



Research into wellbeing services for men with prostate cancer –final report

Prostate Cancer UK

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A report submitted by [ICF International](#)

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Key points

Introduction

The aims of the research were to:

- Develop an indicative ‘map’ of existing services that support the wellbeing of men with prostate cancer;
- Determine whether there are gaps in those services based on either geographical or social factors;
- Determine how accessible these services are – especially for harder to reach groups; and
- Define the nature of the providers providing these wellbeing services, e.g. NHS and the voluntary and community sector.

The study consisted of three phases:

1. **Scoping** – to define the parameters of the study
2. **Research** – to examine six areas across the four nations of the UK, and the provision of wellbeing services in those areas
3. **Analysis** – to draw together the findings from the case study research and the scoping phase in a final report.

Findings

- The emphasis on ‘wellbeing’ is increasing within the context of supporting people with Long Term Conditions (LTCs) – including prostate cancer. Tailoring services is therefore crucial.
- The needs of men with prostate cancer appear to be relatively consistent across the UK.
- Many men do not take a pro-active approach to addressing their health – understanding the challenges in ‘engaging with men’ is fundamental to service provision.
- Provision of wellbeing services for men with prostate cancer is highly inconsistent.
- Wellbeing is best provided as part of a standard pathway. The role of the Clinical Nurse Specialist (CNS) is therefore vital to assist men in navigating these pathways.
- Men’s backgrounds and cultural and linguistic contexts matter; this implies targeting and tailoring services to men with prostate cancer.
- There may be some generic services which are available to people with cancer that can also be accessed by men with prostate cancer – sometimes tailoring is necessary to ensure men engage with them.
- Collaboration between all relevant stakeholders in a local health and social care economy is important.
- In summary, good practice is usually characterised by:
 - An appropriate point of contact for men to signpost them to necessary services that cater to their particular wellbeing needs. Most usually, this is a CNS;
 - Ongoing and holistic needs assessment of the man’s physical, emotional and social wellbeing needs;
 - Integration of wellbeing services with the formal treatment pathway, with buy-in from the clinical team as to the importance of promoting wellbeing services;
 - Services that are relevant to men and are marketed to make them appealing and pertinent to men’s perceptions of wellbeing;
 - Services that make the link between physical wellbeing and emotional wellbeing;
 - Strategic and joined-up co-ordination; and

- An accurate map of wellbeing services to minimise duplication and to maximise collaboration.

Recommendations

- Ensure adequate access to a CNS for men with prostate cancer, including a suitable consultation time for men following diagnosis.
- Promote awareness of 'wellbeing' among CNSs and the wider clinical workforce.
- Promote wellbeing as part of mainstream provision / pathways. Increase funding for pilot initiatives to establish "what works".
- Spread examples of good practice.
- Tailor provision to men with prostate cancer taking account of their community and context.
- Learn what men want and what men need and tailor services accordingly. Coordinate services locally.
- Facilitate partnership and collaboration between organisations providing services to men with prostate cancer.

Executive summary

Introduction

Prostate cancer is the most common cancer among men in the UK. Treatment is complex and the wide range of treatment and surgery options have numerous side effects. These include psychological distress, depression and anxiety. There are also psychological side effects associated with some of the physical problems arising from treatment or surgery, such as erectile dysfunction or urinary problems.

Recent advances in detection and treatment have meant that prostate cancer is often considered as a long term condition (LTC), as men are living longer, although usually with permanent morbidities as a result of treatment. As a result, men have broader support needs aimed at improving their wellbeing. There is currently a lack of knowledge as to whether or not services are meeting wellbeing needs for men with prostate cancer, what is being done and which organisations are providing it.

The aim of this research was to find out more about the service response to address the wellbeing needs of men with prostate cancer. This included:

- Development of an indicative ‘map’ of existing services that support the wellbeing of men with prostate cancer;
- Determining whether there are gaps in those services based on either geographical or social factors;
- Determining how accessible these services are – especially for harder to reach groups; and
- Defining the nature of the providers providing these wellbeing services, e.g. NHS and the voluntary and community sector.

The study consisted of three phases:

1. **Scoping:** defining the parameters of the study and identifying a good mix of case studies to capture the variety of activity taking place in different locations across the UK.
2. **Research:** examination of six areas across the four nations of the UK, analysing the provision of wellbeing services in those areas.
3. **Analysis:** drawing together the findings from the case study analysis and the scoping phase and this report is the presentation of our findings.

Context: wellbeing needs and the policy response

“Wellbeing” is a broad, dynamic and multi-dimensional concept consisting of many different elements interplaying with each other, including emotional wellbeing, mental wellbeing, physical wellbeing, social wellbeing (relationships and family life) and economic wellbeing. Of these, mental wellbeing is a particularly important element. Moreover, mental wellbeing has become more important as a policy concern in healthcare, especially in light of research that has shown that people with LTCs experience greater levels of depression and anxiety, poorer clinical outcomes and a lower quality of life.

Men with prostate cancer have a particular set of mental wellbeing needs, given that cancer is increasingly experienced as a LTC. In addition to this, men face specific barriers in accessing support, given their attitudes to wellbeing and psychological support. Our research identified wellbeing needs specific to men with prostate cancer. These include:

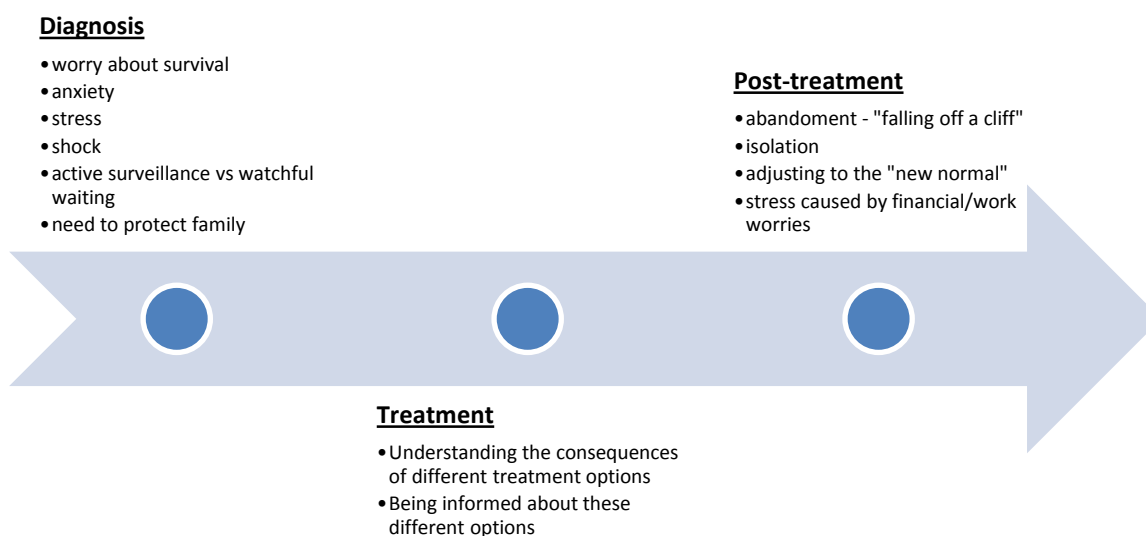
- Anxiety
- Loss of libido and sexual function
- Impact on relationships (spouse and/or family)
- Isolation
- Depression (dealing with mortality)
- Mood swings
- Loss of masculinity
- Negative self-image/low self-esteem
- Stigmatisation (as a result of physical side-effects)
- Abandonment

- Stress (financial and practical worries)

Moreover, different “types of men” can have different needs. This research identified specific requirements for minority ethnic groups, socially disadvantaged men, gay and bisexual men, and single men/men with no families.

Wellbeing needs also change according to the stage of the ‘cancer journey’ – from diagnosis to treatment to follow-up as in Figure 1. Additionally, respondents stated that different treatment options give rise to different wellbeing needs – underlining the importance of information about the consequences of treatment choices.

Figure 1: The cancer trajectory – examples of the change in wellbeing needs



In health and social care policy, addressing wellbeing needs is becoming a growing priority. This is beginning to be reflected by the health services across the four nations. However, despite this growing emphasis, provision of wellbeing services for men with prostate cancer appears to be highly inconsistent. Some features of provision identified by our research included:

- Rural areas typically lack wellbeing support services relative to urban areas;
- The ‘medical model’ of treatment places primary emphasis on physical wellbeing;
- Integration or anchoring of wellbeing services with a hospital, is an important success factor in sustainable provision; and
- Where wellbeing services are available to patients of all cancers, women are more likely to engage with them than men.

Reasons identified by respondents for the variation in provision included:

- Pressure on resources in the NHS means a primary focus on physical wellbeing.
- Some clinicians are more aware of / better than others in discussing wellbeing needs with men with prostate cancer.
- There is limited capacity for nurses and some clinicians to act as signposts for men who are seeking wellbeing services.
- Current provision of wellbeing services is ad hoc and inconsistent, which means that an awareness of what is available in an area rests on the individual knowledge of professionals working there.

Routes into wellbeing services were also considered to be an important factor in determining the up-take of such services by men. In general, integration of such services into the wellbeing pathway was

considered to be an important factor in ensuring men accessed them. However, engaging difficult-to-engage groups was considered more challenging given the difficulties with literacy in such groups, nervousness about dealing with “officialdom” or a general “lack of confidence” as well as the general barriers faced by men in addressing their wellbeing needs.

Findings from the case studies

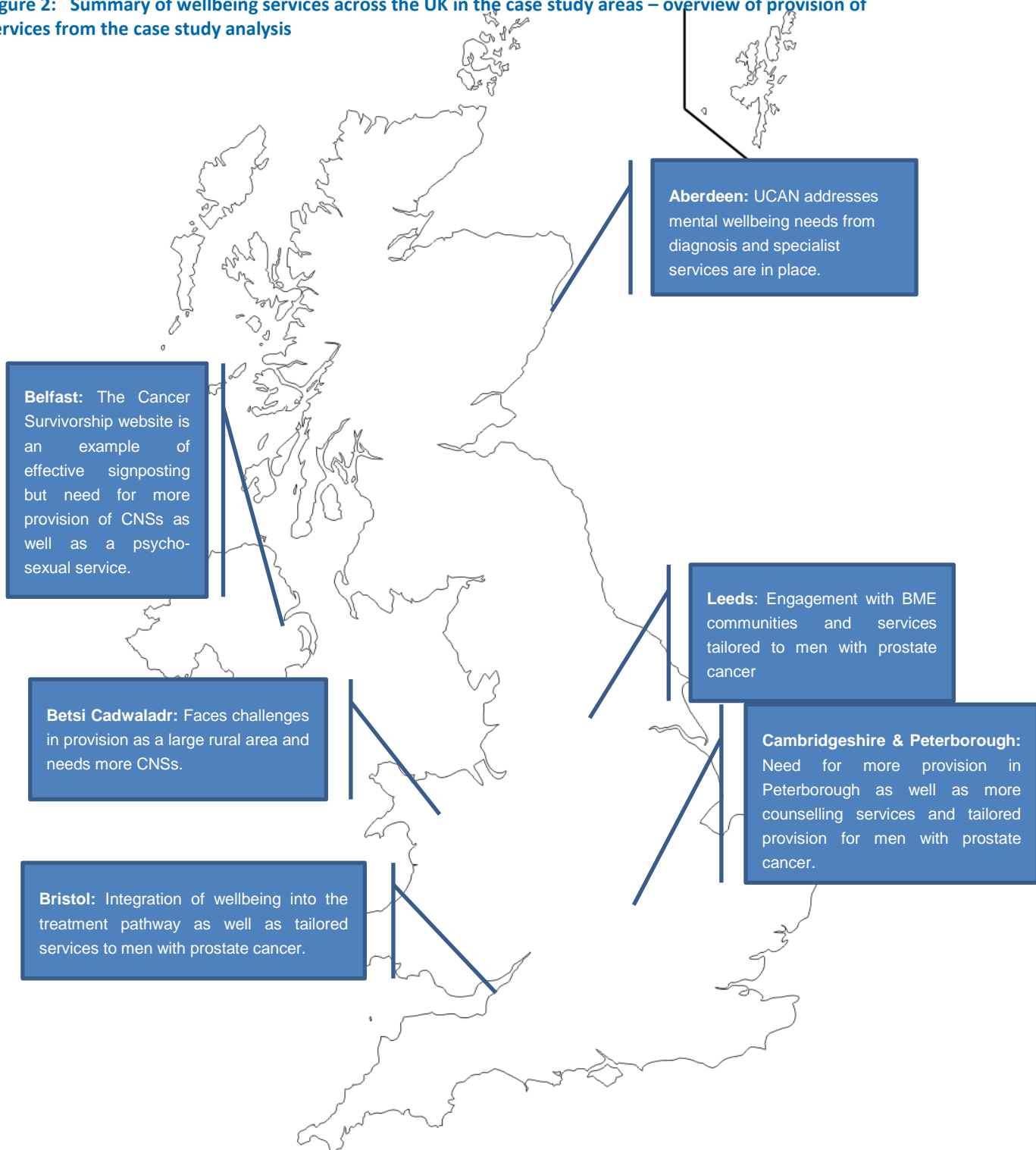
The main findings from the analysis of the six case studies (see Figure 2) are that:

- The needs of men with prostate cancer appear relatively consistent across the UK and mirror those identified in the scoping stage of the research.
- Families are important in leading men towards engaging with their wellbeing, and wellbeing services for men with prostate cancer should be considered in this light.
- Provision of wellbeing services for men with prostate cancer is patchy, because of: lack of resources; low awareness (of the problem and / or support services) among clinicians; over-concentration on ‘the cancer’ relative to ‘the man’; and lack of local strategic direction.
- The voluntary sector plays a fundamental role in providing specialist wellbeing services; the role of health services in England, Scotland, Wales and Northern Ireland is primarily commissioning / planning, funding and referring – and including consideration of wellbeing in ‘mainstream’ services.
- The manner / type of referral makes a difference to the take-up of support services – integration of wellbeing into standard pathways (through a holistic needs assessment, for example) is important. The role of the Clinical Nurse Specialist (CNS) is vital. The extent of local clinical engagement in the ‘wellbeing agenda’ is therefore an important determining factor in the support men receive.
- Cultural context matters, whether this is in terms of engaging minority communities and difficult-to-engage groups in a local community setting, providing services in Welsh for men in Wales or showing awareness of particular local cultural factors that may affect men’s engagement with wellbeing services.
- Targeting and tailoring services to men with prostate cancer is effective. There may be some generic services which are available to people with cancer that can also be accessed by men with prostate cancer. However, sometimes tailoring of these services is necessary to ensure they engage with them.
- Collaboration between all relevant stakeholders in a local health and social care economy is important – the most successful examples of wellbeing services are those that are provided by a partnership between a number of providers across statutory and voluntary services.
- In rural areas, locating wellbeing services near the treatment centre is important to ensure men can access the services while accessing treatment.
- In summary, good practice is usually characterised by:
 - An appropriate point of contact for men to signpost them to necessary services that cater to their particular wellbeing needs. Most usually, this is a CNS;
 - Ongoing and holistic needs assessment of the man’s physical, emotional and social wellbeing needs;
 - Integration of wellbeing services with the formal treatment pathway, with buy-in from the clinical team as to the importance of promoting wellbeing services;
 - Services that are relevant to men and show awareness of local and cultural factors and which are marketed to make them appealing and pertinent to men’s perceptions of wellbeing;
 - Services that understand the link between physical wellbeing and emotional wellbeing;
 - Strategic and joined-up co-ordination; and
 - An accurate map of wellbeing services that are available to men in an area to minimise duplication and to maximise collaboration.

Recommendations

- Ensure adequate access to a CNS for men with prostate cancer, including a suitable consultation time for men following diagnosis.
- Promote awareness of 'wellbeing' among CNSs and the wider clinical workforce, as well as among all stakeholders who come into contact with men with prostate cancer on their treatment pathway
- Promote wellbeing as part of mainstream provision / pathways, through 'good practice in holistic needs assessment', for example.
- Increase funding for pilot initiatives to learn about what works – this provides an evidence base for the commissioning of services.
- Spread examples of best practice examples.
- Tailor provision so that it shows an understanding of the barriers men with prostate cancer face.
- Learn what men want and what men need and tailor services accordingly, including the use of initiatives in the community to engage men from minority communities and difficult-to-engage groups.
- Coordinate services locally to ensure maximum effectiveness and best benefit for men – this should also include an element of strategic overview.
- Facilitate and encourage partnership and collaboration between organisations from all sectors that are involved in the provision of wellbeing services – some of the best examples in the analysis are those services that are delivered by organisations in partnership.

Figure 2: Summary of wellbeing services across the UK in the case study areas – overview of provision of services from the case study analysis



1 Introduction

Prostate cancer is the most common cancer among men in the UK. Men have a lifetime risk of developing prostate cancer of 1 in 8. Survival rates are high – 5 and 10 year survival rates are at 81% and 68% respectively (Cancer Research UK, 2014). 1 in 8 men will get prostate cancer and by 2030, prostate cancer will be the most common cancer in the UK (Movember Foundation 2013). The number of men with prostate cancer will be double its 2010 level by 2030 and the proportion of men who are 5 years from their prostate cancer diagnosis will be triple its 2010 level in 2030 (Macmillan, 2012).

Treatment for prostate cancer is complex. There are a wide range of treatment and surgery options, with numerous side effects. Psychological distress, depression and anxiety are common. Erectile dysfunction and urinary problems, and associated psychological side effects, are also typical (Department of Health, 2012). For example, 63% of patients with prostate cancer state that they are unable to maintain an erection and 38% reported urinary leakage which is associated with lower quality of life scores. NICE recommends specialised support services to help patients address these side effects, especially psychological ones (NICE 2014).

In many cases, men do not undergo active treatment. Instead, they may participate in 'active surveillance' if the cancer is localised, or 'watchful waiting' if the cancer has grown too far to cure, but is not causing symptoms. Both involve regular hospital visits, including blood tests, rectal examinations and biopsies; both can be associated with increased anxiety.

In combination with the factors outlined above as well as the fact the men live for a long time with a prostate cancer diagnosis, prostate cancer is often better understood as a long term condition (LTC). As a result, men with prostate cancer have broader support needs which must be provided (as emphasised by the National Cancer Survivorship Initiative and NHS Improvement's *Adult Survivorship Pathway*). For support with living with a LTC, care should not just include clinical support services, but could also address broader needs about improving *wellbeing* such as: emotional and psychological support; education and information; and physical activity. This might also include other support services such as complementary therapy (e.g. acupuncture and reflexology), vocational rehabilitation and advice on dealing with the financial implications of cancer. Wellbeing is emerging as an important priority in healthcare and addressing it can improve the welfare of patients while making better use of scarce resources.

Despite the importance of these issues, there is a lack of evidence about: whether services are meeting 'wellbeing needs' for men with prostate cancer; which organisations provide services; and whether this is being done equitably.

1.1 The aim of this research is to find out more about the service response to address the wellbeing needs of men with prostate cancer

ICF GHK was commissioned by Prostate Cancer UK to address this gap in knowledge.

The aims of the research were to:

- Develop an indicative 'map' of existing services that support the wellbeing of men with prostate cancer;
- Determine whether there are gaps in those services based on either geographical or social factors;
- Determine how accessible these services are – especially for harder to reach groups; and
- Define the nature of the providers providing these wellbeing services, e.g. NHS and the voluntary and community sector.

To do this, we approached the study in three phases:

1. **Scoping:** the aim of this phase was to define the parameters of the study – especially in identifying a good mix of case studies to capture the variety of activity taking place in different locations across the UK.
2. **Research:** we examined six areas across the four nations of the UK, analysing the provision of wellbeing services in those areas.
3. **Analysis:** this phase involved drawing together the findings from the case study analysis and the scoping phase and this report is the presentation of our findings.

1.2 This report sets out our analysis and recommendations

The method for this study began with a scoping phase. This involved:

- An inception meeting with Prostate Cancer UK to confirm the overall aims and objectives of the study (summarised in an inception note);
- A review of literature to understand the main issues in relation to wellbeing, specifically men's wellbeing and the wellbeing needs of those affected by cancer and those of men with prostate cancer;
- A document review of material related to wellbeing services in the UK (and in each of the individual nations) as well as examining the extent to which wellbeing services are available to men with prostate cancer;
- Scoping interviews with 12 healthcare professionals and 10 expert stakeholders with expertise in the area of prostate cancer; and
- Identification of six case studies for analysis in the second phase of this project.

The research phase involved:

- Examining six areas from across the UK in terms of provision of wellbeing services;
- Reviewing relevant documents from each area to inform our analysis, including commissioning plans, statistical analysis and strategic needs assessments;
- Conducting interviews about wellbeing services for men with prostate cancer with stakeholders in each area, including providers, commissioners and clinicians; and
- Making an assessment of the provision of wellbeing services in those areas on a number of dimensions, including tailoring of services to men with prostate cancer, access, awareness and take-up; and the extent to which there is a joined-up approach to provision.

The analysis phase involved:

- A thematic analysis of the case studies in terms of the provision of wellbeing services to men with prostate cancer;
- Distilling those themes into a number of key findings; and
- Presenting a set of recommendations for improving the provision of wellbeing services for men with prostate cancer.

The report is presented as follows:

- Section 2 sets out the context to wellbeing policy and how this relates to the wellbeing needs of men with prostate cancer, drawing on a document review and interviews with healthcare professionals and stakeholder groups. It begins by outlining the definition of wellbeing, the issues involved as well as the wellbeing needs of people with cancer and a focus on the needs of men with prostate cancer. It then provides an overview of issues identified in the delivery of wellbeing services. It concludes by presenting a brief overview of the policy response to improving wellbeing, especially to people with cancer;
- Section 3 provides an overview of the case studies chosen for this study and the reasons for their selection. It then proceeds to provide an overview and analysis of wellbeing services in each of the areas; and

- Section 4 presents the conclusions and recommendations of the study.

The main body of the report is supported by five Annexes:

- Annex 1 provides the bibliography for the literature review.
- Annex 2 provides the topic guide used in the scoping interviews.
- Annex 3 provides a list of people interviewed as part of the scoping phase.
- Annex 4 sets out the sources (documents and interviews) used to develop the case studies
- Annex 5 presents the topic guide used for the interviews to develop the case studies.

2 Policy context

In this section, we set out the context to the research by drawing on the material gathered in the scoping phase from a review of relevant documents and interviews with healthcare professionals and other stakeholders. We approach it in the following order:

- A discussion of the definitions of wellbeing;
- An examination of the needs of men with prostate cancer;
- An overview of the policy response to addressing those needs; and
- An overview of the current provision of services to men with prostate cancer.

2.1 'Wellbeing' is a broad, dynamic and multi-dimensional concept

The definition of wellbeing as a philosophical (and policy) concept has been evolving for centuries. Despite the breadth of attention, there is general agreement that wellbeing is a multi-dimensional construct (Dodge, Daly, Huyton and Sanders 2012). 'Wellbeing' is taken to refer to outcomes across a range of domains – including economic, social, physiological and psychological, among others. There is also a question of the perspective from which wellbeing is being assessed – whether this is from the perspective of the individual ('subjective' wellbeing, e.g. how good someone feels about their life) or how it compares with norms for wellbeing set down by society ('objective' wellbeing – such as life expectancy).

Drawing these different strands together poses a challenge in offering a common definition for the concept of wellbeing. An example of a broad definition, as provided by Dodge et al. (2012), might be:

"In essence, stable wellbeing is when individuals have the psychological, social and physical resources they need to meet a particular psychological, social and/or physical challenge. When individuals have more challenges than resources, the see-saw dips, along with their wellbeing, and vice-versa."

An alternative definition, offered by the New Economics Foundation (NEF) (2012), is:

"Well-being can be understood as how people feel and how they function, both on a personal and a social level, and how they evaluate their lives as a whole."

There has been a renewed focus on defining wellbeing in recent years because of governments' interest in it as a public policy objective. This is because of the shift away from using economic growth as the sole / primary measure of human welfare and much work has been done in developing a systematic and measurable definition for wellbeing. The commission of economists (comprising Joseph Stiglitz, Amartya Sen and Jean-Paul Fitoussi) set up by French President Nicholas Sarkozy to investigate the measurement of economic performance and social progress is perhaps one of the better known initiatives that was set up with this objective (Stiglitz, Sen and Fitoussi, 2007).

This was mirrored in other countries, including the UK. For example, the cross-departmental Sustainable Development Strategy provided by the Department for Environment, Food and Rural Affairs (Defra) on its website defines wellbeing as:

"...a positive physical, social and mental state; it is not just the absence of pain, discomfort and incapacity"

Similarly, the Department for Education (2010) has presented childhood wellbeing as being:

"...generally understood as the quality of people's lives. It is a dynamic state that is enhanced when people can fulfil their personal and social goals. It is understood both in relation to objective measures, such as household income, educational resources and health status; and subjective indicators such as happiness, perceptions of quality of life and life satisfaction."

Building on such definitions and with a view to developing a measurement for wellbeing, the Office for National Statistics (ONS) (2011) outlined a number of elements that it identified as being central to the measurement of individual wellbeing:

“relationships; health; what we do; where we live; personal finance; education and skills”

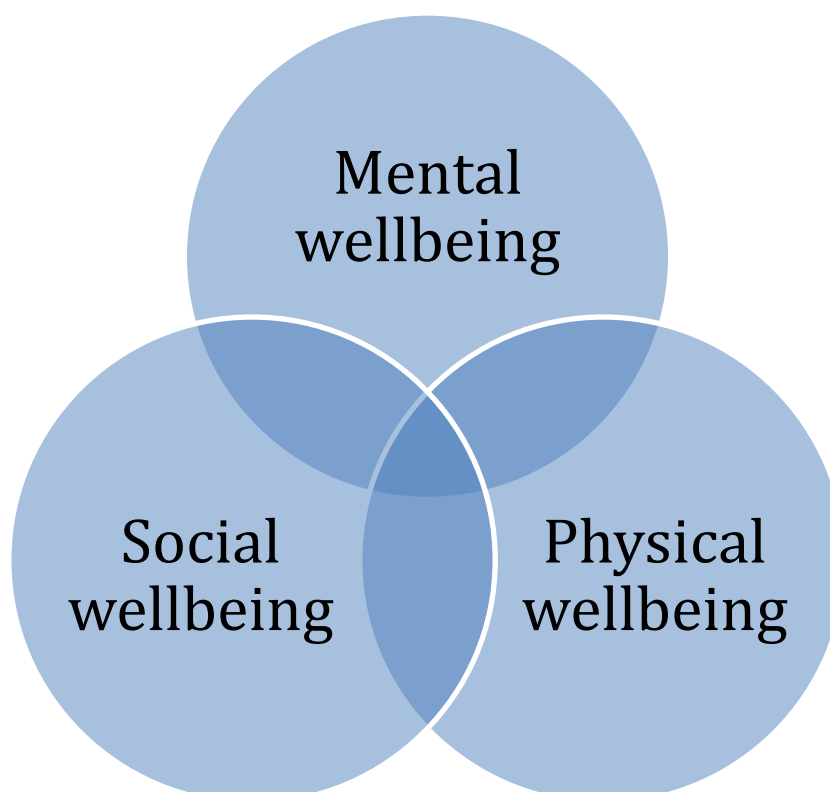
The Department of Health (2014) develops this further and states that, with regard to health in particular, wellbeing should be thought of as follows:

“Wellbeing is about feeling good and functioning well and comprises an individual’s experience of their life; and a comparison of life circumstances with social norms and values.”

It goes further and identifies two dimensions as part of wellbeing – subjective wellbeing (where people are asked how they feel about how well they are) and objective wellbeing (which takes account of basic human needs, such as food, shelter etc.).

Definitions such as the above demonstrate that there are a number of different pillars underpinning wellbeing. Among the most commonly mentioned elements of wellbeing are emotional wellbeing, mental wellbeing, physical wellbeing, social wellbeing (relationships and family life) and economic wellbeing. The relationship between these elements is important. For example, losing one’s job (economic wellbeing) can have a bearing on social wellbeing (pressure on relationships) and emotional wellbeing (stress). Wellbeing is also therefore best understood as a process that is dynamic which is fed by interaction between the various components (Foresight, 2008). Figure 2.1 shows how the relationship between those different types of wellbeing can be modelled.

Figure 2.1 Relationships between different types of wellbeing



2.1.2 Mental wellbeing is a particularly important element of wellbeing

One of the most important elements in the definitions above is mental wellbeing (where the UK is below the EU average, ranking 20th of 27, as identified in the European Quality of Life Survey Report (2012)). This aspect of wellbeing was the subject of the Foresight review on

mental wellbeing in 2008 (Foresight (2008)). This landmark review found that mental wellbeing is not the same as treating or preventing mental illness. Rather, it captures the dynamic nature of mental wellbeing mentioned above.

Building on this, the NEF (2008) synthesised the evidence on achieving mental wellbeing. They presented five steps (partly as an analogy with the ‘five a day’ message for healthy eating) that could improve mental wellbeing. These steps were:

1. **Connect** – the building of relationships;
2. **Be active** – engaging in physical activity;
3. **Take notice** – awareness of personal feelings;
4. **Keep learning** – intellectual development; and
5. **Give** – community involvement or volunteering.

The relationship between mental and physical wellbeing has also received research and policy attention. While it is known that emotional wellbeing can have a bearing on physical wellbeing (for example, stress causing digestion problems), there is also evidence of a relationship in the opposite direction (Harvard Medical School, 2013). In an effort to examine this relationship, there have been moves to determine an appropriate measurement scale to determine how health interventions can impact on individual wellbeing. The Warwick Edinburgh Mental Wellbeing Scale (WEMWBS) (2008) is one such example.

The importance of mental wellbeing as a policy concern in healthcare is particularly evident in the case of LTCs such as heart disease, cancers and asthma, which are not ‘cured’ but managed over time. Research has shown that people who have a LTC experience greater levels of depression and anxiety (Chapman, Perry & Strine 2005 or Sederer, Silver and McVeigh 2006), poorer clinical outcomes and quality of life (Naylor, Parsonage, McDaid, Knapp, Fossey and Galea 2012) as well as poorer experience of care (Quality Health 2013). We discuss how this is relevant to people with cancer, particularly men with prostate cancer, in the next section.

2.2 Men with prostate cancer have a particular set of mental wellbeing needs

In this section, we discuss the mental wellbeing needs of men with prostate cancer. First, we discuss wellbeing needs common to people with cancer. Then we examine the characteristics of men’s attitudes to mental wellbeing. Following this, we then provide an overview of the wellbeing needs of men with prostate cancer as identified by the literature and the scoping interviews.

2.2.1 Cancer is increasingly experienced as a long-term condition; this implies greater consideration of support to address mental wellbeing

Cancer is now frequently experienced as a LTC: 51% of people diagnosed with cancer survive for five or more years; 45% survive for 10 or more years (Cancer Research UK 2014). Cancer survivors can be left with a range of physical, psychological and social needs; some may also need long-term monitoring to detect recurrence. Considering cancer as a LTC implies taking account of the wellbeing needs typical of such conditions.

The majority of cases of depression among people with LTCs go undetected and untreated (Katon 2003). Although fewer cases of depression are reported in men compared to women, it is likely that depression and anxiety is diagnosed later in men when it has a greater negative impact (Forlani, Morri, Ferrari, Dalmonte, Menchetti, De Ronchi and Atti 2013). Only a third of people with cancer actually discuss the emotional impact of the diagnosis with their healthcare professional (Bonito, Horowitz, McCorkle & Chagpar 2013).

There is an extensive literature addressing the wellbeing needs of cancer patients. Most frequently cited unmet needs related to activities of daily living, psychological and informational (Harrison, Young, Price, Butow and Solomon 2009). These needs were corroborated in other research by Macmillan (2006), which found that the physical side-effects of cancer were regarded as being difficult to cope with as “keeping things normal” in

the patient's family. The needs of families of cancer patients were also identified as being important by Adams, Moulton and Watson (2009): being diagnosed with cancer put pressure on one's relationships with family members.

Other, more specific, findings in the literature include:

- Hack et al (2005) found that cancer patients continue to have unmet communication needs, and communication outcomes are enhanced when physicians attend to the emotional needs of patients;
- McDowell et al (2010) found that 21% of people with cancer will also experience depression, particularly those with more advanced cancer;
- Macmillan (2014) found that 22% of people diagnosed with cancer suffer with loneliness as a result of their cancer;
- Chapman et al (2005) found that if unmet needs are not addressed early on, they can persist over time giving rise to psychological needs later in the cancer trajectory; and,
- Macmillan (2011) found that where these issues are not addressed, mortality rates can be higher.

The above findings underline the importance of addressing psychological support needs.

2.2.2 Men face specific barriers in accessing support

While cancer patients do have particular wellbeing needs, men's attitudes to wellbeing and psychological support help to distinguish the needs of men with prostate cancer. Such needs must be viewed in the context of more general issues men face when interacting with health care systems. For example, the Wilkins (2008) report on gender and access to healthcare found that, for men, there were potential tensions between masculinity and asking for the relevant and necessary psychological help (Department of Health and Men's Health Forum (2008)). This was something found by Bloch et al (2007) in their review of the literature, especially in the case of those diseases with low morbidity rates. Men feel that admission of personal difficulty is a "sign of weakness." As such, those wellbeing services targeted at men must take account of the barriers to men in accessing support and the types of support they favour.

There is evidence to suggest that men are not as comfortable at addressing their mental wellbeing needs as women are. For example, in Britain, women are more likely to have been treated for a mental wellbeing problem than men (29% compared to 17%) (ONS 2003), while men are three times as likely to commit suicide as women are (Mental Wellbeing Foundation 2013).

It is worth noting that some studies have found that men will often rely almost entirely on their spouse or partner as their main source of support when addressing their wellbeing, whereas women might have a greater variety of potential sources (Bloch et al. 2007). This tendency to rely on a spouse has consequences for single men in particular, as it means they are particularly vulnerable to psychological issues. In terms of men's attitudes to general wellbeing services, Ipsos Mori (2012) found a particular dislike for group support services among men, unlike women.

In the interviews with healthcare professionals and stakeholders, men's attitudes to health and wellbeing in general were discussed. Overall, they argued that men do not attend to their wellbeing in the same way which women approach it. Moreover, men generally feel that they have a particular role to play in their family and must tend to the wellbeing of others without tending to their own (*"Men have been conditioned not to cry"*).

This limits the scope for addressing the 'wellbeing needs' of such men because, in some cases, men do not identify that they have any such needs. Some respondents stated that this perceived difficulty with men accessing their wellbeing needs should be construed as a wellbeing need in its own right.

Some interviewees cited generational differences. They stated that men can differ in this regard. Older men, in particular, are more likely not to acknowledge the need to address

their wellbeing while younger men are more receptive to it. These respondents expressed caution in adopting a general approach to diagnosing men's wellbeing needs / likely access to services.

2.2.3 Men with prostate cancer have specific wellbeing needs

While we have identified the mental wellbeing needs experienced by cancer sufferers and have also looked in particular at the barriers which male patients experience in accessing support, there is also a set of mental wellbeing needs that are specific to men with prostate cancer. These needs vary by 'type' of man, but there are some common needs identified in both the document review and the scoping interviews.

Men with prostate cancer have a number of physical and psychosocial needs, as found by Eton & LePore (2002). Psychological distress, depression and anxiety are particularly present, and debilitating, among men no longer being treated. For example, Ream et al (2008) found that 72% of men reported a need for psychological care, and 82% reported some depression or anxiety. This high level of reported distress is particularly significant given the general under-reporting of psychological distress by men as stated by Bloch et al (2007).

The most common needs identified are presented in Box 2.1. This is not an exhaustive list but is indicative of the types of wellbeing needs perceived by respondents and identified from the literature. One noticeable pattern is that there is no stable set of wellbeing needs, but rather that needs differed at different stages for many reasons for different types of men. As such, wellbeing is not something to be treated or addressed at any one stage but should be addressed as part of the overall treatment pathway.

Box 2.1 Wellbeing needs of men with prostate cancer identified by respondents

- **Anxiety:** One of the impacts on men following a diagnosis of prostate cancer is a general sense of anxiety about what the future holds. This can range from anxiety about survival to anxiety about potential recurrence to anxiety about the effect that the diagnosis will have on the man's family.
- **Loss of libido and sexual function:** Erectile dysfunction is a consequence of some treatments. The associated loss of libido and sexual function is distressing for many men and contributes to a lessening of a man's sense of masculinity.
- **Impact on relationships (spouse and/or family):** One common pattern among the wellbeing needs is the impact that a diagnosis has on family members. Men may feel a need to shelter their family from the diagnosis and they worry that they have become a burden to their family.
- **Isolation:** Men can feel isolated when diagnosed with prostate cancer. A number of reasons can explain this. For example, the clinician dealing with them may not be aware of the effect of the diagnosis on their wellbeing or men simply can fail to recognise that they have wellbeing needs and are unable to discuss or express emotional distress.
- **Depression (dealing with mortality):** Men with prostate cancer experience depression after diagnosis.
- **Mood swings:** Hormone therapy can give rise to mood swings which are distressing for men.
- **Loss of masculinity:** Men often feel emasculated as a result of treatment for prostate cancer, generally because of hormone therapy. The loss of testosterone contributes to feeling 'less manly'.
- **Negative self-image/low self-esteem:** Low self-esteem is often a need identified in men that have prostate cancer. It can be as a result of the combination and interaction of other wellbeing needs.
- **Stigmatisation (as a result of physical side-effects):** As a result of the treatments

which men undergo to treat their prostate cancer, there can be a number of physical side effects which are distressing to men, such as incontinence. These bring with them a stigmatisation that is difficult for men to handle.

- **Abandonment:** Men diagnosed may feel abandoned and feel without an outlet to share their fears and concerns. This can happen at any stage of the cancer trajectory. For example, there is often a perception that when men have completed treatment, they are 'better' and there is no need to be concerned about them. However, the fear of recurrence is a source of worry and without an outlet to voice this fear, men can feel abandoned (often referred to as "falling off a cliff").
- **Stress (financial and practical worries):** Men who are diagnosed with prostate cancer and need to attend treatment will worry about the financial consequences of being diagnosed. For example, a man who is self-employed may lose his company because of treatment, or a man who lives in an isolated area may have the stress of having to deal with transporting themselves to and from the treatment centre.

2.2.4 Different 'types of men' have different needs

As stated above, the wellbeing needs of men with prostate cancer can vary by "types" of man. In particular, different needs for minority and difficult-to-engage groups of men with prostate cancer were identified. These groups are as follows:

- **Minority ethnic groups:** Under this heading, respondents mentioned the higher incidence of prostate cancer among men in Black African and African-Caribbean communities in particular. Respondents stated that the close-knit nature of such communities was such that it meant that there was little awareness around the wellbeing needs of men in these communities, but this is consistent with the attitudes of men in these communities to health and mental wellbeing needs in particular. Some respondents mentioned that issues around erectile dysfunction and incontinence in particular can carry extra stigma in minority ethnic communities. However, a few respondents said that a positive aspect of such communities was the fact that they were so close-knit and that informal support networks existed for men with prostate cancer.
- **Socially disadvantaged men:** Generally, respondents felt that the needs of men in this group were related primarily to the stress associated with the practical and financial consequences of prostate cancer, e.g. not being able to get time off work for treatment. A few respondents pointed to the fact that men in this category often have difficulty with literacy or lack confidence. This can create extra barriers for them in engaging with their health needs, let alone needs relating to wellbeing.
- **Gay and bisexual men:** This group was also identified by a number of interviewees as a particular group with bespoke needs. One barrier faced by men in this group is in disclosing their sexuality to healthcare professionals which compounds the fact that their wellbeing needs are not addressed.
- **Single men / men with no families:** This group was identified by a number of respondents. The traditional view of men with prostate cancer being supported by families does not apply in this case. Such men who live on their own or have no support network require extra support in addressing their wellbeing needs.

2.2.5 Wellbeing needs change according to the stage of the 'cancer journey'

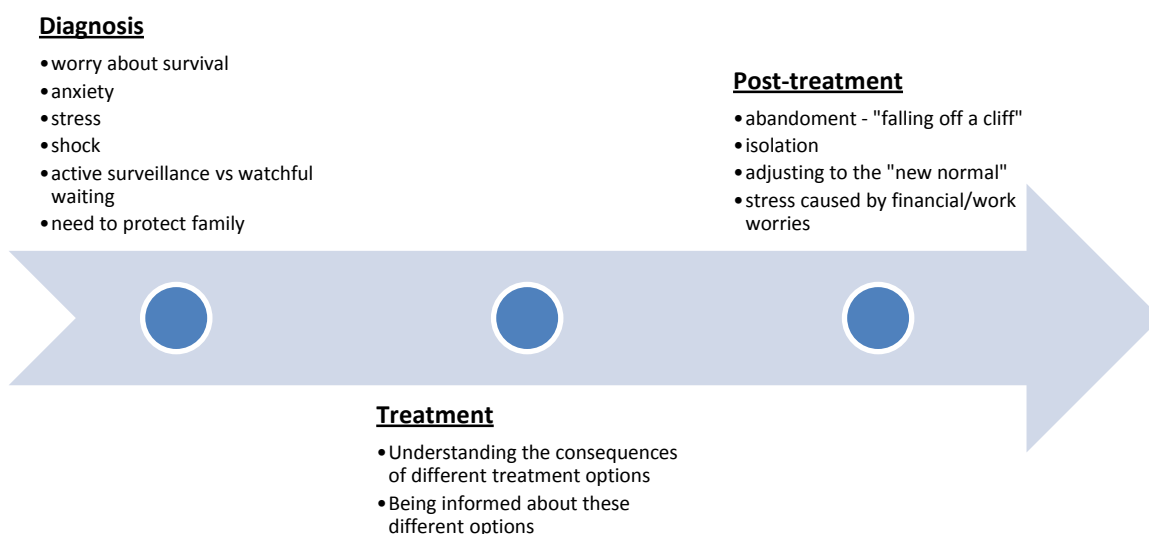
When the specific wellbeing needs of men are taken into account, combined with the needs that arise from living with cancer as a LTC, the needs particular to men with prostate cancer become apparent. The main features of these needs are summarised below.

Wellbeing needs change as men move from diagnosis to treatment and into follow-up. There was broad agreement on the nature of these needs at each stage. However, one need which was identified as being consistent throughout the trajectory was the need for information and to ensure that men were kept as informed as possible about the possible choices and consequences facing them at each stage.

In general, the needs identified at each stage are as follows (summarised in Figure 2.2).

- **Diagnosis:** Men have particular needs at the point of diagnosis. Commonly cited emotions when first diagnosed include anxiety, sadness, anger and confusion. The word “cancer” has a number of connotations that cause significant anxiety to men and this is informed by the interpretation that the patient has of the word itself. As one respondent put it – *“when men hear the diagnosis of cancer, they immediately enter the gloom tunnel”*. Therefore, the most important wellbeing need at this stage is the need for men to deal with the anxiety and apprehension experienced on diagnosis. Men react to this in different ways. In the scoping interviews, some respondents felt that wellbeing concerns are secondary to the shock at diagnosis or are displaced by concerns around survival – the dominant concern for such men is to remove the cancer without considering the consequences or alternative treatment options. Others felt that older men especially acted to protect their families from the consequences of the diagnosis and did not discuss their feelings.
- **Treatment:** Wellbeing needs that arise during treatment depend on the particular treatment path chosen. For example, Couper, Love, Dunai, Ducjesne, Bloch, Costello and Kissane (2009) found that there are significantly higher levels of depression during treatment, specifically hormone therapy. Men with prostate cancer also use more antidepressants than any other cancers (except breast cancer) suggesting that depression during treatment particularly affects men and suggests that they possibly prefer medication to other forms of talking therapies (Khan, Ward, Watson and Rose, 2010). As such, the majority of interview respondents felt that it was important for the patient to be given as clear and as realistic an explanation as possible of the consequences of the particular treatment options. A further point made was that the extent of wellbeing needs can be determined by the length of time between treatment and diagnosis. During this time, men can feel alone without a regular outlet to articulate their fears or concerns or to ask for information.
- **Post-treatment:** one aspect of wellbeing needs in the post-treatment phase is the perception that men feel “they have fallen off a cliff”. As one respondent put it – *“people think that once you’ve had the treatment, that’s it – you’re better”*. Given the understanding of prostate cancer as a LTC, and that men now live with the condition and side effects of treatment for years, another need clearly identified by respondents was the need to assist these men adjust to a post-treatment ‘new normal’.

Figure 2.2 The cancer trajectory – examples of the change in wellbeing needs



2.2.6 Treatment affects wellbeing needs

Treatment options can also give rise to different wellbeing needs because of the different physical side effects to which they give rise. Treatment is also important because evidence suggests that men with prostate cancer are less than satisfied with the care they received after treatment. A study carried out by Ipsos Mori (2012) showed that only half of prostate cancer patients reported that they had a "very good" or "excellent" service after treatment (53%) compared with two in three (66%) colorectal cancer patients and three in five (61%) breast cancer patients.

Studies such as Ream et al (2008), Courtenay (2000), Traegar et al (2009) and Helgason et al (1998) have examined the supportive care needs generated by the side effects of treatment. Table 2.1 describes such treatments, as well as the side effects which they give rise to and the resultant wellbeing need.

One thing that is apparent from Table 2.1 is the bearing that physical symptoms have on mental wellbeing. As one example, a prostatectomy can give rise to incontinence. A result of this is that there can be feelings of social isolation ("he's afraid to go out with friends in case he gets caught out") or stigma ("don't want to smell bad"). According to the results of the *Quality of Life of Cancer Survivors in England* survey (Department of Health, 2012), 38.5% of prostate cancer patients report some degree of urinary leakage and 13% reported difficulty controlling their bowels.

Surgery, like radiotherapy, can also lead to erectile dysfunction. One consequence of this is the loss of libido for men. Men feel less masculine and find their partners less desirable. One respondent described how this affects partners – the lack of sex is not what affects the relationship but rather the fact that men do not find them sexually desirable. In the same survey, 58% of prostate cancer patients reported they were unable to have an erection, and a further 11% claimed difficulty having, or maintaining, an erection.

Hormone therapy as a treatment is described by respondents as making men feel less masculine, which in turn gives rise to low self-esteem. As a result of the lack of testosterone, men have a negative self-image which also adversely affects wellbeing.

These side-effects must also be considered holistically. One can affect the ability to cope with another: men experiencing depression or anxiety can be much more likely to struggle with daily living tasks and the management of lower urinary tract symptoms (LUTS), as Ream et al (2008) showed. Furthermore, Blank and Bellizzi (2006) found that different personality types influence wellbeing, with optimistic personalities tending towards higher levels of wellbeing and ability to cope.

Also, one respondent drew attention to the fact that the relationship between treatment, side-effect and wellbeing is not one-way. Negative mental wellbeing can manifest itself as a physical symptom. For example, anxiety may manifest itself as diarrhoea in a man that is awaiting news about a diagnosis or recurrence.

Table 2.1 Examples of wellbeing need arising from different types of treatment

| Treatment type | Side effect | Implied wellbeing need |
|-----------------|-----------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------|
| Prostatectomy | Pain, impotence and incontinence. | Stigma from incontinence Lack of masculinity Loss of libido Impact on relationships |
| Brachytherapy | During treatment: LUTS. Long-term: LUTS and impotence. | Stigma from incontinence Stress |
| Radiotherapy | During treatment: inflamed bladder and bowel, tiredness, soreness and loss of hair. Long-term: LUTS, impotence. | Stigma from incontinence Stress |
| Hormone therapy | Vary from drug to drug (depending on the type of hormone given). Common side effects include impotence, hot flushes, breast | Loss of masculinity Low self-esteem Negative self-image |

| Treatment type | Side effect | Implied wellbeing need |
|----------------|-----------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------|
| | tenderness, tumour flare pain. Longer-term might include weight gain, memory problems, depression, osteoporosis and increased risk of heart attack. | Depression |
| Orchidectomy | Hot flushes, impotency. | Loss of masculinity Low self-esteem Negative self-image Depression |
| Chemotherapy | During treatment: tiredness, low numbers of blood cells, nausea, hair loss, infertility. | Negative self-image Lack of libido Lack of masculinity |

Physical side effects are not the only side effects that should be considered. Certain treatments may be particularly time-consuming or may require extensive travel which increases the cost of receiving these treatments. These practical concerns can cause stress which adversely affects wellbeing, though not as a result of a physical symptom.

In discussing treatment options, interview respondents stated that it was important that the treatment should not be seen as a self-contained activity and that information about the consequences of the treatment choice was an extremely important need in its own right. Some respondents expressed the view that, in the case of some consultants in particular, the focus was on “treating the cancer” rather than “treating the man”. Also, having access to information as shown by Dale et al (2004) results in a situation where the experience men have of cancer services is enhanced, especially in the case of younger patients (Davison et al 1997). This is especially so, given a study by Clark et al (2001) that suggests men can regret the treatment options chosen, which in turn has a negative bearing on their wellbeing.

2.3 Wellbeing is a growing priority within health and social care policy

In this section, we offer a brief overview of where wellbeing sits as a component of health and social care policy in the UK. We also discuss the extent to which wellbeing services for men with prostate cancer are part of this policy approach. We then examine the role of wellbeing in each of the UK nations, especially in terms of health and social care policy.

As mentioned above, wellbeing policy is a priority that has been identified by the Department of Health (2014) in the broader health and social care agenda. This year, the Department of Health presented an overview of the importance of wellbeing policy in terms of improving public health. Cited benefits of improving mental wellbeing included:

- The resulting increase in life expectancy;
- The role it plays in assisting recovery from illness;
- The association with positive health behaviours in adults and children and broader positive outcomes;
- The implications for how staff and health care providers work and the design of local services; and
- The implications for patient care and treatment costs and the ultimate reduction in the healthcare burden.

In terms of reducing the overall cost of healthcare, there is logic in addressing wellbeing needs earlier in the cancer trajectory. A study by Naylor, C., Parsonage, M., McDaid, D., Knapp, M., Fossey, M., & Galea, A. (2012) has shown that between 12 and 18 per cent of NHS expenditure on treating and managing LTCs is associated with addressing poor mental wellbeing and wellbeing.

Steps have therefore been taken to address this. For example, the development of National Institute for Health and Care Excellence (NICE) guidelines on depression and LTCs, and the introduction of access to more psychological services (Improving Access to Psychological

Therapies (IAPT)) where some of these specialise in LTCs. In addition, some hospitals provide psychological oncology services or access to clinical health psychology services. However, these services vary according to regions and hospitals and further evidence is required to evaluate any inequalities that may exist. Furthermore, services are not specific to cancer or prostate cancer (or even men) where there may be more specific needs.

A further example of the national emphasis now being placed on improving mental wellbeing is evident in the NHS mandate where a need to address the mental and physical health care needs of people with LTCs is identified, particularly where these services are currently not integrated to meet all health care needs (NHS England 2013). This emphasis was echoed in NHS England's (2013) paper *The NHS belongs to the people: a call to action* which committed the NHS to support people with a LTC in self-managing their condition, thus improving their own wellbeing.

In terms of the provision of services to those people who have a LTC in the form of cancer, several charities and other organisations have been at the forefront of helping patients address their mental wellbeing. This can take the form of information booklets or support services. For example, Macmillan¹ offers advice and onward referrals (such as to the Samaritans) for those experiencing depression/anxiety and who feel they would benefit from counselling. Cancer Research UK² also provides information on counselling and offers support and onward referrals. Rethink Mental Illness³ has also produced a factsheet which details physical health and mental wellbeing conditions. However, it is worth noting that such support services can be applied to all cancers which are LTCs and do not specifically relate to prostate cancer.

2.3.1 In England there is an emphasis on wellbeing; institutional arrangements are 'bedding down'

In England, policy is set out in *Improving outcomes: a strategy for cancer* (Department of Health, 2011). It sets an aim of reducing the proportion of patients with unmet psychological needs after treatment (acknowledging the scope for savings as a result of putting such services in place). The extent of institutional reform is worth noting here also, as the main contextual point of note. This includes breaking up the National Cancer Programme and the replacement of Cancer Networks with a smaller number of Strategic Clinical Networks addressing several clinical areas. Additionally, cancer commissioning has been transferred from Primary Care Trusts (PCTs) to Clinical Commissioning Groups (CCGs) and/or NHS England (in the case of particularly specialist services, such as services targeted at men with prostate cancer). It is unclear what effect this change will have for the provision of wellbeing services in particular.

One of the key developments in recent years, especially in terms of the wellbeing agenda, has been the introduction of the National Cancer Survivorship Initiative (NCSI). The NCSI was established in 2007 as an initiative between by the Department of Health and Macmillan Cancer Support, with significant support from NHS Improvement (NCSI 2013). The main objective of the NCSI was to establish and improve the evidence base in survivorship and to put in place a forum to advance and advocate survivorship. As part of its work, the NCSI recently published a report setting out a number of initiatives to improve the survivorship experience for cancer survivors, such as the need for a holistic needs assessment at diagnosis to identify the needs of men with prostate cancer, a treatment summary for GPs that informs them about how far progressed on their treatment journey the patient is or promotion of health and wellbeing events. Additionally, the NCSI also ensured that there were survivorship questions included in the National Cancer Patient Experience Survey which can be used to measure standards and identify the needs of men in England and therefore drive improvements.

¹ <http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Emotionaleffects/Depression.aspx>

² <http://www.cancerresearchuk.org/cancer-help/coping-with-cancer/coping-emotionally/talking-about-cancer/counselling/how-counselling-can-help>

³ <http://www.rethink.org/get-involved/campaigns/20-years-too-soon/facts-physical-and-mental-health>

2.3.2 Policy in Northern Ireland emphasises access to psychological support

Northern Ireland has a slightly different structure to the other devolved nations – the Health and Social Care Trusts combine both health and social care. The key player there is the Northern Ireland Cancer Network; and strategy is predominantly framed by the 1996 *Cancer Services: Investing for the Future*, as well as the more recent Cancer Control Programme (2008). Building on this is Service Framework for Cancer Prevention, Treatment and Care which prioritises the recommendations coming out of the Cancer Control Programme (Department of Health, Social Services and Public Safety (DHSSPS), 2011). It identifies three priorities for improvement in services for people living with cancer:

- Improving access to psychological support;
- Providing new models of follow-up, which focus on health and wellbeing; and
- Improving access to rehabilitation to assist in recovery.

While the Service Framework mentions standard targets for prostate cancer treatment, there is no explicit commitment around wellbeing services.

2.3.3 In Scotland there is an emphasis on holistic needs, including wellbeing

Cancer policy in Scotland is driven by *Better Cancer Care, An Action Plan* (2008), overseen by the Scottish Cancer Taskforce (Scottish Government, 2008). One of the sections in this strategy addresses wellbeing needs and living with cancer. Among the priorities identified are:

- Psychological support for cancer survivors;
- Supporting family and friends;
- Financial advice and assistance; and
- Providing information and communication for patients.

In June 2013, the Transforming Care After Treatment (TCAT) programme was launched. TCAT is a partnership between the Scottish Government, Macmillan Cancer Support, NHS Scotland and local authorities to support a redesign of care following active treatment of cancer (Scottish Government, 2013). One of the pillars of this plan is to give people affected by cancer more support in dealing with the physical, emotional and financial consequences of cancer treatment. However, like other parts of the UK, there is little by way of wellbeing services specifically targeted at men with prostate cancer.

2.3.4 In Wales patient-centred care is taken to include support for wellbeing

Cancer policy in Wales is framed by *Together for Health, Cancer Delivery Plan for the NHS to 2016* (2012). It identifies five outcomes, one of which is that people are placed at the heart of cancer care with their individual needs identified and met so they feel well supported and informed, able to manage the effects of cancer.

Wellbeing services for cancer patients fall under this category and there is specific mention of the tailoring of services to the needs experienced because of cancer. Cancer Network Patient Forums are examples of this and emotional wellbeing is one of the areas that these networks cover. However, wellbeing services for men with prostate cancer are not specifically mentioned.

2.4 Provision of wellbeing services appears to be very patchy

Respondents were asked to speak about where they felt gaps existed in the delivery of wellbeing services for men with prostate cancer, geographically and in terms of the type of service made available and whether such a service was tailored specifically to the needs of men with prostate cancer.

2.4.1 There are some general patterns in the delivery of services

There was agreement among respondents that coverage across the country, in terms of wellbeing services, was patchy and inconsistent. We explore the reasons for that in 2.4.3, but there were some features to this inconsistent provision identified by correspondents:

- Rural areas, in general, can have a dearth of wellbeing support services. Urban areas generally seem to have better provision – for those men in rural areas, there is expense and difficulty in accessing even the lowest level of psychological support;
- This is not something that is particular to prostate cancer. While there is a broader range of wellbeing services for people with cancer, there is still a degree of inconsistent provision;
- The medical model of treatment inadvertently puts an emphasis on physical wellbeing rather than mental wellbeing;
- Where wellbeing services are integrated or anchored with a hospital, they are more likely to be successful in their coverage and sustaining themselves; and
- Where wellbeing services are available to patients of all cancers, women are more likely to engage with them than men.

2.4.2 There is a high degree of variability in the type or service provided; take-up also varies greatly

Respondents generally agreed that while provision of wellbeing services to men with prostate cancer was patchy, there was also huge variation in the level of services available that were bespoke to men with prostate cancer. The most significant characteristic identified by respondents in determining how to “target” a service at men with prostate cancer involved sensitivity in how to make the initial offer to men.

Examples of services that are provided specifically or tailored to men with prostate cancer included:

- “Men in sheds” – these are hobby workshops for men who want to get together and share or learn new woodworking skills, however, they can be tailored to men with prostate cancer and provide an opportunity to bond with other men and to gain medical advice if required;
- “Pub evenings” – where men come together in an informal setting to discuss the effect of prostate cancer. There is no compulsion to discuss prostate cancer but the big draw of such an initiative is the environment in which it is held;
- Peer support groups – where men who have prostate cancer come together to discuss the consequences of treatment and other issues related to their wellbeing;
- Psychosexual counselling – counselling designed to help men who have suffered a sexual impact as a result of their prostate cancer;
- “Living well” courses – courses designed to support men who have been diagnosed with prostate cancer in their physical, emotional and spiritual health; and
- Outdoor adventure programmes – outdoor residential courses where participants embark on an “adventure”. They are designed to help men address the emotional impact of prostate cancer, but in a non-traditional setting.

However, like other wellbeing services for men, the take-up of such services varied – primarily because of men’s attitudes to health and wellbeing.

2.4.3 Interviewees cited several explanatory factors for variations in service availability / access

Respondents offered a number of reasons in order to explain why there is such variability in the provision of both wellbeing services and wellbeing services specifically targeted at men with prostate cancer. These reasons included:

- **Resources:** pressure on resources in the NHS means that the priority is to focus on physical wellbeing, given the relative ‘newness’ of wellbeing as a priority for health services across the UK. Also, for the voluntary sector, a lack of resources means that provision cannot be expanded.
- **Clinicians’ awareness:** the variation in awareness among clinicians of wellbeing needs. Some clinicians are better than others in discussing wellbeing needs with men with prostate cancer. Medicine to address erectile dysfunction might be prescribed, but there will have been no opportunity to explore how the man feels about this.
- **Capacity:** while nurses and some clinicians are extremely keen to engage with wellbeing, there is no capacity for them to act as signposts for men who are seeking wellbeing services.
- **‘Medical model’:** treating medical symptoms rather than also taking account of holistic needs.
- **Profile:** Some respondents stated that prostate cancer has a low profile in the public sphere, which is further compounded by the fact that men have less interest in their wellbeing needs than women so there is less perceived awareness of their wellbeing needs.
- **Lack of strategic direction:** some respondents felt that provision of wellbeing services is “patchwork quilt” in nature. In some cases, there is no join-up between different services and awareness of what is available for patients rests on the institutional knowledge of professionals working in a certain area.

2.4.4 Routes in are a determining factor in up-take of services

For the most part, respondents felt that referral was the main route by which men accessed wellbeing services. There were some examples where self-referral was an option but these were generally for patient support groups and were not specifically targeted or directed at men with prostate cancer.

An important point noted by some respondents was that even where men are referred to such services, they see it as an optional extra. This aligns with the findings above in relation to men’s attitudes to wellbeing services. Usually, a partner or wife is important in ensuring that they access and engage with the wellbeing services.

For the majority of interview respondents, the role of the Clinical Nurse Specialist (CNS) can be critical in this case. If the CNS refers men to services, it is considered as an integrated part of treatment and access to it is not an optional extra. The majority of respondents agreed that where men had access to a CNS, this was a key factor in determining their awareness of wellbeing services. It also provided an avenue for men to ask questions about wellbeing services and to seek out a service that could cater to their particular needs.

A route to awareness identified by a few respondents was the role of family members and loved ones. One respondent with experience of a helpline stated that a significant minority of those people who sought information on wellbeing services were family members. Often, these family members would source the information and then act as a “persuader” to have the man engage with treatment.

Other routes by which men accessed information on wellbeing services identified by respondents included internet searches, attending information sessions with wives/partners and information provided by GPs.

In discussing awareness of wellbeing services, many respondents felt that the marketing of such services was a crucial factor in making men aware of these services and enabling them to engage with them.

2.4.5 Men from difficult-to-engage groups face additional barriers

In terms of the access and awareness of difficult-to-engage groups, respondents stated that access and awareness of services were greater challenges for these groups than they were for men in general. Reasons mentioned for this included:

- Difficulty with literacy and language ability;
- Fear of “officialdom”; and
- Lack of confidence.

There are examples of special initiatives or programmes that have been put in place to remove barriers to wellbeing services for these groups, including:

- Employment of a nurse/outreach worker of the same ethnic background to go into communities and highlight the services available;
- Examples of peer support groups that are exclusive to men of particular backgrounds. Respondents mentioned examples of support groups targeted specifically at black men or gay men.

There were mixed opinions as to whether campaigns targeted at ethnic communities in particular were successful, though the work done by organisations such as BME Cancer Communities and the Black Cancer Initiative was singled out by some respondents for mention.

2.4.6 Services are mainly provided by the voluntary sector

For almost all of the respondents (and also evident in the case studies), the main providers for men with prostate cancer come from the voluntary sector. Examples mentioned included the Prostate Cancer UK helpline, Penny Brohn Cancer Care and Prostaïd. In the case of smaller local groups, they may have a link with the local hospital which then provides a route for men to access those services.

While some examples of wellbeing services are provided by the NHS, these generally focus on physical wellbeing whereas voluntary sector providers had a substantial focus on mental wellbeing.

2.4.7 There may be some lessons from ‘other cancers’

For those respondents that did mention other cancers and whether or not there were lessons or approaches that could be used in the provision of services to men with prostate cancer, there were two main patterns that emerged. First, a number of respondents mentioned that the nature of men’s attitudes to wellbeing meant that wellbeing services had to be specifically targeted in order to engage with men so that makes comparison difficult. The second point noted was that while there are some wellbeing needs common across cancers, patients generally prefer to engage with people who have had the same experiences/treatments as they have had.

3 Case studies

3.1 Introduction

A case study-based approach was used to enable the collection of rich qualitative data and an in-depth analysis of the provision of wellbeing services.

This approach implies certain limitations. The main limitation is that, it is difficult to generalise from six case studies to offer a definitive picture of the situation regarding the provision of wellbeing services around the UK. We do not therefore claim that the analysis that follows is representative of service provision around the UK. However, enough material has been gathered to enable the identification of core themes and issues, which we draw out in Section 3.8.

In selecting the case studies, we identified dimensions of importance upon which to choose our sample. At the inception meeting, we agreed with Prostate Cancer UK that the two main dimensions of importance are:

- Urban-rural: this was primarily to explore issues of access and proximity of men with prostate cancer to wellbeing services; and
- Deprivation: this will allow exploration of general issues around access of services as well as addressing the needs of particular groups.

Using these two dimensions, the six case studies were distributed as shown in Table 3.1.

Table 3.1 Sample framework

| | Urban | Rural |
|--------------|-------|-------|
| Deprived | 3 | 1 |
| Non-deprived | 1 | 1 |

The allocation of case studies was also required to incorporate the important dimension of UK nations. The allocation of cases studies shown in Table 3.2 reflects this but also reflects the population size of each nation.

Table 3.2 Allocation of case studies across UK nations

| Nation | No. of case studies |
|------------------|---------------------|
| England | 3 |
| Scotland | 1 |
| Wales | 1 |
| Northern Ireland | 1 |

Having determined this allocation, we then used the document review and scoping interviews to identify a number of areas which would be useful as case studies. In asking the initial set of interviewees to identify case studies, we did not only request those areas where wellbeing service provision could be considered to be of a high standard, but also those areas where there was room for clear improvement.

Having taken all these considerations into account, as well as the dimensions of importance agreed with Prostate Cancer UK, we identified six case studies which are presented in Table 3.3. In arriving at these particular choices, we have sought to maximise variation across the four nations. For example, two of the urban case studies come from outside England.

Table 3.3 Case studies chosen

| | Urban | Rural |
|----------|--------------------------------------------------------------------|-------------------------|
| Deprived | Leeds (England) Bristol (England) Belfast (Northern Ireland) | Betsi Cadwaladr (Wales) |

| | Urban | Rural |
|---------------------|---------------------|-----------------------------------------|
| Non-deprived | Aberdeen (Scotland) | Cambridgeshire & Peterborough (England) |

In researching each of the case study areas, we followed a number of steps to produce each of the case studies which follow (though in a flexible manner, given the individuality of each area). These steps included:

- Analysis of key documentation including: any background which has emerged from the scoping research on that area; the key strategic documentation related to the provision of cancer care services in the area (e.g. Joint Strategic Needs Assessments (JSNAs), Commissioning Plans etc.);
- Up to 4 interviews with local stakeholders. The topic guide for these interviews is attached in Annex 5. These stakeholders included, but were not limited to:
 - A senior clinician focusing on prostate cancer follow up care (usually a clinical nurse specialist);
 - A community provider supporting men returning to the community after treatment for prostate cancer;
 - A commissioner / health service manager with responsibility in this area; and
 - Wellbeing services providers.
- Using these interviews to gain an understanding and provide an analysis of wellbeing services across a number of themes. As such, the themes explored include:
 - The degree to which wellbeing services in the area are available to men with prostate cancer;
 - Whether or not such wellbeing services are tailored to men with prostate cancer;
 - The degree to which harder-to-help groups, e.g. Black men, are targeted and engaged by wellbeing services providers;
 - The range of providers who provide these services and how they are commissioned; and
 - The factors affecting access to these services.

A full list of the sources consulted can be found in Annex 4. There was variation in the available information, which has resulted in a variation in the comprehensiveness of the results. This was usually associated with the provision of wellbeing services in an area, i.e. in areas where provision was considered to be well developed, there is likely to be more information available, and in areas where provision is less well developed, there is likely to be less.

3.2 Betsi Cadwaladr

Betsi Cadwaladr University Health Board (BCUHB) is geographically the largest in Wales. It provides primary, community, mental wellbeing and acute hospital services across all six counties in North Wales (Anglesey, Gwynedd, Conwy, Denbighshire, Flintshire and Wrexham). It also provides some services to the populations of mid-Wales, Cheshire and Shropshire.

Figure 3.1 Betsi Cadwaladr University Health Board Area

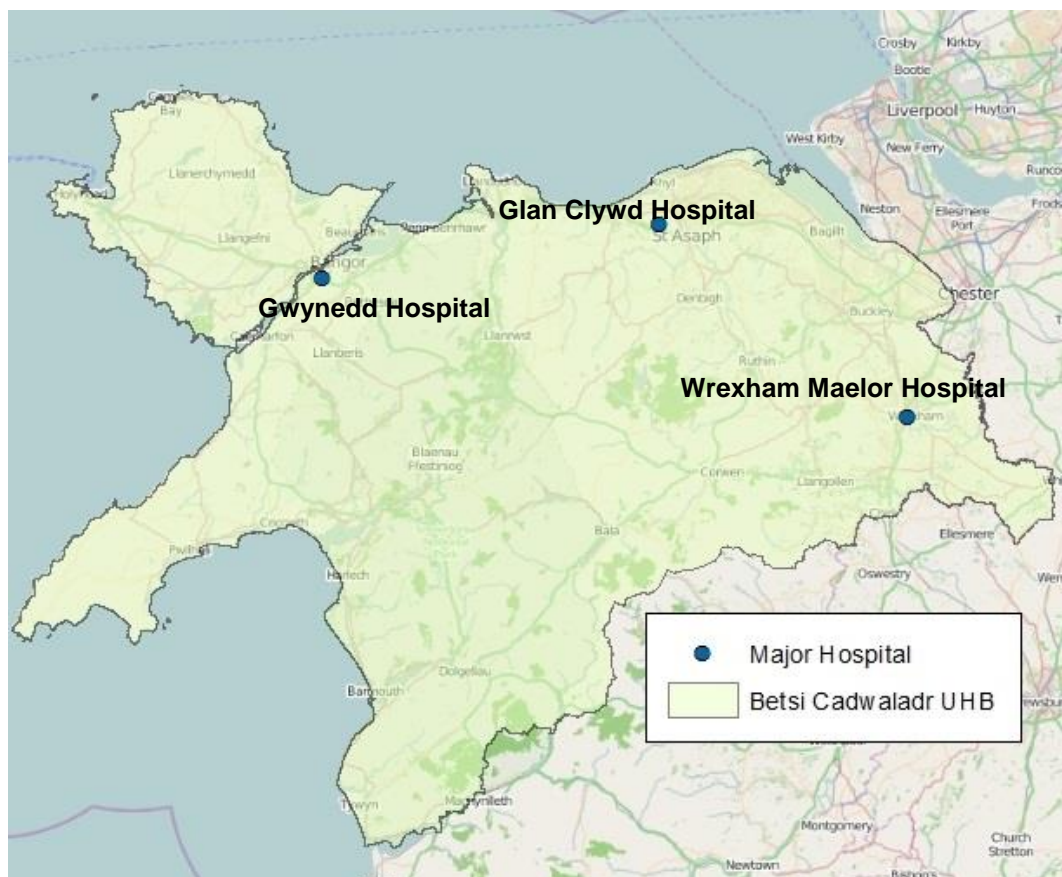


Table 3.4 shows the survival, incidence and mortality from prostate cancer for the Betsi Cadwaladr Health Board. BCUHB has a higher age-standardised incidence of prostate cancer than the UK as a whole, as well as a lower mortality rate and a higher one-year survival rate.

North Wales faces a number of key challenges to the delivery of cancer services. These relate to its rurality, coordination with services in England, and its workforce. Whilst 90% of North Wales’ population live in urban or semi-urban areas, the region is sparsely populated and people may have to travel long distances for treatment and follow up care (BCUHB 2012).

Indeed, whilst all three major hospitals in North Wales offer chemotherapy, radiotherapy is offered only at the North Wales Cancer Treatment Centre, Ysbyty Glan Clwyd, in Rhyl. Moreover, some specialised tertiary services (including brachytherapy) are offered in North West England. As well as imposing a travel burden on patients, this also makes the planning (including the coordination of care) and commissioning of services more challenging.

Lastly, North Wales (along with other more remote parts of the UK) faces challenges in attracting and maintaining its workforce, particularly beyond the main urban centres (BCUHB 2012).

Table 3.4 Summary of survival, incidence and mortality from prostate cancer (all age standardised)

| | Betsi Cadwaladr | UK average |
|-----------------------------------------------|-----------------|------------|
| Survival – one year (percentage) ⁴ | 97.2 | 93.5 |
| Incidence (per 100,000 population) | 113.9 | 104.9 |
| Mortality (per 100,000 population) | 22.2 | 23.8 |

Source: Welsh Cancer Incidence and Surveillance Unit: <http://www.wcisu.wales.nhs.uk/cancer-statistics>; UK figures from NCIN UK cancer e-atlas; and prevalence atlas

3.2.1 Wellbeing service provision in the region

Mental wellbeing needs of men in Betsi Cadwaladr

Interviewees in this area reported mental wellbeing needs broadly in line those outlined in the previous section. Areas which were particularly emphasised included:

- The need for reassurance, and the role other men can play in helping them to deal with this: *'it's that reassurance, and the realisation when they get there [to the support group] that there's lots of men in a similar position'; 'men don't talk... they turn up to a support group and are surprised to find that people they know are going through this too'*;
- Dealing with the side effects of treatment; particularly after treatment is finished. Interviewees suggested that many men *'don't really think about the side effects... and don't deal with it emotionally until after treatment... when they're thinking about getting back to normal'*.

There are also some issues specific to the area. One is the need for Welsh language services (particularly in western North Wales). Distance is also a challenge. This is a predominantly rural area, with services focussed in the Eastern and Central parts. The distances and transport links (particularly public transport) are therefore problematic (one interviewee gave the example of one man having to stay at his sister's house to attend a support group as there was only one bus a day). This is compounded by the fact that this is a relatively immobile population; some of the farming communities are quite isolated, particularly on Anglesey/Ynys Môn.

What services are available?

Interviewees reported a range of services available in this area; additional mapping information was also provided by the [North Wales Cancer Patient Forum](#). These services can be broadly split into: posts (including CNSs and Macmillan one-to-one community oncology nurses); services/units (including the three Macmillan information centres, and the Hospice Day Units); support groups (both prostate cancer specific and generic); more formal psychological support; and other services. These services are mapped in Table 3.5, with key aspects summarised below:

- Posts. Prostate Cancer CNSs are available in Wrexham and Bangor. In addition, Macmillan is currently running a one-to-one community oncology nurse pilot in the Wrexham and North Denbighshire area. These roles are designed to support people, in the community, to live with and beyond cancer; they offer emotional, practical, financial and medical support. Each post covers 8 or 9 GP surgeries. They mainly deal with low-level mental wellbeing issues, and have some formal training (for example basic cognitive behavioural therapy (CBT)).
- Prostate-specific support groups. There are five prostate-specific groups in the area, with wide geographical coverage. One group was spoken to for this study. They meet every three months, offering an informal arena for men to talk to others with similar experiences; some men will keep coming 5, 10, 15 years post-diagnosis, they find their

⁴ Survival (one year) percentage is defined as the proportion of men who have received a diagnosis of prostate cancer in the previous 12 months and who are still alive.

experiences can really help new men come to terms with their diagnosis. The group has around 40 active men, from right across North Wales. The group also offers individual house visits and support; for example, one woman rang up concerned about her recently diagnosed husband, a couple of group members went over for a meal *'she rang on the Friday, we went down on the following Monday... his son came up as well... he was in tears, we said don't worry too much, spoke about the treatments... and they all felt much better... and this man now comes to the meetings and speaks to others'*.

- Other, non-prostate cancer-specific support groups. There are a wide range of other support groups in the area, including some with specific target groups. Of particular note is a support group for men and women of working age (though this is in Chester, North West England); as well as one specifically for gay men (though, again, this is in North West England, not Wales). Interviewees suggested that gender-specific support groups tended to work better, *'sometimes it's quite difficult to mix the sexes'*. This can be for practical reasons, as well as emotional: *'men don't mind going back and having their meetings in the hospital – many are on watchful waiting so are used to going back there... whereas the women don't really want to go back there'*.
- There is some provision of more formal psychological support. This includes: a Tenovus (a charity) counsellor based in Wrexham; a group called Parable, run by the University Health Board (UHB)'s mental wellbeing team, which deals with low level needs via group therapy; plus access to CBT and mindfulness training, generally online. For more intensive needs there is a psychology service based in the local hospice. Relate counsellors are available for support with relationships during cancer. None of these services is prostate cancer specific, and all typically have waiting lists.
- There is some more informal / social innovative support. This includes choirs (again run by Tenovus), and walking groups. One walking group (run with the help of the Macmillan one-to-one nurse) has made attempts to appeal to more men by trying to do more woodcraft type activities; they currently have around 8 or 9 attendees to each session, of whom around 3 would be men.



Table 3.5 Summary of services in Betsi Cadwaladr UHB

| Service name, provider and sector | Summary description | Section(s) of pathway covered by the service | Awareness, Access and take-up | Points of learning / good practice |
|-------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Prostate Cancer CNS | Two CNSs (one a Prostate Cancer UK funded 18 month post), covering the Wrexham and Bangor areas. | Whole pathway, but mainly follow- up/ survivorship. | Access is only to men in Wrexham, and only for this 18 month period | The benefits of CNSs for patient experience are well established (e.g. see the National Cancer Patient Experience Survey) |
| Macmillan one-to-one community nurses | Pilot role designed to support people, in the community, to live with and beyond cancer; they offer emotional, practical, financial and medical support. | Whole pathway. | Covers Wrexham and North Denbighshire (two post holders). No one in Western North Wales. | Post-holders reported that the use of Health Needs Assessments (HNAs) are particularly beneficial, <i>'gives them [the patient] the permission to look at it, and you the permission to talk about it'</i> |
| Hospice Day Units | Five day units, in Gwynedd, Llandudno, St Asaph, Wrexham and Chester. Units offer support services including complementary therapies (e.g. acupuncture and massage), physiotherapy, practical and emotional support. | Whole pathway, including end of life and survivorship. | Not prostate cancer specific. Interviewees mentioned that some survivorship patients are unwilling to go to a hospice as it's associated with the end of life. | None noted. |
| Macmillan Information and Support Centres | Three information and support centres based in Glan Clywd, Wrexham Maelor and Gwynedd Hospital. | Whole pathway. | Centres are based in hospitals, so are convenient for men to access. Interviewees thought generally quite well accessed by men, including those with prostate cancer, but couldn't offer specific numbers. | Lack of CNSs means that fewer men are getting referred onto them. |
| Generic support groups | Eight generic support groups listed on the cancer forum website, throughout the region. These include groups for 'working age guys and girls', bereaved carers and Welsh language groups. Support offered includes informal meetings, walks and other activities. | Whole pathway. | Leaflets handed out to consultants, GPs and at hospitals. Via CNSs (where they exist) and Macmillan Information Centres. | Interviewees suggested that gender-specific groups work better (even if for different conditions), and can be tailored towards men <i>'so if doing relaxation, breath work... do it in a more masculine way'</i> . Try to make the service 'a day out' so they have found that basing the group in Bangor, rather than Carnavon worked better, as people could do other things that day. |
| Prostate cancer-specific support groups | Five prostate-specific groups, in all three regions. Offering a range of support services including informal meetings, walks and other activities. Two support groups were interviewed. One provides meetings alternate | Whole pathway. | Leaflets handed out to consultants, GPs and at hospitals. Via CNSs (where they exist) and Macmillan Information Centres. | Hold meetings in accessible areas, which are convenient for people to get to/ people can combine with other things (as above). Offer home visits, engage with wives/ partners. |



| Service name, provider and sector | Summary description | Section(s) of pathway covered by the service | Awareness, Access and take-up | Points of learning / good practice |
|------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------|------------------------------------|
| | months, including a wellbeing day, talks, and a wellbeing programme focussed on emotional wellbeing. | | | |
| Cancer psychology service | Specialist cancer psychology team specialising in people experiencing difficulties in coping with anxiety. | Whole pathway. | Access through referral through consultant, nurse or GP. | None noted. |
| Tenovus Counselling service | Tenovus cancer charity offers one-to-one emotional support. | Whole pathway. | Face-to-face counselling only available in Wrexham and Mold, though counselling is provided in other forms such as online counselling. | None noted. |
| Relate Counselling | Relate Cymru partnership with North Wales Macmillan Cancer Support, offering free relationship counselling to people affected by cancer. | Whole pathway. | None noted. | None noted. |
| Mindfulness Courses | 8-week courses in mindfulness meditation, offered in Gwynedd and Glan Clwyd. | Follow-up and survivorship. | Not prostate cancer specific. Interviewees suggested that ' <i>not for everybody</i> '. | None noted. |
| Expert Patient Programme Cymru | National self-management programme. | Follow-up and survivorship. | Not prostate cancer specific. Prior national evaluation showed take up predominantly well-educated women. | None noted. |
| Wales National Exercise Referral Scheme (NERS) | Exercise referral scheme targeting all people in Wales with a chronic disease, or who are at risk of a chronic disease. | Follow-up and survivorship. | It can be easier to engage men with exercise programmes – as it is less threatening than some other form of support. | None noted. |

3.2.2 Assessment of provision and lessons learnt

Assessment of provision in the area

The key issue in this area is the lack of prostate cancer CNSs. Currently, there are only two CNSs – one of whom is a Prostate Cancer UK-funded CNS covering the Bangor area (but this is only an 18 month post). Without a CNS men *have 'no key worker, no one supports them through radiotherapy or treatment, if they have a problem they have to call the consultant... unless patients come forward with problems they are probably not addressed'; 'it's that key person that they can contact and who will know about them'*. Without a CNS, patients are also likely to see lots of different health professionals, one interviewee stated that this can make it even harder for men to open up about issues (particularly when the professionals, as they often are, are female).

Even if patients have access to guidance and signposting, interviewees suggested that there were deficiencies in the services available. This gap related both to a lack of services, and services not being appropriately tailored: *'conventional services are not doing very well at all'*. Several interviewees mentioned the need for more innovative, less outwardly cancer-specific, services: *'if it's too medical or fluffy men just think it's not for me'*. One interviewee also suggested that nurses lacked the skills to deal with emotional problems, partly because *'there's a reticence to open up something that they can't do anything about [due to the lack of services to refer on to]'*. Where there are psychological support services (as outlined in 3.2.1), these tend not to be prostate specific, and all will have waiting lists.

Coverage of services throughout North Wales has improved, but remains patchy. This is particularly the case in the Western region of Betsi Cadwaladr, which as well as lacking a Macmillan one-to-one pilot nurse, also has more issues with the lack of Welsh-language provision. Whilst there are one or two Welsh language support groups, and some service provision in Welsh, there are gaps. One interviewee suggested that this lack of provision is particularly important for psychological support: *'there is quite clear evidence that people don't access services because they can't express themselves in their native language... and it is particularly hard to express feelings in a second language'*.

Access, and barriers to access, for men with prostate cancer in Betsi Cadwaladr UHB

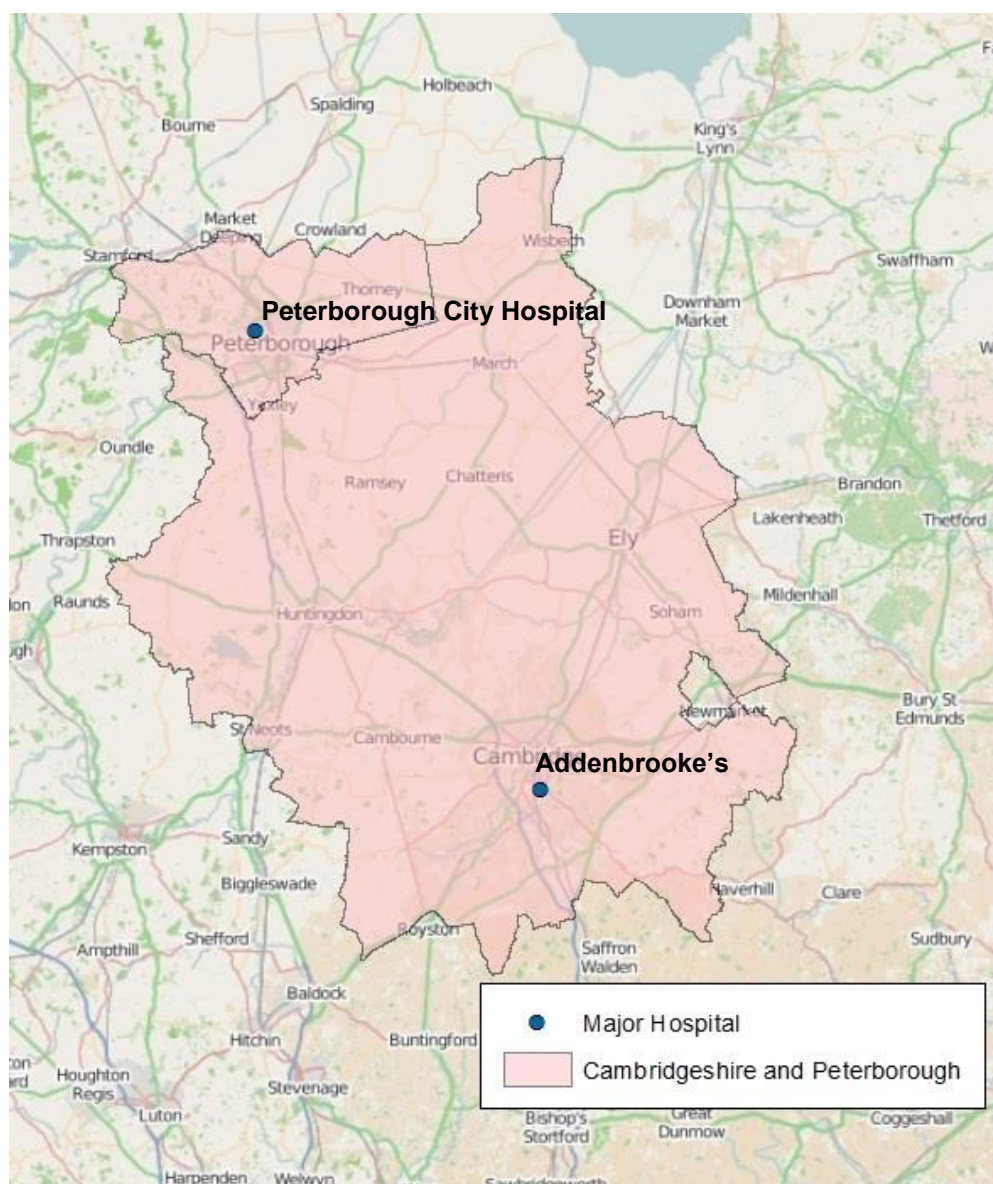
Access and awareness of services is a key problem in the area, primarily related to the lack of CNSs. Without CNSs, there is not always the knowledge and experience within secondary care to refer patients onto community services: *'generally they just go back and are quite lost... and feel very lonely'*. This can be compounded by men often not being in a state to take information in when in a urology clinic. There are similar problems within primary care, with GPs not always having comprehensive information on the services available (or the wellbeing needs of men). The area is fortunate to have an active cancer patient forum, with a comprehensive list of support services on its website; however, not all men will be willing / able to research services in this way.

Interviewees suggested that some services are more easily accessible than others. Emotional support and complementary therapies (such as acupuncture or massage) were mentioned as areas where *'men need a little bit more encouragement'*. Conversely, several mentioned the Prostate Cancer UK/Tenovus/Movember 'Man Van' as an example of good, innovative practice here. Programmes which were not explicitly about prostate cancer (for example exercise programmes, walking clubs, woodwork) were felt to be more accessible, with the caveat that: *'you still have to get people to the stage where they feel ok to go and join a walking group'*.

3.3 Cambridgeshire and Peterborough

The Cambridgeshire and Peterborough CCG area is a predominantly rural area in the East of England; the two largest cities are Peterborough and Cambridge. It is a relatively wealthy area, albeit with pockets of deprivation, particularly in Peterborough City and Wisbech; life expectancy in both is lower than the national average, with the gap widening for men in recent years. Both areas are predominantly White British (91% in Cambridgeshire and 86% in Peterborough), with a significant Pakistani minority in Peterborough (Menter 2005). In addition, both areas have relatively large veteran and gypsy/traveller communities; both these groups have poorer health outcomes, and face significant barriers in accessing services (Cambridgeshire County Council 2013; Peterborough City Council 2013).

Figure 3.2 Cambridgeshire and Peterborough



The area is covered by one CCG, made up of eight Local CCGs. There are two major hospitals: Addenbrooke's (in Cambridge, part of the Cambridgeshire University Hospitals NHS Foundation Trust) and Peterborough City Hospital (part of Peterborough and Stamford Hospitals NHS

Foundation Trust). Addenbrooke's, offers all services, including surgery and brachytherapy, with Peterborough City Hospital offering chemotherapy and radiotherapy only. Community services are provided by Cambridgeshire Community Services NHS Trust.

Incidence and survival of prostate cancer in both areas is significantly higher than the national average; mortality rates are in line with the national average (see Table 3.6).

Table 3.6 Summary of survival, incidence and mortality from prostate cancer (all age standardised)

| | Cambridge | Peterborough | UK average |
|-------------------------------------------------|-----------|--------------|------------|
| Survival – one year (percentage) ^{5,6} | 96.2 | 96.2 | 86.4 |
| Incidence (per 100,000 population) ⁷ | 120.4 | 138.8 | 104.9 |
| Mortality (per 100,000 population) ⁸ | 24.9 | 22.4 | 23.8 |

Source: NCIN UK cancer e-atlas; and NCIN prevalence atlas

3.3.1 Wellbeing service provision in the region

Mental wellbeing needs of men in Cambridgeshire and Peterborough

Interviewees reported that mental wellbeing needs in this area are broadly in line with the national picture, and particularly related to:

- Anxiety and need for support in deciding on treatment options: *'big dilemmas in treatment options... worrying about making the right decision, or wondering whether they've made the right decision'* (Macmillan information manager);
- General need for help to cope with a cancer diagnosis, *'many just think their life is ending'*. In addition, many need support readjusting following diagnosis and the end of treatment, particularly where there are significant side effects.

What services are available?

Prostate cancer patients in Cambridgeshire and Peterborough will be treated in one of two hospitals: Addenbrooke's in Cambridge or Peterborough City Hospital in Peterborough. Access to mental wellbeing services is largely shaped by their location of treatment (many wellbeing services are on the hospital sites), alongside where they live. The services provided are described in Table 3.7. Generally, the provision of services is better in Cambridgeshire (particularly in Cambridge itself) than Peterborough.

The main support centre in the region is the Maggie's Wallace in Cambridge. The centre offers practical, emotional and social support, provided in a home-like setting, *'focussed around the kitchen table'*. Support is offered for all cancers, throughout the pathway, and for carers. Support offered includes professional psychological support and counselling, workshops on a range of topics, in-house support groups, and informal emotional and social support.

In Peterborough, the main support centre is a Macmillan Information and Support Service, based in Peterborough City Hospital. The core role here is to offer information, advice, and signposting to other services. Whilst staff offer some informal emotional support and counselling, they don't have the formal support available at Maggie's: *'Maggie's is what we don't have in Peterborough'*.

⁵ Survival (one year) percentage is defined as the proportion of men who have received a diagnosis of prostate cancer in the previous 12 months and who are still alive.

⁶ Figures only available for the whole Anglia Network

⁷ CCG figures not yet available

⁸ CCG figures not yet available

There is only one prostate cancer-specific support group in the region, based in Cambridgeshire. Maggie's centre is also currently piloting a prostate cancer-specific group, led by a trained counsellor.

Other support services include:

- The day therapies service (Peterborough). Patients can be referred here to access support with anxiety management, CBT, and relaxation therapy. Patients must attend for an entire day;
- 'Moving Forward' courses are offered across the area. These courses are designed for people who have undergone treatment for cancer and are designed to help them with issues such as management of stress, anxiety, low mood and depression, relationships and healthy living, diet and exercise. This can be accessed by patients once treatment is complete, as a way to *'try to get back to normality'*;
- There are also a range of smaller, informal groups such as walking for health and local authority led walks, which patients would be signposted to, in accordance with their interests by Macmillan information service. U3A (University of the Third Age) also offers a way for people to identify activities in line with their interests;
- Patients can also contact their CNS with any concerns, *'they can access us very easily...we phone them back that day'*. This involves some informal emotional support, as well as advice and signposting to other services (such as dieticians, home support and occupational therapists).



Table 3.7 Summary of services in Cambridgeshire and Peterborough

| Service name, provider and sector | Summary description | Section(s) of pathway covered by the service | Awareness, Access and take-up | Points of learning / good practice |
|-------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Prostate Cancer CNS, Addenbrooke's and Peterborough City Hospitals, NHS | Offers a point of contact for men if they need emotional support, or have questions. Can also refer/ signpost on to other services. | Whole pathway. | Two prostate-cancer specific CNSs at Peterborough, 'several' at Addenbrooke's. Peterborough CNSs report being quite stretched. 71% of patients in Peterborough and 68% in Cambridge reported it was easy to contact their CNS (Quality Health 2012a; Quality Health 2012b). | The link between access to a CNS and improved quality of care is well established (National Cancer Patient Experience Survey 2012). CNSs expressed some frustration that they lacked the time to set up/ run a prostate cancer support group, and that they were unable to refer patients for psychological support. |
| Maggie's Wallace, Maggie's Charity, Voluntary sector | Offers practical, social and emotional support. This includes psychological support and counselling, workshops and activities. Informal setting based around a kitchen table. Currently piloting a prostate-cancer specific support group, chaired by a counsellor. Based at Addenbrooke's, Cambridge. | Whole pathway. | Around 20-30 people a day come through the centre; specific prostate cancer numbers not known. They think that prostate cancer patients are attending, though likely in smaller numbers than other cancers. Attendance at the pilot group has been good thus far. | Informal setting is one of the unique aspects of a Maggie's Centre. This is supported by the fact that the rooms are light, pleasant places to be. Provide a very wide variety of support, including psychological support. |
| Cambridgeshire Prostate Cancer Support Association, Voluntary sector | Set up and run by users, support group which meets monthly for social gatherings, or to hear guest speakers. Meetings are held in Cambridge. | Whole pathway. | Prostate cancer-specific group. No information available on the number of members. CNS/information services in both Cambridge and Peterborough are aware of the group and refer men. | No information available. |
| Macmillan Information and Support Centre, Peterborough NHS Trust, NHS | Informal emotional support and signposting to other services. Based at Peterborough City Hospital. | Whole pathway. | Only anecdotal evidence available, suggests that prostate cancer patients are less likely to access services. | Based in the Hospital so picks up footfall. Well informed staff, but limited by the availability of services to refer on to. |
| Macmillan Day Centre, Macmillan, Voluntary sector. | Offers a range of day therapies including relaxation techniques, stress management, occupational therapy and | Whole pathway. | Not prostate-cancer specific. Patients must attend for the full day, can't pick and choose specific | Consider offering ad hoc services, rather than having people attend for the full day. |



| Service name, provider and sector | Summary description | Section(s) of pathway covered by the service | Awareness, Access and take-up | Points of learning / good practice |
|-----------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------|
| Moving Forward course, NHS. | Five week course for those focussed on supporting people to live with and beyond cancer. Content includes healthy living, relaxation and stress management techniques and fatigue management. | Post-treatment; those with stable/early stage disease; those with recurrent disease. | Not prostate-cancer specific. No information available on access by prostate cancer patients, though anecdotal evidence suggested more women attend. | No information available. |

3.3.2 Assessment of provision and lessons learnt

Assessment of provision in the area

Key problems in the area:

- Provision is focussed in Cambridge (and Cambridgeshire more generally); there is a comparative lack of services in Peterborough. Having a Maggie's centre was highlighted as a key benefit for the Cambridgeshire area, but this was too far to travel for patients based (and treated) in the Peterborough area. Similarly, the only prostate-specific support group was based in Cambridgeshire.
- There is a lack of counselling/psychological support opportunities. Access to counselling (apart from through the Maggie's Centre) is only by referral from the GP. This puts an extra barrier in front of men accessing support, and means that only those really willing to 'fight' for access, are likely to receive it. Even if referred by their GP, there remains a lack of provision, with long waiting lists.
- Few services are targeted or tailored specifically for men with prostate cancer. Where men would like specific support, they tend to be referred to either the Cambridgeshire Prostate Cancer Support Association (which is too far for many men to travel, and inappropriate for those who don't want group support), or to Prostate Cancer UK's forums and telephone support service.

Access, and barriers to access, for men with prostate cancer in Cambridge and Peterborough

All interviewees reported that men face more barriers in accessing wellbeing services than women, and all attend in lower numbers. Interviewees reported that the reasons for the reduced number of men accessing services were similar to the picture across the UK, and related to men being less willing to admit and discuss worries and concerns: *'gentlemen in general, they don't want to talk about what's happening and what's wrong'*.

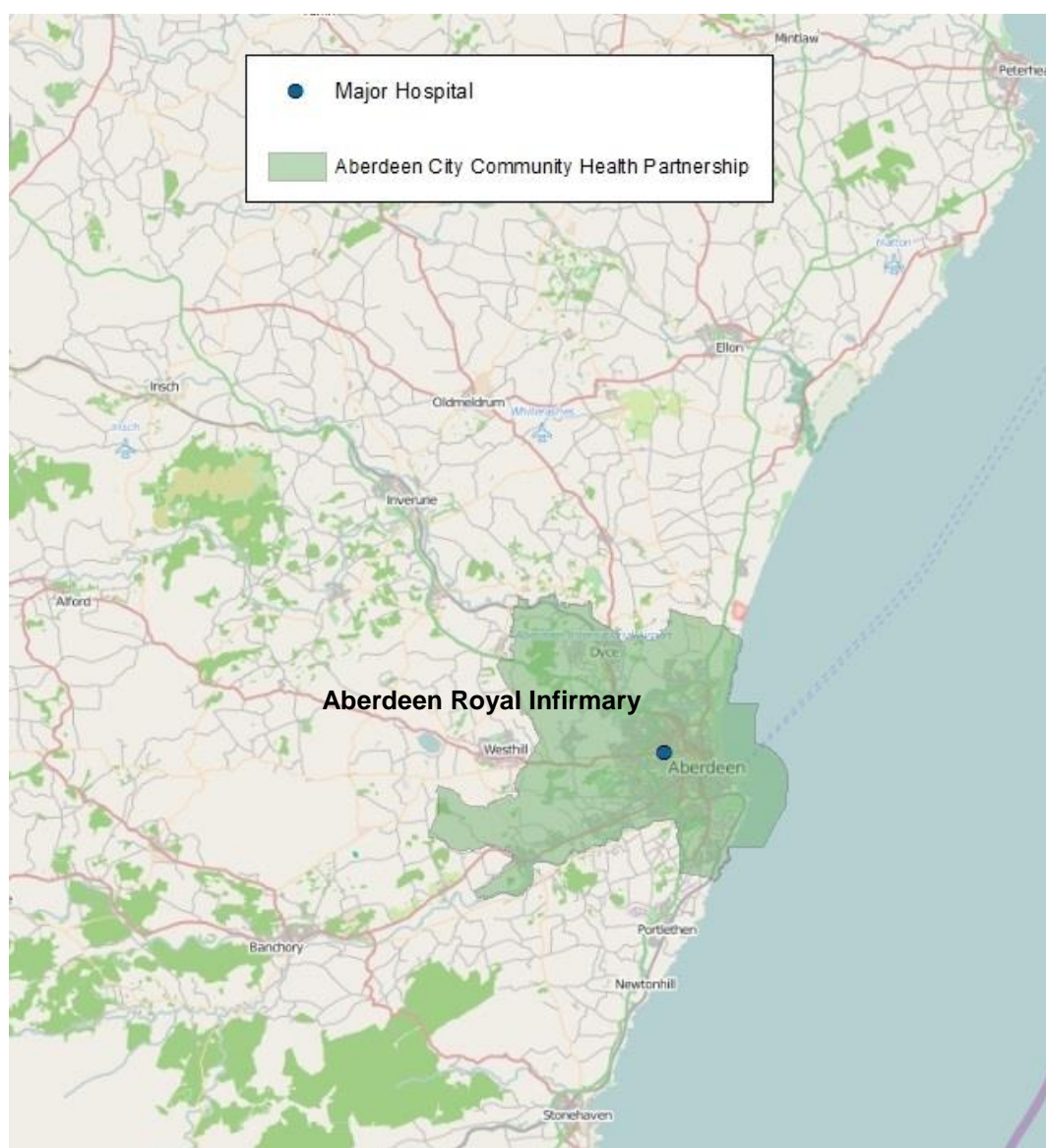
Interviewees did not highlight variation in access by ethnic group/socio-economic status, though one interviewee suggested that younger men, who were still working, faced particular challenges to access; this could be compounded by some services (such as the day therapies service) only being available in working hours.

Access to most services is through self-referral. However, as both Maggie's and the Macmillan Centre are based in hospitals, patients are signposted to services by leaflets, advice from their CNS/consultant, or just because they walked past. Any access to psychological support (apart from at Maggie's) would be through a GP referral.

3.4 Aberdeen

Aberdeen is the third largest city in Scotland, with an estimated population of 224,970 (June 2012 figure), accounting for 4.2% of Scotland’s total population (Aberdeen City Council 2014). Aberdeen City and Shire is one of the most prosperous regional economies in the whole of the UK, largely thanks to its oil and gas industry. Life expectancy at birth for both males and females is higher than the Scottish average, standing at 76.3 years for males, and 80.9 years for females, based on 2008-2010 figures (compared to 75.8 years and 80.4 years, respectively, for Scotland as a whole) (NHS Grampian 2012). Figures from the 2011 census highlight that in the Aberdeen City area, there are higher proportions of people from non-white ethnic groups than the Scottish national average, but that the population is still primarily White. People from Black African or African-Caribbean, or mixed or multiple ethnic groups, make up around 3.3% of the population; men from Black African or African-Caribbean groups have a higher chance of getting prostate cancer than White men.

Figure 3.3 Aberdeen



As seen from Table 3.8, Aberdeen has a lower incidence of prostate cancer than the UK average. Between 2008 and 2010, there were, on average, 292 newly diagnosed cases of cancer per year. This is equivalent to an age-standardised rate of 84.1 new cases per 100,000 of the population (which is significantly lower than the figure of 104.9 for the UK as a

whole). The age-standardised annual male mortality rate from prostate cancer is 21.8 deaths per 100,000 of the population, which is not substantially different from the UK average of 23.8 deaths per 100,000 individuals.

Table 3.8 Summary of survival, incidence and mortality from prostate cancer (all age standardised)

| | Aberdeen | UK average |
|-----------------------------------------------|----------|------------|
| Survival – one year (percentage) ⁹ | 89.4 | 86.4 |
| Incidence (per 100,000 population) | 84.1 | 104.9 |
| Mortality (per 100,000 population) | 21.8 | 23.8 |

Source: NCIN UK cancer e-atlas and prevalence atlas; and ISD Scotland and Grampian JSNA

3.4.2 Wellbeing service provision in the area

Aberdeen's healthcare services are coordinated by NHS Grampian, one of 14 regional NHS boards in Scotland. In relation to cancer specifically, the North Scotland regional cancer network (one of three networks) works across several of the health boards in the North to support the organisation, planning and delivery of cancer services.

There are a number of organisations that provide wellbeing services support for men with prostate cancer in the Aberdeen area. These include the Urological Cancer Charity (UCAN), Clan House and the (recently opened) Maggie's Centre.

UCAN is a key organisation for the delivery of wellbeing/support services to men with prostate cancer across NHS Grampian. The vast majority of men in these areas (estimated by interviewees to be 90% of those with prostate cancer) receive their diagnosis from a UCAN healthcare professional, including from the two lead CNSs. These nurses then become the man's named contact for the duration of their cancer treatment and recovery, and the key individual for assessing and meeting any mental wellbeing needs they may have.

Interviewees identified two main mental wellbeing needs for men who have received a diagnosis of prostate cancer: the need to manage the impact of erectile dysfunction (ED) and loss of continence.

There are a range of services available to UCAN to which men can be referred for these specific or more general mental wellbeing needs. Within NHS Grampian, there are two specialist nurses who are trained in supporting men with ED. All men with prostate cancer can be referred to this specialist service depending on individual circumstances; all men who have had a radical prostatectomy are referred to the service. While interviewees noted that this service is not specifically aimed at meeting mental wellbeing needs, its goal is to improve the support for one of the biggest issues men with prostate cancer face. Other CNSs working with UCAN have undergone more general training in supporting ED and so can meet more basic needs. If required, there are sexual counselling services available for men to be referred to; joint sessions for men and their partners are also available.

The NHS also offers a referral service to provide support for men with incontinence. As with the ED service, the UCAN CNSs refer men to this service to reduce the mental wellbeing impact of this side effect (which they reported is particularly significant for younger men diagnosed with prostate cancer).

UCAN also offers several more general services to support men's mental wellbeing. This includes facilitating a discussion and peer support forum for men with urological cancers in northeast Scotland, and a 'Buddy' network support system for men who are newly diagnosed and a support group for men and their families. The Buddy network provides men with the opportunity to seek additional support from other patients who have been through the

⁹ Survival (one year) percentage is defined as the proportion of men who have received a diagnosis of prostate cancer in the previous 12 months and who are still alive.

treatment (they are called ‘advisors’). The meetings can take place in public places (such as pubs), or via email or telephone. It was also noted that the UCAN care centre in Aberdeen Royal Infirmary is an open resource for men and their families to use throughout treatment and recovery.

Interviewees outlined two further key providers of mental wellbeing services for men in Aberdeen: Clan House and the Maggie’s Cancer Care Centre. The Clan organisation, which has been based in the area for over 25 years, provides support for people with all cancers. It does not offer any clinical support; all support aims to address the non-medical aspects of the disease. The main centre in Aberdeen hosts an ‘emotional support’ service delivered by a team of trained volunteers; for service users who have more substantial needs, there is a team of eight permanent counsellors available. Complementary therapies (such as acupuncture or massage) are also on offer at the centre; around 40 staff, working on a part-time basis offer these services. There is also a dedicated support service for children and families, including supporting them with bereavement. Finally, the centre offers a library and information service. All services are available for people with all types of cancer. The Clan centre also hosts a monthly prostate cancer support group; these are attended by the UCAN CNSs.

The Maggie’s Cancer Care Centre at Aberdeen Royal Infirmary opened in August 2013. It offers a range of support services for men with cancer including discussion groups specifically for men, advice in managing stress, expressive art workshops, creative writing, additional support beyond treatment and support with returning to work after cancer. The Maggie’s and Clan centres refer clients between them if they know that the other centre offers a service that they do not.

Box 3.1 Support needs in remote areas: improving skills and knowledge in ‘mainstream’ services

Given UCAN’s location in northern Scotland, it has become a vital provider of services for patients with urological cancers in the Orkney and Shetland Isles; it is also leading activities to improve the standard of services in these locations. The primary activity for achieving this goal is to develop the skills and knowledge of the primary care staff to meet the specific needs of prostate cancer patients. The main non-NHS support services available in these islands are outreach centres of the Clan organisation.

3.4.3 Assessment of provision

In general, interviewees reported that the Aberdeen area is well equipped to meet most of the mental wellbeing needs of men with prostate cancer. There are two features of the model of support which have been identified by interviewees: firstly, UCAN aims to ensure that mental wellbeing needs can be addressed from diagnosis; and secondly, they ensure that specialist services are available to address the side-effects of treatment.

UCAN reported that one of the strengths of the system in Aberdeen is that mental wellbeing needs begin to be addressed from the point of diagnosis. All men receive their diagnosis in a non-clinical setting. This is normally delivered by a CNS and a recent evaluation found that these diagnosis sessions last 50 minutes on average (*“We’re paid to have time”*); where diagnoses are delivered by consultants, less time is available. The CNSs reported that this time is used to support men and their families with the initial implications of the diagnosis, the next steps in treatment, to outline the possible consequences of different treatment options and to assess possible mental wellbeing needs. A CNS suggested that: *“If you can alleviate distress at source, we believe this reduces problems in future”*.

Interviewees also assessed that, for most of the potential side-effects of treatment that men face, there are specialist services available and accessible to those who need them.

Box 3.2 Access to services in remote and rural locations

The mental wellbeing needs of patients in these locations are much the same as those of

the population in Aberdeen. But, the remote location means it is difficult to access more specialist support services which are primarily found in Inverness or Aberdeen. While the NHS pays for the travel expenses to Aberdeen for men to receive treatment, it does not fund travel for access to mental wellbeing services. Interviewees also noted that a small proportion of the men in these locations are not willing to leave the islands for treatment or support and hence the local GPs and other health services have to provide the support themselves. Interviewees also reported that, because of the highly rural nature of the area, men are less likely to access services because they are concerned at being recognised or information about their condition becoming known in the wider community.



Table 3.9 Summary of services in Aberdeen

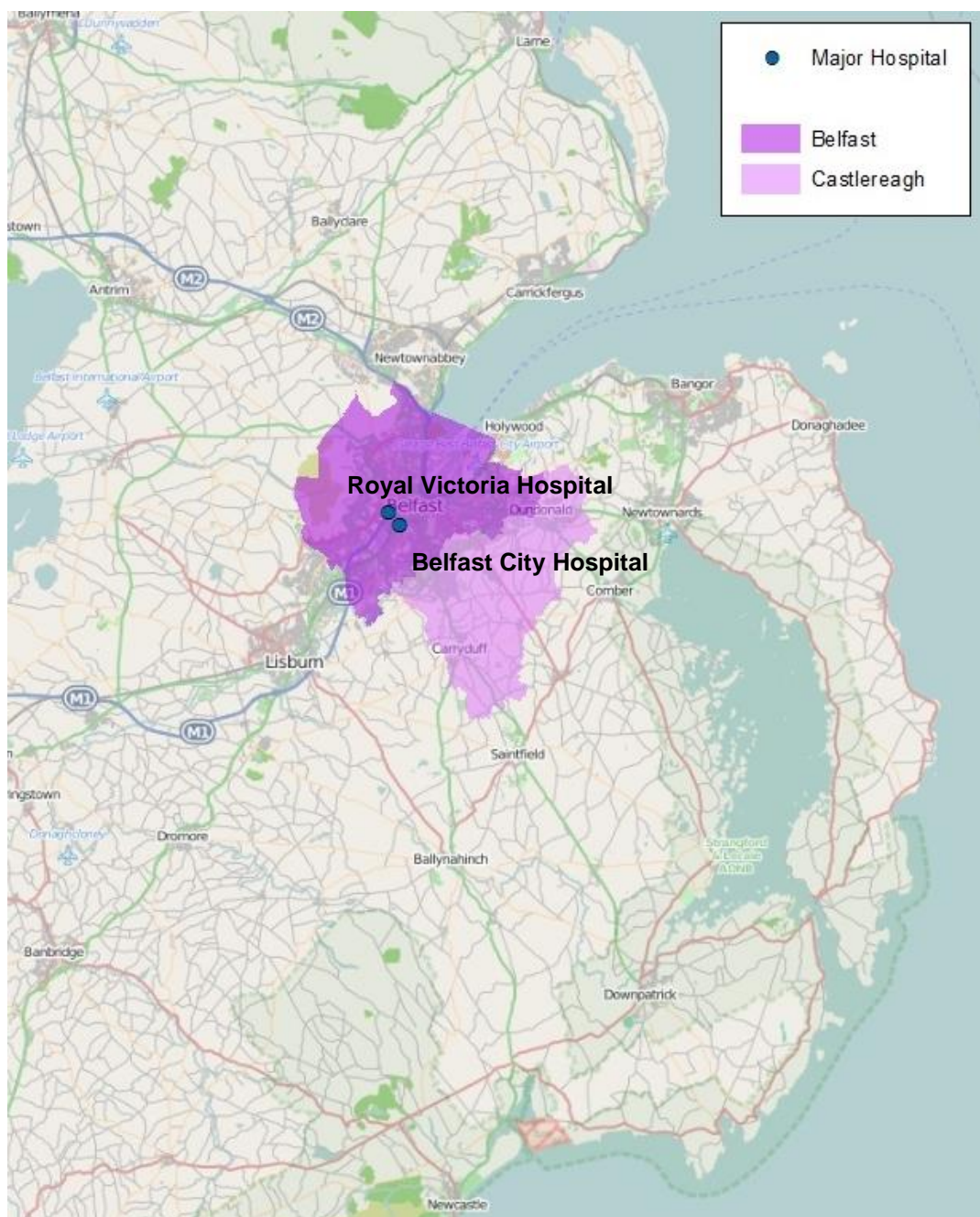
| Service name, provider and sector | Summary description | Section(s) of pathway covered by the service | Awareness, Access and take-up | Points of learning / good practice |
|------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| UCAN – voluntary sector provider delivering NHS services to people with urological cancers in the Aberdeen area. | UCAN acts as a coordinator of services for men diagnosed with prostate cancer in Aberdeen. Support is led by CNSs who are able to refer men to UCAN services or to other specialist NHS providers depending on need. It also offers a range of support services directly (for example, a peer support network for newly diagnosed men and a support group for families). | UCAN coordinates care from diagnosis throughout treatment and follow-up. It also provides support for carers. | Most men (90%) diagnosed with prostate cancer in Aberdeen area will be supported by a CNS from UCAN. The profile of service users is therefore a reflection of the population (largely white; relatively affluent). The service is seen to be accessible. For example, there is a drop-in centre for men or carers to use when required. | Men have direct access to a named nurse throughout their cancer treatment and follow-up. UCAN CNSs try to identify mental wellbeing needs of men from the point of diagnosis. |
| NHS specialist nurse-led ED, and continence services | These services are available for referral for men who would like support with ED or continence issues. Given that such issues affect the wellbeing of men with prostate cancer, interviewees underlined the important of having these services in place to indirectly improve their mental wellbeing. | Follow-up care – UCAN CNS can refer men to this service. | All men having a radical prostatectomy are referred to the service. The service is available for men following other courses of treatment. Specialist physiotherapy services for supporting men before their operation may improve outcomes in this area but is not available. The continence service is thought to be in greater demand for younger men. | Ensuring that services are accessible for treatment side-effects is a crucial step to reducing potential mental wellbeing impacts. |
| Clan House | A long-standing provider of support for people in Aberdeen with cancer. It offers a range of general support for people with cancer (including support with financial planning, for example) as well as specific prostate cancer support services involving UCAN staff. | Primarily follow-up support; support also provided to families. | Service is well-known to local clinicians and seen as accessible. There have been attempts to market services directly to men to increase take-up (targeted advertisements; attempts to boost male volunteers; links with UCAN). | This is a large organisation, able to offer a wide range of non-clinical support services. Longevity means it is well known in the area (particularly by clinicians) boosting signposting. |
| Maggie's Centre | A new provider of support in the area. It includes support services for returning to work. | Primarily follow-up support. | Service is new to the area. | |

3.5 Belfast

Belfast Health and Social Care Trust is the public body responsible for providing health and social care services to the population of Belfast City and part of the borough of Castlereagh (around 340,000 people). Additionally, it also serves as a national hub from which specialist services are provided to all of Northern Ireland.

Belfast City itself is the largest city in Northern Ireland and the eighteenth largest in the United Kingdom with a population of 280,962, according to the 2011 census. The area is almost entirely urban in nature, though there are some rural pockets.

Figure 3.4 Belfast Health and Social Care Trust area (Belfast City Council and Castlereagh Borough Council)



Northern Ireland is the least ethnically diverse nation in the UK. According to the 2011 Census, the White ethnic group accounted for 98.2% of the population. However, Belfast has the highest proportion of residents from minority ethnic groups in Northern Ireland (3.6%).

There are areas of significant disadvantage in the city; some of which are among the most deprived areas in Northern Ireland. Of the 20 most deprived electoral wards in Northern Ireland, 12 of them can be found in Belfast (Northern Ireland Statistics and Research Agency (2010)). Prostate cancer incidence rates differ between the most deprived areas and the least deprived areas – 118 per 100,000 in more affluent areas as opposed to 95 per 100,000 in more deprived area. This is consistent with the UK picture, given that incidence rates are higher in more affluent areas than deprived areas.

The incidence of prostate cancer in Belfast is not significantly different from the UK average, as shown in Table 3.10. There are 182 new cases every year, with an age standardised rate of 102.5 per 100,000. The age-standardised annual male mortality rate from prostate cancer in Belfast is 24 deaths per 100,000 of the population; this is not significantly different from the UK average, or that of Northern Ireland (Northern Ireland Cancer Registry 2013)). Survival rates in Northern Ireland are not significantly different from the UK average either.

Table 3.10 Summary of survival, incidence and mortality from prostate cancer (all age standardised)

| | Belfast | UK average |
|------------------------------------------------|---------|------------|
| Survival – one year (percentage) ¹⁰ | 84.4 | 86.4 |
| Incidence (per 100,000population) | 102.5 | 104.9 |
| Mortality (per 100,000 population) | 24 | 23.8 |

Source: NCIN UK cancer e-atlas; and prevalence atlas

In the main, cancer services in the Belfast Trust are provided across the different hospitals, which include the Royal Hospital, Belfast City Hospital, Mater Hospital and Musgrave Park Hospital. Belfast is also home to Northern Ireland’s Regional Cancer Centre. This is located at the City Hospital in Belfast and facilitates radiotherapy, brachytherapy and a range of outpatient, day case and inpatient services. Men with prostate cancer attend Belfast City Hospital for radical treatment, and receive follow-up in their local cancer unit.

3.5.1 Wellbeing service provision in the region

Mental wellbeing needs in Belfast

Interviewees reported that the mental wellbeing needs of men in Belfast are similar to those of men in other parts of the UK. The needs most commonly identified for men in Belfast can be divided into the following categories:

- Anxiety concerning diagnosis (and the possibility of recurrence): for men who are first diagnosed, they are worried about survival and learning how to cope with a diagnosis of prostate cancer. Related to this is the fear of recurrence – men experience anxiety related to the possibility of recurrence, which is further compounded by feelings of isolation after treatment has ended.
- Coping with the side effects of treatment: Men also experience wellbeing needs because of the treatment course they have adopted and also undergo anxiety in anticipation of the treatment process (University of Ulster and Ulster Cancer Foundation (2011)). The most common such side effects mentioned by interviewees were loss of sexual function, incontinence and fatigue. Of these, loss of sexual function was identified as something that was particularly distressing to men in Belfast.

When discussing the particular needs of men with prostate cancer in Northern Ireland, a number of interviewees stated that there was also a particular cultural context to be taken account in Northern Ireland. Barriers that men face when talking about their wellbeing in general were perceived to be higher in Belfast compared with other areas in the UK – “culturally, Northern Irish men aren’t great at talking about their feelings” or “men just plod on – it’s their coping mechanism”. This was one of the main reasons identified for men’s

¹⁰ Survival (one year) percentage is defined as the proportion of men who have received a diagnosis of prostate cancer in the previous 12 months and who are still alive.

difficulties in discussing loss of sexual function, in particular, especially in the case of older men.

Service provision

Table 3.11 provides an overview of the types of services available to address the mental wellbeing of men with prostate cancer. As seen, in general there are very few services that are targeted directly at men with prostate cancer. One of the notable features of this is that there are no psychosexual services in place to support those men for whom loss of sexual function is a side effect of treatment – something noted by all interviewees as a significant gap in provision for men.

Another gap mentioned by all respondents was the fact that Northern Ireland has fewer CNSs in place to provide support for men with prostate cancer than other regions in the UK. One respondent remarked that if wellbeing services in Northern Ireland were benchmarked with the UK average, one would find that there were around 30 fewer CNSs than would be expected. This lack of a single contact point for men was regarded as being a major obstacle to the development of wellbeing services.

Interviewees generally thought that the ‘wellbeing agenda’ was proceeding at a slower pace than other parts of the UK and that this resulted in specific wellbeing services for men with prostate cancer being less developed than elsewhere.

However, there were some positive aspects identified. The development of the [Northern Ireland Cancer Survivorship website](#) as an information service for people seeking cancer support services is significant in this regard. While the services described are not broken down by tumour type, it does provide a useful overview of the support services which men with prostate cancer might access. However, some respondents noted that older men might not access information in this way.

Additionally, four health and wellbeing events for men with prostate cancer are being organised to be held across Northern Ireland following a grant from the Foundation of Nursing Studies’ (FoNS) Patients First: Supporting Nurse-led Innovation in Practice programme. These events were focussed on introducing men with prostate cancer (and their carers) to a range of services that can help with their physical, emotional, social and financial needs. This built on a conference in 2012 (funded by Macmillan) for men treated radically for prostate cancer which featured presentations on all dimensions of survivorship.

In the main, providers of wellbeing services come from the voluntary sector and are centred around counselling and information services. For example, Macmillan operates support and information centres at Belfast City and Royal Victoria Hospitals. There are other voluntary sector providers, such as Cancer Focus Northern Ireland and Cancer Lifeline who provide counselling services to people with cancer (though the majority of beneficiaries of these services are female). These providers vary in size with UK-wide charities such as Macmillan operating a support and information centre, national charities such as Cancer Focus Northern Ireland and Action Cancer, and local community-based organisations such as Cancer Lifeline in North Belfast.

The MAC (Men Against Cancer) Clinic is a free self referral clinic for men, supported by local business men and run by Belfast City Hospital Uro-oncology CNSs. Men can make an appointment to attend the clinic. It aims to provide a relaxed and welcoming environment to provide information on men’s health, in particular information pertaining to urological cancers and early diagnosis as well as a counselling service. Access to wellbeing services is not considered part of the overall treatment pathway and self-referral is the main route by which men with prostate cancer can access such services, where available.

Commissioning intentions

There is no mention of wellbeing services that are tailored for men with prostate cancer in the 2014/15 Commissioning Plan for Northern Ireland or in the Transforming Your Care Implementation framework. However, the 2013/14 Commissioning Plan did commit Belfast Health and Social Care Trust to work with the Macmillan Information Centre, Trust Psychology Service and community and voluntary sector providers to commission a psycho-

social care model for those living with cancer. A key part of this involves mapping statutory, community and voluntary sector resources available across Belfast Health and Social Trust area. There are no firm time-lines set out in the commissioning plan.

In terms of commissioning intentions, wellbeing services for men with prostate cancer are not considered a priority for commissioners. Interviewees stated that there does not appear to be any intention to commission wellbeing services for men with prostate cancer. The main reason for this is that wellbeing is still considered to be a relatively new issue for healthcare in Northern Ireland – *“commissioners are still getting their head around it.”* Other interviewees noted that provision of wellbeing services for men with prostate cancer was not a priority against the context of financial constraints and the main political focus on A&E services.



Table 3.11 Summary of services in Belfast

| Service name, provider and sector | Summary description | Section(s) of pathway covered by the service | Awareness, Access and take-up | Points of learning / good practice |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Cancer Lifeline, Information & support service, voluntary sector | Professional and confidential counselling services; professional complementary therapies e.g. aromatherapy, reflexology, massage; weekly support group sessions; welfare benefits advice; information mornings; befriending service. | Whole pathway | Self-referral is the main route of access. Services are not specifically targeted at men with prostate cancer and about 30 men with prostate cancer registered with Cancer Lifeline over the last 12 months. | It prides itself on providing a relaxed environment and is designed to look like a “home away from home” for people who access it. The project is run and managed by people directly affected by a cancer diagnosis. |
| Cancer Focus NI, various services, voluntary sector | Cancer Focus Northern Ireland provides a range of services to support people with cancer. These include information and support helpline, a family support service, creative art therapy, counselling services and writing and walking groups. | Whole pathway | Self-referral is the main route for men to the service – the counselling service is the main gateway for men into the service. About 20% of the beneficiaries who access the services are men. | Cancer Focus NI operate a mobile health awareness initiative known as “Keeping Well Van” which has been successful in assisting men to access information on their health – an example of awareness of targeting wellbeing initiatives to men. |
| Macmillan Information Centre, information service, voluntary sector (in partnership with Belfast HSC Trust, Cancer Focus NI, Action Cancer and Friends of the Cancer Centre) | Macmillan operates two information and support centres at Belfast City Hospital and the Royal Victoria Hospital, which offer services including information, counselling, complementary therapy (acupuncture, massage, reflexology), benefits advice and a group activities programme. | Whole pathway | Self-referral is the primary route in. | The Centres are located on site, making it easy for patients to access them and the services they provide. |
| Cancer Survivorship website, information provision, statutory sector | Provides an overview of services for cancer patients in Northern Ireland, including clinical support services. | Whole pathway | Self-referral is the usual avenue of access. The service is not specifically targeted at men with prostate cancer. | The website is an empowering tool for men who wish to be pro-active in looking for support services. |
| Action Cancer, various services, voluntary sector | Provision of a “listening ear” counselling service. | Whole pathway | Self-referral. The service is not targeted at men with prostate cancer in particular. | The “Listening Ear” service is provided to people with cancer and their families. |
| Men Against Cancer counselling service & clinical support service, counselling | Information and counselling support service. Operate a clinic for men to learn about urological cancers in a relaxed and | Whole pathway | Self-referral is the main way by which men access this service. | This service is targeted at men in particular and makes the marketing of its service relevant to men. |



| Service name, provider and sector | Summary description | Section(s) of pathway covered by the service | Awareness, Access and take-up | Points of learning / good practice |
|-----------------------------------|--------------------------|----------------------------------------------|-------------------------------|------------------------------------|
| service, voluntary sector | comfortable environment. | | | |

3.5.2 Assessment of provision and lessons learnt

In general, the provision of wellbeing services for men with prostate cancer in Belfast can best be characterised as patchy. There are significant gaps in provision, mostly in relation to psycho-sexual services and this was something which interviewees identified as a major weakness of provision of wellbeing services in Northern Ireland. Where there are wellbeing services in place, they are not targeted at men with prostate cancer in particular. Moreover, services that are particularly relevant to men with prostate cancer do not exist in some instances, such as psycho-sexual counselling or CNSs.

Interviewees stated that where services were available, it was relatively simple for men to access them. The primary issue pertaining to access concerned the fact that coverage of Belfast is not consistent and that access to wellbeing services can rely on which part of Belfast the man lives.

Awareness among men about the availability of services aimed at improving wellbeing was also considered low but improving. Interviewees stated that the Northern Ireland Survivorship website was a key factor in driving awareness and addressing this situation. This is related to the take-up of these services which is considered to be poor. However, interviewees stated that take-up is related to the background of the individual patient and whether they come from a deprived area. In particular, interviewees stated that it proved difficult to engage men from more deprived socio-economic backgrounds in addressing their wellbeing needs.

While there are fewer men from ethnic minority backgrounds in Belfast compared with other regions in the UK, interviewees stated that awareness among such men of wellbeing services was also quite low. This led to a “double impact” in that general services are patchy, allied to specific barriers relating to language and culture.

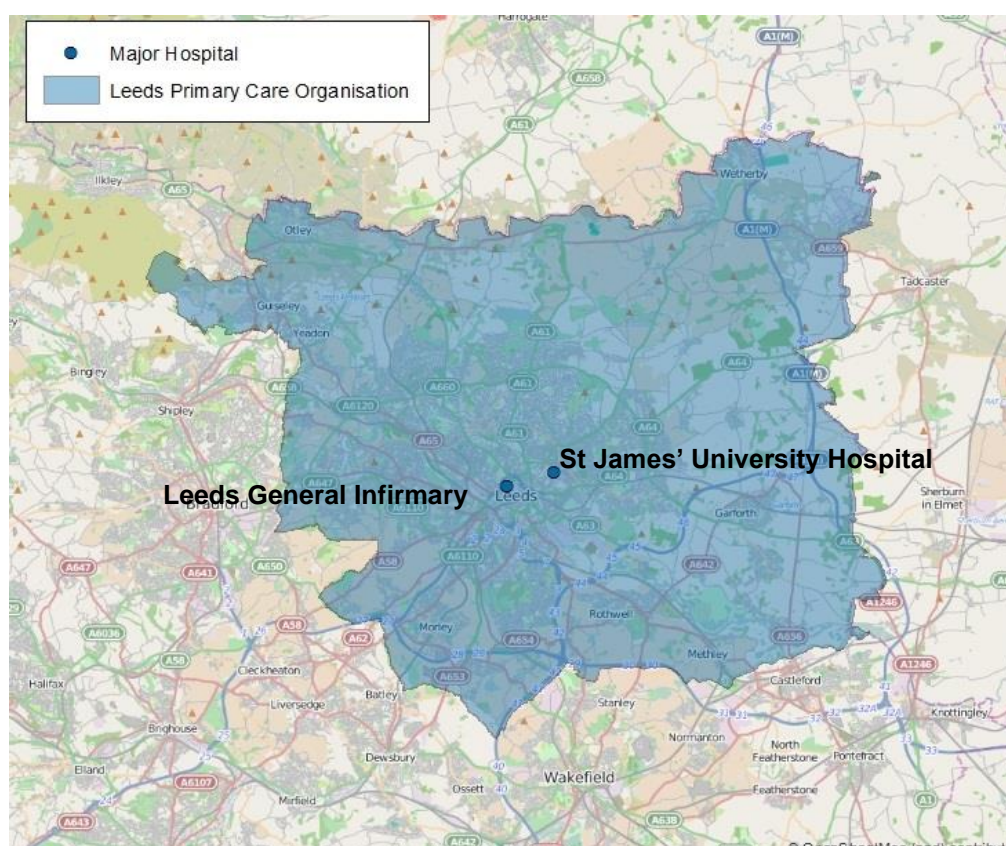
One particular characteristic of the provision of wellbeing services for men with prostate cancer in Belfast is that there is very little “join-up” in terms of provision. There is more to be done to develop a cohesive approach. Establishing a dialogue between the statutory sector and the community and voluntary sector is fundamental to this.

3.6 Leeds

Leeds is the third largest city in the UK, with a population of 751,500 in 2011 (Leeds City Council (2013)). It is almost entirely urban. There are three CCGs covering the city – Leeds North CCG, Leeds South and East CCG and Leeds West CCG.

17.4% of the Leeds population is drawn from 140 minority ethnic groups. Of these, the largest ethnic minorities are Asian (8%) and Black (3.5%). These communities are located in specific areas around Leeds. For example, Chapeltown is the main centre for the Black African community and such areas are usually characterised by high levels of disadvantage.

Figure 3.5 Leeds



While Leeds is an economically strong city, there are areas of significant deprivation¹¹. Leeds is the 44th most deprived local authority area out of 326 local authorities in terms of concentration of disadvantage. 20% of people in Leeds live in the 10% most deprived areas in England and deprivation is primarily found in East and South Leeds (Leeds Church Institute 2010). Health outcomes for people in Leeds are generally worse than those of England on average, especially for those suffering from cancer.

Table 3.12 provides summary information on the incidence, survival and mortality from prostate cancer in Leeds. Mortality rates are in line with the national average. Leeds is significantly different from the UK average in terms of one-year survival.

¹¹ Leeds Church Institute (2010) *Deprivation and Inequality in Leeds*

Table 3.12 Summary of survival, incidence and mortality from prostate cancer (all age standardised)

| | Leeds | UK average |
|------------------------------------------------|-------|------------|
| Survival – one year (percentage) ¹² | 95.4 | 86.4 |
| Incidence (per 100,000 population) | 110.6 | 104.9 |
| Mortality (per 100,000 population) | 24.2 | 23.8 |

Source: NCIN UK cancer e-atlas; and prevalence atlas

Services for men with prostate cancer are provided through the Leeds Cancer Centre, including treatments such as surgery, radiotherapy and chemotherapy. These are delivered on five hospital sites: St James's (surgery, chemotherapy and radiotherapy), Leeds General Infirmary, Seacroft and Chapel Allerton (surgical cancer care) and Wharfedale General. Supportive care services (e.g. complementary therapies (e.g. acupuncture or massage) and financial advice) are also provided by the Leeds Cancer Centre which can be accessed through the Robert Ogden Macmillan Centre at St James' University Hospital.

3.6.1 Wellbeing service provision in the region

Mental wellbeing needs in Leeds

Mental wellbeing needs for men with prostate cancer in Leeds can be divided into the following themes:

- Anxiety around diagnosis. One of the major mental wellbeing needs identified for men with prostate cancer was the need to support men to give them a sense of control over the treatment and care pathway they will have to follow.
- Support for coping with the side effects of treatment, especially emotional support. Men need help in coping with the side effects of the treatments, especially in coping with associated stress.
- Relationship issues. One mental wellbeing need mentioned by respondents concerned the pressure on relationships. For example, hormone treatment can have a bearing on how a man perceives their role in a relationship, in terms of sexual function and their perception of their masculinity.
- For minority ethnic groups, cancer can be a taboo subject. To address the wellbeing needs in these communities, it is necessary to address cultural barriers that men may face. For example, in some minority communities, men may not talk about loss of sexual function which can have an effect on their relationships and may lead to family breakdown. So, support in these cases needs to be culturally sensitive and encourage men to recognise and address those needs.

Service provision

Leeds Cancer Support Service at St James' University Hospital is the main hub for the delivery of wellbeing services in Leeds and it provides a first point of contact for men who wish to access mental wellbeing services. The majority of support services for men with prostate cancer are provided through the Macmillan Robert Ogden Centre, as described in Table 3.13. Among the services provided at the centre are information services on cancer and its side effects, access to counselling services, and information about complementary therapies (including acupuncture, massage and reflexology). Assistance with financial information and other social needs related to cancer and information on support for spouses and family members is also provided. The counselling services and acupuncture services are among the most common services accessed by men with prostate cancer and they are usually signposted to the Centre by the CNS (and other clinical staff).

A number of pilot services designed to focus specifically on men with prostate cancer have been introduced:

¹² Survival (one year) percentage is defined as the proportion of men who have received a diagnosis of prostate cancer in the previous 12 months and who are still alive.

- Prostate Exercise Programme – a 12-week exercise and support programme for prostate cancer patients completing treatment. It includes a 45-minute group exercise session (the exercises are particularly relevant to men with prostate cancer) alongside a 30-minute support session, at which topics such as the emotional effects of cancer, continence and erectile dysfunction are discussed. The programme content has been designed to ensure that it focuses on coping with the side-effects of prostate cancer and treatment. Given that men do not traditionally access support services and groups on their own initiative, they are made aware of it through the hospital. The objective is to assist them to improve their health whilst learning to self-manage their condition and facilitate peer support, but in a community setting, thus encouraging the men to continue exercising after the programme ended.
- The *Can Ability* programme is delivered by Age UK in association with Prostate Cancer UK and is also aimed at men affected by prostate cancer and their families. It provides them with group support, information and physical activity to help them come to terms with living with prostate cancer and coping with the side effects of treatment.
- Age UK also works with Macmillan to provide the Macmillan Prostate Cancer Support Service. This service is targeted at older men with prostate cancer and involves visits by a caseworker to individual men with prostate cancer. Each man is provided with an individual holistic needs assessment to ensure that his particular needs are addressed. They are then provided with information on managing finances, social activities and emotional and psychological wellbeing and can choose to receive regular visits from the caseworker.

In terms of engaging men with prostate cancer from BME communities, the Black Health Initiative, a community-based engagement organisation, provided a Macmillan-funded health clinic to provide screening for prostate cancer, known as a “Men’s Health and Wellbeing MOT.” These clinics were held in community settings to encourage men of minority ethnicities to attend. As a result, awareness of prostate cancer was increased among these men in the community and a support group ‘Brothaz’ was formed.¹³

In Leeds, the provision of services is delivered through partnerships with different groups and respondents stated that this is the main factor that allows for the delivery of effective wellbeing services. There are also currently plans in place to build a Maggie’s Centre at St James’ Hospital to provide further support for cancer patients.

Commissioning

There are no commissioning plans in place for wellbeing services specifically for men with prostate cancer. There is no mention of specific wellbeing services for men with prostate cancer in the Leeds JSNA or the Leeds Joint Health and Wellbeing Strategy. Respondents put this down to a number of reasons:

- Commissioners are driven primarily by cost savings, and in the absence of evidence demonstrating the benefits of wellbeing services, it is unlikely that they will be commissioned; and
- Commissioners are reluctant to fund services for specific cancers. One of the reasons given for this was that commissioners do not wish to begin funding new services, but rather investigate how existing services for patients with all cancers can be used to address the needs of men with prostate cancer.

However, the pilot initiatives designed for men with prostate cancer are going some way to demonstrating how wellbeing services can improve health outcomes. In addition, a number of respondents stated that there is a commissioning agenda developing around the management of LTCs which may lead to more interest in wellbeing services. Establishing more embedded links between different elements of the wellbeing services network is key to ensuring that work towards developing a new pathway is successful.

¹³ http://bmecancer.com/phocadownload/hearme_now_1year_on.pdf



Table 3.13 Summary of services in Leeds

| Service name, provider and sector | Summary description | Section(s) of pathway covered by the service | Awareness, Access and take-up | Points of learning / good practice |
|-------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Prostate Exercise Programme, Leeds Cancer Support, Partnership between voluntary and statutory sectors | 12 week exercise and support programme for prostate cancer patients completing treatment. This includes a carefully designed 45 minute group circuit and 30 minute support sessions. Topics included the emotional effects of cancer, continence and erectile dysfunction. | Whole pathway – support provided for all stages. | Men are made aware of this course through the hospital and while it is not formally embedded in the pathway, it is tending towards this. It reaches men from a broad range of backgrounds. About 30-50 men a year are expected to use this programme. | These services are designed specifically for men with prostate cancer and are delivered by people who are aware of the side-effects of treating prostate cancer and the particular needs which men have. |
| Robert Ogden Macmillan Centre, Leeds Cancer Support, Partnership between voluntary and statutory sectors | A number of services are provided at this centre and include information services about cancer; access to counselling services; complementary therapies (e.g. acupuncture or reflexology); social assistance; and support for spouses/partners/family members. | Whole pathway – support provided for all stages. | The Robert Ogden Centre is situated on site and prostate cancer patients are informed about it as part of their treatment pathway. While the service is not embedded into the pathway, the CNS plays an important role in directing men toward the service. Emotional support services (such as counselling or information on support groups) are the most common services accessed by men with prostate cancer. | The centre is a one-stop shop for men with prostate cancer and while all services are not tailored towards their needs, there are services relevant to their needs. |
| BHI Cancer Support, Black Health Initiative (partnership with Prostate Cancer UK, Macmillan Cancer Support and Public Health Leeds), Voluntary sector | The BHI is a community initiative that provides support for men of Black African or African-Caribbean descent. It previously operated a ‘Men’s Health and Wellbeing MOT’, a Macmillan-sponsored men’s health clinic which was run quarterly until funding ended. Following this, a support group <i>Brothaz</i> was formed, which now has trained ‘buddying and befrienders’. The BHI has also produced a booklet specifically for African Caribbean men affected by prostate cancer. | Whole pathway – support provided for all stages. | Self-referral – BHI have a referral form online. This is targeted primarily at men from BME communities. The number of men attending fluctuates between 8 and 20. | This service has been designed with the specific intention of working with more difficult-to-engage groups such as the BME community. For example, the men’s health MOT clinics were held in community venues to encourage participation from men in BME communities. |
| Macmillan Prostate | This service is targeted at older men who have | Whole | Referral comes from Leeds Teaching | This support project has been |



| Service name, provider and sector | Summary description | Section(s) of pathway covered by the service | Awareness, Access and take-up | Points of learning / good practice |
|------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Cancer Support Project, Age UK & Macmillan, voluntary sector | been diagnosed with prostate cancer. On diagnosis, they are visited by a caseworker from Age UK who works with them to address their physical, emotional, social, financial and practical needs (using an individual holistic needs assessment). They are then signposted to service providers that can help them address those needs. | pathway – support provided for all stages. | Hospitals NHS Trust. Older men are targeted in particular and are visited by an individual caseworker who also conducts a holistic needs assessment on each man to get an overview of the needs which they have. 10-12 men are visited every week. About 50% of the men who are informed about the service ask to receive it. | integrated into the care pathway and is linked to the urology team at St James' hospital. Additionally, it is tailored towards each man and their particular set of needs. |
| Can Ability, Age UK in partnership with Prostate Cancer UK, voluntary sector | The Can Ability programme provides men affected by prostate cancer and their families with group support, information and physical activity to help them come to terms with living with prostate cancer and the side effects of treatment. It also involves one-to-one consultations for the men (including though not limited to counselling), support sessions for family members and signposting to other services. | Whole pathway | Signposting is done by the CNS but self-referral is the route to this service. This service is targeted at older men in particular. | This is an example of a programme that has been designed specifically with men's needs in mind and designed to make it attractive to them. It also involves support services for family members. |
| Leeds Prostate Cancer Support Group | The group offers support to men who have been diagnosed with prostate cancer and their partners. It also provides a forum for further information on the disease by organising quarterly meetings with guest speakers. | Whole pathway – support provided following diagnosis. | Men self-refer to this support group. However, information can be accessed on it through Leeds Cancer Support. | The group operates a buddy system of matching members who have had a specific treatment, have experienced the side effects for at least three years and are willing to share their experience with anyone wishing to take or consider the same treatment. |

3.6.2 Assessment of provision and lessons learnt

Provision of wellbeing services for men with prostate cancer appears better in Leeds than other areas around the UK. There is evidence of initiatives that have been designed to specifically address the wellbeing needs of men with prostate cancer. While it is still early days in the development of such programmes, respondents stated that the provision of wellbeing services in Leeds had a number of positive aspects.

In terms of coverage of the city, services are not limited to residents of any one particular area in Leeds and coverage is considered somewhat better than other regions in the UK. However, some respondents felt that there was scope to improve transport links between North and South Leeds to improve coverage further and to ensure access for these men.

One aspect that interviewees marked out as being particularly positive about the provision of services in Leeds regarded the bespoke nature of the wellbeing services. The Age UK caseworker and Prostate Exercise Programme were highlighted as good examples of services targeted at men with prostate cancer and were cited as good examples for the rest of the country to follow, as well as possibly informing services for patients with other cancers.

Signposting to services was considered a strength of the provision of wellbeing services in Leeds and the role of the CNS was praised by a number of interviewees. While service referral is not formally embedded in the care pathway, there is certainly a tendency in this direction and self-referral to services is made as user-friendly as possible. Related to this is awareness of these services among men with prostate cancer. Once diagnosed, awareness among men is quite high relative to the rest of the UK but there can still be variability especially among men from BME communities.

All interviewees agreed that, in general, the take-up of these services was quite high. This was attributed to the fact that services were (1) tailored towards men and (2) designed to address the particular needs pertaining to men with prostate cancer – “*when men are offered something designed for them, they jump on it*”. As such, a tailored service combined with referral/signposting from the CNS makes it more likely that there will be increased take-up.

One particular aspect of wellbeing services in Leeds is the steps that have been taken to work with BME groups especially. The work done by the BHI is a good example of how to ensure provision of wellbeing support to people in these communities, as shown by the MOT clinics held in local community venues. However, in order to embed these initiatives further, resources will need to be directed to them.

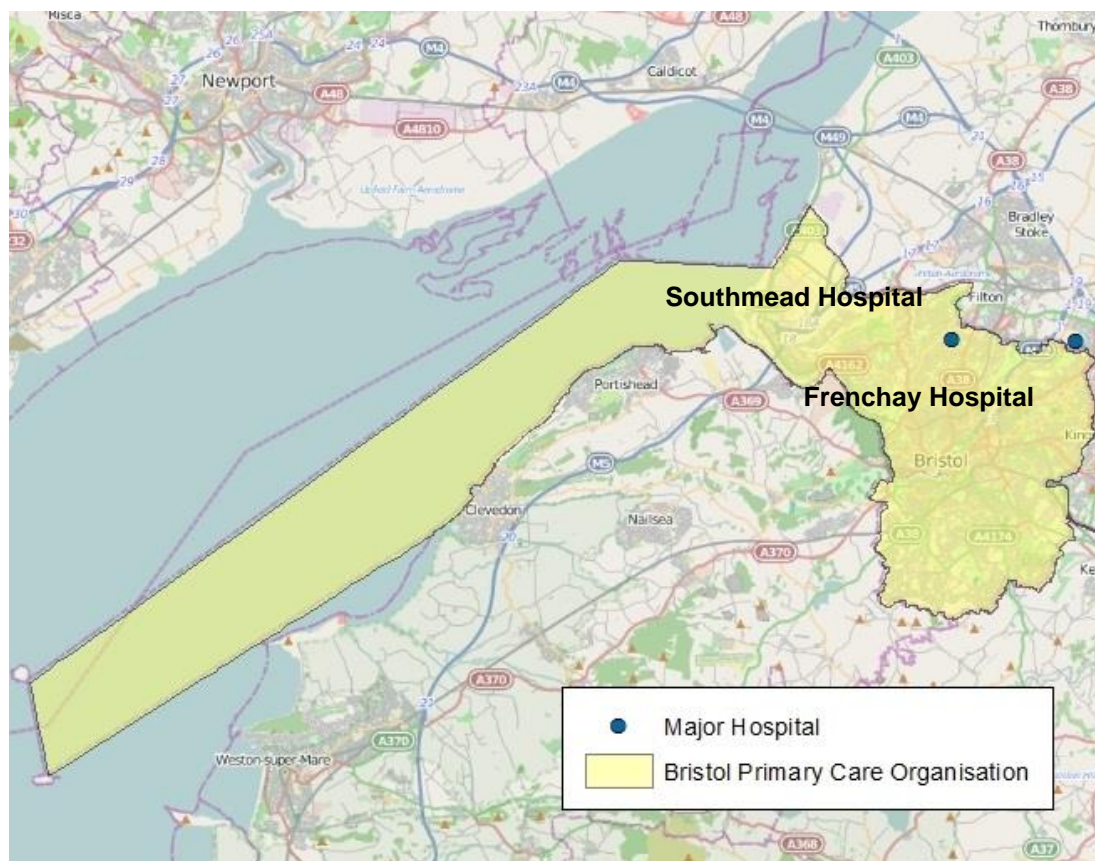
The most positive aspect mentioned by all interviewees and the characteristic of wellbeing services shown to be the most positive is the level of join-up and collaboration between different groups and organisations. Partnerships are key to ensuring effective provision as well as maximising the usefulness of resources and minimising duplication.

3.7 Bristol

Bristol (the area administered by Bristol City Council) is located in the south west of England and is home to a population of 432,500 (2011). It is England's sixth most populous city and has a young population: Bristol has more children aged between 0 and 15 than people aged 65 and over; the growth in child population (34% over the last ten years) is one of the highest in the country.

15% of the population of Bristol were not born in the UK and 6% of Bristol's population are from the Black community.

Figure 3.6 Bristol



In Bristol, some of the most affluent areas in the UK can be found alongside very deprived areas. 14 areas in Bristol are in the most deprived 5% in England and 15% of the population in Bristol live in the most deprived areas of Bristol. Inequalities in health follow from this: there is an estimated gap of up to 10 years in life expectancy for men and 6 years for women.

Incidence of prostate cancer in Bristol is slightly lower from the UK average, and so is mortality, as seen in Table 3.14. Similarly, one-year survival is broadly in line with the national average.

Table 3.14 Summary of survival, incidence and mortality from prostate cancer (all age standardised)

| | Bristol | UK average |
|------------------------------------------------|---------|------------|
| Survival – one year (percentage) ¹⁴ | 93.5 | 86.4 |
| Incidence (per 100,000population) | 99.2 | 104.9 |
| Mortality (per 100,000 population) | 22.1 | 23.8 |

Source: NCIN UK cancer e-atlas; and prevalence atlas

North Bristol Trust (NBT) is the main trust that provides cancer services to the people of Bristol as well South Gloucestershire and North Somerset (a population of 500,000). North Bristol also acts as a regional cancer centre for the population of Avon, Somerset and Wiltshire. The main hospitals are Frenchay and Southmead hospitals. Southmead hospital is home to the bulk of cancer services and has recently moved to a new campus.

NBT also plays a role in leading nationally on cancer survivorship. For example, the prostate cancer multidisciplinary team is one of 11 cancer specific teams within NBT. Each team is made up of a lead cancer clinician, surgeons, oncologist, cancer CNS, histopathologists, consultant radiologists, multidisciplinary team coordinator and clinical trials nurse.

3.7.1 Wellbeing service provision in the region

Mental wellbeing needs of men with prostate cancer in Bristol

The main mental wellbeing needs of men with prostate cancer in Bristol identified by respondents included the following:

- Support in dealing with diagnosis: men need help in coming to terms with diagnosis but also dealing with the fact that they are then coping with prostate cancer as a long term condition.
- Coping with the side effects of treatment, especially the emotional support dimension. Reassurance that men will get through the treatment was also considered important by respondents – seeing someone who had undergone treatment was considered important in providing reassurance to men who had been diagnosed with prostate cancer. Coping with the stigma associated with the various physical side effects (erectile dysfunction and continence) is another area where support services have a role to play.
- Pressure on relationships was identified as another major set of concerns – in terms of lack of sexual function, but also because fatigue brought on by treatment prevented men with helping their partners with household chores and other joint responsibilities.

Services available

NBT is one of 8 Trusts participating in Phase 2 of the National Cancer Survivorship Initiative (NCSI). As part of this (and Phase 1), a number of new initiatives in treatment and follow-up have been rolled out including an electronic holistic needs assessment pilot¹⁵ to analyse all the needs of the patient and health and wellbeing clinics (see Table 3.15). The main aim of these services is to help patients identify the most beneficial services to address and improve their wellbeing, and that this service would be integrated as part of the pathway.

One particular characteristic of provision of wellbeing services in Bristol is the fact that there has been a significant effort to integrate wellbeing into the treatment pathway for cancer but

¹⁴ Survival (one year) percentage is defined as the proportion of men who have received a diagnosis of prostate cancer in the previous 12 months and who are still alive.

¹⁵ An electronic holistic needs assessment pilot is an electronic solution for assessment and care planning. It provides an electronic record of people's concerns, which can be shared among multidisciplinary teams. It can be used to produce a personalised care plan to address the unmet needs of the patient.

also to design services that recognise the barriers that men face and also take account of the particular nature of prostate cancer.

One particular feature of the provision of services in Bristol is the range of courses that educate men (and other cancer patients) about how to improve and address their wellbeing. These courses include Living Well courses (specific for men with prostate cancer) and Energise (an exercise referral programme). The Penny Brohn centre offers a number of courses to cancer patients, not just from Bristol but from around the UK.

Living Well courses are offered at NBT for men with prostate cancer. These are designed to provide care, information and support to those living with and beyond cancer. Following treatment, patients are invited to attend a half/full day event of talks by a range of healthcare professionals. The events provide an opportunity for patients and/or carers to receive information and learn more about important aspects of caring for themselves, including information about health and wellbeing, managing side effects of disease and treatment, diet and exercise, emotional wellbeing, anxiety and stress management and financial advice. Having attended the Living Well day, men are offered the opportunity to attend a Living Well course to further explore their needs. Patients attend seven weekly sessions which can include discussions on coping with continence and erectile dysfunction, as well as learning about the side effects of other treatments and other self-management strategies.

Energise is a pilot exercise referral programme in Bristol specifically for people who have completed cancer treatments. It is operated through a partnership between Bristol City Council, NBT and Sports and Leisure Management Limited. While this is not a service that is targeted specifically at men with prostate cancer, it is a good example of the sort of “proxy” wellbeing service that can be targeted towards men. While the programme is designed at improving physical wellbeing, it also provides a comfortable environment for men to discuss their condition and their emotional needs.

The Penny Brohn Centre offers a “Living Well” course, which provides advice on techniques for people with cancer to support their spiritual, emotional and physical health. They are currently in the process of developing a course for men with active and advanced prostate cancer in association with Prostate Cancer UK.

Prospect Support Group is one of the main support groups for men with prostate cancer in Bristol. One of its most positive features is that it provides a forum for men (and their partners) who have been diagnosed with prostate cancer to discuss the emotional impact of prostate cancer. It also provides a “buddying system” which is an initiative where men who are about to begin treatment are able to speak to other men who have undergone a similar treatment in the past. This provides a forum from which newly diagnosed patients can seek reassurance, information and clarification about the consequences of treatment.

In terms of other forms of emotional support, the Harbour is a Bristol-based charity that provides counselling to people with life-threatening physical illnesses and has links with the North Bristol NHS Trust. This is one of the main voluntary sector organisations in Bristol that provides counselling services to men with prostate cancer and is provided free of charge. Self-referral is the main route to access these services.

In terms of the provision of information and support services, the Macmillan One to One Support Service is an example of another pilot initiative. It was developed as a two year pilot project between Macmillan and NBT and aims at developing a support service for people affected by cancer and their family members. There is also a cancer information and support centre at the Bristol Haematology and Oncology Centre in Bristol itself, which provides information, support and practical advice to people with cancer and their family members. Additionally, a new Macmillan Wellbeing Centre will open this year and will provide emotional, practical and financial support for people affected by any type of cancer, their families, friends and carers.

Commissioning intentions

While wellbeing services for men with prostate cancer are not currently considered to be a priority consideration for commissioners, much work has been undertaken in looking at how to embed wellness and wellbeing services into the formal pathway. A planned pathway is being trialled in NBT and demonstrates how services can be embedded into the treatment pathway for men with prostate cancer. Key to the success of such an approach is the need for a joined-up approach to provision of wellbeing services. Fundamental to this is the need for one person/group to coordinate provision, which has been successfully done in Bristol.

Additionally, the role played by the NBT as part of the NCSI is something that will give further momentum to the interest by commissioners in wellbeing services. Testing self-management and alternative routes of follow-up are both examples of initiatives for which it is possible to identify direct benefits in terms of improving patient care and making better use of scarce resources.

However, given the financial constraints that are on healthcare provision at the moment and the extra resources which tailored wellbeing services for men with prostate cancer would involve means that it will take time for this issue to be higher placed on the agenda.



Table 3.15 Summary of services in Bristol

| Service name, provider and sector | Summary description | Section(s) of pathway covered by the service | Awareness, Access and take-up | Points of learning / good practice |
|--------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Living Well courses, Penny Brohn Cancer Care, Voluntary sector | Penny Brohn centre runs a number of courses to assist people in living with the impact of cancer. They are also working with Prostate Cancer UK to design a number of courses targeted at men with prostate cancer in particular. | Following treatment | Self-referral is the main route by which men access these courses. Penny Brohn operates courses all over England. | It empowers men with prostate cancer to learn what will assist in improving their wellbeing. |
| Energise, Partnership between Bristol City Council, North Bristol Trust and Sports and Leisure Management Ltd, Partnership between sectors | Energise is an exercise referral programme in Bristol specifically for people who have completed cancer treatments. | Following treatment | Referral takes place from a healthcare professional. | The environment is safe, comfortable and motivating to those who want to take up exercise once again. |
| Living Well, North Bristol NHS Trust, Statutory sector (NCSI) | The Living Well half-day events provide an opportunity for patients and/or carers to receive information and learn more about important aspects of caring for themselves, including information about health and wellbeing, managing side effects of disease and treatment, and diet exercise, emotional wellbeing, anxiety and stress management and financial advice. Having attended the Living Well day, men are offered the opportunity to attend a Living Well course to further explore their needs. Patients attend 7 weekly sessions including discussion of continence and erectile dysfunction, as well as anti-cancer treatments/side effects and other self-management strategies. Spouses are also welcome to attend). | Following treatment | Following cancer treatment, patients are invited to attend a half/full day event of talks by a range of healthcare professionals. Each event hosts about 50/60 men. | The programme places an emphasis on equipping patients with the knowledge and skills that they require to empower them to self-manage their needs in the future. |
| Prospect Support Group, Patient support group, voluntary sector | Support group run by survivors. | Whole pathway | Self-referral is the main route by which men access this support group. | The group provides a safe forum for men who have been newly diagnosed to gain reassurance about treatment from those who |



| Service name, provider and sector | Summary description | Section(s) of pathway covered by the service | Awareness, Access and take-up | Points of learning / good practice |
|-------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------|--------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------|
| Cancer & Information Centre at Bristol Haematology and Oncology Centre, North Bristol NHS Trust, Statutory sector | The aim of the Centre is to offer information, practical advice and support to people with cancer, families and friends and also to provide healthcare professionals with an additional resource during any oncology treatments. | Whole pathway | Self-referral is the main route of access. | have. The centre provides a “one-stop” shop on information pertaining to wellbeing services for men with prostate cancer. |
| Macmillan Information Centre, Macmillan, Voluntary Sector | The centre has not started operating yet. | Whole pathway | The centre has not started operating yet. | The centre has not started operating yet. |
| Counselling, The Harbour, Voluntary sector | The Harbour provides a counselling service to people in Bath and Bristol, though this is not specific to men with prostate cancer. | Following diagnosis | Self-referral is the main route of access to these services. | The Harbour is integrated and linked in with the Urology Team in NBT. |
| Macmillan One to One Support Service, Macmillan (in partnership with North Bristol Trust), Voluntary sector | This initiative involves piloting a number of new roles which are designed to facilitate support for people living with and beyond cancer with the aim of improving their quality of life and ability to self-manage their condition, including community nurse, support workers and complex case managers. | Following diagnosis | Referral from the CNS is the preferred route of access. | The individual needs of the man are taken into account when they receive support from this service. |

3.7.2 Assessment of provision and lessons learnt

On the whole, there is a generally positive perception of wellbeing services for men with prostate cancer in Bristol. There is provision of a number of services, both generic and those tailored to those with needs specific to men with prostate cancer.

While respondents felt that there was progress being made in terms of provision of wellbeing services for men with prostate cancer across the wider Bristol area and that while Bristol was making better progress than other places in the UK, there was still space for progress to be made. Building momentum in achieving this was considered important. With respect to the tailoring of services to men with prostate cancer, a wide number of wellbeing services are being designed for men with prostate cancer. However, in order to achieve this fully, respondents stated that clinical teams had to be involved in the provision and resources were required to ensure services addressed the specific needs of men.

In terms of accessing these services, Bristol has made significant progress in terms of putting in place a “shadow pathway” for men to ensure that they access the services. There were some respondents that stated that more needed to be done to achieve this and embedding wellbeing services into the care pathway was the correct approach to take. There were mixed views on awareness. Awareness among surgical patients was high, but awareness outside of this group was variable. One way in which to address this which was recommended was to educate GPs about what is available for men with prostate cancer and enable them to provide adequate support.

All respondents agreed that where men were aware of services and were able to access them, take-up was high and in many cases, services were oversubscribed. One respondent stated that this was indicative of the success that came from targeting services at men.

Respondents were of the opinion that there were still barriers to be overcome in relation to engaging with men from BME communities. This is something which respondents stated would need to be addressed in the future, and that best practice from other areas would need to be adopted to achieve this.

Finally, the level of join-up in terms of delivering services was considered to be developing well, although it was said to be at an embryonic stage. To ensure that a coherent strategic direction could be achieved, a vision of wellbeing services provision had to be “owned” by one person. This is something that is in place in North Bristol NHS Trust and is considered to be one of the successful aspects of the provision of services there. One set of stakeholders which respondents felt needed to be included were GPs, to ensure that they were able to provide appropriate guidance to patients at the start of the pathway (i.e. addressing anxieties around diagnosis) or to address anxiety about recurrence.

3.8 Key findings from the case studies

Having examined the provision of wellbeing services in six areas around the UK, there are a number of characteristics that we have identified as being important to the effective provision of wellbeing services in an area. These are as follows:

- Men need an appropriate point of contact to signpost them to necessary services that cater to their particular wellbeing needs. Most usually, this is a CNS. This person plays an important role in helping men recognise their wellbeing needs and how they change at different stages of the cancer journey. Additionally, they can play an important co-ordinating role in ensuring that men are aware of what services they can access when required.
- Key to ensuring that men's wellbeing needs are being met is ensuring that they are identified at the correct time. In those case study areas where there was robust provision of wellbeing services, a significant feature was the ongoing and holistic needs assessment of the man's physical, emotional and social wellbeing needs.
- Cultural context matters and wellbeing services providers must be aware of this. This is evident in a number of ways – provision of services through the local spoken language (provision of services in Welsh), or awareness of particular stigmas that may feature in a society (Northern Irish men's approach to matters relating to sexuality), or awareness of the community settings in which men are (black communities, for example).
- Wellbeing services are better in those areas where there is an integration of services with the treatment pathway. Addressing wellbeing is considered as important as treatment of the cancer and to achieve this, there must be buy-in from and awareness raised among the clinical team (as well as other professionals involved in the man's cancer journey) about the importance of promoting wellbeing services.
- Wellbeing services that generate the largest interest and take-up among men with prostate cancer are those services which have been designed with the particular needs of men with prostate cancer in mind. Successful services are those that are relevant to men (show an understanding of men's barriers to addressing their own wellbeing) and are designed to address the wellbeing needs arising from a prostate cancer diagnosis.
- Wellbeing services must be made convenient for men. This is a particular challenge in rural areas. For example, transport links have a bearing on how often a man can access wellbeing support services. Using technology can be one way to overcome this, e.g. online counselling.
- There is a relationship between physical and emotional wellbeing. In those case study areas where the provision of wellbeing services appeared effective an understanding of the relationship between physical symptoms of treatment and emotional wellbeing underpinned the provision of services.

Strategic and joined-up co-ordination is a feature of the provision of better wellbeing services. A key element of this in such areas is the availability of an accurate map of wellbeing services that are available to men in an area. Such information can minimise duplication and maximise collaboration and effectiveness. Figure 3.7 presents an overview of the wellbeing services in each of the case studies examined in the previous sections, and highlights characteristics of provision in each. Figure 3.8 shows examples of good practice from each of the case study areas mapped onto a summary pathway.

Figure 3.7 Summary of wellbeing services across the UK in the case study areas – overview of provision of services from the case study analysis

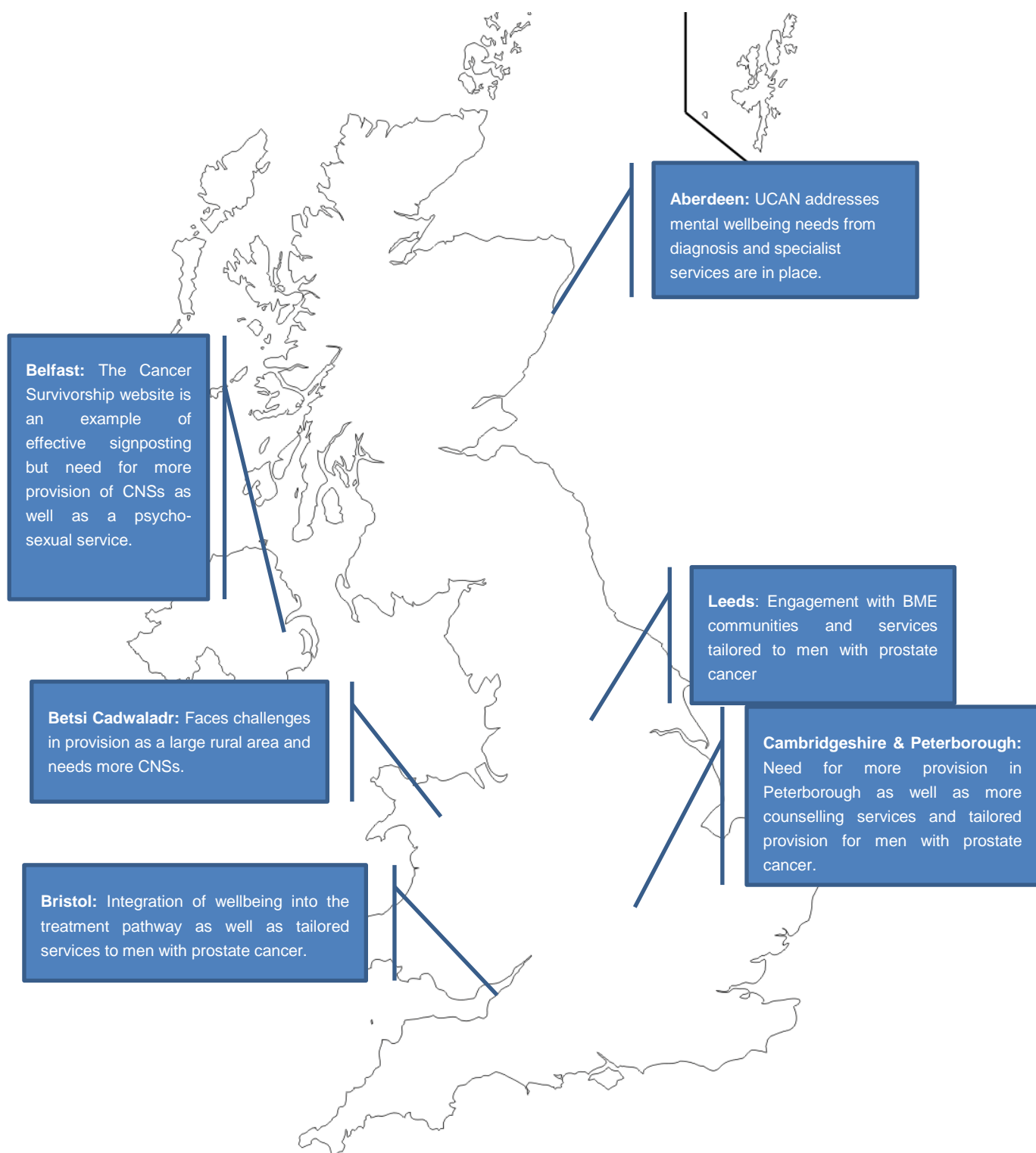




Figure 3.8 Examples of good practice in addressing the wellbeing needs of men with prostate cancer

Diagnosis

- **Belfast:** Men against Cancer self-referral clinic provides information on urological cancer to men
- **Cambridgeshire & Peterborough:** Macmillan Information & Support Centre provides informal emotional support and signposting to other services
- **Belfast:** The Northern Ireland Cancer Survivorship website provides an overview of services for cancer patients, including men with prostate cancer, in Northern Ireland
- **Leeds:** The Black Health Initiative previously operated a 'Men's Health and Wellbeing MOT', a Macmillan-sponsored men's health clinic which was run quarterly until funding ended. This clinic provided a community setting in which men could learn about prostate cancer.

Post-treatment

- **Betsi Cadwaladr:** Macmillan one-to-one community nurses provide support for people in the community to live with and beyond cancer
- **Cambridgeshire & Peterborough:** The "Moving Forward" course is focussed on teaching people techniques to live with, and beyond cancer
- **Aberdeen:** Clan House provides follow-up support to men with prostate cancer and their families.
- **Bristol:** The Penny Brohn centre runs a number of courses to assist people in living with the impact of cancer, including courses specifically targeted at men with prostate cancer.

Treatment

- **Betsi Cadwaladr:** A programme provided by a prostate cancer support group focussed on addressing emotional wellbeing during treatment
- **Aberdeen:** Services available to help men with prostate cancer address incontinence and erectile dysfunction and the resultant effect on wellbeing
- **Bristol:** Energise is an exercise referral programme in Bristol specifically for people who have completed cancer treatments.
- **Leeds:** The Prostate Exercise Programme is a 12 week exercise and support programme for prostate cancer patients completing treatment.

4 Conclusions and recommendations

Here we discuss the main findings of the research and offer a number of recommendations.

4.1 Conclusions

The main findings from the study are that:

- The emphasis on 'wellbeing' is increasing within the context of supporting people with LTCs – including prostate cancer. Wellbeing is a multi-faceted and dynamic concept. Men's wellbeing cannot therefore be addressed by a single action or intervention. Needs also vary by individual circumstances, stage on the prostate cancer journey and other factors. Tailoring services is therefore crucial.
- The needs of men with prostate cancer appear to be relatively consistent across the UK. In the main, they relate to: anxiety around diagnosis (and recurrence); coping with the emotional distress caused by the physical side effects of treatment; and pressure on relationships caused as a result of diagnosis. Wellbeing can also be affected by broader social concerns, such as the financial implications of treatment.
- Many men do not take a pro-active approach to addressing their health. Understanding the challenges in 'engaging with men' is fundamental to service provision. Families appear to be important and wellbeing for men with prostate cancer should also be considered in this context. This offers an opportunity: men can be engaged through, and supported by, family members.
- Provision of wellbeing services for men with prostate cancer is patchy. A number of factors appear to drive this variability, including: lack of resources; low awareness (of the problem and / or support services) among clinicians; over-concentration on 'the cancer' relative to 'the man'; and lack of local strategic direction. The voluntary sector plays a central role in providing specialist wellbeing services; the role of health services in England, Scotland, Wales and Northern Ireland is primarily commissioning / planning, funding and referring – and including consideration of wellbeing in 'mainstream' services.
- Wellbeing should be integrated into standard pathways. There is therefore an important role for holistic needs assessment. The manner / type of referral also seems to be fundamental to take-up of support services. Where men access wellbeing services, it is often because they have been encouraged to do so, be it by a wife or partner, other family member or through a formal referral by a CNS. Information provision / signposting alone is unlikely to be effective.
- The role of CNSs is therefore vital. This is because of: the information they can provide directly to men / their families; regular assessment of needs; and referral and signposting to wellbeing services. The extent of local clinical engagement in the 'wellbeing agenda' is therefore an important determining factor in the support men receive.
- Cultural context matters. This is particularly relevant in terms of engaging minority communities and difficult-to-engage groups. Reducing the barriers faced by men in these groups in addressing wellbeing needs arising from prostate cancer is a key factor in increasing their access to services, e.g. hosting wellbeing clinics in the community. Men from socially deprived backgrounds and men from ethnic minorities (especially black) have particular needs that arise in particular from the challenges in accessing those groups. Gay men also face particular barriers in accessing wellbeing services, as do men who are single or have no family available to them. Additionally, gaps in services provided through the Welsh language means that there are barriers to men in parts of Wales who are unable to express their emotions in a second language.
- Targeting and tailoring services to men with prostate cancer is effective. Men respond well to services that are relevant to their needs and delivered in an environment in which they are comfortable. In advertising or informing men about such services, providers need to be aware of the fact that men can fail to acknowledge that they have wellbeing

needs; using a 'proxy service', such as the 'men in sheds' programme, appears helpful in overcoming this barrier.

- There may be some generic services which are available to people with cancer that can also be accessed by men with prostate cancer. Generic services can be relevant to some of these men's needs but sometimes tailoring is necessary to ensure they engage with them.
- Collaboration between all relevant stakeholders in a region is important. By structuring relationships and partnerships between clinicians, community organisations and voluntary providers, an accurate map of services can be set out as well as a much more effective approach to provision for men. The most successful examples of wellbeing services are those that are provided by a partnership between a number of providers across statutory and voluntary services. This allows for a deeper understanding of the needs of men and draws on the strengths of each.
- In rural areas, locating wellbeing services near the treatment centre is important. In such areas, transport links are scarce so an important factor in ensuring men access wellbeing services is locating them on the hospital site. This also links wellbeing services to the treatment pathway, albeit informally.
- In summary, good practice is usually characterised by:
 - An appropriate point of contact for men to signpost them to necessary services that cater to their particular wellbeing needs. Most usually, this is a CNS;
 - Ongoing and holistic needs assessment of the man's physical, emotional and social wellbeing needs;
 - Integration of wellbeing services with the formal treatment pathway, with buy-in from the clinical team as to the importance of promoting wellbeing services;
 - Services that are relevant to men and which are marketed to make them appealing and pertinent to men's perceptions of wellbeing;
 - Services that understand the link between physical wellbeing and emotional wellbeing;
 - Strategic and joined-up co-ordination; and
 - An accurate map of wellbeing services that are available to men in an area to minimise duplication and to maximise collaboration.

4.2 Recommendations

In light of the findings made above, we make the following recommendations:

- Ensure adequate access to a CNS for men with prostate cancer, including a suitable consultation time for men following diagnosis. The role of the CNS is crucial in determining access to wellbeing services, as well as being a driver for the provision of these services.
- Promote awareness of 'wellbeing' among CNSs and the wider clinical workforce. In order to ensure that wellbeing is considered as an important part of the treatment pathway, all stakeholders who will come into contact with men with prostate cancer need to be involved in the understanding and heightening awareness of wellbeing services.
- Promote wellbeing as part of mainstream provision / pathways. This is probably best done as part of 'good practice in holistic needs assessment'. Integrating wellbeing services within a standard process of needs assessment, referrals and reviews plan gives wellbeing an important status in the eyes of the patient and ensures that they will take a proactive role in addressing and improving their wellbeing.
- Increase funding for pilot initiatives. Provision is patchy and 'what works' is being worked out in different local contexts. There are no set / recommended service models and only

by piloting new services to learn what works best for men can commissioners be provided with evidence that wellbeing has a bearing on health outcomes.

- Spread examples. Even within the limited scope of this research, there are examples of good practice. There is a possible role for Prostate Cancer UK to further explore / document and promote good practice examples (e.g. in the form of 'How to...' guides).
- Tailor provision. Find out about the communities you want to engage; in order to make wellbeing services appropriate for minority communities and difficult-to-engage groups, there needs to be an understanding of the barriers men with prostate cancer in those groups face.
- Learn what men want and what men need and tailor services accordingly. Much work has been done in this field already, but there is space to build on it. Use initiatives in the community to engage men from minority communities and difficult-to-engage groups. Bringing wellbeing services to community settings is an effective way of helping men in minority groups overcome one of the main barriers they face to wellbeing.
- Coordinate services locally. The use of CNSs and holistic needs assessments will play a vital coordinating function. There should also be some strategic overview. The provision of wellbeing services relies on many different components moving together. In order to ensure maximum effectiveness and best benefit for men, coordinating provision is important to be aware of what exists for men and also to ensure that signposting is as informative as possible.
- Partnership and collaboration is crucial. Some of the best examples of wellbeing services are those services that are delivered by organisations in partnership. Organisations can employ relative strengths in designing services that are relevant to men with prostate cancer.

Annex 1 Items reviewed as part of the literature review

Adams, Eike, Mary Boulton, Eila Watson, The information needs of partners and family members of cancer patients: A systematic literature review, *Patient education and counselling* 1 November 2009 (volume 77 issue 2 Pages 179-186

Balderson, N. and Towell, T. (2003), The prevalence and predictors of psychological distress in men with prostate cancer who are seeking support. *British Journal of Health Psychology*, 8: 125–134.

Beaumont, Jen (Office for National Statistics) (2011), Measuring national wellbeing: A discussion paper on domains and measures

Blank, T. O. and Bellizzi, K. M. (2006), After prostate cancer: Predictors of wellbeing among long-term prostate cancer survivors. *Cancer*, 106: 2128–2135

Bloch, S., Love, A., Macvean, M., Duchesne, G., Couper, J., Kissane, D. (2007) Psychological adjustment of men with prostate cancer: a review of the literature. *Biopsycho Soc*, 1(2)

Bonito, A., Horowitz, N., McCorkle, R., & Chagpar, A. B. (2013). Do healthcare professionals discuss the emotional impact of cancer with patients?. *Psycho-Oncology*.

Cancer Research UK (2012) How counselling can help
<http://www.cancerresearchuk.org/cancer-help/coping-with-cancer/coping-emotionally/talking-about-cancer/counselling/how-counselling-can-help>

Cancer Research UK (2014) Cancer Statistics: Key Facts (All cancers combined)
http://publications.cancerresearchuk.org/downloads/Product/CS_KF_ALLCANCERS.pdf

Chapman DP, Perry GS, Strine TW (2005). 'The vital link between chronic disease and depressive disorders'. *Preventing Chronic Disease*, vol 3, no 2, pp 1–3

Clark, Jack A., Nelda P. Wray and Carol M. Ashton Living With Treatment Decisions: Regrets and Quality of Life Among Men Treated for Metastatic Prostate Cancer *Journal of Clinical Oncology*, Vol 19, No 1 (January 1), 2001: pp 72-80

Couper, J. W., Love, A. W., Dunai, J. V., Duchesne, G. M., Bloch, S., Costello, A. J., & Kissane, D. W. (2009). The psychological aftermath of prostate cancer treatment choices: a comparison of depression, anxiety and quality of life outcomes over the 12 months following diagnosis. *Medical Journal of Australia*, 190(7), S86.

Courtenay, WH. (2000) Constructions of masculinity and their influence on men's wellbeing: a theory of gender and health. *Social Sciences and Medicine*.

Dale, J., Jatsch, W., Hughes, N., Pearce, A. and Meystre, C. (2004), Information needs and prostate cancer: the development of a systematic means of identification. *BJU International*, 94: 63–69.

Davison, B. Joyce R.N., Ph.D.; Degner, Lesley F. R.N., Ph.D., Empowerment of men newly diagnosed with prostate cancer, *Cancer Nursing*: June 1997 - Volume 20 - Issue 3 - pp 187-196

De Neve, Diener, Tay & Xuereb (2013). The objective benefits of Subjective Wellbeing. Centre for Economic Performance, LSE

Defra website, Sustainable Development pages:
<http://www.defra.gov.uk/sustainable/government/progress/national/68.htm>

Department of Education (2010) Childhood wellbeing: a brief overview
<http://www.education.gov.uk/research/data/uploadfiles/FinalChildDFEwebsite.pdf> p. 2

Department of Health (2011) National Cancer Strategy
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213785/dh_123394.pdf

- Department of Health (2012) Quality of Life of Cancer Survivors in England
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/267042/9284-TSO-2900701-PROMS-1.pdf
- Department of Health (2013) *The Mandate: a mandate from the government to the NHS Commissioning Board: April 2013 to March 2015*
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/256497/13-15_mandate.pdf
- Department of Health (2014) Wellbeing : Why it matters to health policy
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/277566/Narrative_January_2014_.pdf
- Department of Health (2014) Wellbeing Why it matters to health policy
- Department of Health, Public Safety and Social Services, Northern Ireland (2009) Service Framework for Cancer Prevention, Treatment and Care
- Diener & Chan (2011). Happy people live longer: subjective wellbeing contributes to health and longevity
- Dodge, R., Daly, A., Huyton, J., & Sanders, L. (2012). The challenge of defining wellbeing. *International Journal of Wellbeing*
- Eton, David T and Stephen J LePore, Prostate cancer and health-related quality of life, *Psychooncology*. 2002; 11(4): 307–326
- European Quality of Life Survey (2012). Survey Report
- Foresight (2008) Mental Capital and Wellbeing: Making the most of ourselves in the 21st century
- Forlani, C., Morri, M., Ferrari, B., Dalmonte, E., Menchetti, M., De Ronchi, D., & Atti, A. R. (2013). Prevalence and Gender Differences in Late-Life Depression: A Population-Based Study. *The American Journal of Geriatric Psychiatry*.
- Hack, T. F., Degner, L. F. and Parker, P. A. (2005), The communication goals and needs of cancer patients: a review. *Psycho-Oncology*, 14: 831–84
- Harrison, James, D Young, Jane, Price, Melanie, Butow, Phyllis, Solomon, Michael, , What are the unmet supportive care needs of people with cancer? A systematic review, *Supportive Care in Cancer*
- Harvard Medical School (2013) Emotional Wellbeing and Mental wellbeing
<http://www.health.harvard.edu/category/emotional-wellbeing-and-mental-health>
- Helgason, ÁR; Adolfsson, J; Dickman, P; Fredrikson, M; Steineck, G Distress due to unwanted side-effects of prostate cancer treatment is related to impaired wellbeing (quality of life). *Prostate Cancer & Prostatic Diseases* . 1998, Vol. 1 Issue 3
- Ipsos MORI (2012) Evaluation of Adult Cancer Aftercare Services – Wave 1 Report
- Katon WJ (2003). ‘Clinical and health services relationships between major depression, depressive symptoms, and general medical illness’. *Biological Psychiatry* , vol 54, no 3, pp 216–26
- Khan, N. F., Ward, A. M., Watson, E., & Rose, P. W. (2010). Consulting and prescribing behaviour for anxiety and depression in long-term survivors of cancer in the UK. *European Journal of Cancer*, 46(18), 3339-3344.
- Lara Traeger, Frank J. Penedo, Jeffrey S. Gonzalez, Jason R. Dahn, Suzanne C. Lechner, Neil Schneiderman, Michael H. Antoni, Illness perceptions and emotional wellbeing in men treated for localized prostate cancer, *Journal of Psychosomatic Research*, Volume 67, Issue 5, November 2009, Pages 389-397
- Macmillan (2006) Worried sick: the emotional impact of cancer
http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Campaigns/Impact_of_cancer_english.pdf

Macmillan (2011) Psychological and emotional support provided by Macmillan Professionals: An evidence review

<http://www.macmillan.org.uk/Documents/AboutUs/Commissioners/PsychologicalandEmotionalSupportProvidedbyMacmillanProfessionalsEvidenceReviewJuly2011.pdf>

Macmillan (2012) *Statistics Fact Sheet*

<http://www.macmillan.org.uk/Documents/AboutUs/Research/Keystats/StatisticsFactsheet.pdf>

Macmillan (2013) *By 2020 almost half of Britons will get cancer in their lifetime – but 38% will not die from the disease*

http://www.macmillan.org.uk/Aboutus/News/Latest_News/By2020almosthalfofBritonswillgetancerintheirlifetime%E2%80%93but38willnotdiefromthedisease.aspx

Macmillan (2014) *Loneliness damaging the lives of 400,000 people living with cancer, new research shows*

http://www.macmillan.org.uk/Aboutus/News/Latest_News/Lonelinessdamagingthelivesof400,000peoplelivingwithcancer,newresearchshows.aspx

Macmillan Cancer Support (2012) Depression

<http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Emotionaleffects/Depression.aspx>

McDowell ME, Occhipinti S, Ferguson M, Dunn J, Chambers SK. (2010) 'Predictors of change in unmet supportive care needs in cancer.' *Psychooncology*;19(5):508-16

Mental Wellbeing Statistics: Men & Women <http://www.mentalhealth.org.uk/help-information/mental-health-statistics/men-women/>

Movember Foundation (2013) Men's Health - Prostate Cancer

<http://uk.movember.com/mens-health/prostate-cancer>

National Cancer Survivorship Initiative (2013) *Living with and beyond cancer: Taking action to improve outcomes* <http://www.ncsi.org.uk/wp-content/uploads/Living-with-and-beyond-2013.pdf>

Naylor, C., Parsonage, M., McDaid, D., Knapp, M., Fossey, M., & Galea, A. (2012). Long-term conditions and mental wellbeing: The cost of co-morbidities. The King's Fund (http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/long-term-conditions-mental-health-cost-comorbidities-naylor-feb12.pdf)

National Institute for Health and Care Excellence (2014) *Prostate cancer diagnosis and treatment*

New Economics Foundation (2008) Five ways to wellbeing

New Economics Foundation (2012) Measuring wellbeing: a guide for practitioners

NHS England (2013) The NHS belongs to the people: a call to action

http://www.england.nhs.uk/wp-content/uploads/2013/07/nhs_belongs.pdf

Northern Ireland Cancer Registry (2012) Cancer Incidence and Survival in Northern Ireland Statistics Release <http://www.northernireland.gov.uk/news-dhssps-120612-publication-of-the>

Office for National Statistics (2003) Better Or Worse: A Longitudinal Study Of The Mental wellbeing Of Adults In Great Britain,

Prostate Cancer Foundation of Australia (2009) Maintaining your wellbeing: Information on depression and anxiety for men with prostate cancer and their partners

<http://www.prostate.org.au/articleLive/attachments/1/BEY%20prostate%20booklet.pdf>

Prostate Cancer Foundation of Australia (2013) Wellbeing: Maintaining with wellbeing localised prostate cancer

http://www.prostate.org.au/articleLive/attachments/1/LPCSP/2013/2013_PCFA_Localised_4_Wellbeing.pdf

Quality Health (2013) National Cancer Patient Experience Survey

Ream, E., Quennell, A., Fincham, L., Faithful, S., Khoo, V., Wilson-Barnett, J., Richardson, A. (2008) Supportive care needs of men living with prostate cancer in England: a survey. *British Journal of Cancer*, 98

Rethink (2012) Stop people dying 20 years too soon <http://www.rethink.org/get-involved/campaigns/20-years-too-soon/facts-physical-and-mental-health>

Scottish Government (2008) Better Cancer Care: An Action Plan <http://www.scotland.gov.uk/Publications/2008/10/24140351/0>

Scottish Government (2013) Transforming Care After Treatment <http://www.scotland.gov.uk/Topics/Health/Services/Cancer/TCAT>

Sederer LI, Silver L, McVeigh KH, Levy J (2006). 'Integrating care for medical and mental illnesses'. *Preventing Chronic Disease*, vol 3, no 2, pp 1–3.

Stiglitz, J, Amartya Sen and Jean-Paul Fitoussi (2007) Report by the Commission on the Measurement of Economic Performance and Social Progress http://www.stiglitz-sen-fitoussi.fr/documents/rapport_anglais.pdf

Trask, P (2004) Quality of life and emotional distress in advanced prostate cancer survivors undergoing chemotherapy, *Health and Quality of Life Outcomes* 2004, 2:37

Watson E et al (2012), Personalised cancer follow-up: risk stratification, needs assessment or both, *British Journal of Cancer*

Welsh Government (2012) Together for Health, Cancer Delivery Plan for the NHS to 2016

Welsh Government (2014) Welsh Cancer Patient Experience Survey

Department of Health and the Men's Health Forum (2008) The gender and access to health services study: final report. (authored by Wilkins, D., Payne, S., Granville, G., Branney, P.)

Annex 2 Topic guide for scoping phase interviews

Instructions for the interviewer

Below we have set out the themes for exploration in the scoping phase of the research project. We are using the same topic guide for both healthcare professionals and stakeholders/opinion formers. This is not a detailed set of questions. Given that these are exploratory questions to assist in defining the range of wellbeing services and to aid case study collection, we have identified a number of themes worth exploring with some extra prompts.

We expect that interviews will last between 45-60 minutes. Please ask the interviewee for their permission to record the interview and inform them that no individuals will be identified in reporting the results.

Before the interview commences, please introduce the interviewee to the nature of the research project. ICF GHK has been commissioned by Prostate Cancer UK to research the availability of services aimed at improving wellbeing for men with prostate cancer across the UK (including mental wellbeing), in order to establish if they are receiving the help they need, whether at the point of their diagnosis or treatment. We are currently establishing a definition and framework for the study of wellbeing services, as well as an analysis of the issues affecting access to them. This will be used to inform the second stage – an analysis of the provision of wellbeing services across the UK.

Respondent background

- Explore the interviewee's background, e.g. name, organisation, role in the organisation, familiarity with both prostate cancer and mental wellbeing issues
- Explore their experience, e.g. how long have they been in their current role, have they worked in a similar role before

Theme 1: Need for and nature of wellbeing services

Here we are seeking to establish the nature of wellbeing services challenge (i.e. the sort of needs that men with prostate cancer have)

- What do you think are the broad needs for wellbeing services for men with prostate cancer?
- To what extent / in what ways would you say that different groups have different needs – e.g. do particular ethnic or socio-economic groups have particular wellbeing needs?
- How do men's needs change as they move from diagnosis, into treatment and then into follow-up?
- How do men's needs vary according to different treatments they may have had? (Probably only meaningful for those familiar with prostate cancer)
- What do you feel are the main **mental wellbeing** needs that you think men with prostate cancer have?
 - Are there ways in which can impact on the mental wellbeing needs of men with prostate cancer?
 - Are there ways in which social wellbeing needs can impact on the mental wellbeing needs of men with prostate cancer?

Theme 2: Issues in the delivery of wellbeing services

Here we are seeking to establish where there are gaps in place in the delivery of wellbeing services and if there are any issues in accessing services, both across the board and for harder to reach groups

- How would you describe the provision of wellbeing services to men with prostate cancer?
 - Is there an emphasis on one type of wellbeing service as opposed to other types?

- How would you describe this provision in terms of consistency and accessibility across regions?
- What is your understanding of the extent to which services are tailored or specifically targeted to men with prostate cancer?
- What would you describe as the main issues affecting the availability of wellbeing services to men with prostate cancer?
- Who would you say are the main providers of wellbeing services to men with prostate cancer?
 - Do providers come from the voluntary sector/NHS/private sector?
 - Why do you think this is?
- How easy would you say it is for men with prostate cancer to access these services?
 - Do they need to be referred? If so, by whom?
 - How informed are men about the availability of these services?
 - How do they access this information?
 - How would you describe their take-up of these services?
- In terms of services for difficult-to-engage groups (e.g. ethnic minorities), would you say that they are able to access these services?
 - How informed are they about the availability of these services?
 - Is there a special effort to provide them with information on these services?
 - Does this have an effect? Does it increase their take-up of these services?

Theme 3: Suggestions for main phase of research

Here we want to draw on the interviewee's expertise in order to provide suggestions for the main phase of research (selection criteria for the case study analysis, identifying 'gold standard' areas etc)

- In selecting case studies, we are interested in areas with especially good practice in the provision of wellbeing services, as well as those where there is clear room for improvement. Given this, which areas would you suggest, and why?
- Looking at patients that suffer from other cancers, would you say that there is an approach to the provision of wellbeing services that could be applied to men with prostate cancer? Why?
- Is there anything else you would like to add?

Annex 3 List of interviewees (scoping phase)

| Name | Position | Organisation |
|--------------------------------------|----------------------------------------------------------------|------------------------------------------|
| <i>Healthcare professionals (12)</i> | | |
| Liz Atkinson | Head of Care Services | Cancer Focus Northern Ireland |
| Stephen Douglas | Clinical Nurse Specialist (also member of BAUN) | Morecambe Bay NHS Trust (BAUN) |
| David Scott | Odyssey Project Course Director | Odyssey Project |
| Georgia Diebel | Head of Living Well Services | Penny Brohn Cancer Care |
| Jo Crowley | Community Nurse Specialist | Prostate Cancer UK |
| Catherine Winsor | Community Support Services Manager (London and the South East) | Prostate Cancer UK |
| Louise Jackson | Community Support Services Manager (Midlands) | Prostate Cancer UK |
| Samantha Fairclough | Community Support Services Manager (Wales) | Prostate Cancer UK |
| Steven Rowntree | Community Support Services Manager (North East) | Prostate Cancer UK |
| Craig Millar | Community Support Services Manager (Scotland) | Prostate Cancer UK |
| Louisa Fleure | BAUN Council member (and clinical nurse specialist) | British Association of Urological Nurses |
| John Robertson | PCUK helpline nurse | Prostate Cancer UK |
| <i>Stakeholders (10)</i> | | |
| Professor Sara Faithfull | Professor of Cancer Nursing Practice | University of Surrey |
| Professor Steve Robertson | Professor and Co-Director | Leeds Metropolitan University |
| David Wilkins | Policy Officer | Men's Health Forum |
| Professor Eila Watson | HRH Prince Sultan Professor in Supportive Cancer Care | Oxford Brookes University |
| Robert Banner | Director | Prostaid |
| Sandy Tyndale-Biscoe | Chairman | Prostate Cancer Support Federation |
| Andrea Hall | ASAP programme | Prostate Cancer UK |
| Angela Foll | CEO | Relate (Bedfordshire and Luton) |
| Dr Laura Ashley | Senior Lecturer in Psychology | Leeds Metropolitan University |
| Wendy Smith | Health and Wellbeing Manager | Age UK |

Annex 4 Sources used for case studies

Sources – Betsi Cadwaladr

Interviews

- Sheila Smith, Chairperson – North Wales Cancer Care
- David Maitland Price, Chair, North Wales Prostate Cancer support group
- Amanda Coathup, Macmillan Information Support Co-ordinator
- Lara Davies, Prostate Cancer UK-funded CNS
- Louise Pickering, Macmillan one-to-one community oncology nurse

Documents

- Betsi Cadwaladr University Health Board (2012) Cancer Annual Report 2012
- National Cancer Intelligence Network (2012) Cancer e-atlas
- North Wales Cancer Service website <http://www.wales.nhs.uk/sites3/home.cfm?orgid=456>
- North Wales Cancer Patient Forum <http://www.northwalescancerforum.co.uk/en/>

Sources – Cambridgeshire & Peterborough

Interviews

- Ann Nimmo, Clinical Nurse Specialist
- Lisa Punt, Maggie's Wallace
- Rebecca Hardy, Representative from the Macmillan Information and Support Centre

Documents

- Cambridgeshire County Council & NHS Cambridgeshire (2013) Cambridgeshire Joint Strategic Needs Assessment (JSNA): Summary Report 2012-2013
- Cambridgeshire Insight (2013) NHS Cambridgeshire and Peterborough CCG health profile – July 2013
- Menter (2005) Review of Ethnicity in the East of England
- Peterborough City Council (2013) Joint Strategic Needs Assessment
- National Cancer Intelligence Network (2013) Cancer e-atlas
- National Cancer Intelligence Network (2003) Cancer prevalence e-atlas
- Quality Health (2012a) National Cancer Patient Experience Programme: 2011/12 survey, Cambridge University Hospitals NHS Foundation Trust
- Quality Health (2012a) National Cancer Patient Experience Programme: 2011/12 survey, Peterborough and Stamford Hospitals NHS Foundation Trust

Sources - Aberdeen

Interviews

- Craig Millar, Prostate Cancer UK, Community Support Service Manager (Scotland)
- Neil McLachlan, MCN Manager, North Scotland Cancer Network (NOSCAN)
- Debbie Munro, Cancer Nurse Specialist, Urological Cancer Charity (UCAN)
- Linda Pennet, Cancer Nurse Specialist, Urological Cancer Charity

- Joan Cowie, Clan House, Information Coordinator

Documents

- Aberdeen City Census return 2011
- ISD Scotland data on male genital organ cancers
- NHS Grampian (2012), Aberdeenshire Joint Strategic Needs Assessment

Sources - Belfast

Interviews

- Bryan Irwin, Development manager, Cancer Lifeline
- Deirdre Conlon, Deputy head of care services, Cancer Focus NI
- Joanne Cullen, Cancer services manager, Belfast Health and Social Care Trust
- Liz Atkinson, Head of care services, Cancer Focus NI
- Professor Eilis McCaughan, Professor of Cancer Care, University of Ulster

Documents

- Belfast Health and Social Care Trust (2013) *Commissioning Plan 2013/14*; available at: <http://www.hscboard.hscni.net/lcg/050%20Belfast%20Local%20Commissioning%20Group/1%20Publications/Belfast%20Local%20Commissioning%20Plan%202013-2014.pdf>
- Belfast Health and Social Care Trust (2014) Welcome: <http://belfasttrust-cancerservices.hscni.net/AboutUs.htm>
- Health and Social Care Board & Public Health Agency (2013) Commissioning Plan 2013/14: [http://www.hscbusiness.hscni.net/pdf/Commissioning_Plan_\(1\).pdf](http://www.hscbusiness.hscni.net/pdf/Commissioning_Plan_(1).pdf)
- Health and Social Care Board and Public Health Agency (2014) *Commissioning Plan 2014/15*; available at: <http://www.hscboard.hscni.net/board/meetings/March%202014/Item%2010%20-%2002%20-%20Draft%20Commissioning%20Plan%202014%2015%20%2013%20March%20Board%20PDF%204423KB.pdf>
- Northern Ireland Assembly Research and Information Service (2013) Cancer Services: Northern Ireland and the Republic of Ireland: <http://www.niassembly.gov.uk/Documents/RaISe/Publications/2013/health/14213.pdf>
- Northern Ireland Cancer Registry (2013) Prostate Cancer: Mortality 1993 – 2012: <http://www.qub.ac.uk/research-centres/nicr/FileStore/PDF/Mortality/Filetoupload,439639,en.pdf>
- Northern Ireland Statistics and Research Agency (2010) Northern Ireland Multiple Deprivation Measure 2010 http://www.nisra.gov.uk/deprivation/archive/Updateof2005Measures/NIMDM_2010_Report.pdf
- University of Ulster and Ulster Cancer Foundation (2011) The experience and coping behaviours of men with prostate cancer receiving combined radiotherapy and hormone treatment: <http://www.science.ulster.ac.uk/inr/mcireports>

Sources - Leeds

Interviews

- Heather Nelson, Chief executive, Black Health Initiative
- Sarah Prescott, Health and Wellbeing Coordinator, Age UK Leeds

- Steve Edwards, Service Development Manager for Macmillan
- Tom Mansell, Macmillan Information Project Officer

Documents

- Healthwatch Leeds (2013) *Your guide to clinical commissioning groups in Leeds*
http://www.healthwatchleeds.co.uk/sites/default/files/your_guide_to_clinical_commissioning_groups_in_leeds.pdf
- Leeds Church Institute (2010) *Deprivation and Inequality in Leeds*
- Leeds City Council (2012) *Leeds Joint Strategic Needs Assessment 2012*
<http://observatory.leeds.gov.uk/resource/view?resourceId=1497>
- Leeds City Council (2012) *State of the City: Leeds 2012*
- Leeds City Council (2013) *Leeds Joint Health and Wellbeing Strategy 2013-2015*
http://www.leeds.gov.uk/docs/JHWS_FINAL_webREV%20ZI.pdf
- Leeds City Council (2013) *Leeds Population*
<http://www.leeds.gov.uk/council/Pages/Leeds-population.aspx>
- Leeds Observatory
<http://observatory.leeds.gov.uk/dataviews/tabular?viewId=274&geold=6&subsetId=>
- Public Health Observatories – Area Leeds MCD
<http://www.apho.org.uk/resource/item.aspx?RID=50331>

Sources - Bristol

Interviews

- Dr Jonathan Rees, GP with interest in men's health and urology (helps to run a community Urology service across Bristol, North Somerset and South Gloucestershire)
- Emma Elliott, Clinical Nurse Specialist, North Bristol NHS Trust.
- Georgia Diebel, Head of Living Well Services, Penny Brohn Cancer Care
- Malcolm Gamlin, Prospect Prostate Cancer Support Group

Documents

- Bristol City Council (2012) *Bristol Joint Strategic Needs Assessment*
- Bristol City Council (2013) *Bristol Joint Health and Wellbeing Strategy*
- Bristol City Council (2013) *State of the City 2013: Mayoral Priorities*
http://www.bristol.gov.uk/sites/default/files/documents/council_and_democracy/statistics_and_census_information/State%20of%20the%20City%202013-%20Mayoral%20vision%20v8.pdf
- NHS, Department of Health, Macmillan (2013) *Living with or beyond cancer: Taking action to improve outcomes* <http://www.ncsi.org.uk/wp-content/uploads/Living-with-and-beyond-2013.pdf>
- North Bristol NHS Trust (2013) *Cancer Services Newsletter*

Annex 5 Topic guide used in case study interviews

Instructions for the interviewer

Below we have set out the headings for the data collection for analysis of the case studies chosen for the analysis phase of the research project.

We expect that interviews will last around 45 minutes. Please ask the interviewee for their permission to record the interview and inform them that no individuals will be identified in reporting the results.

Before the interview commences, please introduce the interviewee to the nature of the research project. ICF GHK has been commissioned by Prostate Cancer UK to research the availability of services aimed at improving wellbeing for men with prostate cancer across the UK (with a specific focus on mental wellbeing), in order to establish if they are receiving the help they need, whether at the point of their diagnosis or treatment. We are currently undertaking an analysis of the provision of wellbeing services across the UK using six case studies, of which [REGION] is one.

Respondent background

Explore the interviewee's background, e.g. name, organisation, role in the organisation, familiarity with both prostate cancer and mental wellbeing issues.

Context

In this section of the interview, we are seeking to elicit a description of the characteristics of the region. We will have gathered a lot of summary statistics relating to issues such as prevalence. Here, we are seeking to gather information about particular characteristics or historical traits of the area that we may have missed.

1. How would you describe {AREA NAME} – for example in relation to:
 - a. rural / urban.
 - b. socio-economic status.
 - c. age profile of the population.
 - d. ethnic diversity.
 - e. prevalence of prostate cancer.

Wellbeing service provision in the area

The purpose of this part of the interview will be to gather, from the respondent, their sense of the overall map of provision of wellbeing services in the region. Here, we are looking to support the data we have already collected about provision of

2. What would you say are the main mental 'wellbeing' needs of men with prostate cancer in {AREA NAME}?
3. Overall, how would you describe the provision of services to address these needs?
4. More specifically, please describe the support services provided.

Since we are partly looking to map services, we will need to explore a set of topics for each service discussed – not necessarily with each interviewee – but there is some fact finding to be done (see the table in the report template). Topics include:

- Which organisations provide these services?
- To what extent are these services specifically targeted towards men with prostate cancer?
 - Are there services that are further tailored to other harder-to-reach groups?
 - What sort of services are in place for partners/spouses/family members?
- How do beneficiaries access the services? Are these services part of a formal pathway / network?

- Are there any particular barriers for specific groups? Any good practice in reaching these groups?
 - Any specific approaches to promoting take-up?
 - What is the (approximate) scale of the service, e.g. how many beneficiaries does it support each year?
5. How are wellbeing services commissioned / planned in the area?
- a. Is there a commissioning intention / plan for wellbeing services?
 - b. To what extent is this bespoke to men with prostate cancer?

Assessment of services and lessons learnt

In this section of the interview, we are seeking to elicit an assessment of wellbeing services for men with prostate cancer on a number of distribution networks including:

6. Overall, how would you rate the services provided? Prompt in relation to:
- a. The extent of the coverage of the area
 - b. The extent of tailoring of services to men with prostate cancer
 - c. The ease with which men can access these services
 - d. The awareness of the existence of these services
 - e. The take-up of these services by men with prostate cancer
 - f. The extent to which harder-to-reach groups are aware of and can access wellbeing services
 - g. The level of “join-up” in terms of provision
7. What recommendations would you make to other areas in setting up wellbeing services for men with prostate cancer?
8. Are there any points you would like to make to Prostate Cancer UK in developing this agenda?