3.5) and define the Delphi technique as a methodology (3.6).

Following this, I describe the study design used (3.7) and an account of how the steering group guided this study (3.8). Then I describe each of the three phases of research that I used: in Phase 1 I used descriptive statistics to analyse national datasets thereby identify changes in incidence and treatment usage (3.9); in Phase 2 I used interviews with healthcare professionals to contextualise these changes and understand how these changes might impact on the Service (3.10); and in Phase 3 I used online questionnaires to facilitate consensus (3.11). Finally, I give an account of ethical permissions gained for this study (3.12) and a brief summary of the Chapter (3.13) are also provided.

3.2 What is the NHS Scotland prostate cancer service?

Ontological holism was drawn on in this study to understand the Service. Though the phrase ‘holism’ was credited to Smuts in 1926, a holistic ontology is evident in the works of Aristotle and Plato, Chinese culture, Daoism and Buddhism, and more recently has been used to inform both realist and interpretivist philosophies. Holism is the belief in the existence of a whole and everything that exists is a part of the whole (Weber & Esfeld, 2004). Essentially, all that exists is related. The holist understanding of the world is particularly pertinent in healthcare service research as the unique context in which a healthcare service delivers care is fundamental to understanding and developing healthcare services (Tomoaia-Cotisel et al., 2013; Dobrow et al., 2017; Monat & Gannon, 2018). In this study, the Service was not considered to exist independently of wider healthcare services or public need, and the parts of the Service for example the robotic prostatectomy service, were not considered to exist independently of the Service.

In most applied research, the ontological stance taken also provides an understanding of the nature of reality, for example, that reality can be a construction, or something that 'just exists'. However, using understanding of the nature of reality to inform applied research is controversial. When developing understanding of ontology, philosophers often disregard the importance of the application of a stance in practice (for example, Searle, 2010), and social scientists often expect that ontologies will have a practical application (for example, Latsis, Lawson & Martins, 2007). As a result, researchers often choose one of two camps: ontological foundationalism or anti-ontological pragmatism (Lohse, 2016). Ontological foundationalism advocates for the importance of ontology as laying the foundation for applied research, and anti-ontological pragmatism largely disregards ontology. Though I do believe that ontological considerations are important in applied research, as a result of the unresolved debates within this field, this study was not informed by an understanding of the nature of reality. Rather I aligned with Tsilipakos (2015) in highlighting the confusion currently present within the study of ontology and Van Bouwel (2004) who advocated caution when using ontology to inform applied research.

Holism was used to guide understanding of relationships and interdependency of what existed, but the nature of reality itself was undefined. Rather, pragmatic epistemology was used to understand what could be known of the Service and the context that the Service existed in.

3.3 What could be known of the NHS Scotland prostate cancer service?

Classical pragmatism and pluralism were drawn on to understand what can be known of the NHS Scotland prostate cancer service. This understanding was used to guide participant sampling, arguably the most important part of a Delphi methodology. In this study, what could be known of reality was understood to be shaped by an individual's experience of this reality (Dewey, 1920; 1925; Johnson & Onwuegbuzie, 2004; Misak, 2004; Onwuegbuzie, Johnson & Collins, 2009; Levi, 2012). Essentially, what could be known of the Service was shaped by individual's experiences of the Service. Specifically, this study was informed by Dewey's (1920; 1925) understanding of human experience, where human experience is understood to be the consequences or interpretations of action, which lead to beliefs, and the interpretation of these beliefs then lead to other action, and so on (action-belief cycle). According to Dewey, knowledge is developed or created through continual interpretation of actions and beliefs, where both actions and beliefs are shaped by a cumulation of all prior experiences of reality. Therefore, knowledge was also considered pluralist; pragmatism does not advocate for one dominant knowledge (monism) but accepts that knowledge differs between individuals (pluralism). As such, a single (monist) knowledge of the Service did not exist; all individuals knew the Service through their individual experience of it (pluralist). Therefore, when developing a sampling strategy, it was important to ensure that a range of experiences could be accounted for. What an individual knew of the Service had been interpreted through their own personal and professional interpretation or knowledge system.

3.4 How can different knowledge of the NHS Scotland prostate cancer service be used to understand capacity needs?

As participants knew the Service through their own experiences of it, they had their own views on how capacity should be developed within the Service, and a single (monist) view of what was needed did not exist. Each person had their own individual knowledge system that was developed through their own experiences of reality (action-belief cycles). These knowledge systems provided each person with a framework for inquiry. These inquiry frameworks enabled individuals to determine whether they could accept something or not based on their prior experiences (Dewey, 1920; 1925). As such, the nature of inquiry is also pluralist; there is no one inquiry system or one way of knowing something. Essentially, Dewey argued that an individual uses their inquiry system to determine whether to them, something can be considered true. Pierce (1885) argues that where multiple inquiry systems or people, generally agree that a phenomenon is true, then it is reasonable to consider that it is true. Pragmatic philosophy does not seek to find a universal truth, but rather something that could be considered practically true and therefore, useful. Therefore, where individuals with different experiences of the Service generally agreed, this agreement was practically true.

This understanding of truth has been critiqued in two ways. Firstly, it has been criticised for its fallibility; fallibilism is the argument that beliefs can be accepted even if not proven. However, as Levi (2012) identified, pragmatism is corrigibilist, not fallibilist; in Pierce's theory of truth, it is emphasised that truth can only be accepted as the product of robust inquiry. Secondly, solidarity i.e. the quest for consensus, is fundamental to the pragmatic understanding of truth. Though Rorty (1991) argued for intersubjectivity as far as possible, i.e. the pursuit of a unanimous consensus, Levi (2012) argued that "*it is not always obvious when one should open up one's mind any more than it is when one should close it*" (Levi, 2012, pp. 5) suggesting that there can be good reason for disagreement, or different truths.

3.4.1 What is robust individual inquiry?

As stated, for a general consensus to be practically true, participants' judgements within the study must be the product of robust enquiry. Pierce, James and Dewey drew no distinction between practical thinking and scientific inquiry but drew a distinction between effortless and effortful decision-making, and this is most evident in Dewey's philosophy. Dewey understood everyday decision-making to be habit; past experiences are drawn on to make decisions with little conscious effort (1922). Whereas active or purposeful inquiry, whether for scientific research or to make a significant life decision, requires considerable self-conscious, well-considered and reflective effort (1910), i.e. robust inquiry is effortful decision-making. Though likening the effortful decision making of an experienced person to robust inquiry has been criticised (Sackman, 1974; Goodman, 1987; Reid, 1988; McKenna, 1994; Beech, 2001; Powell, 2003; Hardy et al., 2004), it's value has more recently been recognised (Goodman, 1987; Sackett et al., 1996; Greenhalgh, 2002; Keeney, Hasson & McKenna, 2010; Bae, 2015; Wieringa et al., 2018). The criticism of using effortful decision-making as evidence stems from the understanding that an individual's mechanism of inquiry (knowledge system) may consider something to be true that does not then stand up to more rigorous inquiry. In resolution, Fischer (1978) theorised that the effortful decision-making of an experienced person formed a middle ground between the product of robust, scientific inquiry, and what Dewey (1911; 1939; 1941) termed proposition. And, ultimately, the product of effortful decision-making of an experienced person alone could not be accepted as truth in scientific inquiry (Fischer, 1978; Tucker, 2003; Pendersen & Wright, 2013), but rather a way of informing a problem where a more robust approach was not possible (Lindeman, 1975; Goodman, 1987; Reid, 1988; McKenna, 1994; Beech, 2001; Powell, 2003; Hardy et al., 2004). However, the product of effortful decision-making can be considered true when a general consensus of experienced people generally agree that it is true (Pierce, 1885; 1908; Dewey, 1910; 1922).

3.4.2 Experts, habit and willingness to make decisions effortfully

The validity of this study rested with the experiences or *expertise* drawn on. Therefore, it is important to understand how experience can be used to inform a robust consensus. When seeking to identify people with appropriate experience, using quantity of experience, for example, the number of years within a role, is controversial as it does not relate to knowledge of a topic or quality of decision-making (Crisp et al., 1999; Keeney, Hasson & McKenna, 2001; Hardy et al., 2004 Baker, Lovell and Harris, 2006; Beament & Mercer, 2016). Rather, quality of decision-making should be sought (Fink et al., 1991; Jones & Hunter, 1995; Kenney, Hasson & McKenna, 2001). Quality decision-making is defined as requiring effortful decision-making and active or purposeful inquiry (Dewey, 1910; 1922).

However, the expertise of a healthcare professional is rarely defined in terms of quality decision-making. Rather expertise is defined as being opposite to a novice, where a novice requires effortful decision-making to complete a task relevant to their role, and an expert does not. For example, Benner's (1984) seminal work on intuition to inform clinical judgements posits that a novice requires considerable critical and analytical thinking, i.e. effortful decision-making, to complete a clinical task, whereas the expert makes clinical decisions based on intuition, i.e. habit (Dewey, 1922). And this is largely where arguments for intuition-led or intuition-informed decision-making, like that proposed by Greenhalgh (2002), are most vulnerable to critique; ultimately, the formation of habit or non-analytic and non-critical decision-making is not synonymous with good practice (for example, Beament & Mercer, 2016). Rather, good practice requires an individual to continue making effortful decisions, critique their actions and beliefs, and ultimately continue developing their knowledge system, for example, through critical reflection. Therefore, in this study, an experienced person or expert is defined as an individual who can discuss the capacity development needs of the Service with little effort (habit), but who is able and willing to engage in effortful decision-making. Though it is not easily known which people would be willing to engage in effortful decision-making, the literature agrees that effortful decision-making will occur where participants are likely to be directly affected by decisions made as a result of this study (Fink et al., 1991; Jones & Hunter, 1995; Keeney, Hasson & McKenna, 2010).

3.4.3 Avoiding coercion

To ensure that judgements given reflect participants' own decision-making, participants' contributions should be uncoerced (Tucker, 2003). To inform an uncoerced consensus, this study drew on pluralism, specifically Rescher's (1995) essays on consensus. Fundamentally, pluralism advocates for embracing difference and seeking to understand the cause of difference (Marks & Miller, 1985; Rescher, 1995; Healey, 2003; Philstrom, 2017). However, in healthcare agreement and dominant beliefs (monism) are often needed and pluralism can be difficult to identify with (Ellis, 1980; Self, 1985). However, Rescher's pragmatic approach to pluralism has been described as "*hold[ing] the flame to cognitive, evaluative and practical dimensions of human rationality*" (Murray, 2004, pp. 18) i.e. Rescher is known for translating pluralist epistemology for use in understanding and resolving problems in a practical or useful way. To do this, this study is informed by three arguments made by Rescher in his essays on consensus (Rescher, 1995):

1. As individual judgements are based on an individual's knowledge system, consensus reduces error in judgement;
2. Disagreement should be expected due to diversity in individual knowledge systems, and therefore, consensus should be general, not unanimous (Pierce, 1885; 1908; Levi, 2012), and

dissensus was valuable (Pierce, 1885; 1908; Rescher, 1995; Levi, 2012) as it provided understanding of good reason for disagreement or different truths (Levi, 2012);

3. Instead of seeking a perfect consensus we should look for "*incremental improvements within the framework of arrangements that none of us will deem perfect, but that all of us 'can live with'*" (Rescher, 1995, pp. 4) i.e. where agreement or a dominant belief is needed, such as within healthcare, it is reasonable that participants may move towards a consensus for the greater good if they believe that this consensus will lead to an improvement in the status quo.

Essentially, to understand the capacity development needs of the Service, this study sought to identify topics of consensus and dissensus, i.e. topics that did not reach consensus, on the capacity development needs of the Service and identify good reason for dissensus.

3.5 Approach to inquiry taken in this study

As stated, Pierce, James and Dewey drew no distinction between practical thinking and scientific inquiry but drew a distinction between effortless and effortful decision-making. And this has led to misinterpretations of pragmatic philosophy such as Howe's (1988) methodological 'what works' interpretation that enables inquiry to disregard metaphysical incompatibility between approaches (Misak, 2004; Denzin, 2012). However, pragmatism has a distinct philosophy that Howe's (1988) compatibility thesis overlooks. Pragmatism does not disregard metaphysics but provides an alternative paradigm to understand the world. Rather than beginning with an understanding of reality, pragmatists start with an understanding of life. Essentially, pragmatism argues that scientific research is a series of effortful decisions where the researcher continually draws on their own experiences to guide research in one direction rather than another. According to Morgan (2007; 2014) pragmatism therefore neither transcends metaphysical perspectives, nor relies on these to guide inquiry. Rather, research paradigms are viewed as a set of shared beliefs held by research communities and acknowledges the value that each set of shared beliefs can contribute to understanding of phenomena (Morgan, 2007; 2014). Therefore, researchers can utilize metaphysical perspectives, approaches and methods as required providing they are chosen as the result of effortful decision-making and not habit. To facilitate a consensus (and dissensus) of experts within this study, a consensus methodology was used.

3.6 Delphi technique as a methodology

Though the Delphi technique is now generally accepted as a methodology it is often still referred to as a method (for example, McPherson, Reese & Wendler, 2018) irrespective of how it has been used leading to a lack of transparency. Where methodology is concerned with the strategies used to study phenomena including underlying assumptions, interests and purpose and so inform the way that methods are employed (McGregor & Murnane, 2010; Bryman, 2012; Taylor, Bogdan & DeVault, 2015), methods are the set of procedures used for collecting and analysing data (Strauss and Corbin, 1998) and are informed by the chosen methodology (McGregor & Murnane, 2010). Though the Delphi technique is associated with a procedure, the Delphi technique can utilise a combination of methods to carry out this procedure, such as interviews, systematic or scoping reviews, and a variety of questionnaire styles. In doing so, the Delphi technique informs the strategy used to guide the design and implementation of these methods. As such, within this study, the Delphi technique was considered a methodology used to guide selection and use of methods.

3.7 Study design

The Delphi technique utilises the expertise of carefully selected participants to reach consensus on a topic. Consensus is facilitated in two steps; firstly, an idea generating or issue determining step and secondly, a consensus-facilitating step.

The idea generating or issue determining component of the Delphi is commended in the literature for providing participants with the freedom and opportunity to share their views as well as limiting bias from other sources (Keeney, Hasson & McKenna, 2010). In the idea generating/issue determining step methods are selected to gather data to inform the consensus process. For example, the traditional Delphi utilises a literature review (Linstone, 1978), and the classical Delphi utilises an open-ended questionnaire (Hasson, Keeney & McKenna, 2008). However, a range of different methods have been used including interviews, literature reviews and use of patient case files (Proctor & Hunt, 1994). In this study, to gain understanding of the capacity needs of the Service to meet demand, national datasets were analysed to identify changes in incidence and treatment usage and thereby further understanding of capacity shortage within the Service (Phase 1). Then, interviews with healthcare professionals provided context for these changes, specifically to explain changes in treatment usage and predict how they would change, what impact this change would have on service delivery and organisation, and how this could be better planned for (Phase 2).

Unlike the idea generating/issue determining component, agreement exists on the consensus facilitating component (James & Warren-Forward, 2015; Foth et al., 2016; McMillan, King & Tully, 2016; Waggoner, Carline & Dunning, 2016; Humphrey-Murto et al., 2017); a closed-question questionnaire is developed using data from the first component and is distributed, analysed, revised and re-distributed iteratively until consensus is reached, attrition occurs, or over a pre-determined number of Rounds. In this study, informed by understanding of how treatment usage is predicted to change and the predicted impact that this change will have on the Service, consensus was facilitated on the development needs of the Service (Phase 3). Figure 4 provides an overview of the study design for this study.

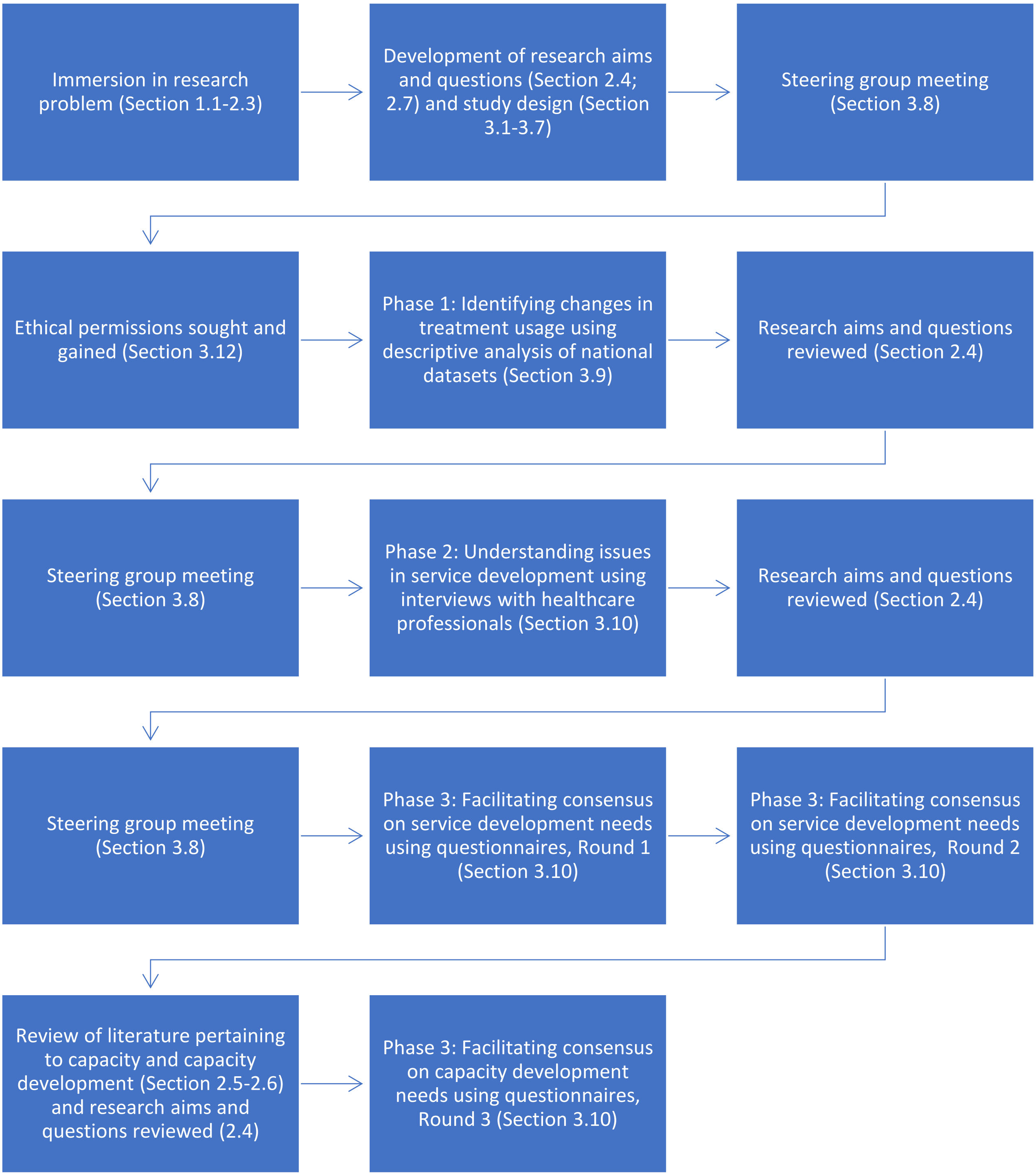


Figure 4: Study design

3.8 Steering Group

This steering group was developed by Prostate Scotland when seeking funding for this study and so was already in place when I was appointed to the project. The steering group consisted of healthcare professionals, patients and representation from the co-funder, Prostate Scotland (Appendix 1) who acted in an advisory capacity throughout the length of this project, with each member appointed to provide their viewpoint in relation to their related expertise. Meetings were chaired either by myself or by my supervisors, which enabled me to focus on presenting information and being involved and immersed in the discussion. Within the Steering Group, as the researcher, I set the agenda and guided discussions towards the information that I needed from the Group to progress with the study. I viewed the Steering Group meetings as an opportunity to view prostate cancer care through the patients, clinicians and third sectors experiences of it. Particularly, the Steering Group provided an opportunity to ensure that I hadn't missed or misunderstood an important perspective and ensured that I had the necessary expertise to guide the research in the direction of the most practically useful findings.

Though this study was fixed in what should be achieved by the project due to the funding agreement, there was some flexibility in the interpretation of the aim and research questions, and some understanding that the project might develop as it progressed. Therefore, the steering group met face-to-face on three occasions: prior to the study commencing, and between Phases of study. In these meetings, the Steering Group advised on: the study design and methods used (Steering Group meeting 1, 2 and 3); the relevance of findings to service development (Steering Group meeting 2 and 3); and the objectives of the subsequent phase of study considering findings (Steering Group meeting 2 and 3). Specifically, decisions were made first by me considering findings and reflection on the research aim and questions, and were then presented to the Steering Group for critical feedback and advice, and to understand their perspectives in relation to this.

Throughout these meetings, the Steering Group advised on two key decisions within the study. I presented these decisions to the Steering Group to understand better the impact of the decision on the outcome of the study from the patient and healthcare professional perspective. The decisions that I presented related to (i) the identification of the most pertinent topics of inquiry, and (ii) the decision not to include patients. Ultimately, I sought to understand the capacity needs of the Service to meet demand, but there were many ways of doing this, and findings from each phase identified different topics for inquiry. Between phases, the Steering Group advised on the most pertinent routes of inquiry. For example, in one meeting it was discussed whether this study should address inequalities in service delivery resulting from geographical and demographic factors, which were found to be related to the context of capacity development within the Service.

Additionally, this study also sought to include patients, as patients are also experts in prostate cancer care, and ethical permissions were gained at the beginning of this study to allow this. However, the study uncovered significant capacity issues within the Service prompting an in depth look at how the Service could be developed to meet demand, and this in-depth look required expertise of service organisation and healthcare professional capabilities that patients would not be able to provide. Though it was pertinent to include patients within this study, the steering group agreed that patients could not meaningfully contribute to the study until further understanding of service need was gained. Rather, considering findings from this study, further research would be required to capture patient views.

Managing diverse steering groups can have challenges, such as access to meetings and member dynamics (Hewlett et al., 2006). However, many issues identified in the literature were not evident in this project. Particularly, I observed that members of the team were respectful of different areas of expertise and actively invited this expertise at appropriate points through the discussion. Further, patients involved were familiar with Prostate Scotland and working with clinicians and so appeared to be comfortable in feeding into discussions. On reflection, it is evident that there was key expertise missing from the group; only Urology medical consultants (doctors registered with the GMC) provided the healthcare professional perspective, and so the Oncology, nurse and allied health professional perspective was missing. However, as discussions did not favour one treatment modality, part of the Service, or discipline, over another, I don't believe that this impacted on the steering of the project and so, it was not felt that there was a need to address this within the project.

3.9 Phase 1: Identifying changes in treatment usage from national quantitative data

As no publications were found to understand how increasing incidence and developments in treatment modalities had changed demand on the different parts of the Service as stated in section 2.2.8, this study began with a quantitative analysis of national health data. I used a breadth of data to create a picture of prostate cancer incidence and treatment usage across the Service. As a result, not all data collected was relevant to the direction of inquiry that this study took. To ensure a succinct narrative I have included only how I selected and collected data (3.11.1) and managed and analysed data (3.11.2) in relation to changes in incidence and treatment usage only. A summary of all data collected is provided in Appendix 2.

3.9.1 Selecting and collecting data

To understand how patient demand on the Service had changed with time, national datasets were used. Specifically, health data held by Scotland's electronic Data Research and Innovation Service (eDRIS) were identified. An application to eDRIS was made to access these data, and to gain access to all data requested eDRIS linked National Records of Scotland (NRS) census data and Information Services Division (ISD) health data. To protect patient confidentiality due to small numbers in some categories, the information analyst at eDRIS grouped some data. Specifically, data about patients age <45 was not requested due to low incidence in this age range, data about patients aged 45-54 and ≥85 were grouped together respectively, and data relating to NHS Orkney, NHS Shetland and NHS Western Isles were also grouped. Though I initially requested data from 1992 to reflect the development of the opportunistic screening protocol in the UK, I was advised by the ISD analyst to request data from 1996 instead to reflect changes in data recording and linkage that occurred between 1996 and 1997. To aid subsequent analysis of treatment usage data, census data identifying the number of men living in each Health Board by single year of age was also collected; this dataset was publicly available. The data and datasets selected are summarised in Table 9.

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Table 9: Scottish health and census data used in Phase 1

SOURCE	**DATASET**	**DATA**
NATIONAL RECORDS OF SCOTLAND	Mid-year population estimates: Scotland and its NHS Board areas by single year of age and sex	Scottish male population by NHS by single year of age from 45 years old and above between 1996-2012
SCOTLAND'S ELECTRONIC DATA RESEARCH AND INNOVATION SERVICE (EDRIS)	Scottish Cancer Registry (SMR06)	For all men diagnosed with prostate cancer betweeen 1996-2012 aged 45 and over
	- Tumour information	Health Board at diagnosis
	- Tumour diagnostic information	Year of diagnosis; age at diagnosis; Gleason Score at diagnosis
	- Tumour treatment information	Time from diagnosis until first treatment for each treatment modality (chemotherapy, hormone therapy, surgery, radiotherapy) where applicable

3.9.2 Managing and analysing data

To prepare for analysis, data were coded in line with coding frame shown in Table 10. Then descriptive statistics were used to organise and summarise data (Holcomb, 2016). Specifically, this analysis sought to (i) calculate the actual change in population, incidence and treatment usage, and (ii) determine whether changes in incidence or treatment usage were the result of changes in population or incidence respectively, or the result of another factor. To do this actual change in population, incidence and treatment usage data were weighted. Specifically, incidence data were weighted per 10,000 men using age, sex and Health Board specific population data, and the percentage of men diagnosed who had each treatment were calculated, i.e. treatment usage data were weighted using incidence data.

Given that no publications were found to understand how increased incidence and developments in treatment modalities had changed demand on the different parts of the Service as stated in section 2.2.8, findings from this Phase were used direct subsequent Phases of research towards the parts of the Service where capacity shortage was evident. In addition to giving direction to the next Phase, findings on actual change of treatment usage were included in the interview schedule.

3.10 Phase 2: Contextualising changes in treatment usage using interviews with healthcare professionals

Interviews with healthcare professionals were used to contextualise findings in Phase 1, specifically to explain changes in treatment usage and predict how they would change, what impact this change would have on service delivery and organisation, and how this could be better planned for. In this section, I describe how I sampled and recruited healthcare professionals (3.12.1), how I developed the interview schedule (3.12.2) and how I conducted face-to-face interviews (3.12.3). I then describe how I transcribed the interviews (3.12.4), how I coded data using NVivo (3.12.5), why I chose content analysis as my analytic method (3.12.6) and how I analysed data using content analysis (3.12.7). This was the final of the two phases of research used to determine the capacity development issues of the Service that would then inform the consensus part of the study.

Table 10: Coding frame for descriptive statistical analysis

REQUESTED DATA	CODING FRAME
YEAR OF DIAGNOSIS	Compiled into four groups: 1997-2000, 2001-2004, 2005-2008, 2009-2012.
AGE AT DIAGNOSIS*	Compiled into ten-year cohorts: 45-54, 55-64, 65-74, 75-84, 85+.
GLEASON SCORE AT DIAGNOSIS	Data has been re-analysed to group Gleason Score (GS) by ISUP grading (ISUP): ISUP1 includes GS1- GS6, ISUP2-3 includes GS7, ISUP4, includes GS8, and ISUP5 includes GS9-10.
TREATMENT MODALITY	Active surveillance**: men diagnosed with ISUP1-3 were stratified into the following cohorts: treatment within 91 days, 92-183 days, 184-365 days, more than 365 days, and no recorded treatment.
	Watchful waiting**: men diagnosed with ISUP4-5 were stratified into the following cohorts: treatment within 91 days, 92-183 days, 184-365 days, more than 365 days, and no recorded treatment.
	Surgery: For each year of diagnosis, patients were divided into two categories; patients had surgery and those who did not.
	Radiotherapy: For each year of diagnosis, patients were divided into two categories; patients who went on to have radiotherapy and those who did not.
	Hormone therapy: For each year of diagnosis, patients were divided into three categories; patients recorded as having hormone therapy prior to or on the same day as radiotherapy (neo-adjuvant treatment), those who had hormone therapy but were not counted in the above treatment, and those who did not have hormone therapy.
	Chemotherapy: For each year of diagnosis, patients were divided into two categories; patients who had chemotherapy and those who did not.

** Age at diagnosis was weighted per 10,000 men aged 45 or older (or aged in accordance with the specified cohort), living in a given Managed Cancer Network (MCN) region each calendar year by using publicly available census data.*

***As active surveillance and watchful waiting are not recognised by ISD as a treatment, time to treatment and ISUP Grade (1-5) were used as a proxy to determine the number of men on each of these treatment pathways, i.e. men diagnosed with ISUP Grade 1-3 prostate cancer who experienced a delay in treatment were likely to have received active surveillance, and men diagnosed with ISUP Grade 4-5 prostate cancer who experienced a delay in treatment were likely to have received watchful waiting.*

3.10.1 Sampling and recruitment

In this study, knowledge of the Service was understood to be shaped by an individual's experience of the Service. Therefore, participants were sampled to ensure that different experiences of the Service were included. To do this, criterion sampling was used. Criterion sampling is a form of purposive sampling that facilitates the recruitment of participants based on pre-defined criteria (Bryman, 2012). Two criteria were selected ensure diversity of experience; role and region. Professional role was selected as a criterion to include different disciplinary perspectives and experience of the different roles within the Service including culture within the Service (Ford & Harding, 2004). Sampling criteria included all healthcare professionals involved in delivering specialist treatment and care of men with prostate cancer. As limited evidence was available to identify the healthcare professionals delivering specialist treatment and care, this was assumed to be specialist nurses, oncologists and urologists, but this list was not prescriptive. Region was selected as a criterion to reflect the unique challenges of delivering specialist services across a geographically diverse country. To ensure experience was included across the Service regions and geographies, participants were drawn from each of the three Managed Cancer Network (MCN) regions; North of Scotland (NoSCAN); East of Scotland (SCAN) and West of Scotland (WoSCAN).

As NHS email addresses are not publicly available, I had restricted access to the target population. Therefore, I used two alternative approaches to recruitment. Firstly, contact details of participants were gained from Prostate Scotland, which are extensive and include healthcare professionals with a specialist interest in prostate diseases from across Scotland including those not directly affiliated with the charity, my own personal networks, and through networking with potential participants at conferences, particularly the Scottish Urology Society conference that invites healthcare professionals with an interest in Urology from across Scotland irrespective of discipline. Secondly, to ensure further reach of recruitment, snowball sampling was also employed by encouraging healthcare professionals invited to participate to forward the invite to interview email to their colleagues who also met the criteria.

Healthcare professionals contacted received a personalised email (Appendix 3) with attached participant information sheet (Appendix 4), inviting them to interview. Where healthcare professionals did not respond after two weeks, they were resent the original email. If participants still did not respond, they were not contacted again.

As capacity shortage was identified as a Scotland-wide problem (NHS National Services Scotland, 2019) and as changes in treatment usage identified in Phase 1 were similar across Scotland, it was anticipated that data saturation would be achieved quickly during data collection (Wray, Markovich & Manderson, 2007; Corbin & Strauss, 2008; Saunders et al., 2018). Data saturation is the collection of data until "*nothing new is apparent*" (Saunders et al., 2018, pp 1895) or until "*the researcher begins* *to hear the same comments again and again*" (Grady, 1998, pp 26). Though data saturation is considered a point or event in the data collection process after which data collection should stop (Saunders et al., 2018), Strauss and Corbin (1998) argue that there will always be potential for newness and instead encourage the researcher to continue collecting data until data collection becomes counterproductive. Therefore, though data saturation was expected to be achieved quickly, data collection continued until participants across all professional roles and MCN regions had contributed, i.e. whilst data collection was productive. This study sought to sample healthcare professionals as described in Table 11. As it was anticipated that other healthcare professionals in addition to specialist nurses, oncologists and urologists were involved in delivering specialist treatment and care of men with prostate cancer, these were included in the sampling matrix as "*other*".

As there is little agreement on recommended sample size for qualitative research (Guest, Bunce & Johnson, 2006; Green & Thorogood, 2018), it was anticipated that up to 20 participants would be interviewed, allowing for more than one person to be interviewed within each part of the sampling matrix if needed. During data collection, ethical permission was gained to increase this sample size to 30 participants and recruitment stopped when all relevant professional roles had contributed from each MCN region. As predicted, data saturation had been reached prior to this.

3.10.2 Schedule development

Firstly, findings from Phase 1 were used to develop the interview schedule, included as Appendix 5. Specifically, changes in treatment usage identified were summarised and participants were asked questions relating to these changes. For example, when asking about active surveillance, the change identified was summarised as "*around 23% of men diagnosed in 2012 were not known to receive any form of treatment. This number increases each year. At least 60% of these men are thought to be on an active surveillance care plan*." Following the verbalisation of each change in treatment usage, participants were asked four questions about each trend: (i) how can you explain this change, (ii) how do you expect this to change in the future, (iii) what impact will this have on service delivery and organization, and (iv) how can services better plan to accommodate this change? Then, to ensure all service developments were accounted for, guided by the wider prostate cancer care context in Scotland described in Chapter 2, participants were asked to predict the main service development issues in the coming 10 years, and about the impact of future service development concerns, such as the implementation of robotic prostatectomy services and the shift of care to the community.

Table 11: Phase 2 sampling matrix

	Managed Cancer Network region		
Speciality	East	North	West
Specialist nurse	n≥1	n≥1	n≥1
Oncologist	n≥1	n≥1	n≥1
Urologist	n≥1	n≥1	n≥1
Other	n≥1		
Total	**n≥10**		

Though researchers often adopt structured, semi-structured or unstructured interview methods, these methods exist on a continuum with no clearly defined boundaries between each (Miles & Gilbert, 2005; Clifford et al., 2016). Due to the quantity of information to be gathered, a more structured approach was used though still allowing flexibility to explore some comments within each interview if required. Question construction was guided by Turner's (2010) recommendations for the development of interview schedules; questions were designed to be open-ended, neutral and clearly worded, and ensure an obvious transition between topics.

Most participants interviewed were specialist nurses, oncologists and surgeons and could respond to all questions asked. However, some participants had knowledge of one part of the Service only. Where this was thought to be the case, participants were asked to describe their role within the Service and were asked only questions from the interview schedule relevant to their role.

3.10.3 Conducting interviews

When conducting face-to-face interviews, interview location is not always given important consideration in research beyond resolving the practical issues of meeting face-to-face. However, the interview setting can alter the way in which the verbal exchange occurs, and the content discussed (Herzog, 2005). Therefore, interview settings should be familiar to the participant (Seidman, 1991) allowing participants to talk more freely (Gillham, 2000), and where appropriate, interviews not of an emotive or personal nature should be undertaken at the participants workplace (Adler & Adler, 2002). In this study, interviews were completed at a location of the participants choosing, and participants chose to undertake these interviews in their workplace, usually in their office.

Additionally, participants were asked for permission to record interviews. Though there are clear benefits of recording interviews, mainly the opportunity to listen back to interviews and create a verbatim script to assist with analyses (Fernandez & Griffiths, 2007), Al-Yateem (2012) cautions that recording interviews may affect the quality of data obtained through making participants feel uneasy or uncomfortable. Al-Yateem (2012) found that though participants accepted recordings as part of the interview process, some engaged more with the process when not recorded. Therefore, to make the recording device less intrusive, interviews were recorded on a mobile phone. This also provided the ability to back-up and password protect the interview recordings immediately following interview.

3.10.4 Transcribing interviews

All interviews were transcribed verbatim excluding non-speech and intonation sounds such as laughter, emphasis and pauses. This level of transcription is enough when analysis is guided by a pursuit for information, meanings and perceptions (Oliver, Serovich & Mason, 2005; Bailey, 2008) as required in this study.

3.10.5 Coding data

Following transcription, data must first be organised in a way that will enable analysis. This process is known as decontextualization (Spencer, 2014); decontextualization is the process of extracting data from a dataset, allowing it to become generalisable (Morse, 2016). Data coding is the method most used for decontextualizing transcripts (Jones, 2007).

Following transcription, data were moved into NVivo (QSR, Version 10) for further data management. NVivo is a commonly used qualitative data analysis software package that has been shown to facilitate the management and analysis of interview data in accordance with different methodologies (Zamawe, 2015), simplify coding and data retrieval (Bezeley, 2007; Zamawe, 2015), improve the accuracy of findings (Mclafferty & Farley, 2006; Bezeley, 2007), improve the transparency of the analytical process and allow the researcher to maintain control over the coding and analysis process (Mclafferty & Farley, 2006).

When coding, text was first fragmented to datum, where a datum constituted only one comprehensible idea, episode or piece of information (Tesch, 1990). This allows for the extraction of all data assigned the same code for later comparison and data recontextualization (Tesch, 1990). Due to this, codes are integral to the way that data is recontextualised and subsequently analysed (Dey, 1993; Jones, 2007; Bengtsson, 2016). As such, it was important to know how data would be analysed prior to beginning this process.

3.10.6 Choosing content analysis

The analysis of qualitative data requires the construction of a context within which to understand the data (Krippendorff, 2004). Content and thematic analysis are commonly used and distinct methods of interview data analysis (Braun & Clarke, 2006; Sandelowski & Leeman, 2012), and both methods require the construction of a context for making sense of data (Krippendorff, 2004; Vaismoradi, Turunen & Bondas, 2013). Specifically, content analysis enables the understanding, construction and development of the context from the participants perspective only to determine trends or structures in the text (Krippendorff, 2004; Hseih & Shannon, 2005; Pope & Mays, 2006; Bengtsson, 2016), whereas thematic analysis enables the integration of the researchers understanding within the development of the context to assist the emergence of themes (Loffe & Yardley, 2004; Braun & Clarke, 2006; Vaismoradi, Turunen & Bondas, 2013). Though in this study, it was not possible for the researcher to disregard their own experiences and interpretations of the Service when designing the study (Dewey, 1910; 1920; 1922; 1925; Morgan, 2007; 2014), it was important to disentangle the researchers own experiences and interpretations to give voice only to healthcare professionals interpretations throughout the analytic process. Content analysis has proven useful in guiding analysis and reporting of findings from similar types of exploratory research (Green and Thorogood, 2004; Green & Thorogood, 2018), and was chosen for being an ‘unobtrusive’ method of data analysis (Vaismoradi, Turunen & Bondas, 2013).

3.10.7 Using content analysis

Hsieh and Shannon (2005) identify three approaches to content analysis: conventional, directed and summative. The approach taken depends largely on the research question and what is already known on the topic: summative content analysis focusses on quantifying word usage and inferring meaning through this; conventional content analysis encourages the exploration of the text to develop understanding on topics where little is known; and directed content analysis requires researchers to utilise existing knowledge to determine the initial coding scheme and/or the relationship between codes (Hsieh & Shannon, 2005).

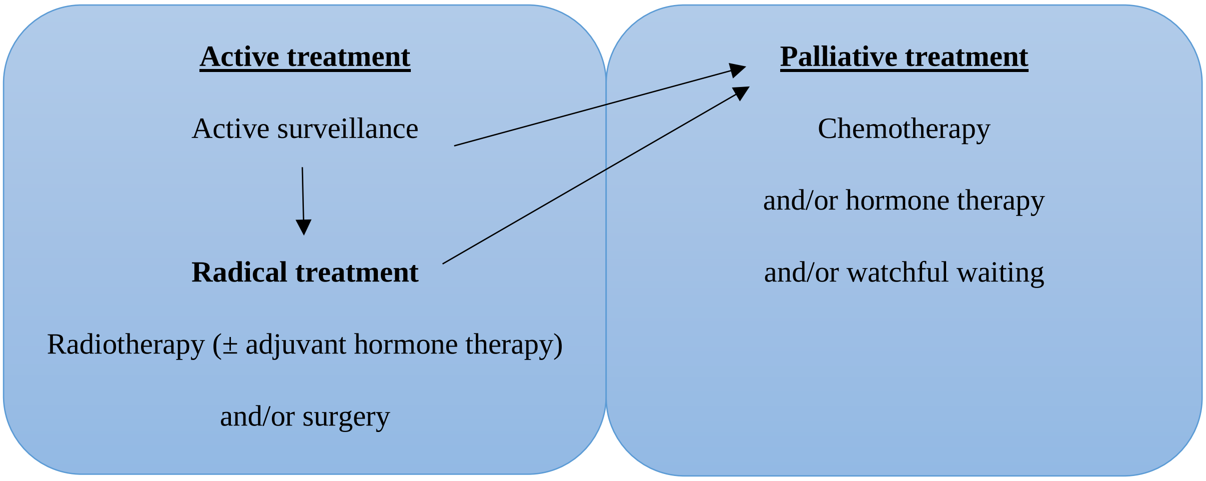
So as not to decontextualize data from the services in which they were linked, a directed approach to content analysis was used. The structure of the treatment pathway (Figure 5) was used as the initial coding frame as the treatment pathway (i) mapped to the interview transcript, (ii) mapped to trends in treatment usage identified in the previous phase of research, and (iii) represented a common structure that was accepted by healthcare professionals across the Service; using the treatment pathway as the initial coding frame allowed the coding process to stay rooted in the study and avoiding meaning or context being inferred from other sources. All data not fitting within this coding frame were coded as “*other*” for later consideration and following completion of coding, these data were reviewed and data not relating to the research question were removed (Burnard, 1991; Burnard, 1995). For relevant data, new codes were developed to encompass these (see Figure 6).

Relevant coded data were then condensed to *meaning units*. To do this, each datum was reduced by describing it in fewer words, but without losing its meaning (Graneheim & Lundman, 2004; Bengtsson, 2016). For example, when asked why a trend in treatment usage had decreased, one participant responded that they "*think this is because the men are more aware of alternative treatments now, including active surveillance in that*" (Participant 14). *This was reduced to "awareness of active surveillance has led to decreased usage of [treatment]*".

Meaning units were then organised to categorise data with the aim of subsequently developing themes (Bengtsson, 2016). However, I found the reality of this step challenging, as for me, NVivo hindered the process of iteration and reflection. To resolve this, a mind mapping tool, GoConqur was used to map meaning units around codes. Mind mapping has been shown to be reflective of thought processes in qualitative analysis, which are usually non-linear and random (Meier, 2007) and though this software was also found to be challenging at times, data visualisation helped considerably with the categorisation process. As these mind maps were large, they could not be included usefully as an appendix, so I include part of one as an example in Figure 7.

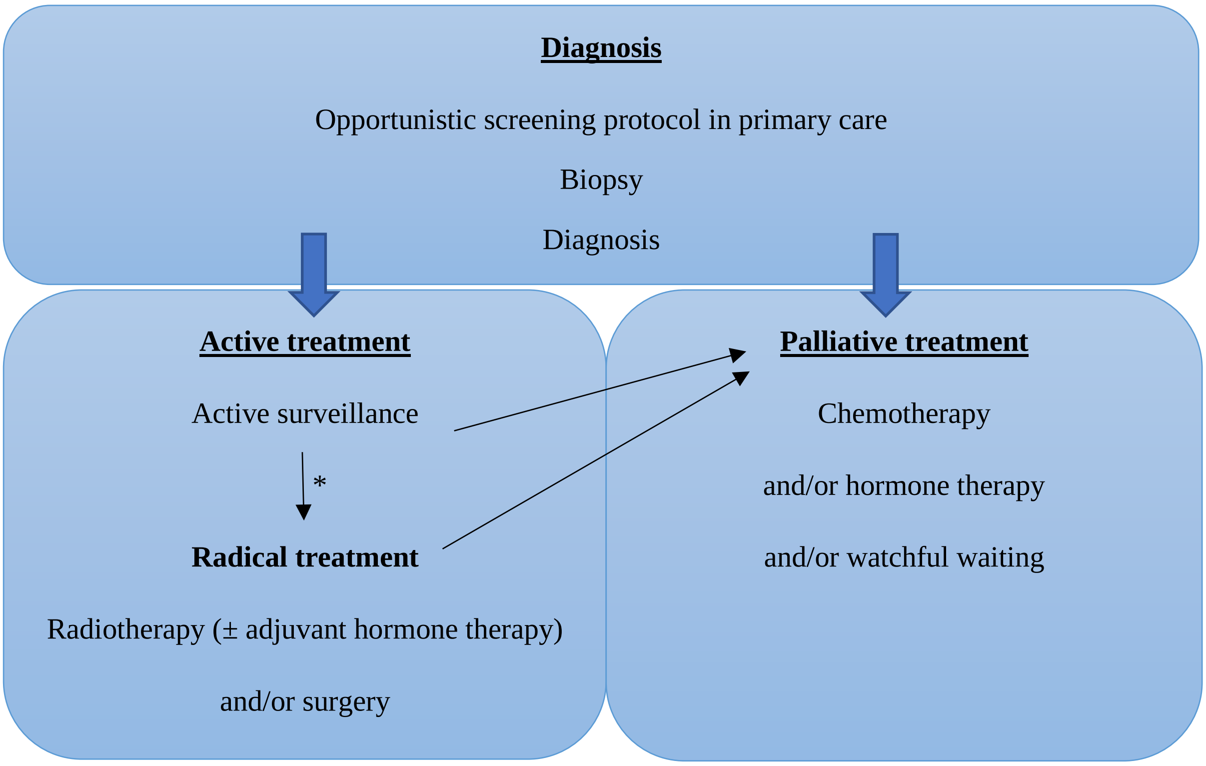
As the first step in development of themes involves grouping similar meaning units (Erlingsson & Brysiewicz, 2014), the data visualisation resulting from the initial mapping exercise proved useful in identifying similarities in meaning units between codes. The meaning units that emerged from the data around each service or code (Figure 6), provided understanding of the capacity development issues of that service. Then, the capacity development issues across all services were compared to gain understanding of the capacity development issues of the Service as a whole. This level of analysis proved enough to determine trends in capacity development issues both within each part of the Service and across the Service as a whole.

As no publications were found to understand the issues that prevented the Service from developing to meet demand, this Phase used understanding of change in service usage (gained in Phase 1), predicted change and the impact of predicted change gained in this Phase, to identify issues that were hindering the ability of the Service to meet demand. In addition to giving direction to the next Phase, data collected in this Phase were used to develop the first questionnaire schedule and issues identified were used to direct data analysis.



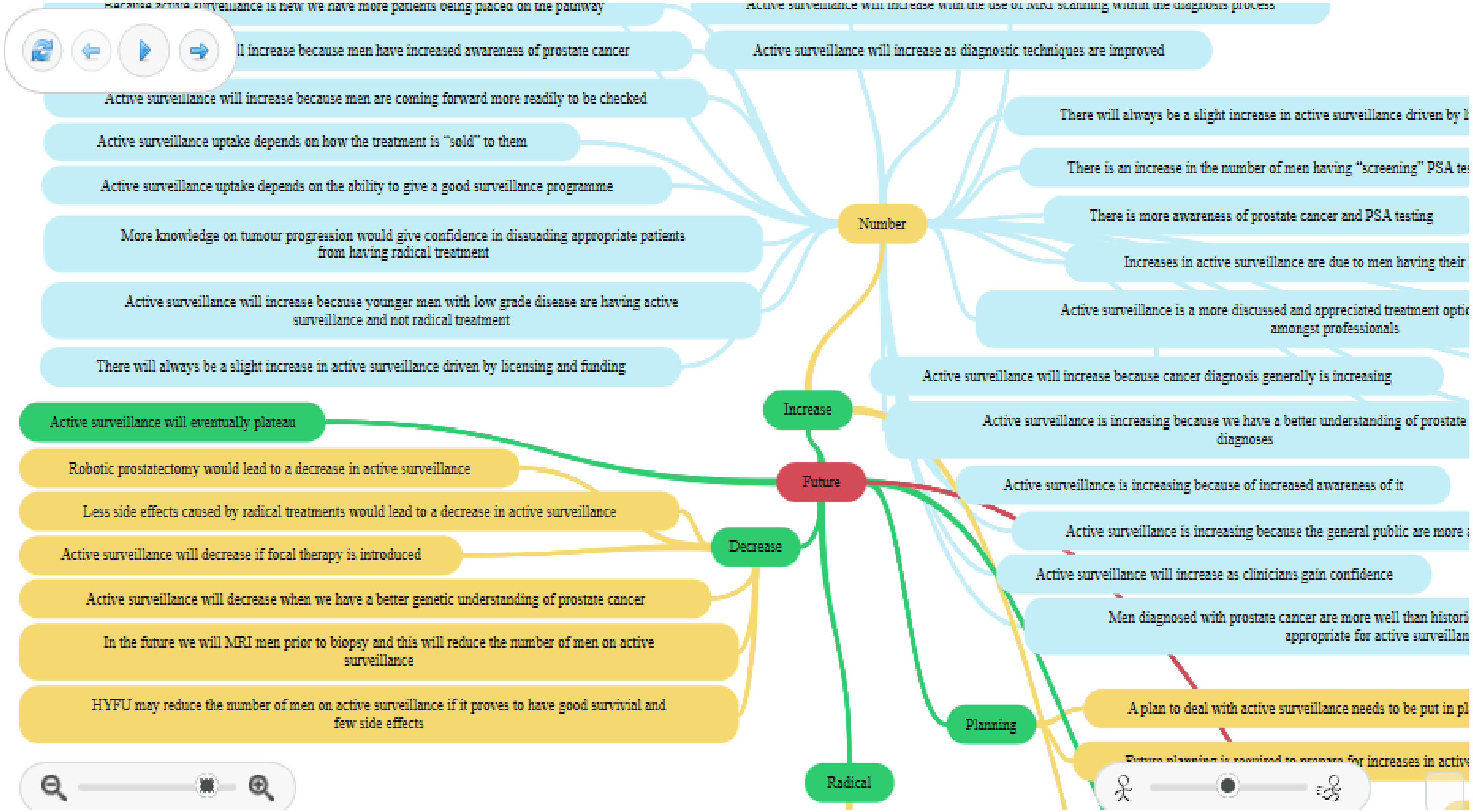
Arrows represent patient decision-making, a change in patients' health status, and/or prostate cancer progression or recurrence

Figure 5: General structure of the NHS Scotland prostate cancer service treatment pathway used as an initial coding frame



*Arrows represent patient decision-making, a change in patients' health status, and/or prostate cancer progression or recurrence. Thick blue arrows indicate movement from diagnosis to treatment. * Following diagnosis, patients may begin treatment either with active surveillance or radical treatment to reflect ISUP Grade and patient choice.*

Figure 6: Coding frame after initial coding complete



Because active surveillance is new we have more patients being placed on the pathway

ll increase because men have increased awareness of prostate cancer

Active surveillance will increase because men are coming forward more readily to be checked

Active surveillance uptake depends on how the treatment is "sold" to them

Active surveillance uptake depends on the ability to give a good surveillance programme

More knowledge on tumour progression would give confidence in dissuading appropriate patients from having radical treatment

Active surveillance will increase because younger men with low grade disease are having active surveillance and not radical treatment

There will always be a slight increase in active surveillance driven by licensing and funding

Active surveillance will eventually plateau

Robotic prostatectomy would lead to a decrease in active surveillance

Less side effects caused by radical treatments would lead to a decrease in active surveillance

Active surveillance will decrease if focal therapy is introduced

Active surveillance will decrease when we have a better genetic understanding of prostate cancer

In the future we will MRI men prior to biopsy and this will reduce the number of men on active surveillance

HYFU may reduce the number of men on active surveillance if it proves to have good survivial and few side effects

Active surveillance will increase with the use of MRI scanning within the diagnosis process

Active surveillance will increase as diagnostic techniques are improved

There will always be a slight increase in active surveillance driven by

There is an increase in the number of men having "screening" PSA

There is more awareness of prostate cancer and PSA testing

Increases in active surveillance are due to men having their

Active surveillance is a more discussed and appreciated treatment amongst professionals

Active surveillance will increase because cancer diagnosis generally is increasing

Active surveillance is increasing because we have a better understanding of prostate diagnoses

Active surveillance is increasing because of increased awareness of it

Active surveillance is increasing because the general public are more

Active surveillance will increase as clinicians gain confidence

Men diagnosed with prostate cancer are more well than appropriate for active

A plan to deal with active surveillance needs to be put in

Future planning is required to prepare for increases in active

Figure 7: Excerpt of mind map for active surveillance

3.11 Phase 3: Facilitating consensus of healthcare professionals

To facilitate consensus of healthcare professionals on the capacity needs of the Service, a closed-question questionnaire was developed using data from Phase 2 and was distributed, analysed, revised and re-distributed iteratively. In this section, I describe how I sampled and recruited healthcare professionals (3.13.1), explain why I used an online platform (3.13.3) and a 3 Round Delphi protocol (3.13.3), describe questionnaire development (3.13.4), and how I piloted the first questionnaire (3.13.5). I then describe how the questionnaire developed over iterations (3.13.6; 3.13.7; 3.13.8) and what feedback I gave between Rounds (3.13.9), and describe why and how I maintained participant anonymity throughout this study (3.13.10), and finally, how I measured consensus (3.13.11).

3.11.1 Sampling and recruitment

As in Phase 2, a combination of criterion and snowball sampling were used. Participants were sampled based on their role (specialist nurse, oncologist and urologist) and region (NoSCAN, SCAN and WoSCAN) as summarised in Table 12. Though in Phase 2, the experiences of other healthcare professionals were drawn on such, these professionals largely provided experience of their own part of the Service and often had limited knowledge of the issues of the Service as a whole.

To recruit, two methods of recruitment were employed:

I. All participants contacted to participate in Phase 2 who met the Phase 3 recruitment criteria were invited to participate, and these potential participants were encouraged to forward the invite to their colleagues
II. To reach as many potential participants as possible, gatekeepers were also sought for each MCN region in the form of Urology MCN management. The use of gatekeepers is recommended where contact details for relevant participants are difficult to obtain (Armstrong et al., 2000; Evans et al., 2004; Almasio et al., 2005). However, only one gatekeeper was successfully identified.

Table 12: Phase 3 sampling matrix

	Managed Cancer Network region		
Speciality	East	North	West
Nurse	n≥1	n≥1	n≥1
Oncologist	n≥1	n≥1	n≥1
Urologist	n≥1	n≥1	n≥1
Total	**n≥9**		

Where possible, healthcare professionals received a personalised email inviting them to participate in this study (Appendix 6). This email included a participant information sheet (Appendix 7) and a link to the R1 questionnaire. Where participants or potential participants did not respond after two weeks, participants were resent the original email. If participants did not respond at this point, they were not contacted again.

When recruiting to a Delphi study, Murphy (et al., 1998) suggests that experts should not be known personally to the researcher, whereas Evans (2004) cautions against contacting participants unknown to the researcher. As urologists, oncologists and specialist nurses with direct involvement in the NHS Scotland prostate cancer service represent a small population, and due to my involvement with Prostate Scotland early in this study and professional networking at events, it was practically impossible to be either known to all or not known to all participants without diminishing the composition of the expert panel. As the composition of the expert panel is considered the most important factor in Delphi studies, participants were recruited irrespective of professional relationships.

3.11.2 Using an online platform

Part of the appeal of the Delphi technique has always been the logistical benefits; the Delphi technique is useful where consensus is required in large sample sizes, or time, cost and logistics might make the use of other methods impossible (Linstone & Turoff, 1975). As such, Delphi studies are commonly distributed online (Mullen, 2003; Drury et al., 2013; Oostendorp et al., 2015; Pezaro & Clyne, 2015). As the Bristol Online Survey has been widely used in Delphi studies (Drury et al., 2013; Oostendorp et al., 2015; Pezaro & Clyne, 2015), it was selected as the platform for this study. Though the use of an online platform proved useful, it was not without its challenges like those reported by Young and Jamieson (2001).

3.11.3 Number of Rounds

A 3 Round Delphi process was employed in this study to facilitate consensus. Though the number of Rounds used to reach consensus in a Delphi process varies, it is recommended that no more than 4 rounds are employed to prevent participant fatigue, 3 rounds being advocated (Beech, 1999; Greatorex & Dexter, 2000; McMillan, King & Tully, 2016). The decision to use 3 rounds was decided a priori.

3.11.4 Questionnaire development

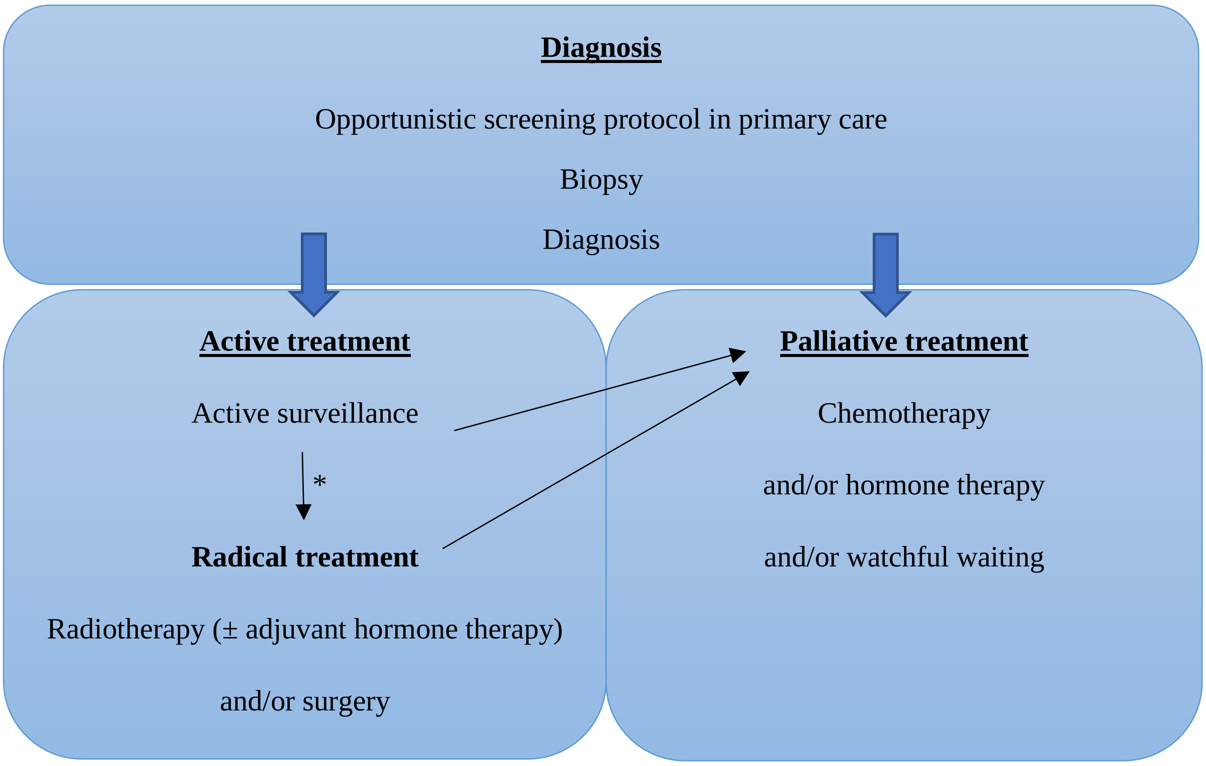
This Delphi study employed questionnaires iteratively to establish consensus on the capacity development needs of the Service. To achieve this, data from interviews with healthcare professionals in Phase 2 were used to inform the development of the first questionnaire (Appendix 8). This section describes questionnaire content, structure, question styles used, and use of comment boxes.

3.11.4.1 Informed by findings from interviews with healthcare professionals

When the first questionnaire was initially drafted to facilitate consensus on the capacity needs of the Service, it read as a list of required resources such as more specialist nurses, more or better clinic rooms, etc, and as such was unlikely to provide useful insight into the needs of the Service. The steering group agreed that the questionnaire should be refined to enable consensus to be facilitated on service developments needed to meet demand, and in doing so provide understanding of the capacities needed to enable this. Raw interview data, the coding frame used and further developed in Phase 2, and mind maps of meaning units developed during Phase 2 analysis, were used to inform questionnaire development. Specifically, all service developments proposed by healthcare professionals at interview for diagnosis or treatment services were included within the first questionnaire. For inclusion in the questionnaire, each proposition was reduced to its simplest form, for example, "*diagnostic services should be a one stop shop*" and "*orchidectomy should be discussed as a treatment option with patients*" (Appendix 8).

3.11.4.2 Structure of questionnaires

When drafting the first questionnaire, the coding frame shown developed in Phase 2 as repeated in Figure 8, was used to organise propositions. The questionnaire was then restructured to reduce the number of questions asked and still provide a logical flow to the questions included in each Round. In Round 1 (R1) findings from the content analysis of interview data were structured around three topics: the organisation of secondary and tertiary care, multidisciplinary working, and patient follow-up. In Round 2 (R2) and Round 3 (R3) questionnaires were restructured to reflect the service design and the emerging consensus. R2 topics were as follows: the multidisciplinary team, diagnostics and active surveillance, radical treatment, and palliative oncology. In R3, topics were service delivery, the diagnostic pathway, active treatments, and palliative treatments.



*Arrows represent patient decision-making, a change in patients' health status, and/or prostate cancer progression or recurrence. Thick blue arrows indicate movement from diagnosis to treatment. * Following diagnosis, patients may begin treatment either with active surveillance or radical treatment to reflect ISUP Grade and patient choice.*

Figure 8: Coding frame used to organise propositions in Delphi questionnaire

3.11.4.3 Question style

Though Delphi studies are commonly associated with the use of 'ranking' questions and Likert scales (Beech, 1997; Kennedy, 2000; Hasson, Keeney & McKenna, 2008; McMillan, King & Tully, 2016), Mead and Moseley (2001) urge consideration of question style within a Delphi to ensure that the style reflects the question asked, and variation in question style is recommended to reduce participant fatigue. No single question style was chosen for this Delphi, rather question style was chosen to suit the question asked. In total, four question styles were used: participants were provided with multiple responses to a statement and asked to select the response that they most agreed with; participants were asked to select all relevant statements; five-point Likert scales (R1 only); and open-ended questions were used in the final section of the questionnaire.

3.11.4.4 Self-rating expertise

As the validity of a Delphi study lies with a participant having the appropriate experience to give an informed judgement, it was important that participants only responded to the questions that they had the experience to answer and methods of self-rating expertise are often used to ensure this (Linstone & Turoff, 1975; Gordon, 1994; Culley, 2011). To ensure that participants only answered the questions that they felt able to, each question contained the response "*not relevant to my expertise*" allowing participants to give no response. As these participants did not have the appropriate expertise, they were not included when calculating consensus for the given statement.

3.11.4.5 Comment boxes

Comment boxes were included after each question asked to enable participants to give open feedback to guide consensus development, disagree with questions asked and suggest new lines of questioning or propositions. This is considered good practice in some Delphi studies and is thought to prevent attrition due to participant frustration when no mechanism of feedback is provided (Sackman, 1975; Linstone & Turoff, 1975; Greatorex & Dexter, 2000).

3.11.5 Piloting the questionnaire

Though it is recommended that Delphi questionnaires are piloted to conceptualise the study, refine questions, and ensure the correct interpretation of all questions (Prescott & Soeken, 1989; Toronto, 2017), piloting within the potential participant population may affect validity, introduce bias, and impact on contribution to the Delphi process. Therefore, the Director of Prostate Scotland (co-funder of the study) and member of the Steering Group reviewed the R1 questionnaire. As the Director works closely with a clinical advisory group to Prostate Scotland and has a good knowledge of key service issues and technological developments in the field, the Director had the experience required to review the questionnaire.

Two changes were made to the questionnaire following review in addition to minor rephrasing of statements. Firstly, the proposed protocols for patient follow-up were unified across all treatment groups. Secondly, Adam showed concern that the current questionnaire did not take into consideration potential changes to service design resulting from ongoing studies based in Scotland. Adam suggested two projects for inclusion in the questionnaire, and Managed Cancer Network reports were reviewed for further ongoing research and one further study was found. At the end of the R1 questionnaire an 'ongoing research' section was added to include these projects and participants were asked to comment on the potential impact of these studies on capacity development in services.

3.11.6 Round 2: Understanding dissensus and introducing new propositions

Delphi processes are often criticised for their failure to acknowledge dissensus focusing instead on the pursuit of consensus (Hejblum et al., 2008). As statements reach consensus it is common to exclude these from the process including them again only in the final round. Therefore, only statements that did not reach consensus in R1 were included in R2. Additionally, where participants provided new propositions or judgements in comment boxes in R1, these were also included for consideration in R2. To gain understanding on the emerging dissensus and identify further propositions, comment boxes in R2 prompted participants to state why they disagreed with statements.

3.11.7 Round 3: Consolidating consensus and dissensus and introducing new propositions

Beyond presenting statements again for participants to rank or respond to, little guidance is provided on the purpose of, or how to develop an R3 questionnaire (Linstone & Turoff, 1975; Green et al., 1999). Throughout R1 and R2, consensus and dissensus had been facilitated on many statements. However, healthcare professionals had agreed or disagreed with statements without knowledge of the emerging consensus; healthcare professionals had taken each statement and considered it largely in isolation of the other statements. Therefore, R3 was used to consolidate topics of consensus and dissensus, i.e. in R3 for each part of the diagnostic and treatment pathway, healthcare professionals were given the opportunity to determine whether (i) all topics of consensus that are compatible, and (ii) re-evaluate topics of dissensus considering the emerging consensus. To do this, the questionnaire grouped consensus statements (statements that had reached consensus in either R1 or R2) and presented these to participants for judgement. For example, the following statement grouped 9 consensus statements and asked participants whether they agree or disagreed:

> "*The management of side effects requires a dedicated team that is nurse- led. This team should be responsible for the treatment and management of erectile dysfunction, incontinence, bladder irritability and bowel issues across both surgical and radiotherapy services as required. This team should also be involved with patients both pre and post treatment and should be organised around tertiary and sub-specialist services*."

In addition to shortening the length of the questionnaire, this afforded healthcare professionals the opportunity to consider the emerging consensus as a service and not a series of isolated statements. Following this, any dissensus statements (statements that had not reached consensus in R1 or R2) were then listed to allow participants to consider these alongside the proposed service.

3.11.8 Round 3: Understanding capacity needs

Capacity development is considered bottom-up empowerment of sustainable change (Potter & Brough, 2004; Pavlovic et al., 2009; Bennett et al., 2010; Carneiro et al., 2015). During development of the R3 questionnaire it became apparent that this process was facilitating consensus on what a quality prostate cancer service should look like and was not facilitating consensus on how the Service could be developed to meet demand. Rather than adding statements to the existing sections of the questionnaire which may have influenced participant responses, a section was added to the end of the R3 questionnaire titled "*further consideration*". Statements proposed methods of developing capacity within the Service guided by findings from the content analysis of interviews with healthcare professionals in Phase 2 and by the emerging consensus.

3.11.9 Against the need for individual feedback

Typically, to facilitate consensus within a Delphi study, participants are provided with feedback on how participants individually responded compared with the collective response for each question (Fischer, 1978; Goodman, 1987; McKenna, 1994; Du Plessis, 2007; McMillan, King & Tully 2016). However, the rationale or underpinning theory behind providing participants with a reminder of their own response is not clear. Within a group discussion, areas of consensus and dissensus would naturally emerge and participants would not be reminded of where they stood on the matter at a prior time point unless it was with the aim of resolving conflict or dissensus. When reflecting on how this consensus is likely to occur, Rescher (1995) argues that in an imperfect world, instead of seeking a perfect consensus we should look for "*incremental improvements within the framework of arrangements that none of us will deem perfect, but that all of us 'can live with'*" (Rescher, 1995, pp. 4) and Rescher goes on to argue that in areas such as healthcare where there is an ethico-moral imperative to reach consensus on the way forward, that people will generally agree providing that they believe that what has been proposed is an improvement on what is currently done. As no rationale for the use of individual feedback between Rounds was given in the literature, only group feedback was given throughout in order that participants could judge with each iteration whether they could accept the emerging consensus or not.

3.11.10 Anonymity

Anonymity is a key characteristic of the Delphi technique (Dalkey & Helmer, 1963; Mead & Moseley, 2001; Sharkey & Sharples, 2001; McMillan, King & Tully, 2016; Waggoner, Carline & Dunning, 2016; Humphrey-Murto et al., 2017) that allows consensus to be facilitated without issues that arise between participants such as participant dominance or fear of not being accepted (Turoff &

Hiltz, 1996; Sharkey & Sharples, 2001) and as such, participants remained anonymous to each other throughout.

3.11.11 Quantifying consensus and dissensus

In line with Pierce's (1885; 1908) theory of truth, a general consensus was considered practically true in this study. As quantifying consensus is thought to be theoretically like quantifying acceptable levels of attrition (Green et al., 1999), understanding of attrition was used to guide decision-making on how consensus should be quantified in this study. Though ideally researchers endeavour towards 0% attrition, inevitably attrition in research occurs. According to research guidelines and methodological papers, attrition of 20-30% is generally accepted, after which concerns are raised about the validity and reliability of the study (Fewtrell et al., 2008; Amico, 2009). In this study, quantifying consensus at ≥70% agreement (or <30% disagreement), would allow for every participant working within a certain role or region to disagree with a statement, and the statement could still reach consensus. Therefore, consensus in this study was quantified as ≥80% agreement. As Delphi studies are often criticised for the prioritisation of consensus over dissensus (Du Plessis, 2007; Hejblum et al., 2008; Vernon, 2009) dissensus was also explicitly defined and measured as <80% agreement. Using these thresholds, data were categorised as 'statement accepted' (80-100% agreement), 'dissensus' (21-79% agreement), and 'statement rejected' (0-20% agreement).

3.12 Ethical permissions

All phases of this study were considered by the University of Stirling's School of Health Sciences Ethical Committee and approved by Chair's Action following minor amendments on and further minor amendments were approved by Chair's Action to increase sample size during Phase 2 data collection. As this study focused on service development, NHS approval through the Integrated Research Application System (IRAS) was not required and this was confirmed through communication with a regional research and development office. Ethical permissions were gained, and data were collected, prior to the Genera Data Protection Regulation (GDPR) and the Data Protection Act 2018.

Before access could be provided to national datasets for use in Phase 1, ethical approval also had to be gained through application to Scotland's electronic Data Research and Innovation Service (eDRIS). To minimise risk to anonymity, care was taken to ensure that populations were not likely to be small, for example, due to the low incidence of prostate cancer in men aged below 45, data relating to men aged 45 and over only was requested, and data relating to NHS Orkney, NHS Shetland and NHS Western Isles was combined to form an NHS Islands category. To maintain confidentiality, datasets were sent as password protected files on a CD-ROM and data was stored in password protected files in a University networked folder. Due to the level of information accessed, an application to the Privacy Advisory Committee and onsite analysis through NHS National Services Scotland National Safe Haven was not required. Additionally, as this was a service development study, ethical permission through the Integrated Research Application System (IRAS) was not required.

As this study asked healthcare professionals only to participate, the potential for risks and burdens for participants were considered low (Social Research Association, 2003). However, as participants were asked their own opinions on the needs of the Service, there was a professional risk to participants. Therefore, maintaining anonymity and confidentially of participants was important in this study. Additionally, as described earlier in this Chapter, anonymity is crucial to a successful Delphi study (McMillan, King & Tully, 2016; Waggoner, Carline & Dunning, 2016; Humphrey-Murto et al., 2017). The following methods were used to maintain anonymity and confidentiality.

Firstly, in Phase 2 and Phase 3, participants contact details and participants contacted were recorded in a password-protected spreadsheet stored in a secure, password-protected university computer. Secondly, in Phase 2, interview transcripts were assigned a participant identifier and a separate, password-protected spreadsheet stored in a secure, password-protected university computer was used to link participant identifiers with participants. Only I had access to these spreadsheets.

Thirdly, in Phase 2, following transcription, voice recordings were deleted, and interview transcripts were stored in a secure, password-protected university computer. Following transcription, data were also edited to remove as much identifiable data as possible. [ ] was used to indicate where sensitive data had been edited to preserve anonymity in transcripts. For example, if the participant explicitly disclosed their place of work during the interview, this was edited to [Health Board] or [hospital] as appropriate. However, transcripts could not be fully anonymised as for example, healthcare professionals often identified service designs that were unique to their Health Board or hospital. The inability to anonymise the data for these reasons is known as deductive disclosure (Sieber, 1992; Tolich, 2004), and concern was taken during subsequent analyses and reporting of findings to ensure participants identities were not revealed.

Finally, collecting data using online platforms had proven controversial due to privacy and confidentiality concerns, most recently due to concerns over online platforms recording participants' IP address, making participants and their locations identifiable (Regmi et al., 2016). This was less likely to be a problem when collecting data from healthcare professionals as it was anticipated that questionnaires would be completed from an NHS computer. However, to minimise the risk of this, Bristol Online Survey was used. Bristol Online Survey is an online platform developed specifically for use in academic research.

In addition to the ethical concerns listed above, it was also important to ensure that all healthcare professionals had given informed consent in both Phase 2 and Phase 3. Consent is the process by which researchers show respect for the autonomy of participants and practice beneficence (Oeye, Bjelland & Skorpen, 2007). This process ensures that participants are informed of the research process, the benefits and drawbacks of the research, and are aware of their right as a participant to withdraw from the research process at any time (Holloway & Galvin, 2016). At interview, participants were provided with an ‘invite to interview’ email that included a participant information sheet outlining the purpose of the study and how their data would be used, and prior to interview, written consent was obtained. As part of this written consent, participants were explicitly asked for permission to record interviews, and reminded that they could withdraw from the study at any time. In Phase 3, participants were also provided with an ‘invite to participate’ email that included a participant information sheet outlining the purpose of the study and how their data would be used, and a consent form was embedded at the start of the R1 questionnaire reminding participants that they could withdraw from the study at any time.

3.13 Summary

This Chapter was structured in two parts: (i) the underpinning philosophy that provides an account of how the world was viewed during investigation, and (ii) the study design detailing the procedures that were chosen a priori to investigation of the phenomenon.

Philosophy:	This Delphi study was informed by ontological holism and epistemological and methodological pragmatism and pluralism.
Study design:	Delphi studies are undertaken in two distinct steps: an idea generating or issue determining step and a consensus facilitating step; Phase 1 identified change in demand within the Service using a descriptive statistical approach to analyse national health data; Phase 2 then determined the issues hindering service development through interviews with healthcare professionals, which asked healthcare professionals to predict how and why treatment usage would change in the future and how services could better plan for changes; Phase 3 to understand how capacity should be developed within the Service, consensus was facilitated on service development needs with healthcare professionals by iteratively distributing, analysing and revising online questionnaires.

Findings 1: Identifying changes in treatment usage using descriptive analysis of national datasets

4.1 Introduction

No publications were found which explained how increased incidence and developments in treatment modalities had changed demand within the NHS Scotland prostate cancer service (the Service). To understand how demand on the Service had changed, I mined and analysed data to present a comprehensive overview of usage of prostate cancer treatment in Scotland. This Phase of research was the first step in determining issues.

As I used a breadth of data to create a picture of prostate cancer incidence and treatment usage across Scotland, analysis produced several findings. These findings indicated to two service issues: inequality in service delivery resulting from geographical and demographic factors, and increased treatment usage resulting from increased incidence and developments in treatment modalities. I sought guidance from the steering group who considered increased treatment usage to be the most pertinent issue given missed waiting time targets (NHS National Services Scotland, 2019). Therefore, this chapter presents findings from analysis of national datasets to provide a descriptive analysis of changes in incidence and treatment usage. This provides understanding of how usage of the Service had changed (RQ1).

Following this introduction (4.1), I provide findings for Phase 1 including a description of the 45 and over, Scottish male population (4.2), Scottish prostate cancer population (4.3), active prostate cancer treatment usage (4.4), and palliative prostate cancer treatment usage (4.5), before giving an account of the benefits and limitations that I found when using national datasets (4.6) and providing a brief summary of findings (4.7).

Specifically, I used these findings to summarise historical changes in population, incidence and treatment usage and presented as tables or graphs. Using population data allowed me to speculate whether increased demand on the Service was due to increased incidence and developments in treatment modalities, or also due to changes in population size. I did this by weighting incidence data per 10,000 men using age, sex and Health Board specific population data, and weighting treatment usage data with incidence data, i.e. calculating the percentage of men diagnosed who were treated with each treatment modality. Some health data were incomplete; percentage of incomplete data for each treatment modality is given in Appendix 11.

4.2 45 and over, Scottish male population

Between 1996 and 2012, the 45 and over, Scottish male population increased by 1.01-1.02% each year from 890,844 to 1,121,481 men. This increase was consistent across all 5-year age cohorts used to organise the data. The number of men within each of these age cohorts increased by 0.96-1.09% each year. During this time, West of Scotland Managed Cancer Network (WoSCAN) had the largest population with 45.17-46.62% of the population living there during this period and the remainder of the population was divided between East of Scotland Managed Cancer Network (SCAN) and North of Scotland Managed Cancer Network (NoSCAN), with 26.96-27.59% and 26.42-27.40% of men living within each Managed Cancer Network (MCN) region respectively during this period. The disproportionate size of the WoSCAN region is due to the inclusion of the Greater Glasgow and Clyde Health Board which alone had 19.85-21.62% of the population. As expected, the size of the population decreased with age with those aged 45-54 accounting for 34.58-36.22% of the population. This was similar across all MCN regions with the 45-54 age cohort accounting for 32.99-36.76%, 34.40-36.33% and 35.64-36.41% of the NoSCAN, SCAN and WoSCAN populations respectively.

4.3 Scottish prostate cancer population

The average annual incidence of prostate cancer increased from 2037 diagnoses per year in 1997-2000 to 3,003 diagnosis per year in 2008-2012 (47%), as shown in Table 13, equating to an additional 81 men diagnosed with prostate cancer each month in Scotland in 2012. The change in incidence in NoSCAN was found to be smallest, increasing from 585 men diagnosed per year in 1997-2000 to 810 in 2009-2012 (39%). Then, WoSCAN where incidence was found to increase from 865 men diagnosed per year to 1274 (47%). Finally, the largest increase in incidence was found in SCAN, where incidence increased from 588 men diagnosed per year to 919 (56%). Though more men were diagnosed each year in WoSCAN, WoSCAN had a larger male population than NoSCAN and SCAN.

When incidence data were weighted with population data, as shown in Table 14, likelihood of being diagnosed with prostate cancer increased from 22 men per 10,000 men living in Scotland in 1997-2000, to 27 men in 2009-2012. Men are most likely to be diagnosed with prostate cancer in SCAN (30 men per 10,000 in 2009-2012) and least likely to be diagnosed in WoSCAN (26 men per 10,000 in 2009-2012).

In Scotland, incidence increased across all age cohorts though a shift towards younger diagnosis was evident, with diagnoses in the 45-54 age cohort increasing by 152% (n=67) between 1997-2000 and 2009-2012, and diagnosis in the 75-84 age cohort increasing by only 5% (n-38) in the same period. All MCNs followed a similar pattern as shown in Figure 9. Though men aged 65-74 still accounted for most diagnoses across all regions, a shift towards younger diagnosis was evident across all MCN regions.

Table 13: Prostate cancer average annual incidence

	1997-2000	2001-2004	2005-2008	2009-2012
SCOTLAND	2,037	2,520	2,763	3,003
NOSCAN	585	650	727	810
SCAN	588	747	884	919
WOSCAN	865	1,123	1,152	1,274

Table 14: Prostate cancer average annual incidence per 10,000 men

	1997-2000	2001-2004	2005-2008	2009-2012
SCOTLAND	22	26	27	27
NOSCAN	24	25	26	27
SCAN	24	29	32	30
WOSCAN	21	26	25	26

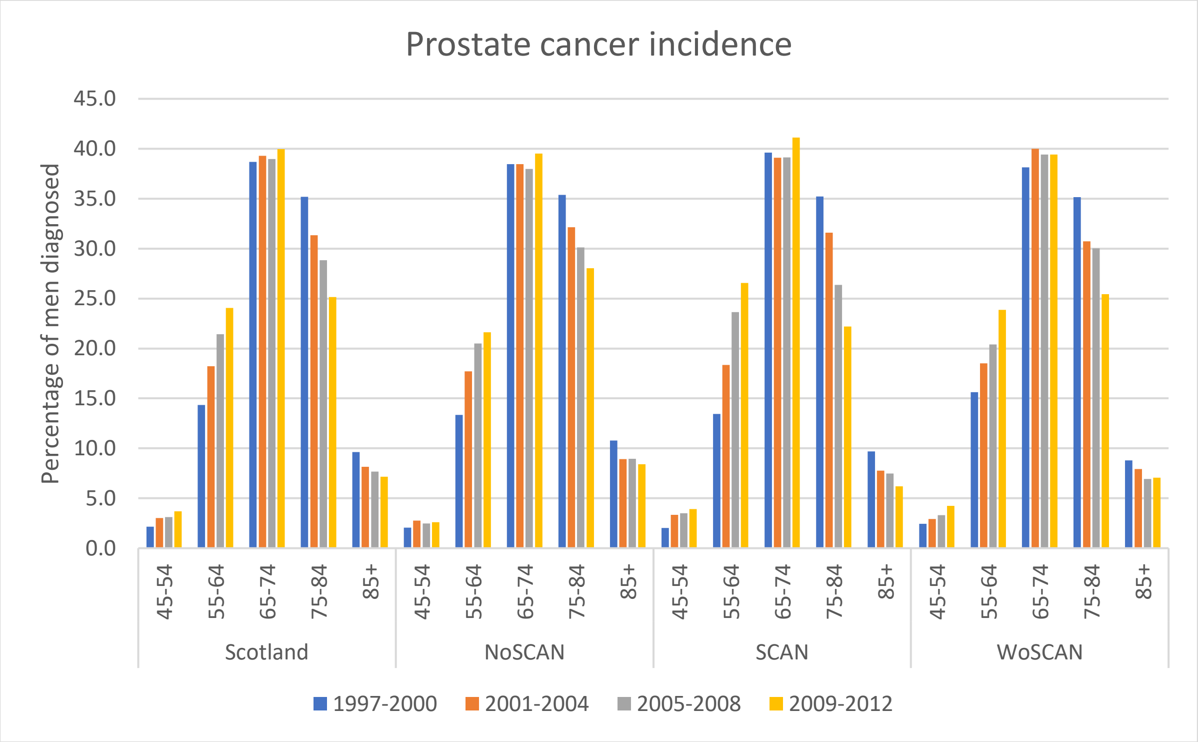


Figure 9: Percentage of men with prostate cancer diagnosed by age, each year in Scotland and in each Managed Cancer Network (MCN) region

The trend towards younger diagnosis was still evident when weighted with population data as shown in Figure 10. And though risk of prostate cancer diagnosis increased with age, this difference had reduced with time and this was most evident in SCAN where men aged 65 and over were equally likely to be diagnosed with prostate cancer. Most prominently, men in SCAN are equally likely to be diagnosed with prostate cancer aged 65 to 74 than aged 85 or over.

Overall, incidence has increased leading to increased demand on the Service. And as increased incidence of prostate cancer is thought to result from increased detection and not a genuine increase in likelihood of developing prostate cancer, younger men are likely to be diagnosed with a low grade prostate cancer and are therefore, likely to engage with the Service for longer, for example by using active surveillance to delay radical treatment. The next section gives trends in these active treatments.

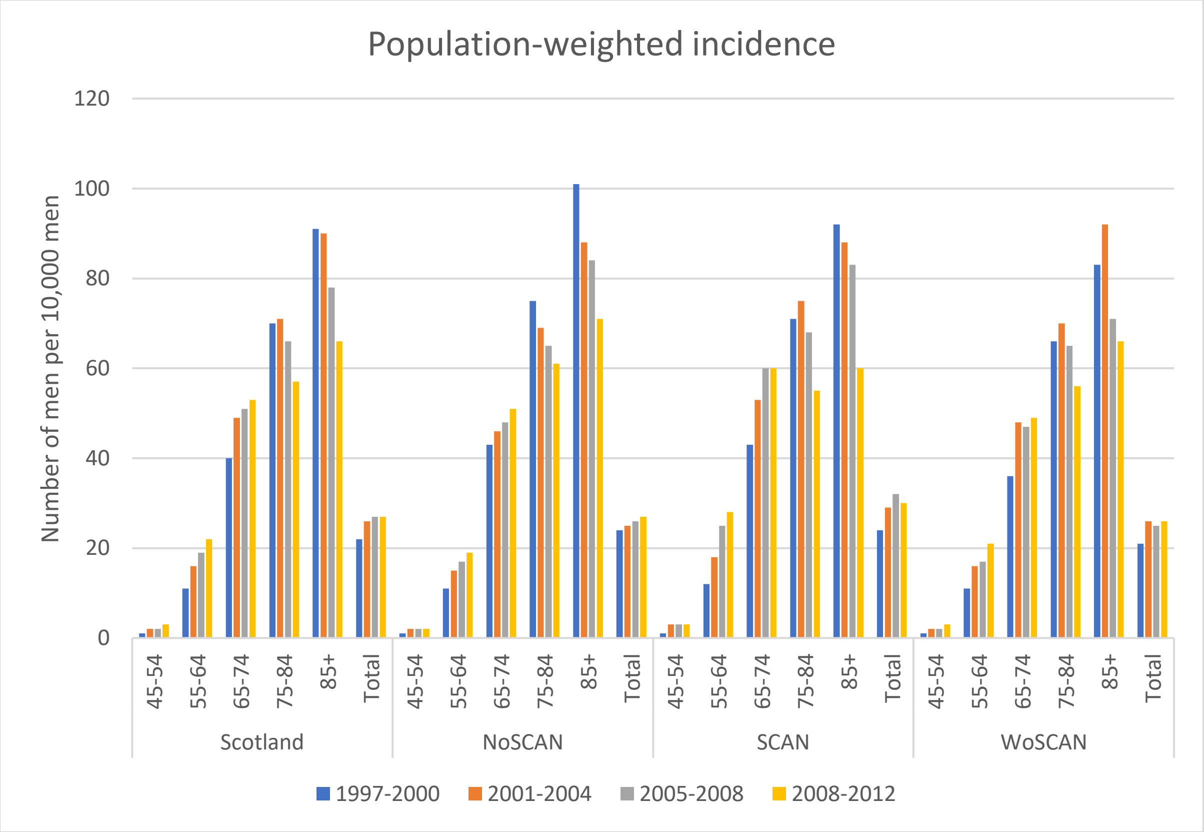


Figure 10: Prostate cancer incidence per 10,000 men by age and year of diagnosis in Scotland and in each Managed Cancer Network (MCN) region

4.4 Active prostate cancer treatment usage

Active prostate cancer treatments include active surveillance, radiotherapy and surgery. Active surveillance was developed to delay radical treatments, namely radiotherapy and surgery, and morbidity associated with these treatments (European Association of Urology guidelines, 2019). This section first addresses actual usage of treatments, then treatment data is weighted by age and year specific incidence data.

As active surveillance is not coded in national datasets, government waiting time targets (NHS National Services Scotland, 2019) and treatment guidelines (EAU guidelines, 2019; National Institute for Health and Care Excellence, 2019) were used to estimate the number of patients likely to have engaged with active surveillance. Specifically, patients diagnosed with ISUP Grade 1-3 who were recorded as having a delay to treatment of >91 days were considered to have had active surveillance. Though men with ISUP Grade 3 prostate cancer would not be recommended active surveillance (EAU guidelines, 2019), categorising patients by ISUP Grade is recent, and national data does not facilitate differentiation between ISUP Grade 2 and 3. As patients with ISUP Grade 3 would also be unlikely to engage with watchful waiting (EAU guidelines, 2019; NICE, 2019) it was reasonable to include this in active surveillance estimates. As men are only discharged from active surveillance follow-up when other treatment is indicated, active surveillance usage has a substantial impact on service capacity. So, active surveillance data was analysed by days until treatment to understand what proportion of men stay on active surveillance pathways, and what proportion progress to need other treatment.

Overall, both active surveillance usage and radical treatment usage increased between 1997-2000 and 2009-2012, as shown in Figure 11. Active surveillance usage increased in Scotland from 425 men per year to 1160 men per year (172.9%) and radical treatment usage increased from 1044 per year to 1360 per year (23.2%). And these trends were evident across all MCNs where active surveillance usage increased by 142.5% (n=151), 167.9% (n=319) and 203.8% (n=265) in NoSCAN, WoSCAN and SCAN respectively and where radical treatment usage increased by 35.1% in SCAN (n=113) and WoSCAN (n=138), and 19.8% (n=65) in NoSCAN. The increase in radical treatment is attributed to increased usage of radiotherapy and not surgery. Overall, radiotherapy usage increased from 440 to 854 patients per year (94.1%), whereas surgery decreased from 717 to 590 patients per year (17.7%). These trends were evident across all MCNs where radiotherapy increased by 92.2% (n=119), 94.5% (n=171) and 96.2% (n=125) in NoSCAN, WoSCAN and SCAN respectively, and surgery decreased by 9.7% (n=22), 12.2 (n=30) and 30.2% (n=74) in SCAN, WoSCAN and NoSCAN respectively.

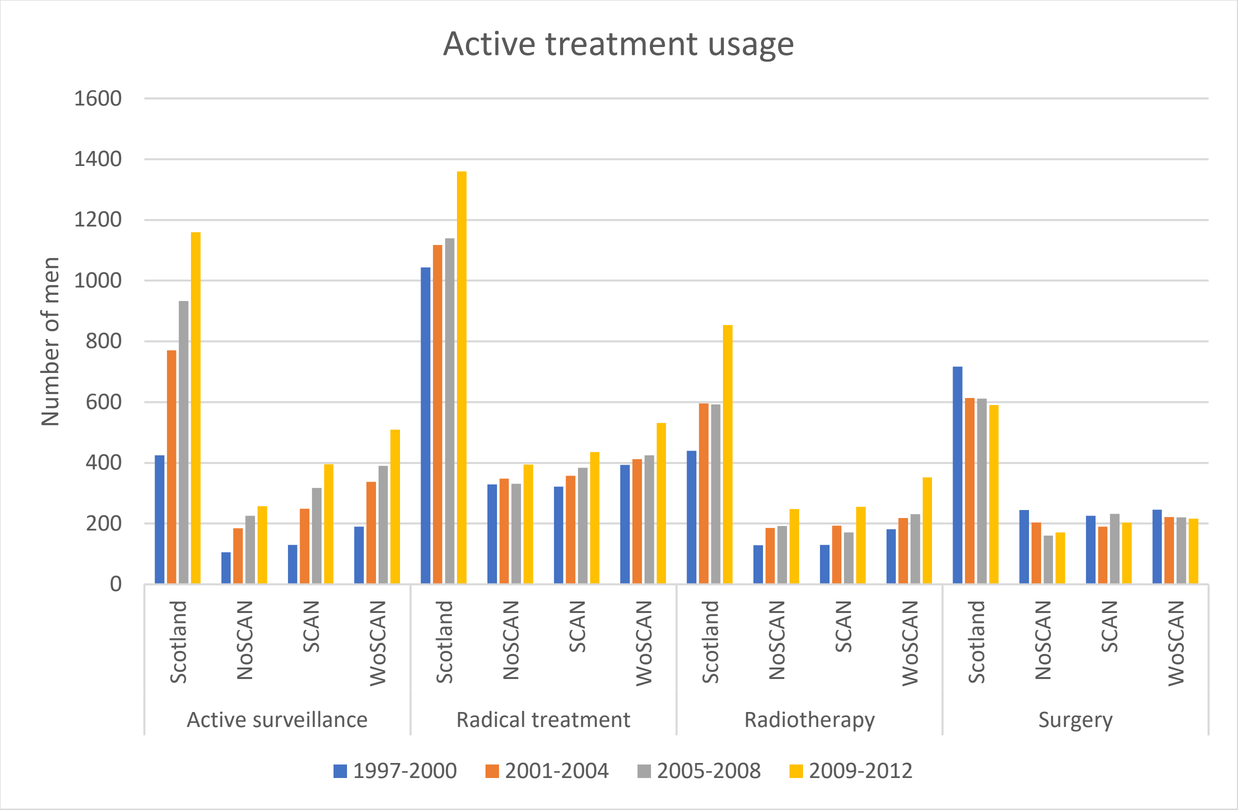


Figure 11: Number of patients who had active treatment

When weighted with incidence data, active surveillance usage increased from 20.9% (n=425) of patients diagnosed in 1997-2000 to 38.6% (n=1160) in 2009-2012, as shown in Figure 12. These increases were mostly due to an increase in the number of men who needed further treatment within 182 days of diagnosis (10.1% (n=206) of patients diagnosed with prostate cancer in 1997-2000 increasing to 14.9% (n=447) in 2009-2012), and patients who have not progressed to need further treatment (4.9% (n=99) in 1997-2000 of patients diagnosed with prostate cancer increasing to 18.0% (n=542) in 2009-2012). Patients were equally likely to have active surveillance in SCAN (n=130) and WoSCAN (n=190) with 22.0% of patients having active surveillance in 1997-2000 rising to 42.9% (n=395, 209) of patients in 2009-2012, and least likely to have advice surveillance in NoSCAN where active surveillance usage increased from 17.9% (n=106) to 31.7% (n=509) of patients diagnosed only. Though engagement with active treatment usage was the same in SCAN and WoSCAN, men in SCAN were more likely to progress to need further treatment.

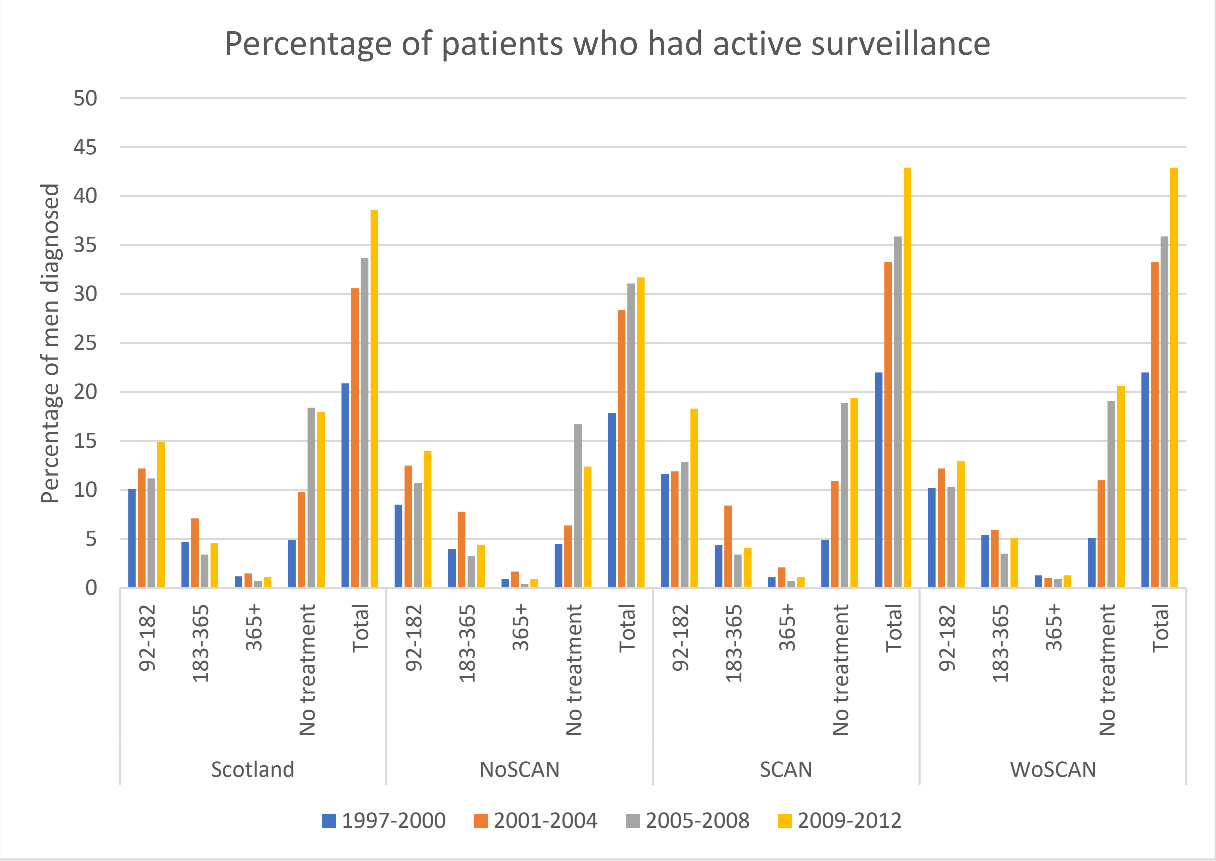


Figure 12: Percentage of patients who had active surveillance by length of treatment and year of diagnosis in Scotland and in each Managed Cancer Network (MCN) region

Though the number of patients having radical treatment increased in Scotland, the percentage of patients treated decreased from 51.2% (n=1044) to 45.3% (n=1360) in Scotland, as shown in Figure 13, reflective of increases in active surveillance usage. This was evident in all MCN regions, though men diagnosed in WoSCAN were least likely to receive radical treatment, reflective of the greater proportion of men in WoSCAN using active surveillance and not progressing to need further treatment. Decreased radical treatment usage was also evident across all age groups in Scotland and this was also evident across all MCN regions.

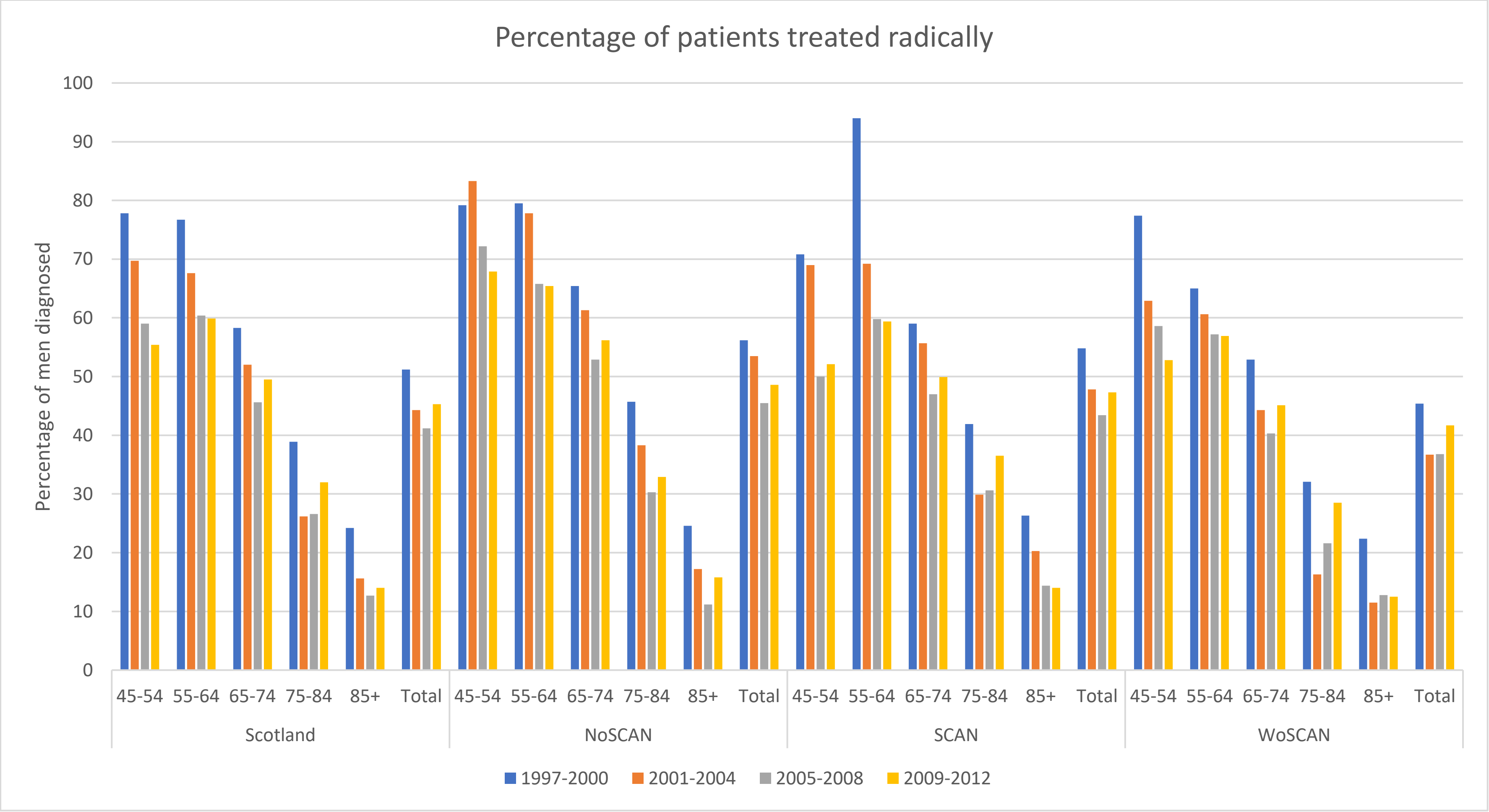


Figure 13: Percentage of patients who had radical treatment by age and year at diagnosis in Scotland and in each Managed Cancer Network (MCN) region

Despite decreases in the percentage of men having radical treatment, men were more likely to be treated with radiotherapy; 21.6% (n=440) of men diagnosed had radiotherapy in 1997-2000 increasing to 28.4% (n=854) of men in 2009-2012, as shown in Figure 14. And this increase was evident across all MCN regions with the percentage of patients having radiotherapy increasing from 20.9% (n=181), 22.1% (n=130) and 22.1% (n=129) in 1997-2000 to 27.6% (n=352), 27.7% (n=255) and 30.6% (n=248) in 2008-2012 in WoSCAN, SCAN and NoSCAN respectively. Overall, younger men were less likely to have radiotherapy than in previous years with the percentage of patients having radiotherapy decreasing from 39.2% (n=17) and 40.5% (n=118) to 28.4% (n=32) and 34.2% (n=247) in the 45-54 and 55-64 age cohorts respectively, likely to be the result of increased active surveillance usage. And radiotherapy usage increased across all other age groups in Scotland and this was also evident across all MCN regions.

Consistent with overall radical treatment usage, men were less likely to be treated with surgery; 35.2% (n=717) of men diagnosed had surgery in 1997-2000 increasing to 19.7% (n=590) in 2008-2012, as shown in Figure 15. This decrease was evident across all age cohorts, reflective of increased active surveillance and radiotherapy usage. These decreases were also evident across MCNs. And though likelihood of having surgery differed between MCNs in 1997-2000 (41.8% (n=245), 38.5% (n=226) and 28.5% (n=246) in NoSCAN, SCAN and WoSCAN respectively), likelihood of having surgery was more similar across MCNs in 2008-2012 (22.2% (n=204), 21.1% (n=171) and 16.9% (n=216) in SCAN, NoSCAN and WoSCAN respectively), though men are still less likely to have surgery if they live in WoSCAN.

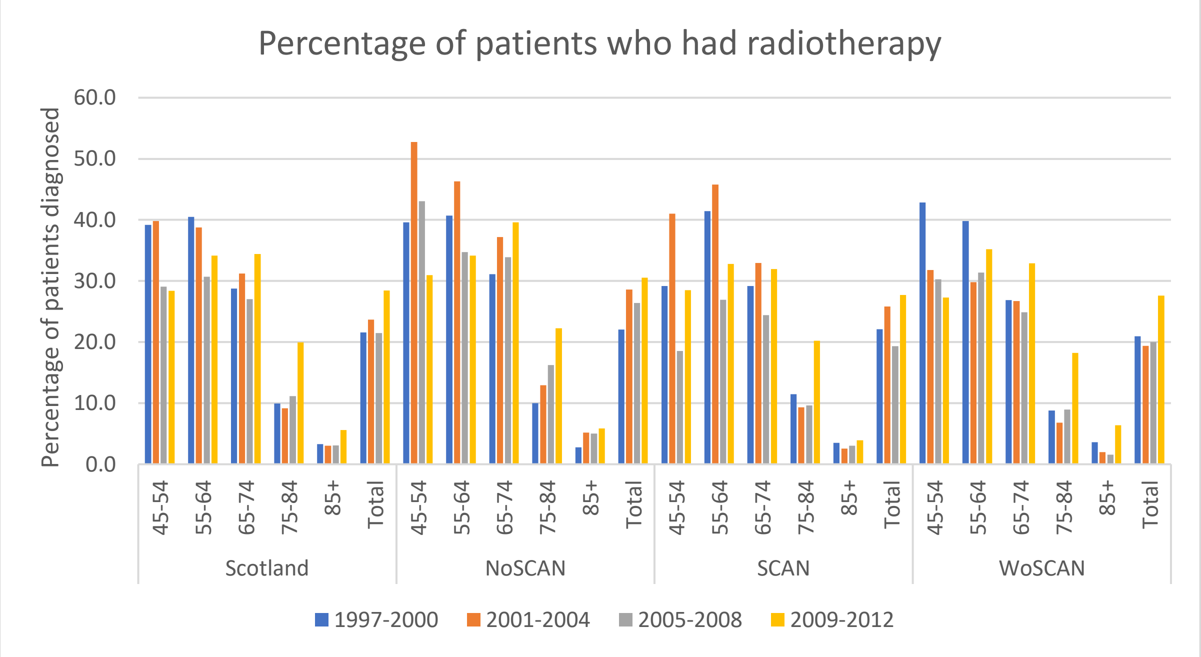


Figure 14: Percentage of patients who had radiotherapy by age and year at diagnosis in Scotland and in each Managed Cancer Network (MCN) region

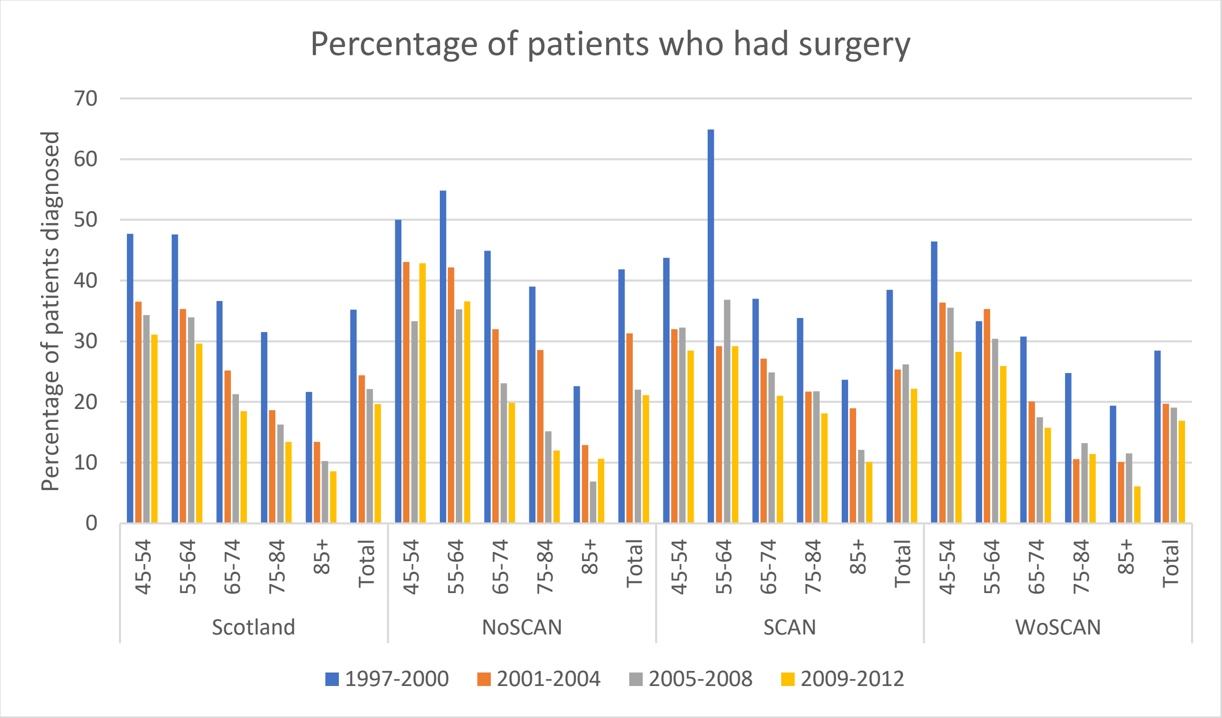


Figure 15: Percentage of patients who had surgery by age and year at diagnosis in Scotland and in each Managed Cancer Network (MCN) region

Overall, usage of active treatments increased in Scotland. Specifically, usage of active surveillance and radiotherapy increased whilst usage of surgery decreased. This is likely to be reflective of a shift towards younger diagnosis and known developments within the treatment pathway (2.2.5; 2.2.6). Specifically, increased usage of active surveillance represents a substantial increase in demand on the Service as many men will remain on active surveillance indefinitely.

4.5 Palliative prostate cancer treatment usage

Palliative care encompasses care for people who are not eligible to be treated with curative intent and is primarily concerned with slowing disease progression and treating symptoms of a disease (NICE, 2019). In prostate cancer care, palliative treatments include watchful waiting, hormone therapy and chemotherapy. Unlike active treatment protocols where patients will receive one treatment and then progress onto the next if needed, palliative treatment protocols are less prescriptive, and patients may have multiple lines of treatment, and stop and start treatments multiple times. However, from these data it was only possible to determine when they were first treated with chemotherapy and hormone therapy. As watchful waiting is not recorded as a treatment, it was only possible to determine whether a patient's first recorded treatment was delayed or whether the patient was not recorded as having treatment, and not whether a patient had watchful waiting at any point. Like active surveillance estimates, government waiting time targets (NHS National Services Scotland, 2019) and treatment guidelines (EAU guidelines, 2019; NICE, 2019) were used to estimate the number of patients likely have engaged with watchful waiting as a first treatment only. Specifically, patients diagnosed with ISUP Grade 4-5 who were recorded as having a delay to treatment of >91 days were considered to have had watchful waiting as their first treatment.

Overall, usage of palliative care services decreased, likely the result of younger diagnosis, and known developments in radiotherapy (2.2.6), as shown in Figure 16. The number of patients who engaged with watchful waiting as a first treatment decreased by 31.2% (n=270) across Scotland between 1997-2000 and 2008-2012. Though hormone therapy increased by 18.4% (n=212) during this period, when patients who were recorded as given hormone therapy prior to, or on the same day as radiotherapy (neoadjuvant with radiotherapy) were excluded, hormone therapy usage was found to decrease by 22.4% (n=183). Only chemotherapy increased (by 400% (n=200) between 1997-2000 and 2008-2012) as it was a new treatment in the palliative pathway (2.2.7). All trends were consistent across MCN regions.

The percentage of patients who had watchful waiting as their first treatment decreased steadily from 1997-2000 until 2005-2008, and then decreased sharply in 2009-2012, as shown in Figure 17. As this sharp decrease was evident across all MCNs, it is likely to be the result of continued development of the palliative pathway and emergence of new evidence and treatments.

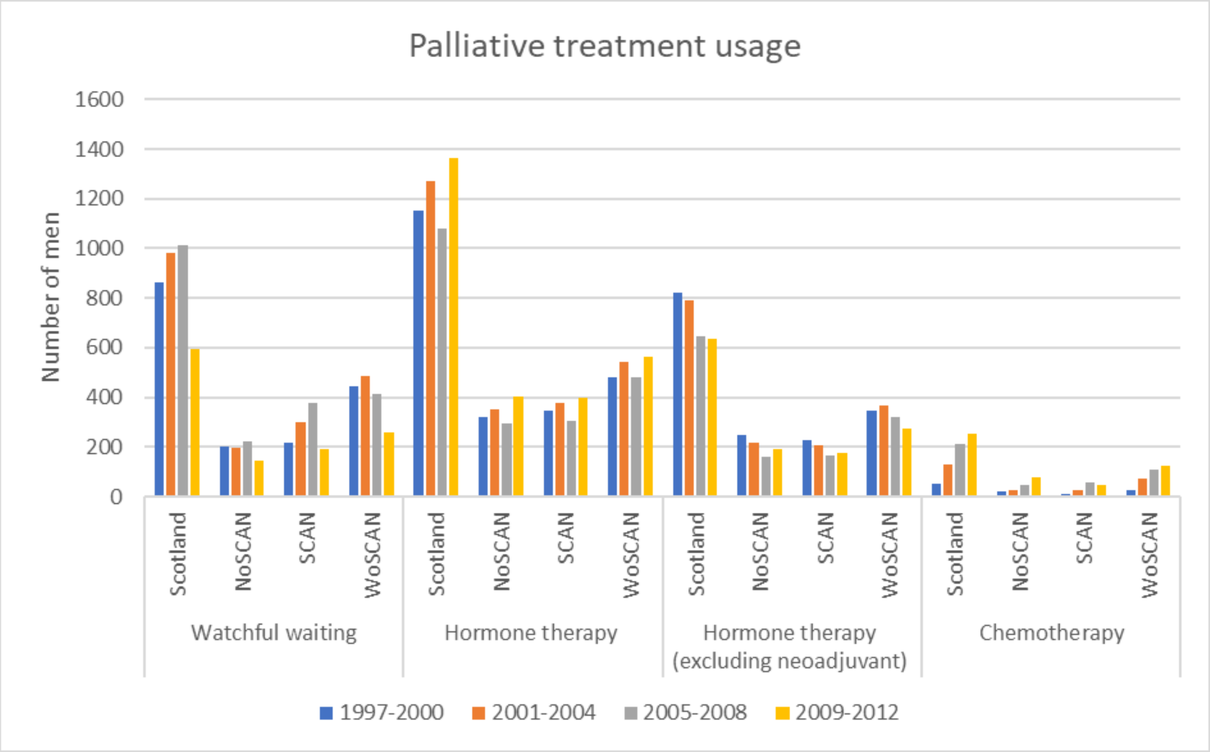


Figure 16: Number of men who had palliative treatment

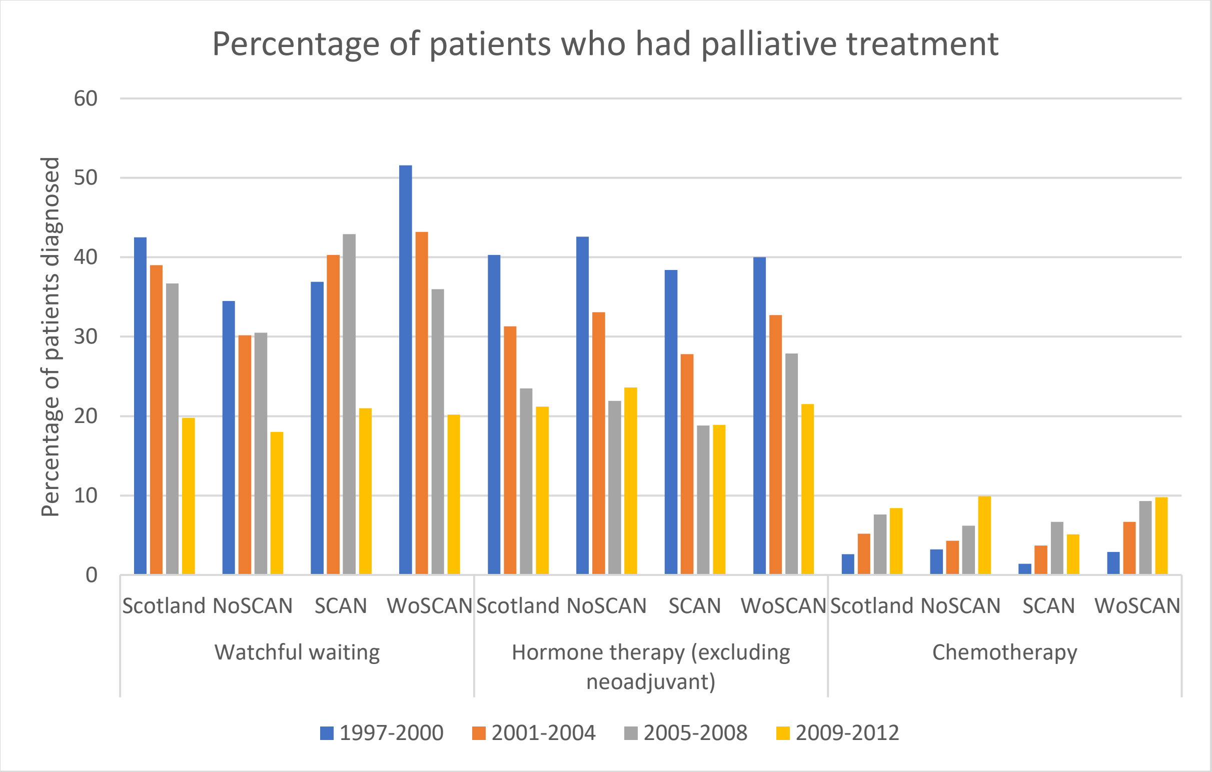


Figure 17: Percentage of patients who had palliative treatment by age and year at diagnosis in Scotland and in each Managed Cancer Network (MCN) region

Hormone therapy (excluding neoadjuvant) usage also decreased in Scotland from 40.3% (n=820) to 21.2% (n=637) of patients beginning treatment, and this was consistent across all MCNs. And chemotherapy usage increased from 2.6% (n=52) to 8.4% (n=252). Though these trends were consistent across MCN regions, men in SCAN were less likely to treat patients with chemotherapy, and chemotherapy usage increasing from 1.4% (n=8) to 5.1% (n=59) only in SCAN. This is likely to be the result of younger diagnosis in SCAN compared with other MCN regions, leading fewer men to require treatment for metastatic disease.

As only the first line of treatment with each modality was provided, it was not possible to know whether decreased usage of each treatment modality reflects a decrease in demand on this part of the Service. Palliative treatment protocols are developing rapidly to include multiple lines of treatment (2.2.7), so patients are being treated more intensively and for longer periods of time.

4.6 Using national datasets

When I started this research, I understood my role in quantitative research to be passive. However, through this phase of research, I realised how my interaction with the data was shaping the findings of this study. My active role within this research was evident in choosing which data to collect, development of the coding frame, choosing which findings to present, and how the findings were then presented (Hacking, 1990; 1992; Abrahamson et al., 2016; Zyphur & Pierides, 2017), which together created a representation of demand within the Service. To mitigate my impact on this representation, I used NICE (2019) and EAU (2019) guidelines to guide development of the coding frame, and then discussed the findings with the Steering Group and with healthcare professionals during interviews to ensure that the most accurate representation was presented. Further, discussion and feedback from supervisors, reading published literature, and continual reflection also helped to mitigate my impact. The remainder of this section gives an account of the limitations of this representation resulting from the use of national datasets.

This Phase used national datasets to understand changes in service usage, specifically census and cancer registry data were used to detect trends in incidence and treatment usage. There are clear benefits to using national datasets including access to health data for a whole population, access to routine data recorded over a long period, and the avoidance of issues related to sampling error and selection bias (Bain et al, 1997). Other benefits include the cost-effectiveness and efficiency of data collection, and general acceptance of the value of national datasets.

Though the value of using national datasets is clear, the value of each national dataset dependant on the completeness and accuracy of the dataset. Though there is a sparsity of publications critiquing the completeness and accuracy of census data, the Office for National Statistics (ONS) do provide their own critique of the data and try to account for missing data (ONS, 2012). As reflected in this methodology (ONS, 2012), the quality of Scottish census data is likely to be high.

Unlike census data, cancer registry data has been widely reviewed in the literature. Some studies report only 54-69% accuracy in cancer registry datasets (Counsell, Collie & Grant, 1996; Lucke, Hole & Mackie, 1997). However, this is due to issues with system transfer between sites and not due to incorrect coding (Information Services Division, 2008) and studies prior to this time point reported 95-100% accuracy (Brewster, Crichton & Muir, 1994; Brewster, Muir & Crichton, 1995; Melia et al., 1995). However, criticism of data accuracy still exists (Malin et al., 2002). No review of prostate cancer registry data was identified, though evaluations of other cancer registries show high levels of accuracy (Brewster, Crichton & Muir, 1994; Brewster, Muir & Crichton, 1995; Melia et al., 1995; Brewster & Stockton, 2008), though Malin (et al., 2002) cautions that care should be taken when analysing data relating to treatment modality and grade. A recent audit from ISD reported 87% completeness in cancer registry data in 2018 data (Information Services Division Scotland, 2019). This study used treatment modality data and found that datasets were incomplete. For transparency, a summary of incomplete data are included in Appendix 11.

In addition to completeness and accuracy, the value of national datasets also relates to how meaningful the data collected is. In this study, the meaningfulness or validity of datasets was problematic. Particularly, the routine data collected by the Scottish cancer registry did not accurately reflect prostate cancer treatment. Particularly, cancer registry data is recorded for first usage of each treatment modality only and this led to several issues with managing and analysing data. Where possible, issues were accounted for within the data coding frame used and the validity of treatment coding is discussed for each modality below: active surveillance and watchful waiting, radiotherapy and surgery, and hormone therapy and chemotherapy.

Active surveillance and watchful waiting were not recorded as a treatment in cancer registry datasets in Scotland. In this study, men who experienced a delay between diagnosis and treatment of >91 days were considered to have engaged with active surveillance or watchful waiting. As a result, government waiting time targets (NHS National Services Scotland, 2019) and treatment guidelines (EAU guidelines, 2019; NICE, 2019) were used to estimate the number of men likely to have engaged with active surveillance and watchful waiting. However, this was also problematic as cancer registry datasets to not differentiate between 3+4 and 4+3 Gleason Score; men with a 3+4 cancer are likely to be offered active surveillance, but men with a 4+3 are not. Additionally, a man may not engage with watchful waiting as a first treatment, but may engage with it later, and so trends in watchful waiting are unlikely to be reflective of true usage of the treatment. Rather, decreases in watchful waiting usage reflect developments in the palliative care pathway that have led to better tolerance and efficacy of treatment (EAU guidelines, 2019).

Radiotherapy and surgery are not solely used for the radical treatment of prostate cancer. Rather, both radiotherapy and surgery can be used in the treatment of advanced cancer, though this is not recommended in guidelines yet (EAU guidelines, 2019; NICE, 2019). It was not possible to confidently differentiate between radiotherapy and surgery as radical or as palliative treatments, so trends given reflect usage of treatments for either purpose. And as the palliative use of these modalities are not currently recommended (EAU guidelines, 2019; NICE, 2019), it is likely that these numbers will be small.

Though orchidectomy is still recommended as a surgical treatment for prostate cancer (EAU guidelines, 2019; NICE, 2019) it is not commonly given (Atta et al., 2019) and so was not discussed earlier in this thesis. However, at one time, due to the lack of palliative treatment available to men with metastasis prostate cancer, orchidectomy was a common procedure. In this study, the number of men having surgical treatment includes orchidectomy and radical prostatectomy. Radical prostatectomy and orchidectomy impact very differently on the Service from length of time taken to perform the procedure, to the type of support needed before and after treatment. Again, it was not possible to confidently differentiate between radical prostatectomy and orchidectomy, so trends given reflect total usage of surgery. Therefore, decrease in usage of surgery may not be reflective of reduced usage of the surgical service, but reductions in orchidectomy procedures. In other regions of the UK both radical prostatectomy and radiotherapy usage increased during this period (Eylert et al., 2015).

Trends in hormone therapy were also complicated by use of hormone therapy at different points in the treatment pathway; neoadjuvant or adjuvant with radical radiotherapy, and as a palliative treatment. In this study, efforts were made to differentiate between the hormone therapy administered radically and palliatively; where hormone therapy was recorded as given prior to or on the same day as radiotherapy, it was coded as neoadjuvant or adjuvant treatment. All other recordings of hormone therapy were coded as administered palliatively. Where a person was coded as receiving neoadjuvant or adjuvant hormone therapy with radiotherapy, it was not possible to determine whether they then progressed to require palliative hormone therapy also, so trends in hormone therapy are not reflective of patients who had recurrence following radiotherapy with hormone therapy, though these numbers are expected to be low (Hamdy et al., 2016).

Finally, palliative pathways now involve multiple lines of hormone therapy and chemotherapy treatment. As only the first treatment of each modality is recorded in the cancer registry dataset, these trends do not account for multiple lines of treatment. Rather, they are reflective of the number of patients having treatment only, not the number of treatments administered within the Service.

Overall, analysis of the cancer registry was useful in developing understanding of treatment usage across the Service. Specifically, alongside understanding of the treatment pathway provided by treatment guidelines (EAU guidelines, 2019; NICE, 2019) and interviews with healthcare professionals, cancer registry data were useful in understanding capacity shortage as existing throughout the Service and not in some parts only. However, validity of treatment modality coding was problematic. Delayed treatment modalities were missing from the dataset, though usage of active surveillance is known to have a substantial impact on service capacity as men on active surveillance protocols are not discharged until other treatment is indicated (EAU guidelines, 2019; NICE, 2019). Also, surgery and hormone therapy are recommended for use at different points in the treatment pathway and cancer registry data does not reflect this (EAU guidelines, 2019; NICE, 2019). Ultimately, treatment modality data recorded in the Scottish cancer registry dataset is not reflective of practice but helped to develop understanding of capacity shortage within the Service.

4.7 Summary

As no publications were found to explain how increased incidence and developments in treatment modalities had changed demand within the Service, I mined and analysed data from national datasets to present a comprehensive overview of usage of prostate cancer treatment in Scotland. Specifically, I presented findings from analysis of national datasets to provide a descriptive analysis of changes in incidence and treatment usage in this Chapter. This provided understanding of how usage of the Service had changed (RQ1). The following changes were evident:

Incidence:	Incidence of prostate cancer has increased in Scotland by 47% equating to an additional 81 men diagnosed with prostate cancer each month in Scotland. This increase was evident across all age cohorts, though larger increases were seen in younger men. When weighted, incidence was found to have plateaued, though this was not consistent across regions, and while risk of developing prostate cancer was still greater later in life, this was reducing.
Active treatment:	Overall, usage of active treatments increased in Scotland. Specifically, the number of men who had active surveillance and radical treatments increased. However, the percentage of patients who had radical treatment decreased. When radical treatments were analysed, the number and percentage of men having surgery decreased, and radiotherapy increased (though percentage increased only in older men). These findings are likely the result of increased active surveillance usage, and radiotherapy as a safer treatment option in men with comorbidities or frailty.
Watchful waiting:	As national datasets did not record watchful waiting, the number and percentage of patients having watching waiting as a first treatment could be estimated only. Overall, in Scotland watchful waiting as a first treatment has decreased, reflective of improvements in other treatment modalities and a shift towards younger diagnosis.
Hormone therapy:	Hormone therapy has increased in Scotland reflective of increased usage of radiotherapy. When neoadjuvant hormone therapy was excluded, hormone therapy usage decreased, reflective of improvements in other treatment modalities and a shift towards younger diagnosis.
Chemotherapy:	Chemotherapy usage increased in Scotland by 400% as a result of emerging evidence and approval by the Scottish Medicines Consortium

Overall, more men were diagnosed with prostate cancer in Scotland and a shift towards diagnosis at a younger age. This is thought to have contributed to increased active treatment usage and decreased palliative treatment usage. Active surveillance and radiotherapy usage increased whilst surgery usage decreased reflective of a shift towards younger diagnosis and known developments within the treatment pathway (2.2.5; 2.2.6). And increased usage of active surveillance represents a substantial increase in demand on the Service as many men will remain on active surveillance indefinitely. Therefore, demand on biopsy and active treatment parts of Service have increased substantially. Though the number of men being treated palliatively had decreased, it was not possible to know whether this reflected a decrease in demand on this part of the Service. Palliative treatment protocols are developing rapidly to include multiple lines of treatment (2.2.7), so patients are being treated more intensively and for longer periods of time.

The next Chapter uses interviews with healthcare professionals to predict how usage of the NHS Scotland prostate cancer is predicted to change (RQ1), and gain understanding of why the NHS Scotland prostate cancer service was unable to meet demand (RQ2). Changes in the number of men treated with each modality identified in this Phase were used to guide development of the interview schedule.

Findings 2: Understanding issues in service development using interviews with healthcare professionals

5.1 Introduction

Demand within the NHS Scotland prostate cancer service (the Service) had increased, but the Service had not developed to meet this demand as shown in waiting time targets (NHS National Services Scotland, 2019). Though reports in Scotland warned of an expected drop in funding in healthcare (Christie commission, 2011), cancer services were generally protected against budgetary constraints (Scottish government, 2008a; 2016a), and the clinical workforce has grown consecutively since 2012 (Scottish government, 2018a). Though staffing in Urology services was raised as a recent concern (Scottish government, 2018a). Beyond this, no publications were found to explain why the Service had not developed to meet demand.

In Phase 1, I found that capacity shortage may exist across all parts of the Service. Therefore, I interviewed healthcare professionals working across the Service to predict how usage of the Service is predicted to change (RQ1), and gain understanding of why the Service was unable to meet demand (RQ2). Following this introduction (5.1), I summarise the participant sample (5.2). Then I provide an account of healthcare professionals' predictions on changes in treatment usage (5.3), I provide a definition for quality care as understood by the healthcare professionals interviewed, which emerged as a key driver in service development (5.4). I then list the five issues hindering service development within the Service: a lack of cohesion (5.5) and leadership (5.6), the training of a multi-disciplinary workforce (5.7), and understanding the role of the patient (5.8) and primary care (5.9) within the Service. Finally, I reflect on my position in relation to the research and finding value in my understanding of the data (5.10) and briefly summarise findings (5.11).

5.2 Participants

24 healthcare professionals were recruited from across Scotland. Though most participants were interviewed in person (n=21), two participants were interviewed via phone and one participant asked for the interview schedule and provided written responses. Consent was provided by all 24 participants prior to interview, though one person interviewed was new in post and did not consent to having the interview recorded due to lack of confidence, so consent was gained to take extensive notes during the interview instead. A detailed breakdown of participants is given in Table 15. As only a small number of specialist Allied Health Professionals worked within the Service, Managed Cancer Network (MCN) region is not given for these participants to maintain anonymity.

Table 15: Participant characteristics and method of interview

Participant number	Job role	Managed Cancer Network region	Interview
1	Nurse	WoSCAN	In person
2	Oncologist	WoSCAN	In person
3	Urologist	NoSCAN	In person
4	Urologist	NoSCAN	In person
5	Nurse	WoSCAN	In person
6	Urologist	WoSCAN	In person
7	Oncologist	WoSCAN	In person
8	General Practitioner	NoSCAN	Via phone
9	Nurse	WoSCAN	In person
10	Nurse	NoSCAN	In person
11	General Practitioner	WoSCAN	Via phone
12	Nurse	SCAN	In person
13	Allied Health Professional	N/A	In person (permission not given to record)
14	Nurse	SCAN	In person
15	Oncologist	WoSCAN	In person
16	Urologist	WoSCAN	In person
17	Urologist	WoSCAN	In person
18	Allied Health Professional	N/A	In person
19	Nurse	SCAN	In person
20	Urologist	SCAN	In person
21	Oncologist	WoSCAN	In person
22	Oncologist	SCAN	In person
23	Allied Health Professional	N/A	In person
24	Allied Health Professional	N/A	Written

As shown in Table 16, there was little difference in levels of participation between nurses (n=7), urologists (n=6), oncologists (n=5), and other (n=6). However, differences in participation were evident between the West (n=10), East (n=5) and North (n=3) MCN regions, and no oncologists working in the North participated. No reason for these differences is known.

Table 16: Summary of participant characteristics by specialisation and region

	Managed Cancer Network region		
Speciality	East	North	West
Nurse	3	1	3
Oncologist	1	0	4
Urologist	1	2	3
Other	6		

As stated, the Service is composed of a diverse range of healthcare professionals. As such, gaining an understanding of the full complement of healthcare professionals working within the Service was challenging. Though some healthcare professionals involved in the Service would be registered with professional bodies such as the Royal College of Radiologists and the British Association of Urological Surgeons only some of these bodies record the specialism of healthcare professionals at the level needed to inform this study. Additionally, many healthcare professionals within the Service worked across specialisms. For example, a renal surgeon may also consult with patients with prostate cancer. As knowledge of the Service was understood to be shaped by an individual's experience of the Service, it was important that participants reflected this diversity of experience. As such, recruitment was not limited to people with a *specialism* in prostate cancer, but an *interest* in prostate cancer. As a result, gaining accurate data on the population sampled from was not possible.

5.3 Understanding the impact of historic and predicted service usage

During interviews, healthcare professionals were presented with the historic changes in treatment usage identified in Phase 1 and asked why each trend had occurred and how they expected trends to change in the future, followed by questions about the impact of any further changes. When describing historic trends, healthcare professionals identified substantial capacity shortage across the entire Service including palliative care services and raised concerns that resources had not increased at the same rate as incidence or treatment usage. The quote below illustrates current efforts and anxieties relating to service capacity:

> "*I strongly believe, I'm actually having meetings just now with the general manager, because we're actually having to have a second oncology clinic because of numbers and volumes, etc, so that means the oncologist coming from [centralised service or 'hub' to peripheral health board]. We, for example, have an eight day cut off where patients coming from biopsy, for biopsy for prostate, coming to get results, but from the figures that we're looking at just now it's at least 13, 14 days which sounds not a lot when you say well that's only like six days but if you look at that, that's 8 days and then you put that into percentage and that's like 80%*

> *more delay on what, when the results are actually available. So, it's not necessarily even from right now, it's from a current problem which I'm not being able to meet the demand. Now we have a good service here, and we have a service that is actually geared towards doing these things. We've redesigned as much as we probably can, and we're struggling. Now if you go back to the projected figures of 28% or whatever, if you increase, and bearing in mind that's an increase in the numbers of diagnosis, not an increase in the numbers of referrals or investigations, or folk coming to be told that they don't have cancer, or folk getting treated for symptoms that they presented with and they didn't at the same time, then it, I don't know, we certainly, if that 28% happened this year or next year, it would just absolutely, just sweep everything off its feet and we'd be completely lost. So, my discussions with the managers are, 1. We're struggling a bit just now, 2. This is not going to get any better, but there's the figures and it's going to get worse over the next few years*." Participant 1

This finding drew attention to the severity of the capacity problem within the Service. And led some healthcare professionals to identify the capacity needs of the Service as those what would enable "*radical changes that are needed to say, new models of working. I think the tinkering round the edges and the making small changes is important in terms of making small cycles of change, but at a fundamental level for us to deal with capacity we need to look at bigger changes*" (Participant 9). Therefore, the capacity needs of the Service were not necessarily more of current capacities, but the development of capacities that would empower or enable more substantial change.

When predicting change, all healthcare professionals predicted an increase in demand for all treatments across all parts of the Service. However, healthcare professionals conceded that there was a possibility that some treatment options could eventually decline. Decline was predicted to be the result of changing patterns of presentation, for example changes in the number of men presenting with early or advanced stage cancer, or the implementation of technological advances, for example advances in surgical or radiotherapy technologies leading to clear indication that one modality is better than the other, or the integration of new technologies such as focal therapy, and not due to a decrease in the number of patients requiring treatment. However, these changes were unlikely to be imminent, and so all healthcare professionals were anticipating increased demand.

Though it was clear that service development had been ongoing to meet increased demand across all parts of the Service, the Service had not developed capacities quickly enough to meet this demand. When healthcare professionals described current service developments, it was clear that the development of service capacity to meet increased service usage was not the sole driver of service developments. Rather, healthcare professionals' understanding of quality care had also driven service developments.

5.4 Healthcare professional's understanding of quality care

Concerns regarding capacity shortage were realised when the Service began missing Government implemented measures of quality care. The Scottish government first measured the quality of the Service against its ability to meet waiting time targets (Scottish government, 2000; 2008a; NHS National Services Scotland, 2019), and then more recently with adherence to protocols (Scottish government, 2016a). During data analysis, quality care emerged as a primary driver of service development. However, the understanding of quality driving service developments was conceptualised differently within the Service than it was within government. Specifically, the use of waiting time targets to measure quality implemented within government were identified as "*stifling*" (Participant 22) service development and were understood to be without scientific rationale. Overall, waiting time targets were found to divert focus from the development of quality services:

> *"Treatment targets can actually compromise innovation and change in practice although the theory of course is that they drive it, but if all the management is focussing on is achieving a target, they don't have time to listen to the new ideas. They don't have inclination of money to invest in the future, they're just trying to hit their target for this month."* Participant 17

It was evident that a culture shift had occurred within the Service and understanding of quality was changing. One participant described the prior quality culture as "*nihilistic*" (Participant 21) referring to the prior limited scope of medical intervention predominantly focussed on treatment of the cancer alone. However now, quality care was understood to be holistic, widening the focus of the practitioner to the treatment of the person as a whole in addition to the cancer. And this change in culture led to a change in priorities for service development; quality services were not just about meeting waiting time targets, but ensuring that these targets were met in a way that also adhered to understanding of quality within the Service:

> "*We have to try and get patients seen quickly and appropriately so they need to see the right person at the right time. The consultations need to be done in the right way. We need to think holistically. Ideally using a holistic needs assessment tool. We need to think about supportive services afterwards so that we facilitate self-management and reduce reliance on secondary care*." Participant 9

As a lack of evidence exists to inform service development generally, this quality culture was found to be integral in shaping service development, and services were developed only where the quality of the service could be maintained or improved and not solely to meet waiting time targets:

> "*The problem is that you don't want to arrange [treatment] too early in the pathway to feed, to, to meet a necessity rather than what is correct*." Participant 1

Overall, the Service was viewed as standing apart from other UK regions, and other countries, in this approach to quality:

> "*We're the only place in the UK that offers this holist-, completely holistic, multidisciplinary [treatment service] right the way through, so it's interesting*." Participant 18

And a holistic, multidisciplinary approach was evident in driving service development throughout Scotland, alongside a more conservative approach to diagnosis and treatment than other countries which healthcare professionals felt was now being "*validated*" (Participant 16).

Healthcare professionals within the Service were actively developing the service to (i) meet the increased treatment usage described in Phase 1, (ii) accommodate changing treatment pathways described in Chapter 2, (iii) meet waiting time targets, or government quality measures, and (iv) meet healthcare professionals' own expectations of a quality service. During analysis of interview data, five issues were evident within the Service that had hindered service development: a lack of cohesion (5.5) and leadership (5.6), the training of a multi-disciplinary workforce (5.7), and defining the role of the patient (5.8) and primary care (5.9) within the Service.

5.5 Cohesion

Though traditionally the Service was led by Urologists, developments in treatment pathways led to the reconfiguration and reprioritisation of prostate cancer treatment pathways across Scotland, which led to a substantial increase in service complexity (1.4; 2.2). And the development of multidisciplinary team meetings was useful in providing a "*forum where [other specialities] can put in [their] input*" (Participant 5). However, when healthcare professionals described service development issues, they identified specialities as working in isolation and often competing for resource, resulting in "*petty politics*" (Participant 22) and hindered the ability of the Service as a whole to plan ahead and develop as specialisms put their needs before that of the Service as a whole:

> "*If we could get people talking together, staff, on the way forward, it would be great. And it has been tried, but it never works, sadly because they all want the best for their patients, whether that's surgery or oncology, so they're always fighting. Sad. Sad but true.*"
> Participant 14

And healthcare professionals, including some Urologists, raised concerns over the impact of "surgical bias" (Participant 24) and Urologist dominance within the service. For example, "*patients will be referred from a [General Practitioner] to a urologist so they need to meet the urologist first of all who's a keen surgeon then patients are influenced by the first person they see, so if a surgeon thinks they might be able to sell surgery, then patients will still go for surgery*" (Participant 2). And as a result, many healthcare professionals asked for more "*more together working*" (Participant 5), and more "*cohesive working to plan ahead*" (Participants 14), though no mechanism for this was proposed.

5.6 Leadership

In addition to cohesive working, the Service lacked leadership or oversight of service developments resulting in "*wee pockets of things happening everywhere*" (Participant 5) and "*everybod[y] reinventing that wheel*" (Participant 5). Healthcare professionals described service developments as change that was designed and implemented individually within each Health Board, putting significant pressure on local services to resolve capacity shortage issues without the support of their colleagues in other Health Boards or knowledge of "*what works, what doesn't work*" (Participant 5). Healthcare professionals were unified in wanting more oversight of service developments, and a unified approach to service development:

> *"Why do we have 14 different area drug and therapeutic committees that decide what should and should not be prescribed in a way that leads to post, post book prescribing. In Scotland 5 and a half million people should be one overarching strategic approach to healthcare that is broadly standardised across Scotland. Ensures that there's equity of access, so if you live in the north end of Lewis you have the same quality and access to services as you do if you live in the centre of our biggest cities. And I'm not sure sometimes if that's the case at the moment."* Participant 16

To achieve this, healthcare professionals identified MCNs as best placed to "*shape and design*" (Participant 16) service developments. However, MCNs were considered underdeveloped, often guided by the larger Health Boards within the region and with little power to make a difference:

> "*And I suspect the same is true [in other MCNs] is where the bigger Boards will dominate the discussions with their problems and there's not really a network as such. You know [one Health Board in the MCN] sets up a solution, [another Health Board in the MCN] sets their solution, they're not the same… [MCN is] just a titch of a role that has no teeth so if you really want to make it effective they have to have some role in funding and governance, at the moment it's just token shop I think. I'm not sure that government or Health Boards would want them to be anything other than that… how effective are [MCNs]? Not really. But they probably could be more effective in assuring equitable delivery of care across the whole network. And how do you do that, I don't know, how you give them the teeth but that might be something if they're going to be revamped, how you do that.*" Participant 17

And each MCN was in a different stage of development, with the most advanced, considered "*integrated*" (Participant 4) and the least advanced considered "*broken*" (Participant 4) further complicating the ability of MCNs to lead or have oversight of service development. However, without leadership, healthcare professionals within the Service will continue to use the capacity of the Service to develop individual, local solutions to often national problems.

5.7 Training a multi-disciplinary workforce

To understand why issues with training a multi-disciplinary workforce is hindering service development, the evolution of the multi-disciplinary workforce and what the Service gained with this evolution is briefly summarised. Then issues in training the multidisciplinary workforce is described.

The specialist nurse role had emerged as an early service development to accommodate increased demand as a result of the increased treatment usage identified in Chapter 4. The main rationale given for this was the cost-effectiveness of the specialist nurse role:

> *"It's a cheaper way. You can have 3 nurse specialists for the price of a single consultant."* Participant 12

These roles allowed medical consultants to hand over part of their workload, most prominently active surveillance follow-up, without the cost of employing additional medical consultants. When discussing this re-allocation of workload, it was clear that the development of specialist nurse roles had been successful for reasons beyond freeing up medical consultant time:

> "*The nurse specialist is going to be the way forward, cos they're the best at following these patients up."* Participant 4

Most substantially, when healthcare professionals identified examples of what they believed to be quality care, they identified care delivered by multi-disciplinary teams. And within these teams, nurses were not acting to relieve the workload pressures of another discipline, but rather were found to have a distinct, discipline-specific role within the service:

> "*[Specialist nurse service] is quite an independent service. So, we take patients right through from initial diagnosis, what I, what I mean by that is patients are referred straight to consultants, they have their biopsy done… then they come back to us for results, we give them their diagnosis of prostate cancer, we then help them through that process, we arrange all of their investigations that they require, and then we bring them back, talk through the results of that from our MDT, and we're, give them treatment options and discuss that through with them as well, and even after they've had their definitive treatment, if that's what they're, if that's what is required then we go ahead and follow them up afterwards*." Participant 5

And as a result, all healthcare professionals interviewed identified "*an increased need for cancer nurse specialists*" (Participant X) within the Service. And more recently, other disciplines had developed specialist roles within the Service such as pharmacists and physiotherapists. However, the recruitment and training of specialist nurses and allied health professionals were significant service development concerns:

> *"How do you broadly train someone for a specialist role. And that's the difficulty. Some of the skills are transferable, but the knowledge isn't, and we've got three new nurse specialists. One's been in post for just over a year, one 10 months, one maybe 7/8 months and they still need a lot of input even though they've been doing their job for that length of time and they need a lot of support and that, that's fine take a group of nurses and try and train them in some way, well how many of them are going to get jobs that that education fits. You almost have to kinda take the keen person when the opportunity arises and throw everything at them and support them for a year or two. When I started in the [specialist] job, I job shared for a year and even at the end of that year, I needed a lot of input and support for a further year and you know, you accept you don't know everything anyway."* Participant 12

With the expectation that nurses and allied health professional roles would continue to develop to enable demand within the Service to be met, recruiting and training of specialist nurses and allied health professionals was a concern raised across interviews with some specialist nurses and allied health professionals also identifying changes in undergraduate curricula that will hinder opportunities for specialist recruitment, and identified specialist vacancies elsewhere in the UK that recruiters had been unable to fill. No healthcare professional identified a successful solution to recruiting and training and reported attempts to develop training programmes had been unsuccessful, so specialist nurses and allied health professionals continued to be trained on-the-job with a substantial investment over multiple years from all colleagues within the team.

5.8 Role of the patient

In addition to the developing role of the specialist nurses and allied health professionals, healthcare professionals were exploring other models of care to develop services to meet changed demand. Primarily to manage increases in the number of patients using active treatments (4.4) healthcare professionals were exploring the possibility of greater responsibility for patients in patient's own follow-up care. It was clear that healthcare professionals wanted to promote patient autonomy, and were anticipating greater involvement from patients to meet demand:

> "*We will be expecting more from our patients thereafter as well*." Participant 14

However, healthcare professionals were concerned that not all patients would manage greater responsibility in their care, and healthcare professionals were hesitant to adopt different follow-up protocols with different patients. Within interviews, it was not evident whether patient's experiences had been drawn on to help to resolve this service development issue. Rather, healthcare professionals were drawing on their own experiences with patients to develop the Service in line with what they thought that patients wanted, often putting themselves in patients' shoes to do this:

> "*That is the crux of the issue in that, do you want it done well or do you want it done conveniently, and personally as I say, I'd rather have it done well.*" Participant 12

Due to uncertainty in how patients might adopt more responsibility in their care, healthcare professionals were also exploring delegation of this responsibility to primary care.

5.9 Role of primary care

Like patients, primary care was also identified as having a developing role within the Service, particularly in the follow-up of patients during and after active treatments (4.4), but also in the ongoing treatment and support of patients on palliative care pathways where demand was also increasing (2.2.7; 4.5). However, concerns were raised over General Practitioners (GP) capabilities to fulfil their current roles, namely PSA screening and general patient support during and following treatment, and it was unlikely that this would change. Reasons given for this included short appointment times, "*their current numbers and as well as that, to educate them. A GP might have 2 patients with prostate cancer in his books or whatever, you can't expect them to be an expert on that*" (Participant 5), in addition to pressures to adopt roles from other specialities, *"non-clinical issues really, the paperwork, chasing the points and all this sort of stuff"* (Participant 8), and "*it's just as expensive to have a GP seeing a patient as it is to have [a medical consultant] seeing a patient, where it's, if you can have in the hospital, you'll have speciality doctors, you can have nurse practitioners where that is their clinical expertise"* (Participant 4). And healthcare professionals were divided on whether follow-up in primary care was best for patients. On one hand, participants believed that follow-up care should happen in the community:

> "*To me that's where all that should happen, is out there where people live a normal life. Coming to hospitals, I don't think that's natural for anybody to do that.*" (Participant 5)

However, other healthcare professionals believed that "*they've had specialist treatment and they should have specialist follow-up, firstly from a functional point of view because of prostate cancer treatment's cancer specific side effect profile, but once that's done from a PSA point of view because… its quite a specialist follow-up regime*" (Participant 10). And as a result, increased responsibility had not been delegated to primary care. However, national policies advocating that care move to the community, combined with ongoing capacity shortage within the Service meant that healthcare professionals were under pressure to move follow-up care outside of the hospital setting.

5.10 Understanding the value of my knowledge

Within this Phase of research, I became more aware of my presence as a researcher and how this might be influencing the study. This awareness formed part of the sense-making process that guided this research (Charmaz, 2006). Though it was not possible for me to disregard my own understanding when developing the study (Dewey, 1910; 1920; 1922; 1925; Morgan, 2007; 2014) or research questions (Charmaz, 2006; Creswell, 2013), I sought to disentangle my own experiences and interpretations throughout the analytic process to allow me to give voice to healthcare professionals only. This desire to be unobtrusive was particularly evident in the way that I analysed data within this Phase. Specifically, I used content analysis to enable the understanding, construction and development of the context from the participant's perspective only (Krippendorff, 2004; Hseih & Shannon, 2005; Pope & Mays, 2006; Bengtsson, 2016). However, following reflection, I now have greater appreciation for the understanding that I gained throughout this research to provide the context for data analysis and interpretation.

This lack of appreciation of my own understanding stemmed from my lack of experience in qualitative inquiry, and from my separation from clinical practice, which caused me to become critical of my identity as a nurse. When I began my PhD journey, I intended to return to clinical practice in some capacity on completion. However, as my PhD journey progressed, I realised that returning to practice would not be straightforward. Rather, it is more accepted that nurses will progress clinically before progressing academically, and professional doctorate programmes have developed in recognition of this (Ellis & Lee, 2005). However, this is at odds with career trajectories in other professions, which generally recommend studying towards a doctorate qualification early. As my studies progressed, I became increasingly aware of the tensions between doctorate studies and clinical practice. Most evidently, I learned that the nursing role had not progressed to accommodate nurse academics returning to clinical practice (Hawkins & Fontenot, 2009; Andreassen & Christensen, 2018) and so a return to clinical practice was unlikely to happen. As a result, though an academic's career is argued to begin when they are accepted into a particular community or collective (Laudel & Glaser, 2007), I found that my credibility as a nurse academic was not linked to my acceptance within an academic community, but my acceptance within the clinical community.

Acceptance within the clinical community was important to my identity as a nurse. As such, I found interviewing participants about their role within clinical practice particularly challenging, as it led me to question my credibility as a nurse. This is not uncommon and stems from the tensions and narratives surrounding academic nursing roles (Leonard, McCutcheon & Rogers, 2016) and an understanding that nurse academics were ‘out of touch’ with clinical practice (McNamara, 2009; Ousey & Gallagher, 2010). In response, I sought to immerse myself in current thought in clinical practice to remain ‘in touch’. In addition to this research, I was able to do this through my continued engagement with Prostate Scotland, memberships that I gained with professional organisations, and networking with healthcare professionals. However, as a result of my lack of identity, I did not feel that that I could have something meaningful to say about clinical practice. I also felt that not accurately representing my colleagues’ collective voice or misinterpreting or misunderstanding this voice would hinder my acceptance within this community, and hinder my ability to provide findings that were practically and clinically useful, which in turn could help me to solidify my credibility and identity as a nurse and standing within the clinical community. Therefore, though I found this lack of identity challenging, it benefitted my ability to undertake this research.

5.11 Summary

Together, descriptive analysis of health data in Phase 1, and interviews with healthcare professionals in Phase 2 sought to determine issues within the NHS Scotland prostate cancer service by understanding how usage of the NHS Scotland prostate cancer service had changed and was predicted to change (RQ1), and why the NHS Scotland prostate cancer service had been unable to meet demand (RQ2). This Chapter presented the following findings:

Predicted change (RQ1):	Building on findings from Phase 1 that identified that incidence and active surveillance were increasing (4.3; 4.4) and understanding that demand in the palliative care pathway was changing to treat fewer patients, but for longer and with more lines of treatment (2.2.7; 4.5), healthcare professionals identified increased demand across all services, including palliative care services.

Considering predicted increases in demand, healthcare professionals within the Service were actively developing the Service. Specifically, to (i) meet the increased treatment usage identified in findings reported in Chapter 4, (ii) accommodate changing treatment pathways identified in Chapter 2, (iii) meet waiting time targets, or government quality measures, and (iv) meet their expectations of a quality service. To meet demand, services had “*redesigned as much as [they] probably can, and [they’re] struggling”* (Participant 1) (5.3). Therefore, “*radical changes that are needed to say, new models of working… the tinkering round the edges and the making small changes is important in terms of making small cycles of change, but at a fundamental level for us to deal with capacity we need to look at bigger changes*” (Participant 9) (5.3). Essentially, in addition to seeking increased capacities to enable more of the same care, services were also exploring ways to transform care. When exploring new models of working, healthcare professionals identified five issues that hindered the Service's ability to meet demand (RQ2): lack of cohesion (5.5) and leadership (5.6) within the Service, the training of a multi-disciplinary workforce (5.7), and defining the role of the patient (5.8) and primary care (5.9) within the Service.

Cohesion:	With the integration of multiple specialities, prior service developments led to a substantial increase in service complexity (1.4; 2.2). And though MDT meetings provided a forum for speciality-specific input, little cohesion was evident between specialities, which hindered service planning and development.
Leadership:	Within the Service, there was limited oversight or leadership of service developments, leading to capacities being used to develop services locally with little knowledge of service developments happening elsewhere in Scotland, which one participant terms "*reinventing that wheel*" (Participant 5). Though MCNs were considered best placed to provide this oversight, they were currently too underdeveloped to adopt this role.
Training:	Specialist nurses were employed within the Service as a cost-effective solution to developing capacity shortage considering increased demand on the Service identified in Chapter 4. However, specialist nurses and other specialist nurses and allied health professionals are widely considered an asset to services and service development. However, recruiting and training these specialists required significant investment from within the Service.
Patient role:	Predominantly as a result of increased usage of active treatments (4.4), healthcare professionals were exploring the patient role and whether more responsibility could be given to patients in their follow-up. However, healthcare professionals were concerned that not all patients would be able to manage increased responsibility.
Primary care role:	Like patients, primary care was identified as having a role in the follow-up of patients during and after active treatment, but also in the ongoing treatment and support of patients on palliative care pathways. However, concerns were raised over the capability of primary care to adopt further roles

During interviews, healthcare professionals provided a wealth of information on possible service developments or propositions that could help to resolve capacity shortage, and these developments were hindered by a lack of cohesion, leadership, training routes, and understanding of how patients and primary care could be involved within the Service. Propositions included "*prostate cancer treatment services should be led by three MCNs*" and "*pre-biopsy patient meetings should be led by nurse specialists*" (Appendix 8). These propositions were collated within the questionnaire in the next Phase of research. Facilitating consensus on these propositions gave direction to service developments nationally and provided a greater understanding of the capacity needs of the Service. The next Chapter identifies how capacity should be development within the Service to meet demand (RQ3).

Findings 3: Facilitating consensus on capacity development needs within the NHS Scotland prostate cancer service

6.1 Introduction

The Urology cancer service had not met Scottish waiting time targets, and this had been anecdotally attributed to capacity shortage in the NHS Scotland prostate cancer service (the Service) due to increased incidence of prostate cancer in Scotland (2.2; 4.3), but was also likely to result from a changed treatment pathway (2.2), increased usage of active treatments (4.4) and more lines of palliative treatment (2.2; 4.5), meaning that the Service was treating more men, for longer, and with more treatment modalities and lines of treatment. Healthcare professionals were struggling to meet current demand across the Service, were actively developing services to meet demand and predicted further increases in demand (5.3). Ultimately, to meet demand healthcare professionals advocated for "*radical changes that are needed to say, new models of working… at a fundamental level for us to deal with capacity we need to look at bigger changes*" (Participant 9). Though the Scottish Government had acknowledged the need for service reform (Scottish government, 2008a; Christie commission, 2011; Scottish government, 2012a; 2016a; 2018a), it was unclear what reform was needed.

The Dephi technique was chosen to facilitate consensus on the needs of the Service utilising the expertise and experiences of relevant healthcare professionals. Phase 2 analysis was used to inform the development of the Round 1 questionnaire. Specifically, all service developments proposed by healthcare professionals at interview to develop diagnostic or treatment services were included within the first questionnaire, for example, "*diagnostic services should be a one stop shop*" and "*orchidectomy should be discussed as a treatment option with patients*" (Appendix 8).

Round 1 (R1) and Round 2 (R2) questionnaires were used to establish topics of consensus and dissensus across the diagnostic and treatment pathway. Specifically, to understand how capacity should be developed within the Service to meet demand (RQ3), this phase built on understanding of the five issues identified as hindering the Service's ability to meet demand (RQ2): lack of cohesion (5.5) and leadership (5.6) within the Service, training of a multi-disciplinary workforce (5.7), and defining the role of the patient (5.8) and primary care (5.9) within the Service. Then, to fully understand the capacity needs of the Service, Round 3 (R3) was used to consolidate the consensus and dissensus that had emerged on these topics, i.e. for each part of the diagnostic and treatment pathway, healthcare professionals were given the opportunity to determine whether (i) all topics of consensus were compatible, and (ii) re-evaluate topics of dissensus considering the emerging consensus.

As the Delphi process progressed, my understanding of the research problem developed, as described in Section 2.4. Specifically, during development of the R3 questionnaire, I realised that findings reflected integral issues within the Service as a whole and the solution to the research problem did not lie within individual parts of the Service, but was systemic. Therefore, rather than seek to understand how capacity should be developed within the NHS Scotland prostate cancer service (the Service) to meet demand (RQ3) through understanding the design and delivery needs of each individual part of the Service, I also sought to understand how capacity needs to be developed in the Service as a whole.

When considering the capacity needs of the Service as a whole, the sustainability of the Service was a key consideration as change must be sustainable to have successfully developed capacity (2.5) (UNDP, 2006; 2008; Green & Bennett, 2007). Many of the changes proposed in R1 and R2 would only be effective if the Service underwent no further changes, which was unlikely given the speed that healthcare develops (Appleby, 2013; Braithwaite, 2018). Further, healthcare professionals had voiced that the Service was not able to meet current demand as capacity had not been developed quickly enough to meet changing demands (5.3), and as reflected in Section 2.2, further change in demand is anticipated.

The Delphi technique had been chosen as an approach to enable anticipation of future need. However, during interviews, it became apparent that future need would result from the implementation of technological advances that could not be predicted. However, to develop capacity, there was a need to anticipate these changes. Guided by understanding of capacity development as the bottom-up empowerment of sustainable change (2.5) (Potter & Brough, 2004; Pavlovic et al., 2009; Bennett et al., 2010; Carneiro et al., 2015), findings from interviews with healthcare professionals and data collected from R1 and R2 questionnaires were used to gain insight into the needs of the Service. Given the lack of cohesion (5.5) and leadership (5.6) evident in guiding service developments, R3 also facilitated consensus nationally how to meet demand within the Service. To do this, a section was added to the end of the R3 questionnaire titled "*further consideration*".

Following this introduction (6.1), I summarise the participant sample (6.2), and provide consensus (and dissensus) on the development of Managed Cancer Network (MCN) led care guided by national working groups (6.3), multi-faceted training programmes for specialist nurses and allied health professionals (6.4), the role of the patient (6.5) and the role of community and primary care (6.6). Finally, I reflect on considerations made when using the Delphi methodology (6.6) including my role as a facilitator (6.6.1) and risk of groupthink (6.6.2) and provide a brief summary of findings (6.7).

Data relevant to each finding are presented in tables. Data presented are the statement and corresponding percentage agreement for each Round, and a dash indicates where a statement was not included in a Round. Where participants identified a statement as "*not relevant to [their] expertise*" (3.11.4.4), these participants were not included in calculating percentage agreement, so the number of participants who agreed or disagreed with a statement (n) only is also provided. Where consensus was reached to accept a statement (≥80% agreed with the statement) the statement is shown in green, where a statement was dissented (21-79% agreed with the statement) the statement is not coloured, and where consensus was reached to reject a statement (≤20% agreed with the statement) the statement is shown in red. Finally, in each table, statements are ordered in relation to the patient pathway, i.e. diagnosis, then active surveillance, then radical treatments, and then palliative treatments. For each part of the pathway, statements that were accepted are presented first, then statements that were dissented, and then rejected.

6.2 Participants

16 healthcare professionals were recruited from across Scotland to take part in 3 rounds of a Delphi survey. Potential participants were contacted by email with a link to the Round 1 questionnaire. As it is not possible to gain access to NHS email addresses, healthcare professionals contacted to participate in Phase 2 interviews were contacted again by me, with the assistance of a member of the WoSCAN Urology team, who distributed the invite to participants throughout the West of Scotland. A breakdown of participants is given in Table 17.

Of the health professionals who participated in the interviews (phase 2), 56% participated in Round 1 of the Delphi (n=10). They made up 63% of Delphi participants. As shown in Table 18, specialities from each MCN region were represented. However, fewer nurses (n=4) participated in the Delphi than oncologists (n=6) and urologists (n=6), and fewer healthcare professionals working in the North (n=4) participated than the East (n=6) and West (n=6).

As shown in Table 19, 75% of participants (n=12) completed all Rounds of the Delphi survey. Only 11 identifiers of the participants are known; at least 1 urologist working in the East, and at least 2 healthcare professionals working in the West did not complete all Rounds. No reason for this attrition is known.

6.3 Managed Cancer Network led care guided by national working groups

During interviews, healthcare professionals advocated for more cohesion (5.5) and leadership of service developments (5.6). And these needs were reflected in consensus reached. As shown in Table 20, consensus was reached to reject the current model of Health Board-led prostate cancer care in Scotland. To reform the way that prostate cancer care was led in Scotland, healthcare professionals were divided over whether MCN-led or nationally-led care was best (Table 20, Statement 1). Ultimately, healthcare professionals advocated for a more centralised leadership structure "*be it regional or national*" (written feedback from Participant 13, R1) to deliver care cohesively:

Table 17: Participant characteristics and summary of participation throughout this study

Participant number	Job role	Managed Cancer Network region	Interview participant	Participated in…		
				Round 1	Round 2	Round 3
1	Nurse	SCAN	✓	✓	✓	✓
2	Oncologist	SCAN	✓	✓	✓	✓
3	Oncologist	WoSCAN	✓	✓	✓	✓
4	Urologist	NoSCAN	✓	✓	✓	✓
5	Urologist	NoSCAN	✓	✓	✓	✓
6	Nurse	NoSCAN	✓	✓	✓	✓
7	Urologist	SCAN	✓	✓	✓	✓
8	Nurse	SCAN	✓	✓	✓	✓
9	Oncologist	WoSCAN		✓	✓	✓
10	Oncologist	NoSCAN		✓	✓	✓
11	Oncologist	WoSCAN		✓	✓	✓
12	Urologist	SCAN	✓	✓	✓	*
13	Urologist	WoSCAN		✓	✓	*
14	Oncologist	WoSCAN	✓	✓		
15	Nurse	WoSCAN		✓		
16	Urologist	SCAN		✓		

*One urologist did not give a participant identifier in Round 3, so it is not possible to know which urologist participated.

Table 18: Summary of participant characteristics by specialisation and region – Round 1

	Managed Cancer Network		
Speciality	East	North	West
Nurse	2	1	1
Oncologist	1	1	4
Urologist	3	2	1

Table 19: Summary of participant characteristics by specialisation and region – Round 3

	Managed Cancer Network			
Speciality	East	North	West	Unknown
Nurse	2	1	0	-
Oncologist	1	1	3	-
Urologist	1	2	0	1

> "*Each health board also needs a direct say in the management of prostate cancer, but ultimately responsibility should lie with each MCN so that changes and protocols can be discussed and chosen in a democratic fashion. However national planning also plays a role as the MCN's should all be roughly equivalent with no 'outlying' ideas. However, a rigid national plan for each MCN would be too much as there has to be some degree of flexibility within each MCN to account for patient and population variations*." Written feedback from Participant 5, R1

And consensus was reached for the further development of MCNs (Table 20, Statement 2-3).

Challenges to the development of a MCN-led Service were also identified. Healthcare professionals identified the needs of the Service as requiring equality or equity of services nationally, centralisation of services regionally, a voice for individual Health Boards in service development, guidance and oversight of Health Boards, democracy in decision-making, flexibility in implementation of service developments, and empowerment of the specialisms. And this was reflected in other consensus reached, for example, consensus was reached that some tasks should be the responsibility of specialisms and not the MCN (Table 20, Statement 4).

The need for specialisms to have their own identity throughout the study. Though healthcare professionals advocated more cohesive working between regions, healthcare professionals were divided over the need for specialisms to work more cohesively in R1 (Table 20, Statement 5a-c). Guided by participant comments, improved "*methods of integration and communication*" (Table 20, Statement 5d) between specialities and healthcare professionals was proposed, and reached consensus.

To understand how the organisational structure of the Service could be reformed to provide cohesion and leadership in line with emerging consensus, a two-part structure to leadership of the Service was proposed (Table 20, Statements 6-9), guided by findings from Phase 2 and the emerging consensus (3.11.9). Firstly, national, speciality-specific working groups were proposed to design quality care (Table 20, Statement 5-6) and communicate this with MCNs (Table 20, Statement 7) or in line with agreed "*terms of reference*" (written feedback from Participant 9, R3). In this reformed structure, MCNs would be then be responsible for the regional, multidisciplinary implementation of quality care (Table 20, Statement 8). And healthcare professionals reached consensus to accept this service reform.

Table 20: Consensus on the structure for the prostate cancer service design and implementation.

Statement	Round 1 (n=16)	Round 2 (n=13)	Round 3 (n=12)
1. Prostate cancer services should be…			
…led by Health Boards	6% (n=16)	-	-
…led by MCNs	63% (n=16)	-	-
…Scotland-wide	31% (n=16)	-	-
2. MCNs should be further developed	93% (n=14)	-	-
3. Within prostate cancer services, Managed Cancer Networks need to be responsible for…			
a. …auditing services	100% (n=16)	-	100% (n=12)
b. …planning ahead for the introduction of advances in treatment	94% (n=16)	-	100% (n=12)
c. …keep government up to date with advances in treatment	94% (n=15)	-	100% (n=12)
d. …managing the impact of centralisation on Health Boards	93% (n=14)	-	100% (n=12)
e. …the delivery of equitable care across the region	87% (n=16)	-	100% (n=12)
f. …have a role in funding and governance	71% (n=14)	80% (n=10)	100% (n=12)
4. [Some] tasks should be the responsibility of the relevant speciality and not be the responsibility of the MCN	-	89% (n=9)	-
5. Urology and uro-oncology services should…			
a. …work separately, but with better lines of communication	44% (n=16)	-	-
b. …work in the same capacity that they currently do	31% (n=16)	-	-
c. …work together within the one overarching service	25% (n=16)	-	-
d. Methods of integration and communication between urology and uro-oncology services should be improved	-	83% (n=12)	100% (n=12)
6. Prostate cancer services require the development of Scotland-wide surgery, radiotherapy and hormone therapy/chemotherapy working groups	-	-	100% (n=12)
7. These groups should be responsible for the design of speciality specific 'gold standard' care for patients living in Scotland	-	-	100% (n=12)

8. These working groups should be responsible for communicating with Managed Cancer Networks	-	-	92% (n=12)
9. Managed Cancer Networks should be responsible for the regional multidisciplinary implementation of ‘gold standard’ care	-	-	91% (n=12)

6.4 Multi-faceted training programmes for specialist nurses and allied health professionals

To meet demand, healthcare professionals were actively developing the Service to (i) meet the increased treatment usage identified in findings reported in Chapter 4, (ii) accommodate changing treatment pathways described in Chapter 2, (iii) meet waiting time targets, or government quality measures, and (iv) meet healthcare professionals’ own expectations of a quality service (5.4). To achieve this, during interviews healthcare professionals identified the need for further development of specialist nurse and allied health professional roles (5.7). However, the absence of efficient methods of training specialist nurses and allied health professionals had hindered service development (5.7). This section begins with an account of consensus relating to quality care within the Service as holistic, multidisciplinary care, and then establishes the need for the further development of specialist nurses and allied health professionals roles, before describing consensus on how nurses and allied health professionals healthcare professionals should be trained for specialist roles within the Service.

During interviews, healthcare professionals understood quality care to be holistic and not solely focussed treatment of the prostate cancer alone, and quality care was found to be a key driver in service development (5.4). And this understanding of quality care was also evident within data from questionnaires, as shown in Table 21. For example, consensus was reached for the incorporation of counselling services within active surveillance (Table 21, Statement 1), and the extension of current follow-up and side effect services to support men following radical treatment (Table 21, Statements 2-9) and palliative care (Table 21, Statement 10). Further indicating that capacities were needed to enable the development of this holistic approach to prostate cancer care within the Service. Reflecting data gathered during interviews (5.4), further development of specialist nurses and allied health professional roles were needed to develop quality services, as shown in Table 22.

Table 21: Consensus on the development of holistic services

Statement	Round 1 (n=16)	Round 2 (n=13)	Round 3 (n=12)
1. Active surveillance should incorporate counselling services	91% (n=11)	-	100% (n=12)
2. Support services should be involved with men prior to receiving treatment	90% (n=10)	-	92% (n=12)
3. Follow-up clinics should include a supportive role	100% (n=13)	-	91% (n=11)
4. Clinics are currently not flexible enough to provide a supportive role to patients	82% (n=11)	-	91% (n=11)
5. A service is required to manage erectile dysfunction	87% (n=16)	-	92% (n=12)
6. A service is required to manage incontinence	94% (n=16)	-	92% (n=12)
7. Erectile dysfunction and incontinence support to be made available to radiotherapy patients	94% (n=16)	-	92% (n=12)
8. A service is required to manage bladder irritability	69% (n=13)	91% (n=11)	92% (n=12)
9. A service is required to manage bowel problems	67% (n=12)	91% (n=11)	92% (n=12)
10. A service is required to manage pain caused by bone metastases	78% (n=11)	70% (n=10)	100% (n=11)

Table 22: Consensus on the development of nurse-led roles within the Service

Statement	Round 1 (n=16)	Round 2 (n=13)	Round 3 (n=12)
1. Patient diagnosis should be given by a nurse	56% (n=16)	56% (n=9)	83% (n=12)
2. Treatment options should be discussed with a patient in the first instance by a nurse	44% (n=16)	50% (n=10)	82% (n=11)
3. The diagnostic pathway should be nurse-led	73% (n=15)	100% (n=12)	80% (n=10)
4. Pre-biopsy counselling should be nurse-led	93% (n=14)	-	91% (n=11)
5. With the exception of the initial post-operative review, post-operative care should be nurse-led	-	75% (n=8)	83% (n=6)
6. Radiotherapy follow-up should be nurse-led	87% (n=15)	-	83% (n=12)
7. Surgical follow-up should be nurse-led	64% (n=14)	75% (n=8)	90% (n=10)
8. Side effects services should be nurse led	69% (n=11)	100% (n=10)	92% (n=12)
9. There is a need to develop a nurse specialist role to support patients with symptoms, side effects and treatment queries on an as and when required basis	81% (n=16)	-	100% (n=12)
10. Side effects services should be nurse led	69% (n=11)	100% (n=10)	92% (n=12)

Like at interview (5.7), healthcare professionals reached consensus for the further development of specialist nurse roles across the Service, including the development of multiple nurse-led services (Table 22, Statement 3-8 and 10). Though within the Service, most specialist nurses and allied health professional roles were filled with specialist nurses, recently roles within the Service had also developed for other allied health professionals. And though some healthcare professionals such as physiotherapists were involved in only one part of the Service, other healthcare professionals like pharmacists had potential to be involved in many parts of the Service. The specialist pharmacist role was new to the Service, but an expansion of this role had been proposed during interviews, and so healthcare professionals were asked whether specialist pharmacists could lead on some parts of the Service, as shown in Table 23. Though the same support was not evident for specialist pharmacists to be involved in services to the same extent as nurses, there was support for the development of the specialist pharmacist role in palliative care services (Table 23, Statement 9-11) where specialist pharmacists had recently been employed.

During interviews, healthcare professionals identified benefits of developing specialist nurse roles within the Service beyond freeing up medical consultant time, and where services were considered high quality, they were generally multidisciplinary (5.7). However, though healthcare professionals were asked to select the discipline best equipped to undertake different tasks, it was clear from comments it was not the discipline of the healthcare professional that was important. Rather, that the healthcare professional should have both "*the interests and expertise*" (written feedback from Participant 9, R1 questionnaire) for the role, and should ultimately be the best at performing this role irrespective of discipline. For example, the discipline "*depends somewhat on the area and staff available. In [Health Board], we have a [specialist nurse] who is as good, if not better, at discussing treatment options than many consultants, but that is not true of every Health Board*" (written feedback from Participant 3, R2). Therefore, service developments and recruitment to roles within the Service are not solely related to the development of specialist nurse and allied health professional roles. Rather they are also about understanding the interests and capabilities of the team to identify the best person, not discipline, to fill any gaps. Currently, recruitment to clinical posts within the Scottish NHS are generally discipline-specific, rather than specific to an individual's capabilities.

Regardless, the need for further development of specialist nurse roles to enable service development were evident both during interview (5.7) and in this phase of the study. As consensus was reached to develop more nursing roles within the Service, healthcare professionals were asked how nurses should be trained. Consensus was reached that training should be multi-faceted; nurses should be trained through engaging with a training programme, through networking with individuals in similar posts and could be supported through the development of a national nursing and allied health professional working group (Table 24). Though this represents a reform in specialist nursing education and development, multi-faceted training approaches happen in other healthcare professions.

Table 23: Consensus on the development of specialist pharmacist roles within the Service

Statement	Round 1 (n=16)	Round 2 (n=13)	Round 3 (n=12)
1. Pre-biopsy counselling should be pharmacist-led	0% (n=12)	-	-
2. Biopsy services should be pharmacist-led	0% (n=14)	-	-
3. Patient diagnosis should be pharmacist-led	0% (n=12)	-	-
4. Initial treatment discussions should be pharmacist-led	0% (n=16)	-	-
5. Active surveillance should be pharmacist-led	0% (n=12)	-	-
6. Pre-operative care should be pharmacist-led	7% (n=14)	-	-
7. Post-operative care should be pharmacist-led	0% (n=12)	-	-
8. Side effects service should be pharmacist-led	6% (n=16)	-	-
9. Chemotherapy prescription should be pharmacist-led	42% (n=12)	-	-
10. Chemotherapy monitoring should be pharmacist-led	31% (n=13)	-	-
11. Bisphosphonate delivery should be pharmacist-led	33% (n=12)	-	-
12. Chemotherapy administration should be pharmacist-led	8% (n=13)	-	-
13. Men receiving neo-adjuvant hormone therapy should be pharmacist-led	0% (n=12)	-	-
14. Radiotherapy follow-up should be pharmacist-led	0% (n=15)	-	-
15. Surgical follow-up should be pharmacist-led	0% (n=14)	-	-
16. Long term hormone therapy follow-up should be pharmacist-led	0% (n=16)	-	-
17. Watchful waiting should be pharmacist-led	0% (n=15)	-	-

Table 24: Consensus on training of specialist nurses

Statement	Round 1 (n=16)	Round 2 (n=13)	Round 3 (n=12)
Training programmes for nurse specialists should be developed	80% (n=15)	-	100% (n=12)
Nurses should be trained through networking with individuals in similar posts	93% (n=15)	-	100% (n=12)
Prostate cancer services require the development of a Scotland-wide nursing and allied health professional working group	-	-	100% (n=12)

6.5 Role of the patient, and primary and community care

During interviews, healthcare professionals also identified the need for a further developed role for patients (5.8), and primary and community care (5.9) within the Service to meet demand. However, healthcare professionals were concerned about the capabilities of patients, and primary and community care to adopt further responsibilities. Specifically, healthcare professionals were unsure on the level of responsibility patients could manage in their own care (5.8) and raised concerns about the capability of primary care to undertake their current role of prostate cancer screening (5.9). Therefore, service development had stalled, particularly in relation to follow-up of active treatments. This section gives consensus on the development of the role of patients, and primary and community care within the Service, which ultimately concluded that specialist roles and responsibilities should remain with secondary and tertiary care healthcare professionals, though patients should have more choice in their own care.

During interviews, healthcare professionals also identified a further developed role for patients within the Service, specifically to manage increased demand from the increased usage of active treatment identified in Phase 1 (4.4; 5.8). However, healthcare professionals were unsure on the level of responsibility patients could manage in their own care and therefore, development had stalled (5.8). Data from questionnaire responses showed that healthcare professionals were keen to continue developing opportunities for patient choice within the treatment pathway as shown in Table 25, for example with pre-biopsy counselling (Table 25, Statement 1), and the development of treatment discussions with patients on palliative treatment pathways to be equitable with active treatment pathways (Table 25, Statement 2-3). However, as shown in Table 26, though healthcare professionals wanted patients to have more responsibility in their follow-up (Table 26, Statement 1), healthcare professionals rejected that patients should have a role in monitoring their own Prostate Specific Antigen (PSA) levels even with regular specialist support (Table 26, Statements 2-5). Rather, consensus was reached for follow-up to remain in secondary care, as shown in Table 26, as "*only certain patients will be suitable for self-monitoring*" (written feedback from Participant 1, R2) reflecting findings from interviews with healthcare professionals (5.8).

Table 25: Consensus on patient choice and role

Statement	Round 1 (n=16)	Round 2 (n=13)	Round 3 (n=12)
1. Pre-biopsy counselling is required to discuss pros and cons of biopsy	92% (n=13)	-	91% (n=11)
2. Initial treatment discussions are required to discuss treatment plans with patients receiving palliative care	92% (n=12)	-	100% (n=12)
3. Orchidectomy should be discussed as a treatment option with patients	90% (n=10)	-	100% (n=12)

Table 26: Consensus on patient role in radical treatment follow-up

Statement	Round 1 (n=16)	Round 2 (n=13)	Round 3 (n=12)
1. Patients should be given more responsibility during follow-up	83% (n=12)	-	-
2. The follow-up of active surveillance should involve patients self-monitoring their PSA level	27% (n=15)	-	-
a. Active surveillance follow-up should be led by secondary care via patients self-monitoring PSA with contact details of secondary care staff for concerns	-	0% (n=13)	-
b. Active surveillance follow-up should be led by secondary care via patients self-monitoring PSA and a return visit to secondary care	-	15% (n=13)	-
3. The follow-up of post-prostatectomy patients should involve patients self-monitoring their PSA level	43% (n=14)	-	-
a. During the initial period following radical prostatectomy, follow-up should be led by secondary care with patient self-monitoring PSA	-	20% (n=10)	0% (n=9)
…if patients should self-monitor their PSA, this should be patient led with contact details of secondary care staff if concerns arise	-	56% (n=9)	-
…if patients should self-monitor their PSA, this should be with return visits to secondary care	-	33% (n=9)	-
…if patients should self-monitor their PSA, this should be with regular telephone review	-	11% (n=9)	-
b. Prior to discharge, follow-up for patients who have undergone radical prostatectomy should be led by secondary care with patient self-monitoring PSA	-	71% (n=9)	11% (n=9)
…if patients should self-monitor their PSA, this should be patient led with contact details of secondary care staff if concerns arise	-	14% (n=7)	-
…if patients should self-monitor their PSA, this should be with return visits to secondary care	-	14% (n=7)	-
…if patients should self-monitor their PSA, this should be with regular telephone review	-	11% (n=9)	-
4. The follow-up of post-radiotherapy patients should involve patients self-monitoring their PSA level	27% (n=15)	-	-
a. During the initial period following radiotherapy, follow-up should be led by	-	9% (n=12)	-

secondary care with patient self-monitoring PSA			
…if patients should self-monitor their PSA, this should be patient led with contact details of secondary care staff if concerns arise	-	56% (n=9)	-
…if patients should self-monitor their PSA, this should be with return visits to secondary care	-	22% (n=9)	-
…if patients should self-monitor their PSA, this should be with regular telephone review	-	22% (n=9)	-
b. Prior to discharge, follow-up for patients who have undergone radiotherapy should be led by secondary care with patient self-monitoring PSA	-	27% (n=11)	0% (n=12)
…if patients should self-monitor their PSA, this should be patient led with contact details of secondary care staff if concerns arise	-	50% (n=10)	-
…if patients should self-monitor their PSA, this should be with return visits to secondary care	-	30% (n=10)	-
…if patients should self-monitor their PSA, this should be with regular telephone review	-	20% (n=10)	-
5. The follow-up of patients taking neo-adjuvant hormone therapy should involve patients self-monitoring their PSA level	13% (n=15)	-	-

Table 27: Consensus on radical treatment follow-up in secondary care

Statement	Round 1 (n=16)	Round 2 (n=13)	Round 3 (n=12)
1. The follow-up of post-radiotherapy patients…			
a. …after functional outcomes are achieved, should led by secondary care and utilise virtual clinics	-	36% (n=11)	100% (n=12)
b. …should table place in secondary care only	60% (n=15)	-	-
c. …prior to functional outcomes being achieved, should take place under current mechanisms of follow-up	-	25% (n=12)	58% (n=12)
d. …prior to functional outcomes being achieved, should be led by secondary care and utilise virtual clinics	-	17% (n=12)	-
e. …after functional outcomes are achieved, should take place under current mechanisms of follow-up	-	9% (n=11)	-
f. …after functional outcomes are achieved, should be led by secondary care with telephone review	-	0% (n=11)	-
2. The follow-up of post-prostatectomy patients…			
a. …should take place in secondary care only	50% (n=14)	-	-
b. …after functional outcomes are achieved, should be led by secondary care and utilise virtual clinics	-	33% (n=9)	78% (n=9)
c. …prior to functional outcomes being achieved, should be led by secondary care and utilise virtual clinics	-	30% (n=10)	33% (n=9)
d. …prior to functional outcomes being achieved, should take place under current mechanisms of follow-up	-	10% (n=10)	-
e. … after functional outcomes are achieved, should take place under current mechanisms of follow-up	-	22% (n=9)	11% (n=9)
f. …after functional outcomes are achieved, should be led by secondary care with telephone review	-	0% (n=10)	-

Driven by increased demand from increased usage of active treatments (4.4), developing palliative care pathways (2.2; 4.5), and government policy (2.2.8), the development of the primary care role was proposed as one method of meeting demand within the Service (5.9). However, healthcare professionals raised concerns about the capability of primary care to undertake their current role of prostate cancer screening (5.9). Consistent with interview data, healthcare professionals reached consensus that primary care practitioners did not have the capabilities to perform their current role as shown in Table 28 (Statement 1), though no alternative to this model currently exists or was proposed. Though healthcare professionals "*don't think this is true of all primary care services*" (written feedback from Participant 10, R2), concern was raised that primary care could be "*dangerously reassuring*" (written feedback from Participant 4, R2) of PSA results leading to late presentation to secondary care.

Considering these concerns, healthcare professionals did not identify increased role and responsibility for primary care practitioners as the solution to meeting demand. And this was largely due to the lack of "*volume*" (written feedback from Participant 9, R2), "*knowledge*" (written feedback from Participant 3, R3) and "*expertise*" (written feedback from Participant 3, R2) in primary care currently. During iterations of questionnaires, some statements such as Statement 2, 5 and 9d (Table 28) were not repeated in all Rounds. Instead, they were revised in line with participant comments, or were made obsolete by the emerging consensus. For example, when asked about follow-up care, participants responded to the development of capacity for clinic correspondence management if follow-up moved to primary care (Table 28, Statement 2). However, the consensus on follow-up that emerged did not include primary care involvement, and so this statement was not repeated. However, for transparency these statements are included where relevant. Specifically, consensus was reached that follow-up by primary care practitioners would create increased workload in secondary care through correspondence management (Table 28, Statement 2), largely because primary care "*don't have the knowledge*" (written feedback from Participant 4, R2) to monitor PSA levels. As a result of this perceived lack of capability, healthcare professionals reached consensus that primary care practitioners shouldn't be involved in following up patients on active surveillance (Table 28, Statement 3). However, some support was evident that primary care practitioners should have a role in supporting follow-up of patients after radical treatment (Table 28, Statement 4-7), but this did not reach consensus.

Table 28: Consensus on the role of primary care in supporting prostate cancer care

Statement	Round 1 (n=16)	Round 2 (n=13)	Round 3 (n=12)
1. GPs are equipped to counsel men effectively on PSA testing at diagnosis	57% (n=14)	33% (n=9)	18% (n=11)
2. Primary care follow-up would create a need for clinic correspondence management	85% (n=13)	-	-
3. The follow-up of active surveillance should take place in primary care…			
a. … by GPs	0% (n=15)	-	-
b. … by practice nurses	0% (n=15)	-	-
c. … by specialists	7% (n=15)	-	-
d. … only with the presence of rapid access mechanisms feeding back into secondary care	13% (n=15)	-	-
e. … with a return visit to secondary care	40% (n=15)	23% (n=13)	8% (n=12)
4. Secondary care holds onto patients too long after treatment	25% (n=12)	17% (n=12)	-
5. Prostate cancer specialists and primary care should work side by side when following men up	79% (n=14)	-	-
6. The follow-up of post-prostatectomy should take place in primary care…			
a. … by GPs	7% (n=14)	-	-
b. … by practice nurses	0% (n=14)	-	-
c. … by specialists	7% (n=14)	-	-
d. … only with the presence of rapid access mechanisms feeding back into secondary care	36% (n=14)	-	-
… … following treatment	-	0% (n=10)	-
… … prior to discharge	-	11% (n=9)	-
e. … with a return visit to secondary care	20% (n=14)	-	-
… … following treatment	-	40% (n=10)	56% (n=9)
… … prior to discharge	-	11% (n=9)	-
7. The follow-up of post-radiotherapy should take place in primary care…			
a. … by GPs	0% (n=15)	-	-
b. … by practice nurses	0% (n=15)	-	-
c. … by specialists	0% (n=15)	-	-
d. … only with the presence of rapid access mechanisms feeding back into secondary care	33% (n=15)	-	-
… … following treatment	-	0% (n=12)	-
… … prior to discharge	-	27% (n=11)	0% (n=12)
e. … with a return visit to secondary care	27% (n=15)	-	-

… … following treatment	-	50% (n=12)	33% (n=12)
… … prior to discharge	-	0% (n=11)	-
8. A service should be provided in primary care for...			
a. ...supporting weight management	100% (n=15)	-	80% (n=10)
b. ...supporting diabetes	100% (n=15)	-	80% (n=10)
c. ...cholesterol monitoring	100% (n=14)	-	80% (n=10)
d. …blood pressure monitoring	100% (n=14)	-	80% (n=10)
9. A service should be provided in the community for...			
a. ...long term hormone therapy prescription	88% (n=16)	-	100% (n=12)
b. …neo-adjuvant hormone injection administration	100% (n=16)	-	-
c. …long term hormone injection administration	100% (n=16)	-	-
d. …patient support when receiving hormone injections	67% (n=12)	82% (n=11)	-
e. ...oral drug dispension	100% (n=13)	-	100% (n=12)
f. …a uro-oncology nurse injection service should provide long term and neo-adjuvant hormone therapy as well as support to these patients	-	-	45% (n=11)
10. Long term hormone therapy should be…			
a. … nurse-led	100% (n=15)	62% (n=13)	50% (n=12)
b. … GP-led	-	39% (n=13)	50% (n=12)
11. The follow-up of patients' receiving long term hormone therapy should take place in primary care…			
a. … by GPs	13% (n=16)	-	-
b. … by practice nurses	13% (n=16)	-	-
c. … by [prostate cancer] specialists	13% (n=16)	-	-
d. … only with the presence of rapid access mechanisms feeding back into secondary care	50% (n=16)	-	-
e. … with a return visit to secondary care	13% (n=16)	-	-

Support for developing the role of primary care was most evident in the delivery of palliative care pathways. Consensus was reached for involvement of primary care practitioners in the care of patients receiving long term hormone therapy treatment including management of common side effects of long term hormone therapy use (Table 28Driven by increased demand from increased usage of active treatments (4.4), developing palliative care pathways (2.2; 4.5), and government policy (2.2.8), the development of the primary care role was proposed as one method of meeting demand within the Service (5.9). However, healthcare professionals raised concerns about the capability of primary care to undertake their current role of prostate cancer screening (5.9). Consistent with interview data, healthcare professionals reached consensus that primary care practitioners did not have the capabilities to perform their current role as shown in Table 28 (Statement 1), though no alternative to this model currently exists or was proposed. Though healthcare professionals "*don't think this is true of all primary care services*" (written feedback from Participant 10, R2), concern was raised that primary care could be "*dangerously reassuring*" (written feedback from Participant 4, R2) of PSA results leading to late presentation to secondary care.

Considering these concerns, healthcare professionals did not identify increased role and responsibility for primary care practitioners as the solution to meeting demand. And this was largely due to the lack of "*volume*" (written feedback from Participant 9, R2), "*knowledge*" (written feedback from Participant 3, R3) and "*expertise*" (written feedback from Participant 3, R2) in primary care currently. During iterations of questionnaires, some statements such as Statement 2, 5 and 9d (Table 28) were not repeated in all Rounds. Instead, they were revised in line with participant comments, or were made obsolete by the emerging consensus. For example, when asked about follow-up care, participants responded to the development of capacity for clinic correspondence management if follow-up moved to primary care (Table 28, Statement 2). However, the consensus on follow-up that emerged did not include primary care involvement, and so this statement was not repeated. However, for transparency these statements are included where relevant. Specifically, consensus was reached that follow-up by primary care practitioners would create increased workload in secondary care through correspondence management (Table 28, Statement 2), largely because primary care "*don't have the knowledge*" (written feedback from Participant 4, R2) to monitor PSA levels. As a result of this perceived lack of capability, healthcare professionals reached consensus that primary care practitioners shouldn't be involved in following up patients on active surveillance (Table 28, Statement 3). However, some support was evident that primary care practitioners should have a role in supporting follow-up of patients after radical treatment (Table 28, Statement 4-7), but this did not reach consensus.

Table *28*, Statement 8), and hormone therapy prescription, administration and support (Table 28, Statement 9a-e), though healthcare professionals were divided over who should then be ultimately responsible for the management of this patient population (Table 28, Statement 10-11). Due to the support for community care involvement within palliative care, combined with concerns about the capability of primary care to have any involvement with care delivery within the Service, in R3 participants were asked whether they supported the development of a community pharmacy service (Table 29). Community pharmacy services have developed to support the provision of specialist cancer services throughout the UK (Lindsay et al., 2015; Edwards et al., 2018). However, community pharmacy services were not raised by healthcare professionals during interviews. Rather, healthcare professionals raised primary care as the only community care option. So, community pharmacy services were proposed at the end of the R3 questionnaire (3.11.8). Though consensus was reached that community pharmacy could assist with at least one aspect of palliative prostate cancer care, consensus was not reached on what aspect this could be. Like with primary care, healthcare professionals raised concerns about the capability of community pharmacy to undertake these roles and responsibilities and identified the need for shared information systems with secondary care to enable this development.

Finally, considering the concerns raised regarding the capability of primary care to undertake current roles and also to develop further roles within the Service, healthcare professionals were asked whether primary care practitioners should be included within national prostate cancer working groups for the development and implementation of community-based interventions and services, and consensus was reached on this, as shown in Table 30. Community care practitioners, such as community pharmacists, were not included in this statement as they had not been included within the questionnaire prior to Round 3.

Table 29: Consensus on the development of a community pharmacy service

Statement	Round 1 (n=16)	Round 2 (n=13)	Round 3 (n=12)
A community pharmacy service should be developed for…	-	-	82% (n=11)
…the administration of long-term hormone therapy	-	-	64% (n=11)
…the administration of neo-adjuvant hormone therapy	-	-	55% (n=11)
…support to patients receiving hormone therapy	-	-	55% (n=11)
…long term hormone follow-up	-	-	27% (n=11)
…the administration of oral chemotherapy	-	-	18% (n=11)

Table 30: Consensus on the inclusion of primary care within prostate cancer working groups

Statement	Round 1 (n=16)	Round 2 (n=13)	Round 3 (n=12)

Primary care practitioners should be included within [national] prostate cancer working groups for the development and implementation of community-based interventions and services	-	-	100% (n=12)

Asking patients to have more responsibility in their own care or asking primary care to adopt or share follow-up and supportive care would have reduced capacity needed within the Service. However, capabilities do not currently exist outside of the Service to enable this to occur. Therefore, consensus was reached for care to remain within the Service, as shown in Table 27.

6.6 Using Delphi methodology

Delphi methodology was used to give understanding of the capacity needs of the Service to meet demand. Though many approaches exist to understand the capacity needs of healthcare services, the resources required to study all aspects of a national service would have been substantial using many of these. Therefore, the Delphi technique was used to facilitate understanding of the capacity needs of the Service by drawing on existing experience of the Service. Within a healthcare context, the Delphi technique had been used to reach consensus on clinical research priorities, service planning, professional characteristics and competencies, and in health education (Powell, 2003; James & Warren-Forward, 2015; Foth et al., 2016; McMillan, King & Tully 2016; Waggoner, Carline & Dunning, 2016; Humphrey-Murto et al., 2017). Where face-to-face consensus methods can incorporate bias due to interpersonal factors and personality characteristics such as dominance and submission and the pressure to conform (Fischer, 1978; Goodman, 1987; Jaraith & Weinstein, 1994; Murphy et al., 1998; James & Warren-Forward, 2015; McMillan, King & Tully, 2016; Humphrey-Murto et al., 2017), the anonymity of the Delphi process particularly benefits problem solving within hierarchical organisations such as the NHS (Beech, 1999). Ultimately, the Delphi technique can be used in situations where other methods would not be feasible to combine the judgements of a diverse panel of experts in a robust way. And the results of Delphi studies are generally accepted making change more likely. For example, Beech (2001) found that the Delphi process led to a greater acceptance of the results amongst staff and line managers who expressed satisfaction with the outcome of the Delphi technique. In this study, it provided understanding where there was a lack of evidence to guide capacity development efforts. In completing this Phase of research, consideration had to be given to my role within the research, and risk of groupthink.

6.6.1 Facilitating a Delphi

Within a Delphi study, the role of the researcher or *facilitator* is generally discussed in terms of their administration skills, as it is argued that the facilitator should not influence the process (Gordon, 1994). This is because historically the Delphi technique was considered to take a reductionist or quantitative turn after the idea generating or issue determining step (Stewart, 2001) making further contact between the researcher and the researched unnecessary. However, my research did not seek to reduce the Service, but drew on experts to reconstruct the Service in R3 (3.11.7) considering consensus (and dissensus) reached in R1 and R2. With limited guidance in the literature on the role of the facilitator in a Delphi study that did not seek to be reductionist, I was guided by understanding of my role as a researcher.

When undertaking this study, I understood the process of research to be effortful decisions that I made by drawing on my own experiences and research methodologies and approaches (3.5) (Dewey, 1910; 1920; 1922; 1925; Morgan, 2007; 2014). Like with the development of research questions (2.4) I developed a research protocol guided by my understanding of the research problem that I had *a priori*. When doing so, I developed the research protocol that I believed would answer the research question in the most practically useful way. Specifically, I sought to understand how capacity should be developed within the Service through understanding the design and delivery needs of all parts of the Service. I then employed methods within this study to enable me to achieve this. However, as these Delphi Rounds progressed, my understanding of the problem developed leading me to reconsider the focus on capacity development over service delivery. Guided my understanding of the research process, I understood my role to include the development of my own understanding of the research problem, which enabled me to employ the best tools in the best way to enable participants to provide the best data; ‘best’ being that which facilitates the most practically useful findings.

Through effortful decision-making, I made the decision to amend the *a priori* protocol of this study to include a section titled “*further considerations*” at the end of R3 (3.11.8). This section provided a short list of propositions that had been developed to reflect findings from interviews with healthcare professionals and the emerging consensus. In doing so, I was able to better understand the needs of the Service by considering the Service as a whole. Though the Delphi technique can be employed to reduce a research or practical problem, this is not always the case and further research is needed to guide researchers in facilitating Delphi’s that do not seek to be reductionist.

6.6.2 Groupthink

Additionally, given that the Delphi is a consensus method, the risk of creating an opportunity for groupthink also needs consideration. Groupthink is a theory that explains why members of a small, cohesive group will follow a false consensus, i.e. a consensus that they do not believe to be correct

(Janis, 1972). In this study it was argued that rather than seek a perfect consensus, we should look for "*incremental improvements within the framework of arrangements that none of us will deem perfect, but that all of us 'can live with'*" (Rescher, 1995, pp. 4), i.e. where agreement or a dominant belief is needed, such as within healthcare, it is reasonable that participants may move towards a consensus for the greater good if they believe that this consensus will lead to an improvement in the status quo. This understanding of why healthcare professionals may reasonably change their mind during this study does not fall foul of groupthink. Rather, a key benefit of the Delphi methodology lies in the anonymity that it gives; participants are separated from group dynamics when responding and respond in line with their own judgements without fear of criticism, reducing the likelihood of following a false consensus (Crisp et al., 1999; Keeney, Hasson & McKenna, 2001; Hardy et al., 2004 Baker, Lovell & Harris, 2006). Also, the healthcare professionals who participated within this study are not part of a small, cohesive group as reflected in Section 5.5. Rather they are members of a national service that spans regions, disciplines and specialities, each with their own interests and priorities. And limited research exists to understand how groupthink may influence the consensus of a heterogenous group (Madigosky & van Schaik, 2016). Finally, and most importantly, this study posited that healthcare professionals may only change their mind where they believe that the emerging consensus is for the greater good and will lead to an improvement in the status quo, which represents a compromise rather than false consensus.

6.7 Summary

The Service was "*struggling*" (interview participant 1) and healthcare professionals had "*redesigned as much as [they] probably can"* (interview participant 1) to meet demand and needed "*radical changes… new models of working*" (interview participant 9) to delivery care (5.3). Though the Scottish Government had acknowledged the need for service reform (Scottish government, 2008a; Christie commission, 2011; Scottish government, 2012a; 2016a; 2018a), it was unclear what reform was needed. These findings built on issues that had hindered service development identified during interviews, to understand how capacity should be developed within the Service to meet demand (RQ3). As reflected in interview data, new models of working were needed to meet demand. This Chapter presented the following findings:

Development of MCNs and national specialism-specific working groups:

> To resolve lack of cohesion (5.5) and provide more leadership over service developments (5.6), a two-part structure service leadership reached consensus. To meet demand, national, speciality-specific working groups are needed to design quality care and MCNs should be developed to guide regional, multidisciplinary implementation of quality care.

Multi-faceted training programmes for specialist nurses and allied health professionals:

> To deliver a holistic approach to patient care (5.4) and to develop services to meet demand (5.7), the Service required further development of specialist nurses and allied health professional roles. However, the efficient recruitment and training of specialist nurses and allied health professionals raised concerns during interviews (5.7). To resolve this, questionnaire data identified a need for a multi-faceted training programme to train specialist nurses and allied health professionals that includes training programmes, networking with other specialist nurses and allied health professional and the development of a Scotland-wide nursing and allied health professional working group.

Role of the patient, and community and primary care

> To manage increased demand, healthcare professionals had considered increased responsibility for patients in their own care (5.8) and primary and community care to support and follow-up patients (5.9). However, healthcare professionals were concerned about the capabilities of both groups to manage further roles or responsibilities (5.8; 5.9). These concerned were reflected in consensus during this phase and also in written comments given by participants. As a result, consensus was reached for care to remain with secondary and tertiary care practitioners.

The next Chapter discusses findings and orients them within the wider literature.

Discussion

7.1 Introduction

In Scotland, the quality of cancer care is measured against adherence to waiting time targets (Scottish government, 2016a), and urological cancer services have missing these waiting time targets to a greater extent than any other cancer care service (NHS National Services Scotland, 2019). Though incidence of prostate cancer had increased (Deas, 2018; Scottish Public Health Observatory, 2018) and treatment pathways had developed (European Association of Urology guidelines, 2019; National Institute for Health and Care Excellence, 2019), I did not find publications that identified the impact of these changes on the NHS Scotland prostate cancer service's (the Service's) ability to meet demand or what capacities the Service needed to develop to meet demand. Within this study, capacity was understood to be everything needed to enable the Service to meet demand including capacity assets and capacity needs. And capacity development was understood to be the bottom-up empowerment of healthcare professionals within the Service to obtain and maintain capacity to meet and continue meeting demand.

To understand the capacities needed to develop the Service to meet demand, I asked how usage of the NHS Scotland prostate cancer service had and was predicted to change (RQ1), why the NHS Scotland prostate cancer service had not met demand (RQ2), and how capacity should be developed within the NHS Scotland prostate cancer service to meet demand (RQ3). Using three phases of research, informed by an overarching Delphi methodology, I found that the number of men diagnosed and treated actively had increased, and palliative treatment usage had increased, likely as a result of developments in treatment protocols. When I interviewed healthcare professionals, they identified capacity shortage as existing throughout the Service, and were anticipating further capacity shortage resulting from increased demand. However, healthcare professionals were not developing services with the goal of meeting waiting time targets, but with the goal of improving quality within the Service. Through analysis of interview data, I identified several factors hindering service development, specifically a lack of cohesion and leadership in developing the Service, absence of an effective and efficient training programme for specialist nurses which hindered necessary role development, and lack of understanding of the level of responsibility that patients, and primary and community care can manage. To develop capacity within the Service, healthcare professionals reached consensus for the development of national, treatment specific working groups, and the further development of Managed Cancer Networks (MCNs) to guide development and implementation of quality care, multi-faceted training programmes for specialist nurses and allied health professionals, and for prostate cancer care to largely remain within secondary care.

In this Chapter, I present a framework for capacity development in the Service. To do this, I orient my findings within the wider literature drawing on learning from studies reviewed in Section 2.6, which identified (i) finite resources, (ii) capabilities and (iii) collaborations as necessary to the successful development of capacity within healthcare services. Firstly, I outline quality care within the Service as directing capacity development efforts (7.2). I then discuss findings from this research in relation to the shortage of finite resources within the Service (7.3). Then, considering this shortage, I discuss the need for development of capabilities (7.4) including service development capabilities (7.4.1), and the capabilities of patients (7.4.2), primary and community care practitioners (7.4.3) and specialist nurses and allied health professionals (7.4.4). Following which, I discuss the need for development of collaborations to support the Service (7.5). Finally, I provide a summary of the capacities needed to meet demand in the Service (7.6).

7.2 Quality prostate cancer care as the goal of capacity development

In Section 2.6, capacity development was defined as the bottom-up empowerment of healthcare professionals. The aim or goal of capacity development within the Service was understood to be to develop and maintain capacity to meet and continue meeting demand, which reflected the rationale for this study (1.5). However, to meet demand, healthcare professionals had already "*redesigned [services] as much as [they] probably [could], and [they're] struggling"* (Participant 1) (5.3). To resolve capacity issues, healthcare professionals proposed "*radical changes… new models of working… the tinkering round the edges and the making small changes is important in terms of making small cycles of change, but at a fundamental level for us to deal with capacity we need to look at bigger changes*" (Participant 9) (5.3). To meet demand, healthcare professionals were exploring ways to transform care, in addition to seeking increased capacities to enable more of the same care.

However, this transformation was not found to be solely driven by the number of patients within the Service and their engagement resulting from the development of new treatment modalities and additional lines of treatment. Rather, transformation was driven by healthcare professionals understanding of quality prostate cancer care, of which the number of patients and their engagement were only one part. Healthcare professionals understanding of quality care was not found to align with the Scottish government's measurement of quality care, such as waiting time targets. Instead, healthcare professionals were generally hesitant to develop the Service to meet waiting time targets because they were at odds with healthcare professionals understanding of quality prostate cancer care. As a result, waiting time targets were viewed as "*stifling*" (Participants 22) needed service developments.

Scottish government recognise the importance of quality as directing service development. For example, the 2020 vision route map (Scottish government, 2012a) to the 2020 quality healthcare strategy (Scottish government, 2010a) positioned quality as the core driver for healthcare reform. However, a core issue throughout relevant policy documents is the misalignment between ambitions of cancer services, how quality healthcare is defined and how good care is measured in cancer services. It is the ambition of Scottish government to develop cancer services "*to become one of the highest performing cancer healthcare systems internationally*" (Scottish government, 2016a, pp. 51). To enable the development of internationally renowned care, the Scottish government defined quality healthcare to align with the United States Institute of Medicine goals where quality healthcare was understood to be patient-centred, safe, effective, efficient, equitable and timely (Scottish government, 2008a) and this was then measured using waiting time targets. Understanding of quality was later refined to safe, effective and person-centred healthcare (Scottish government, 2010a) removing efficient, equitable and timely from definitions of quality, but waiting time targets continued as the measurement of good care. Now understanding of quality in cancer services has been devolved to the National Cancer Quality Performance Indicator (QPI) programme (Scottish government, 2016a) which provides a framework for measuring adherence to protocols and waiting time targets, but has otherwise not furthered understanding of quality in cancer care (Scottish government, 2016a).

Given that quality has been positioned as central to reform (Scottish government, 2010a; 2012a) and was found to be the main driver of development within the Service, further understanding is needed of how healthcare professionals conceptualise and use understanding of quality to develop services. Further efforts are needed to create a shared understanding of quality in Scotland to direct capacity development efforts.

7.3 Finite resources

A review of capacity development frameworks presented in Section 2.6 found that specific quantities of finite resources such as finances, equipment, workspaces, and staffing, were required to enable healthcare services to function as intended (LaFond, Brown & MacIntyre, 2002; Baillie et al., 2007; Cohen et al., 2013; Patterson, Smith & Bellamy, 2013; Bobo, 2014; Mirzoev et al., 2014; Wallar et al., 2016). Increases in finite resources were required within the Service to enable optimal functioning of the Service, resulting from increased usage of the Service.

This research found that all parts of the Service have experienced increased demand. Firstly, incidence was found to have increased between 1997 and 2012 meaning that more men required treatment within the Service. These men were more likely to utilise active treatment services and less likely to utilise palliative treatment services. Increased usage of active treatment is thought to be the result of: the shift towards diagnosis at a younger age, meaning that men are likely to be diagnosed with earlier grade cancer and be fit for radical treatment; increase uptake of opportunistic screening leading to increased diagnosis of indolent cancer (EAU guidelines, 2019); and development of radiotherapy leading to the radical treatment of men who are not fit for surgery (EAU guidelines, 2019). Particularly, increased usage of active surveillance represents a substantial increase in need, as men on active surveillance protocols are not discharged until other treatment is indicated. Secondly, though the number of men using palliative services decreased, this did not represent a decrease in usage of this part of the Service. Rather, palliative treatment protocols had developed rapidly leading to availability of more lines of treatment (EAU guidelines, 2019; NICE, 2019). As a result, service usage had increased. And increased usage caused by more lines of treatment is reflected in increases in the number of men who had chemotherapy each year. Though differences were evident between regions, trends changed uniformly across Scotland suggesting uniform increases in need across the Service. This increase in need and resulting capacity shortage was not found to relate to the ageing Scottish population, but resulted from developments in technologies related to the diagnosis and treatment of prostate cancer such as PSA testing, radiotherapy and chemotherapy.

Increased demand resulting from technological developments is consistent with findings by Appleby (2013) who urged consideration of the impact that developments in technologies have on finite resources. Ultimately, capacity shortage has occurred in the Service as a result of more men requiring treatment, for longer, and with more lines of treatment available requiring more finite resources to meet demand. However, a lack of some resources was evident from interviews with healthcare professionals. Most relevantly, healthcare professionals recognised that recruiters had been unable to fill prostate cancer specialist nurse vacancies elsewhere in the UK. These findings reflected other studies of the Service which found a lack of willingness of nurses to specialise due to the resulting isolation from other nurses, lengthy work weeks, and increasing caseloads resulting in burnout, the developing nature of the role, the lack of specialism at ward level, and limited promotion opportunities (Ream et al., 2009; Leary et al., 2016).

A shortage of finite resources was recognised by Scottish government who pledged improved efficiency of finite resources, including efficiency of the healthcare workforce (Scottish government, 2012a) and equipment and workspaces (Scottish government, 2018a), to ensure saturation of finite resources across the Service. Considering lack of finite resources available to maintain the Service (Scottish government, 2016a; 2020a), healthcare professionals advocated for "*radical changes… to say, new models of working… the tinkering round the edges and the making small changes is important in terms of making small cycles of change, but at a fundamental level for us to deal with capacity we need to look at bigger changes*" (Participant 9) (5.3), i.e. transformational change or service reform. Service reform involves a foundational shift in culture and/or structure to create a new state or model of care (Dougall, Lewis & Ross, 2018), and the Scottish Government have acknowledged that service reform is needed in healthcare to meet not only increasing demand, but also the changing demands of the public (Scottish government, 2008a; 2016a). Informed by reform in NHS England (Department of Health, 2007; Leatherman & Sutherland, 2008), the Better Cancer Care action plan (Scottish government, 2008a) actioned reform across Scottish cancer services, most relevantly with the implementation of waiting time targets and the development of the Scottish Cancer Taskforce that later implemented the national cancer quality performance indicators (QPIs) in 2016 (2.2.8). Further, the Christie commission (2011) explicitly identified the need for further reform considering budgetary constraints and increasing demand across NHS Scotland, advising community- and function-driven service development. In response, and informed by further reform in NHS England, the 2020 vision route map (Scottish government, 2012a) to the 2020 quality healthcare strategy (Scottish government, 2010a) pledged further reform. Then, the Beating Cancer Action Plan (Scottish government, 2016a) highlighted the ongoing implementation of a transformational change programme that included cultural transformation and further integration of primary and secondary care. And in 2018, in response to unmet waiting time targets, the Scottish government pledged the design and implementation of new models of care. Though to date, approaches to reform within policy have been largely top-down and driven by government directives, there is a growing body of evidence that acknowledges bottom-up (Braithwaite, 2018) or "*from within*" (Dougall, Lewis & Ross, 2018, pp. 5) approaches as the most effective approach to reform. This study identified a need 'from within' the Service for reform to meet demand.

Considering the shortage of finite resources available, reform of the Service through the development of capabilities and collaborations was identified as needed to develop capacity within the Service.

7.4 Capabilities

Capability development is an important component of capacity development (2.6). Capabilities are the skills required to complete a task (Helfat & Peteraf, 2007; Lichtenthaler & Lichtenthaler, 2009) including hard skills such as professional or academic training and knowledge, and soft skills such as personal attributes. This Section discusses the need for service development capabilities (7.3.1), as well as the need to develop the capabilities of patients (7.3.2), primary and community care practitioners (7.3.3), and specialist nurses and allied health professionals (7.3.4) to meet need.

7.4.1 Service development capabilities

Firstly, as healthcare develops rapidly (Appleby, 2013; Braithwaite, 2018), there is need for healthcare professionals to continually evaluate the needs of the Service in line with demand and develop the Service accordingly. Public services in Scotland are long-standing and culturally entrenched structures that have been criticised for being too rigid to easily accommodate change (Christie commission, 2011; Scottish government, 2012a; 2018a). And these rigid healthcare structures hinder service development (Christie commission, 2011; Braithwaite, 2018). As a result, service development in Scotland generally involves form-led, structure-led or top-down change rather than function-led, bottom-up or ‘from within’ change (Christie commission, 2011; Braithwaite, 2018; Dougall, Lewis & Ross, 2018). This ultimately leading to ineffective change being imposed on healthcare services (Braithwaite, 2018; Dougall, Lewis & Ross, 2018). Certainly, NHS Scotland policy generally directs efforts towards altering healthcare structure (Scottish government, 2008a; 2010a; 2016a) and gains from this approach are generally modest (Braithwaite, 2018). The biggest gains are seen with cultural shifts and bottom-up change (Braithwaite 2018; Dougall, Lewis & Ross, 2018). Braithwaite (2018) describes change in healthcare services as moving “*to its own rhythm*” (pp. 1) and advocates that services need to be empowered to realise change. Where government documents identify a need for sustainability, efforts are generally directed at the creation and then maintenance of a new sameness or status quo, rather than focussing on the sustainability of change itself (Scottish government, 2012a; 2018a). Whilst some definitions of sustainability focus on the normalisation or institutionalisation of a change, other definitions describe sustainability as continual development or innovation (Shediac-Rizkallah & Bone, 1998; Johnson et al., 2004; Fleiszer et al., 2015). As healthcare develops rapidly (Braithwaite, 2018), to enable the Service to meet demand and also continue meeting demand, there is a need for the Service to develop the capabilities needed to enable ongoing development as the prostate cancer care landscape continues to change.

7.4.2 Patients

To meet care need considering current resources, during interviews healthcare professionals recounted their learnings from service development efforts to alleviate capacity shortage within the Service through giving patients greater responsibility in their own follow-up care. However, patient capabilities were raised as a barrier to these service developments. Specifically, healthcare professionals were concerned that not all patients would manage greater responsibility in their care and were hesitant to adopt different follow-up protocols with different patients. As a result, though healthcare professionals reached consensus that patients should have more responsibility in their follow-up care, healthcare professionals did not reach consensus to include patient self-monitoring of PSA levels within their follow-up care (6.5). However, healthcare professionals did not present any account throughout this study of patient involvement informing this decision-making or service development efforts. Rather, healthcare professionals drew on their own experiences of patient consultations to guide their decision-making. As such, it remains unclear whether patients could have more responsibility in their care and whether this is viable route to alleviating capacity shortage within the Service. This section explores the literature on patient capabilities.

Recognition of the importance of patient experience in service development is evident throughout Scottish policy (Scottish government, 2008a; 2010a; 2012a; 2016a; 2018a). Informing policy, the

Christie commission report (2011) advocated the development of services around "*the needs of people and communities, their needs, aspirations, capacities and skills, and work to build up their autonomy and resilience*" (pp. 26), and so healthcare services in Scotland have a responsibility to develop considering patient and public capabilities, and to develop those capabilities. To facilitate this development, services should draw on all relevant expertise to place emphasis on patient experience to co-produce services in order to "*better use each other's assets, resources and contributions to achieve better outcomes or improved efficiency*" (Loeffler & Hine-Hughes, 2013, pp. 8). As such, co-production of services should involve exploration with patients on how to better utilise patient capability to meet demand. However, policy gives limited guidance on how much healthcare services can ask of patients, for example, whether it is reasonable to expect patients to take responsibility for their own follow-up care if they have the capability to do so, and whether it is reasonable to provide different follow-up care to different patients to account for different capabilities within the patient population.

The Patient Rights (Scotland) Act (2011) provides some guidance on the roles, responsibilities and reasonable expectations of patients; specifically, (i) healthcare must take into account the needs of the patient, whilst allowing and encouraging the patient to participate as fully as possible, and (ii) that the desirability of action delivering healthcare should be proportionate, and otherwise appropriate, to the circumstances of each case. This indicates that it is reasonable to give increased responsibility to some patients and not others dependant on a patients' individual capability to enable patients to participate as fully as possible in their care. The right of a patient to participate as fully as possible in a patient's own care is a pertinent area of reform in Scottish healthcare (Bolton, 2015; Chan et al., 2017). However, the development of follow-up care in the Service has stalled as a result of a lack of guidance on the level of involvement that can reasonably be asked of a patient considering patient capabilities (6.5). As Scottish government are directing services to develop services considering patient capabilities, further guidance and support is needed to support services to meet demand.

7.4.3 Primary and community care

During interviews healthcare professionals reflected on the capability of primary care to have increased responsibility in the specialist care of men with prostate cancer. Consensus was reached for greater involvement of primary care in the palliative care pathway such as in the management of common side effects of long term hormone therapy use, and hormone therapy prescription, administration and support. The integration of palliative cancer care services with primary care reflects recent service developments in the UK (Abel & Kellehear, 2016; Meiklejohn et al., 2016; Foster et al., 2018; Millington-Sanders & Noble, 2018) and internationally (Le et al., 2017; Clarke, Nightingale & Cunliffe, 2018; Meier et al., 2017) and is reflected in primary care frameworks (Gold

Standards Framework, 2012), though many of these publications focus primarily on end of life care only and not all palliative care. Regardless, publications concluded that there was a need for primary care to have increased involvement in palliative cancer care largely due to greater capability within primary care to deal with the range of needs patients have including the need for ad-hoc appointments to manage symptoms and side effects as they develop, the management of co-morbidities, and the need for support to self-manage (Meiklejohn et al., 2016; Foster et al., 2018; Millington-Sanders & Noble, 2018). As such, the need for increased involvement for primary care to support patients in the palliative pathway reflects recommendations from the Christie commission report (2011) to develop function rather than form-led support.

However, in the final phase of this study, healthcare professionals reached consensus that primary care practitioners did not have the capabilities needed to perform their current role in the prostate cancer care opportunistic screening protocol and that healthcare professionals should not adopt further responsibilities in active treatment follow-up, though healthcare professionals recognised that capability was higher in some primary care services than in others. These findings are consistent with concerns raised in the wider literature (Rai et al., 2007; National Screening Committee Prostate Cancer Risk Management Programme, 2016). Though there are clear concerns related to capabilities of primary care practitioners to be the involved in specialist care, the drive for involvement of primary care practitioners continues in policy. The development of 'partnership working' was a key policy objective of the newly devolved Scottish government (Scottish Office, 1997; Scottish Executive, 1999; Woods, 2001) and is now evident throughout Scottish policy (Scottish government, 2008a; 2010a; 2012a; 2016a; 2018a). The shift towards partnership working by Scottish government (1997) was informed by a need to develop capacity within NHS Scotland considering financial limitations (Scottish Office, 1997; Scottish Executive, 1999; Woods, 2001), as well as to improve health and reduce inequality given Scotland's significantly reduced health outcomes (Walsh, Taulbut & Hanlon, 2008; Taulbut et al., 2014), and to develop a service that was designed from the patient's viewpoint. Though partnership working has been successful in many areas, Weir (1999) cautioned that it was not a solution for all service delivery issues. And the necessity of moving aspects of specialist care to primary care has not been revisited following national integration of social care, healthcare and community care services. As a result, healthcare professionals within the Service are divided over whether this is the best model of care for patients and are struggling to realise partnership working given current capabilities in primary care, and the imperative to deliver specialist care locally has had a substantial impact on the wellbeing of primary care practitioners and has led to widespread recruitment concerns (British Medical Association, 2014; Royal College of General Practitioners, 2014).

These findings highlight a need for reconsideration of widespread integration of healthcare services considering the new health and social care landscape and echo the Christie commissions (2011) emphasis on the development of function-led over form-led care. Findings concluded that specialist follow-up of active treatment should continue within secondary care, and so the solution to capacity shortages may not lie within further integration of primary and secondary care services.

7.4.4 Specialist nurses and allied health professionals

This study found that further development of specialist nurse capabilities was required, and that a lack of effective training for specialist nurses had hindered the Service's capacity to develop to meet demand. Though training of nurse specialists emerged as a pertinent topic in this study, it was also evident that services are developing to include specialist pharmacists and physiotherapists and so the capability development of allied health professionals is also important. However, as there are no specialist training programmes for allied health professionals either, the lack of effective training evident with specialist nurses is likely to extend to specialist allied health professionals too.

Healthcare professionals described specialist nurses training as requiring substantial input from other members of the prostate cancer care team, usually doctors registered with the GMC who had previously undertaken the role, over years. This investment needed from other members of the team, to train specialist nurses, is also echoed in the literature (Rosser et al., 2004; Sibbald, Shen & Mcbride, 2004; Ream et al., 2009). Though nurses working within the Service have various levels of qualifications and clinical experience (Ream et al., 2009; Leary et al., 2016) these do not translate directly to the development of clinical competency needed for specialist roles (Gledhill et al., 2017) leaving specialising nurses lacking the required capabilities for the role. During interviews, no successful method of training specialist nurses was identified, and the lack of effective training had hindered service development.

In this study, consensus was reached for the development of multi-faceted training programmes to develop the capability needed for a specialist prostate cancer care role. Specifically, nurses should engage with a training (or education) programme, through networking with individuals in similar posts, and be supported through the development of a national nursing and allied health professional working group. The need for multi-faceted training is reflected in current nursing training lines, such as the newly implemented Royal College of Nursing credentialing system that requires assessment of clinical competence in addition to post-graduate level study (RCN, 2017). However, limited guidance can be found on efficient and effective methods of how nurses can develop this needed clinical competence. Certainly, multi-faceted training programmes are not new in healthcare, and recently have been particularly successful in training nurse leaders (for example, Debono et al., 2014) and palliative care specialist nurses (for example, van Kampen et al., 2015). Additionally, another successful model of multi-faceted specialist training is the medical training pathway, where doctors registered with the GMC develop needed capabilities by specialising over years through a combination of postgraduate level education programmes, on-the-job training, workplace rotations, and mentorship. However, using medical training pathways as a model for specialist nurses and allied health professionals training would require substantial reform in the way that specialist nurses and allied health professional roles are planned, and recruited and trained for. However, the development of a national working group offers the opportunity for specialist nurses and allied health professionals to network and learn from each other, develop specialist nurses and allied health professionals training pathways to develop capabilities within the Service, and also presents some resolution to the isolation that has been experienced by specialist nurses and allied health professionals working within the Service (Ream et al., 2009; Leary et al., 2016).

7.5 Collaborations

In addition to finite resources and capabilities, collaborations are also essential to meet demand. This section discusses the collaboration needed within the Service itself to meet demand, before discussing the collaborations needed between the Service and other organisations or services to meet demand.

The need for collaboration within the Service was recognised within findings. Particularly, healthcare professionals identified a lack of cohesion (5.5) and leadership (5.6) within the Service that had hindered service development to meet demand. From this, healthcare professionals reached consensus for the creation of national working groups and the further development of MCNs to develop and implement care in Scotland respectively (6.3) to improve collaboration within the Service. This section posits cohesion as a useful framework for national and multidisciplinary group working, and then positions the type of leadership needed within the Service in relation to the wider literature, before describing how the need for the further development of MCNs and the development of national working groups (6.3) reflect the wider literature.

Though there are many ways of developing stronger teams, such as through team building, organisational strengthening and relationship building, cohesion offers a good framework to describe the type of collaboration needed within the Service. Cohesion refers to the strength of relationships and solidarity within a community (Kawachi & Berkman, 2000; Office of Disease Prevention and Health Promotion, 2010) or the unitedness of a group in obtaining its goal or purpose (Carron, Brawley & Widmeyer, 1998; Tekleab, Quigley & Tesluk, 2009) and includes factors such as interpersonal trust, norms of reciprocity and mutual aid (Coleman, 1990; Putnam, 1993; Kawachi & Berkman, 2000). Pertinently, high cohesion relates to the absence of latent conflict from longstanding difference that can result from inequities (Kawachi & Berkman, 2000) such as the regional differences that exist across the Service, or functional diversity (Tekleab et al., 2016) such as the differences that exist in the Service between disciplines and specialities. Though these differences can have a negative impact on cohesion, this is not always the case. For example, functional diversity has been found to have a curvilinear relationship with cohesion, where little diversity and high diversity can strengthen cohesion (Lau & Murnigham, 1998; Webber & Donahue, 2001; Tekleab et al., 2016). Specifically, where there is a mutual respect for each other's differences (Lau & Murnigham, 1998; Gibson & Vermeulen, 2003). The significance of mutual respect in good team cohesion was evident within this study. For example, in high quality service provision, nurses were not found to be relieving the workload pressures of doctors registered with the GMC, but all healthcare professionals had distinct discipline-specific roles, indicating an acknowledgement and respect of disciplinary skills across the team. Therefore, cohesion offers a framework for healthcare professionals within the Service spanning regions, disciplines and specialities to utilise different experiences and priorities to develop the Service.

To enable capacity development to occur, there is a need for an infrastructure, concrete work plans, and policy, legislation, and regulations that reflect the needs of the capacity development programme itself (Baillie et al., 2007; Cohen et al., 2013; LaFond, Brown & MacIntyre, 2002; Wallar et al., 2016; Wolfram, 2016). Healthcare professionals did not identify the need for a leadership figure within the Service, but rather the need for leadership of service developments to prevent inequity in service delivery, i.e. to prevent "*everybod[y] reinventing that wheel*" (Participant 5), to relieve pressure on local capacities to design and implement local solutions to capacity shortage and ultimately, to lead service reform. And leadership of service reform does not require traditional healthcare leadership styles and structures (Edmonstone & Western, 2002; Donnelly, 2003; McCallin, 2003; O'Reilly & Reed, 2011; Parker, 2013; Freund, 2017; Brewer et al., 2018). Rather evidence suggests that leadership should not be a single hierarchical position, but a systemic, service-wide process based on shared values (Denhardt & Denhardt, 2002; Berwick, Ham & Smith, 2003), where a group works to coordinate the Service towards achieving a goal or for a purpose (Berwick, Ham & Smith, 2003), like through the development of MCNs and national working groups. And, the development of groups to lead service development will provide a greater degree of structural and psychological empowerment within the Service through encouraging innovation (Laschinger et al., 2004; Knol & Van Linge, 2009; Bonias et al., 2010; Solansky, 2014) and ultimately, service reform.

To enable improved collaboration through the development of cohesion and leadership within the Service, healthcare professionals rejected the current model of Health Board led care in place of MCN led care. This is not the first time that MCNs have been championed as a method of leadership in Scotland (Scottish Office, 1997; Scottish Executive Health Development Letter, 2001; 2007; Scottish government, 2008a). Following devolution, MCNs were identified as vehicles for change by Scottish government (Scottish Office, 1997; Scottish Executive Health Development Letter, 2001). And the development of MCNs was a prominent focus in the better cancer care action plan (Scottish government, 2008a). Specifically, MCNs were championed for facilitating the development of clinical management guidelines and protocols and were tasked with improving the quality of care of patients. As a result, it was proposed in 2007 that MCNs should be further developed to enable this (Scottish Executive Health Development Letter, 2007) and this was reflected in the cancer care policy that followed (Scottish government, 2008a).

However, the focus on developing MCNs has been lost from recent policy (Scottish government, 2010a; 2016a; 2018a). During interviews, MCNs were identified as best placed to "*shape and design*" (Participant 16) the Service, thereby alleviating local pressures on Health Boards. However, though MCNs had been given some responsibilities such as monitoring waiting time targets (Scottish government, 2008a; 2016a), MCNs had not been developed to enable leadership over local services, described by one healthcare professionals as having "*no teeth*" (Participant 17) to make a difference. Healthcare professionals reached consensus to develop MCNs reflecting guidance in the Scottish Executive Health Development Letter (2007) that detailed why and how MCNs should be developed, but findings from this study suggest a need for development beyond these recommendations, most prominently having a role in the funding and governance of the Service. The presence of an accepted leadership structure and an established need for MCN development (Scottish Office, 1997; Scottish Executive Health Development Letter, 2001; 2007; Scottish government, 2008a) is an asset to NHS Scotland; the presence of MCNs places NHS Scotland in a better position to reform healthcare than other regions of the UK, where there is a lack of allegiance, leadership and leadership structures to guide reform (Hunter et al., 2015; Timmins, 2015; Tweed et al., 2018; Dougall, Lewis & Ross, 2018).

However, it was also evident during interviews that a degree of national, as well as regional, oversight was required in Scotland and consensus was reached that not all tasks should be the responsibility of MCNs. Rather, some tasks should remain the responsibility of specialities. Consensus was reached national, speciality-specific working groups should be responsible for the design of quality care within the Service, with MCNs developing responsibility for the regional, multidisciplinary implementation of quality care within the Service. And these national working groups could be crucial in driving forward NHS Scotland's ambition of becoming "*one of the highest performing cancer healthcare system internationally*" (Scottish government, 2016a, pp. 51).

Currently, NHS Scotland has not committed to a plan for meeting international ambitions. Policy states that this ambition will be recognised through improved data sharing, the development of data and informatics, QPIs that measure adherence to protocols, and use of personal experience surveys to inform practice (Scottish government, 2016a). However, this does not situate Scottish cancer care within the international arena; no clear understanding of what good cancer care in Scotland is, is conveyed. Certainly, good cancer care is subjective and deeply entrenched in politics and culture. For example, in the United States, good healthcare was often viewed as unrestricted access to medical consultants, and tests and treatments, which has led to increasing healthcare costs (McGlynn et al., 2003; Berwick, Nolan & Whittington, 2008; Bultas et al., 2016; Burstin, Leatherman & Goldmann, 2016). In Scotland, the steadfastness of healthcare professionals and politicians towards the founding belief of the NHS as free access to treatment for all has led to a more conservative approach to healthcare delivery within the Service that healthcare professionals felt was now being "*validated*" (Participant 16). At the most basic level, the development of national working groups will provide healthcare professionals with a platform to develop cohesion within the Service and lead service development and reform, relieving pressures locally. At another level, the development of national working groups will provide healthcare professionals with a platform to position care within an international context and make explicit the factors that drive quality care within Scotland to meet current international ambitions (Scottish government, 2016a) and also to provide a shared understanding of what quality prostate cancer care is in Scotland. However, it must also be noted that where policies are not supportive of bottom-up or 'from within' reform, the ability of MCNs and national working groups to enact change will be limited (Kakabadse, Korac-Kakabadse & Kouzmin, 2003; Hewison & Griffiths, 2004; Markuns et al., 2010; Storey & Holti, 2012; Zachariadis et al., 2013; Anderson et al., 2015).

Though healthcare professionals focussed on collaboration within the Service, this does not mean that collaboration between the Service and other organisations or services are not necessary to meet demand, but is reflective of pertinent issues within the Service. The model of collaboration identified in this study provides a platform to develop formal or informal, and centralised or decentralised networks, collaborations, partnerships, and coalitions as needed to meet demand (LaFond, Brown & MacIntyre, 2002; Baillie et al., 2007; Cohen et al., 2013; Wolfram, 2016). Including with the third sector (Christie commission, 2011; Scottish Council for Voluntary Organisations, 2014), with Scottish government, and with other health and social care services and bodies (Public Bodies (Joint Working) Act, 2014). With the creation of logical points of contact to support service development planning through better use of MCNs and national working groups, there will be improved opportunity to establish successful collaborations that have a shared vision, power and responsibility within the development as needed to develop capacity to meet demand (Baillie et al., 2007; Cohen et al., 2013; Patterson, Smith & Bellamy, 2013; Bobo, 2014; Mirzoev et al., 2014; Schell et al., 2014; Wolfram, 2016).

7.6 Summary

Though incidence of prostate cancer had increased (Deas, 2018; Scottish Public Health Observatory, 2018) and treatment pathways had developed (European Association of Urology guidelines, 2019; National Institute for Health and Care Excellence, 2019), I did not find publications that identified that impact of these changes on the Service's ability to meet demand or what capacities the Service needed to develop to meet demand, and urological cancer services have missing waiting time targets to a greater extent than any other cancer care service (NHS National Services Scotland, 2019). The structure of healthcare services make change difficult to realise, and Scottish government generally implement form-led, structure-led or top-down change, which is ultimately ineffective in developing necessary change in a resource-restricted healthcare service. Rather, function-led, bottom-up or ‘from within’ change has been found to be the most effective way to meet healthcare demands, and the findings from this research reflect this. This Chapter presented a capacity development framework for the Service to meet demand informed by findings from this study. In this study, capacity was defined as everything needed to enable the Service to meet demand including capacity assets and capacity needs. Capacity development was defined as the bottom-up empowerment of healthcare professionals within the Service to meet and continue meeting demand.

Goal of capacity development:	Both healthcare professionals and Scottish government were aligned in using understanding of quality to direct capacity development. However, Scottish government provided limited and misaligned understanding of how quality cancer care should be conceptualised in Scotland. Therefore, healthcare professionals were using their own understanding of quality care to drive development. As such, further understanding is needed to conceptualise quality in Scottish prostate cancer care to direct capacity development efforts.
Finite resources:	Considering the lack of finite resources available to maintain the Service (Scottish government, 2016a; 2020a), to meet demand healthcare professionals advocated for “*radical changes… new models of working*” (Participant 9) to meet demand. Scottish government accept that change is needed (Scottish government, 2008a; 2016a; Christie commission, 2011), but direct top-down, rather than bottom-up change.
Capabilities:	First, there was a need for service development capabilities to enable the Service to respond quickly to changes in demand. Secondly, there was a need for more guidance to understand how an individual patient’s capabilities could be used within the Service. Thirdly, there was recognition that primary care services did not have the capabilities needed for involvement in active treatment and follow-up, though some involvement in palliative care treatment and follow-up was needed. Finally, there was a need to develop more efficient training pathways to support the specialisation of nurses and allied health professionals.

Collaborations: Within the Service, greater collaboration was required to improve cohesion and leadership was needed. To enable this, consensus was reached on a two-part structure for collaboration involving national, speciality-specific working groups are needed to design quality care and MCNs should be developed to guide regional, multidisciplinary implementation of quality care. These working groups then provide logical points of contact with organisations and services to collaborate to co-produce and inform service development.

Conclusion

8.1 Introduction

I conclude this study in this Chapter. Following this introduction (8.1), I summarise the key findings of this study (8.2). I then summarise how my own actions and experiences guided this study (8.3) and give the implications of these findings for government and regulatory bodies, prostate cancer specialists, primary and community care practitioners, and patients (8.4) before giving an account of future work needed (8.5). Finally, I provide a brief summary of the main points of this study (8.6).

8.2 Key findings

This study gave voice to healthcare professionals involved in the delivery of specialist prostate cancer care in Scotland to understand how change needs to be realised within the NHS Scotland prostate cancer service (the Service). Considering a lack of evidence to understand capacity shortage within the Service and direct capacity development efforts, this study drew on the expertise of healthcare professionals across Scotland to facilitate a consensus on the solution to capacity shortage. Specifically, this study developed a capacity development framework for the Service, which was presented in Chapter 7. The capacity development framework understood capacity development to be guided by an overarching goal or aim (8.2.1) and require finite resources (8.2.2), collaborations (8.2.3) and capabilities (8.2.4). Also, importantly, there was a need to consider sustainability of the capacity development efforts (8.2.5).

8.2.1 Capacity development goal

Firstly, it is important that capacity development initiatives have a shared goal to guide efforts. In this study, healthcare professionals were found to align with Scottish government in using quality to drive service developments. In Scotland, the quality of cancer care is measured using waiting time targets, and urological services have missed these waiting time targets to a greater extent than any other cancer care service. However, this study found that healthcare professionals did not believe that waiting time targets reflected quality cancer care and had developed the Service in line with their own understanding of quality cancer care. Ultimately, there was a need to conceptualise quality in Scottish cancer care to guide service development and ultimately, capacity development efforts.

8.2.2 Service reform and sustainability of change to manage lack of finite resources

This study identified increased engagement of patients with the Service, which resulted from increased incidence, prevalence and more lines of treatment, leading to a substantial increase in demand within the Service. This study found that healthcare professionals were managing service-wide capacity shortage by actively developing services, whilst anticipating further capacity shortage, but no single solution was evident. Healthcare professionals advocated for "*radical changes… new models of working*" (Participant 9). This did not mean that more finite capacities would not be needed, but that efficiency and productivity could be improved with current finite resources through service reform. However, reform in the Scottish healthcare service has been difficult to realise as a result of historical and culturally entrenched healthcare structures. Scottish healthcare policies utilise these structures to guide service reform rather than through focussing on what is needed on the cancer care frontline. Importantly, there was a lack of capacity development capacities that would enable healthcare professionals to manage change, including increased numbers of patients engaging with the Service, technological advances, and changes in the expectations of care. This framework addressed this lack of capacity by providing an infrastructure that should better support the Service to meet need, but also to provide a platform for the sustainability of service development as an inherent function of the Service.

8.2.3 An infrastructure for collaboration and capability development

To meet demand, healthcare professionals advocated the development of national, speciality specific working groups and Managed Cancer Networks (MCN) to develop cohesion and leadership within the Service and ultimately, guide service development to meet demand. To develop services to meet demand, further development of specialist nurses and allied health professionals roles was also a priority. However, current training models lack efficiency and exert a significant demand on the Service. Given that there is no current solution to the development of clinical competency for specialist nurses, healthcare professionals advocated the development of a multi-faceted training programme. Finally, given lack of capabilities, healthcare professionals reached consensus for follow-up and supportive care, except for some aspects of palliative care, to remain within secondary care. However, there is a recognised need for patients and primary care to help to guide service development, and with the development of national and regional working groups, this need could be realised. There was also a need for further understanding of the role and responsibility that patients can reasonably expect and be given in their own care.

8.3 Strengths and limitations

As the Delphi technique utilises the expertise of carefully selected participants to facilitate consensus (James & Warren-Forward 2015; Foth et al., 2016; McMillan, King & Tully, 2016; Waggoner, Carline & Dunning, 2016; Humphrey-Murto et al., 2017), the validity of this study rested with the experiences or *expertise* drawn upon. In this study, healthcare professionals were sampled if they identified as delivering specialist treatment and care to men with prostate cancer. The expertise of healthcare professionals is recognised as an asset in healthcare development (Goodman, 1987; Sackett et al., 1996; Greenhalgh, 2002; Keeney, Hasson & McKenna, 2010; Bae, 2015; Wieringa et al., 2018). And this was reiterated in this study where healthcare professionals voiced a need for more sharing of expertise, specifically to understand "*what works, what doesn't work*" (Participant 5) to stop "*everybod[y] reinventing that wheel*" (Participant 5) (5.6), and also to aid training of further specialists (5.7). However, recognition of the value of healthcare professional expertise in service development is lacking in policy as reflected in the Christie commission report (2011) that highlighted the underuse of healthcare professional expertise. However, healthcare professional expertise has been useful both nationally (Dougall, Lewis & Ross, 2018) and internationally (Braithwaite et al., 2017) in leading healthcare service development and reform.

Though healthcare professional expertise is a strength of this study, it is also a limitation. Though the sample drawn on are heterogenous, i.e. they are span regions, disciplines and specialities, except for two General Practitioners (GP) interviewed in Phase 2, they are all clinical prostate cancer care specialists. In this study, what could be known of the Service was shaped by individual's cumulative experiences of the Service (Dewey, 1920; 1925). Essentially, healthcare professionals are limited to their own experiences; healthcare professionals can only propose and make judgement on what they know of possible service developments and solutions to capacity shortage i.e. they may not be aware of the breadth of change possible. For example, in this study, healthcare professionals focussed on the issues with shifting care to primary care and did not propose community pharmacy services as an alternative. Though, healthcare professionals noted a lack of capability in both populations, which could account for this. Also, healthcare professionals make judgements based on their own inquiry framework, developed from their interpretations of beliefs and actions (Dewey, 1920; 1925). This can result in confirmation bias within the data. Confirmation bias is the interpretation of information to align with one's own beliefs. Though healthcare professionals spanned regions, disciplines and specialities, there was a strong unifying culture of patient care present in the data. As culture and beliefs help to shape individuals' knowledge frameworks (Dewey, 1920; 1925; Levi, 2012) this culture will have influenced how healthcare professionals responded in this study. However, this culture has been developed through repeated exposure to prostate cancer care in Scotland and is not unlinked to what makes these individuals experts.

Ultimately, the use of healthcare professional expertise is the core strength of this study, and evidence suggests that healthcare professionals are the key to successful development of the Service (Christie commission, 2011; Braithwaite et al., 2017; Braithwaite, 2018; Dougall, Lewis & Ross, 2018). As such, this study gives voice to the specialists delivering prostate cancer care across Scotland to guide service development and reform in the Service to meet demand.

8.4 Reflection on my PhD journey

Throughout this thesis, I included sections reflecting on my PhD journey. These reflective sections captured how my own experiences and actions guided this study. I describe my understanding of my role as a researcher in relation to the research question and the research participants, which I grappled with throughout this study and became a major frustration. This frustration was centered around my grappling with how my own understanding of the research problem and context should be integrated with the data, which contributed to my choosing content analysis as a method of analyzing interview data (3.10.6), and reflected on in more depth (5.10).

When analysing interview data, as a nurse it was possible that I was more receptive to the issues relating to my own discipline. But, the need for development of specialist nursing roles was raised extensively in each interview in relation to all parts of the Service. Some healthcare professionals also identified the development of specialist nurse roles as the main service development issue within the Service. However, the need for the development of specialist nurse roles could not be separated from the need for the development of allied health professional roles; it was sometimes unclear whether healthcare professionals were identifying the development of nursing roles as nursing was the discipline best suited to service needs, or because nurses were more commonly employed in the Service than allied health professionals.

To capture key points in the journey of understanding my role as a researcher, I provided the following reflections: personal position (1.8), refining the research problem (2.4), my approach taken to the methods (3.5), my role within the Steering Group (3.8), my decision to use content analysis (3.10.6), using national datasets (4.6), understanding the value of my own knowledge (5.10), and my role in facilitating a Delphi (6.6.1).

By the end of this study, I understood the process of scientific research to be effortful decision-making that I made by drawing on my own experiences. I developed insight into the need to carefully plan and employ the best tools in the best way to enable participants to provide the best data; ‘best’ being that which facilitates the most practically useful findings. This understanding provided me with a starting point to further explore my role as a researcher and how this might change when embarking on different research projects, and as my expertise grows.

Through the process of undertaking this research, my clinical identity has taken a backseat to the burgeoning learning of becoming immersed in research. The strength that my clinical background brought was a coal-face understanding of the delivery of care within NHS Scotland. The strength coming out of this doctoral work is producing a framework which will enable prostate services to reflect upon and develop their capacity to improve care. Better Cancer Care is a core policy name, but it also underpins both my clinical and academic identities.

8.5 Implications

The main implications of this study relate to governing and regulatory bodies (8.5.1), healthcare professionals working within the Service (8.5.2), primary and community care practitioners (8.5.3), and patients (8.5.4), who this study seeks to benefit.

8.5.1 Scottish government

This study found that there was a key role for government in the development of the Service. Particularly, there was a need to develop an understanding of how the Scottish healthcare service may be able to provide internationally renowned care that is shared with healthcare professionals. To do this, there was a need to define what quality cancer care is for Scotland and align measures of quality care to reflect this definition. Additionally, there was a need to support the development MCNs to adopt additional responsibilities in line with the needs of the Service. It was also clear from the wider literature that where healthcare professionals are not supported by government, their ability to develop the Service to meet demand will be limited (Kakabadse, Korac-Kakabadse & Kouzmin, 2003; Hewison & Griffiths, 2004; Markuns et al., 2010; Storey & Holti, 2012; Zachariadis et al., 2013; Anderson et al., 2015), and so the support of the Scottish government is crucial to the development of the Service to meet current demand.

8.5.2 Prostate cancer care specialists and healthcare management

Given lack of cohesion and leadership within the Service, this study provides national consensus on the direction of service development and reform needed to meet demand. This study identified clear areas of development that require government support to resolve. However, other areas can be progressed from within the Service. Particularly the development of national, speciality specific working groups to provide an ongoing, national approach to developing quality in prostate cancer care. These national working groups will also reduce pressures on local services to find solutions to managing changing demand and the developing prostate cancer care landscape. As it was unclear whether consensus was reached for patient follow-up to remain within the Service as this was where care belonged or as a result of a lack of capable alternatives, the development of national working groups will provide a platform for engagement of patients and primary care and other relevant people to further develop follow-up protocols if required. Though there is still no easy answer to training specialist nurses and allied health professionals, this study did provide some guidance on how this can be realised. Particularly, investment in a national platform for specialist nurses and allied health professionals to continue developing these roles, share experiences, support training, and guide reform in specialist nurses and allied health professional training if this is needed.

8.5.3 Primary and community care practitioners

This study has clear implications for primary and community practitioners. Prostate cancer care specialists were aware of the current capacity shortage within primary care. Considering this, consensus was reached to include primary care practitioners within national, speciality specific working groups to support service developments. Also, prostate cancer care specialists reached consensus for the involvement of community pharmacy services to support service development, but the role that community pharmacy services would have was unclear. However, this consensus alluded to prostate cancer specialists being open to considering other methods of delivering prostate cancer care in the community that does not draw exclusively on primary care capacity.

8.5.4 Patients and other people affected by prostate cancer

It is intended that this study will benefit all people affected by prostate cancer. In this study, there was a need for patients to have a clearer voice in guiding service developments. The development national and regional working groups should provide a platform for patient experiences to directly inform care at all stages of development and implementation. Ultimately, this study sought to improve the experience of all people affected by prostate cancer through aiding the development of quality prostate cancer care in Scotland.

8.6 Future work

There is a clear need for further research. Firstly, though usage of treatment services generally changed uniformly across Scotland, there were clear regional differences. Currently, social patterning resulting from unique, regional patterns of inequality has been used to understand health behaviours in WoSCAN (Gray & Leyland, 2009; Cowley, Kiely & Collins, 2016) offers the best explanation to differences in health behaviours across Scotland. Further research is needed to understand the factors influencing patterns of presentation with prostate cancer and treatment usage across Scotland. Secondly, further research is needed to conceptualise quality as the driver of cancer care in Scotland, and how quality can be measured usefully considering international ambitions (Scottish government, 2016a). Scottish government and healthcare professionals working within the Service were found to have the same ambition of delivering quality care, but defined quality differently. There is a need for these understandings to converge for service development to continue fruitfully. Thirdly, further research is needed to understand the responsibility that patients can or should have in their own care, particularly considering recent reform in patient autonomy that has not yet been realised within service developments (Bolton, 2015; Chan et al., 2017). Any change in understanding of patient autonomy will have substantial impact on healthcare delivery and guidance is needed to understand the implications of this in practice. Finally, the Service is developing rapidly to meet demand. And this development is moving too fast for traditional research approaches to keep up. This issue is not unique within healthcare (Lornas, 2000; Swan et al., 2007; Walshe & Davies, 2013; Cheetham et al., 2018). And in situations such as this the development of an embedded researcher or researcher-in-residence position has proven useful (Swan et al., 2007; Cheetham et al., 2018). Embedded researchers form part of the clinical team to support generation and use of findings to meet emerging need (Swan et al., 2007; Cheetham et al., 2018). Certainly, this position could support the development of national and regional working groups and inform the development of national and regional protocols in a timely manner.

8.7 Summary

Considering a lack of evidence to inform development of the Service to meet demand, and the lack of cohesion and leadership present within the Service, this study gave voice to the specialists delivering prostate cancer care across Scotland to guide service development and reform in the Service to meet demand. This study provides a starting point to develop the capacities needed to meet current demand and improve cohesion and leadership to meet future demands.

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Appendix 1: Steering group members

Adam Gaines – Prostate Scotland (co-funder)

Alan McNair – Senior Research Manager, Chief Scientist Office

Alan McNeill – Urologist

Karina Laing – Urologist

Rob Leister – Patient

Seamus Teahan – Urologist

Stephen Bird – Patient

Steve Bramwell – Urologist

Appendix 2: Data selected

SOURCE	DATASET	DATA
NATIONAL RECORDS OF SCOTLAND	Mid-year population estimates: Scotland and its NHS Board areas by single year of age and sex	Total Scottish population by NHS Board by single year of age from 45 years old and above between 1996-2012
		Scottish male population by NHS by single year of age from 45 years old and above between 1996-2012
SCOTLAND'S ELECTRONIC DATA RESEARCH AND INNOVATION SERVICE (EDRIS)	Scottish Cancer Registry (SMR06)	For all men diagnosed with prostate cancer between 1996-2012 aged 45 and over
	- Person information	Time until death where applicable; cause of death where applicable
	- Tumour information	Health Board at diagnosis; SIMD (deciles) at diagnosis; prevalence
	- Tumour diagnostic information	Year of diagnosis; age at diagnosis; Gleason Score at diagnosis
	- Tumour stage	TNM at diagnosis (2012 only)*
	- Tumour treatment information	Time from diagnosis until first treatment for each treatment modality (chemotherapy, hormone therapy, surgery, radiotherapy) where applicable

*TNM stage was only recorded for patients with prostate cancer from 2012 onwards

Appendix 3: Invite to interview email

Dear XXX,

We want to know your views on the future of prostate cancer treatments and services.

You are being invited to take part in this study. Further details are available in the attached Participant Information Sheet.

The projected increase in incidence of prostate cancer in Scotland will impact on service organisation and delivery requirements. Prostate Scotland and the Cancer Care Research Centre, University of Stirling are collaborating in a piece of research to inform future service requirements. The results of this project will help guide service organisation and delivery in Scotland.

If you would like to take part in this study please reply to this email.

If you are aware of any colleagues who may be interested, please forward this information on. We are recruiting urologists, oncologists, nurse consultants and specialists, specialists physiotherapists and all other healthcare professionals with an interest in prostate cancer services.

Thank you.

Yours sincerely,
Ashleigh Ward
PhD Researcher

Email: a.l.ward@stir.ac.uk
Telephone: 01786 466106

Appendix 4: Information sheet for interview participants

Participant Information Sheet

Interviews with Healthcare Professionals

Prostate Cancer Services and Treatment: Planning for the Future

You have been invited to take part in an interview. The following information gives more information about the project and outlines what to expect at interview.

What is the purpose of this study?

The projected increase in incidence of prostate cancer in Scotland will impact on service organisation and delivery requirements. Prostate Scotland and the Cancer Care Research Centre, University of Stirling are collaborating to inform future service requirements. The results of this project will help guide service organisation and delivery in Scotland.

Why have I been invited to participate?

You have been identified as someone with relevant knowledge and expertise in the field of prostate cancer services.

Interviews

Interviews will take place in person at a time and location that is suitable to you. Interviews will contextualise previous findings, project future incidence and treatment patterns and establish service requirements in relation to projected demands.

I would like to participate.

If you would like to participate please reply to the invite to interview email or contact Ashleigh Ward (contact details are provided below). If you would like more information, please get in touch with Ashleigh. If you agree to participate you can leave the study at any time.

I do not want to be interviewed.

You do not have to participate in this study. If you would like to participate, but do not want to be interviewed you can participate in the questionnaire phase of this study. The questionnaire phase will reach consensus on future service requirements. If you are unable to take part at interview, we would be grateful for your input at this point.

If I participate in the interviews, do I have to participate in the next stage also?

The participant information sheet relates to the interview stage of the research only. You will be contacted separately about participation in the questionnaire phase at a later stage.

What happens next?

When you respond to the invite to interview email, Ashleigh will be in touch to arrange an interview. All interviews will take place at a time and location that is convenient to you. Interviews will be conducted by Ashleigh Ward and are expected to take place between March and May of this year. Interviews will be auto recorded and all recordings will be destroyed following transcription.

Confidentiality.

Your participation will be kept confidential. All information relating to your interview will be assigned a participant number and be kept separately from any identifiable information.

What will happen to the results of the project?

This study will produce a report that will be given to the Scottish Government. You will also receive a written summary of the study. Participant quotes may appear in the report and other publications, but these will be anonymised. No participant will be identifiable from quotes used. Findings will also be presented at conferences, published in academic journals and published within Ashleigh’s PhD thesis.

Further information

This research is funded by Prostate Scotland and the University of Stirling.

Ashleigh is a doctoral student at the University of Stirling. Ashleigh is supervised by Prof Liz Forbat and Dr Nicola Cunningham. Both Liz and Nicola work within the Cancer Care Research Centre at the University of Stirling.

This project has been approved by the University of Stirling ethics committee.

Thank you for taking the time to read this.

If you wish to contact someone who is not a member of the research team, please contact the Deputy Head of School.

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Appendix 5: Interview schedule

The following data comes from an analysis of data held by ISD. ISD categorise treatment as hormone therapy, radiotherapy, chemotherapy, surgery and other. ISD do not code for active surveillance or watchful waiting care pathways. The purpose of these interviews is to gather as many different opinions as possible of the topic of service delivery and organisation. In this interview, you will be asked a series of questions related to each treatment type. After this, you will then be asked questions regarding implications on services. Everyone is asked the same questions. Please answer any questions that you feel are suited to your speciality.

Section 1

Around 23% of men diagnosed in 2012 were not known to receive any form of treatment. This number increases each year. At least 60% of these men are thought to be on an active surveillance care plan.

1. Do you think that these men will require future treatment for prostate cancer?
2. What treatment are these men likely to receive?
3. The number of men who can be categorised as being on an active treatment care plan are increasing each year. How do you think that this trend will look like in the future?
4. What impact will this change have on service delivery and organisation?
5. How can we better plan to accommodate for this change?

Surgery includes all surgical procedures used in the treatment of prostate cancer not including biopsy. The proportion of men receiving surgery as a treatment for prostate cancer is decreasing. This is due to a reduction in the proportion of men receiving surgery as a first treatment. The proportion of men undergoing surgery has decreased by one third since 1997.

6. How would you explain the decrease in the proportion of men receiving surgery as their first treatment?
7. How do you expect trends in surgical treatments to change in the future?
8. What impact will this have on service delivery and organisation?
9. How can we better plan to accommodate for this change?

The percentage of men receiving radiotherapy has increased each year since 1997.

10. How would you explain this?

11. How do you expect this to change in the future?
12. What impact will this have on service delivery and organisation?
13. How can we better plan to accommodate for this change?
14. The number of men receiving hormone therapy is increasing. This is largely due to the number of men receiving hormone therapy prior to radiotherapy. What impact will this have on service delivery and organisation?
15. How can we better plan to accommodate this?

The number of men diagnosed with a Gleason grade of 8 or more who are not receiving treatment is increasing, whereas the number of men receiving hormone therapy as their final or only treatment has remained constant in recent years.

16. How would you explain this?
17. How do you expect this to change in the future?
18. What impact will this have on service delivery and organisation?
19. How can we better plan to accommodate for this change?

Although the number of men receiving chemotherapy as a treatment for prostate cancer remains low, the proportion of men receiving chemotherapy has quadrupled since 1997.

20. How would you explain this?
21. How do you expect this to change in the future?
22. What impact will this have on service delivery and organisation?
23. How can we better plan to accommodate for this change?

Section 2

24. Given the data we have been talking about, what do you think the main issues for secondary care are for the next 10 years?
25. If robotic prostatectomies are introduced across all SCAN regions, what impact do you see this having on services?
26. What do you see as the staffing implications for those rises/falls in use of each service area? This could include staffing numbers, training and impact on other professionals such as physiotherapists and ED nurses.
27. What do you think is the most under-resourced part of the patient pathway at present?

28. Given the data we have been talking about, what do you think the main issues for primary care will be over the next 10 years?
29. What aspects of follow-up/survivorship care do you think could be managed via primary care?
30. Is there any specific role for primary care for managing the delivery of non-surgical treatments?

Appendix 6: Invite to Delphi email

UNIVERSITY OF STIRLING
prostate scotland
prostatescotland.org.uk
Cancer Care Research Centre
Linking reality with science

Dear XXX,

We want to know your views on the future of prostate cancer treatments and services.

You are being invited to take part in this study. This study will allow you to give your views on the future of prostate cancer treatments and services in Scotland. On completion of this phase of research a report will be produced that will be given to the Scottish Government. This phase of research will consist of a series of questionnaires that will be spaced approximately 4 weeks apart. It is important that all participants commit to completing all rounds of questionnaires. It is estimated that 3 rounds will be required. Following completion of this study you will be sent an email to thank you for your contribution.

For this stage of the study we are inviting healthcare professionals in the following roles to participate:

Urologist
Radiation Oncologist
Medical Oncologist
Nurse specialist

If you are aware of any colleagues who may be interested, please forward this information on.

Please find the participant information sheet attached. If you would like to take part in this study please click on this link and it will take you directly to the questionnaire:
https://stirling.onlinesurveys.ac.uk/delphi-1-v4

Questionnaires must be completed by midnight on Friday 18th December.

Thank you.

Yours sincerely,
Ashleigh Ward
PhD Researcher

Email: a.l.ward@stir.ac.uk
Telephone: 01786 466106

Appendix 7: Information sheet for Delphi participants

Participant Information Sheet

Delphi Questionnaire for Healthcare Professionals

Prostate Cancer Services and Treatment: Planning for the Future

What is the purpose of the study?

The projected increase in incidence of prostate cancer in Scotland will impact on service organisation and delivery requirements. Prostate Scotland and the Cancer Care Research Centre, University of Stirling are collaborating to inform future service requirements. The results of this project will help guide healthcare decisions in Scotland.

Questionnaires

This phase of research uses a questionnaire based technique to reach consensus. It is estimated that 2-3 rounds of questionnaires will be required to reach consensus. Questionnaires will be emailed to you approximately 4 weeks apart and should take 15-20 minutes to complete. We may contact you to discuss some of your responses. If this happens we will contact you by email and discussion can take place via email or telephone. When the study is complete, we will email you to let you know and to thank you for your contribution. This is the last phase of this study.

I would like to participate

If you would like to participate please click on the link provided in the “invite to interview” email.

Confidentiality

Your participation will be kept confidential to those outside of the immediate research team. Participant quotes may appear in the report and other publications, but these will be anonymised. No participant will be identifiable from quotes used.

What will happen to the results of the project?

This study will produce a report that will be given to the Scottish Government. You will also receive a written summary of the study. Findings will also be presented at conferences, published in academic journals and published within Ashleigh’s PhD thesis.

Further information

This research is funded by Prostate Scotland and the University of Stirling.

Ashleigh is a doctoral student at the University of Stirling. Ashleigh is supervised by Prof Liz Forbat and Dr Nicola Cunningham. Both Liz and Nicola work within the Cancer Care Research Centre, University of Stirling.

This project has been approved by the University of Stirling ethics committee.

Thank you.

If you wish to contact someone who is not a member of the research team, please contact the Deputy Head of School

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Appendix 8: Delphi questionnaire Round 1

Page 1: Information and Consent

Prostate Cancer Services and Treatment: Planning for the Future

I understand that I can withdraw at any time, without giving any reason.
I agree that the research team at the University of Stirling can collect and hold data given by me during this phase of research.
I understand that if you use any of my information/direct quotes they will be made anonymous so that no-one will be able to identify me.
I agree to be contacted with regards to answers that I have given after submission of my completed questionnaire.
1. I have read and I understand the information sheet entitled 'Phase 2: Delphi Questionnaire for Healthcare Professionals.'
[Control]I understand and agree with the above statements

2. Please select the role that best fits your expertise:
[Control]Urologist
[Control]Clinical Oncologist
[Control]Medical Oncologist
[Control]Nurse Specialist

3. Please enter the Health board(s) that you work within as part of your job plan:
[Control]

4. Please enter your preferred email address:
[Control]

Page 2: Instructions

Please read the following before continuing with the questionnaire.
Please allow approximately 30 minutes for completion of this questionnaire.

This questionnaire will address four key areas:

Organisation of secondary and tertiary care
Multidisciplinary working
Patient follow-up
Ongoing research and additional comments

Question format:

You will be asked questions in four different formats:

1. You will be asked to rank how well you agree with a statement.
2. You will be asked to select a response or statement that you agree with most.
3. You will be asked to select all points that are key to a statement.
4. You will be asked open ended questions.

Comments:

A comment box can be found under each question. Please use this box to add any information that you think has been missed or to include additional information.

There will also be an opportunity at the end of the questionnaire for final comments.

Not relevant to my expertise:

This questionnaire will cover a range of topics. Please select this response if you do not feel that the topic is within your area of expertise.

Page 3: Organisation of Secondary and Tertiary Care

Section 1 of 3 is the largest section within this questionnaire. You will be asked to respond to 10 questions.

During previous phases of research, some participants stated that although healthcare should continue to be delivered at a local Health board level, larger structures should guide and lead this care.

5. Prostate cancer treatment services should be led by...

[Control]14 Health boards

[Control]3 Managed Cancer Networks (MCNs)

[Control]2 regions

[Control]Scotland wide

[Control]Not relevant to my expertise

Comments

[Control]

6. Within prostate cancer services, Managed Cancer Networks (MCN) need to...

	Strongly disagree	**Disagree**	**Undecided**	**Agree**	**Strongly agree**	**Not relevant to my expertise**
...be further developed	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
...be responsible for the delivery of equitable care across the region	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]

...audit services	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
...be responsible for the education of staff	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
...have a role in funding and governance	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
...plan ahead for the introduction of advances in treatment	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
...keep government up to date with advances in treatment	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
...manage the impact of centralisation on Health boards	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]

Comments

[Control]

7. Diagnostic services

	Strongly disagree	**Disagree**	**Undecided**	**Agree**	**Strongly agree**	**Not relevant to my expertise**
Primary care are not equipped to counsel men effectively on PSA testing	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
When a man is referred to secondary care, they should be counselled on receiving further investigations for prostate cancer prior to biopsy	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Diagnostic services should be part of a “one stop shop”	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Initial treatment discussions should occur as part of the diagnostic pathway to minimise treatment bias	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]

Pre-biopsy MRI should be completed on all men with a suspected prostate cancer	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Pre-biopsy MRI should be completed on men with a suspected low grade prostate cancer only to avoid unnecessary biopsying	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]

Comments

[Control]

During previous phases of research, participants highlighted a lack of consensus over an accepted definition for active surveillance. Two key stances were highlighted:

1. The primary goal of active surveillance is to defer treatment and due to the nature of this treatment, some men will not require radical treatment.
2. The primary goal of active surveillance is to avoid radical treatment in men and due to the nature of this treatment, some men will still require treatment.

8. Active surveillance is primarily a mechanism to...

[Control]...delay radical treatment until it is required
[Control]...avoid treating men who will not progress to require treatment
[Control]Not relevant to my expertise

Comments

[Control]

During previous phases of research, participants highlighted that in some Health boards active surveillance was once an oncology-led treatment. Some participants highlighted that active surveillance would benefit from greater oncology input.

9. Active surveillance should be managed by...

[Control]...urology
[Control]...oncology
[Control]...both urology and oncology
[Control]Not relevant to my expertise

Comments

[Control]

10. Active surveillance...

	Strongly disagree	Disagree	Undecided	Agree	Strongly agree	Not relevant to my expertise
...requires a Scotland wide protocol	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
...is expensive and therefore will lead to men being treated earlier	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
...leads to an unmet psychological burden on patients	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
...should incorporate counselling services	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
...will lead to an increased demand on radiology services more than prostatectomy services	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
...in the future, will lead to decreased demand on biopsy/pathology services	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
...should be delivered in a location that is convenient to the patient instead of by a specialist	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
...patient education should be given pre-diagnosis for the patient to fully appreciate active surveillance as a treatment option	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]

Comments

[Control]

11. Surgical services

	Strongly disagree	**Disagree**	**Undecided**	**Agree**	**Strongly agree**	**Not relevant to my expertise**
As services become centralised, both diagnostics and follow-up services should continue to operate at a local Health board level	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Robot assisted surgery will lead to surgical bias in treatment discussions	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Robot assisted surgical equipment should be multispeciality	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Services are not currently prepared for robot assisted surgery	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Robot assisted surgical teams should consist of 3-4 surgeons	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
A surgeons' job plan should employ a hub and spoke model within a robot assisted surgical service	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]

Comments

[Control]

12. Medical oncology services

	Strongly disagree	**Disagree**	**Undecided**	**Agree**	**Strongly agree**	**Not relevant to my expertise**
Uro-oncologists should review complex patients only	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Separate clinics are required for patients receiving hormone therapy and chemotherapy	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]

Separate clinics are required for pre and post chemotherapy patients	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Separate clinics are required for new and returning patients	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Initial treatment discussions are required to discuss treatment plans with patients	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Neo-adjuvant hormone therapy should be prescribed by nurse specialists 2-3 months before consultation with an oncologist	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Different hormone therapies require different follow up protocols	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Uro-oncologists require consultant cross cover for patients to be reviewed and treated in their absence	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Uro-oncologists require medical back up cover for clinic time	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]

Comments

[Control]

13. Medical oncology services continued...

	Strongly disagree	**Disagree**	**Undecided**	**Agree**	**Strongly agree**	**Not relevant to my expertise**
Delivering chemotherapy at peripheral centres decreases consultant workload	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Chemotherapy should be delivered in local day units	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]

All patients commencing a long term hormone therapy should have a DEXA scan	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Better links to community palliative care are required	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Men on palliative care pathways require more support than is currently given	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Orchidectomy should be discussed as a treatment option with patients	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Buses should be employed to transport patients to and from chemotherapy appointments	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]

Comments

[Control]

The following items were highlighted as the most important under-resourced areas in the patient pathway at present.

Please select the areas that you identify as the most important bottlenecks within current services.

For the purposes of this study a bottleneck is defined as "any part of the system where patient flow is obstructed causing waits and delays. It interrupts the natural flow and hinders movement along the care pathway, determining the pace at which the whole process works." NHS Institute of Innovation and Improvement (2008)

http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/bottlenecks.html

14. Please select the areas that you identify as the most important bottlenecks within current services.

[Control]Primary care diagnosis

[Control]Primary care follow-up services

[Control]Prescription and distribution of drugs within primary care

[Control]Biopsy service

[Control]Imaging and radiology

[Control]Active surveillance

[Control]Immediate post-operative pathway

[Control]Medical oncology clinics

[Control]Radiation oncology clinics

[Control]Patient follow-up

[Control]Managing the introduction of newly approved treatments

[Control]Multidisciplinary team meetings

[Control]Absorbing charity funded roles within NHS budgets

Please include any further comments and state any important causes of bottlenecks that are not included in the list above:

[Control]

Page 4: Multidisciplinary Working

15. Urology and uro-oncology services should...

[Control]...work together within the one overarching service

[Control]...work separately, but with better lines of communication

[Control]...work in the same capacity that they do currently

[Control]Not relevant to my expertise

Comments

[Control]

16. The focus of prostate cancer multudisciplinary team (MDT) meetings:

[Control]All patients need to be discussed within MDTs

[Control]Only complex cases should be discussed within MDTs

[Control]All patients need to be discussed by the MDT, but only complex cases need to be discussed face to face

[Control]We do not have to discuss patients at MDTs

[Control]Not relevant to my expertise

Comments

[Control]

17. The following services should be led by...

	...nurse specialists	**...pharmacists**	**...medics (with nurse specialist support)**	**...medics only**	**Not relevant to my expertise**
Pre-biopsy patient meetings	[Control]	[Control]	[Control]	[Control]	[Control]
Biopsy services	[Control]	[Control]	[Control]	[Control]	[Control]

Patient diagnosis	[Control]	[Control]	[Control]	[Control]	[Control]
Initial treatment discussion	[Control]	[Control]	[Control]	[Control]	[Control]
Active surveillance	[Control]	[Control]	[Control]	[Control]	[Control]
Pre-operative care	[Control]	[Control]	[Control]	[Control]	[Control]
Post-operative care	[Control]	[Control]	[Control]	[Control]	[Control]
Side effect services	[Control]	[Control]	[Control]	[Control]	[Control]

Comments

[Control]

18. The following services should be led by... (continued)

	...nurse specialists	**...pharmacists**	**...medics (with nurse specialist support)**	**...medics only**	**Not relevant to my expertise**
Chemotherapy prescription	[Control]	[Control]	[Control]	[Control]	[Control]
Chemotherapy administration	[Control]	[Control]	[Control]	[Control]	[Control]
Chemotherapy monitoring	[Control]	[Control]	[Control]	[Control]	[Control]
Bisphosphonate delivery	[Control]	[Control]	[Control]	[Control]	[Control]
Monitoring men receiving neo-adjuvant hormone therapy	[Control]	[Control]	[Control]	[Control]	[Control]
Radiotherapy follow-up	[Control]	[Control]	[Control]	[Control]	[Control]
Surgical follow-up	[Control]	[Control]	[Control]	[Control]	[Control]
Long term hormone therapy follow-up	[Control]	[Control]	[Control]	[Control]	[Control]
Watchful waiting	[Control]	[Control]	[Control]	[Control]	[Control]

Comments

[Control]

19. Recruitment and training of nurse specialists

	Strongly disagree	**Disagree**	**Undecided**	**Agree**	**Strongly agree**	**Not relevant to my expertise**
Recruitment of nurse specialists in the future will be difficult	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Training of nurse specialists is difficult	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Training programmes for nurse specialists should be developed	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Nurses should be trained through networking with individuals in similar posts	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]

Comments

[Control]

20. Supporting men with side effects of treatment and symptoms of disease progression

	Strongly disagree	**Disagree**	**Undecided**	**Agree**	**Strongly agree**	**Not relevant to my expertise**
A service is required to manage bladder irritability	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
A service is required to manage bowel problems	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
A service is required to manage erectile dysfunction	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
A service is required to manage incontinence	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]

A service is required to manage pain caused by bone metastases	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Availability of erectile dysfunction and incontinence support to be made available to radiotherapy patients	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Support services should be involved with men prior to receiving treatment	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Support services should be organised around tertiary and sub-specialist services	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Support services should be delivered in secondary care	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Management of side effects requires a dedicated team	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
There is a need to develop nurse specialist roles to support patients with symptoms, side effects and treatment queries on an as and when required basis	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]

Comments

[Control]

21. The following services should be provided by primary care:

	Strongly disagree	**Disagree**	**Undecided**	**Agree**	**Strongly agree**	**Not relevant to my expertise**
Neo-adjuvant hormone injection administration	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Long term hormone injection administration	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]

Uro-oncology nurse service to administer relevant injections	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Patient support when receiving hormone injections	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Weight and diabetes management support	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Oral drug dispension	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Diabetes, blood pressure and cholesterol monitoring	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Bisphosphonate administration	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Chemotherapy administration	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Prescription of long term hormone therapy	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Support to patients who become unwell whilst receiving chemotherapy	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Management of side effects from radical treatment	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Management of non-complex side effects from radical treatment only	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
A men's health clinic equipped to address prostate cancer related needs in men both pre and post diagnosis	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]

Comments

[Control]

Page 5: Patient Follow-up

This is the third section of this questionnaire and the final section with this style of questioning.

22. Follow-up of patients who have had radical treatment

	Strongly disagree	Disagree	Undecided	Agree	Strongly agree	Not relevant to my expertise
Post-radiotherapy patients cannot be followed up in the same manner as post-surgery patients	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Only men at a high risk of recurrence should be followed up in secondary care	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Men who are stable 2 years following treatment should be followed up in secondary care	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Men who are at low risk of recurrence can be followed up by telephone	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Men who are at low risk of recurrence should have contact details of specialists to consult if problems or concerns arise instead of follow-up at regular intervals	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Men should be given more responsibility during their follow-up	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Follow-up clinics should include a supportive role	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Clinics are currently not flexible enough to provide a supportive role to patients	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Secondary care holds onto patients for too long after treatment	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]

Prostate cancer specialists and primary care should work side by side when following men up	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]
Primary care follow-up would create a need for clinic correspondence management	[Control]	[Control]	[Control]	[Control]	[Control]	[Control]

Comments

[Control]

Multi-answer questions:

Please select a maximum of **3** responses for each multi-answer question in this section.

Comments: If there is an option that we have not considered, please use the comment box to include this alternative option.

23. The follow-up of active surveillance should...

[Control]...take place in secondary care only

[Control]...take place in primary care by GPs

[Control]...take place in primary care by practice nurses

[Control]...take place in primary care by specialists

[Control]...take place in primary care only with the presence of a rapid access mechanism feeding back to secondary care

[Control]...involve patients self-monitoring their PSA level

[Control]...be completed by telephone review

[Control]…should occur in primary care with a return visit to secondary care every X months

[Control]Not relevant to my expertise

If you selected the response "**...a return visit to secondary care every X months**", please state the number of months that you feel is most appropriate for this follow-up and leave any **additional comments** here:

[Control]

24. The follow-up of post-prostatectomy patients...

[Control]...should take place in secondary care only

[Control]...should take place in primary care by GPs

[Control]...should take place in primary care by practice nurses

[Control]...take place in primary care by specialists

[Control]...should take place in primary care only with the presence of a rapid access mechanism feeding back to secondary care

[Control]...involve patients self-monitoring their PSA level
[Control]…should occur in primary care with a return visit to secondary care every X months
[Control]Not relevant to my expertise

If you selected the response "**...a return visit to secondary care every X months**", please state the number of months that you feel is most appropriate for this follow-up and leave any **additional comments** here:

[Control]

25. The follow-up of post-radiotherapy patients...
[Control]...should take place in secondary care only
[Control]...should take place in primary care by GPs
[Control]...should take place in primary care by practice nurses
[Control]...take place in primary care by specialists
[Control]...should take place in primary care only with the presence of a rapid access mechanism feeding back to secondary care
[Control]...involve patients self-monitoring their PSA level
[Control]…should occur in primary care with a return visit to secondary care every X months
[Control]Not relevant to my expertise

If you selected the response "**...a return visit to secondary care every X months**", please state the number of months that you feel is most appropriate for this follow-up and leave any **additional comments** here:

[Control]

26. The follow-up of patients' receiving neo-adjuvant hormone therapy...
[Control]...should take place in secondary care only
[Control]...should take place in primary care by GPs
[Control]...should take place in primary care by practice nurses
[Control]...take place in primary care by specialists
[Control]...should take place in primary care only with the presence of a rapid access mechanism feeding back to secondary care
[Control]...involve patients self-monitoring their PSA level
[Control]…should be by telephone review
[Control]…should occur in primary care with a return visit to secondary care every X months
[Control]Not relevant to my expertise

If you selected the response "**...a return visit to secondary care every X months**", please state the number of months that you feel is most appropriate for this follow-up and leave any **additional comments** here:

[Control]

27. The follow-up of patients receiving long term hormone therapy...
[Control]...should take place in secondary care only
[Control]...should take place in primary care by GPs
[Control]...should take place in primary care by practice nurses
[Control]...take place in primary care by specialists
[Control]...should take place in primary care only with the presence of a rapid access mechanism feeding back to secondary care
[Control]…should be by telephone review
[Control]…should occur in primary care with a return visit to secondary care every X months
[Control]Not relevant to my expertise
If you selected the response "**...a return visit to secondary care every X months**", please state the number of months that you feel is most appropriate for this follow-up and leave an **additional comments** here:
[Control]

28. The follow-up of watchful waiting patients...
[Control]...should take place in secondary care only
[Control]...should take place in primary care by GPs
[Control]...should take place in primary care by practice nurses
[Control]...take place in primary care by specialists
[Control]...should take place in primary care only with the presence of a rapid access mechanism feeding back to secondary care
[Control]…should be by telephone review
[Control]…should occur in primary care with a return visit to secondary care every X months
[Control]Not relevant to my expertise
If you selected the response "**...a return visit to secondary care every X months**", please state the number of months that you feel is most appropriate for this follow-up and leave any **additional comments** here:
[Control]

Page 6: Ongoing Research and Additional Comments

This is the final section of this questionnaire.

We are also aware of some ongoing research projects that may help to shape the delivery of prostate cancer services in Scotland. These projects are listed below.

If you are not aware of the project or the topic is not relevant to your area of expertise then please state this.

Transforming Care After Treatment (TCAT): Holistic Needs Assessment

The introduction of an end of treatment summary and holistic needs assessment to enable to development of individualised and person-centred follow-up services.

29. Please state briefly how you see this project shaping prostate cancer service delivery in the future.

[Control]

Transforming Care After Treatment (TCAT): One Stop Shop Intervention/Recovery Clinic following Surgery

To prepare and inform people about what to expect after completion of treatment including tailored follow-up, advice and support for side effects of treatment.

30. Please state briefly how you see this project shaping prostate cancer service delivery in the future.

[Control]

Enhanced Recover after Surgery Exemplar Pathway

An ERAS pathway aims to shorten recovery periods whilst engaging the patient within the recovery process. The pathway commonly consists of 4 points:

Pre-operative assessment, planning and preparation before admission.

Reducing the physical stress of the operation.

A structured approach to immediate post-operative and during (peri-operative) management, including pain relief.

Early mobilisation.

(NHS Institute for Innovation and Improvement, 2008)

http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/enhanced_recovery_programme.html

31. Please state briefly how you see this project shaping prostate cancer service delivery in the future.

[Control]

32. If you are aware of other ongoing research projects that may also shape prostate cancer service delivery and that we have not mentioned, please detail these below.

[Control]

33. The results of this study will advise on future models of delivery for prostate cancer services. Please give any final comments on model building, or service design or delivery in prostate cancer services.

[Control]

The End

This is the end of the questionnaire.

Thank you for your time!

The next round of questionnaires will be distributed in January 2016.

Page Break

Appendix 9: Delphi questionnaire Round 2

Page 1: Instructions

Thank you for completing the first questionnaire.

Please read the following before continuing with the questionnaire.

Consensus was reached on many topics in Round 1 (R1).

This questionnaire will focus only on reviewing areas of disagreement highlighted in R1.

This questionnaire should take no more than 20 minutes to complete. Many of the questions ask you to give a brief rationale for your response. These questions are important in understanding why participants disagree on a given topic or statement.

All responses are assigned a code automatically via the survey software and will remain anonymous.

This questionnaire will address four key areas:

- Service structure and delivery
- Diagnostics and active surveillance
- Radical treatment
- Palliative oncology

Feedback:

A summary of responses to the previous questionnaire are given throughout in the form of percentages (%) after the relevant response.

Individual feedback will not be provided.

As some questions allowed for multiple responses, feedback for some questions may exceed 100%.

Question format:

You will be asked questions in three different formats:

You will be asked to select a response or statement that you agree with most.

You will be asked to select all statements that you agree with.

You will be asked to state why you agree or disagree with a statement.

Comments:

A comment box can be found under each question.

You will be asked to:

- Give additional comments
- State why you disagreed with a statement
- There will also be an opportunity at the end of the questionnaire for final comments.

Not relevant to my expertise:

This questionnaire will cover a range of topics. Please select this response if you do not feel that the topic is within your area of expertise.

1. Please enter your preferred email address:

Page 2: Multidisciplinary team

2.

Managed Cancer Networks should be responsible for the education of staff (79% of participants agreed with this statement in R1)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise
Managed Cancer Networks should have a role in funding and governance (71% of participants agreed with this statement in R1)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise
Tasks should be the responsibility of the relevant speciality and not be the responsibility of the MCN (new response)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise
Primary care should provide a men's health clinic equipped to address prostate cancer related needs both pre and post diagnosis (75% of participants agreed with this statement in R1)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise
Methods of integration and communication between urology and uro-oncology services should be improved (response rephrased from R1)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise

If you disagree with any of the above responses, please state why:

3. [New question] Please select all occasions at which patients should be discussed at MDT meetings

- At diagnosis
- Following disease progression
- When a patient becomes castrate resistant
- Other (please detail below)
- Not relevant to my expertise

Please include any additional comments here:

Page 3: Diagnostics and active surveillance

4.

Biopsy services should be nurse led (79% of participants agreed with this statement in R1)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise
Initial treatment discussions should occur as part of the diagnostic pathway (79% of agreed with this statement response in R1)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise
Active surveillance will lead to an increased demand on radiology services when compared with demands on radical treatments (77% of participants agreed with this statement in R1)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise
Pre-biopsy MRI should NOT be completed on all men with a suspected prostate cancer (60% of participants agreed with this statement in R1)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise
Pre-biopsy MRI should NOT be completed on men with a suspected low grade prostate cancer to avoid unnecessary biopsying (60% of participants agreed with this statement in R1)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise
Active surveillance will NOT lead to an increased demand on biopsy/pathology services (58% of participants agreed with this statement in R1)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise
Primary care services are equipped to counsel men effectively on PSA testing (57% of participants agreed with this statement in R1)	Please select I agree with this statement I disagree with this statement

	Undecided Not relevant to my expertise

If you disagree with any of the above responses, please state why:

5. Patient diagnosis should be...

- Consultant-led (56% of participants selected this response in R1)
- Nurse-led (56% of participants selected this response in R1)
- Undecided
- Not relevant to my expertise

Please include any additional comments here:

6. Initial treatment discussion should be...

- Consultant-led (56% of participants selected this response in R1)
- Nurse-led (44% of participants selected this response in R1)
- Undecided
- Not relevant to my expertise

Please include any additional comments here:

7. [Rephrasing of a previous question] Active surveillance should be...

- Consultant led (with nurse specialist support) and managed by urology
- Consultant led (with nurse specialist support) and managed by both urology and oncology
- Nurse-led and managed by urology
- Nurse-led and managed by both urology and oncology
- Nurse-led under the guidance of the MDT
- Undecided
- Not relevant to my expertise

Please include any additional comments here:

8. Active surveillance follow up should be led by secondary care via:

- Current mechanism of follow-up
- Monitoring in primary care and a return visit to secondary care
- Patient self-monitoring PSA with contact details of secondary staff for concerns
- Patient self-monitoring PSA and telephone review
- Patient self-monitoring PSA and a return visit to secondary care
- Utilise virtual clinics (new response)
- Not relevant to my expertise

Please include any additional comments here:

Page 4: Radical treatment

9.

Pre-operative care should be consultant-led with nurse specialist support (79% of participants agreed with this statement in R1)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise
Services are not currently prepared for robot assisted surgery (77% of participants agreed with this statement in R1)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise
Secondary care DOES NOT hold onto patients too long after treatment (75% of participants agreed with this statement in R1)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise
Robot assisted surgical teams should NOT consist of 3-4 surgeons (67% of participants agreed with this statement in R1)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise
A surgeons’ job plan should employ a hub and spoke model within a robot assisted surgical service (67% of participants agreed with this statement in R1)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise
Surgical follow-up should be nurse led (64% of participants agreed with this statement in R1)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise
Neo-adjuvant hormone therapy should NOT be prescribed by nurse specialists 2-3 months before	Please select I agree with this statement

consultation with an oncologist (58% of participants agreed with this statement in R1)	I disagree with this statement Undecided Not relevant to my expertise

If you disagree with any of the above responses, please state why:

10. [Rephrasing of a previous question] With the exception of the initial consultant post-operative review of the patient, post-operative care should be...

- Consultant-led with nurse specialist support
- Nurse-led
- Undecided
- Not relevant to my expertise

Please state briefly why you selected the above response.

11. Following radical treatment, patients should be followed up initially...

- For two years
- Until PSA has stabilised
- Until functional outcomes are achieved
- Not relevant to my expertise

During the initial period following radical prostatectomy, follow-up should...

- Take place under current mechanisms of follow-up
- Be led by primary care with a rapid access mechanism feeding back into secondary care
- Be led by secondary care with monitoring in primary care and a return visit to secondary care
- Be led by secondary care with patient self-monitoring PSA
- Be led by secondary care and utilise virtual clinics (new response)
- Not relevant to my expertise

If patients should self-monitor their PSA, this should be...

- Patient led with contact details of secondary care staff if concerns arise
- With regular telephone review
- With return visits to secondary care

During the initial period following radiotherapy, follow-up should...

- Take place under current mechanisms of follow-up
- Be led by primary care with a rapid access mechanism feeding back into secondary care
- Be led by secondary care with monitoring in primary care and a return visit to secondary care
- Be led by secondary care with patient self-monitoring PSA

- Be led by secondary care and utilise virtual clinics (new response)
- Not relevant to my expertise

If patients should self-monitor their PSA, this should be...

- Patient led with contact details of secondary care staff if concerns arise
- With regular telephone review
- With return visits to secondary care

Please include any additional comments here:

12. Patients should be discharged from radical treatment follow-up

- 5 years following radical treatment
- Other (please give details in the comment box below)
- Not relevant to my expertise

Prior to discharge, follow-up for patients who have undergone radical prostatectomy should...

- Take place under current mechanisms of follow-up
- Be led by primary care with a rapid access mechanism feeding back into secondary care
- Be led by secondary care with monitoring in primary care and a return visit to secondary care
- Be led by secondary care with patient self-monitoring PSA
- Be led by secondary care with telephone review
- Be led by secondary care and utilise virtual clinics (new response)
- Not relevant to my expertise

If patients should self-monitor their PSA, this should be...

- Patient led with contact details of secondary care staff if concerns arise
- With regular telephone review
- With return visits to secondary care

After this initial period, follow-up should...

- Take place under current mechanisms of follow-up
- Be led by primary care with a rapid access mechanism feeding back into secondary care
- Be led by secondary care with monitoring in primary care and a return visit to secondary care
- Be led by secondary care with patient self-monitoring PSA
- Be led by secondary care with telephone review
- Be led by secondary care and utilise virtual clinics (new response)
- Not relevant to my expertise

If patients should self-monitor their PSA, this should be...

- Patient led with contact details of secondary care staff if concerns arise

- With regular telephone review
- With return visits to secondary care

Please include any additional comments here:

Support and Side Effect Services

13.

Support services should be organised around tertiary and sub-specialist services (69% of participants agreed with this statement in R1)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise
Side effect services should be nurse led (69% of participants agreed with this statement in R1)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise
A service is required to manage bladder irritability (69% of participants agreed with this statement in R1)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise
A service is required to manage bowel problems (67% of participants agreed with this statement in R1)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise
Management of side effects requires a dedicated team (50% of participants agreed with this statement in R1)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise

If you disagree with any of the above responses, please state why:

Page 5: Palliative oncology

14.

Watchful waiting should be nurse led (79% of participants agreed with this statement in R1)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise
Primary care should NOT administer bisphosphonates (71% of participants agreed with this statement in R1)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise
Uro-oncologists require medical back up for clinic time (67% of participants agreed with this statement in R1)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise
Different hormone therapies require different follow-up protocols (67% of participants agreed with this statement in R1)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise
Separate clinics are required for patients receiving hormone therapy and chemotherapy (50% of participants agreed with this statement in R1)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise
Nurse specialists should review all non-complex patients (new statement)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise

If you disagree with any of the above responses, please state why:

15. Long term hormone therapy follow-up should be...

- Nurse-led (consensus reached in R1)
- GP-led (new response)
- Undecided

- Not relevant to my expertise

Please state briefly why you selected the above response.

16.

Men on palliative care pathways require more support than is currently given (78% of participants agreed with this statement in R1)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise
A service is required to manage pain caused by bone metastases (78% of participants agreed with this statement in R1)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise
Primary care should provide patient support when receiving hormone injections (70% of participants agreed with this statement in R1)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise
Secondary care should be responsible for supporting patients whilst receiving chemotherapy (67% of participants agreed with this statement in R1)	Please select I agree with this statement I disagree with this statement Undecided Not relevant to my expertise

If you disagree with any of the above responses, please state why:

Page 6: Additional comments

17. The results of this study will inform future models of delivery for prostate cancer services. Please give any final comments on model building, or service design or delivery in prostate cancer services.

The end

This is the end of the questionnaire.

Thank you for your time!

The final round of questionnaires will be distributed in April 2016.

Appendix 10: Delphi questionnaire Round 3

Page 1: Page 1

Thank you for your continued participation.

Please read the following before continuing with the questionnaire.

This questionnaire proposes models of service built on and developed throughout this Delphi.

This questionnaire should take no more than 20 minutes to complete.

All responses will be entered into a database upon receipt and will remain anonymous.

This questionnaire will address the following key areas:

- Service delivery
- The diagnostic pathway
- Active surveillance
- Robot assisted surgical service
- Surgical and radiotherapy follow-up
- Support services
- Palliative care

Additional comments

Further considerations: This section will ask you to consider points that were not raised within this process, but may be relevant to the emerging consensus

Feedback

All statements reached consensus unless otherwise stated. Statements that did not reach consensus in previous rounds are indicated with the percentage of participant agreement in Round 2 (R2) or with “new question” to indicate that the question has not been asked before.

Individual feedback will not be provided.

As some questions allowed for multiple responses, **feedback for some questions may exceed 100%.**

Questions

You will be asked to select a response from a drop-down menu. Responses reflect current consensus/dissensus.

Comment boxes are also provided to allow you to give additional feedback.

There will also be an opportunity at the end of the questionnaire for final comments.

Not relevant to my expertise:

This questionnaire will cover a range of topics. Please select this response if you do not feel that the topic is within your area of expertise.

1. Please enter your email address:

Page 2: Service delivery

2. Within prostate cancer services, Managed Cancer Networks need to be responsible for the delivery of equitable care across the region, auditing services, planning ahead for the introduction of advances in treatment, managing the impact of centralisation on Health Boards and have a role in funding and governance (consensus reached)

- I agree
- I disagree
- Not relevant to my expertise

Managed Cancer Networks should also be responsible for the education of staff (75% of participants agreed in R2)

- I agree
- I disagree
- Not relevant to my expertise

3. Methods of integration and communication between urology and uro-oncology services should be improved (consensus reached)

- I agree
- I disagree
- Not relevant to my expertise

4. Nurses should be trained through networking with individuals in similar posts, and through the development of training programmes (consensus reached)

- I agree
- I disagree
- Not relevant to my expertise

5. Primary care should provide a men's health clinic equipped to address prostate cancer related needs both pre and post diagnosis (50% of participants agreed in R2)

- I agree
- I disagree
- Not relevant to my expertise

6. If you disagree with any of the above please state why, or give additional comments here:

Page 3: Diagnostic pathway

PSA counselling in primary care

7. Active surveillance should be discussed as part of PSA counselling in primary care (adapted from previous consensus)

- I agree
- I disagree
- Not relevant to my expertise

8. GPs are NOT equipped to counsel men effectively on PSA testing (68% of participants agreed in R2)

- I agree
- I disagree
- Not relevant to my expertise

9. If you disagree with any of the above please state why, or give additional comments here:

Referral to secondary care and biopsy

10. As services become centralised, biopsy services should continue to operate at a health board level (consensus reached)

- I agree
- I disagree
- Not relevant to my expertise

11. The diagnostic pathway should be nurse-led (60% of participants agreed in R2)

- I agree
- I disagree
- Not relevant to my expertise

12. If you disagree with any of the above please state why, or give additional comments here:

13. Pre-biopsy counselling should be nurse-led and is required to discuss pros and cons of biopsy (consensus reached)

- I agree
- I disagree
- Not relevant to my expertise

14. Active surveillance should be discussed during pre-biopsy counselling (adapted from previous consensus)

- I agree
- I disagree
- Not relevant to my expertise

15. Diagnostic clinics should be part of a one stop shop (consensus reached)

- I agree
- I disagree
- Not relevant to my expertise

16. If you disagree with any of the above please state why, or give additional comments here:

Biopsy and other investigations

17. Pre-biopsy MRI should be completed on all men with a suspected prostate cancer (55% of participants agreed in R2)

- I agree
- I disagree
- Not relevant to my expertise

18. Pre-biopsy MRI should be completed on all men with a suspected low grade prostate cancer to avoid unnecessary biopsy (70% of participants agreed in R2)

- I agree
- I disagree
- Not relevant to my expertise

19. If you disagree with any of the above please state why, or give additional comments here:

Diagnosis and treatment options

20. Patient diagnosis should be delivered by a nurse (56% of participants agreed with this in R2)

- I agree
- I disagree
- Not relevant to my expertise

21. Treatment options should be given as part of the diagnostic pathway (consensus reached)

- I agree
- I disagree
- Not relevant to my expertise

22. Treatment options should be discussed with a patient in the first instance by a...

- ...Nurse (50% of participants agreed with this in R2)
- ...Medic (50% of participants agreed with this in R2)
- Not relevant to my expertise

23. Treatment options should be discussed with palliative patients as they are with patients eligible for active treatment (consensus reaches)

- I agree
- I disagree
- Not relevant to my expertise

24. If you disagree with any of the above please state why, or give additional comments here:

Patients should be discussed at MDT when...

25. ...a patient is first diagnosed with prostate cancer (consensus reached)

- I agree
- I disagree

- Not relevant to my expertise

26. ...disease progression occurs (54% of participants agreed in R2)
    - I agree
    - I disagree
    - Not relevant to my expertise
27. ...a patient becomes castrate resistant (54% of participants agreed in R2)
    - I agree
    - I disagree
    - Not relevant to my expertise
28. If you disagree with any of the above please state why, or give additional comments here:

Page 3: Diagnostic pathway

PSA counselling in primary care

29. Active surveillance should be discussed as part of PSA counselling in primary care (adapted from previous consensus)
    - I agree
    - I disagree
    - Not relevant to my expertise
30. GPs are NOT equipped to counsel men effectively on PSA testing (68% of participants agreed in R2)
    - I agree
    - I disagree
    - Not relevant to my expertise
31. If you disagree with any of the above please state why, or give additional comments here:

Referral to secondary care and biopsy

32. As services become centralised, biopsy services should continue to operate at a health board level (consensus reached)
    - I agree
    - I disagree
    - Not relevant to my expertise
33. The diagnostic pathway should be nurse-led (60% of participants agreed in R2)
    - I agree
    - I disagree
    - Not relevant to my expertise
34. If you disagree with any of the above please state why, or give additional comments here:

35. Pre-biopsy counselling should be nurse-led and is required to discuss pros and cons of biopsy (consensus reached)

- I agree
- I disagree
- Not relevant to my expertise

36. Active surveillance should be discussed during pre-biopsy counselling (adapted from previous consensus)

- I agree
- I disagree
- Not relevant to my expertise

37. Diagnostic clinics should be part of a one stop shop (consensus reached)

- I agree
- I disagree
- Not relevant to my expertise

38. If you disagree with any of the above please state why, or give additional comments here:

Biopsy and other investigations

39. Pre-biopsy MRI should be completed on all men with a suspected prostate cancer (55% of participants agreed in R2)

- I agree
- I disagree
- Not relevant to my expertise

40. Pre-biopsy MRI should be completed on all men with a suspected low grade prostate cancer to avoid unnecessary biopsy (70% of participants agreed in R2)

- I agree
- I disagree
- Not relevant to my expertise

41. If you disagree with any of the above please state why, or give additional comments here:

Diagnosis and treatment options

42. Patient diagnosis should be delivered by a nurse (56% of participants agreed with this in R2)

- I agree
- I disagree
- Not relevant to my expertise

43. Treatment options should be given as part of the diagnostic pathway (consensus reached)

- I agree
- I disagree
- Not relevant to my expertise

44. Treatment options should be discussed with a patient in the first instance by a...

- ...Nurse (50% of participants agreed with this in R2)
- ...Medic (50% of participants agreed with this in R2)
- Not relevant to my expertise

45. Treatment options should be discussed with palliative patients as they are with patients eligible for active treatment (consensus reaches)

- I agree
- I disagree
- Not relevant to my expertise

46. If you disagree with any of the above please state why, or give additional comments here:

Patients should be discussed at MDT when...

25. ...a patient is first diagnosed with prostate cancer (consensus reached)

- I agree
- I disagree
- Not relevant to my expertise

26. ...disease progression occurs (54% of participants agreed in R2)

- I agree
- I disagree
- Not relevant to my expertise

27. ...a patient becomes castrate resistant (54% of participants agreed in R2)

- I agree
- I disagree
- Not relevant to my expertise

28. If you disagree with any of the above please state why, or give additional comments here:

Page 4: Active treatments

Active surveillance

29. Active surveillance should be nurse-led (67% of participants agreed in R2)

- I agree
- I disagree
- Not relevant to my expertise

30. Active surveillance should be managed under the care of urology (75% of participants agreed in R2)

- I agree
- I disagree
- Not relevant to my expertise

31. Active surveillance follow-up should occur through...

- ...current mechanisms of follow-up (31% of participants agreed in R2)
- ...the utilisation of virtual clinics (31% of participants agreed in R2)
- ...the monitoring of patients in primary care with return visits to secondary care (23% of participants agreed in R2)
- I disagree with the above
- Not relevant to my expertise

32. Active surveillance should incorporate counselling services (consensus reached)

- I agree
- I disagree
- Not relevant to my expertise

33. If you disagree with any of the above please state why, or give additional comments here:

Robot assisted surgical service

34. Pre-operative care should be medic led with nurse support (consensus reached)

- I agree
- I disagree
- Not relevant to my expertise

35. With the exception of the initial post-operative review, post-operative care should be nurse-led (75% of participants agreed in R2)

- I agree
- I disagree
- Not relevant to my expertise

36. 3-4 surgeons should be employed per robot and should work to a hub and spoke job plan (consensus reached)

- I agree
- I disagree
- Not relevant to my expertise

37. If you disagree with any of the above please state why, or give additional comments here:

Surgery and radiotherapy follow-up

38. As services become centralised, follow-up services should continue to operate at a health board level (consensus reached)

- I agree
- I disagree
- Not relevant to my expertise

If you disagree please state why, or give additional comments here:

39. Radiotherapy follow-up should be nurse-led (consensus reached)

- I agree
- I disagree
- Not my area of expertise

40. Surgical follow-up should be nurse-led (75% of participants agreed in R2)

- I agree
- I disagree
- Not my area of expertise

41. If you disagree with either of the above please state why, or give additional comments here:

42. Neo-adjuvant hormone therapy should NOT be prescribed by nurses 2-3 months before consultation with an oncologist (60% of participants agreed in R2)

- I agree
- I disagree
- Not relevant to my expertise

If you disagree please state why, or give additional comments here:

43. Men who are at low risk of disease recurrence should be followed up by telephone review (consensus reached). This mode of follow-up should begin...

- After treatment
- After functional outcomes are achieved or PSA has stabilised
- Men should not be followed up by telephone review
- Not relevant to my expertise

If so, these men should have contact details of specialists should concerns arise instead of follow-up at regular intervals (reached consensus)

- I agree
- I disagree
- Men should not be followed up by telephone review
- Not relevant to my expertise

If you disagree with the above please state why, or give additional comments here:

44. Following treatment, surgical patients should be followed up in secondary care with...
    - ...monitoring in primary care and return visits to secondary care (40% of participants agreed in R2)
    - ...virtual clinics (30% of participants agreed in R2)
    - ...patients self monitoring PSA (20% of participants agreed in R2)
    - I disagree with the above
    - Not relevant to my expertise

45. Following treatment, radiotherapy patients should be followed up...
    - ...in primary care with return visits to secondary care (50% of participants agreed in R2)
    - ...under current mechanisms of follow-up (25% of participants agreed in R2)
    - I disagree with the above
    - Not relevant to my expertise
46. Initial methods of follow-up should occur until...
    - ...functional outcomes are achieved (64% of participants agreed in R2)
    - ...PSA has stabilised (45% of participants agreed in R2)
    - I disagree with the above
    - Not relevant to my expertise
47. If you disagree with any of the above please state why, or give additional comments here:

48. After this point, surgical follow-up should involve...
    - ...virtual clinics (33% of participants agreed in R2)
    - ...partient self monitoring PSA (22% of participants agreed in R2)
    - Take place under current mechanisms of follow-up (22% of participants agreed in R2)
    - I disagree with the above
    - Not relevant to my expertise
49. After this point, radiotherapy follow-up should involve...
    - ...virtual clinics (36% of participants agreed in R2)
    - ...patients self-monitoring PSA (27% of participants agreed in R2)
    - ...a primary care led follow-up with a rapic access mechanism feeding back into secondary care (27% of participants agreed in R2)
    - I disagree with all of the above
    - Not relevant to my expertise
50. Patient should then be discharged...

- ...5 years after treatment (36% of participants agreed in R2)
- ...according to their risk adapted discharge date (new response)
- ...after functional outcomes are reached/PSA has stabilised and given quality information for self-assessment and rereferral into the service (new response)
- I disagree with the above
- Not relevant to my expertise

51. If you disagree with any of the above please state why, or give additional comments here:

Side effects

52. The management of side effects requires a dedicated team that is nurse- led. This team should be responsible for the treatment and management of erectile dysfunction, incontinence, bladder irritability and bowel issues across both surgical and radiotherapy services as required. This team should also be involved with patients both pre and post treatment and should be organised around tertiary and sub-specialist services (consensus reached)

- I agree
- I disagree
- Not relevant to my expertise

53. There is a need to develop nursing roles to support patients with symptoms, side effects and treatment queries on an as and when required basis (consensus reached)

- I agree
- I disagree
- Not relevant to my expertise

54. If you disagree with any of the above please state why, or give additional comments here:

Page 5: Palliative Treatment

A service should be provided in the community for...

55. ...supporting weight management, diabetes and cholesterol monitoring (consensus reached)

- I agree
- I disagree
- Not relevant to my expertise

56. ...long term hormone therapy prescription and oral drug dispension (consensus reached)

- I agree
- I disagree
- Not relevant to my expertise

57. ...a uro-oncology nurse injection service to provide long term and neo-adjuvant hormone therapy as well as support to these patients (consensus reached)

- I agree
- I disagree
- Not relevant to my expertise

58. If you disagree with any of the above please state why, or give additional comments here:

Chemotherapy administration should be delivered locally (consensus reached)

59. Oral chemotherapy should be administered...
    - ...in primary care
    - ...in local day units
    - I disagree
    - Not relevant to my expertise
60. Injectable chemotherapy should be administered...
    - ...in primary care
    - ...in local day units
    - I disagree
    - Not relevant to my expertise
61. IV chemotherapy should be administered...
    - ...in primary care
    - ...in local day units
    - I disagree
    - Not relevant to my expertise
62. If you disagree with any of the above please state why, or give additional comments here:

63. Secondary care should be responsible for supporting patients whilst receiving chemotherapy (consensus reached)
    - I agree
    - I disagree
    - Not relevant to my expertise
64. Chemotherapy prescription should be medic led with nurse support, and chemotherapy administration and monitoring should be nurse-led (consensus reached)
    - I agree
    - I disagree
    - Not relevant to my expertise
65. Bisphosphonate administration should be nurse-led...
    - ...in secondary care clinics (67% of participants agreed in R2)
    - ...in primary care (33% of participants agreed in R2)

- I disagree with the above
- Not relevant to my expertise

66. Long term hormone follow-up should be...

- ...nurse-led from secondary care (62% of participants agreed in R2)
- ...GP-led (38% of participants agreed in R2)
- I disagree with the above
- Not relevant to my expertise

67. If you disagree with any of the above please state why, or give additional comments here:

Side effects and support

68. A pain management service for patients with bone metastases is required (70% of participants in R2 agreed)

- I agree
- I disagree
- Not relevant to my expertise

69. Pain management services should be situated... (new question)

- ...as part of the dedicated side effects team
- ...as part of the Macmillan nursing service
- ...with support services for advanced cancer
- ...independantly
- A pain service is not required
- I disagree with the above
- Not relevant to my expertise

70. If you disagree with any of the above please state why, or give additional comments here:

Treatment

71. Orchidectomy should be discussed as a treatment option with patients (consensus reached)

- I agree
- I disagree
- Not relevant to my expertise

72. Watchful waiting should be nurse-led (73% of participants agreed in R2)

- I agree
- I disagree
- Not relevant to my expertise

73. Nurse should review all non-complex patients (57% of participants agreed in R2)

- I agree

- I disagree
- Not relevant to my expertise

74. If you disagree with any of the above please state why, or give additional comments here:

75. Cross cover is required to allow patients to be treated during consultant absence (consensus reached)

- I agree
- I agree and medical cover is required for clinic time (71% of participants agreed in R2)
- I disagree with the above
- Not relevant to my expertise

76. Separate clinics are required for pre and post chemotherapy patients (consensus reached)

- I agree
- I agree and separate clinics are also required for hormone and chemotherapy patients (30% of participants agreed in R2)
- I disagree with the above
- Not relevant to my expertise

77. Follow-up clinics should include a supportive role and clinics are currently not flexible enough to provide a supportive role to patients (consensus reached)

- I agree
- I agree and this is also an issue in active treatment (new response)
- I disagree
- Not relevant to my expertise

78. If you disagree with any of the above please state why, or give additional comments here:

Page 6: Additional comments

79. This research aims to inform future service design and delivery in Scotland. Please add any additional comments here.

Page 7: Further consideration

The service models proposed within this Delphi process have developed considerably since the first questionnaire. This page proposes to:

- summarise areas of consensus
- resolve areas of dissensus
- propose service models that are utilised within other areas of healthcare where they may benefit the emerging consensus

80. Managed Cancer Networks should be responsible for the regional multidisciplinary implementation of 'gold standard' care

- I agree
- I disagree
- Not relevant to my expertise

If you disagree please state why, or give additional comments here:

81. Primary care practitioners should be included within MCN prostate cancer working groups for the development and implementation of community based interventions and services

- I agree
- I disagree
- Not relevant to my expertise

If you disagree please state why, or give additional comments here:

82. Prostate cancer services require the development of Scotland-wide surgery, radiotherapy and hormone therapy/chemotherapy working groups

- I agree
- I disagree
- Not relevant to my expertise

The design of speciality specific 'gold standard' care for patients living in Scotland

- I agree
- I disagree
- I disagree with the development of this working group
- Not relevant to my expertise

Prostate cancer services also require the development of a Scotland-wide nursing and AHP working group

- I agree
- I disgaree
- Not relevant to my expertise

These working groups should be responsible for communicating with MCNs

- I agree
- I disagree
- I disagree with the development of these working groups
- Not relevant to my expertise

If you disagree with any of the above please state why, or give additional comments here:

83. A community pharmacy service should be developed for...

- The administration of long term hormone therapy
- The administration of neo-adjuvant hormone therapy
- Support to patients receiving hormone therapy
- Long term hormone follow-up
- Bisphosphonate administration
- The administration of oral chemotherapy
- The administration of chemotherapy by injection
- I agree with none of the above
- Not relevant to my expertise

Please give additional comments here:

The end and thank you

Thank you for taking the time to participate in this Delphi. Your input has been vital in the completion of this research.

This is the last questionnaire.

All participants will be provided with a final report for their information.

Appendix 11: Treatment modality data and percentage of patients with missing or not known data

Table 31: Percentage of patients who had surgery

	AGE	1997-2000	2001-2004	2005-2008	2009-2012
SCOTLAND	**45-54**	47.7 (+2.8)	36.5 (+7.2)	34.3 (+5.5)	31.1 (+0.7)
	55-64	47.6 (+2.5)	35.3 (+6.5)	34.0 (+3.8)	29.6 (+0.4)
	65-74	36.6 (+3.1)	25.2 (+6.9)	21.3 (+4.7)	18.5 (+0.3)
	75-84	31.5 (+2.9)	18.7 (+6.6)	16.3 (+4.8)	13.4 (+0.4)
	85+	21.7 (+2.6)	13.4 (+7.9)	10.3 (+3.5)	8.6 (+0.2)
	Total	35.2 (+2.9)	24.4 (+6.8)	22.1 (+4.5)	19.7 (+0.4)
NOSCAN	**45-54**	50.0 (+0.0)	43.1 (+5.6)	33.3 (+1.4)	42.9 (+0.0)
	55-64	54.8 (+0.3)	42.2 (+3.3)	35.2 (+0.5)	36.6 (+0.4)
	65-74	44.9 (+1.2)	32.0 (+2.9)	23.1 (+0.6)	19.8 (+0.2)
	75-84	39.0 (+1.4)	28.6 (+4.1)	15.2 (+0.9)	12.0 (+0.6)
	85+	22.6 (+0.8)	12.9 (+5.2)	6.9 (+1.9)	10.7 (+0.0)
	Total	41.8 (+1.1)	31.3 (+3.6)	22.0 (+0.8)	21.1 (+0.3)
SCAN	**45-54**	43.8 (+4.2)	32.0 (+3.0)	32.3 (+4.0)	28.5 (+0.0)
	55-64	64.9 (+1.9)	29.2 (+0.9)	36.8 (+2.0)	29.2 (+0.2)
	65-74	37.0 (+1.9)	27.1 (+1.4)	24.9 (+2.2)	21.0 (+0.2)
	75-84	33.8 (+1.3)	21.7 (+2.4)	21.8 (+2.5)	18.1 (+0.1)
	85+	23.7 (+3.5)	19.0 (+1.7)	12.1 (+2.7)	10.1 (+0.0)
	Total	38.5 (+1.9)	25.4 (+1.7)	26.2 (+2.3)	22.2 (+0.2)
WOSCAN	**45-54**	46.4 (+3.6)	36.4 (+11.4)	35.5 (+8.6)	28.2 (+1.4)
	55-64	33.3 (+4.1)	35.3 (+12.0)	30.4 (+7.4)	25.9 (+0.5)
	65-74	30.8 (+5.2)	20.1 (+12.7)	17.5 (+9.2)	15.7 (+0.4)
	75-84	24.8 (+5.0)	10.6 (+11.0)	13.2 (+8.7)	11.4 (+0.5)
	85+	19.4 (+3.3)	10.1 (+13.8)	11.6 (+5.6)	6.1 (+0.6)
	Total	28.5 (+4.8)	19.7 (+12.1)	19.1 (+8.4)	16.9 (+0.5)

Table 32: Percentage of patients who had radiotherapy

	AGE	**1997-2000**	**2001-2004**	**2005-2008**	**2009-2012**
SCOTLAND	**45-54**	39.2 (+4.5)	39.8 (+7.9)	29.1 (+8.1)	28.4 (+0.7)
	55-64	40.5 (+3.3)	38.8 (+8.4)	30.7 (+6.0)	34.2 (+0.6)
	65-74	28.8 (+3.2)	31.2 (+7.4)	27.0 (+6.2)	34.4 (+0.6)
	75-84	9.9 (+3.0)	9.2 (+7.5)	11.2 (+6.4)	20.0 (+0.6)
	85+	3.3 (+2.2)	3.0 (+7.4)	3.1 (+4.7)	5.6 (+0.3)
	Total	21.6 (+3.1)	23.7 (+7.6)	21.5 (+6.1)	28.4 (+0.6)
NOSCAN	**45-54**	39.6 (+2.1)	52.8 (+4.2)	43.1 (+1.4)	31.0 (+0.0)
	55-64	40.7 (+1.0)	46.3 (+4.3)	34.7 (+2.2)	34.1 (+0.4)
	65-74	31.1 (+1.2)	37.2 (+3.0)	33.9 (+1.8)	39.6 (+0.4)
	75-84	10.0 (+1.4)	12.9 (+6.0)	16.2 (+1.7)	22.2 (+0.4)
	85+	2.8 (+0.8)	5.2 (+5.6)	5.0 (+1.5)	5.9 (+0.0)
	Total	22.1 (+1.2)	28.6 (+4.5)	26.4 (+1.8)	30.6 (+0.4)
SCAN	**45-54**	29.2 (+4.2)	41.0 (+1.0)	18.5 (+5.6)	28.5 (+0.0)
	55-64	41.5 (+4.1)	45.8 (+0.9)	26.9 (+3.1)	32.8 (+0.2)
	65-74	29.2 (+2.1)	33.0 (+1.3)	24.4 (+3.5)	31.9 (+0.3)
	75-84	11.5 (+1.6)	9.3 (+2.0)	9.7 (+3.8)	20.2 (+0.2)
	85+	3.5 (+2.2)	2.6 (+1.7)	3.0 (+3.0)	3.9 (+0.0)
	Total	22.1 (+2.3)	25.8 (+1.5)	19.3 (+3.5)	27.7 (+0.2)
WOSCAN	**45-54**	42.9 (+6.0)	31.8 (+15.2)	30.3 (+13.2)	27.3 (+1.4)
	55-64	39.8 (+4.3)	29.8 (+15.6)	31.4 (+10.9)	35.2 (+1.0)
	65-74	26.9 (+5.2)	26.7 (+13.8)	24.9 (+11.0)	32.9 (+1.0)
	75-84	8.8 (+5.1)	6.8 (+12.2)	9.0 (+11.1)	18.2 (+1.0)
	85+	3.6 (+3.3)	2.0 (+12.4)	1.6 (+8.8)	6.4 (+0.8)
	Total	20.9 (+4.9)	19.4 (+13.6)	20.0 (+10.9)	27.6 (+1.0)

Table 33: Percentage of patients who had hormone therapy

	AGE	1997-2000	2001-2004	2005-2008	2009-2012
SCOTLAND	**45-54**	46.0 (+5.1)	38.8 (+14.1)	29.7 (+18.6)	26.1 (+3.2)
	55-64	55.6 (+4.5)	45.9 (+14.5)	31.9 (+19.5)	37.2 (+2.8)
	65-74	58.6 (+4.0)	52.4 (+12.3)	40.9 (+19.2)	47.4 (+2.0)
	75-84	59.0 (+4.3)	54.9 (+12.2)	44.7 (+20.0)	54.6 (+3.4)
	85+	42.9 (+3.2)	38.3 (+12.0)	32.7 (+15.9)	39.0 (+5.1)
	Total	56.5 (+4.1)	50.5 (+12.7)	39.1 (+19.3)	45.4 (+2.8)
NOSCAN	**45-54**	43.8 (+2.1)	43.1 (+8.3)	31.9 (+23.6)	32.1 (+2.4)
	55-64	53.8 (+1.3)	46.3 (+10.4)	31.4 (+24.3)	38.0 (+3.3)
	65-74	56.1 (+1.8)	56.2 (+6.4)	43.4 (+22.5)	53.4 (+2.7)
	75-84	58.6 (+2.2)	59.3 (+9.8)	46.7 (+24.0)	57.0 (+5.3)
	85+	42.9 (+1.2)	40.5 (+6.9)	34.2 (+16.9)	42.6 (+6.3)
	Total	55.0 (+1.8)	53.7 (+8.3)	40.8 (+22.8)	49.7 (+3.9)
SCAN	**45-54**	35.4 (+6.3)	36.0 (+12.0)	22.6 (+15.3)	22.2 (+2.8)
	55-64	58.5 (+5.1)	50.0 (+12.6)	29.2 (+18.3)	34.7 (+1.7)
	65-74	62.6 (+3.3)	51.8 (+10.6)	36.6 (+19.3)	43.1 (+1.0)
	75-84	61.5 (+3.4)	54.0 (+12.0)	38.5 (+20.4)	57.2 (+1.5)
	85+	42.5 (+4.4)	39.2 (+11.2)	29.2 (+18.6)	42.5 (+3.5)
	Total	59.1 (+3.7)	50.7 (+11.5)	34.3 (+19.2)	43.2 (+1.5)
WOSCAN	**45-54**	51.2 (+6.0)	38.6 (+18.9)	33.6 (+18.4)	26.4 (+3.7)
	55-64	54.8 (+5.9)	42.7 (+17.9)	34.6 (+17.4)	38.7 (+3.4)
	65-74	57.5 (+5.9)	50.7 (+16.6)	42.9 (+17.3)	46.9 (+2.4)
	75-84	57.3 (+6.3)	52.8 (+13.9)	47.4 (+17.2)	51.3 (+3.3)
	85+	43.1 (+3.9)	36.2 (+15.7)	34.7 (+13.1)	33.9 (+5.3)
	Total	55.7 (+5.9)	48.4 (+16.1)	41.7 (+17.1)	44.3 (+3.1)

Table 34: Percentage of patients who had chemotherapy

	AGE	1997-2000	2001-2004	2005-2008	2009-2012
SCOTLAND	**45-54**	2.3 (+4.5)	5.3 (+7.9)	5.8 (+7.3)	4.7 (+0.7)
	55-64	1.4 (+3.6)	1.7 (+8.8)	3.8 (+4.6)	3.2 (+0.2)
	65-74	0.6 (+3.3)	1.3 (+7.8)	1.6 (+5.0)	2.2 (+0.3)
	75-84	0.5 (+3.4)	0.8 (+7.5)	0.9 (+5.2)	1.0 (+0.4)
	85+	0.1 (+2.8)	0.7 (+7.6)	0.4 (+3.8)	0.2 (+0.2)
	Total	0.6 (+3.4)	1.3 (+7.8)	1.9 (+5.0)	2.1 (+0.3)
NOSCAN	**45-54**	4.2 (+2.1)	5.6 (+5.6)	2.8 (+2.8)	6.0 (+0.0)
	55-64	1.3 (+0.6)	2.2 (+6.7)	2.7 (+1.7)	4.1 (+0.1)
	65-74	0.9 (+1.3)	1.0 (+4.5)	1.7 (+1.3)	3.0 (+0.3)
	75-84	0.6 (+1.7)	0.5 (+6.5)	0.8 (+1.3)	0.8 (+0.4)
	85+	0.0 (+1.2)	0.0 (+6.0)	0.4 (+1.5)	0.0 (+0.0)
	Total	0.8 (+1.4)	1.1 (+5.7)	1.5 (+1.4)	2.5 (+0.3)
SCAN	**45-54**	2.1 (+4.2)	5.0 (+1.0)	4.0 (+3.2)	2.8 (+0.0)
	55-64	0.9 (+4.1)	1.6 (+0.7)	3.3 (+1.4)	2.2 (+0.2)
	65-74	0.1 (+2.3)	0.4 (+1.3)	1.2 (+2.0)	1.1 (+0.1)
	75-84	0.4 (+1.9)	0.6 (+2.1)	0.9 (+2.4)	0.5 (+0.1)
	85+	0.0 (+3.1)	1.3 (+1.3)	0.4 (+2.3)	0.4 (+0.0)
	Total	0.3 (+2.5)	0.9 (+1.4)	1.7 (+2.0)	1.3 (+0.1)
WOSCAN	**45-54**	1.2 (+6.0)	5.3 (+14.4)	8.6 (+12.5)	5.6 (+1.4)
	55-64	1.7 (+5.0)	1.4 (+15.1)	4.8 (+9.4)	3.5 (+0.3)
	65-74	0.7 (+5.5)	2.1 (+13.8)	1.9 (+9.7)	2.5 (+0.4)
	75-84	0.4 (+5.6)	1.1 (+11.7)	1.0 (+9.7)	1.5 (+0.5)
	85+	0.3 (+3.9)	0.8 (+12.6)	0.3 (+6.9)	0.3 (+0.6)
	Total	0.7 (+5.3)	1.7 (+13.3)	2.3 (+9.5)	2.5 (+0.5)