

# Final report

April 2014



## For the Evaluation of Prostate Cancer UK's Information and Helpline Services



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# Executive Summary

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This report sets out the findings from the evaluation of Prostate Cancer UK's Information and Helpline services. The findings are based on:

- **Background research and secondary data analysis** of information and previous reports provided by Prostate Cancer UK, including helpline satisfaction surveys and Google Analytics;
- 14 telephone **interviews with members of staff** across Prostate Cancer UK;
- A **focus group with the specialist nurses** who staff the helpline;
- 50 telephone **interviews with users** of Prostate Cancer UK's helpline and information service;
- 15 telephone **interviews with health professionals that have used** Prostate Cancer UK's services;
- Fieldwork in six **health and community settings**, as well as one depth interview;
- Eight **focus groups with people who have not used Prostate Cancer UK's services**, all aged over 50 with six groups of men and two women;
- 10 **follow-up telephone interviews** with a selection of the service users.

The helpline is a core service and is growing rapidly. Prostate Cancer UK literature is the most common way for users to find out about the helpline, although the internet – and in particular, the charity's website – has grown in importance. Satisfaction rates are very high. Only 2% of users said nothing changed after their call, illustrating the impact the service has; more than 80% felt that the specialist nurses helped in a way health professionals could not. Growth in the latest year (2012-13 compared to 2011-12) has been most pronounced in London and the East Midlands, with use spiking among those aged 61-75. Use is over-concentrated in London and the South East, compared to other regions of the UK. In terms of ethnicity, use of Prostate Cancer UK's helpline is broadly reflective of the population. It is notable that target populations such as Black African and Black Caribbean are also over concentrated in London, however Prostate Cancer UK does not significantly over represent these groups. Prostate Cancer UK should go further to reach more Black African and Black Caribbean users, given that these groups are higher risk.

The **information service** includes booklets, fact sheets and audiovisual resources. There were a total of 415,000 information materials distributed in 2012-13, an increase of 18% on the previous year. A majority of orders are made through the internet (56%), with another 26% through the helpline. As with the helpline, **satisfaction rates are high** and **use is over-concentrated in London and the South-East**, relative to other areas. The Tool Kit is a folder of information tailored to men, with 3,132 sent out in 2012-13, up 1.3% on the previous year. A key part of Prostate Cancer UK's information service is the charity's online presence. The internet is an important source of orders of information, but users also look at the **website** in its own right. Use of the site is **over-concentrated in London** relative to other regions. The charity also has a nascent presence on Facebook and Twitter. The

growing importance of the internet as a source of health information means that growing the charity's online presence will be a priority over coming years.

Based on feedback from a range of sources, Prostate Cancer UK staff are **confident that the information produced by Prostate Cancer UK is of a high quality**. Although staff interviewed broadly knew the information and services available, there was an expressed desire to **know more and for greater internal communication** – particularly in view of the pace of change in the organisation. The strengths of the information service are understood by staff to be the breadth and depth of information available in a balanced and jargon-free form. The helpline is considered to benefit from expert input from specialist nurses; some staff considered the helpline to be the most valuable source of support available from Prostate Cancer UK.

Specialist nurses expressed some concern that a **culture of target-setting** puts a focus on quantity over quality. A recurring theme of interviews with staff was that, in view of the quality of the information and services, staff consider the **priority to be widening their distribution**. This can be achieved by **raising awareness** of the charity's information and services. An important channel for this is **health professionals**, who are considered the first port of call for men diagnosed with prostate cancer and their families. Staff also expressed a desire for **more research into and outreach** to groups such as those with literacy issues or other **barriers to accessing information**.

Most of the service users interviewed were **very satisfied** with Prostate Cancer UK's information and services. In general, service users appreciated the quality of information: the clarity and jargon-free language used, as well as the breadth and detail available. The information was considered accurate and reliable. Helpline users often appreciated having **more time** than they were able to have with health professionals. Very few respondents reported having any concerns about contacting Prostate Cancer UK. There were not many suggestions for improvements; one improvement would be more specific support for carers; some participants also wanted more information on side effects than they had accessed. The most often cited benefits of contact with Prostate Cancer UK were **useful information and increased confidence/reassurance**. Service users can also use the information to have **better discussions with or even challenge their health professionals**. Some users go beyond this and use Prostate Cancer UK information to make **treatment decisions**. Most users anticipated using the charity's services again only if necessary. However, there was a high level of appreciation for the charity and many participants would be **willing to do something for the charity** (volunteer/donations). There was evidence of ongoing engagement through the Online Community.

The health professionals interviewed who were already in touch with Prostate Cancer UK were **highly satisfied** with the organisation. Many had a long-standing relationship with the charity, but new users often found Prostate Cancer UK through a web search. Among those that had introduced the charity's information more recently, there were examples of the **information being preferred to other sources of information**. Health professionals praised the quality and design of the information. The accuracy was also considered vital as that meant it complemented what health professionals were telling patients and their families about prostate cancer. Health professionals valued having something they can give to patients to take away, since they recognised that patients and their families **may not be able to absorb all of the information given in a clinical setting**. Some health professionals also mentioned using Prostate Cancer UK information, especially the Tool Kit, as a **source of education for nurses**. Health professionals revealed a reluctance to give the Tool Kit to

patients, considering it too broad and not specific to an individual's case. The helpline was also not recommended very strongly. Prostate Cancer UK can do more to make clear to health professionals what information and services are available. The main criticism was of the website, which some health professionals suggested should store details and not always ask for donations.

The site visits showed **mixed levels of awareness and use of Prostate Cancer UK's services within the specialist cancer settings**. While Maggie's Centre in Glasgow used and was satisfied with the charity's information, awareness was more mixed among staff within the Northern Irish hospital cancer unit. Satisfaction with and usage of specific Prostate Cancer UK booklets were found to be high, but staff were not referring patients to the helpline. While there was some use of Prostate Cancer UK information within the Welsh cancer hospital, its presence as a charity was **marginal compared to the 'embedded' charities** within the hospital such as Macmillan and the local charity Tenovus; and staff criticised Prostate Cancer UK's **lack of Welsh language material and Welsh branding** which were seen as key to credibility within Wales. Within the non-cancer settings, awareness and use of the charity's services was high for the specialist cancer nurse at HMP Whatton, but **awareness of the charity was low among non-cancer specialist staff** within both HMP Whatton and the other non-cancer services visited. Staff at the settings visited made a number of **suggestions as to how Prostate Cancer UK could help them in their role**, including:

- **Easy Read material** (including to support diagnosis, decision making around treatment and aftercare, and electronic material which could be locally adapted)
- **Volunteer providing support** for patients within clinics
- Funding of **specialist nurse**
- **Support group** for patients' wives/partners
- **Awareness raising of symptoms** among staff/patients/carers within settings such as older people's mental health, prisons, learning disabilities' services
- **Awareness raising of Prostate Cancer UK's services** e.g. how to access the helpline and provision of appropriate material including not only online but also printed material such as leaflets and posters, and DVDs/adverts for local use
- Focus on **how Prostate Cancer UK can support staff** e.g. raise awareness of how Prostate Cancer UK can support GPs, training packages for staff, short electronic newsletters
- Long-term **outreach work with marginalised groups** such as Gypsies and Travellers and becoming culturally informed on their needs.

The eight **focus groups with 72 non-users of Prostate Cancer UK's services** in communities across the UK found three key themes relating to preferences around the receipt of health information: **men prefer to visit a GP for information** but only when absolutely necessary; **women play a role in encouraging GP visits**; and willingness to engage with personal health issues varies by sociocultural background with the women's Black and minority ethnic group raising **cultural stigma around discussing health issues**. The three groups which were asked about **telephone helplines** were not enthusiastic about them as a means of accessing health information voicing **negative perceptions** in particular around operators lacking specialist knowledge. All the focus groups contained some



participants who were **reluctant to use the internet for health information**, with concerns mainly centering on reliability of information on the internet, but with issues also raised around the internet provoking anxiety inducing descriptions of illness and fears of online scams. The visually impaired and D/deaf groups raised **particular barriers around internet use relating to their disability**. Overall, focus group participants were aware of prostate cancer but specific **knowledge around risk factors and symptoms was mixed and in some cases low**, with some participants expressing clear **misconceptions and misunderstanding** about the condition. In general **awareness of Prostate Cancer UK was low**. The focus groups evidenced an **appetite for clear and simple information** and strong support was given to the draft Easy Read material which was shown to three of the groups. Issues around literacy and language as a barrier to understanding the booklets were raised by the BME women's group and in particular the D/deaf group, while the over 80s men and the visually impaired group focused on visual impairment as a barrier. Focus group participants were asked to give **advice to Prostate Cancer UK on how to reach people** such as themselves, with recommendations including:

- **TV and radio campaigns**
- **Information in community, sports and religious venues**
- **Information at GP surgeries**
- **Remove the stigma from prostate cancer**
- **Informative but not frightening information**
- **Appropriate and accessible information for specific groups** such as D/deaf, visually impaired and transgender people.

The **overall findings** of the evaluation are that **Prostate Cancer UK has highly satisfied users of its services**, both health professionals and people affected by prostate cancer. However work remains to be done to **raise the profile both of prostate cancer (e.g. awareness of symptoms and risk factors), and of Prostate Cancer UK**. This applies both **within communities**, including potentially isolated/marginalised groups; and **among health professionals**, in particular non-cancer specialists within primary and secondary care, whom the evaluation found to be important and trusted intermediaries. It will also be vital that Prostate Cancer UK ensures that it has the **capability to track and monitor** the effectiveness of any work to increase its reach.

To aid this further improvement, we have identified a number of individual recommendations which are set out below, most applying across the organisation but a few specific to the helpline and to the information service.

1. **Prostate Cancer UK should undertake work to promote greater awareness and understanding of prostate cancer symptoms, risk factors and when to seek medical help; and to 'bust' myths and misunderstandings about the condition. This work should build on the suggestions made in the site visits and focus group research e.g.: posters which can be put up in inpatient and community health settings; DVDs; radio and TV adverts; and articles including linking in to specialist publications/channels such as audio magazines for the visually impaired, prison magazines and Prisoner TV.**

2. Prostate Cancer UK should ensure that the information service and helpline are prominent in Prostate Cancer UK's marketing and communications activity. This activity should include a focus on strategically important target groups and areas where this evaluation has evidenced that there may be currently lower awareness and take up of services (e.g. non-cancer specialist health professionals, regions outside London and the South East, areas with high concentrations of older Black African and Black Caribbean men).
3. Prostate Cancer UK's programme to engage with more health professionals should be a strategic priority for the whole organisation, and should build on the links established by the site visits for this evaluation to explore further how to engage professionals who are not already in touch with Prostate Cancer UK, particularly non-cancer specialists. Prostate Cancer UK should in particular explore its levels of engagement with health professionals in the regions where data analysis shows levels of take up of its services are lower. Prostate Cancer UK should give consideration to the specific ideas generated by the health professional interviews and the site visits about how to engage better with health professionals.
4. The information team and helpline service should proactively build and maintain strong links with Prostate Cancer UK's emerging regional and national infrastructure, and use local intelligence to target increased activity, particularly at under-served men, as well as referring service users between the helpline and regional teams where appropriate. Furthermore the information team and helpline service should develop an understanding of the local and regional infrastructure of the NHS and third sector, enabling them to build up relationships with community groups and care providers as well as the local NHS.
5. Prostate Cancer UK should further research whether there is a business need for material in languages other than English (including British Sign Language and Welsh).
6. Prostate Cancer UK should roll out the Easy Read material and use it as an opportunity to strengthen its links with community groups and care providers for whom it will be particularly useful and welcomed, building on the links established within the focus groups and site visits components of the research. Consideration should be given to: developing further Easy Read material to assist patients throughout the patient journey, and to support professionals to involve all patients as fully as possible in decisions about their care. Further research should be undertaken as to whether it needs to be adapted to make it culturally appropriate for particular communities.
7. The information service and helpline teams should work with the marketing and communications team to identify innovative ways to reach more men, including targeted outreach work to reach those who are potentially at higher risk (e.g. older people, African Caribbean men) and those who are isolated/marginalised. For this to be effective it will be important to identify and work with/through trusted intermediaries such as the community groups and health settings with whom we worked in the research for this evaluation. The programme of work should include: research into understanding how potential and actual users may benefit from social media; giving consideration to the specific ideas about ways in generated by the focus groups, site visits and health professionals interviews; and building on the links within communities and health

settings created by the evaluation to further develop and road test ideas. (For example Prostate Cancer UK could work with the sheltered housing day centre in Wallasey to develop strategies to reach older men living in sheltered housing and care homes who may not access information online or in community settings.).

8. Prostate Cancer UK should give consideration to how it may track and monitor whether or not it is reaching the highest risk/potentially isolated and marginalised population groups. This may include undertaking regular qualitative research with these groups as they are unlikely to be captured by standard data monitoring processes.
9. Prostate Cancer UK should provide its information in a range of formats taking into account the preferences, needs and capacities of different groups including those who cannot or do not feel comfortable accessing health information online.
10. Prostate Cancer UK should clarify to its service users how they may continue to be involved with the organisation. The information team should consider how the volunteers and groups could be used further by, for example, using them to not just to test out emerging new materials but to brainstorm on what new “ways in” would enable men like them to access Prostate Cancer UK’s services.
11. Prostate Cancer UK should consider how best to support relatives, partners and carers and draw on their skills and time as a resource, building on specific suggestions made in the research such as the need for a support group for wives. It should further investigate the need and feasibility of creating a dedicated section of the website, and of networking / buddying / creating a forum for relatives and partners of men affected by prostate cancer. It should also review its links with national and local carers’ groups and charities which may be a key means of promoting awareness of its services, including the helpline, among relatives, partners and informal carers.
12. In order to improve response rates, Prostate Cancer UK should make clear to its staff and to service users why monitoring information is needed to improve services, and how the information will be protected. Prostate Cancer UK should ask its service users questions about disability and gender (male, female, transgender). It should also consider whether there is a business need to collect information in relation to sexuality and religion or belief, and on users’ subsequent use of information, taking into account the potential impact on response rates of increasing the data collection ‘burden’.
13. Prostate Cancer UK should seek to ensure that an increase in calls to the helpline is targeted at those who need the service most, and is not driven solely by a rapid turnover of calls from the ‘worried well’, by targeting marketing appropriately.
14. Prostate Cancer UK should engage the specialist nurses e.g. through a regular forum to ensure they have opportunities to contribute their views to debates within the charity and, in particular, shape the strategy for the helpline; and should either explain to them why there is a need to record activity every thirty minutes, or review the need for this information to be recorded.



- 15. Consideration should be given to the development of a follow up call system and how best to meet the needs of callers aged 70+ and D/deaf callers. The helpline team should continue to develop its links with Prostate Cancer UK's emerging regional infrastructure, referring service users between the helpline and regional teams where appropriate.**
- 16. Prostate Cancer UK should take into account in its marketing of the helpline both the high levels of satisfaction found in the evaluation among helpline users, and the negative attitudes and preconceptions found in the focus groups about the value of helplines. For example, it should highlight that it provides specialist, knowledgeable staff who are able to offer appropriate, accurate and up to date advice to callers.**
- 17. The information team should consider briefings for staff, and other forms of awareness raising, to ensure staff are aware in more detail about what they offer. This could include asking all staff where and how they can promote the information service.**
- 18. In the next review or re-design of the Tool Kit, Prostate Cancer UK should explore the suggested improvements made by interviewees e.g. scope to reduce its size and shape, without reducing the amount of information that people can get from it.**
- 19. Prostate Cancer UK should raise awareness of the Tool Kit 'offer' among both health professionals and people affected by cancer, including communicating the variety of formats in which it can be accessed and the fact that it is updated regularly.**

# 1 Purpose and context

1.1 This report sets out the findings from the evaluation of Prostate Cancer UK's Information and Helpline services. The purpose of the evaluation is to:

- Find out more about Prostate Cancer UK's target audiences;
- Measure the impact of the information and how it contributes to improving the health and wellbeing of men affected by prostate cancer and their families;
- Gain a better understanding of how people use the Tool Kit, which elements are most useful and the outcomes it enables them to achieve;
- Find out how the information complements / compares with other sources of information and support available to men with prostate cancer;
- Influence the strategic development of the Information Service, with the learning from this evaluation to ensure the Information Service is reaching those most in need of the information in a more structured and targeted way;
- Gather intelligence and make recommendations to help effectively target men who are currently not accessing the information. This includes audiences that are less engaged with and who are less likely to currently use Prostate Cancer UK information;
- Understand the impact of helpline calls and emails on the health and wellbeing of callers and their families, examining if, how and why the support has led to change;
- Find out how the helpline compares with / complements other sources of support that men affected by prostate cancer are accessing;
- Understand how callers think the service could be improved or whether there are any gaps in the support offered; and
- Gather intelligence and make recommendations to help effectively open up the service to more men and remove barriers to access, and enable ongoing monitoring of outcomes.

1.2 To achieve the above objectives, on the evaluation took a mixed method approach. This combined quantitative and qualitative methods: to analyse the current usage of the information service and helpline; identify the impact of the service on health professionals and people affected by cancer who have used the services; and explore the views of health professionals and members of the public who have not used the services. The findings are based on:

- Background research and secondary data analysis of information and previous reports provided by Prostate Cancer UK, including helpline satisfaction surveys and Google Analytics;
- 14 telephone interviews with members of staff across Prostate Cancer UK;
- A focus group with the specialist nurses who staff the helpline;

- 50 telephone interviews with users of Prostate Cancer UK's services;
- 15 telephone interviews with health professionals that have used Prostate Cancer UK's services;
- Fieldwork in six health and community settings, as well as one depth interview;
- Eight focus groups with non-users (people who have not used Prostate Cancer UK's services), six with men and two with women;
- 10 follow-up telephone interviews with a selection of the service users.

## Context

- 1.3 Prostate Cancer UK is the leading UK charity for men with prostate cancer and prostate problems. The charity was set up in 1996, initially under the name The Prostate Cancer Charity, with the aim of increasing spending on prostate cancer and raising awareness of the disease.
- 1.4 More than ten thousand men die of prostate cancer each year. That is more than one man every hour, and the number of men with the disease is rising. It is already the most common cancer in men and it is predicted to become the most prevalent of all cancers in the UK by 2030.
- 1.5 A major problem in tackling the condition is that **prostate cancer is not widely known about or understood**. Even as general awareness grows, most men have little understanding of the disease and the risks they face as they get older.
- 1.6 Furthermore, over time, there has been a lack of investment in research about the disease. Tests for diagnosing prostate cancer are often unreliable and there are widespread differences in care. Many men are faced with a **confusing array of treatments** which often carry risks of damaging side effects, such as incontinence, loss of sex drive and difficulties having sex. These have a powerful impact on men's bodies and their psychological health.
- 1.7 In this context, **Prostate Cancer UK's purpose** is to help more men survive prostate cancer and enjoy a better quality of life. It aims to achieve this by supporting men living with prostate cancer and prostate disease, and the effects of treatment, by **providing specialist information and support services**; finding answers by funding research into the causes and treatment of prostate disease; and leading change, by campaigning, creating conversations and co-operating with others.
- 1.8 Prostate Cancer UK has a number of strategic objectives for 2012-2015<sup>1</sup>, including:
- Our services will reach more men across the UK, improving their experiences of care and quality of life;
  - Men at higher risk of prostate cancer, including African-Caribbean men, will be more aware of the disease, their risk and the support available to them;
  - We will help healthcare professionals working with men with prostate cancer to improve their knowledge so men can have the best care and support possible;

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<sup>1</sup> How will we know we are making a difference? Strategic objectives 2012-15

- More people will be aware of prostate cancer, the scale of the problem, the requirement for greater research investment and the needs of men;
- Family members of men with prostate disease have the support and information they need.

1.9 These translate into ambitious plans for the development of its services, with the aim of reaching over 20,000 helpline callers and 2,000 email enquirers each year by 2015, while developing the service as a hub for referral to new specialist services, such as help with fatigue or bereavement. Across its services, it is committed to **increasing access from other parts of the UK** and reaching out to groups of men who are less likely to use the helpline and email response service.

1.10 Evaluation is increasingly important as Prostate Cancer UK seeks to expand its services. The additional funding from the Movember Foundation, which has been critical to the charity's recent expansion, comes with expectations of evaluation of spending and measuring the impact on people affected by prostate cancer.

### Ongoing change

1.11 This evaluation has taken place in the context of rapid change at Prostate Cancer UK. This is significant since over the course of this evaluation a number of actions have been taken that seek to address some of the recommendations arising from this research (in part reflecting the preliminary findings of this research). These include:

- Developing an Easy Read resource
- Developing a more cooperative relationship with support groups
- Doing more to support Specialist nurses to work from home
- Setting up a 'clinical forum', organised by Prostate Cancer UK staff
- Renaming the 'helpline service' the 'Specialist Nurse Telephone Service'.

1.12 Some of these changes are not reflected in the report, since the terminology and questions asked refer to the point in time the research took place. For instance, participants were asked about a 'helpline service' rather than the 'Specialist Nurse Telephone Service'.

1.13 Moreover, it is important that any actions that have been taken are not assumed to have addressed a need identified in this report. Any such actions should be evaluated to determine whether they have the impact desired.

## 2 Methodology

2.1 Our research is based on the following sources of information.

### Helpline survey

2.2 The helpline survey consists of 313 respondents in total. This survey was carried out in spring 2013 by Prostate Cancer UK (it was completed in May 2013). The survey was sent out by post or by email. Almost all of the people who accessed the nurse led helpline or email support service were invited to take part.

2.3 We have carried out simple analyses of the questions answered and also performed cross tabulations to look at how specific groups responded to particular questions. Responses vary by question and particularly where cross tabulations are used, the samples can be small. See, for instance, Appendix A figure 8 for a complete breakdown of responses by region.

2.4 **This is not an unbiased sample**, coming as it does from a selection of service users who have been willing to provide feedback. This may reflect good will towards the charity.

### Activity data from Prostate Cancer UK

2.5 Activity data relating to the helpline and information services was supplied by Prostate Cancer UK and gathered through Raiser's Edge, the charity's database. The full range of information that we looked at is set out here:

- 11-12 Age & Lit Type
- 11-12 All Publications by Category
- 11-12 All Publications
- 11-12 Ethnicity & Lit Type
- 11-12 Ethnicity & Region
- 11-12 Ethnicity & Status
- 11-12 Region & Status
- 11-12 Status & Lit Type
- Email Service April 2011 - March 2012
- Helpline Report 11-12
- 12-13 All Publications
- Email Service 12-13
- Ethnicity & Status 12-13
- Helpline Report 12-13
- Lit Type & Age Range 12-13
- Lit Type & Ethnicity 12-13
- Lit Type & Status 12-13
- Publications Service 12-13
- Region & Ethnicity 12-13
- Region & Status 12-13

2.6 We have also used user feedback received via printed questionnaires placed inside new publications. These publications were (with number of responses in brackets): 2008 A guide for newly diagnosed men (258); 2009 PSA and beyond (49); 2009 Living with hormone therapy (218); 2010 Recurrent prostate cancer (7); 2010 Enlarged prostate cancer (5); 2011 Living with and after prostate cancer (12).



### Data from Google Analytics

2.7 This was used to look at the use of the website. We received login details for the Google Analytics pages and accessed this data between August 2013 and September 2013. In terms of the analytics pages, we analysed data from September 2012 to August 2013. Specifically, we looked at:

- All Domains - Information pages
- u - Domain Rollup (for all visits to the website).

### Service User interviews

2.8 We conducted 50 semi-structured telephone interviews with service users. The service users had all contacted Prostate Cancer UK and had given Prostate Cancer UK consent to be contacted for further evaluation research.

2.9 Each interview lasted around thirty minutes. These were carried out in autumn 2013. Of the 50, the details for 19 came from the helpline survey and 31 from the database of users who had ordered material from the website.

2.10 The interviews covered

- The journey towards Prostate Cancer UK
- Information needs
- The helpline
- The Tool Kit
- Outcomes
- Future contact.

2.11 We are aware that the sample is not unbiased. Firstly, all of the respondents have sought and used the charity's services. We are interviewing a subset of users who expressed a willingness to be contacted again; this could reflect good will towards the charity. Also, within the self selecting group who have expressed a willingness to be interviewed at this stage, there may be a further bias towards those feeling relatively well and able to participate.

2.12 The interviews carried out are not part of a random sample. Instead, our approach sought to get a balanced distribution across different regions and ages, while focussing on men diagnosed with prostate cancer.

2.13 Of the 50:

- 14 were from London and the South East, 31 from elsewhere in the UK and 5 did not have a region recorded<sup>2</sup>;

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<sup>2</sup> We tried to fill in gaps in data about the service user e.g. their age and location, but not all respondents chose to answer these questions.

- 38 were diagnosed with prostate cancer, another 7 were friends and family of diagnosed men, 5 were concerned men or family and friends of concerned men;
- 40 were male and 10 female;
- 4 were in the 31-40 age bracket, 11 were aged between 41-50, 14 were between 51-60; 11 were between 61-70, 7 were between 71-80, 2 were over 80 and 1 person's age was unknown<sup>3</sup>.

2.14 The answers to each question were coded where possible and an attempt made to group answers in common responses – for instance capturing where respondents described how they used information they gained from Prostate Cancer UK. The interviews were semi-structured and not all respondents answered all questions, for reasons such as a question not being relevant to a given user or the user not being able to recall information.

#### Health professional interviews

2.15 We conducted 15 interviews with health professionals to whom Prostate Cancer UK had previously sent its information materials, carried out by telephone in September 2013. The health professionals had all agreed with Prostate Cancer UK that they could be contacted for further research. The interviews covered:

- About you
- Contact with Prostate Cancer UK
- Usefulness of information resources
- Tool Kit
- Helpline
- Final Questions.

2.16 This was based on a sample of health professionals provided by Prostate Cancer UK. This is not an unbiased sample, as they are health professionals known to Prostate Cancer UK and therefore health professionals who use its services.

#### Interviews with Prostate Cancer UK staff

2.17 We conducted 14 interviews with Prostate Cancer UK staff from a cross-section of teams. The interviews were carried out either by telephone or in person between July 2013 and September 2013. The interviews covered:

- How much do staff know about the information and helpline services?
- How are the information and helpline services viewed?
- How could the information and helpline services further support staff?
- What else could the information and helpline services provide?

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<sup>3</sup> We tried to fill gaps in data about the service user e.g. their age and location, but not all respondents chose to answer these questions.

- What support do people affected by prostate cancer get from the helpline?
- What might stop people accessing the services?

2.18 We have analysed the responses of the staff interviewed. Again this is not an unbiased sample as Prostate Cancer UK suggested the staff members we interviewed. It is also worth noting that there have been a number of staffing changes at Prostate Cancer UK since these interviews were conducted.

#### Focus group with specialist nurses

2.19 We organised a two-hour focus group with the specialist nurses who staff the helpline. The key lines of enquiry covered:

- What the nurses needed to continue providing a quality service
- The barriers to men accessing the service – and how they might be overcome
- The strong and weak points of the helpline
- The perceived main benefits of the helpline
- How far the service meets the needs of different users.

2.20 The focus group was attended by a facilitator and an assistant facilitator who took detailed notes of the discussion. One member of staff was unable to attend the focus group and another wanted to give further comments following the group. Both were contacted by telephone.

#### Follow up service user interviews

2.21 We interviewed 10 service users from the first round of interviews. Of these, seven were with men diagnosed with prostate cancer and three were family/friends. The interviews covered the following:

- Information consulted before the first interview
- Information consulted recently
- Health information seeking behaviour
- Use of information
- Evidence of behavioural change
- Future additional support.

#### Site visits

2.22 We undertook seven healthcare setting site visits (one was an in-depth telephone interview). In selecting the settings we strove to ensure: a spread of locations across all nations within the UK (including areas of low take up of Prostate Cancer UK services such as the East Midlands and Northern Ireland); a mix of specialist cancer settings - within both secondary and tertiary care and within the community - and non-cancer settings; a mix of statutory and voluntary sector services; and a mix of settings serving the general population and those serving specific population groups at risk of being overlooked or marginalised. The purpose of these visits was to speak with a variety of staff and practitioners who interact with men with prostate cancer. The

main lines of enquiry included gathering detail about the work that they do around prostate cancer and cancer; about their use and distribution of information; and their awareness of and views about Prostate Cancer UK and ways in which the charity could help them in their work.

2.23 Three of the settings visited provide cancer services: **Velindre Cancer Centre** in Cardiff, a tertiary specialist cancer centre; **The Northern Ireland Cancer Centre at Belfast City Hospital**; and **Maggie's Centre** in Glasgow, a voluntary sector provider of services to people affected by cancer.

2.24 The other settings focus on providing healthcare services to specific population groups: **Nottinghamshire NHS Trust's Local Services Division**, which works with people with learning disabilities and older people's mental health; the Healthcare Unit in **HM Prison Whatton** in Nottinghamshire; the NHS outreach team working at **The Passage**, the largest voluntary sector homeless organisation in London; and **GypsyLife** (the depth interview), a non-funded community organisation that works with the Gypsy and Traveller community.

2.25 The mix of settings is summarised in the table below.

SITE	COUNTRY/REGION	SPECIALIST CANCER (ACUTE, TERTIARY, COMMUNITY)/ NON-CANCER	STATUTORY VOLUNTARY	GENERAL POPULATION / SPECIFIC POPULATION GROUP
Velindre Hospital	Wales	Cancer (acute tertiary)	Statutory	General
Northern Ireland Cancer Centre	Northern Ireland	Cancer (acute secondary)	Statutory	General
HMP Whatton	East Midlands	Non-cancer	Statutory	Specific (prisoners)
Notts Local Services Division	East Midlands	Non-cancer	Statutory	Specific (learning disabilities and older people's mental health)
GypsyLife (interview)	East Midlands	Non-cancer	Voluntary	Specific (Gypsies and Travellers)
The Passage	London	Non-cancer	Statutory services delivered in Voluntary setting	Specific (homeless)
Maggie's	Scotland	Cancer (community)	Voluntary	General

### Non user focus groups

- 2.26 We carried out a total of eight focus groups with non-users of Prostate Cancer UK's services across the UK between November 2013 and January 2014. We strove to ensure a good spread of focus groups across the four nations of the UK, avoiding at the client's request the London and the South East region which has already been the focus of previous Prostate Cancer UK research, and including areas of low take up of Prostate Cancer UK services such as East Midlands and Northern Ireland. We targeted groups of non-users who are at particular risk of prostate cancer (Black and minority ethnic groups particularly African/African Caribbean groups) or whose needs might be at risk of being overlooked (D/deaf, visually impaired, over 80s, gay/bisexual/transgender and residents of economically deprived areas). All groups were held with the over 50 age group as the age group most at risk of prostate cancer. The majority (six) of the groups were with men, but two were held with women as being potentially important conduits to health information for men. All groups were held in community locations used by the participants.
- 2.27 The focus groups were held in the following locations and with the following groups:
- West Bromwich African Caribbean Resource Centre, West Bromwich, England – six men aged over 50 from African/African Caribbean descent;
  - The Firs Club, Leicester, England – 13 men aged over 50 who are D/deaf;
  - North Road Methodist Church, Durham, England – six gay and bisexual men and male to female transgender women, aged over 50;
  - Granville Court Centre, Wallasey, England – three men aged over 80 living in sheltered accommodation;
  - Coatbridge Indoor Bowling Club, Coatbridge, Lanarkshire, Scotland – eight men aged over 50 living in an economically deprived area;
  - Bayview Resource Centre, Bangor, Northern Ireland – eight men aged over 50 with visual impairment;
  - Community Space, Newport, Wales – 18 women aged over 50 from Black and minority ethnic (BME) backgrounds;
  - Six Bells Community Centre, Six Bells, Wales – ten women aged over 50 living in an economically deprived area.
- 2.28 The main lines of enquiry centred on how people access health information, and what are considered to be trusted sources of information; people's views on telephone helplines (in three groups only); awareness of prostate cancer and risk factors; awareness of Prostate Cancer UK; views on Prostate Cancer UK material distributed to the groups (including, at three groups, draft Easy Read material); ideas on how Prostate Cancer UK may reach them and meet their needs.
- 2.29 The focus groups are summarised in the table below.



FOCUS GROUP	COUNTRY / REGION	GENDER	AGE GROUP	POPULATION GROUP
West Bromwich Resource Centre	West Midlands	Male	50+	African Caribbean
Firs Club	East Midlands	Male	50+	D/deaf
North Road Methodist Church	North East	Male / transgendered female	50+	Gay and bisexual men, transgendered women
Granville Court	North West	Male	80+	80+ residents of sheltered housing
Coatbridge Bowling Club	Scotland	Male	50+	Economically deprived area
Bayview Resource Centre	Northern Ireland	Male	50+	Visually impaired
Community Space Newport	Wales	Female	50+	Black and minority ethnic
Six Bells Community Centre	Wales	Female	50+	Economically deprived area

## Report structure

- 2.30 The rest of this report is structured around each of the research methods.
- 2.31 Each chapter begins with a summary of the findings linked to each aspect of the research, before the main findings are drawn together in chapter 9, 'Conclusions and recommendations'.

## 3 Analysis of helpline and information services data

### Summary

The helpline is a core service and is growing rapidly. Prostate Cancer UK literature is the most common way for users to find out about the helpline, although the internet – and in particular, the charity’s website – has grown in importance. Satisfaction rates are very high. Only 2% of users said nothing changed after their call, illustrating the impact the service has; more than 80% felt that the specialist nurses helped in a way health professionals could not. Growth in the latest year (2012-13 compared to 2011-12) has been most pronounced in London and the East Midlands, with use spiking among those aged 61-75. Use is over-concentrated in London and the South East, compared to other regions of the UK. In terms of ethnicity, use of Prostate Cancer UK’s helpline is broadly reflective of the population. It is notable that target populations such as Black African and Black Caribbean are also over concentrated in London, however Prostate Cancer UK does not significantly over represent these groups. Prostate Cancer UK should go further to reach more Black African and Black Caribbean users, given that these groups are higher risk.

The information service includes booklets, fact sheets and audiovisual resources. There were a total of 415,000 information materials distributed in 2012-13, an increase of 18% on the previous year. A majority of orders are made through the internet (56%), with another 26% through the helpline. As with the helpline, satisfaction rates are high and use is over-concentrated in London and the South-East, relative to other areas. The Tool Kit is a folder of information tailored to men, there were 3,132 sent out in 2012-13, up 1.3% on the previous year.

A final part of Prostate Cancer UK’s information service is the charity’s online presence. We know the internet is an important source of orders of information, but users also look at the website in its own right. Use of the site is over-concentrated in London relative to other regions. The charity also has a nascent presence on Facebook and Twitter. The rising importance of the internet as a source of health information means that growing the charity’s online presence will be a priority over coming years.

### The helpline

- 3.1 The helpline is a core service of Prostate Cancer UK. It allows callers to speak with specialist nurses about all conditions that affect the prostate. This includes not only those concerned or diagnosed with prostate cancer, but also family, friends or partners – anyone affected by prostate cancer. Furthermore, although prostate cancer is the main condition, the service provides for other issues around the prostate, such as prostatitis or enlarged prostate. Health professionals can use the service as well.

- 3.2 There were more than 6,000 calls in 2012-13. We have compared this with the data from the 2011-12 activity report to give a sense of growth over time. The number of users has grown 14% in the latest year and 20% since 2010-11 (see appendix A, figure 1).
- 3.3 In terms of the regional distribution of users, growth has been pronounced in Greater London (43% since 2010-11, to 865 users), exceeded only by the East Midlands (45% growth, but from a lower base). The largest absolute figure is the South East, with 1,341 users in the latest year (see appendix A, figure 2).
- 3.4 We have analysed the age of users as a proportion of overall use (see appendix A, figure 3), which in 2011-12 was 5,498<sup>4</sup> and in 2012-13 was 6,272. As expected, use spikes around 66-70 years. The three most significant groups are 61-65 (14% of callers in the latest year), 66-70 (18%) and 71-75 (11%). There has been an increase in the share of people aged 60 and under, to 33% of users from 28% the year before, although this in part reflects a decline in those whose age is unrecorded.
- 3.5 The table below looks at the ethnicity of users over time. The ethnic breakdown of users is broadly unchanged year on year, while 10% do not state their ethnicity.

*Figure 1: Helpline users by ethnicity*

<b>Ethnicity</b>	<b>2011-12</b>	<b>Share</b>	<b>2012-13</b>	<b>Share</b>
Asian Bangladeshi	6	0%	3	0%
Asian Indian	68	1%	62	1%
Asian Pakistani	15	0%	28	0%
Asian Other	58	1%	46	1%
Black African	48	1%	59	1%
Black Caribbean	70	1%	74	1%
Black Other	22	0%	27	0%
Chinese	10	0%	8	0%
Mixed White & Asian	8	0%	6	0%
Mixed White & Black African	5	0%	2	0%
Mixed White & Black Caribbean	7	0%	12	0%
Mixed Other	7	0%	12	0%
White British	4,429	81%	5,057	81%
White Irish	81	1%	84	1%
White European	61	1%	25	0%
White Other	101	2%	117	2%
Other	1	0%	2	0%
Not Stated	501	9%	648	10%
<b>Total</b>	<b>5,498</b>	<b>100%</b>	<b>6,272</b>	<b>100%</b>

Source: Helpline report 2011-12; Helpline report 2012-13

<sup>4</sup> This is different from the 5,447 that is from the 2011-12 Annual Service Activity Report

3.6 We have compared the ethnic breakdown with demographic figures for England and Wales (see appendix A, figure 5). The main findings are:

- White British
  - The share of users accounted for by those describing themselves as White British is 81%, 90% of responses when excluding not stated.
  - Demographic data for England and Wales puts the share of the population that is White British at 81%. **In the age group over 50, this rises to 90%.**
- Black Caribbean and Black African
  - The share of users who describe themselves as Black Caribbean is 1.2% - 1.3% when excluding not stated. This compares with 1.1% of the population of England and Wales, **0.9% of those aged over 50.**
  - The share of users who describe themselves as Black African is 0.9% - 1.0% when excluding not stated. This compares with 1.8% of the population of England and Wales, 0.5% of those aged over 50

3.7 However, Prostate Cancer UK knows that Black Caribbean and Black African men are at higher risk of prostate cancer and these are therefore target groups. Looking more closely at the location of these ethnic groups, the Black Caribbean population of London is 4.2% and the Black African population is 7.0%, far exceeding the share in other regions (see figure 2). As a share of the over 50 population, this changes to 4.8% for the Black Caribbean population and 3.5% for Black African (see Appendix A, figure 6 for a more complete breakdown across regions).

*Figure 2: Census 2011, selected ethnicities and region*

	<b>Black African</b>	<b>Black Caribbean</b>	<b>Other Black</b>
Region	All ages	All ages	All ages
North East	0.4%	0.0%	0.0%
North West	0.8%	0.3%	0.2%
Yorkshire and The Humber	0.9%	0.4%	0.2%
East Midlands	0.9%	0.6%	0.2%
West Midlands	1.1%	1.5%	0.6%
East	1.2%	0.6%	0.2%
London	7.0%	4.2%	2.1%
South East	1.0%	0.4%	0.2%
South West	0.5%	0.3%	0.2%
Wales	0.4%	0.1%	0.1%

Source: Census 2011, ONS Crown Copyright Reserved [from Nomis on 9 October 2013]

3.8 We have looked at the top five ways in which people hear about the helpline service and how that has changed over a three year period. We see a number of conclusions:

- The literature is consistently the most important source of information about the helpline. (We cannot say whether the information convinces service users to call, or if those who intend to contact the helpline are most likely to source the details through the literature.)

- The internet - and in particular the charity's website - has notably increased in importance.
- The role of health professionals appears small, but this may reflect that health professionals share Prostate Cancer UK literature, which is being given as the source (see below).

*Figure 3: Helpline service by source*

2010/2011	%	2011/2012	%	2012/13	%
Charity's Literature	22.30%	Charity's Literature	27.20%	Prostate Cancer UK Literature	29.48%
Not Recorded	12.80%	Charity's Website	20.20%	Prostate Cancer UK Website	26.07%
Charity's Website	11.70%	Literature - Other	10.50%	Not Stated	12.39%
Internet	11.60%	HP Referral	7.80%	HP Referral	5.85%
HP Referral	8.30%	Word of Mouth	3.50%	Word of Mouth	4.13%

Source: 2011-12 Annual Service Activity Report; Helpline report 12-13; note before 2012/13, the charity is referred to as TPCC in the reports

3.9 This is supported by health studies, which suggest that the internet now plays a crucial role in signposting people to health advice before and after diagnosis<sup>5</sup>.

3.10 We have also carried out more detailed analysis of how helpline users found out about the service (using the data gathered in the **helpline survey**, see Appendix A, figure 7<sup>6</sup>). It is worth noting that the questionnaire did not specifically present as a option Prostate Cancer UK's information. The main findings of this were:

- Healthcare professionals are an important source of information.
- The main response to this question was 'other' suggesting that people find out about the helpline from other sources, for example the internet, friends and family/word of mouth, Prostate Cancer UK information etc.
- Newspapers were mentioned more by older users, those aged 61-70 and particularly 71-80.
- Health professionals are important for male respondents and less so for females - reflecting the contact men diagnosed with prostate cancer have with health professionals (see appendix A, figure 8).

3.11 According to the helpline survey, those reporting themselves as diagnosed with prostate cancer are more likely to have first heard about the helpline service through their **health professional** than other groups. Health professionals were cited 49 times out of a total of 151 people diagnosed with prostate cancer (32%), compared with 13% for those concerned about prostate cancer and 21% of the time for friends, family or partners (see Appendix A, figure 10). This

<sup>5</sup> See for example Illac et al (2013) in a study about prostate cancer among Australian men and the shift from the 'passive' to 'active patient' as discussed in Murphy (2006).

<sup>6</sup> Note, the questionnaire did not offer 'Prostate Cancer UK information' as a possible answer to this question, therefore this may be one of the factors in the large response to 'other'.



underlines the importance of health professionals as a source of information for diagnosed men, reinforcing the importance of Prostate Cancer UK reaching health professionals.

- 3.12 If the person is not diagnosed with prostate cancer, they are more likely to have heard about the helpline through **other channels**. For example, 23 out of 69 people concerned about prostate cancer (33%) found out about the **helpline through newspapers** (see appendix A, figure 10), second only to 'other' as a source for this group. This has implications for raising general awareness about Prostate Cancer UK prior to diagnosis. A study on health professionals<sup>7</sup> found that neither the GPs nor the pharmacists in the study were proactively raising the issue of the prostate with male patients.
- 3.13 The most frequent thing users say they are primarily phoning for is **medical or factual information** (37%), but 18% were looking for guidance about options, 16% help with fears and anxieties and 16% a better understanding of their condition (see appendix A, figure 11). Significantly more people **between 71 and 80** were phoning for guidance about options, likely reflecting the increased prevalence of prostate cancer in this age group (see Appendix A, figure 12).
- 3.14 Only 2% of users indicated that that nothing had changed as a result of the helpline call. We can conclude from this that the service does have an impact on users. (See Appendix A, figure 13.)
- 3.15 Among the outcomes asked about, the most frequently selected is **'I know where to seek more help if I need it'** (74% of users ticked to indicate this); followed by 66% of users that indicated **'I gained useful factual information about my/my partner's condition'**; and 52% indicated **'I feel calmer and reassured'**.
- 3.16 Significantly, **82% of the helpline** users surveyed agreed that contact with the Specialist Nurse helped in a way that health professionals were unable to. However:
- More men between 50 and 80 disagreed with this statement than other age groups (appendix A, figure 14);
  - Proportionally more men disagreed than women (appendix A, figure 15);
  - Those diagnosed with prostate cancer were slightly more likely to answer 'no' (although it is important to note that the difference is marginal: 27 out of 139, 19%, compared with 18% overall), (appendix A, figure 16).
- 3.17 This may be indicative of the fact that someone with a diagnosis of prostate cancer may have already developed a strong relationship with their own healthcare professional.
- 3.18 **Every respondent** that answered the question asking if they would recommend the service to others with the same condition said yes (there are 11 non-responses).
- 3.19 Satisfaction rates are very high. Asked if they were satisfied with the phone call, 90% responded 'very'. A similar amount said the conversation had been 'very' useful; 88% and 89%, respectively,

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<sup>7</sup> Survey & Marketing Service, Qualitative Research Report: GP's/Pharmacists, (2013) for Prostate Cancer UK

responded 'very' to the questions of whether the call had met their expectations and if the information was useful.

**Figure 4: Helpline user survey: satisfaction**

		Count	%
Were you satisfied with the conversation and what you learned?	Very	278	90.3%
	Quite	28	9.1%
	A little	1	0.3%
	Not at all	1	0.3%
Was the conversation useful for you?	Very	276	89.6%
	Quite	30	9.7%
	A little	0	0.0%
	Not at all	2	0.6%
Did the help you received from the call meet your expectations?	Very	268	88.2%
	Quite	33	10.9%
	A little	2	0.7%
	Not at all	1	0.3%
How useful was the information the nurse gave you?	Very	275	89.0%
	Quite	30	9.7%
	A little	1	0.3%
	Not at all	3	1.0%

Source: Helpline user survey

- 3.20 Asked specifically about the Specialist Nurses, response rates are again very favourable. For example, asked how supportive users found the nurse, 96% said 'very'.
- 3.21 Comparing the information that the caller was looking for with the satisfaction levels, we see some differences. Asked if the conversation was useful, the group looking for **medical or factual information** that was very satisfied was 94%, but the share among those looking for **guidance about options** that was very satisfied was lower **at 80%**. This may reflect the fact that specialist nurses are **not** able to tell someone **exactly what course of action to pursue**, instead can only present the range of options (see appendix A, figure 20). Similarly, those looking for help with fears and anxieties were less satisfied, with 83% answering 'very'. Although, it may be those that are anxious are less likely to report very high satisfaction.
- 3.22 Again looking at whether the conversation was useful, within the group that reported being 'quite' satisfied (rather than the large number who reported being 'very' satisfied), most had been **diagnosed with prostate cancer**. Those diagnosed with prostate cancer and those concerned about it reported being marginally less satisfied than partners, friends or family (see appendix A, figure 21). This is reflected in males being marginally less satisfied than females (see appendix A, figure 22).
- 3.23 Looking at how well callers understood the topics the nurses explained to them, within the **71-80 age group**, there are more callers saying quite rather than very (19% against 12% for the total) (see appendix A, figure 23). This group may need more help understanding the information given to them and Prostate Cancer UK should explore a distinct offering for older users.

3.24 We have analysed the proportion of helpline users by region and compared this to the proportion of new cases of prostate cancer per year, to understand which regions have the best provision and also to pinpoint gaps in the service.

- The data confirms that services are over-concentrated in the South East and London, relative to elsewhere in the UK.
- The lowest levels of provision occur in East of England, North East and East Midlands.

*Figure 5: Helpline use by region compared with the incidence of prostate cancer*

Region	Share of helpline users	Share of new cases per year	Difference
South East	24.6%	13.9%	10.7%
Greater London	15.9%	9.3%	6.6%
North West	13.9%	10.9%	3.0%
South West	10.0%	10.7%	-0.7%
Northern Ireland	1.4%	2.5%	-1.1%
Scotland	5.5%	7.1%	-1.6%
West Midlands	7.2%	9.3%	-2.2%
Wales	4.2%	6.1%	-1.8%
East Midlands	4.3%	7.5%	-3.3%
North East	8.1%	12.0%	-4.0%
Eastern	5.1%	10.7%	-5.6%

Source: Cancer incidence, males, ICD10 C61 : Prostate, 2008-2010. National Cancer Intelligence Network (NCIN), UK Cancer Information Service (UKCIS), accessed June 2013; Helpline report 2012-13 (NB North East includes Yorkshire and Humberside)

3.25 Prostate Cancer UK should investigate the reasons for differences in use by region. For instance, in view of the importance of health professionals as a source of information on Prostate Cancer UK's helpline, Prostate Cancer UK should explore whether it has less of a relationship with health professionals in the regions where levels of use are lower.

3.26 Similarly, the internet is an important source of information; it could be that the over-concentration in the South East and London in part reflects the higher rates of internet use in these regions, with fewer people never having used the internet<sup>8</sup>.

3.27 Furthermore, research suggests that older men are less likely to have access to the internet<sup>9</sup>. BME groups in particular may have less access to the internet<sup>10</sup>, with some considering it a luxury.

## The information service

3.28 The charity's suite of information materials includes booklets, leaflets, fact sheets and audiovisual resources, including hard copies that can be ordered and downloadable information.

<sup>8</sup> ONS Internet Quarterly Update

<sup>9</sup> Prostate Cancer UK (2012), Communication needs of older men: a selective review of the evidence

<sup>10</sup> Prostate Cancer UK (2012), Communicating with older men: Key findings from focus group research

- 3.29 The Tool Kit is a folder of information that can be tailored to the specific information needs of men who have been diagnosed with prostate cancer. It contains individual fact sheets, covering a range of information needs, including diagnosis, treatment and side effects.
- 3.30 In the latest year, there were more than 415,000 information materials distributed (recorded as 'leaflets' but referring more generally to information materials), an increase of 18% on the year. Orders were up 20% to 6,836 (see appendix B, figure 1). Looking specifically at the Tool Kit, there were 3,135 sent out in the latest year, up 1.3% on the year before (see appendix B, figure 2).
- 3.31 The following table looks at factsheets but that have been ordered separately (copies will also have been included as part of the complete Tool Kit, which aren't recorded here). The most popular of these is on diet and prostate cancer, followed by hormone therapy and external beam radiotherapy – again, however, this only reflects leaflets that were ordered separately from the Tool Kit. The figures do not include leaflets sent out as part of the Tool Kit.

*Figure 6: Tool Kit content - Additional sheets ordered*

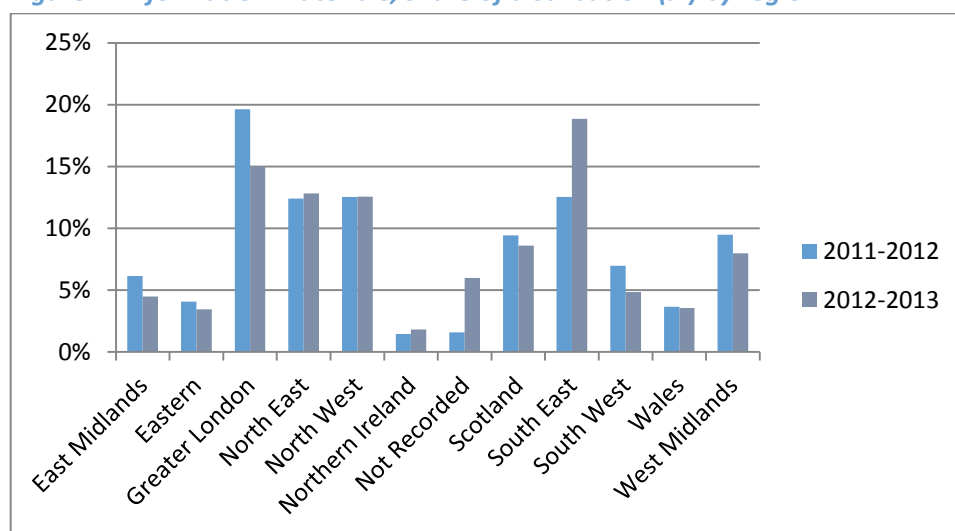
Name	No. of Leaflets		
	2011-12	2012-13	% change
Diet & Prostate Cancer	10269	10792	5.1%
Hormone Therapy	5561	7631	37.2%
External Beam Radiotherapy	6497	6642	2.2%
Active Surveillance	4307	5974	38.7%
How Prostate Cancer is Diagnosed	5871	5929	1.0%
Urinary Continence/Pelvic Floor Exercises	4996	5342	6.9%
Radical Prostatectomy	3773	4990	32.3%
Sex & Prostate Cancer	4933	4465	-9.5%
A-Z of Medical Words	2178	4394	101.7%
Brachytherapy	2808	4027	43.4%
Advanced Prostate Cancer	1752	2656	51.6%
Localised Prostate Cancer	1865	2390	28.2%
Second line hormone therapy	1698	2225	31.0%
Chemotherapy	1075	1782	65.8%
Clinical Trials	1252	1611	28.7%
Locally Advanced Prostate Cancer	1410	1559	10.6%
Pain & Advanced Prostate Cancer	1677	1450	-13.5%
Watchful Waiting	1419	1438	1.3%
Bisphosphonates	683	1246	82.4%
Cryotherapy	768	1222	59.1%
HIFU	914	1124	23.0%
Radiotherapy for advanced prostate cancer	1329	834	-37.2%
Degarelix	231	31	-86.6%
Travel and Prostate Cancer		12	n/a

Source: 11-12 All Publications; 12-13 All Publications

- 3.32 The table below looks at the regional breakdown of users of the hard copies of information materials distributed.

- Together, **London and the South East** account for 34% of the literature distributed in the latest year.
- Over the past year, there was a switch to a greater share in the South East and a smaller share in London.
- Outside of these regions, there was little change in the regional breakdown. The next most significant regions were the North East and North West (accounting for 13% each). This is a potentially interesting finding as it contrasts with figures for access to the helpline.

**Figure 7: Information materials, share of distribution (%) by region**

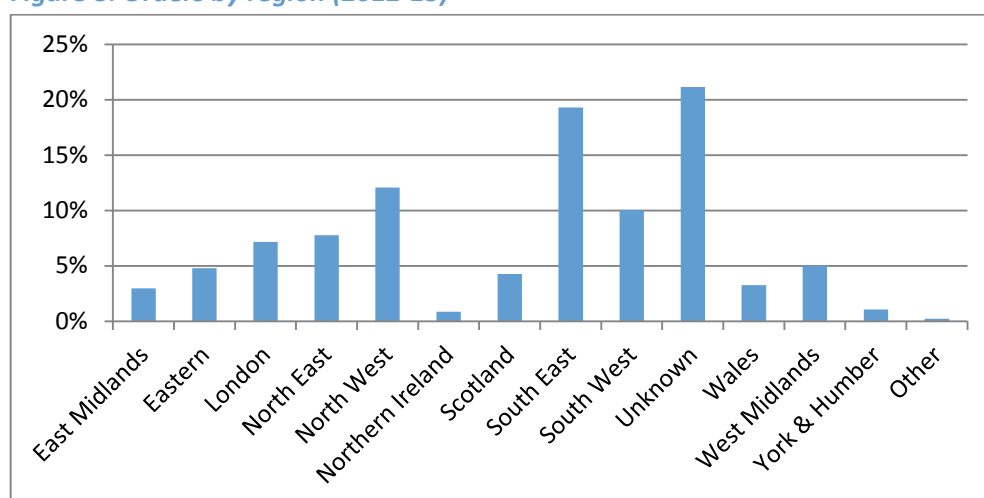


Source: 2011-12 Ethnicity & Region; 2012-13 Ethnicity & Region

### 3.33 In terms of the information service, looking only at 2012-13 data for orders, we find:

- the South East accounts for the largest share of orders, 19%;
- London and Greater London together only account for 7% of orders. The South West, North West and North East all had a greater share of the total number of orders (10%, 12% and nearly 8% of orders, respectively).

**Figure 8: Orders by region (2012-13)**



Source: Information service 12-13



- 3.34 26% of the publication orders are made through the helpline. The remainder are from other sources; of this, 56% (41% of total orders) came through the internet<sup>11</sup> (see appendix B, figure 4).
- 3.35 Looking at the status of the people who ordered leaflets, we find that a majority of the known distribution (i.e. excluding those unrecorded or unknown) goes to health professionals, however fully 53% is unrecorded (See figure 9). This underscores the importance of health professionals as a source of information for users. Similarly, from the feedback from questionnaires conducted over 2008-2011<sup>12</sup>, a clear majority had received the booklet from their health professional (more than 80%).
- 3.36 In terms of orders, 26% of literature requests came through the helpline. In terms of status, the most common group is 'diagnosed self' (30%), followed by unknown, then health professionals (18%). This shows that health professionals typically place larger orders, particularly compared to 'diagnosed self'.

*Figure 9: Share of distribution (leaflets and orders) by user group*

Total	Health Professional	Not Recorded	Diagnosed self	Other	Total
No. of Leaflets	33%	53%	3%	12%	100%
No. of Orders	18%	25%	31%	26%	100%

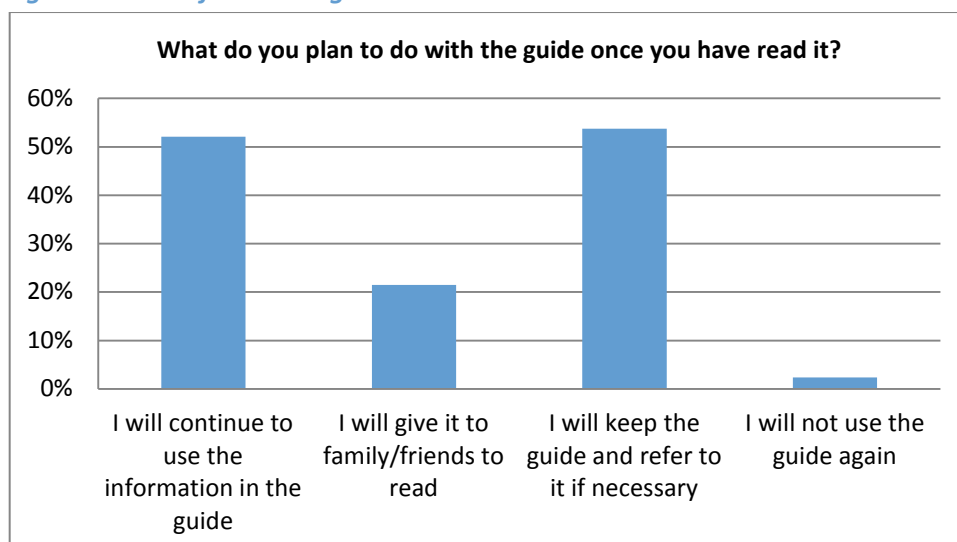
Source: 12-13 Lit Type and Status

- 3.37 We have looked at how users are using the data, through data gathered through feedback forms sent with the publications over 2008-2011. Asked if they thought they would contact the charity for more information after using the guide, more than 30% said they plan to contact the charity for more information, with the rest saying they had all the information they needed at present. 34% said they had contacted the charity before.
- 3.38 Specifically asked what they would do subsequently with the publication, most said they would continue using it personally, either actively continuing to use the information (52%) or keeping it and referring to it when necessary (54%). This information could be useful on an ongoing basis and Prostate Cancer UK should consider implementing a system to record this going forward.

<sup>11</sup> 'Internet' is how the response was recorded – nor further detail is available

<sup>12</sup> Feedback received from various publications (number of responses in brackets): 2008 A guide for newly diagnosed men (258); 2009 PSA and beyond (49); 2009 Living with hormone therapy (218); 2010 Recurrent prostate cancer (7); 2010 Enlarged prostate cancer (5); 2011 Living with and after prostate cancer (12)

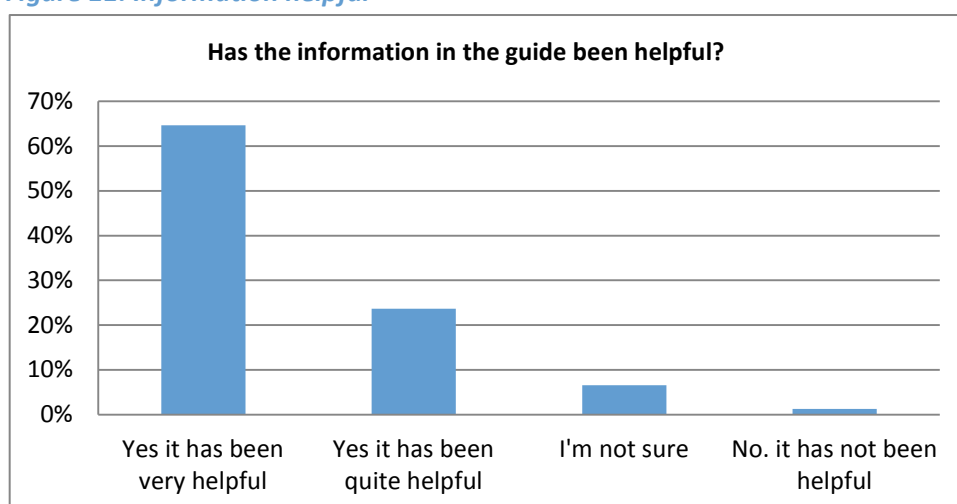
**Figure 10: Use after reading**



Source: Feedback from questionnaires 2008-2011, question 4, n=712 (NB some selected more than one response)

3.39 In terms of satisfaction, we know that the men found the information useful, and a majority found the information 'very useful'. This is consistent with previous findings.

**Figure 11: Information helpful**



Source: Feedback from questionnaires 2008-2011, question 2, n=528

3.40 The table below compares the proportion of information distributed by region with the proportion of the average new cases of prostate cancer per year. The data shows:

- This confirms that the services are over-concentrated in London and the South East and to a lesser extent the North West, Scotland and the North East.
- The most under provisioned areas are Eastern and the South West.

*Figure 12: Leaflets by region compared with incidence of prostate cancer*

Region	Share of leaflets	Share of new cases per year	Difference
Greater London	15.9%	9.3%	6.6%
South East	20.1%	13.9%	6.1%
North West	13.4%	10.9%	2.5%
Scotland	9.1%	7.1%	2.0%
North East	13.6%	12.0%	1.6%
Northern Ireland	1.9%	2.5%	-0.5%
West Midlands	8.5%	9.3%	-0.9%
Wales	3.8%	6.1%	-2.3%
East Midlands	4.8%	7.5%	-2.7%
South West	5.3%	10.7%	-5.4%
Eastern	3.7%	10.7%	-7.0%

Source: Cancer incidence, males, ICD10 C61 : Prostate, 2008-2010. National Cancer Intelligence Network (NCIN), UK Cancer Information Service (UKCIS), accessed June 2013; Publications 2012-13 (NB North East includes Yorkshire and Humberside)

- 3.41 Given the importance of the leaflets for raising awareness of Prostate Cancer UK and its services, increasing provision could have a knock on effect of wider use of all services.
- 3.42 From the data provided on **leaflets** take-up (Region and Ethnicity 2012-13), it appears that in some parts of the country, notably **London**, there is evidence that a good range of ethnicities are being reached (via leaflets). However, the key conclusion from the table illustrating region, ethnicity and publications is the extremely high number of '**not recorded**' responses. This makes it difficult to draw firm conclusions as there may be significant reach into different ethnicities which is simply not recorded and perhaps the apparent success of London's reach into a wider community is due to better data collection.

## Website

- 3.43 The website is an important part of Prostate Cancer UK's services, acting both as a direct source of information and also as a portal for users to order more information from Prostate Cancer UK and find out about the range of services on offer. In terms of the entire website, in the year to the end of September, there have been more than 1 million visitors and more than 750,000 unique visitors.
- 3.44 In terms of the information pages, from January 2013 to September 2013, there were more than 350,000 visits and almost 270,000 unique visitors. Looking by city, use is biased heavily towards London, with 21% of visits from this city, compared to around 2% for cities such as Birmingham, Manchester and Leeds (see appendix C, figure 1).
- 3.45 Returning visitors are more engaged, looking at an average of 3.2 pages, compared to 3.0 for new visitors. Similarly, visits are more than a minute longer (see appendix C, figure 2).
- 3.46 Further to this, Prostate Cancer UK has nearly 7,000 likes on Facebook and close to 9,000 followers on Twitter. To put this in context, Breast Cancer Care, a leading UK breast cancer charity, has 41,000 likes on Facebook and 89,000 followers on Twitter. The two charities are not comparable in terms of turnover, but their missions (specialist site specific cancer charities in the UK) are similar and this provides a useful benchmark. We are aware that the social media presence is in its nascence and is a developing aspect of the charity's communications. Prostate

Cancer UK should consider research into understanding how users benefit from social media, this would give the best chance to expand its social media presence in the best way to meet the needs of users.

- 3.47 Most visits to our information pages are from a desktop. The information page is a suitable measure of users, omitting some of the traffic that passes straight through the site without engaging. In total, around two thirds of visits are from desktops, compared to around 18% from mobile devices and 15% from tablets. Tablet and desktop users are more engaged than mobile users, with a lower bounce rate, viewing more pages per visit and spending longer on average (see appendix C, figure 3).

#### Emails

- 3.48 The e-mail service allows users to send questions to Prostate Cancer UK to be answered by specialist nurses. This permits answers from specialists, but without necessitating direct contact.
- 3.49 Growth in the email service is evident. In 2012-13, there were 661 emails, with 134 email call backs. This compares with 381 email enquiries in 2011-2012, of which 69 led to call backs. Growth year in year was 73% overall (appendix D, figure 1).
- 3.50 In terms of the subject of the emails to the specialist service, the following table compares the top 5 reasons in 2011-12 to the same in 2012-13. Signs and symptoms was the most important reason in 2012-13, with 52 emails compared to just 18 in the previous year, followed by advanced disease and diagnostic investigations.

**Figure 13: Emails by subject**

2011-12	Number of emails	2012-13	Number of emails
Other Business	45	Signs & Symptoms	52
Clinical Trials	27	Advanced Disease	50
Hormone Therapy	24	Diagnostic Investigations	47
Treatment Options	24	PSA Monitoring	39
Advanced Disease	23	Hormone Therapy	34

Source: Email service 12-13; Email service April 2011 – March 2012

## 4 The staff perspective

### Summary

Based on feedback from a range of sources, Prostate Cancer UK staff are confident that the information produced by Prostate Cancer UK is of a high quality. Although staff broadly knew the information and services available, there was an expressed desire to know more and for greater internal communication – particularly in view of the pace of change in the organisation.

The strengths of the information service are understood by staff to be the breadth and depth of information available in a balanced and jargon-free form. The helpline is considered to benefit from expert input from specialist nurses; some staff considered the helpline to be the most valuable source of support available from Prostate Cancer UK. Specialist nurses expressed some concern that a culture of target-setting puts a focus on quantity over quality.

A recurring theme is that, in view of the quality of the information and services, staff consider the priority to be widening distribution. This can be achieved by raising awareness of the charity's information and services. An important channel for this is health professionals, who are considered the first port of call for men diagnosed with prostate cancer and their families. Staff also expressed a desire for more research into and outreach to groups such as those with literacy issues or other barriers to accessing information.

- 4.1 This section sets out the common themes from the interviews with Prostate Cancer UK staff. All quotes in this chapter are from non-helpline staff member interviewees, except for those cited as being from specialist nurses staffing the helpline.
- 4.2 There is a high level of confidence within the organisation that the information produced by Prostate Cancer UK is high quality. This was based on feedback that staff had received, and which was discussed in the interviews, from service users, health professionals, volunteers and support groups, as well as the externally accredited Information Standard. This has broadly been endorsed by the service users who have so far been engaged in the research – as set out in the next section.

### How much do staff know about the information service?

- 4.3 Most staff described in broad terms what the information service does, and what it can offer to people affected by prostate cancer. All members of staff who have regular contact with people affected by prostate cancer and / or health professionals referred people to the information service.
- 4.4 There were several comments from staff members expressing **a desire to learn more** about the information service and the range of its products, so that they could be more proactive about promoting and sign-posting e.g. when new publications are produced. There was recognition

that this happens, to some extent, but staff still felt it would be useful to do more so all parts of the charity felt empowered to talk knowledgeably about its services.

“If we’ve got an event and they’re [the information service team] not coming, we could have a pre-briefing – they could tell us about any changed advice or new publications”.

“Make sure they’re reporting back on the work they’ve put together – make us more tooled up on what we have to offer.”

- 4.5 These comments were made in the general context of Prostate Cancer UK growing rapidly as a charity and establishing more services and activities. Staff felt it was generally hard to ‘keep up’ with the pace of change.

### How is the information service viewed?

- 4.6 The information service was regarded very highly by all members of staff. The range of publications was seen as impressive, enabling Prostate Cancer UK to meet the diverse information needs of many different men.

“It’s seen as hugely valuable. It has rigour and credibility. There’s been a lot of input over the years to develop it as a professional service.”

“It’s regarded highly by the volunteers.”

- 4.7 The use of clinical review and testing draft information products with volunteers were identified as factors that contributed to a key strength of the information service: the simplicity and clarity of language used and the absence of jargon.

“It’s plain language rather than jargon.”

- 4.8 There was one comment that Prostate Cancer UK’s printed materials could be “a little on the dry side”, in that the design is not very innovative. However, this was seen as a necessity as some men would not be attracted by unusual design.

- 4.9 Specific changes, such as making it easier for website visitors to order larger numbers of publications, were seen as particularly helpful for professionals and support groups.

“The quality of information is very good. It gives credibility to the support groups [that use Prostate Cancer UK materials].”

### How could the information service further support staff?

- 4.10 Suggestions for how the information service could further support staff include:

- Producing materials that are specifically targeted at football supporters, in support of the Football League Partnership
- Adding a dedicated option on the website so that support groups can directly order material in bulk, instead of having to go through the Support group development manager
- Helping to strengthen the role of the emerging regional offices so that they distribute more information in future and are seen by people as another way that people can access information

- Arranging to have more members of the information service team at events where Prostate Cancer UK has a presence, to give information to men – generally or in response to specific questions from individuals.

4.11 In line with the observation in paragraph 4.5, there was a more general comment that Prostate Cancer UK needed an “over-arching information and communications strategy” to ensure co-ordination and forward planning between the information service team, marketing and communications, policy and strategy.

## What else could the information service provide?

4.12 This question elicited a few suggestions from staff:

- Developing proactive relationships with health service professionals
- Producing information that is specifically targeted at men who would not be able to use existing written material, such as men with low levels of literacy, men with sight impairments and men with learning disabilities
- Reaching out to men who do not use the service, to identify the barriers and review the materials in light of their feedback
- Linked to the above point, finding ways to reach out to men who do use the service, but do not use information they get and / or are not satisfied by it
- Doing more proactive work to identify locations and events to promote information products – although that may not be the responsibility of the information service team
- Mapping the distribution of information service materials and targeting activity to “launch” Prostate Cancer UK’s presence in different parts of the country and / or with different groups of health professionals.

“We could offer a better service to professionals. They’re our main gateway. The ideal is that they would give our information to their patients.”

“What can we do for men who access the service but don’t do much with the information?”

“I’m a bit frustrated that there is nobody who is going out and finding places to promote our material. It’s a bit piecemeal. Our information should be everywhere!”

4.13 Some of these suggestions may have been addressed since the evaluation began or may be addressed by actions staff weren’t aware of (although this would reinforce the importance of communication and coordination within the organisation).

## How could the information service be improved?

4.14 The most common response to this question addressed a wider point about **Prostate Cancer UK’s visibility**. The priority for improvement wasn’t honing the products further, but significantly raising awareness of them amongst health professionals and the wider public.

“We’ve got these great products – we need to make sure people know they’re there and access them more than they do. That’s a comms [communications team] responsibility as well, not just the information service.”



“The quality of what we do is very good – we just don’t have enough reach.”

- 4.15 Linked to raising awareness, one member of staff emphasised the importance of creating **additional “routes” for men** to get to the information service, such as “non-paper based forms of delivery, like easy to use apps.”

“The service is excellent. The improvements we are trying to make are about increasing the width and breadth, getting more men to us the service by offering more ‘routes’”

- 4.16 Another improvement suggested by a member of staff was for Prostate Cancer UK to **talk to more men and their families** about their information seeking behaviour, “to assess where the information service should go”. The discussions could ask where men and their families go, when looking for health information, including non-medical settings like community centres, and use that intelligence to distribute material through a wider range of channels.

### What do staff think of the online information videos?

- 4.17 Staff were positive about the online information videos. They were seen by several members of staff as one example of how Prostate Cancer UK can offer information in ways that don’t rely on a high level of literacy.
- 4.18 Staff in roles that involved regular contact with people affected by prostate cancer believed that men often appreciated hearing other people’s stories – offering reassurance that they are “not the only ones” and showing that men can live happy and fulfilling lives with and beyond prostate cancer.

“They’re very valuable, as an alternative [to written materials].”

- 4.19 The support group development manager relayed that the feedback on the videos had been “excellent” because they featured “men talking in their own language, telling their own story”, as opposed to hearing things expressed in clinical language. The volunteer training manager relayed similar feedback from some volunteers about the importance of offering a “variety” of ways for men to get more information.

“They put things forward in a frank and clear and easy-to-digest way. People who may be too embarrassed to call up [the helpline] can access them.”

### How much do staff know about the helpline?

- 4.20 All staff were aware of the helpline and could describe, to varying levels of detail, what it offered to callers. All staff in roles outward-facing roles could give examples of how they promoted and signposted to the helpline.
- 4.21 The Community Support services lead described how the emerging regional centres are developing a relationship with the helpline that involves two-way referrals, where the helpline refers people to local centres when they need locally specific information.
- 4.22 A few members of staff talked in terms of the helpline providing “advice”, whereas the charity is clear that the helpline provided information. It may be worth clarifying, internally, that the helpline provides information, rather than advice.

## How is the helpline viewed by staff?

4.23 The helpline was rated very highly by all staff, who gave a number of reasons for this:

- The knowledge and professionalism of the specialist nurses
- The high standard of clinical input
- Positive feedback from men who had used the service, whom staff had encountered through events and work with volunteers and support groups
- The understanding that the helpline offered something that was uniquely helpful – the chance for men to talk and ask questions in a non-medical setting and get expert but clear and plainly expressed answers

“It’s the absolute jewel in the crown.”

“It’s the number one asset of the charity – but not enough people know we’ve got professionals here.”

## What support do people affected by prostate cancer get from the helpline?

4.24 Staff cited a range of different types of support:

- **Time** to ask questions and follow-up questions and explore options, in contrast to many medical settings where men don’t have the time they want to explore issues. Time was by far the most commonly cited form of support described by staff.
- **A balanced view** in contrast to some health professionals who might e.g. have a fixed view on the best treatment option
- The ability to **ensure that people understand** the information they are being given
- **Information on the full range of treatments**, where some health professionals might not be fully up-to-date and so be unaware of potential treatment options
- For **concerned men**, the chance to ask questions that can bust “myths” about the prostate, about prostate checks and treatments
- For men who have **recently been diagnosed**, the ability to talk and ask questions, once they had started to gather their thoughts and questions about ‘what happens now’
- **Further sign-posting** e.g. to the Tool Kit and the peer support service.

“Time with professionals, time to chat through the options. You won’t get that from GPs.”

“The time men get with health professionals is not enough; the helpline allows people more time, more drawn out consideration of information and decision making.”

## What are the barriers to accessing the service?

- 4.25 In line with the points made in paragraph 3.13, a number of staff members highlighted the first barrier as **a lack of awareness** about Prostate Cancer UK as a whole.

“[The main problem] is lack of awareness – the profile of the organisation is a whole isn’t strong enough.”

- 4.26 In addition, some members of staff identified a potential additional barrier in that some people might know about the helpline but not appreciate what it offers. This tallies with some of the discussion in the focus groups with the specialist nurses, which is summarised below.

- 4.27 In addition, staff felt there were a number of barriers relating to the attitudes and behaviours of some men:

- A “stiff upper lip” attitude of not wanting to be seen as someone who needs help
- Specifically, the very name ‘helpline’ could put some people off
- People not knowing what questions to ask
- Linked to the above point, some men might have a concern but be unable to verbalise it because they don’t have “the right language” to express it
- The worry of “not being a burden”
- Embarrassment about talking about health matters and, in particular, sensitive issues like impotence and incontinence.

- 4.28 The support group development manager raised one specific point about some support groups, which have their own helpline, treating Prostate Cancer UK’s as “the competition”. In reality, the support groups only offer peer support, as opposed to medical information, but their attitude of competitiveness remains.

“We can promote it by saying “We can help you work out what you want to ask”. That way we can address the fact that people are in a muddle and might not know what they’re after.”

“The word ‘helpline’ might be off-putting – some men might have questions and not feel like they need help.”

## What do staff think of the Tool Kit – how could it be improved?

- 4.29 All staff were aware of the Tool Kit, but only a few had detailed knowledge. Staff generally perceived it to be an important part of Prostate Cancer UK’s offer, making available comprehensive and detailed information.

“It’s incredibly comprehensive, regularly updated and peer-reviewed.”

- 4.30 There were a few suggestions for improvement, although these were often rather tentative as most staff had limited exposure to the Tool Kit. Suggestions include:

- Creating a downloadable online version

- Further streamlining the contents – although more staff felt the thoroughness of the pack was an advantage and would be welcomed by most men.

4.31 The question raised by a few members of staff related to how the Tool Kit was used by health professionals i.e. that Prostate Cancer UK was “handing over control” of how the Tool Kit is used, but wasn’t able to track how it was used.

“It can be used differently by different health professionals. The question is how it’s used.”

“The Tool Kit is a pretty chunky beast.”

4.32 One staff member interviewee also raised an issue about the challenge of ensuring that up-to-date hard copies were being used by health professionals, after an interviewee had seen old versions being used in a hospital.

### Who are the key audiences for the service – how far are their needs being met?

4.33 There was a general consensus that Prostate Cancer UK’s key audience were men aged 50, and their families, who were diagnosed with prostate cancer or who were more likely to develop the condition.

4.34 However, several staff were also keen that Prostate Cancer UK do more targeted outreach and tailor services toward groups who may be currently under-served, such as:

- Men from Black and Minority Ethnic communities – and African and African Caribbean men in particular
- Men with learning disabilities
- Men with sight problems and other sensory impairments.

4.35 There was a sense that Prostate Cancer UK was “getting better” in terms of catering to a more diverse range of men. A number of members of staff pointed to the charity’s increased work with gay and bisexual men and the wider range of services for relatives as examples of becoming more inclusive.

“There are signs that [the message] is getting out that it’s a service for more than just men.”

4.36 However, most staff felt that it was important for the charity to constantly challenge itself and continue to improve. A couple of members described the ‘typical’ service user as a well-educated, middle class, white retiree living in London or the South East. In the past, the charity had catered to this audience by e.g. producing materials that rely on a high level of literacy to the potential exclusion of other groups.

4.37 A number of staff also **identified health professionals** as a key audience, linked to comments earlier in the interviews about their importance in sign-posting to Prostate Cancer UK’s services.

“Our services are high quality, but not enough people know about them – not enough health professionals are sign-posting to them.”

4.38 The Health Professionals Engagement Manager described the work that she and her team were taking forward on this agenda. The team are looking to adopt a more targeted and tailored approach, focusing on priority professional like urologists and oncologists and targeting specific materials e.g. targeting information about the PSA test to GPs.

4.39 Specific activities include:

- Making the website more “professional friendly”, such as having a section specifically addressed to health professionals
- Promoting more examples of Prostate Cancer UK’s work with health professionals
- Targeting journals that are read by health professionals
- Using social media and LinkedIn groups
- Continued use of events and conferences, and looking at more targeted regional events
- Potentially appointing “champions” of Prostate Cancer UK in health settings, building on funded posts that the charity is currently investing in.

“We need to target health professionals – most men’s first port of call will be a health professional. They are the enablers. If we can switch them on to our services – through grants, quality standards, work with them to understand what’s going on, what they need – [we can] increase our visibility with men.”

## How do the services make a difference to people’s lives?

4.40 Staff members mostly highlighted the main differences as providing comfort and re-assurance and reducing anxiety by:

- offering a combination of unpressured time and expertise (on the helpline in particular)
- providing continuous support – the helpline which can be called numerous times, information which can be returned to in their own time, and more materials can be provided on request
- providing an objective, professional view
- showing that they are “not the only one” to be affected by prostate cancer.

“Information takes away some of the lack of empowerment.”

4.41 A few members of staff focused in more on the benefit of the service being to help men become “informed patients” by:

- equipping them with the information they need to ask the right questions of health professionals
- allowing them to double check their understanding of the condition, their treatment options and side effects

- enabling them to ask questions which they might be embarrassed to ask face-to-face of their health professional e.g. because the health professional is a young woman.

“They have a real impact on men’s experience. Information support can deal with the emotions they have, and answer their questions to decrease anxiety.”

“[The information] gives them an ice-breaker to broach difficult conversations, it gives them more confidence.”

## What are the common barriers to the services?

4.42 Staff highlighted that barriers are at three different levels.

4.43 At the level of Prostate Cancer UK there were related barriers:

- People do not know about the charity
- People may be aware of the charity but not realise the services it offers
- Prostate Cancer UK’s material assumes a high level of literacy.

4.44 At the level of health professionals:

- Health centres run by or associated with other cancer charities may prefer to give out their own / their funder’s’ materials
- Some health professionals prefer not to signpost or give out too much information because they fear it will cause confusion and / or anxiety
- Some health professionals might fear that signposting patients will be interpreted as “passing them on”.

“Some professionals are quite precious.”

4.45 At the individual level:

- Some men may simply prefer not to know
- Feelings of embarrassment
- Low levels of literacy
- Sensory impairments which might affect an individual’s ability to access information in different forms
- Lack of access to the internet / a telephone .

4.46 A few members of staff were concerned that Prostate Cancer UK was perceived to be too focused on London and the South East, and in some cases was too “London-oriented” and had not, until recently, put significant investment in delivering services across the different Celtic Nations and regions of England.

“The organisation is very London-focused in terms of staff, headquarters, meetings, but there’s a whole tranche of the organisation outside London. There is a risk that the organisation is talking to itself and doesn’t meet the need of all users.”

- 4.47 Many staff were keen that Prostate Cancer UK should continue to look to identify barriers and find new ways to address this by creating more “ways in” to the services.

### How could people’s experience of the service be improved?

- 4.48 Specific suggestions included:

- Investing more in emerging regional infrastructure so that men and their families see Prostate Cancer UK as a “local service”
- Across Prostate Cancer UK, reviewing the outcomes it wants to help men achieve, based on increased feedback from men and their families, to ensure that they are focused on the things that matter most to them
- Ensuring people are aware of the range of Prostate Cancer’s services, so people who use the information service also know about support groups and volunteering opportunities (where appropriate)
- Using more images for older men i.e. men aged 75 and over – based on a concern that charity’s materials presented images of younger men
- Creating more “ways in” to the services e.g. mobile phone apps and other forms of non-paper based distribution
- Creating more participative experiences e.g. encouraging more use of diaries and mapping personal journeys
- Considering how Prostate Cancer UK’s information service can help to tackle ‘myths’ and confusing media stories
- Considering the scope for providing more information on preventing prostate cancer. This could help engage younger men, but the staff member recognised that the research base may not be strong enough.

“We can have a think about how we provide information when there are stories in the Daily Express about a new form of treatment – how eating six parsnips a day can protect you against prostate cancer.”

### Are there any gaps in the range of services provided?

- 4.49 Most staff were unsure of gaps, but individuals highlighted specific areas of work that Prostate Cancer UK could do more of:

- Providing more services locally, through the emerging regional infrastructure
- Using more videos to communicate information
- Involving more men who have used and benefited from Prostate Cancer UK e.g. having them talk at events
- Providing more information about possible worst case scenarios.

- 4.50 One member of staff also highlighted that the information produced by Prostate Cancer UK currently suits an engaged market, but not the un-engaged. Information could be produced to raise awareness in different settings and for other audiences, for example university students.



## What one thing would you change?

4.51 As with the above question, some staff could not identify specific change, and some answered the question more in terms of “What else / what more should we be doing”, including:

- More outreach and targeted work with under-served groups
- More profile-raising work
- Providing more information about how people can have an ongoing relationship with the charity, through volunteering, fund-raising and acting as case studies
- Giving volunteers and support groups, including independent support groups, more of a role in helping to make suggestions for new services and test emerging tools and publications.

“The organisation needs to be famous enough for the people who need the services to access them.”

## Specialist nurse workshop

4.52 As part of the fieldwork with Prostate Cancer UK staff, we conducted a facilitated two-hour workshop with all but one of the specialist nurses. The outstanding specialist nurse was interviewed separately using a topic guide that followed the same structure as the workshop questions.

## What are some of the barriers preventing people from using the service?

The nurses identified a number of barriers, echoing many of those identified by other staff:

- Lack of awareness of Prostate Cancer UK
- Lack of awareness of what prostate cancer is and what we can offer – some callers contact Prostate Cancer UK for the wrong reasons (e.g. booking follow-up medical appointments)
- A lot of information is given to people when they are diagnosed - this might confuse recipients about the different points of contact, their purposes, what the next steps are for them
- At the individual level, many men are reluctant to talk about prostate cancer and issues like erectile dysfunction
- Some men will prefer face-to-face conversations, instead of phone calls, particularly older men and men with hearing problems
- Other men express an “apologetic” concern that they are “taking up time”.

4.53 Taking the discussion further about why different men might – or might not – call, the specialist nurses described a tendency for callers to be white, middle class and more articulate people. Other groups might be less confident in communicating their concerns and therefore avoid calling.

- 4.54 They questioned whether, for some men, a dedicated helpline service would be beneficial e.g. for different Black and Minority Ethnic groups.

### What do you need to deliver a quality service

- 4.55 The nurses generally felt that they had the things they needed to deliver a good service, including:
- The knowledge they had within the team
  - Access to training and development opportunities
  - Input from a clinical adviser
  - Decent equipment, including a functioning call-handling system – though the nurses would prefer cordless head-sets of a high-enough standard, and support to work from home
  - A new call-back mechanism, although that wasn't used very frequently.
- 4.56 The conversation moved on to a general concern about the charity's strategy for the helpline and three concerns in particular.
- 4.57 The pressure to increase numbers was in danger of 'putting quantity before quality' – attracting a large number of calls from the worried well, when the organisation should be focusing on men who are less likely to seek help but need it most. The nurses were not aware of the rationale for increased targets, other than a need to reassure funders.
- 4.58 Linked to this, there was some concern that they were being implicitly blamed for not speaking to enough men, when their ability to increase the numbers of caller is very limited, and the responsibility for raising the profile of the charity lies across all parts of the organisation. There was a concern that they were being asked "Why aren't you speaking to more men?" when the question should be "How can all of us get more men to use the helpline?"
- 4.59 The requirement to record activity every thirty minutes made the nurses feel like they had to "justify their time" in a way that no other parts of the charity were required to. They didn't feel the management need for this kind of information was sufficiently explained.

"There's a feeling that the helpline service is becoming more like a call centre."

Specialist nurse

"Where is the groundwork for [the targets]?"

Specialist nurse

### What are the strong points of the helpline service? What could be improved?

- 4.60 The nurses identified a number of important strong points of the service:
- The strong knowledge base of the team, with individuals who have particular areas of expertise

- The ability to offer people time
- The ability to offer an objective and balanced view.

4.61 The specialist nurses felt a number of things could further improve the service, including:

- More informed input from Prostate Cancer UK's research department so that they could give callers more detailed information in response to new developments
- Helping the nurse team to feel "less isolated" could help interaction between them and rest of the organisation – it was hoped that the move to new offices could help this
- More generally the feeling of physical isolation reflected a sense that they could have a more engaged role, being able to give feedback and offer more input. They felt that they weren't asked what they considered to be the priorities in the coming years.

4.62 One suggestion was that a working group could be established between the research team, information team and specialist nurses to discuss clinical developments, anticipating what developments Prostate Cancer UK need to have a view on, and keep staff informed and engaged.

4.63 A similar involvement with the communications team could ensure co-ordination between the media work and the impact on the helpline. The group cited one example of an advert placed in a national newspaper which led to a very busy day on the helpline which they were not told about / consulted on in advance.

### **What are the main benefits of the helpline?**

4.64 The specialist nurses were confident that they helped men and their families in a number of ways:

- Providing good and up-to-date support, in relation to a cancer which people generally know little about
- Addressing misplaced concerns about the condition and impact of treatments
- Providing reassurance, including through being able to ask follow-up questions
- For diagnosed men, time to work through options, and time for people to ask questions
- In terminal or potentially terminal cases, the helpline can provide additional comfort – people can say things to someone anonymous they're not yet ready to say to others, they can check what their options are, they can be given a realistic appraisal of their situation.

4.65 The nurses also used this question to explore how to ensure it continues to benefit people in future, through:

- Offering more support on survivorship as society ages and more men live with and beyond prostate cancer

- Offering more specific, tailored services like the fatigue service, covering things like survivorship and sexual health
- Counselling and psychological support, but this might need dedicated counsellors
- It would be good to follow-up with users after they have called, i.e. 6 months later, to see if the helpline made a difference and how they reflect on their experience of it (did people think it was informative? Did it give non-biased information?). Prostate Cancer UK could consider implementing a tool for this going forward.

## 5 The service user perspective

### Summary

Most of the service users interviewed were very satisfied with Prostate Cancer UK's information and services. In general, service users appreciated the quality of information: the clarity and jargon-free language used, as well as the breadth and detail available. The information was considered accurate and reliable. Helpline users often appreciated having more time than with health professionals.

Very few respondents reported having any concerns about contacting Prostate Cancer UK. There were not many suggestions for improvements; one improvement would be more specific support for carers; some participants also wanted more information on side effects than they had accessed.

The most often cited benefits of contact with Prostate Cancer UK were useful information and increased confidence/reassurance. Service users can also use the information to have better discussions with or even challenge their health professionals. Some users go beyond this and use Prostate Cancer UK information to make treatment decisions.

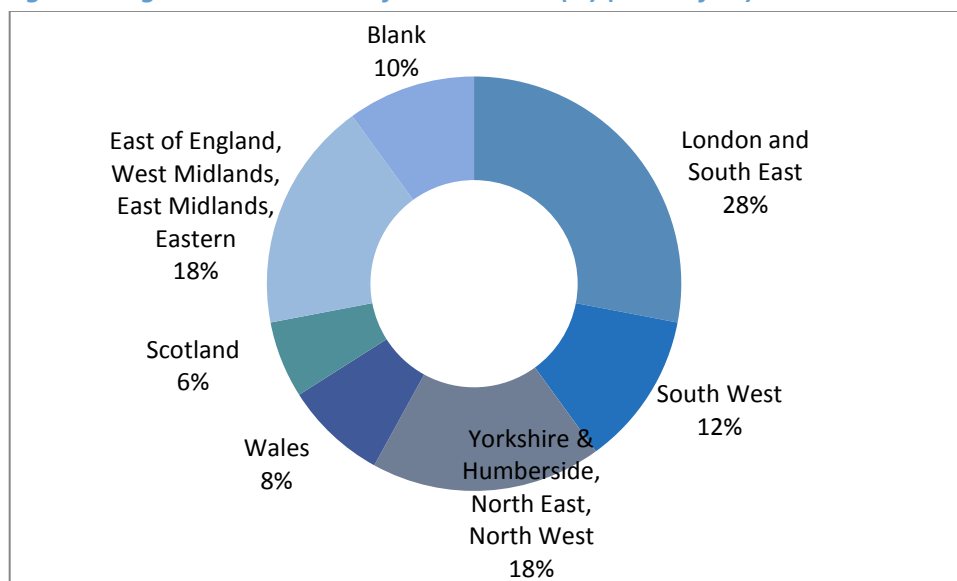
Most users anticipated using the charity's services again only if it is necessary. However, there was a high level of appreciation for the charity and many participants would be willing to do something for the charity (volunteer/donations). There was evidence of ongoing engagement through the Forum.

### Initial service user interviews

- 5.1 This section summarises the key findings of the initial service user interviews, set out by each group of questions in the topic guide which covered the following themes:
- The journey towards Prostate Cancer UK
  - Information Needs
  - The helpline
  - The Tool Kit
  - Outcomes
  - Future contact
- 5.2 All quotes within this section are from diagnosed or concerned men, except where specified as being from friends/family members.
- 5.3 Of the 50 interviewed for this final report:

- 14 were from London and the South East, 31 from elsewhere in the UK and 5 did not have a region recorded<sup>13</sup>;

**Figure 1 Regional breakdown of service users (%) (Total of 50)**

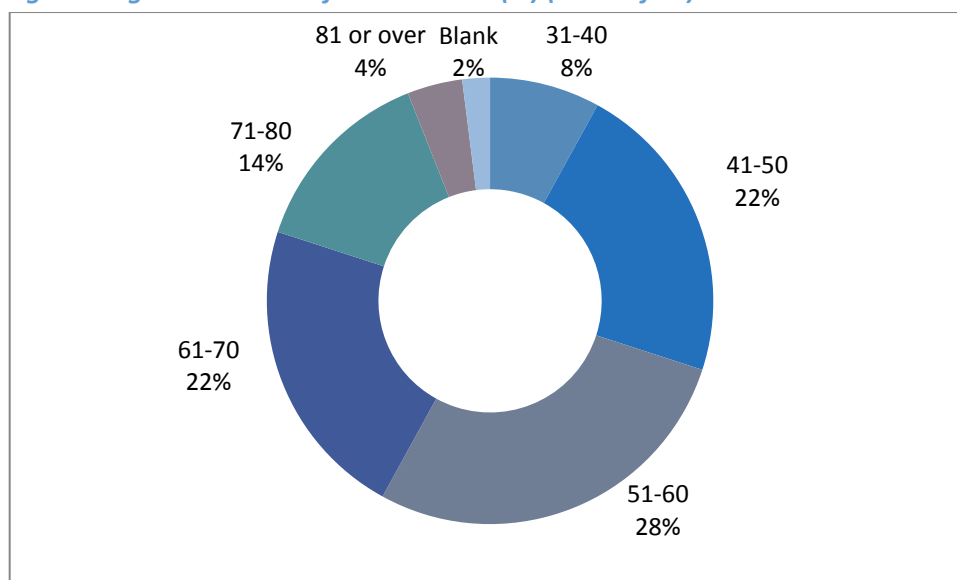


- 38 were diagnosed with prostate cancer, another 7 were friends and family of diagnosed persons, 5 were concerned men or family and friends of concerned men;
- 40 were male and 10 female;
- 4 were in the 31-40 age bracket, 11 were aged 41-50, 14 were aged 51-60; 11 were aged 61-70, 7 were aged 71-80, 2 were over 80 and 1 was of unknown age<sup>14</sup>.

<sup>13</sup> We tried to fill in gaps in data about the service user e.g. their age and location, but not all respondents chose to answer these questions.

<sup>14</sup> We tried to fill in gaps in data about the service user e.g. their age and location, but not all respondents chose to answer these questions.

Figure 2 Age breakdown of service users (%) (Total of 50)



### The journey towards Prostate Cancer UK

5.4 This section of the interview covered the following questions:

- How did you first hear about Prostate Cancer UK?
- What did you want to get out of contacting Prostate Cancer UK?
- Which part of the charity did you contact first?
- How often have you contacted/used services?
- Did you have any concerns or hesitations?

5.5 Most interviewees **found out about Prostate Cancer UK** from either the internet or from health professionals, with a few hearing about the charity from advertising, from a friend or from promotional material.

5.6 Most **wanted to get from the contact** either general information or information about treatment, with a few wanting to find out about side effects. A few wanted to find out about symptoms and two to hear others' experiences.

5.7 The majority **first contacted Prostate Cancer UK** via its website, although this reflects the nature of the sample, as most had volunteered to take part in evaluation after ordering publications online. Of these, most went on from looking at the website to order information including leaflets, brochures and the Tool Kit, while some went from the website to the Online Community and a few from the website to the helpline. Several however had no further contact with the charity. A few interviewees' first contact with the charity was via the leaflets/Tool Kit, the helpline or in one case the Online Community.

*"I'm still a regular on the Forum – now I'm starting to help other people."*

5.8 Several interviewees could not recall **how often they had contacted Prostate Cancer UK**. Of those who did answer, most had contacted the charity only once or twice, although a couple had rung the helpline three times. A small minority reported themselves to be higher frequency



users, a few reporting that they were regular Online Community users and a few regularly consulting the website for information.

- 5.9 Only a few interviewees reported having had **concerns or hesitations** about contacting Prostate Cancer UK. One mentioned being anxious about who would answer the call; another, issues around confidentiality. Two interviewees mentioned being concerned about the quality of the service – one had a poor experience with a Macmillan helpline previously and had been concerned that Prostate Cancer UK would be the same.

“...I was anxious, didn’t know what I would be told and what I was expecting. Who would I be talking to?”

### Information Needs

- 5.10 This section covered the following questions:

- So far, what has been most useful to you about your contact?
- What did you get that you didn’t get elsewhere e.g. from health professionals?
- What has been less useful to you?
- Were there any gaps in what Prostate Cancer UK has to offer?

- 5.11 When asked what **had been most useful** to them, the Tool Kit, information about treatment and the helpline were the most popular answers. Some also cited clarity of information, learning from shared experiences and learning about side effects. A few cited the Online Community, while a couple cited reassurance, and improved communication with their doctor.

“Literature explained it to layman ... put me in a whole different ballgame ... my understanding began to grow so when I had future meetings I could talk on the same wavelength with my oncologist and know what I was talking about.”

“Talking to somebody [on the helpline] – much better than looking at the information on the website. You can always think of something to ask you wouldn’t have asked otherwise.”

- 5.12 When asked about **what they had got from Prostate Cancer UK that they had not got elsewhere**, the most popular answers related to the quality of its information and attaining more knowledge, and information on side effects. Some also cited talking with health professionals and getting reassurance. A couple also cited the charity having more time than health professionals, and they found the information about diet and the toilet card to be things that they could not get from a health professional.

“Information I trust – there’s a lot of it out on the web – a lot is American – don’t know if all the treatments are available in Europe. Felt it was a resource I could trust.” (Friend/family)

“The consultant either treated me as if I knew everything or was blasé about not going into detail. ... Without this Tool Kit I would have been floundering.”

- 5.13 Only a few interviewees identified anything that was **less useful** to them, respectively: not all treatment options being applicable to them; the Tool Kit being less relevant to people with a relatively low level condition and more geared towards people in advanced stages; the advice

being difficult to put into practice; and the lack of a male nurse to speak to, especially around sexual issues.

- 5.14 Only a small minority of interviewees were able to identify **gaps in what Prostate Cancer UK had to offer**: a few identified support for family/friends as a gap, and a few wanted more information about side effects. Single interviewees identified financial advice and providing too much information as gaps. Two mentioned having extended opening hours of the helpline.

“More information on the incontinence – exactly how bad things could be ... explain the bad scenarios too.” (Friend/family)

“I was looking for concise information, instead I got a large pack that was off-putting because there was so much of it.”

“[There’s] not so much around for people who are supporting people with cancer. ... What would be really beneficial for me would be to speak to other people in a similar situation to myself – very little around. As the disease progresses I will miss not having that.” (Friend/family)

### The helpline

- 5.15 This section covered the following questions:

- Where did you hear about the helpline?
- Why did you call and did you get what you wanted?

- 5.16 Nearly all interviewees who identified how they had **heard about the helpline** cited the website. The small number that mentioned other sources respectively cited a TV advert, a support group and two who said the Tool Kit.

- 5.17 The interviewees who identified **why they had contacted the helpline** mainly wanted information (some general, others about specific issues such as treatment options or worrying symptoms) though a couple had wanted a general chat. Most felt that they had got what they wanted.

“The consultants will tell you what will happen but they speak a language that the lay person doesn’t understand. Prostate Cancer UK talk in language that you understand.”

“Knowing that I could pick up the phone and speak to a specialist nurse helped enormously. It can be difficult getting through to your own specialist nurses, trying to get through to a consultant is virtually impossible.”

- 5.18 One female interviewee suggested users should have the choice to speak to a male nurse on the helpline. Another interviewee mentioned that weekend access could be another improvement:

“Someone available on the helpline at the weekend. Only through the week can be a hindrance.”

### The Tool Kit

- 5.19 This section covered the following questions:

- Have you seen or used the Tool Kit?
- How useful has the Tool Kit been to you?

- What do you use it for?
- How could it be improved?
- Have you used any other information from Prostate Cancer UK?

5.20 A majority stated that they had **heard of or used the Tool Kit** while a minority confirmed that they had not.

5.21 The majority who commented about the **usefulness of the Tool Kit** responded that they had found it useful or very useful, some calling it comprehensive and some finding it easy to read. One however qualified this by stating that while it had been very useful to read once, after reading it once he had switched to using the easier to carry around Macmillan booklet for ongoing reference.

*“I’d recommend anyone to have it [the Tool Kit]. When you see a doctor you don’t remember all the questions you want, get seven minutes with the doctor – it’s better to teach yourself some of these things.”*

*“We weren’t sure if my husband needed to have a PSA test before going back to see the consultant – we checked and the Tool Kit told us the answer. We always check the Tool Kit and the answer’s there. ... [layout] makes it easy to find out what you want very quickly.”*  
(Friend/family)

5.22 When asked **what they had used the Tool Kit for**, the most frequently cited answers were improved understanding of/discussions with health professionals, information about treatments, and a group that said they read it all. Some used it for general information, reassurance or dietary information.

*“I keep the booklet on hormone therapy in my day planner, I can write down information.”*

*“I use it for taking to see the surgeon...It is there to help me follow through points and know what questions I should be asking.”*

5.23 Some interviewees were able to suggest **improvements to the Tool Kit** although some felt no improvements were needed. There were no clear themes to the suggested improvements with single interviewees identifying the following: put Tool Kit online so users could self-print; make it a uniform paper size and provide a folder; avoid repetition; regular updates following treatment evolution; make it smaller and easier to carry around like Macmillan booklets; include more personal stories and specific information on side effects; include more detail.

5.24 Some of these suggested improvements already exist; for example, the Tool Kit is available online and can be printed, it has a folder, and is updated regularly. This highlights the importance of communicating with users and potential users what is on offer.

5.25 Only a minority of interviewees were able to identify and discuss **other Prostate Cancer UK information they had used**. Of these some said they had used booklets/brochures (one specifying the travel booklet and another that they used the audio version of booklets). A few made comments about the quality of the material: some felt the brochures were very good/useful/easy to use and a couple praised the website as “useful” and “intuitive”. One

stated that they liked the real life examples in the material, while another used Prostate Cancer UK material over that of other cancer charities as it was more specialised.

“Examples of real experience help to make it real. You get a feeling that other people have been there.”

“Macmillan’s website is very good but is a jack of all trades for all cancers. Prostate Cancer UK has one website for that cancer, greater depth of information, so I use their website 95% of the time.”

- 5.26 One interviewee compared Prostate Cancer UK material unfavourably with that of the American Prostate Society; while another stated that while its material contained too much about fundraising, it was a good source of information. Interestingly, he commented that he had found the Father’s Day film to be “*good and informative*” but that his wife had criticised it as “*depressing*”.

### Outcomes

- 5.27 This section covered the following questions:

- Overall how has your contact helped you?
- What have you done differently as a result?

- 5.28 Interviewees were asked to summarise how **their contact with Prostate Cancer UK had helped them** overall. The most frequently cited answers related to the usefulness of the information, providing reassurance/confidence and being helpful. A couple of interviewees cited engagement with health professionals and having access to shared experiences.

“When you get diagnosis you feel like you’re drowning, lost emotionally – useful to talk to someone and feel you’re not alone and understand the processes you’re going through...A rock in a dark place.”

“It gave me enough information to be able to go back to the medics and seek further tests.”

“It seemed a respected charity, partly because it is endorsed by health professionals and also because as a brand it looks very professional.”

“I was mentally armed by the Tool Kit – I wouldn’t be surprised by anything. I didn’t need to call Prostate Cancer UK because I had all the information in the Tool Kit.”

- 5.29 Interviewees were asked to identify **actions that they had taken as a result** of the Prostate Cancer UK information. It should be noted that prompts needed to be given for interviewees to understand the question and how to answer it, with the usual prompts being asking questions of health professionals and changes to diet. This should be borne in mind in interpreting the data as lifestyle changes (diet, exercise, alcohol) and improved engagement with health professionals were the most popular answers. A couple cited informing decisions about treatment, while some said that they had done nothing as a result of the information.

“The main thing is the knowledge – I’m not afraid to ask questions now.”

*“I didn’t just want to [watchfully] wait. ... After reading the Tool Kit I decided to take a firmer course of action [i.e. brachytherapy].”*

*“Tool Kit gives you a little booklet to take to the appointment to ask questions and gives space for answers – I used this. ... it suggested things I might like to ask I wouldn’t have thought of.”*

### Future contact

- 5.30 Interviewees were divided in their views about what **contact they imagine having with Prostate Cancer UK in the future**, some seeing this as likely and helpful; some being unsure and seeing it as contingent on developments in their health; and some viewing it more negatively in that they hoped that they would not need it (i.e. they would be cured).

*“[if] my situation changes ... I would prefer to contact Prostate Cancer UK over my doctor. It’s good to hear from men their stories.”*

*“Depends on Dad’s treatment, if it got to a stage where different treatments were possible and we needed information, the website would be one of our first ports of call.” (Friends/family)*

*“I want to get on with life, don’t want to be reminded.”*

- 5.31 One participant, who expressed a very high level of satisfaction with his use of the charity’s services, expressed doubts over whether Prostate Cancer UK could help further since the nurses on the helpline wouldn’t know his case as well as his own doctor:

*“Conscious if I were to ring again, it would only be a general chat. You wouldn’t have all my symptoms, so it would be only on a general basis. More arms length, you don’t know me and I don’t know you, whereas I go to my GP and he knows me.”*

- 5.32 Of the minority who specified future contact beyond information/support-seeking, some saw themselves as donating or as volunteering, while a couple envisaged recommending the charity to others or helping on the Online Community.

*“Every time we speak to someone we hear of someone who has been diagnosed, we’re saying ‘get the Tool Kit’, we’re spreading the word – and asking people to make a donation.”  
(Friend/family)*

*“I would like to give something back to them but it’s not that easy...doesn’t seem to be an easy way to give money, other than a fun run every year.”*

- 5.33 Prostate Cancer UK service users did not object to being asked to donate, with some users showing a desire to ‘give back’ to the charity. This contrasted with some health professionals who, as regular users of the site, opposed being asked every time to donate.

### Service user follow ups

- 5.34 Following the initial 50 service user interviews, we also carried out follow up interviews with selected service users. In total, we interviewed 10 service users from the first round of interviews. This section summarises the key findings of the interviews, set out by each question in the topic guide, which covered the following:

- Information consulted before the first interview

- Information consulted recently
- Health information seeking behaviour
- Use of information
- Evidence of behavioural change
- Future additional support

5.35 All quotes within this section are from service users.

#### About the Service Users

5.36 We interviewed ten service users who had taken part in the first round of interviews. This was limited to those who agreed in the first interview to take part in a second interview.

5.37 We asked the potential participants a set of screening questions:

- Have you used any new information from Prostate Cancer UK?
- Have you used any of the same information from Prostate Cancer UK since we last spoke?
- Has the Prostate Cancer UK information you looked at previously led you to make any changes or decisions since we last spoke?

5.38 If the answers to the above questions were all 'no', we considered the potential participant was unlikely to be able to contribute in a further interview.

5.39 Although we did not formally seek to capture information on the situation of those who answered 'no' to all of the above, this group often described themselves as **past-treatment** - in the "monitoring stage" or on "active surveillance" – and **no longer felt the need for more information**.

5.40 Of the ten interviews we carried out, seven are diagnosed men and the remaining three are partners/family.

#### Information consulted before the first interview

5.41 This section covered the following questions:

- Looking back, what are your views on the information/helpline call you received/made?
- Did it give you the information you were looking for?
- Do you think it was reliable and accurate?
- Do you still use the information?

5.42 On reflection, all of the participants were happy with the **information that they had received previously**. Participants described the information as "very useful", "worthwhile", and "reassuring". One participant described the information as essential:

*"The helpline is an essential service. Most reliable, best information is Prostate Cancer UK, particularly the helpline."*

5.43 The element of the helpline that was praised was being able to speak to people, which wasn't possible for all participants through their health professionals. Another participant mentioned that the "helpline was great" and was better than Macmillan or Cancer Bacup.

5.44 Participants **all** felt that the information was **accurate and reliable**.

5.45 If there was any information that participants felt they didn't get enough, it was knowledge of side effects. For instance:

"In retrospect, we would like more info on long term side effects. This may reflect the way treatments have changed, but I don't think [husband's name] would have gone for the Prostatectomy...he says he didn't appreciate the consequences in terms of side effects."

5.46 This was repeated by another participant.

"With hindsight, I wouldn't have chosen to have surgery...Maybe if the website could clarify more what the chances are for each procedure, what statistics on how many people get side effects...I know it is there, but to make it even clearer - some people they need it even clearer."

5.47 It is worth noting that other participants mentioned that they had received information on side effects from Prostate Cancer UK. However, it is clear that information on side effects is very important to many participants and as the second quote above suggests, users want this information to be as clear as possible.

#### Information consulted recently

5.48 This section covered:

- Since we last spoke, have you used any other of Prostate Cancer UK's services?
- If yes, how helpful was this for you? How did it help you?
- If you have used any of our information booklets or fact sheets, were they easy to use and understand? Did they answer all of your questions?
- Since we last spoke, have you looked for or received information about prostate cancer from any other sources? Why were you seeking more information?

5.49 Asked if they had used any **more of the Prostate Cancer UK's** services since the first interview, four said 'no' and one wasn't sure whether they had used the helpline prior to the previous interview or after. Notably, two of the four that said 'no' mentioned that they were thinking of phoning the helpline for further advice.

5.50 Four said they had been on the website, three of whom mentioned using the Online Community. The other uses the website for information. One person who used the website did not necessarily go straight to Prostate Cancer UK. They said:

"I might just put some stuff in because I've read the latest research, more often than not Prostate Cancer UK has an article on it. I go to the internet and put something in, if Prostate Cancer UK comes up as a hit, I go as my first choice to that site."

5.51 Asked how this had helped, the Online Community users mentioned the value of support from others in terms of reassurance. One participant said of the Online Community:



“It is like community, a band of brothers...I can speak to other partners. You can learn from other people. When you are feeling down, you are frightened, you can find out from other people. You get reassurance from them.”

- 5.52 Of the information on the website, one participant was glad to have access to information “24/7”. Similarly, the participant that had used the helpline (but not sure if it was after the previous interview) said:

“I have always found the helpline very helpful. Sometimes even when I think I know something, the helpline can confirm this.”

- 5.53 One person mentioned that they had **ordered the Tool Kit**. This was specifically a result of the researcher asking about the Tool Kit in the first interview.

- 5.54 Asked whether the information they used was **easy to understand** and whether it **answered all of your questions**, all of the participants that had used a source of information agreed that it was easy to use. Although, one person commented that they “don’t always understand everything on the website”. Another mentioned of the website:

“Yes, easy to use. But I prefer the Tool Kit to trawling the internet.”

- 5.55 Of the Online Community, one participant mentioned that it is necessary to be wary of different opinions and that people may seek to “justify their decision” – this was not considered deliberate, rather a bias that you should be aware of.

- 5.56 Asked about information sought from **any other sources**, few of the participants said they had received any other information. One mentioned information from the “national press”; while two mentioned their doctor. One of those that mentioned their doctor had received more information leaflets. This was a direct result of asking questions, which reflects the knowledge they have as a result of Prostate Cancer UK and the Tool Kit in particular.

#### Health information seeking behaviour

- 5.57 This section covers:

- At this stage, do you feel you have all of the information that you need? If not, what would you find helpful?

- 5.58 Nearly all of the participants felt they had as much **information that they need at present**.

- 5.59 One mentioned that they have enough information at present, but:

“We need to start seeking information now. So we are prepared for the blood results. Left alone...you get told it is advanced: they can’t cure it, can only treat it. They give you treatment. If you’re doing well, they tell you off you go. Then you are out of the system until you see them again. They don’t really tell you what to look out for.”

- 5.60 Specifically, they wanted information around what to expect from the blood tests. There was also a question of when it was best to pursue a course of radiotherapy.

- 5.61 Similarly, another participant (at a different stage in the interview) mentioned that their course of hormone therapy was coming to an end and that they had some questions they might put to the helpline:

“What I think I will do is get in touch with the helpline about after you finish [treatment]. What I want is a bit of reassuring - that you don’t get time to talk to your doctor about. I think, oh my goodness, I didn’t mention that. You don’t have time”

- 5.62 Again, the helpline was valued because it allowed the participants to seek advice and gave them the time which it might be hard to get from health professionals.

- 5.63 However, most of the participants felt they had enough information through a combination of the information that they received from health professionals and Prostate Cancer UK. For instance, one person said:

“We’re experts in this now, but that has only come about through using the Prostate Cancer UK helpline over the years.”

#### Use of information

- 5.64 This section covered:

- What did you do with the information you received from Prostate Cancer UK?
- How often have you consulted the information?
- When do you prefer to look at health information?
- Do you talk to anyone else about the information you have received?

- 5.65 All of the participants with hard copies of the information said that they **keep it in a particular place** at home and that they can refer to it.

- 5.66 However, asked **how often they refer to the information**, one participant mentioned that:

“We found it very overwhelming. When you read something, it brings up a lot of questions, but it is very one-dimensional. It is not the kind of thing I would go into regularly, I would rather talk to somebody.”

- 5.67 Another two participants mentioned that they rarely use the information now. However, this was a result of not needing more information.

- 5.68 In general, participants said they use the information less now than they did at the beginning of their treatment. Even so, one person who said they were still accessing information “two or three times a week” – this was an Online Communityuser. There was a wide range in how often people said they used the information.

- 5.69 Asked **when they like to look at information**, several points in the cancer journey were mentioned:

- Before or following contact with health professionals;
- When knowledge increases;

- When treatment changes;
- Before getting test results (not mentioned as part of this question, but elsewhere in the interview);
- When thinking about issues or not feeling well.

5.70 Something that came across more than once was not knowing if the cancer might be contributing to the way people feel:

“Because it is a treatment that I have had, it stays on your mind. Whenever you are not feeling 100%, you tend to think it is because of that. I find my energy levels are not what they used to be. Maybe I should go and look at the stuff that I have or speak to an adviser [helpline].”

5.71 Asked about the **time of day** when they prefer to look at information, several participants mentioned the evenings or weekends. Participants also mentioned they often look at information when alone.

5.72 Asked whether they talk to others about the information, a number of participants mentioned talking with their partners. One participant mentioned that she talks to her husband about his health, but would not talk to other members of the family:

“I don’t often talk to my family, we try to carry on as normal.”

5.73 Another few participants said they discuss their condition with family and friends; with one elaborating that they can point friends to Prostate Cancer UK information if they have questions.

5.74 Some participants said they actively recommend Prostate Cancer UK information to others – i.e. people who they think should get checked or if someone they know has prostate cancer.

#### Evidence of behavioural change

5.75 This section covers:

- To what extent has the Prostate Cancer UK information (including verbal info from the specialist nurses on the helpline) you have received led to any change in your behaviour?
- What, if any, improvements or changes have these led to?
- Has any other information you have used prompted a change in behaviour?

5.76 Asked about any **behavioural changes** brought about by the Prostate Cancer UK information, two participants mentioned treatment choices. One mentioned:

“I resisted their [Health Professionals’] recommendation to have my prostate removed because it is progressing slowly. You’re able to ask questions not just listen.”

5.77 This person continued:

“One of the deciding factors is not having surgery is the side effects. The Tool Kit is very frank, and is honest about the numbers – 2 in 100, 4 in 100, 6 in 100 – that I got from the Tool Kit.”

5.78 One person mentioned getting treatment for erectile dysfunction. He said that Prostate Cancer UK information, particularly seeing the statistics on the website (he also mentioned the value of

seeing the problems other people have on the Online Community) led him to ask his doctor about this:

“Saw some of the information on Prostate Cancer UK – which percent of the male population has this problem... my GP put me on Cialis – works a lot better now.”

- 5.79 This participant mentioned that the changes he had made as a result of Prostate Cancer UK had contributed to his quality of life. Similarly, another pursued a course of treatment for ‘hot flushes’:

“They may have said something about treatments to use for hot flushes in the booklet and due to it last time I saw oncologist I said there are treatments out there [ie for hot flushes], and he put me on an anti-depressant.”

- 5.80 A few participants mentioned that they felt calmer as a result of their use of the information. It was also mentioned that the information “helps with health professionals” and allows you to take a “more active role”.
- 5.81 More specific changes to behaviour that featured in the responses were exercising and changing diet.
- 5.82 Asked about the **improvements or changes brought about**, being calmer and reassured were again mentioned by a number of participants. One partner stated:

“It’s more for me [rather than husband]...I’m comforted by it, and that enables me to support him.”

- 5.83 Explaining how the Online Community made them feel less anxious, one participant stated:

“It’s a very subtle way that helps you, it’s not like medicine that works, but it’s like medicine on the mind. Coming to terms with what is happening, being able to phrase it...a little more confidence. I’m feeling bad this minute, but it will get better.”

- 5.84 No other information was considered to have led to a change in behaviour.

#### Future additional support

- Do you feel you have enough support at present?
- If not, has anything stopped you from receiving more support?
- What, if any, future support do you think would be helpful to you?

- 5.85 Most of the participants mentioned having **enough support at present**.

- 5.86 However, one participant mentioned:

“Yes, I think so. I’ve got phone numbers I can ring, specialist nurse. There’s also a cancer support centre in Swansea - Maggie’s. I can always pop in there; I know I can visit there if I need to.”

- 5.87 But this participant also said “I’ve still got a cloud over me, really” due to uncertainty over their condition. They didn’t feel there was anything stopping them from seeking support and they were aware of support that is available, but hadn’t sought any support to alleviate this

uncertainty. Asked what support they might want in the future, this participant revealed concern over the way their condition could progress:

“It’s difficult for me to know how it will go for me. Obviously, if you are going to look on the negative side, I might become quite ill.”

- 5.88 Another partner mentioned that they thought support specifically for carers would be beneficial:

“A friend of ours died a few years ago, I bumped into his wife. I realized the 5-10 minutes conversation, the difference it made. Doesn’t make things better...lightens the load. I’ve struggled to find that. That’s something I would find useful going forward.”

- 5.89 Asked if anything had stopped them from seeking this support for carers, this participant answered:

“Maybe because it didn’t jump out at me. It might be there and I haven’t found it.”

- 5.90 The researcher asked another participant, who said earlier in the interview that they might contact the helpline over concerns about their energy levels, what might be preventing them from seeking support:

“I just feel I don’t want to make an issue of something – it’s not troubling me...in a very serious way. I feel hesitant sometimes. It’s like toothache, you wait until the toothache is so bad you need to phone the dentist...a bit reluctant to contact helpline.”

- 5.91 Similarly, another participant suggested they would like to speak to someone, noting that:

“Friends are aware but don’t want to hear the ins and outs.”

- 5.92 In terms of what may be preventing them from seeking support, this participant mentioned that they would like to speak with “someone closer” to them (note, this was not specifically in response to the question).

- 5.93 Asked about what support they might like in the future, a number of participants mentioned getting some support post-treatment. One said:

“What would be helpful to me, maybe asking for the moon, to be able to phone Prostate Cancer UK one year down the line...to ask is there anything you can offer...Is there anything I am missing? Is there anything more that could help me in the state that I am in now?”

- 5.94 Another said:

“No one can tell you if treatment has done what it’s supposed to do - hopefully I’ve been cured – but till someone says you’re in total remission ... that’s the only thing in the future.”

- 5.95 Another participant had some specific questions about what would happen at the end of their treatment and mentioned that they would welcome any post-treatment information that could help. This seems to reflect a desire to establish that they are at a point where they can move on.

- 5.96 Asked if there was anything else that they would like to comment on, some participants praised the charity. Another mentioned specifically that they were aware of more media attention for the charity. There is:

“more awareness in media. TV adverts, books, campaign to make people aware has got a lot better...Bill Bailey ads...There seems to be a greater awareness. I had no inkling you could have a PSA test on demand from 50 from your doctor – I would have had that because my father died at 60 from prostate cancer.”

## Service user typologies

- 5.97 Based mainly on the 50 service user interviews and the 10 follow up interviews, but also drawing on other parts of the research, we have identified six service user typologies (Appendix E); active information seekers; active information users; conduit users; older users; non users; and health professionals.
- 5.98 For each, we identify high level characteristics of the user type; their information needs; the kinds of Prostate Cancer UK services they access; their information seeking behaviour; what they think of the services they receive from Prostate Cancer UK; what else Prostate Cancer UK can provide; and recommendations on how else Prostate Cancer UK can engage this user type.
- 5.99 The service user typologies can be found at the end of this report in Appendix E. A summary of the high level characteristics of each user type can be found below.

Service User Typologies	
<p><b>Typology 1: Active information seeker</b></p> <ul style="list-style-type: none"> <li>• Mixed levels of health knowledge</li> <li>• Well educated; possibly a professional/managerial background</li> <li>• Web savvy</li> <li>• Accustomed to seeking health information</li> <li>• Likely to go beyond medical professionals for health information</li> <li>• May have a partner or family member supporting them</li> </ul>	<p><b>Typology 2: Active information user</b></p> <ul style="list-style-type: none"> <li>• Similar characteristics to the Active Information Seeker (typology1): i.e. well educated, web savvy, accustomed to seeking information.</li> <li>• However, Active Information Users <b>go beyond active information seekers</b> and use the information to help <b>make a decision</b></li> </ul>
<p><b>Typology 3: Conduit user</b></p> <ul style="list-style-type: none"> <li>• Partner/ family member/ friend of a man diagnosed with/concerned about prostate cancer</li> <li>• Seeking information to support a man who may be elderly or is unlikely to access health information</li> <li>• May also be supporting a man who has other barriers to accessing information (disability)</li> <li>• Uses the information needs to fill often basic information needs</li> <li>• May also benefit personally from the information in terms of support and reassurance</li> </ul>	<p><b>Typology 4: Older user</b></p> <ul style="list-style-type: none"> <li>• Older man (over 70)</li> <li>• Seeking information to fill often basic information needs</li> <li>• Often takes a 'matter of fact' approach and wants practical advice</li> <li>• Mixed use of internet/helplines: some are internet savvy, confident about health information; others will not be.</li> </ul>
<p><b>Typology 5: Unaware non-user</b></p> <ul style="list-style-type: none"> <li>• Low levels of health knowledge</li> <li>• May have a low levels of literacy or other barriers to accessing information e.g. poor English skills</li> <li>• Unlikely to seek health information proactively.</li> <li>• Does not go beyond medical professionals for health information.</li> <li>• No partner or family member who finds information on his behalf / a partner or family member who are equally unlikely to seek information</li> </ul>	<p><b>Typology 6: Health professionals</b></p> <ul style="list-style-type: none"> <li>• Seeking information to inform others</li> <li>• Or to keep themselves up to date or other staff</li> <li>• Want to know about what is available (events/services)</li> <li>• But acts under time pressure</li> <li>• Appreciates Prostate Cancer UK information (free, quality info)</li> <li>• Their own views on how to make the information more health professional-friendly.</li> </ul>

## 6 The health professional perspective

### Summary

The health professionals we interviewed who were already in touch with the charity were highly satisfied with Prostate Cancer UK.

Many had a long-standing relationship with the charity, but new users often found Prostate Cancer UK through a web search. Among those that had introduced the charity's information more recently, there were examples of the information being preferred to other sources. Health professionals praised the quality and design of the information. The accuracy was also considered vital as that meant it complemented what health professionals were telling patients and their families about prostate cancer.

Health professionals valued having something they can give to patients to take away, since they recognised that patients and their families may not be able to absorb all of the information given in a clinical setting. Some health professionals also mentioned using Prostate Cancer UK information, especially the Tool Kit, as education for nurses.

Health professionals revealed a reluctance to give the Tool Kit to patients, considering it too broad and not specific to an individual's case. The helpline was also not recommended very strongly. Prostate Cancer UK can do more to make clear to health professionals what information and services are available. The main criticism was of the website, which some participants suggested should store details and not always ask for donations.

6.1 This section sets out the common themes from the interviews with health professionals. In total, we interviewed 15 health professionals. This section summarises the key findings of the interviews, set out by each question in the topic guide, which covers the following themes:

- Information about the health professionals
- Contact with Prostate Cancer UK
- Usefulness of information resources
- Tool Kit
- Helpline
- Concluding questions

6.2 All quotes within this section are from health professionals.

### About the health professionals

6.3 This section of the interview covered the following questions:



- Can you tell me a bit more about your role?
- What contact do you have with men affected by prostate cancer in your work?
- Who comes to you with prostate cancer issues?

6.4 We interviewed a range of different professions, with specialist nurses the biggest group (this comprises clinical nurse specialists, specialist cancer nurses, uro-oncology nurse specialists and a continence nurse specialist). We also interviewed four Macmillan information managers, as well as a health improvement officer, a research radiographer, a cancer information manager, and a support worker at a hospice.

6.5 A majority of the health professionals have had direct contact with men and families affected by prostate cancer over a range of points in their journey.

6.6 In terms of demographics, health professionals suggested that those they see tend to be older - reflecting the incidence of prostate cancer in older men - and white British. The ethnicity of participants was thought to reflect the makeup of the local population. Two health professionals mentioned that there was a large local Polish population and resultantly they see Polish people.

6.7 Asked about the socio economic status of the people they saw, only one health professional mentioned that the people they see tend to be more 'middle class', most felt that those they interacted with reflected the local population.

6.8 There was also a clear tendency for men to bring partners and/or family members with them for consultations or when seeking information. A continence nurse specialist highlighted the importance of the role of women, saying that they seem to be more aware of this service – implying that they can be an important reason that men come.

## Information needs

6.9 This section covers the following questions:

- How did you hear about Prostate Cancer UK?
- Have you contacted Prostate Cancer UK before? If so, what for?
- What information were you looking for when you ordered information from Prostate Cancer UK?
- Why were you looking for that information?
- What did you do with the information you ordered?
- How often have you visited the site since and what for? Have you contacted Prostate Cancer UK in any other ways since?

6.10 Most of the health professionals we interviewed have a long-standing relationship with Prostate Cancer UK (we would note that there is a possible bias inherent in this). For example, one stated:

*“It was just out there – can’t remember how I first heard about [Prostate Cancer UK].”*

6.11 This is reflected in a range of contact over time. Some had worked with the Prostate Cancer Charity as well.

- 6.12 However, among those health professionals that either hadn't previously used Prostate Cancer UK or were looking to expand their provision of prostate cancer information, it was mentioned that Prostate Cancer UK appears prominently on Google when performing a web search. One mentioned that a person from the 'Prostate Cancer UK office in Sunderland came in with information'.
- 6.13 The information is used for two things, mainly, to inform patients and to help health professionals stay informed and up to date. The information service can particularly help when it comes to patients, since health professionals may have limited time with them. One commented:
- “Time in the clinic is a factor, may only have thirty minutes...the information gives them something to take away with them and use in their own time.”
- 6.14 Given that patients may be in shock and may also be starting from a very low level of understanding and prior knowledge, it may take a number of interactions to help them fully understand their conditions and options. Therefore, having something that people can take away and read at their own pace was considered crucial.
- 6.15 A number of health professionals also stated that the information is useful for informing and educating staff. Specifically, the Tool Kit is considered by some to be useful for educating staff. This may reflect the comprehensive range of information, for example of all treatment options. One health professional commented that:
- “Nurses are happy to receive information, but may not have time to seek it out.”
- 6.16 In terms of what happens with the information, the leaflets and booklets are mainly shared with patients and most also give the helpline and/or website, in case patients want more information and support. In general, the health professionals preferred to give the information to men themselves, rather than for people to find information themselves (e.g. from a shelf). This was to avoid men picking up information that may not be appropriate to their circumstances or needs. This is reflected in a reluctance to give the Tool Kit to men/families, as it may not be appropriate for every given situation. The only exception to this is sensitive information (for example on sexual health) that men may not be comfortable discussing.
- 6.17 Most of the health professionals we spoke to say they use the website regularly or often. The primary use was to order information, but a number also mentioned looking around the website or showing it to patients/sharing the web address. One health professional revealed that they only go on the website when Prostate Cancer UK emails with links.

## Usefulness of information

- 6.18 This section covers:
- How useful was the information that you ordered? Did it answer your questions or meet your needs?
  - Could the information have been improved in any way? If so, how?
  - Was there information you were looking for that you didn't find? What was that?

- Did you look for/find the information elsewhere? If yes – where did you look for/find it?
- Is there anything that Prostate Cancer UK provides that you cannot find elsewhere?
- Thinking more generally, are there any gaps that Prostate Cancer UK could fill?
- If you passed the information on, did you pick up any feedback on the information?
- What is the main value of the information to you as a health professional?
- Would you recommend Prostate Cancer UK's information materials to:
  - others in your role
  - other health professionals
  - patients and or family members
- If you could improve or add to the information you used, what would you do?
- Do you use prostate cancer information from other organizations/charities? If so, which ones?

6.19 Satisfaction levels were generally high. One commented:

*“Absolutely marvellous...very easy to use.”*

6.20 A few health professionals expressed misgivings about the website, asking why it can't store login details - act more like “Amazon” (i.e. remembering users). The limit on the number of orders was also questioned, as well as the fact that some information is only available for download and cannot be ordered.

6.21 However, health professionals generally commented on the usefulness of the information and that it is easy to use and free of jargon. Also, the range of information available was commended.

6.22 It was mentioned a few times specifically that the information was preferred to Macmillan information on prostate cancer. For instance, one health professional working in a Macmillan patient information centre mentioned:

*“Doctor actually prefers it [Prostate Cancer UK information on prostate cancer] to Macmillan...It is clearer and better.”*

6.23 Another health professional mentioned that they thought:

*“Prostate Cancer more specialist stuff than Macmillan produce e.g. impact of hormone treatment on emotions; diet. They are addressed in the Macmillan booklet, but Prostate Cancer UK is more specific.”*

6.24 There was mostly no information that could not be found. The Health Improvement Officer suggested that more information on the examination for prostate cancer could be useful. He is working to engage groups, including BME groups, and noted that the perceived intrusiveness of

the examination could be a barrier to people getting tested. As such, having information on whether there are alternative examinations and on the reason for the test could be valuable.

- 6.25 In terms of using other sources, one had used a cancer network in the local area and some information came from hospitals with in-house information produced. Macmillan, Cancer Research UK and NHS were also mentioned as sources. One mentioned that they use further information for their own knowledge, but not for patients.
- 6.26 Some of the literature, such as information on diet, hormone therapy and sexual health, was mentioned as being only available through Prostate Cancer UK, as well as specific sheets for example on degarelix or bisphosphonates. The urgent pass toilet card was also mentioned.
- 6.27 In terms of gaps that Prostate Cancer UK could fill, suggestions included:
- Conferences for staff
  - Meetings for men to talk to each other
  - Cancer support groups (especially beyond treatment)
  - Seminars on supporting health professionals
  - Possible online training for health professionals or short courses
  - Bringing health professionals and the public together (for instance events, where they can learn from each other)
  - More images supportive of gay partners.
- 6.28 A theme that emerged was support for health professionals to help them better understand what information is available and what support is available. It was thought that many health professionals may not have the time themselves to find out what information was out there.
- 6.29 In terms of feedback, one person criticised the branding:
- “black books are a sign of death...run by young graduates in London – their way of thinking about what is catchy, what makes Prostate Cancer UK look good doesn’t make sense to people a few generations older.”
- 6.30 However, the information was also praised as “looking good”, so overall there was a mixed response on the appearance/branding.
- 6.31 In general, the content was found to be helpful and easy for people to read. Although, from the responses it was evident that many health professionals had not received very specific feedback from users.
- 6.32 In terms of the main value, what came across clearly was that dealing with patients that are informed is easier. Other important highlights were:
- Information complements what health professionals say
  - Provides reassurance to patients
  - Something that can be taken away (physical information)

- Up to date information
- Professional/objective information
- Free of charge.

6.33 All of the health professionals say they would recommend the information to others in their role, other health professionals and to patients and/or family members.

6.34 Most of the participants either didn't think the information could be improved or added to or didn't have any strong suggestions.

6.35 In terms of the suggestions that we did receive, one person thought getting out to clinics more to see how nurses actually use the information would be valuable, possibly influencing design. An example is given:

“The bulky information is A5 – some of it is A4. The patients want it as small as possible, so it can be hidden. “

6.36 One supported getting more media coverage, which was seen as effective, for example:

“Prostate Cancer UK adverts...on the backs of all the doors in toilets on motorway.”

6.37 One participant supported sharing some of the information in different ways, such as using modern technology, through for instance apps. Another participant specifically mentioned having information in Polish (a second health professional mentioned in the interview that language may be a barrier for some of the Poles that they see); they currently suggest NHS Choices as a health resource that directs people towards health information in other languages.

6.38 One participant pointed out that when printed the leaflets didn't always look good:

“Some can't be ordered and have to be printed off...But prefer to order them in because they look more professional.”

6.39 Finally, one participant wanted to see more information presented visually rather than in text.

6.40 The only other charities mentioned as being used were Macmillan and Cancer Research UK.

## Tool Kit

6.41 This section covers:

- Are you aware of Prostate Cancer UK's Tool Kit? Have you used it?
- How do you use it?
- Have you picked up any feedback on the Tool Kit?

6.42 Only three participants were unaware of the Tool Kit. The rest had all had heard of the Tool Kit and use it. However, the interesting finding is that all but one say they don't give them to patients, at least not directly, because the Tool Kit contains too much information and is not tailored.

“It is a wealth of information, but can be too much...not every treatment option is going to be appropriate.”

6.43 In general, health professionals seem to prefer giving less information that is more tailored to patients – so prefer giving specific leaflets rather than a whole Tool Kit. A few of the health professionals said that they mention its availability to patients, meaning they could order it themselves.

6.44 A number of health professionals use it internally for education purposes, either for their own knowledge or sharing it with staff. It is considered a useful resource in this respect owing to the breadth and depth of information.

6.45 The Tool Kit is well regarded in terms of quality. One person mentioned:

“Amazed how few people know about it [the Tool Kit]...nurses may not have time to seek out the information.”

6.46 Again, any issue seems to be of quantity rather than quality of information. One health professional said they:

“Had to explain to someone why they can't have all treatment options.”

6.47 This was seen as being too time consuming and difficult a process to make it worth using.

## Helpline

6.48 This section covers:

- Do you refer people to the Prostate Cancer UK helpline? Have you ever done?
- What do you refer them for?
- From conversations you've had, what do you think the helpline actually offers to users, not just men, but users generally?
- Have you ever used the helpline for professional advice? Did you know you could do this?
- Have you picked up any feedback on the helpline?
- Is there any other prostate cancer information and resources you signpost to patients/colleagues?

6.49 Most health professionals said they do not refer people to the helpline. In some cases, this is owing to another helpline existing (e.g. Macmillan have their own). One participant mentioned that people seem happy with the existing information they had received (from the health professional) and did not appear to require more information.

6.50 One health professional said they refer to the website, but didn't know much about the helpline:

“We don't know the number, would need to look it up as don't have anything obvious with the number on. Also don't know what people get from the helpline, so probably another reason I haven't referred people to it.”

- 6.51 However, a number of health professionals said they did refer to the helpline. It is seen as being useful for patients that want more information and cannot get hold of health professionals at the hospital. It can also serve as a second opinion. One health professional mentioned that it can be helpful to:

“refer to someone impartial...can help when someone is suspicious of advice.”

- 6.52 This chimes with the earlier point that health professionals see Prostate Cancer UK’s information chiming with their own advice.
- 6.53 Overall, the helpline is viewed as a reliable source of information by anyone that uses it. It was thought useful for people to be able to talk to someone, and one participant also mentioned the benefits of buddying-up via the helpline.
- 6.54 However, one limitation of the helpline was flagged:

“The nurses on the helpline cannot decide for them either, so sometimes they feel it hasn’t moved them forward”.

- 6.55 Another interviewee suggested it focuses on the clinical/medical information, rather than potential benefits.
- 6.56 The health professionals we interviewed did not use the helpline service regularly as a source of information; given their often specialist roles, they didn’t often seem to feel they needed it.
- 6.57 None of the health professionals had picked up any feedback on the helpline service.
- 6.58 Only one additional bit of information was mentioned, which was audio information for a patient that struggled with reading the leaflets.

## How can Prostate Cancer UK can further help

- 6.59 This section covers:
- Thinking more widely, how could Prostate Cancer UK further help you in your role?
- 6.60 Conferences for staff and nurses were again mentioned as a way for Prostate Cancer UK to help further. Raising awareness among nurses more generally about the disease was seen as an effective way to increase early diagnosis.
- 6.61 Highlighting services available in local areas is seen as being important – if more people know about the services, more will use it. Local support groups are also mentioned as important. Broadly there is a theme of more local services.
- “Get more people out of London – that will increase their credibility...They need to be on the shop floor if they want [professionals] to engage. “
- 6.62 Similarly signposting people to more services where health professionals themselves are unable to provide answers was considered something that Prostate Cancer UK could help. The health improvement officer was interested in more information on prevention.

- 6.63 In terms of additional remarks, one person related the usefulness of using 'lunch and learn' sessions with companies to relay information.
- 6.64 A few participants also took the opportunity to praise Prostate Cancer UK, one highlighting the role it plays as a campaigner in the area of prostate cancer, and another again highlighting the benefit of getting quality information free of charge.



## 7 Healthcare settings site visits

### Summary

The site visits showed mixed levels of awareness and use of Prostate Cancer UK's services within the specialist cancer settings. While Maggie's Centre in Glasgow used and was satisfied with the charity's information, awareness was more mixed among staff within the Northern Irish hospital cancer unit. Satisfaction with and usage of specific Prostate Cancer UK booklets was found to be high, but staff were not referring patients to the helpline. Although there was some use of Prostate Cancer UK information within the Welsh cancer hospital, its presence as a charity was marginal compared to the 'embedded' charities within the hospital such as Macmillan and the local charity Tenovus; and staff criticised Prostate Cancer UK's lack of Welsh language material and Welsh branding which were seen as key to credibility within Wales. Within the non-cancer settings, awareness and use of the charity's services was high for the specialist cancer nurse at HMP Whatton, but awareness of the charity was low among non-cancer specialist staff within both HMP Whatton and the other non-cancer services visited.

Staff at the settings visited made a number of suggestions as to how Prostate Cancer UK could help them in their role, including:

- Easy Read material (including to support diagnosis, decision making around treatment and aftercare, and electronic material which could be locally adapted)
- Volunteer providing support for patients within clinics
- Funding of specialist nurse
- Support group for patients' wives/partners
- Awareness raising of symptoms among staff/patients/carers within settings such as older people's mental health, prisons, learning disabilities' services
- Awareness raising of Prostate Cancer UK's services e.g. how to access the helpline and provision of appropriate material including not only online but also printed material such as leaflets and posters, and DVDs/adverts for local use
- Focus on how Prostate Cancer UK can support staff e.g. raise awareness of how Prostate Cancer UK can support GPs, training packages for staff, short electronic newsletters
- Long-term outreach work with marginalised groups such as Gypsies and Travellers and becoming culturally informed on their needs.

- 7.1 This section sets out the findings regarding the visits to six healthcare settings, plus one depth interview. In selecting the settings we strove to ensure: a spread of locations across all nations within the UK (including areas of low take up of Prostate Cancer UK services such as the East Midlands and Northern Ireland); a mix of specialist cancer settings - within both secondary and tertiary care and within the community - and non-cancer settings; a mix of statutory and voluntary sector services; and a mix of settings serving the general population and those serving specific population groups at risk of being overlooked or marginalised.
- 7.2 Three of the settings visited provide cancer services: **Velindre Cancer Centre** in Cardiff, a tertiary specialist cancer centre; **Northern Ireland Cancer Centre at Belfast City Hospital**; and **Maggie's Centre** in Glasgow, a voluntary sector provider of services to people affected by cancer. The other settings focus on providing healthcare services to specific population groups: **Nottinghamshire NHS Trust's Local Services Division**, which works with people with learning disabilities and older people's mental health; the Healthcare Unit in **HM Prison Whatton** in Nottinghamshire; the NHS outreach team working **at The Passage**, the largest voluntary sector homeless organization in London; and **Gypsylife** (the depth interview<sup>15</sup>), a non-funded community organization that works with the Gypsy and Traveller community.

## Site Summaries

- 7.3 Below we provide summaries of each of the sites visited (further detail provided in Appendix F on the work of each of these settings in relation to cancer and the provision of cancer information). The rest of this chapter focuses on the sites' awareness/usage of Prostate Cancer UK's information and helpline, and suggestions on how Prostate Cancer UK might help them in their role.

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<sup>15</sup> The Gypsylife interviewee is from the Gypsy/Romany and Traveller community and has undertaken extensive work within the community on improving health and education outcomes.

## Velindre Cancer Centre

Velindre Cancer Centre in Cardiff is a tertiary centre which provides specialist cancer services to over 1.5 million people in South East Wales and beyond. It is one of the largest cancer centres in the UK. The majority of prostate patients are referred to Velindre by DGH urology surgeons and prostate multi-disciplinary teams across South East Wales for radiotherapy treatment. The centre also runs clinics in local district general hospitals in the region. Cancer Research Wales, Tenovus and Macmillan all have rooms in the hospital staffed by volunteers, and their information, particularly Macmillan's, dominate the patient and carer information on display. This is usually branded as Welsh information and often available in both English and Welsh, which some staff considered to be an important aspect of 'brand credibility' in Wales. Staff were most likely to give patients Macmillan information, as well as Velindre's own bespoke information. The Patient and Carer Information and Support Manager felt that the Clinical Nurse Specialist had the greatest level of interaction with patients around their information and support needs. She reflected that she rarely gets visited by the 70+ age group, and also that the older age group prefer booklets while younger patients prefer online information. Staff reflected on the importance of patients' wives as a source of support to men affected by prostate cancer and of information to the CNS on patients' wellbeing. Most interviewees felt that Velindre did not see as many Black and minority ethnic patients as would be expected from the demography of the area served.

### Key learning-

- i) **Once a relationship with particular charities is established it can be difficult to persuade staff to take up/refer to other charities' services. This is linked not only to the accuracy and quality of the charity's information, but the relationship built through e.g. providing volunteers within the hospital and Welsh specific material.**
- ii) **The key staff member in terms of patient information and support was the CNS (rather than the staff member specifically responsible for that area).**
- iii) **Black and minority ethnic men are thought to be under-accessing services, despite the raised risk of prostate cancer within some groups.**

## The Northern Ireland Cancer Centre at Belfast City Hospital

The Northern Ireland Cancer Centre at Belfast City Hospital provides a range of cancer treatments, including surgery, radiotherapy and chemotherapy, as well as an outpatient and inpatient service. It also specialises in the treatment of rare or less common cancers. Staff see patients throughout their cancer journey. There is broad recognition of the need for information to support patients and families and the reception/waiting room is well stocked with information. A uro-oncology project nurse is Macmillan-funded and is preparing an information pack which would be given to prostate cancer patients. This would feature PSA test records, information, and decision-making help sheets. The Information and Support Radiographer is funded by 'Friends of the Cancer Centre' and plays a support role for radiotherapy patients and their families. This involves signposting information but also providing less formal support such as chatting with patients.

Although in demographic terms prostate cancer patients in Northern Ireland were considered fairly homogenous, the information needs of a patient were thought to vary widely and depend on the personality in question. The men (with prostate cancer) who were considered most in need of support were those with a decision to take, such as whether to pursue active surveillance or surgery, or between surgery and radiotherapy.

### Key learning-

- i) Support needs vary by person. However, there are points in the prostate cancer journey where people might need more support i.e. treatment decisions.
- ii) Funded positions can complement the basic offer available at a hospital and can give the charity a footprint in a local area.

## Maggie's Centre Glasgow

Maggie's provides free practical, emotional and social support to people with cancer and their family and friends. The centre is focussed on creating a relaxed and open environment in which patients and their families can come for support. The centre seeks to alleviate as far as possible the anxiety associated with a cancer diagnosis. Anxiety was thought to be one of the main barriers for men with prostate cancer. There is a diverse range of classes and support available, such as benefits advice (considered important for attracting a range of users), yoga classes, and counselling; however, one of the main types of support is more informal, with those visiting the centre able to sit and 'have a cup of tea', talking with the cancer support nurses, other people or just relaxing alone. There is a broad range of information available in the centre, including Prostate Cancer UK, but often information was conveyed through conversation rather than relying on booklets.

### Key learning-

- i) Anxiety can be a major barrier to men being able to fully utilise the support available. Men and their families may require a non-clinical and informal environment to overcome this barrier.
- ii) Providing a range of support, including financial support, can ensure that a broad range of users access the services.

## Nottinghamshire Healthcare NHS Trust Local Services Division

The visit focused on two services delivered by the Division: Mental Health Services for Older People (covering over 65s and both organic and functional mental health); and Learning Disabilities. Staff interviewed in both services raised 'diagnostic overshadowing' as a key issue for their patients, as clinical symptom(e.g. in the case of prostate cancer, more frequent urination) could be seen by staff/carers – key intermediaries to patients accessing services - as behavioural and linked to their mental health/learning disability. The staff member who worked within older people's inpatient mental health services highlighted that physical health was a key area of improvement for his service but that it focused in the main on conditions such as diabetes, with awareness of prostate cancer currently low. The interviewees who worked with people with learning disabilities had had little experience of prostate cancer within their caseload but felt that more cases were likely to be found in the future with the rising life expectancy of people with learning disabilities. The community based staff's work included health promotion but no work had been undertaken in relation to prostate cancer and the staff were not aware of any resources on this issue suitable for their client group. The staff highlighted that information channels such as the internet, TV and radio campaigns, telephone helplines and football-based campaigns would not be accessed by their client group. Going to places like the community centre for people with learning disabilities, and providing DVDs and Easy Read material which could be locally adapted, were seen as the most effective means of reaching them. The hospital based staff member stressed that different information was needed in that setting e.g. Easy Read information on treatment options and how to explain diagnosis.

### Key learning-

- i) **Proactive work is needed to raise staff/carers awareness of the signs and symptoms of prostate cancer as they are vital intermediaries within these client groups where there is a danger of 'diagnostic overshadowing'.**
- ii) **Specific strategies are needed to develop material for these client groups, to cater for different levels of cognitive understanding and the most effective routes of access.**

## HMP Whatton

HMP Whatton is a national treatment centre for male sex offenders. The largest age group is aged 50+. Prisoners who are diagnosed by the in-reach GP as suspected cancer cases come under the Senior Practice Nurse (End of Life Cancer Care Lead) in the Healthcare Unit. The nurse meets the patient and explains that she is their named nurse, and offers support. Prostate patients are offered either Prostate Cancer UK or Macmillan information. The Senior Practice Nurse offers all cancer patients the opportunity that she meets with their family if the patient is still in touch with them, and would also be willing to facilitate prisoners accessing telephone helplines (they would not be able to do this by themselves). Cancer patients are managed as long as possible on the prison wings. There are multi-disciplinary team meetings about patients as needed which meet regularly. Cancer patients are also supported by prisoners who have been trained to support individuals with long term conditions. When the patients reach the palliative stage they are moved into a special end-life unit. The Unit also undertakes health promotion work. At the time of the researcher's visit there was no cancer information on display anywhere: and interviewees said no information on the signs and symptoms of prostate cancer was made available in the prison. The Unit frequently uses CDs and DVDs as a source of health information, which are the preferred format of information given the restrictions placed upon internet and telephone use in the prison, with routes such as the prison TV and radio channels and the prison magazine also seen as useful.

### Key learning-

- i) **Proactive and targeted work is needed to reach this client group which is not able to access information within the community or via media such as the internet and telephones.**
- ii) **Offender health teams and in-reach health professionals are key intermediaries.**

## Working with marginalised groups

Our research into working with marginalised groups identified significant need for support, but extensive barriers to providing it. GypsyLife is working to improve health outcomes for the Gypsy/Romany and Traveller community, but particular barriers, including a distrust of doctors, illiteracy, and cultural beliefs make it challenging to provide effective support. This interview identified a patient approach, building trust through a presence 'on the ground' as one way to overcome some of these barriers.

Some similar issues emerged in our interviews at the Passage. In particular for some homeless people, literacy can be an issue leading to a reluctance to engage with health information. In this instance information needs to be simple, concise and come from a trusted source. There may also be a problem identifying the symptoms of prostate cancer due to the existence of underlying conditions which in turn may mask the symptoms e.g. alcohol misuse. Staff at the Passage felt that some homeless people would not want to engage with a raft of information but would rather receive more specific instruction around actions.

### Key learning-

- i) **There is a need to work intensively to develop support for particular marginalised groups. This can require very specific actions and relationship-building with stakeholders.**
- ii) **In the case of the Gypsy/Romany and Traveller Community, building trust within the community was considered important and would require time to develop this relationship; by contrast, staff at the Passage felt that the information was best to come directly from staff, which would require building relationships with key intermediaries such as NHS outreach teams.**

## Awareness of/views on Prostate Cancer UK

- 7.4 Interviewees were asked if they had heard of Prostate Cancer UK and of the Prostate Cancer UK Helpline and Tool Kit before the researcher contacted them about the visit. If they had, interviewees were asked how they had heard about it, whether they had ever used its information, helpline and services and views on them including comparison with other organisations, recommendations for improvement and any gaps. They were also asked if they used prostate cancer information from other organisations/charities or signposted/provided any other information about prostate cancer to patients, families and friends and/or colleagues.

### Velindre Cancer Centre

- 7.5 The **Patient and Carer Information Manager** at Velindre Cancer Centre noted that a knowledgeable patient who helps at the weekly prostate outpatient clinic takes Prostate Cancer UK leaflets to the clinic, and indeed she had first heard about Prostate Cancer UK from this patient. She reported that he prefers the Prostate Cancer UK information to the Macmillan information on prostate cancer and would prefer it to be provided. The Information Manager orders Prostate Cancer UK information to stock the information stand for the annual Prostate Cancer Month event, and also provides their information when she does information days at the

prostate outpatient clinic. However she does not stock Prostate Cancer UK information in the Information Centre, because Macmillan booklets cover all tumour sites making it possible to have a comprehensive and eye-catching matched display of booklets. She noted that the change in Prostate Cancer UK's brand colour had meant she had had to throw a lot of stock away. She was positive about the new Prostate Cancer UK Welsh Area Manager, feeling that she could call on her as needed. She had, for example, given her information about away days for prostate cancer patients. However she noted that Prostate Cancer UK were not local and had only just come to Wales. She was very positive about her dealings with Macmillan Cancer Support e.g. their efficiency in quickly filling leaflet orders, and has recently been given funding by Macmillan to improve the Centre and make it more accessible.

- 7.6 The **Clinic Co-ordinators** at Velindre had not heard of Prostate Cancer UK, but also could not name any other organisations or charities whose information Velindre provided (despite being surrounded by various organisations' leaflets in the waiting area in which they worked).
- 7.7 The **Clinical Nurse Specialist (CNS)** at Velindre had heard of Prostate Cancer UK, and had used its information though could not specify which, and felt their information to be good and appropriate. While he did not feel there was any difference in quality with the information provided by others, he noted that Macmillan had been around longer so he was more aware of their information, which he felt to be straightforward and easy to read. He praised the Tenovus-Prostate Cancer UK 'Man Bus' which was being established to go around providing information.
- 7.8 The **Consultant** at Velindre had also heard of Prostate Cancer UK, but had not used their information. He felt Macmillan to be "embedded" in Velindre in terms of information booklets in a way that Prostate Cancer UK was not, seeing the latter's lack of profile in Wales as part of the problem. He cited the Macmillan booklet on side effects as very good with its website information also seen as providing high quality, balanced and appropriate information - "patients who have gone to the Macmillan website don't come back with funny ideas". He noted that the Velindre in house bespoke information mirrored what Macmillan says. He emphasised that prostate cancer specific information for Welsh patients could not just roll out NHS England information and would require groundwork to develop it; for example on the treatment options available to Welsh but not English patients. It would also need to be in both English and Welsh: "it's a credibility thing ... if you want to be seen to be engaging with the Welsh population it needs to be both".
- 7.9 The Information Manager also noted that Macmillan provides a Welsh version of their leaflets but that Prostate Cancer UK does not. While she had found there was not much call for the Welsh versions at the moment, she felt this would increase as schoolchildren in Wales were now educated in Welsh meaning that they might not know medical terms in English.
- 7.10 The Information Manager, the CNS and the Consultant were all aware of the Prostate Cancer UK helpline, but had no patients they knew to have used it and had not used it themselves for professional advice.
- 7.11 Only the CNS was previously aware of the Tool Kit, which he had used for different patients. He had found it "useful to have the variety of different things you can pull out about different problems".



### The Northern Ireland Cancer Centre

- 7.12 All interviewees at The Northern Ireland Cancer Centre were aware of Prostate Cancer UK.
- 7.13 However not all used Prostate Cancer UK's resources. Two specific Prostate Cancer UK booklets that were deemed to be very useful were regularly used; these were the **brachytherapy** and the **external beam** booklets. The value of these two booklets was also noted by the uro-oncology project nurse.
- 7.14 Both the **Consultant** and the **non-specialist cancer nurse** were the most likely to point men toward the Prostate Cancer UK website to guide decision making and question formation. The **information and support radiographer** explained how she had used the Prostate Cancer UK website: "When I started this post, I was just typing everything into the internet to see what I could come up with. There was some info I wanted on prostate cancer, that's how I found them. And then the brachytherapy person mentioned to me about Prostate Cancer UK."
- 7.15 None of the interviewees had physical copies of the Prostate Cancer UK information in their offices. The **non-specialist cancer nurse** explained that "we usually download the prostate cancer booklets from the internet and hand them to the patient. I don't have any in my office."
- 7.16 Although interviewees had heard of the Prostate Cancer UK **helpline**, patients were not sign posted there. The Consultant felt that the helpline was not very well used. He felt that the helpline might be useful when a patient has been diagnosed and wants some specific information, for example, on the meaning of their Gleason score. The non-specialist cancer nurse felt that some men would simply be too embarrassed to use the helpline. She explained that "they hardly talk to their GPs so they won't ring up the helpline. But we have a 24 hour chemo helpline run by the Belfast Trust. Some men will use it all the time and some will not use it ever. Some people just don't want to bother. Some men are embarrassed. Sometimes it is because they are in denial, but sometimes they don't want to ring up and end up admitted to the hospital."
- 7.17 In terms of improvements, the information and support radiographer suggested that Prostate Cancer UK could be more vocal about the support information that they offer and raise awareness of their existence and of the signs and symptoms of prostate cancer. She noted that at "different times of year we have different people coming, say with a stand, to show staff and patients all the services that are available. The information that is available is very useful for staff too; people may be interested in fundraising too."

### Maggie's Centre Glasgow

- 7.18 Maggie's in Glasgow does stock Prostate Cancer UK information. This tends to focus on treatment choices and side effects, as opposed to diagnosis and symptoms, as people using the centre tend to have already been diagnosed.
- 7.19 The **Cancer Support Specialist** who runs the prostate cancer support groups (who had previously worked for Macmillan) was the person most involved with the Prostate Cancer UK information. He mentioned that he "really likes the branding" and that he is using more of the Prostate Cancer UK information for prostate cancer - he likes that it is "not too clipped". However, the other CSS was also very aware of Prostate Cancer UK, having come across the charity "some years ago in nursing".

7.20 In terms of possible improvement that could be made, the first CSS suggested that Prostate Cancer UK could **provide more information “that focuses on the emotional impact”**, since “a lot of the information that men are seeking is for where they can play a role [in their own care]”. Any further **information about self-care** would therefore help. Also, increasingly, men seem to want to impact other peoples’ lives, for example their sons, by **raising awareness of prostate cancer**. The CSS also observed regarding the Prostate Cancer UK website that “the more information you have...the more you need to stay on top of how people navigate to the information”. This was a general point and was said with reference to the present and future growth of Prostate Cancer UK.

7.21 However, the staff were very positive about what Prostate Cancer UK was doing and the sense of “community” that was building up around prostate cancer, with one person saying “I can only compare it to what happened around breast cancer”.

#### Notts NHS Trust Local Services Division

7.22 The **Junior Matron** working in acute inpatient **older people’s mental health** services had not heard of Prostate Cancer UK. His wards did not stock any information on prostate cancer from it or other organisations, and he knew of no resources provided or signposted to patients around this issue.

7.23 None of the interviewees who worked with people with **learning disabilities**, both in the community and in inpatient settings, had heard of Prostate Cancer UK. None stocked any information on prostate cancer from it or other organisations. None of them knew of any resources provided or signposted around this issue to people with learning disabilities.

#### HMP Whatton

7.24 The **Head of Healthcare** at HMP Whatton had “heard of the name [Prostate Cancer UK] but not of what they do.” She put this down to the fact that her previous job had related to cancer services, rather than her current role.

7.25 The **GP**, who worked a couple of times a week in HMP Whatton delivering inreach services but who mainly worked at a local general practice, had also heard of the organisation but had never used its services. She was not aware of the existence of the helpline or the Tool Kit. The GP did not use any other prostate cancer information either at Whatton or in her general practice.

7.26 The **Senior Practice Nurse (cancer lead)** at HMP Whatton said that she had known about Prostate Cancer UK for a long time “I often get literature through the post from [them] and have some Prostate Cancer UK leaflets and booklets, I’ve used them”. She had given prostate cancer patients the leaflets in the past and none had come back and said they don’t understand them. She felt they were comparable in quality to Macmillan’s – “I found them equally informative”. If a prostate issue arose she would go first to Prostate Cancer UK “because you’re specifically sticking to prostate cancer” or to Macmillan – “I usually stick to Prostate Cancer UK and Macmillan”. She knew of the helpline’s existence from the back of the leaflets but had never used it herself or referred a patient so to do, but “I’m aware that if I needed information I could go through and ring the helpline”. She was however not aware of the existence of the Tool Kit.

#### GypsyLife

7.27 The interviewee at GypsyLife was aware of Prostate Cancer UK.

- 7.28 This interviewee stressed that any information presented to the Gypsy and Traveller community must be **appropriately designed** and **culturally appropriate**. Written information would not be appropriate due to literacy issues. As such, appropriate information would contain simple words. The interviewee explained that big words create confusion. The interviewee stated that “when engaging with Gypsy-Travellers, you would need to approach it in a child-like way.” Additionally, some words were seen as inappropriate. For example, the word ‘doctor’ translates as ‘poison giver’.
- 7.29 The interviewee felt that the **Easy Read** material being developed by Prostate Cancer UK would not be well received. Images of the penis, ejaculation, blood, and a man using the toilet would be seen as unclean or pornographic.
- 7.30 The interviewee also felt that using a **helpline** for information would also be inappropriate for the Gypsy and Traveller community. He reported that a member of the community had tried this once before, but had found it very confusing and frustrating. According to the interviewee, “it was more of a hindrance than a help.”

### The Passage

- 7.31 The awareness of Prostate Cancer UK of the NHS nurses providing outreach services to homeless people was low. The male nurse observed “I think I have heard of Prostate Cancer UK. I remember a few years ago there was a poster with some posthumous advice from Bob Monkhouse saying “I died of prostate cancer, you should get checked.” Was that Prostate Cancer UK?”
- 7.32 The female nurse had not heard of Prostate Cancer UK and said that the only specialist charity she had heard of was Breast Cancer UK. She asked if other specialised cancers had a specialised charity e.g. for lung cancer. She suggested that Prostate Cancer UK should **do some more advertising**.

### How Prostate Cancer UK can help

- 7.33 Interviewees were asked to suggest ways in which Prostate Cancer UK could help them in their role.

### Velindre Cancer Centre

- 7.34 Both the **CNS and Information Manager** were very positive about Prostate Cancer UK developing **Easy Read material**, which the latter felt would be very useful for patients with dementia and learning disabilities. Although the Information Manager highlighted that Velindre also had some bespoke Easy Read material of its own, the CNS felt this was an area in which it could improve.
- 7.35 The **CNS** suggested that Prostate Cancer UK could help Velindre by playing a role in the projects they were currently looking at developing around **post treatment survivorship**, e.g. fatigue issues. The **Consultant** suggested that it would be helpful to have someone – possibly a volunteer - **supporting patients on non-clinical issues in the clinic**. He compared the current lack of this in his clinic with the breast cancer clinic which has a patient support person who sorts out welfare support and liaises with palliative care in the community - “that sort of support would make a big difference”. The CNSs did not have time to talk through non-clinical issues. He cited a patient he had seen that afternoon whom he had told was soon to die, who would have

benefited from someone having the time to talk through the practical and emotional implications with him, which staff did not have the time to do – “we have to get on with clinic”.

### The Northern Ireland Cancer Centre

- 7.36 All interviewees pointed to the need for a **specialist prostate cancer nurse** who was funded by Prostate Cancer UK. The Consultant stated that “the health service in Northern Ireland is finding it very difficult to get funding and the charity sector could provide this.” He pointed out that **Macmillan** has specialists in hospitals who were “good”, but stressed that “we need prostate cancer specific stuff.” He pointed out that Prostate Cancer UK “are really good at funding for the research side of stuff, but we need nurses in hospitals too.” He felt that these nurse specialists should look after “end of life men”, and “would be great at developing new protocols around prostate cancer.” The uro-oncology project nurse suggested the current lack of a prostate CNS was one of the “biggest barriers” in meeting the needs of patients, stressing the importance of talking to patients, rather than just giving them written information. She feared that without talking to people, “if you just hand someone a pack, they will take it home and put it in the drawer.”

### Maggie’s Centre Glasgow

- 7.37 In terms of how Prostate Cancer UK could provide further support, the **Cancer Support Specialists** suggested that the charity produce a “clipped **newsletter for health professionals**. Maybe information on what is going on, what is available in the area”; and a **prostate cancer support group for wives** - “we know some wives want to talk specifically to other wives, who know what they are going through”.

### Notts NHS Trust Local Services Division

- 7.38 The Junior Matron in **older people’s acute inpatient mental health services** stressed the importance of **raising awareness** – “a definite one”. He raised the issue of ‘diagnostic overshadowing’ in mental health, commenting that “too often we [staff] take the role of vets – people come and tell us their problems/pains, and we see behaviours – knowing signs/symptoms [of prostate cancer] would be useful for staff too, and carers”. He reflected on the current lack of awareness of prostate cancer in wards and compared this to issues such as diabetes which were centred on in the current push to improve physical healthcare within mental health.
- 7.39 He also felt the **Easy Read material** being developed by Prostate Cancer UK would “definitely be of use” and said that “we would stock this on wards”. He stressed however that a range of material to cover different capacity and understanding levels was needed for older people’s mental health services, not just Easy Read.
- 7.40 The Junior Matron stated that the interview had raised his awareness of the issue of prostate cancer and the need to raise its profile in older people’s mental health services.
- 7.41 The interviewees working with people with **learning disabilities** in the community and in inpatient settings also asked to be sent the Prostate Cancer UK **Easy Read** material once finalised. These interviewees also stated that the interview had raised their awareness about the importance of the issue of prostate cancer and incorporating it into their practice. When asked how Prostate Cancer UK could help them in their role these interviewees had a number of suggestions.

- 7.42 The **community nurse** suggested someone from Prostate Cancer UK coming to **give information to their patients' group** and providing **adaptable Easy Read material** : “information we can use to doctor/make our own”. It would be good to have this electronically “*so we can adapt it to the person*” as Easy Read material doesn’t suit everyone. “Some people don’t like symbols, feel insulted”.
- 7.43 The **health facilitator**, who also worked with people with learning disabilities in the community, suggested **Easy Read materials** – “the key”; **electronic newsletters** – “no point sending paper – I wouldn’t even open it”; and promoting **greater awareness of the helpline among staff and carers** of people with learning disabilities. She considered that the helpline would be useful for staff and informal and formal carers (but not people with learning disabilities themselves) “but we don’t know about it”. She suggested a poster advertising the helpline in GP practices, libraries and supermarkets and shopping areas. “More advertising in shopping areas would be good – everyone accesses shops – not everyone goes to GPs or libraries.”
- 7.44 The nurse working with people with learning disabilities in the local hospital asked for Easy Read material about diagnosis and treatment, and information aimed at carers of people with learning disabilities. He emphasised that the Easy Read material he needed in a hospital setting was not about “signs and symptoms” but rather about “diagnosis, treatment options, aftercare – it’s difficult and challenging with people with learning disabilities to support them to make a choice of treatment.” He warned however that this would need to be “customised” as “a book with five options in would send them over the top”.
- 7.45 Regarding information aimed at carers of people with learning disabilities, he emphasised that “formal and informal carers are critical to the whole healthcare economy for people with learning disabilities.” There was often a problem in carers identifying a problem existed leading to delays in diagnosis and to most people with learning disabilities (with any illness) being admitted to hospital as emergency admissions. “Usually you just see a change in behaviour. They can’t articulate why ... where on earth does a carer start? Often the carer doesn’t even take them to the GP, and say ‘he always does that’.” He emphasised the “need to educate the carers but they can be hard to reach”, especially where care is provided by the family rather than by paid carers and residential care. “I’m not sure they’re good at identifying signs and symptoms and doing something about that”. This could present problems not only in diagnosis but also after discharge from hospital when the patient went back to the carers.

#### HMP Whatton

- 7.46 HMP Whatton interviewees had several ideas about how Prostate Cancer UK could help them in their role.
- 7.47 The **Senior Practice Nurse (cancer lead)** felt that a leaflet aimed just at prisoners on prostate cancer would not be “practical”, but stressed the potential importance of the **helpline** for prisoners who are “disadvantaged [compared to patients in the community] as they don’t have their nearest and dearest with them ... they go out for bad news with a prison officer they sometimes don’t know, and then are locked up alone ... if you just want to speak to your family, you can’t once that door is locked – must be quite terrifying. Sometimes they hear the C word and they’ve got no one to discuss it with.” She hoped that “if the helpline received a telephone call from someone in HMP Whatton, that’s not a barrier ... the patient is the patient in the end of the day”. She highlighted however that prisoners would not be able to freely access the helpline

(although they had 24/7 access to a Samaritans telephone) so if they saw the helpline advertised on a Prostate Cancer UK leaflet they “might not even consider it as an option”. She reflected that she therefore needed to “say that they can ring if I sit with them” and stated that “maybe in future that’s something I could actively promote”.

- 7.48 The **GP** highlighted the need to **raise awareness** of Prostate Cancer UK’s **information resources**, and **how to access the helpline**. She stressed the difficulty in accessing online resources within a prison setting: “Hard copy printed material to share with prisoners would be useful.” Within her general practice, however, she felt that an awareness of the online resources available would be more useful - “patients want that more than the hard stuff.” More generally, she suggested Prostate Cancer UK needed to **raise awareness of what it could offer health professionals and the benefits of using its services**, noting “I don’t know what Prostate Cancer UK can do to support me in my role as a GP”.
- 7.49 The **Head of Healthcare** suggested that as the prison was keen to add health promotion adverts into the prisoner TV channel, Prostate Cancer UK could **provide a health promotion advert to go on the prisoner TV channel**: “stick it on a DVD, short, sharp e.g. one minute. Needs to be on a DVD – e.g. on the symptoms of prostate cancer to be looking out for. Doesn’t need to be made specifically for prisons, we can use something generalist”. She also highlighted that TV was a useful format for prisoners with learning disabilities – “visuals are better to retain, can be repeated, not lengthy”.
- 7.50 The Head of Healthcare also noted that she would be happy to run a **screening programme** “for any cancers where a screening tool is available”. The Healthcare Team had done an audit on dementia screening and the Senior Practice Nurse is looking at doing a bowel cancer screening programme. However she stressed that high prevalence diseases within the prison population such as asthma, diabetes and COPD were more of a priority currently – while cancer was high prevalence, access to services was considered good and patients do not have long waits – so other areas are more of a cause for concern.
- 7.51 The Head of Healthcare was keen that she be sent the Prostate Cancer UK **Easy Read** material once finalised – “we would love it – other prisons would too. The prison population has a higher proportion of people who need that. E.g. people with learning disabilities and mental health problems.”
- 7.52 The **Mental Health Assistant Practitioner** asked for DVDs, Easy Read and Easy Speak material and visual material – “anything that makes it easier for our people who struggle a bit”.
- 7.53 The **Disability Awareness Co-ordinators** (prisoners trained to support patients) suggested several ways to **raise awareness about prostate cancer** among prisoners. They suggested **information on prostate cancer** could be displayed on the healthcare notice boards on the prison wings (rather than in the Healthcare Unit which were less likely to be looked at by prisoners). They also suggested putting **an article on prostate cancer in the prison magazine** and, like the Head of Healthcare, supported putting **information on prostate cancer on the prisoner TV channel** - “everyone’s aware of that, it has information about the whole prison”. They felt an effective way to raise awareness would be through **talks about prostate cancer** with a) the DACs – “we can pass it on - every wing has a DAC” and b) the older prisoners’ group - a social group to try and get people off the wing who are retired from prison work, which starts at



age 55 (or younger for people who are medically retired). The group is already targeted by the Healthcare Unit for blood pressure checks as “it catches the people who wouldn’t go to Healthcare”.

- 7.54 The **prison lead on personality disorder** (previously the Safe Custody Manager) suggested that a **staff training package** would be useful, i.e. a session on the symptoms of prostate cancer. Staff in both Healthcare and Safer Custody could then deliver it to prisoners on a regular basis. There had been “brilliant feedback” from the DACs and the prison ‘listeners’ (prisoners trained to support other prisoners’ around mental and emotional wellbeing) about dementia awareness sessions delivered by the interviewee after doing a one hour free training session with the Alzheimer’s Society (funded through the dementia friends training national programme). The interviewee also felt the DACs would be a good group to deliver training to, along with delivering ongoing sessions on the Older People’s Wing (for prisoners aged over 50, which has 40-60 prisoners). This interviewee also suggested an **article on prostate cancer in the prison magazine** would be a good way to raise awareness as the magazine “is in someone’s cell so prisoners can look at it again and again – good, they can ask questions of others”.

#### Marginalised group

- 7.55 The interviewee from Gypsylife suggested that a **community nurse** may be an effective way of disseminating information in an appropriate way to the Gypsy and Traveller community, observing that “Prostate Cancer UK could provide an important link between the health service and the community if they knew how to do it.” He explained that there is a precedent for this - **Macmillan nurses** have become active within the community from around ten years ago. The interviewee explained that “Macmillan is very good in our community. They are a trusted source of information. A good ten-fifteen years ago, there was a lot of breast and cervical cancers in women. Macmillan nurses came in at the Sherwood site. Initially the families were quite rude. Over time, a trust has been build up. It is not a large number of people, but some families will engage with Macmillan.”
- 7.56 Importantly, the interviewee described how the Macmillan nurses were **culturally informed**. The interviewee stressed the need for cultural understanding. For example, a nurse must be the same gender as their patient and all interaction must take place on an interactive, face-to-face basis. Exactly how to begin to engage the community is also important. He saw **engaging with women** to be important as there is a more positive view among women that men should have health screening. As wives are not allowed to work, a husband’s death would mean the women lose everything. He explained that “we tend to start with a group of women. We put some cakes on and give a voucher, we talk about things and people start to engage. It might take some weeks before they will start to engage, but then they share information. It takes years to build up engagement.”
- 7.57 When it comes to **engaging with men**, the interviewee reported that a different strategy is needed. Meetings take place on an ad-hoc basis when men are in one place at one time, such as following a church meeting. The interviewee also suggested that Appleby fair would be a good place for Prostate Cancer UK to make contact with men, noting that “there are six fairs across a country. You would have a bit of coffee and cake, and just men in an informal setting. Prostate Cancer UK would have to be there with respected members of the community in order to do that. You could give away bubble-blowers; that would create a buzz, an excitement and from there things would move forward.”

- 7.58 The nurses at The Passage were both interested to learn more about Prostate Cancer UK's work. One said: "now we know that they are there we can look on their website for information."

### Continuing contact

- 7.59 Interviewees were asked if they received or would wish to receive the Prostate Cancer UK email Health Professional Newsletter.
- 7.60 The Velindre CNS and Patient Information Manager both asked to be sent the Health Professionals Newsletter email. However both the Registrar and Consultant said that they would delete it if sent it as they received so many emails. The Information Manager said she had a copy of the Prostate Cancer UK publications catalogue somewhere, but did not know where it was. She was given a copy and said that she would order some more information from it.
- 7.61 The Consultant at the The Northern Ireland Cancer Centre already received the Newsletter, but the information and support radiographer asked to be added to the database.
- 7.62 The interviewees at Maggie's Centre in Glasgow already received the electronic newsletter and had the publications catalogue.
- 7.63 All the interviewees at Nottinghamshire NHS Trust, working in older people's mental health and with people with learning disabilities in the community and in a hospital setting, asked to receive the electronic newsletter and some also asked for the publications catalogue.
- 7.64 At HMP Whatton the Senior Practice Nurse (cancer lead) and the GP both asked to be sent the Health Professionals electronic Newsletter and the Publications Catalogue. The Head of Healthcare did not want these, feeling that this would be more appropriate for the Senior Practice Nurse (Cancer Lead) than for her.
- 7.65 The Gypsylife interviewee wanted to receive the publications catalogue, but only by email (he did not have a postal address).



## 8 Focus groups

### Summary

The eight focus groups with 72 non-users of Prostate Cancer UK's services in communities across the UK found three key themes relating to preferences around the receipt of health information: men prefer to visit a GP for information, but only when absolutely necessary; women play a role in encouraging GP visits; and willingness to engage with personal health issues varies by sociocultural background with the women's Black and minority ethnic group raising cultural stigma around discussing health issues. The three groups which were asked about telephone helplines were not enthusiastic about them as a means of accessing health information voicing negative perceptions in particular around operators lacking specialist knowledge. All the focus groups contained some participants who were reluctant to use the internet for health information, with concerns mainly centering on reliability of information on the internet, but with issues also raised around the internet provoking anxiety inducing descriptions of illness and fears of online scams. The visually impaired and D/deaf groups raised particular barriers around internet use relating to their disability.

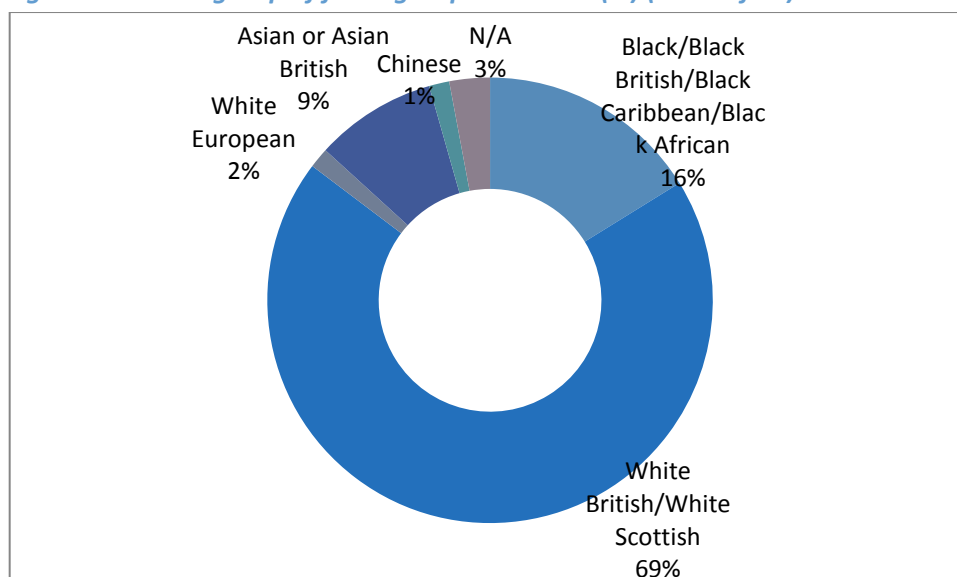
Overall, focus group participants were aware of prostate cancer but specific knowledge around risk factors and symptoms was mixed and in some cases low, with some participants expressing clear misconceptions and misunderstanding about the condition. In general awareness of Prostate Cancer UK was low.

The focus groups evidenced an appetite for clear and simple information and strong support was given to the draft Easy Read material which was shown to three of the groups. Issues around literacy and language as a barrier to understanding the booklets were raised by the BME women's group and in particular the D/deaf group, while the over 80s men and the visually impaired group focused on visual impairment as a barrier. Focus group participants were asked to give advice to Prostate Cancer UK on how to reach people such as themselves, with recommendations including:

- **TV and radio campaigns**
- **Information in community, sports and religious venues**
- **Information at GP surgeries**
- **Remove the stigma from prostate cancer**
- **Informative but not frightening information**
- **Appropriate and accessible information for specific groups** such as D/deaf, visually impaired and transgender people.

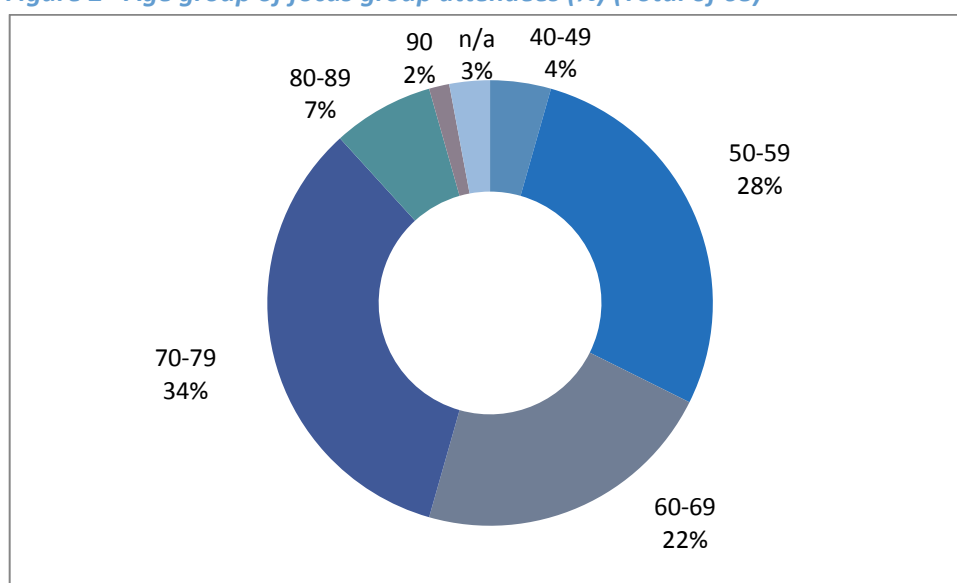
- 8.1 A total of eight focus groups took place across the UK between November 2013 and January 2014.
- 8.2 We strove to ensure a good spread of focus groups across the four nations of the UK, avoiding at the client's request the London and the South East region which has already been the focus of previous Prostate Cancer UK research, and including areas of low take up of Prostate Cancer UK services such as East Midlands and Northern Ireland. We targeted groups of non-users who are at particular risk of prostate cancer (Black and minority ethnic groups particularly African/African Caribbean groups) or whose needs might be at risk of being overlooked (D/deaf, visually impaired, over 80s, gay/bisexual/transgender and residents of economically deprived areas). All groups were held with the over 50 age group as the age group most at risk of prostate cancer. The majority (six) of the groups were with men, but two were held with women as being potentially important conduits to health information for men. All groups were held in community locations used by the participants.
- 8.3 Focus groups were held in the following locations:
- West Bromwich African Caribbean Resource Centre, West Bromwich, England – six men aged over 50 of African/African Caribbean descent;
  - The Firs Club, Leicester, England – 13 men aged over 50 who are D/deaf;
  - Durham, England – six gay and bisexual men and male to female transgender women, aged over 50;
  - Granville Court Centre, Wallasey, England – three men aged over 80 living in sheltered accommodation;
  - Coatbridge Indoor Bowling Club, Coatbridge, Lanarkshire, Scotland – eight men aged over 50 living in an economically deprived area;
  - Bayview Resource Centre, Bangor, Northern Ireland – eight men aged over 50 with visual impairment;
  - Community Space, Newport, Wales – 18 women aged over 50 from Black and minority ethnic (BME) backgrounds; and
  - Six Bells Community Centre, Six Bells, Wales – ten women aged over 50 living in an economically deprived area.
- 8.4 The focus groups were attended by 42 men and 30 women, a total of 72 participants. Participants were given a form to fill in, so that we could determine the ethnic group that they identified with. Of those 72, four did not complete this form. Of those that did (i.e. out of the 68 participants for which we have ethnicity details) 46 identified as White British, White English, White Welsh, White Scottish or White Irish; 11 identified as Black, Black British, Black African or Black Caribbean; six as Asian or Asian British; one as Chinese; one as White European; and one as other.

*Figure 1 – Ethnic group of focus group attendees (%) (Total of 68)*



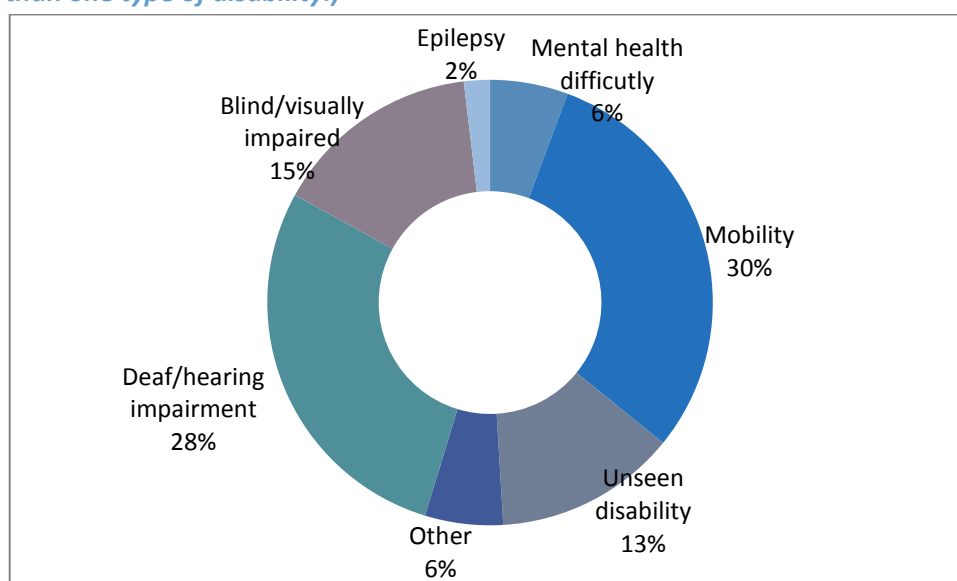
- 8.5 The overwhelming majority of participants were over 50; just 3 were under 50. More specifically, 19 participants were 50-59; 15 were 60-69; 23 were 70-79; 5 were 80-89; 1 was over 90; and, two declined to state their age, although the researchers are confident both were over 50.

*Figure 2 –Age group of focus group attendees (%) (Total of 68)*



- 8.6 The majority of participants considered themselves to have a disability (40). 25 did not consider themselves to have a disability and three did not respond. Among disabilities, mobility (16) and deaf/hearing impairment (15) were the most commonly selected. A number of participants selected multiple disabilities. These figures reflect not only the fact that two focus groups (D/deaf and visually impaired) were held with disabled people, but also the age of the participants (all over 50). Older people are more likely to have a range of conditions than the general population, which is an important consideration for Prostate Cancer UK given the age profile of people affected by prostate cancer.

**Figure 3 – Disabilities reported by focus group attendees (%) (Total of 53 reported disabilities, among 40 participants who considered themselves to have a disability i.e. some reported more than one type of disability.)**



## Health information preferences

8.7 Participants were asked where they prefer to receive health information. To prompt a discussion on this topic, participants were asked where they would go for information if they were worried about a specific health issue. Throughout the focus groups, three key themes emerged. These were:

- Men prefer to visit a GP for information, but only when absolutely necessary;
- Women play a role in encouraging GP visits; and
- Willingness to engage with personal health issues varies by sociocultural background.

### Men prefer to visit a GP for information, but only when absolutely necessary

8.8 In all focus groups, participants described a general reluctance amongst men to engage with any health related information. For example, in the men's BME group in West Bromwich, one participant described how:

*"Men are not like women. Women get up, they look in the mirror and they know something is up with their body. Men don't bother with that sort of thing."*

8.9 Similarly, in the Bangor, Northern Ireland focus group, participants suggested that the pervasive attitude amongst men in the country was to "carry on" until there was no choice but to seek help. One participant explained:

*"I wouldn't go to the doctor because I never have. I think this is a typical male response in Northern Ireland...if I can carry on, I carry on."*

8.10 Although reluctant to seek out any health information, the majority of male participants suggested that their GP would be the first point of call for information, although this would be only when absolutely necessary. There was some confusion around the best time to visit a GP,

but most participants felt they would not go in response to a vague symptom, such as frequent urination. In fact, a common theme that emerged once the Prostate Cancer UK information had been disseminated and reviewed by the groups was a lack of clarity on the most appropriate time to visit a GP in response to prostate symptoms (this is discussed in more depth later on in this chapter). The point at which participants became concerned enough to visit the GP was generally after a more specific and concerning symptom had been experienced, for example, on finding blood in the urine. One participant at the men's BME group in West Bromwich stated:

“If I had blood in my urine the doctor would know he could find me there [at the surgery] in the morning.”

#### **Female relatives play a role in encouraging GP visits**

- 8.11 Most male participants felt that a visit to the GP would be more likely following encouragement from a female relative. For example, when asked what he would do if he was concerned about a health issue, one participant at the visually impaired group in Northern Ireland stated:

“I wouldn't do anything...not until it gets so bad that the wife has to send me to the doctor.”

- 8.12 Similarly, a 90 year old male participant at the focus group in Wallasey described how his daughters (who were both nurses) helped him understand health issues and would arrange doctor's appointments for him.

- 8.13 The idea that female family members support men in terms of access to health information, and specifically, arrange doctor's appointments was reinforced at the women's focus group in Six Bells, Wales where one participant had recently encouraged her husband to have a prostate check. However, the group acknowledged that speaking to male relatives about personal health issues was not always easy.

“I'm in a very traditional marriage and my husband would not come to me if he had a health issue.”

“Men keep illnesses from their wives; [they think] if you don't talk about it, it goes away”

- 8.14 Although the women in the BME group at Newport also agreed that they would strongly encourage their male family members to go to the GP if they had symptoms, the group agreed that “some men don't listen to women, especially regarding sexuality [sic]”<sup>16</sup>. In general, the BME women's group felt that men do not speak to women about their health.

#### **Sociocultural differences in willingness to engage with health information**

- 8.15 A number of sociocultural differences around men's willingness to engage with health information were evident. In particular, ethnicity was suggested as an influential factor in the willingness to engage with health information.

- 8.16 During the women's BME group in Newport, the issue of BME men and access to health information and support was raised. In particular, the BME women's group felt that their husbands would be unlikely to seek out health information, especially in relation to prostate

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<sup>16</sup> The participant was referring to sexual health as opposed to sexuality.

cancer. There were two broad reasons for this. The first was the stigma around discussing health issues in general. The second was the cultural appropriateness of health information in terms of language and content.

- 8.17 In terms of the first issue, the stigma around discussing health issues, a woman of African descent at the women's BME group described how "in our culture men don't like to speak about their problems." The women described how men were even more reluctant to discuss issues relating to parts of the body that are considered taboo. For example, one woman stated:

"Most of Africa don't like homosexuals so there is an issue with the anal investigation...culture can kill you."

- 8.18 Similarly another woman in the group described how her brother had received treatment for prostate cancer, but she considered this was usual. She said:

"My brother had prostate cancer, but he lived in the right area with the right people there. But a lot of his friends could not accept anal investigation."

- 8.19 The stigma around prostate cancer health checks was not discussed to such an extent in the men's BME group, although this may be indicative of a general reluctance to discuss prostate related health checks. This was pointed out by a member of the group, who later revealed he had been recovering from prostate cancer:

"Some of my peer group don't like the idea of going to the doctor for the check, but I have been and I tell other people to go."

### Helpline

- 8.20 In three of the focus groups, participants were asked for their opinions of telephone helplines. In general, focus group participants were not enthusiastic about using a telephone helpline. It was clear that it would be important for Prostate Cancer UK to counter negative perceptions about telephone helplines in promotional material about this service.
- 8.21 A commonly held negative perception of helplines was the idea that helpline operators lacked knowledge. For example, one participant feared that the operator would be "reading from a script". Similarly, other participants feared the operator they spoke to would not be equipped to deal with specific questions.
- 8.22 Only one participant at the bowling club in Coatbridge suggested that he would consider using a helpline, but this would be as a last resort after consulting a doctor or nurse. He stated "if they don't know I can phone the helpline". Another participant suggested that in speaking to a "general helpline, you just get generalities".
- 8.23 The participants at the visually impaired focus group in Bangor also had reservations about phoning a helpline. One participant cited embarrassment as the reason he would not phone. Another suggested that you may get moved from one operator to another. The participants were also concerned that a helpline would not be answered by a person; that they would be required to navigate a complex switchboard; and the operator would not be able to provide tailored and specific information. One participant was also worried about the length of time it would take for someone to answer the phone, and the level of personal information that he would be required to give about himself.

- 8.24 At the gay, bisexual and transgender group in Durham, one participant had phoned a helpline for information relating to epilepsy, but had been disappointed. He stated: “For a simple matter it could be very useful, but if it is something neurological, it is not so good. This is too complex.” Another member of the Durham group had attempted to use a helpline to contact a physiotherapist. However, he found it impossible to explain his “pain and the location. That has to be done in person”. The group agreed that the person who answers the phone has to be a specialist.

#### Internet

- 8.25 Within all groups, there was a general reluctance among some participants to use the internet for health information. Three main reasons for this emerged, these were: (1) concerns around the reliability of information; (2) a desire to avoid anxiety inducing descriptions of illness; and, (3) fears around online scams.
- 8.26 At the BME group in West Bromwich, the participant who had been treated for prostate cancer felt that health information on the internet did not reflect the positive outcome that was likely with early diagnosis. He said:
- “If you go on the internet you can check your symptoms, but then you get anxious. Because you have these symptoms, and because people used to die of this cancer, you think it is bad.”
- 8.27 Only one participant at the group in West Bromwich said that he would use the internet for health information, but this would be to get tips for preventing illness rather than treating it. However, the same participant went on to say that the internet could not always be trusted and sometimes contradicted information from his GP. He said:
- “The internet told me if I get up three times in the night to go to the toilet, this could be bad. But my GP said this was normal.”
- 8.28 At the group in Northern Ireland participants described how the internet was a ‘taboo’ place for people with a visual impairment. Some group members who had a lower level of visual impairment were still reluctant to use the internet. One participant stated: “I wouldn’t touch the internet with a barge pole”. This participant felt it was very easy to be misled by the internet. All participants stated that they were aware of potentially unreliable information on the internet. Interestingly, one participant who had been very vocal about the “misinformation on the internet” tried to promote a ‘cure’ for cancer to the group. He claimed the ‘Budwig diet’ (eating cottage cheese and flax seed) would cure cancer and he encouraged the group to Google this.
- 8.29 One participant had had a positive experience with the internet. He had been diagnosed with a rare degenerative eye condition that he had never heard of before. He searched online for information relating to the condition and now uses a specialist charity’s website. He said he trusted this website because he had no choice; it was the only website he could find. Other participants felt that government websites and charity websites would be trusted. Conversely, participants felt that untrustworthy websites would ask for money.
- 8.30 The women’s group at Six Bells disagreed over whether the internet was a trustworthy source of information. However there was a general agreement that the internet contained some unreliable information. Participants felt that by using the internet, they would be exposed to

scams. Participants shared a similar view to the group in Northern Ireland that the internet could be used to extort money from people. One participant said:

*“The internet is always trying to sell you things and take your money. There are cons on the internet.”*

8.31 Only two of the participants in the group at Coatbridge, Scotland had used the internet to find health information. For one participant, Wikipedia was his preferred source of information. Another participant was more confident in finding information from a wider variety of sources. He said “you can type in exactly what you want and find information” depending on the depth of detail required.

8.32 The gay, bisexual and transgender group in Durham were more positive about using the internet. One reason for this was expressed by a trans-gender participant who said: “for transgender people, we need the internet. There are very few doctors [with transgender expertise].” Another participant explained that the internet was useful for providing the detail that doctors had no time to provide. He explained: “GPs don’t have time to explain, so they just give you a leaflet, so the internet is more useful”. However, one member of the group was less positive about the internet. He said:

*“I don’t trust the internet for anything. I don’t know who writes it. I don’t have the expertise to question it. I’m not qualified. You have to be careful where you look. Some websites are obviously someone with a mission. Others, like the NHS, are more professional”.*

8.33 Only four of the 13 members of the D/deaf group in Leicester used the internet. The main barrier for this group was the ability to understand written English as opposed to BSL. This group reported many barriers in engaging with the NHS relating to difficulty accessing interpreters, whether at scheduled GP or hospital appointments, accessing emergency care or even being able to understand a short hospital appointment letter written in English.

## Awareness of prostate cancer and Prostate Cancer UK

### Awareness of prostate cancer

8.34 Overall, focus group participants were aware of prostate cancer. However, specific knowledge (for example about risk factors and symptoms) was mixed and in some cases low, with some participants holding clear misconceptions/misunderstandings about the condition.

8.35 For example, few participants across the focus groups could provide specific details of the risk factors, which include being over 50, having a family member with prostate cancer, and being of African or Caribbean descent.

8.36 Although all of the participants at the BME men’s group in West Bromwich had heard of prostate cancer, half did not know that black men, over 50s and those with a brother/father who had prostate cancer were at increased risk. When the group were told of an increased risk amongst the over 50s, one participant stated: “but I know someone who got it before 50.” The group also displayed scepticism around the idea that black men had a higher risk of having the cancer. The group were keen to point out that many diseases that once were thought of as ‘black’ diseases were in fact prevalent amongst other populations. For example, one participant stated: “Mediterranean people get sickle cell too.”



- 8.37 The women's BME group in Newport, Wales had a mixed awareness of prostate cancer. Some participants were very familiar with the disease, but this may have reflected past experience. For example, two members of the group had been health professionals and another participant mentioned she had a family member who had prostate cancer. Within the group some participants had no awareness of prostate cancer. One participant asked if she could take the information away for her sister who she thought might have symptoms of prostate cancer. The women's BME group was also sceptical that African Caribbean and African men had a higher risk of having prostate cancer. One participant sought to explain this by suggesting that fewer black men went to the doctor and consequently, fewer were diagnosed. It was also suggested that "black men are not articulate and middle-class so they miss out [on health care]". One participant mentioned that "red meat" was a contributing factor to prostate cancer.
- 8.38 The group in Bangor, Northern Ireland also displayed a vague awareness of prostate cancer. They had all heard of the disease. However, there was little awareness of any detail around the condition and there was no knowledge of symptoms. The group did not know of any factors that may increase a person's risk of prostate cancer, including age. Many of the group believed that prostate cancer may be a lifestyle cancer with obesity, drinking and smoking considered as possible risk factors – "all the usual things", one participant said.
- 8.39 At the gay and transgender group in Durham all members had heard of prostate cancer. All but one participant said that they were aware of different risk factors. However, when asked what the risk factors may be, a confused picture emerged. Two participants felt that smoking and drinking increased a person's risk. Another felt that diabetes increased risk. When prompted, the group suggested that over 50s would be more at risk than younger people. Again, when prompted, the group suggested that ethnicity may be relevant, but no specifics of this were given. One participant suggested that people of Chinese descent may have a lower incidence of cancer.
- 8.40 The women's group in a deprived area in Wales had all heard of prostate cancer. They were aware that older men were more at risk. Nobody knew that African Caribbean and African men (the group was all White British) or those with family members that had the disease were also more at risk.
- 8.41 The men's group in a deprived area in Scotland had all heard of prostate cancer, but had very little detail beyond that. A couple of men thought that passing blood in urine or pain when passing urine may be symptoms but were not sure, and one had been confused as when he went to his GP with these symptoms, the GP told him it would be an infection and gave him antibiotics. Some of the group had had a PSA test but they did not fully understand what this was for. There was almost no awareness of the risk factors, although when prompted, some members agreed that age could be a risk factor. One person suggested that poor hygiene could be a contributing factor.
- 8.42 All three members of the over 80 group in Wallasey said they had heard of prostate cancer, and two of the participants had a mutual friend who had died of it. Participants did not have a detailed knowledge on who was more at risk. One participant thought a fall or a knock could lead to cancer as it "wakes it up". There was also confusion over gender and prostate cancer with one participant asking if prostate cancer affects men more than women.

- 8.43 One of the participants, who was on medication for enlarged prostate and regularly visited his GP surgery for this, noted that the Prostate Cancer UK material he was shown at the focus group was the first time he had ever been given any information which explained his condition and symptoms. He clearly strongly valued having access to this information and understanding what was happening to him.

#### Awareness of Prostate Cancer UK

- 8.44 A general lack of awareness of Prostate Cancer UK was evident, although awareness varied between groups. In three of the focus groups not a single participant had heard of Prostate Cancer UK. Specifically, these groups were; (1) over 50s D/deaf men in Leicester; (2) over 50s women in a deprived area in Wales; and (3) over 80s men in sheltered housing in Wallasey.
- 8.45 Only one member of the over 50s visually impaired men's group in Bangor, Northern Ireland had heard of the charity. This member of the group has previously worked for a health charity.
- 8.46 All but one of the members at the men's BME group had heard of Prostate Cancer UK. The remaining members of the group stated that they had seen adverts or flyers for the charity. One participant had attended a community event aimed at black men in Birmingham where a team from Prostate Cancer UK had given a talk. He also said he had been to a recent match at Aston Villa where men had made speeches about prostate cancer during half time.
- 8.47 At the gay, bisexual and transgender group in Durham, four out of six had heard of Prostate Cancer UK. Three of the four were aware of the helpline. One participant had seen adverts for Prostate Cancer UK on gay websites. Two participants had seen adverts at bus stops, and both of these participants had noted the helpline number. One participant felt that there were more adverts for the charity in London.
- 8.48 Although some members of the BME women's group in Newport, Wales claimed to have heard of Prostate Cancer UK, there was little understanding of what the charity did. Those that had heard of it said they had seen it advertised or had seen it on the TV. One participant thought there was a London bias, suggesting it was "advertised more in London".
- 8.49 Three out of the eight participants at the men's group in a deprived area in Scotland recognised the charity's name. One of these participants had seen some of the leaflets before. The rest had not come across the charity at all.

#### The information

- 8.50 Focus group participants were shown a combination of the following resources:
- Booklets - Know your Prostate; A guide for newly diagnosed men; Diet and Activity; Information for African and African Caribbean men; When you're close to a man with prostate cancer; Know your prostate
  - Gay and bi-sexual information printed from internet
  - Z Card
  - Draft Easy Read material
  - Large print booklet

- Audio files.

### Immediate response to the information

- 8.51 After consulting the information, the majority of participants in all the focus groups had immediate questions around symptoms of prostate cancer. Most wanted to know how they could be sure vague symptoms, such as frequent urination, warranted a visit to the GP. In response to reading the symptoms, a number of men indicated that they would be likely to go to the GP for a check-up.
- 8.52 At the men's BME group in West Bromwich, there was a consensus among the group that the booklets were not detailed enough in terms of early symptoms. One participant said that "I need to be clear about how it starts, what triggers it" Another stated that "I need to get the feel of what it is about more." All participants agreed, when the researcher prompted, that a short symptom guide at the front of the book would be helpful. This suggests an appetite for clear and simple information about when men should go to the doctor, which was also backed up in discussions among other focus groups.
- 8.53 After listening to the audio file at the visually impaired group in Bangor, one participant said that "if you don't pass blood you're never going to go to the GP." Another said, "What is going to start the alarm bells ringing?" A further participant said "listening to that information has made me want to go to the doctors to get checked out."
- 8.54 At the Coatbridge focus group in Scotland, one participant who had read the Easy Read material said "I have all these symptoms". Prompted by the researcher, he thought he might be more likely to get it checked having seen the leaflet.

### The booklets

- 8.55 In the BME men's group in West Bromwich, participants were shown 'A Guide for Newly Diagnosed Men', as well as the 'Information for African and African Caribbean men'. Half the men felt the colour of the booklets was negative. Furthermore, they felt that this would deter them from picking up the booklet in a GP's surgery:
- "The colour is doom and gloom. Cancer is a negative thing anyway, even though we can live with it now."
- "It's like food, if it's not pleasing to the eye, you won't eat it! The colour doesn't grab you. It's not exciting. I mean look at it!"
- 8.56 In terms of the booklet content, one participant stated that "the letters are big enough. I can read them. When you open it you can see what it says. That's good." No one in the group disagreed with this statement. In terms of the language, two participants were open about the fact they felt the booklet used "doctor's talk", which they considered to be overly complex. This focus group was not shown the draft Easy Read material but these comments back up the clear support for the simple, clear information in the Easy Read material on signs and symptoms displayed by those groups who were shown it (see below).
- 8.57 The participant who had been diagnosed with prostate cancer (and who given his experience with cancer presumably had more knowledge of language around the condition) said:

"We can all read, but when we calculate this information in our heads we lose it."

- 8.58 At the women's BME group in Newport, Wales, there was a generally positive response to the booklets. Comments included: "very helpful"; "good for families to know"; "the booklet gives all the agencies you can talk to". When asked about the style of the booklets, the majority of the group felt that it was "easy to understand". However, some members of the group were less positive about the images depicting the male reproductive system. The image was seen to be an explicit depiction of a naked man. One group member said:

"If my husband saw me reading this leaflet he would say 'what are you doing? Why are you reading this?'"

- 8.59 Many group members agreed with this, and all women understood why this would be an issue, even if their own husbands would not be concerned. This seemed to be a particular issue for the South Asian members of the group and may be reflective of particular cultural norms.
- 8.60 Low levels of literacy also emerged in this group as a barrier to understanding the information. It was also thought that the information should be made available in different languages for people who did not understand English very well. One woman suggested that if her husband saw the Z Card in his mother tongue, he would be inspired to pick it up.
- 8.61 At the women's group in Six Bells, Wales, participants were generally positive about the booklets. The information was described as "straightforward" and "easy to understand". The participants were also positive about the booklet style, one saying that the logo was good because "you don't even know it is for cancer". Prompted to suggest any improvements, most of the group thought there was nothing that could be done to improve the quality of the information. Diverging from the views of the women at BME focus group in Newport, members of the group at Six Bells felt that the images of the male reproductive system were appropriate and useful:
- "It's just a body, you see worse on the programme on TV when the men get their testicles out".
- 8.62 The diagram was praised for its "simplicity", and one participant stated that "I didn't know where the prostate was before". Another suggested that there should be more images of real bodies.
- 8.63 Language was raised as an issue with participants suggesting the need for Welsh language material. However, none of the group members spoke Welsh, so they did not feel it was an issue for them that the booklet was only in English.
- 8.64 When asked whether they thought a male family member would read the information, most of the group thought it was unlikely. One participant thought they would "especially if they have symptoms". Others felt men would be too embarrassed. One participant said that "my husband wouldn't pick this up of there are people around". To overcome this, another participant suggested putting the information in men's toilets. To this end, the Z card was thought to be useful as it could easily be put in a pocket.
- 8.65 At the gay, bi-sexual and transgender focus group in Durham, there was a generally negative response to the look and the colour of the booklets. Some group members felt that the booklets were off-putting, and some felt they were not attention grabbing. Echoing responses from the BME men's group, one participant strongly criticised the colour. He said "Black and cancer...looks

funereal". Another called the booklets "sinister and grim". There was broad agreement that the booklets could be more attractive and brighter. One participant commented that the booklet looked like it had been "designed by a corporate designer" and there was also some criticism of the blue writing against the black being hard to see.

- 8.66 With specific regard to the content, participants felt that the booklets were trustworthy. One participant said that "it is like a textbook, you can tell a good textbook from a bad one, depending on if they speak with authority, but not too much authority." Participants felt that the booklets had achieved the right balance and the tone was pitched at the right level.
- 8.67 With regard to the 'Diet and Activity' booklet, one participant (who reported that he suffered from stress) said: "it's alright saying watch diet and exercise, but when you are stressed it is very hard. And that adds to the stress...it's stress upon stress."
- 8.68 At the men in a deprived area focus group in Scotland, 'the Diet and Activity' booklet elicited a reaction similar to the participant in the Durham group. Overall, the booklet seemed to create agitation rather than encourage readers to consider their behaviour. Participants were particularly sceptical about the dietary advice, especially the advice to eat five-a-day, un-processed meat and non-grilled meat. One participant felt that because "everyone enjoys a Lorne sausage and dairy foods" these should still be eaten. Avoiding such foods would deny a person some much needed pleasure. The advice on grilled meat was considered to be at odds with other health advice a participant had come across, which advised grilling meat as opposed to frying it. The cost of buying healthy food was considered prohibitive. One participant asked what the government was doing as he felt that individuals should not have to bear the additional cost associated with eating more healthy foods. One participant said "it's all mights and maybes". Without definitive answers around the impact of certain food on health, he felt that he would be unlikely to follow dietary advice.
- 8.69 At the over 80s group in Wallasey, participants were positive about the 'Know your Prostate' booklet in terms of design. Only one participant read the content and described it as "very good." He contrasted it with the Easy Read material which could be quickly read, saying "you have to settle down and have a read [of the booklet]".
- 8.70 At the D/deaf men's group in Leicester, only one participant said he would be able to understand the booklet. The remainder of the group reported that they would not be able to read anything that was not in British Sign Language.

#### Gay and bi-sexual information

- 8.71 Participants at the group in Durham were generally positive about the gay and bisexual information printed out from the internet. One participant commented that the information "doesn't pull punches. It talks about tops and bottoms, the different roles in gay relationships, which I think is good". He later said, "I learned a few things...particularly for men such as myself who prefer the receptor role."
- 8.72 One participant, a male to female transgender woman, felt strongly that there should be similar specific information for transgender people, as there was for gay and bisexual people. She said "we get lumped with LGBT, but 99% of trans people aren't gay". This was considered particularly relevant as some transgender people may believe their prostate has been removed when this is not the case and are unclear on the implications of their gender reassignment for prostate

health, particularly given the paucity of information given by health professionals on this issue. This participant highlighted that changes in gender reassignment surgery meant that there were different implications for prostate health for those who had undergone the procedure as she had several years ago, and those undergoing it more recently.

### The Z Card

- 8.73 The Z Card was presented to the men's BME group in West Bromwich, the women's BME group in Newport, and the women's group in Six Bells. At the BME men's group, all group members were confused about how to open the z guide. Most did not fully open it. The z guide was dismissed in favour of the booklets. However, at both the women's focus groups (in Newport and Six Bells), the participants liked the Z Card and described it as "easy" and full of "everything you need to know", another participant said "it is quite adequate on its own".

### Easy Read

- 8.74 Three focus groups were shown the draft Easy Read material. Overall, the material was very well received. The images depicting sexual and urinary issues were considered appropriate and necessary by the groups. However, as stated above the BME women's group's had a negative reaction to the mechanical diagram of the male reproductive system in the booklet. This suggests whilst many groups are happy to engage with image of the body, cultural sensitivities need to be taken into account.

- 8.75 At the over 80s group in Wallasey, the Easy Read material was read cover to cover by two participants. The third felt unable to read the information without his magnifying glass. Both participants confirmed that they understood the pictures. They also felt the words were "very easy to follow" and "quite straightforward". Both felt the booklet provided the right amount of information, and in particular was "enough to make you understand without going into medical detail." Despite the graphic nature of the images, the participants felt they were suitable and necessary, even though one had previously expressed strong disapproval of a TV women's health advert which was considered offensive and embarrassing to watch.

"For someone who's got the problems, yes – you aren't going to learn if there's no diagrams."

"You can't take offence – what they're saying is quite true, I've experienced quite a lot of this. ... What else could they do to explain it? There's nothing new in a man being in the nude".

- 8.76 When asked which material was most appropriate to have at the sheltered housing day centre, the Easy Read or the booklet, the participants agreed on the former as "it's a bigger print and easy to follow". The organiser of the group stated that the day centre would be keen to stock copies of the material in the centre, as residents used the centre as an information 'library' about issues such as health.
- 8.77 At the men in a deprived area focus group in Scotland, there was an overwhelmingly positive response to the Easy Read material. The participants were very happy with the images and felt they were very clear. When specifically asked about some of the more controversial images (e.g. a penis and ejaculation), the men were entirely comfortable with them. One man stressed how he liked the "large print as I can read it without glasses".
- 8.78 The D/deaf men's group in Leicester responded much more positively to the Easy Read material than the booklets, feeling that the visual material made it easier for them to engage with the

accompanying written English. The group had no issue with the explicit pictures and all felt the general content was appropriate for D/deaf people. However, some participants were confused by the list of symptoms to look out for as this was printed on a separate page from the previous explanatory sentence, and so was difficult to understand. It was felt D/deaf people would need a clearer explanation. Some other participants also asked clarifying questions over this list and about symptoms and the material was clearly not fully understood by all.

### Large print

- 8.79 The large print material was shown at the focus group in Northern Ireland for visually impaired men. It was not well received. Only one participant felt able to read the text. Another participant stated that he would require such a large text size to see the words that the document would be as “thick as a telephone directory”. For those who could not read the large print material, the need to have a trusted person to relay the written information emerged as an issue. Furthermore, the men were reluctant to have a third party read the material as they felt the content was too personal.

“I get frustrated with literature. I’m not taking this home [the large print booklet]. There’s no point. There’ll be nobody there for weeks and then when someone does come round I may not be comfortable reading this with them.”

“Leaflets are only useful if you have a partner who could read it and explain what it is about, but if someone else is reading it, they put more emphasis on a point or a phrase. They read it differently to how you would.”

### Audio

- 8.80 The audio material was positively received by the visually impaired group in Bangor. All the participants understood the information and thought it was clear. However, the issue of how to access the information was raised. Participants felt that they would be unable to listen to the audio files over the internet as the website would be difficult to navigate. Similarly, participants were concerned about navigating the website to find the helpline number to order the CD. Overall though, the group felt that if they could get hold of the CD they would be able to use it and this would be the preferred format.

## Ideas for reaching people

- 8.81 At the end of each of the focus groups, participants were asked to imagine they were giving one piece of advice to the Chief Executive of the charity about how to reach them and meet their needs. The following advice was given.

### Prostate Cancer UK should campaign on TV and radio

- 8.82 In particular adverts on TV were seen as the best way to get information across to a wide audience. At the Coatbridge group in Scotland, one participant complained:

“You don’t hear about it [prostate cancer]...Every night this week there has been an advert on TV about erectile dysfunction...Get it on there.”

- 8.83 Similarly, at the BME women’s group in Newport, one participant said “there is more advertising about strokes on TV. I’ve seen the prostate cancer adverts, but there are not as many of them”. Others also agreed the TV was a good place to advertise and stated “most people watch TV”.



Having a quick advert was thought best, with a priority to outlining the symptoms and advising people to see their GP.

- 8.84 A suggestion by the visually impaired participants was to advertise the audio CD on the radio, or on Sound Vision Ulster, an audio magazine for Northern Ireland. A blind participant suggested making sure the GP has the helpline number. He does not use Braille [according to the organiser, only 10% of blind people do – although other statistics suggests this may be as low as 1%].

#### Information should be available in community, sports and religious clubs

- 8.85 At the BME men's group in West Bromwich, participants agreed that getting information into public places like pubs and shopping centres would be effective. For example, putting information in men's toilets was seen as a good idea.
- 8.86 The women's group in a deprived area in Wales also felt that posters in toilets, golf clubs, sport centres, rugby clubs, football clubs and the post office would help raise awareness. In general, the participants agreed that having the information in places where there are only men would encourage them to read and use it. The researcher pressed on this point, asking if they thought men would really use the information in such an environment (given the reluctance to engage in health issues earlier identified), and the participants all thought it was likely.
- 8.87 At the men's group in a deprived area in Scotland, one participant thought "supermarkets, sports clubs and community centres" would be an ideal place to disseminate information. Another suggested using a mobile caravan with information about prostate cancer... "where people can walk in, like for a blood donation".
- 8.88 Religious groups were seen as another place where information could be shared. At the women's BME group in Newport, priests and Imams were considered a trusted source of information. Churches, mosques and temples were all mentioned. One participant suggested that a "big talk" was not necessary, but information prior to the service would be more appropriate. It was stressed that culture and language would be important considerations for anything delivered in this setting. Similarly, at the men's BME group in West Bromwich, the importance of religion was discussed implicitly or explicitly. For example, one participant said he would only trust God about health - "I only trust God 100% - you can't trust anyone else."
- 8.89 In the gay, bisexual and transgender group in Durham, participants called on Prostate Cancer UK to develop a specific leaflet on this issue similar to the material for gay and bisexual people and felt that transgender charities/websites would be a good place to disseminate information about prostate health for transgender people.
- 8.90 One participant suggested spreading information through charities that engage with people over 50 – confirming Age UK as an example. He also suggested nursing homes and centres for older people.

#### Information should be available at the GP

- 8.91 In the group in Durham, one participant suggested information be provided in "clinic, hospitals and doctor's surgeries". Similarly at the women's BME in Newport, group participants suggested that surgeries and other health centres should play a video about prostate cancer on a TV in their waiting room. The over 80s group in Wallasey agreed that their GP should be able to



provide them with information on prostate cancer as this would be their first point of call if they had any health worries.

### Remove the stigma from prostate cancer

8.92 At the group in Durham, participants felt that it was important to encourage people to come forward if they have symptoms. The group felt that it important to avoid “prudery”, especially around the rectal examination, as it was far better to get tested early.

8.93 The BME men’s group in West Bromwich, proposed one way to overcome the stigma around prostate cancer. They suggested that more young people should be informed through the internet. One participant said:

“Young people are the generation of tomorrow. We live in a multimedia world. I’m not into the internet or the iPhone, but more information could go on to the internet for the younger generation. You need to educate the youngsters. It’s an internet era. Put it all on Facebook and Skype for them.”

8.94 Similarly, the BME group in Newport also felt that getting young men involved in health awareness would be beneficial. This was thought to be important both for raising awareness more generally, but also because young men could inform their fathers and uncles about the disease, whereas “with all good intentions...some men won’t listen to their women”. Suggestions of places to contact younger people included cinemas, youth groups, sex clinics, pubs, sports clubs.

### Information should be informative but not frightening

8.95 At the BME men’s group in West Bromwich, one participant described how adverts should strike a balance between being attention grabbing and scary. He suggested adverts with a subtle message designed to spark people’s attention and interest (e.g. a series of adverts asking “have you checked?”) would be better than being too scary and ‘in your face’. Another participant agreed that it was important not to frighten people.

8.96 Similarly, at the women’s BME group in Newport most of the participants agreed that “talking softly”, and telling men that they “prevention is better than cure” would help encourage more men to go to the GP.

### Reaching D/deaf and blind and visually impaired people

8.97 The D/deaf group in Leicester unanimously agreed that a DVD in sign language would be the most appropriate way of getting information across to the D/deaf community. The group were pleased that Prostate Cancer UK had expressed an interested in the D/deaf community by organising the focus group, and one person offered to help the charity develop an appropriate signed DVD. At the end of the group, the organiser explained that some health services were providing signed DVDs on other issues (e.g. Sign Health Deaf Wellbeing and BSL Healthy Minds.) She recommended exploring the website of the company Remark!, who have many BSL DVDs.

8.98 The visually impaired group in Bangor did not want to receive information in written form, even if this was large print. Instead, an audio CD was the preferred format.

## 9 Conclusions and recommendations

- 9.1 The **overall findings** of the evaluation are that **Prostate Cancer UK has highly satisfied users of its services**, both health professionals and people affected by prostate cancer. However, work remains to be done to **raise the profile both of prostate cancer (e.g. awareness of symptoms and risk factors) and of Prostate Cancer UK**. This applies both **within communities**, including potentially isolated/marginalised groups, and **among health professionals**, in particular non-cancer specialists within primary and secondary care, whom the evaluation found to be important and trusted intermediaries. It will also be vital that Prostate Cancer UK ensures that it has the **capability to track and monitor** the effectiveness of any work to increase its reach.
- 9.2 To aid this further improvement, we have identified a number of **individual findings and accompanying recommendations**, which are set out below. These are divided into recommendations for the organisation as a whole, and for the helpline and information service only. We have drawn out for each finding the aspect of the evaluation on which the finding draws, in most cases drawing from a number of different aspects of the research.

### Cross-organisation findings and recommendations

#### Increasing awareness/understanding about prostate cancer

- 9.3 The focus groups showed low understanding with regard to the signs, symptoms and risk factors of prostate cancer and when medical help should be sought, and in some cases a degree of confusion/misunderstanding. This was backed up by the site visits in non-cancer specialist settings which showed little evidence of promotional activity/professional awareness around this issue in comparison to other conditions such as diabetes.

#### Recommendation One

**Prostate Cancer UK should undertake work to promote greater awareness and understanding of prostate cancer symptoms, risk factors and when to seek medical help; and to 'bust' myths and misunderstandings about the condition. This work should build on the suggestions made in the site visits and focus group research e.g. posters which can be put up in inpatient and community health settings; DVDs; radio and TV adverts; and articles including linking in to specialist publications/channels such as audio magazines for the visually impaired, prison magazines and Prisoner TV.**

#### Raising the profile of Prostate Cancer UK

- 9.4 While there is already work going on across Prostate Cancer UK to raise the profile of the charity, there needs to be stronger and more consistent liaison between the information service and helpline teams and the marketing and communications team.
- 9.5 The need to raise the profile of the information service and the helpline was a very strong and consistent message from the staff interviews, and was reinforced by the focus groups with non-users and the organisational site visits; particularly in relation to raising the awareness of Prostate Cancer UK among non-cancer specialist NHS staff such as GPs,

community nurses, health facilitators, outreach and inreach teams and the acute sector, who the evaluation found to be important and trusted intermediaries with patients and the public.

- 9.6 Our analysis of the helpline and information service data showed take up of Prostate Cancer UK services to be over-concentrated in London and the South East. While the share of users from African Caribbean and African populations is proportionate to their representation within the 50+ age group, given their increased risk of prostate cancer Prostate Cancer UK should be aiming to increase the awareness and take up of their services among these population groups.

### **Recommendation Two**

**Prostate Cancer UK should ensure that the information service and helpline are prominent in Prostate Cancer UK's marketing and communications activity. This activity should include a focus on strategically important target groups and areas where this evaluation has evidenced that there may be currently lower awareness and take up of services (e.g. non-cancer specialist health professionals, regions outside London and the South East, areas with high concentrations of older Black African and Black Caribbean men).**

### **Greater engagement with health professionals**

- 9.7 Prostate Cancer UK is already embarking on an increased programme of activity to engage with more professionals. There was a strong and consistent message from the staff interviews around the need to engage with more health professionals as they are important and trusted intermediaries and sign-posters for men and their families. The service user interviews and focus groups reinforced the importance of health professionals as a trusted source of information.
- 9.8 The health professional interviews and site visits enabled us to hear from health professionals themselves specific ideas to improve engagement (although it should be stressed that the health professionals who were already in touch with Prostate Cancer UK were largely satisfied with the services it provides). These included:
- Providing proactive support to help health professionals establish support networks in parts of the country where they do not exist – as well as helping men, this could help reduce pressure on professionals if men are better able to support each other
  - Having a dedicated section on the site (work on this is already underway) possibly including a forum
  - Changing the log-in to the website so that it stores details and, in the words of a health professional interviewee, “functions like Amazon” i.e. it remembers the health professional's previous orders and makes suggestions
  - Given that a number of health professionals use their materials to educate their colleagues, asking them what else would help with this e.g. finding what additional questions their colleagues ask that Prostate Cancer UK could help to answer

- Clarifying the Prostate Cancer UK 'offer' to professionals i.e. how it can support them in their work (e.g. availability of the helpline to them as a source of advice)
- Tailoring the Prostate Cancer UK offer to professionals working with specific patient/population groups to show how they may meet their needs (e.g. providing material which may be adapted/used by the professionals for their client group)
- Provide volunteers to support busy clinicians' work e.g. supporting patients on non-clinical issues in clinics
- Considering funding specialist prostate cancer nurses in hospitals
- Talking to Local Pharmaceutical Committees about how to strengthen links with pharmacists and tap into their public health campaigns
- Conferences for staff
- Seminars on supporting health professionals
- Possible online training for health professionals or short courses
- Bringing health professionals and the public together (for instance events, where they can learn from each other).

9.9 The site visits particularly highlighted the need to engage with non-cancer specialist health professionals who can be key intermediaries in raising the awareness of signs and symptoms of prostate cancer and helping ensure early detection – e.g. GPs, community nurses and health facilitators; and those working with large groups of older men such as older people's mental health professionals, sheltered housing staff and offender health teams. In other unpublished pieces of research Si has undertaken for clients we have also found pharmacists to be an increasingly important and effective professional group in this regard. This has also been highlighted in research undertaken by Prostate Cancer UK<sup>17</sup>.

The evaluation found that the lowest levels of take up of the helpline are in the East of England, the North East and the East Midlands regions; and take up of information material is lowest in the Eastern and South West regions. It would be interesting to explore further whether this is linked to levels of engagement with health professionals in these regions.

### Recommendation Three

**Prostate Cancer UK's programme to engage with more health professionals should be a strategic priority for the whole organisation, and should build on the links established by the site visits for this evaluation to explore further how to engage professionals who are not already in touch with Prostate Cancer UK, particularly non-cancer specialists. Prostate Cancer UK should in particular explore its levels of engagement with health professionals in the regions where data analysis shows levels of take up of its services are lower. Prostate Cancer UK should give consideration to the specific ideas generated by the health**

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<sup>17</sup> Scoping research on awareness training for pharmacists, Prostate Cancer UK (2013)

professional interviews and the site visits about how to engage better with health professionals.

## Stronger regional and national infrastructure

- 9.10 Developing a strong regional / local presence across the country would enable Prostate Cancer UK to build up relationships with more health professionals and, through them, contact more men. The site visits indicated that further consideration needs to be given to the Prostate Cancer UK 'brand' in the Celtic Nations, especially in Wales e.g. in relation to the provision of Welsh language material. The need to 'get out of London more' and provide more local services was also highlighted in the health professional interviews.

### Recommendation Four

**The information team and helpline service should proactively build and maintain strong links with Prostate Cancer UK's emerging regional and national infrastructure, and use local intelligence to target increased activity, particularly at under-served men, as well as referring service users between the helpline and regional teams where appropriate. Furthermore the information team and helpline service should develop an understanding of the local and regional infrastructure of the NHS and third sector, enabling them to build up relationships with community groups and care providers as well as the local NHS.**

## Improving accessibility

- 9.11 A number of staff expressed the concern that Prostate Cancer UK's material, because it is information heavy and relies on a high level of literacy, appeals to a fairly narrow constituency – well-educated, literate people who are comfortable managing large amounts of information. These concerns were not echoed in service user interviews, but that may reflect the nature of sample.
- 9.12 In the focus group research some concerns were expressed about the Prostate Cancer UK material in relation to literacy, e.g. by the organiser of the GBT group in Durham, and literacy was also raised as an issue by the offender health team, the GypsyLife interviewee and the Glasgow Maggie's centre. The women's BME group, the homeless outreach team and the HMP Whatton cancer nurse raised the need for material in languages other than English, and the D/deaf group specifically the need for BSL material. A couple of the health professionals already in touch with Prostate Cancer UK, who were interviewed, mentioned the need for material in Polish. The Velindre team highlighted the need for Welsh language material, seen as an issue of credibility and potentially becoming more important with the increase in Welsh language education in schools.
- 9.13 The D/deaf group found the Easy Read material much more accessible than the leaflets, as did the men's group in the deprived area and the 80+ men's group. Some of the organisations visited in the site visits (e.g. Velindre, HMP Whatton, and Nottinghamshire NHS Trust Local Services Division) also welcomed strongly the provision of Easy Read material, although some (e.g. in HMP Whatton and the Local Services Division) stressed the need for a range of materials to cater for a range of mental capacities, cognitive abilities and personal preferences around information. The learning disabilities team emphasised the importance of providing the material electronically to enable them to tailor it to the people they were working with.

- 9.14 The Easy Read material was ‘road tested’ at some of the focus groups and generally received positive feedback, although some concerns around the cultural appropriateness of explicit material for some communities were raised in the BME women’s group and the GypsyLife interviewee. The sample size of the specific groups involved was insufficient to draw clear conclusions on this point.

#### **Recommendation Five**

**Prostate Cancer UK should further research whether there is a business need for material in languages other than English (including British Sign Language and Welsh).**

#### **Recommendation Six**

**Prostate Cancer UK should roll out the Easy Read material and use it as an opportunity to strengthen its links with community groups and care providers for whom it will be particularly useful and welcomed, building on the links established within the focus groups and site visits components of the research. Consideration should be given to: developing further Easy Read material to assist patients throughout the patient journey, and to support professionals to involve all patients as fully as possible in decisions about their care. Further research should be undertaken as to whether it needs to be adapted to make it culturally appropriate for particular communities.**

### **Creating more “ways in”**

- 9.15 One way to increase the reach of Prostate Cancer UK is to create more “ways in” to the information service and helpline. We are aware that the social media presence of Prostate Cancer UK is in its nascence and is a developing aspect of the charity’s communications.
- 9.16 The focus groups and site visits gave a number of detailed ideas about how to reach more people, many focusing on proactively going out to engage with people in the places where people generally are/engage with information and some with how to engage people from particular groups. These included:
- adverts on TV and radio
  - audio magazine for visually impaired
  - getting information into public places like pubs, shopping centres and men’s toilets
  - storylines in TV soaps
  - a mobile caravan with information about prostate cancer
  - religious groups
  - transgender charities/websites
  - charities that deal with people over 50 e.g. Age UK
  - nursing homes and centres for older people
  - surgeries and other health centres more

- reaching young people through the internet, cinemas, youth groups, sex clinics, pubs, sports clubs
- DVD in British sign language
- audio CD
- proactive and culturally appropriate strategies to reach potentially isolated groups such as people with learning disabilities, mental health service users, offenders, homeless people and Gypsies and Travellers, all of whom experience poorer health outcomes than the general population (e.g. prison TV and radio, working with community centres for people with learning disabilities or outreach teams working with homeless people or Gypsies and Travellers).

9.17 Throughout the focus groups there was a theme of people feeling reluctant to use the internet for health information. In these and in the site visits it became clear that the internet is not the preferred/possible information source for many potential information users and that a variety of formats continues to be needed, particularly if the needs of potentially marginalised groups are to be met. Those working with people with learning disabilities and offenders, and the D/deaf group, all cited DVDs as the preferred format as the internet was little/not used by their populations, and the visually impaired group asked for audio material for similar reasons. For example the GP who was interviewed contrasted her general practice population patients who in general wanted online information, with her offender health work where hard copies were needed. Similarly at the sheltered housing day centre more traditional formats such as leaflets and DVDs continued to be used more than the internet and some residents rarely left the sheltered housing limiting their potential engagement with information outside the centre.

9.18 Reaching such groups will require intensive and targeted outreach work. While this may not yield the same numbers as more general campaigns, they have the potential to help those most in need.

### **Recommendation Seven**

**The information service and helpline teams should work with the marketing and communications team to identify innovative ways to reach more men, including targeted outreach work to reach those who are potentially at higher risk (e.g. older people, African Caribbean men) and those who are isolated/marginalised. For this to be effective it will be important to identify and work with/through trusted intermediaries such as the community groups and health settings with whom we worked in the research for this evaluation. The programme of work should include: research into understanding how potential and actual users may benefit from social media; giving consideration to the specific ideas about ways in generated by the focus groups, site visits and health professionals interviews; and building on the links within communities and health settings created by the evaluation to further develop and road test ideas. (For example Prostate Cancer UK could work with the sheltered housing day centre in Wallasey to develop strategies to reach older men living in sheltered housing and care homes who may not access information online or in community settings.).**



### Recommendation Eight

**Prostate Cancer UK should give consideration to how it may track and monitor whether or not it is reaching the highest risk/potentially isolated and marginalised population groups. This may include undertaking regular qualitative research with these groups as they are unlikely to be captured by standard data monitoring processes.**

### Recommendation Nine

**Prostate Cancer UK should provide its information in a range of formats taking into account the preferences, needs and capacities of different groups including those who cannot or do not feel comfortable accessing health information online.**

## Working with volunteers and support groups

- 9.19 Several service users stated that they could be interested in volunteering for Prostate Cancer UK, but were not sure what form that would take.
- 9.20 The feedback from the staff interviews was that many support groups were very positive about Prostate Cancer UK. There was positive feedback in the service user interviews about the OnlineCommunity.

### Recommendation Ten

**Prostate Cancer UK should clarify to its service users how they may continue to be involved with the organisation. The information team should consider how the volunteers and groups could be used further by, for example, using them to not just to test out emerging new materials but to brainstorm on what new “ways in” would enable men like them to access Prostate Cancer UK’s services.**

## Working with relatives, partners and carers

- 9.21 The site visits and focus groups confirmed the importance of relatives, partners and carers both as a source of support for patients, and as a means of transmitting health information and facilitating access to health services. This was for example highlighted in relation to the general population of prostate cancer patients by the Velindre, Glasgow and Belfast site visits, and in relation to specific population groups such as people with learning disabilities where relatives act as informal carers and can be ‘gatekeepers’ to accessing health services. The learning disabilities site visit also highlighted the potential value of the helpline as a source of information and support for carers.

The relatives and partners contacted for this evaluation were as positive about the information materials and the helpline as the men who had used the services. However, a number of them stated it would also be useful for them to talk to others in the same position, for example through a forum. The research was carried out with a small sample, so this issue may require further research, but it is possible that Prostate Cancer UK may be able to address an unmet need amongst partners and relatives.



## Recommendation Eleven

**Prostate Cancer UK should consider how best to support relatives, partners and carers and draw on their skills and time as a resource, building on specific suggestions made in the research such as the need for a support group for wives. It should further investigate the need and feasibility of creating a dedicated section of the website, and of networking / buddying / creating a forum for relatives and partners of men affected by prostate cancer. It should also review its links with national and local carers' groups and charities which may be a key means of promoting awareness of its services, including the helpline, among relatives, partners and informal carers.**

## Improving data collection and monitoring

- 9.22 The data analysis carried out for this evaluation confirmed that there are a number of data gaps. Many questions are already being asked of service users, e.g. geographical location, ethnicity and age, but a large number of 'other' or 'unknown' responses limit the potential usefulness of this data and potentially undermine Prostate Cancer UK's ability to track and monitor its reach and identify geographical/ethnic/age variations. A crucial aspect of achieving a higher response will be to convey to the user – and, importantly, to any staff with whom the user interacts - the relevance and importance of the questions asked in terms of future service improvement; and how personal information will be protected. The current low response rate implies that improvements need to be made in this regard.
- 9.23 Furthermore there are data gaps such as, most importantly disability and gender (including transgender), with information on sexuality and religion or belief also currently not collected. Nor are information users asked what they will do subsequently with the information. The focus groups, all of which were undertaken with the over 50s age group, unsurprisingly found a high number of participants to have one or more disabilities, highlighting the importance of taking account of and monitoring disability in work with this age group, which was also underlined in the site visits. The focus groups and site visits also raised issues around the importance of gender particularly within certain cultures (e.g. suggesting that men in some ethnic minority communities, including the African Caribbean, South Asian and Gypsy and Traveller communities, would feel more comfortable engaging with male than female relatives around prostate issues).
- 9.24 There is however a balance to be struck between achieving a comprehensive understanding of users and having a robust data set through achieving a high response rate. Asking too many questions might discourage users from responding which needs to be taken into account in considering whether further questions should be asked of service users. This should only be done where there is a strong business need.

## Recommendation Twelve

**In order to improve response rates, Prostate Cancer UK should make clear to its staff and to service users why monitoring information is needed to improve services, and how the information will be protected. Prostate Cancer UK should ask its service users questions about disability and gender (male, female, transgender). It should also consider whether there is a business need to collect information in relation to sexuality and religion or**

belief, and on users' subsequent use of information, taking into account the potential impact on response rates of increasing the data collection 'burden'.

## Specific helpline findings and recommendations

### Strategy for the helpline

- 9.25 While confident that they are delivering a high-quality service, the specialist nurses are unclear about the strategy for the helpline and, in particular, the rationale for and potential implications of hitting the ambitious targets for increasing call numbers.
- 9.26 The service user interviews found that callers highly value the helpline nurses having more time to give than busy health professionals such as GPs. Both the interview and the analysis of the helpline survey showed high levels of satisfaction among users with the helpline service. Both health professionals and helpline users highlighted the reassurance provided by knowing the helpline is staffed by specialist nurses, encouraging them to use/refer to the helpline.
- 9.27 However, the focus groups with non-users showed evidence of negative attitudes and resistance towards the idea of accessing telephone helplines about health issues, particularly around the perception that they will be staffed by people with insufficient specialist knowledge.
- 9.28 The organisers of the D/deaf focus group raised the issue of how to ensure the helpline can meet the needs of D/deaf people and offered to assist in taking this forward. Analysis of the helpline survey also showed lower understanding of the information given to them among the 70+ age group.

### **Recommendation Thirteen**

**Prostate Cancer UK should seek to ensure that an increase in calls to the helpline is targeted at those who need the service most, and is not driven solely by a rapid turnover of calls from the 'worried well', by targeting marketing appropriately.**

### **Recommendation Fourteen**

**Prostate Cancer UK should engage the specialist nurses e.g. through a regular forum to ensure they have opportunities to contribute their views to debates within the charity and, in particular, shape the strategy for the helpline; and should either explain to them why there is a need to record activity every thirty minutes, or review the need for this information to be recorded.**

### **Recommendation Fifteen**

**Consideration should be given to the development of a follow up call system and how best to meet the needs of callers aged 70+ and D/deaf callers. The helpline team should continue to develop its links with Prostate Cancer UK's emerging regional infrastructure, referring service users between the helpline and regional teams where appropriate.**

## Recommendation Sixteen

**Prostate Cancer UK should take into account in its marketing of the helpline both the high levels of satisfaction found in the evaluation among helpline users, and the negative attitudes and preconceptions found in the focus groups about the value of helplines. For example, it should highlight that it provides specialist, knowledgeable staff who are able to offer appropriate, accurate and up to date advice to callers.**

## Specific information service findings and recommendations

### Raising the profile of the information service internally

- 9.29 The information service is rated very highly within Prostate Cancer UK and is seen as an important source of expertise. However, staff also reported that they would like to know more about the service and what it does. In turn, that would make them more confident about promoting and signposting to the service.

## Recommendation Seventeen

**The information team should consider briefings for staff, and other forms of awareness raising, to ensure staff are aware in more detail about what they offer. This could include asking all staff where and how they can promote the information service.**

### The Tool Kit

- 9.30 The majority of service users were very satisfied with the information they got from the Tool Kit, and one of the general messages from service users is that they prefer to get as much information as possible. Areas of particular value included treatment options and side effects, which in some cases helped users to make decisions on their care.
- 9.31 Some interviewees were able to suggest improvements to the Tool Kit although there were no clear themes to the suggested improvements. Single interviewees identified the following: put Tool Kit online so users could self-print; make it a uniform paper size and provide a folder; avoid repetition; regular updates following treatment evolution; make it smaller and easier to carry around like Macmillan booklets; include more personal stories and specific information on side effects; include more detail.
- 9.32 Some of these suggested improvements already exist; for example, the Tool Kit is available online and can be printed, it has a folder, and is updated regularly. This highlights the importance of communicating with users and potential users what is on offer.
- 9.33 While the Tool Kit forms a key part of Prostate Cancer UK's 'offer' to health professionals (both in terms of supporting patients and as a source of education for staff), the site visits showed relatively low awareness among health professionals of this product.

## Recommendation Eighteen

**In the next review or re-design of the Tool Kit, Prostate Cancer UK should explore the suggested improvements made by interviewees e.g. scope to reduce its size and shape, without reducing the amount of information that people can get from it.**

### **Recommendation Nineteen**

**Prostate Cancer UK should raise awareness of the Tool Kit 'offer' among both health professionals and people affected by cancer, including communicating the variety of formats in which it can be accessed and the fact that it is updated regularly.**

## Appendix A – Data analysis - helpline

This section contains supporting data for chapter 3 and appears in the order in which it is referenced in the main body of the report.

**Figure 1: Helpline users**

	2009-2010	2010-2011	2011-2012	2012-2013
<b>Helpline users</b>	5,174	5,220	5,498	6,272

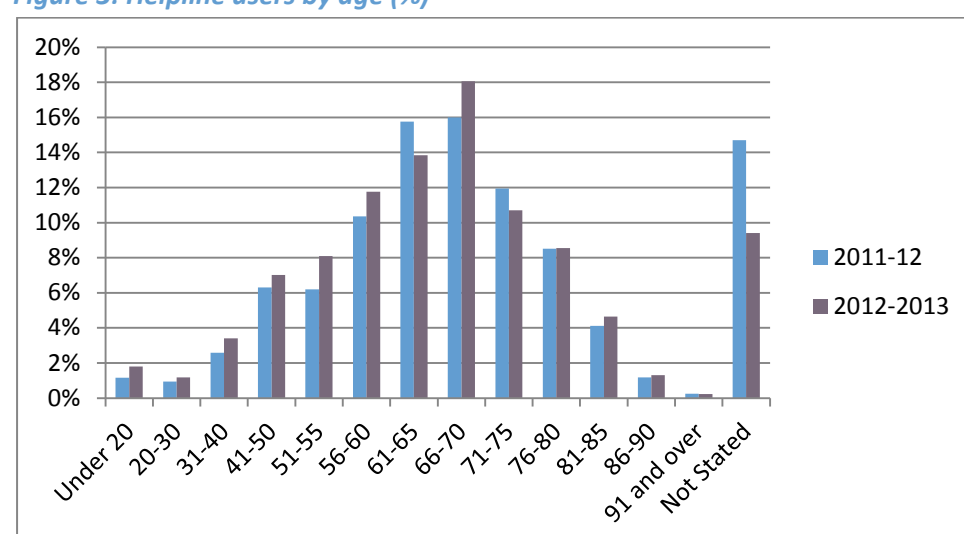
Source: 2011-12 Annual Service Activity Report; Helpline report 2011-12; Helpline report 2012-13

**Figure 2: Helpline users by region**

	No.	No	No	%
Region	2010/2011	2011/2012	2012/13	Percent change (vs 2010/2011)
South East (Excluding London)	1268	1081	1341	6%
Greater London	604	752	865	43%
North West	601	574	758	26%
South West	578	505	545	-6%
North East & Yorkshire & The Humber	468	359	439	-6%
West Midlands	318	255	391	23%
Scotland	297	273	298	0%
Eastern	267	229	278	4%
East Midlands	160	236	232	45%
Wales	167	160	231	38%
Northern Ireland	84	76	75	-11%
Overseas	56	69	60	7%
<b>Total</b>	<b>5220</b>	<b>5447</b>	<b>6272</b>	<b>20%</b>

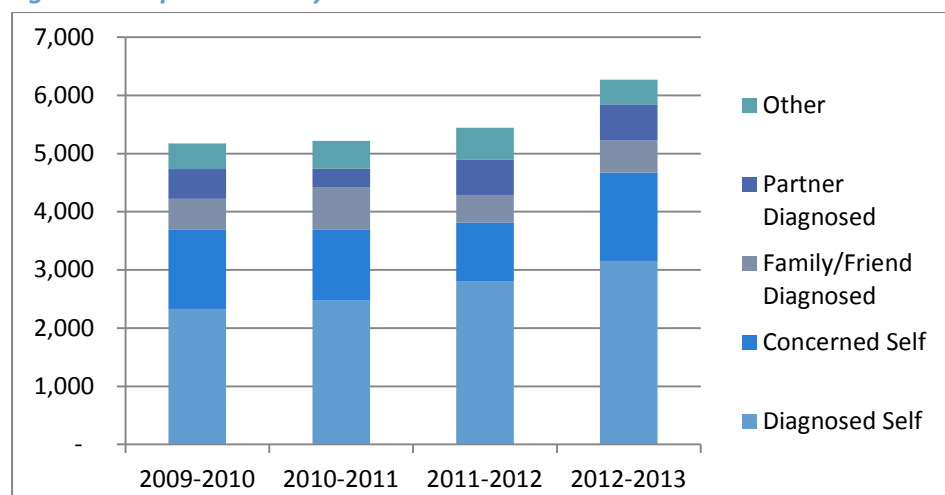
Source: 2011-12 Annual Service Activity Report; latest year's data from Prostate Cancer UK

**Figure 3: Helpline users by age (%)**



Source: Helpline report 2011-12; Helpline report 2012-13

*Figure 4: Helpline users by status*



Source: 2011-12 Annual Service Activity Report; Helpline report 12-13

Figure 5: England and Wales: Ethnic Group

Ethnicity	All ages	Share	Aged 50 and over	Share
All categories: Ethnic group	56,075,912	100.0%	19,385,844	100.0%
White: English/Welsh/Scottish/Northern Irish/British	45,134,686	80.5%	17,448,458	90.0%
White: Irish	531,087	0.9%	292,092	1.5%
White: Gypsy or Irish Traveller	57,680	0.1%	10,374	0.1%
White: Other White	2,485,942	4.4%	413,958	2.1%
Mixed/multiple ethnic group: White and Black Caribbean	426,715	0.8%	33,947	0.2%
Mixed/multiple ethnic group: White and Black African	165,974	0.3%	12,742	0.1%
Mixed/multiple ethnic group: White and Asian	341,727	0.6%	27,509	0.1%
Mixed/multiple ethnic group: Other Mixed	289,984	0.5%	28,424	0.1%
Asian/Asian British: Indian	1,412,958	2.5%	325,791	1.7%
Asian/Asian British: Pakistani	1,124,511	2.0%	146,737	0.8%
Asian/Asian British: Bangladeshi	447,201	0.8%	45,094	0.2%
Asian/Asian British: Chinese	393,141	0.7%	68,246	0.4%
Asian/Asian British: Other Asian	835,720	1.5%	133,506	0.7%
Black/African/Caribbean/Black British: African	989,628	1.8%	104,157	0.5%
Black/African/Caribbean/Black British: Caribbean	594,825	1.1%	179,391	0.9%
Black/African/Caribbean/Black British: Other Black	280,437	0.5%	29,243	0.2%
Other ethnic group: Arab	230,600	0.4%	27,806	0.1%
Other ethnic group: Any other ethnic group	333,096	0.6%	58,369	0.3%

Source: 2011 Census, ONS, DC2101EW - Ethnic group by sex by age

*Figure 6: Census 2011, ethnicity and region, under 50 and 50 plus*

	Black African	Black Caribbean	Other Black	Black African	Black Caribbean	Other Black
Region	0-49	0-49	0-49	50 and over	50 and over	50 and over
North East	0.6%	0.1%	0.1%	0.1%	0.0%	0.0%
North West	1.2%	0.3%	0.3%	0.2%	0.3%	0.1%
Yorkshire and The Humber	1.2%	0.4%	0.3%	0.2%	0.4%	0.1%
East Midlands	1.3%	0.7%	0.3%	0.2%	0.6%	0.1%
West Midlands	1.7%	1.6%	0.8%	0.2%	1.4%	0.1%
East	1.7%	0.6%	0.3%	0.3%	0.5%	0.1%
London	8.2%	4.0%	2.5%	3.5%	4.8%	0.8%
South East	1.4%	0.4%	0.2%	0.2%	0.3%	0.1%
South West	0.7%	0.3%	0.3%	0.1%	0.2%	0.1%
Wales	0.6%	0.1%	0.1%	0.1%	0.1%	0.0%

Source: 2011 Census, ONS Crown Copyright Reserved [from Nomis on 9 October 2013]

*Figure 7: Age of caller and where they first found out about the Helpline Service at Prostate Cancer UK*

		Where did you first find out about the Helpline Service at Prostate Cancer UK?					Total
		Your health professional	TV or radio	Newspapers e.g. Daily Mirror	Marks and Spencer	Other	
Age or caller	30 or younger	1	0	0	0	2	3
	31-40	0	1	0	0	5	6
	41-50	2	0	1	0	14	17
	51-60	16	4	4	4	36	64
	61-70	36	5	24	1	54	120
	71-80	10	5	20	1	38	74
	81 or over	7	0	6	0	8	21
Total		72	15	55	6	157	305

Source: Helpline Survey

*Figure 8: Gender of caller and where they first find out about the Helpline Service at Prostate Cancer UK?*

		Where did you first find out about the Helpline Service at Prostate Cancer UK?					Total
		Your health professional	TV or radio	Newspapers e.g. Daily Mirror	Marks and Spencer	Other	
Gender of caller	Male	60 (23%)	12	52	6	130	260
	Female	9 (0.2%)	3	2	0	26	40
Total		69	15	54	6	156	300

Source: Helpline Survey



**Figure 9: Location\_or\_IP \* Where did you first find out about the Helpline Service at Prostate Cancer UK? Crosstabulation**

			Where did you first find out about the Helpline Service at Prostate Cancer UK?					Total
			Your health professional	TV or radio	Newspapers e.g. Daily Mirror	Marks and Spencer	Other	
Location_or_IP		Count	21	5	22	4	43	95
		% within Location_or_IP	22.1%	5.3%	23.2%	4.2%	45.3%	100.0%
	East Midlands	Count	2	0	2	0	13	17
		% within Location_or_IP	11.8%	0.0%	11.8%	0.0%	76.5%	100.0%
	East of England	Count	11	1	6	0	18	36
		% within Location_or_IP	30.6%	2.8%	16.7%	0.0%	50.0%	100.0%
	London	Count	10	1	5	0	20	36
		% within Location_or_IP	27.8%	2.8%	13.9%	0.0%	55.6%	100.0%
	North East	Count	1	0	1	0	4	6
		% within Location_or_IP	16.7%	0.0%	16.7%	0.0%	66.7%	100.0%
	North West	Count	4	0	9	0	6	19
		% within Location_or_IP	21.1%	0.0%	47.4%	0.0%	31.6%	100.0%
	Scotland	Count	2	2	1	0	6	11
		% within Location_or_IP	18.2%	18.2%	9.1%	0.0%	54.5%	100.0%
	South East	Count	3	3	3	0	14	23
		% within Location_or_IP	13.0%	13.0%	13.0%	0.0%	60.9%	100.0%
	South West	Count	7	0	3	0	13	23
		% within Location_or_IP	30.4%	0.0%	13.0%	0.0%	56.5%	100.0%
	Wales	Count	4	1	2	0	9	16
		% within Location_or_IP	25.0%	6.3%	12.5%	0.0%	56.3%	100.0%
	West Midlands	Count	6	1	0	2	11	20
		% within Location_or_IP	30.0%	5.0%	0.0%	10.0%	55.0%	100.0%
	Yorkshire and Humberside	Count	2	1	1	0	5	9
		% within Location_or_IP	22.2%	11.1%	11.1%	0.0%	55.6%	100.0%
Total		Count	73	15	55	6	162	311
		% within Location_or_IP	23.5%	4.8%	17.7%	1.9%	52.1%	100.0%

Source: Helpline Survey

**Figure 10: Where did you first find out about the Helpline Service at Prostate Cancer UK? \***  
**Status as caller Crosstabulation**

		Status as caller								Total
		Diagnosed with prostate cancer	Concerned about prostate cancer	A partner of a person diagnosed with prostate cancer	A partner of a person concerned about prostate cancer	Friend or family of a person diagnosed with prostate cancer	Friend or family of a person concerned about prostate cancer	Health professional	Other	
Your health professional	Count	49	9	7	1	2	0	0	3	71
	% within source	69.0%	12.7%	9.9%	1.4%	2.8%	0.0%	0.0%	4.2%	100.0%
	% within Status as caller	32.5%	13.0%	33.3%	20.0%	10.0%	0.0%	0.0%	14.3%	24.4%
Newspapers e.g. Daily Mirror	Count	18	23	1	0	1	0	1	6	50
	% within source	36.0%	46.0%	2.0%	0.0%	2.0%	0.0%	2.0%	12.0%	100.0%
	% within Status as caller	11.9%	33.3%	4.8%	0.0%	5.0%	0.0%	50.0%	28.6%	17.2%
Other	Count	75	31	11	4	14	2	1	12	150
	% within source	50.0%	20.7%	7.3%	2.7%	9.3%	1.3%	.7%	8.0%	100.0%
	% within Status as caller	49.7%	44.9%	52.4%	80.0%	70.0%	100.0%	50.0%	57.1%	51.5%

Source: Helpline Survey (not all of the possible responses, as this was difficult to fit into a page)

**Figure 11: Which would you say was your most important reason for contacting us?**

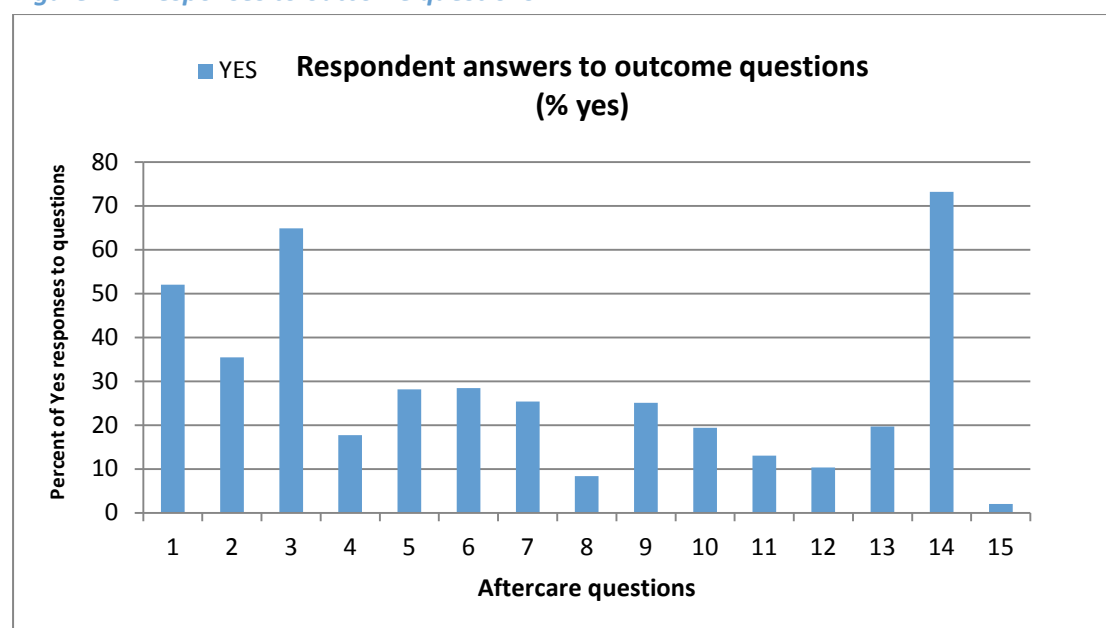
		Frequency	Percent	Valid Percent*
Valid	Medical or factual information	104	33.2	36.9
	Guidance about my options	50	16.0	17.7
	Practical support or suggestions	29	9.3	10.3
	Help with fears and anxieties	46	14.7	16.3
	A better understanding of my condition	45	14.4	16.0
	Other	6	1.9	2.1
	n/a	2	.6	.7
	Total	282	90.1	100.0
Missing		31	9.9	
Total		313	100.0	

Source: Helpline Survey (\*percent of responses, excludes missing)

**Figure 12: Which would you say was your most important reason for contacting us? \* Age or caller Crosstabulation**

			Age or caller							Total
			30 or younger	31-40	41-50	51-60	61-70	71-80	81 or over	
Which would you say was your most important reason for contacting us?	Medical or factual information	Count	1	0	7	23	44	21	5	101
		% within reason for calling	1.0%	0.0%	6.9%	22.8%	43.6%	20.8%	5.0%	100.0%
		% within Age or caller	50.0%	0.0%	41.2%	39.0%	40.0%	32.8%	25.0%	36.3%
	Guidance about my options	Count	0	1	5	8	17	15	3	49
		% within reason for calling	0.0%	2.0%	10.2%	16.3%	34.7%	30.6%	6.1%	100.0%
		% within Age or caller	0.0%	16.7%	29.4%	13.6%	15.5%	23.4%	15.0%	17.6%
	Practical support or suggestions	Count	1	3	1	8	10	4	2	29
		% within reason for calling	3.4%	10.3%	3.4%	27.6%	34.5%	13.8%	6.9%	100.0%
		% within Age or caller	50.0%	50.0%	5.9%	13.6%	9.1%	6.3%	10.0%	10.4%
	Help with fears and anxieties	Count	0	1	2	12	19	8	4	46
		% within reason for calling	0.0%	2.2%	4.3%	26.1%	41.3%	17.4%	8.7%	100.0%
		% within Age or caller	0.0%	16.7%	11.8%	20.3%	17.3%	12.5%	20.0%	16.5%
	A better understanding of my condition	Count	0	0	2	8	17	14	4	45
		% within reason for calling	0.0%	0.0%	4.4%	17.8%	37.8%	31.1%	8.9%	100.0%
		% within Age or caller	0.0%	0.0%	11.8%	13.6%	15.5%	21.9%	20.0%	16.2%
	Other	Count	0	1	0	0	2	2	1	6
		% within reason for calling	0.0%	16.7%	0.0%	0.0%	33.3%	33.3%	16.7%	100.0%
		% within Age or caller	0.0%	16.7%	0.0%	0.0%	1.8%	3.1%	5.0%	2.2%
Total		Count	2	6	17	59	110	64	20	278

Figure 13: Responses to outcome questions



Where:

1	I feel calmer and reassured
2	I feel less anxious about the future
3	I gained useful factual information about my/my partner's condition
4	I gained ideas on coping with my/my partner's condition
5	I have a better understanding of my/my partner's treatment
6	I have a better understanding of my/my partner's treatment options
7	I have a better understanding of the side effects of my/my partner's treatment
8	I felt more able to manage my/my partner's side effects
9	I am more confident to discuss my/my partner's condition with another health professional
10	I am more confident to discuss my/my partner's treatment with another health professional
11	I am more confident to discuss my/my partner's condition with family and friends
12	I am more confident to discuss my/my partner's treatment with family and friends
13	I am more able to get on with my day to day life
14	I know where to seek more help if I need it
15	Nothing changed because of the call

Source: Helpline Survey

**Figure 14: Age or caller \* Did your contact with a Specialist Nurse help to address your needs in a way that your healthcare professionals were unable to do?**

		Did your contact with a Specialist Nurse help to address your needs in a way that your healthcare professionals were unable to do?		Total
		Yes	No	
Age or caller	30 or younger	3	0	3
	31-40	6	0	6
	41-50	10	3	13
	51-60	48	13	61
	61-70	88	19	107
	71-80	53	11	64
	81 or over	15	1	16
Total		223	47	270

Source: Helpline Survey

**Figure 15: Gender of caller \* Did your contact with a Specialist Nurse help to address your needs in a way that your healthcare professionals were unable to do?**

		Did your contact with a Specialist Nurse help to address your needs in a way that your healthcare professionals were unable to do?		Total
		Yes	No	
Gender of caller	Male	184	45	229
	Female	33	3	36
Total		217	48	265

Source: Helpline Survey

**Figure 16: Status as caller \* Did your contact with a Specialist Nurse help to address your needs in a way that your healthcare professionals were unable to do?**

		Did your contact with a Specialist Nurse help to address your needs in a way that your healthcare professionals were unable to do?		Total
		Yes	No	
Status as caller	Diagnosed with prostate cancer	112	27	139
	Concerned about prostate cancer	49	10	59
	A partner of a person diagnosed with prostate cancer	19	2	21
	A partner of a person concerned about prostate cancer	3	1	4
	Friend or family of a person diagnosed with prostate cancer	16	1	17
	Friend or family of a person concerned about prostate cancer	2	0	2
	Health professional	1	1	2
	Other	14	5	19
Total		216	47	263

Source: Helpline Survey

**Figure 17: Age or caller \* Did your contact with a Specialist Nurse help to address your needs in a way that your healthcare professionals were unable to do?**

		Did your contact with a Specialist Nurse help to address your needs in a way that your healthcare professionals were unable to do?		Total
		Yes	No	
Age or caller	30 or younger	3	0	3
	31-40	6	0	6
	41-50	10	3	13
	51-60	48	13	61
	61-70	88	19	107
	71-80	53	11	64
	81 or over	15	1	16
Total		223	47	270

Source: Helpline Survey

**Figure 18: Gender of caller \* Did your contact with a Specialist Nurse help to address your needs in a way that your healthcare professionals were unable to do?**

		Did your contact with a Specialist Nurse help to address your needs in a way that your healthcare professionals were unable to do?		Total
		Yes	No	
Gender of caller	Male	184	45	229
	Female	33	3	36
Total		217	48	265

Source: Helpline Survey

**Figure 19: Which would you say was your most important reason for contacting us? \* Did your contact with a Specialist Nurse help to address your needs in a way that your healthcare professionals were unable to do?**

		Did your contact with a Specialist Nurse help to address your needs in a way that your healthcare professionals were unable to do?		Total
		Yes	No	
Which would you say was your most important reason for contacting us?	Medical or factual information	71	19	90
	Guidance about my options	37	8	45
	Practical support or suggestions	22	5	27
	Help with fears and anxieties	34	4	38
	A better understanding of my condition	33	7	40
	Other	3	2	5
	7	0	1	1

*Figure 20: Was the conversation useful for you? \* Which would you say was your most important reason for contacting us? Crosstabulation*

			Which would you say was your most important reason for contacting us?							Total
			Medical or factual information	Guidance about my options	Practical support or suggestions	Help with fears and anxieties	A better understanding of my condition	Other	n/a	
Was the conversation useful for you?	Very	Count	98	39	27	38	43	3	2	250
		% within Was the conversation useful for you?	39.2%	15.6%	10.8%	15.2%	17.2%	1.2%	.8%	100.0%
		% most important reason	94.2%	79.6%	93.1%	82.6%	97.7%	50.0%	100.0%	89.3%
	Quite	Count	6	9	2	7	1	3	0	28
		% within Was the conversation useful for you?	21.4%	32.1%	7.1%	25.0%	3.6%	10.7%	0.0%	100.0%
		% most important reason	5.8%	18.4%	6.9%	15.2%	2.3%	50.0%	0.0%	10.0%
	Not at all	Count	0	1	0	1	0	0	0	2
		% within Was the conversation useful for you?	0.0%	50.0%	0.0%	50.0%	0.0%	0.0%	0.0%	100.0%
		% most important reason	0.0%	2.0%	0.0%	2.2%	0.0%	0.0%	0.0%	.7%
Total		Count	104	49	29	46	44	6	2	280
		% within Was the conversation useful for you?	37.1%	17.5%	10.4%	16.4%	15.7%	2.1%	.7%	100.0%
		% most important reason	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

Source: Helpline Survey



Figure 21: Was the conversation useful for you? \* Status as caller Crosstabulation

			Status as caller								Total
			Diagnosed with prostate cancer	Concerned about prostate cancer	A partner of a person diagnosed with prostate cancer	A partner of a person concerned about prostate cancer	Friend or family of a person diagnosed with prostate cancer	Friend or family of a person concerned about prostate cancer	Health professional	Other	
Was the conversation useful for you?	Very	Count	131	62	20	5	20	2	2	18	260
		% Was conversation useful?	50.4%	23.8%	7.7%	1.9%	7.7%	.8%	.8%	6.9%	100.0%
		% within Status as caller	87.3%	91.2%	95.2%	100.0%	100.0%	100.0%	100.0%	85.7%	90.0%
	Quite	Count	17	6	1	0	0	0	0	3	27
		% Was conversation useful?	63.0%	22.2%	3.7%	0.0%	0.0%	0.0%	0.0%	11.1%	100.0%
		% within Status as caller	11.3%	8.8%	4.8%	0.0%	0.0%	0.0%	0.0%	14.3%	9.3%
	Not at all	Count	2	0	0	0	0	0	0	0	2
		% Was conversation useful?	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.0%
		% within Status as caller	1.3%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	.7%
Total		Count	150	68	21	5	20	2	2	21	289
		% Was conversation useful?	51.9%	23.5%	7.3%	1.7%	6.9%	.7%	.7%	7.3%	100.0%
		% within Status as caller	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

Source: Helpline Survey

*Figure 22: Was the conversation useful for you? \* Gender of caller Crosstabulation*

			Gender of caller		Total
			Male	Female	
Was the conversation useful for you?	Very	Count	227	39	266
		% within Was the conversation useful for you?	85.3%	14.7%	100.0%
		% within Gender of caller	88.0%	97.5%	89.3%
	Quite	Count	29	1	30
		% within Was the conversation useful for you?	96.7%	3.3%	100.0%
		% within Gender of caller	11.2%	2.5%	10.1%
	Not at all	Count	2	0	2
		% within Was the conversation useful for you?	100.0%	0.0%	100.0%
		% within Gender of caller	.8%	0.0%	.7%
Total		Count	258	40	298
		% within Was the conversation useful for you?	86.6%	13.4%	100.0%
		% within Gender of caller	100.0%	100.0%	100.0%

Source: Helpline Survey

*Figure 23: How well did well did you understand the topics the nurse explained you? \* Age or caller Crosstabulation*

			Age or caller							Total
			30 or younger	31-40	41-50	51-60	61-70	71-80	81 or over	
How well did well did you understand the topics the nurse explained you?	Very	Count	3	6	15	60	107	60	17	268
		% within nurse understand	1.1%	2.2%	5.6%	22.4%	39.9%	22.4%	6.3%	100.0 %
		% within Age or caller	100.0 %	100.0%	88.2%	93.8%	89.2%	81.1%	85.0%	88.2%
	Quite	Count	0	0	2	4	12	14	3	35
		% within nurse understand	0.0%	0.0%	5.7%	11.4%	34.3%	40.0%	8.6%	100.0 %
		% within Age or caller	0.0%	0.0%	11.8%	6.3%	10.0%	18.9%	15.0%	11.5%
Total		Count	3	6	17	64	120	74	20	304
		% within nurse understand	1.0%	2.0%	5.6%	21.1%	39.5%	24.3%	6.6%	100.0 %
		% within Age or caller	100.0 %	100.0%	100.0 %	100.0 %	100.0 %	100.0 %	100.0 %	100.0 %

Source: Helpline Survey

## Appendix B – Data analysis - Information services

This section contains supporting data for chapter 3 and appears in the order in which it is referenced in the main body of the report.

**Figure 1: All Publications**

<b>Publications</b>	<b>2011-12</b>	<b>2012-13</b>	<b>% change</b>
No. of Leaflets	353,315	415,353	18%
No. of Orders	5,709	6,836	20%

Source: 11-12 All Publications; 12-13 All Publications

**Figure 2: Tool Kits**

<b>No. of Leaflets</b>	<b>2011-12</b>	<b>2012-13</b>	<b>% change</b>
Standard Tool Kit	2683	2239	-17%
Toolkit folder	0	314	-
Advanced Toolkit	115	128	11%
Health Professional Toolkit	298	454	52%
<b>Total</b>	<b>3096</b>	<b>3135</b>	<b>1%</b>

Source: 11-12 All Publications; 12-13 All Publications

**Figure 3: Most distributed publications (2012-13)**

<b>Publication</b>	<b>Total Leaflets</b>
Z Card	104,627
Know Your Prostate	30,696
Diet and Risk Leaflet	21,967
Diagnosis Booklet	19,615
Living with Hormone Therapy	19,311
African Caribbean Leaflet	16,188
PSA Booklet	14,428
Living with and after prostate cancer	13,776

Source: Publications service 12-13

Figure 4: Order by source

Order type	Action Type		Total
	HPL - Literature Request	LIT - Literature Request	
E-mail		435	435
Email Callback	1		1
Evening Call	15		15
Internet		2860	2860
LC	1756	1119	2875
Letter		25	25
Not Recorded		146	146
Order Form		64	64
Staff Order		7	7
Unknown	18	130	148
VM Callback		41	41
VM/Call Back	8	312	320
Total	1798	5139	6937

Source: Publications service 12-13

## Appendix C – Data analysis – Website

This section contains supporting data for chapter 3 and appears in the order in which it is referenced in the main body of the report.

**Figure 1: Users by City**

City	Visits	% New Visits	New Visits	Bounce Rate	Pages / Visit	Avg. Visit Duration	3 minutes or more on site (Goal 1 Conversion Rate)	3 minutes or more on site (Goal 1 Completions)
London	73,504	74.97%	55,105	44.98%	2.92	00:02:59	23.25%	17,089
(not set)	9,528	81.77%	7,791	52.76%	2.57	00:02:45	20.91%	1,992
Birmingham	7,594	76.11%	5,780	42.45%	3.12	00:03:19	25.88%	1,965
Manchester	7,051	76.39%	5,386	42.04%	3.16	00:03:12	25.10%	1,770
Leeds	6,336	75.68%	4,795	41.67%	3.26	00:03:09	25.35%	1,606
Edinburgh	5,912	75.29%	4,451	37.92%	3.45	00:03:34	27.54%	1,628
Glasgow	5,676	76.43%	4,338	38.74%	3.22	00:03:11	25.78%	1,463
Sheffield	5,551	74.92%	4,159	40.71%	3.35	00:03:23	26.55%	1,474
Liverpool	4,904	75.94%	3,724	42.27%	3.21	00:03:12	25.92%	1,271
Norwich	4,659	74.63%	3,477	38.31%	3.44	00:03:30	28.12%	1,310
Total	351,473	76.58%	269,164	43.83%	3.04	00:03:08	24.55%	86,299

Source: Google analytics, All Domains - Information pages, Location, 20130101-20130930

**Figure 2: New vs returning**

Visitor Type	Visits	% New Visits	New Visits	Bounce Rate	Pages / Visit	Avg. Visit Duration	3 minutes or more on site (Goal 1 Conversion Rate)
New Visitor	269,164	100.00%	269,164	43.43%	2.99	00:02:51	24.00%
Returning Visitor	82,309	0.00%	0	45.14%	3.21	00:04:04	26.37%
	351,473	76.58%	269,164	43.83%	3.04	00:03:08	24.55%

Source: Google analytics, All Domains - Information pages, New vs Returning, 20130101-20130930

**Figure 3: Technology**

Device Category	Visits	% New Visits	New Visits	Bounce Rate	Pages / Visit	Avg. Visit Duration	3 minutes or more on site (Goal 1 Conversion Rate)	3 minutes or more on site (Goal 1 Completions)
desktop	234,303	75.89%	177,813	40.15%	3.22	00:03:21	26.18%	61,335
mobile	65,128	84.02%	54,718	57.77%	2.16	00:01:53	16.57%	10,791
tablet	52,042	72.12%	37,532	40.95%	3.37	00:03:22	27.33%	14,224
	351,473	76.84%	270,063	43.53%	3.04	00:03:05	24.57%	86,350

Source: Google analytics, All Domains - Information pages, Overview, 20130101-20130930

## Appendix D – Data analysis - Emails

This section contains supporting data for chapter 3 and appears in the order in which it is referenced in the main body of the report.

*Figure 1: Total emails*

	Total	Total callbacks	Total emails per presenting issues
2011-2012	312	69	381
2012-2013	527	134	661

Source: Email monthly stats Apr 12 - March 13; Email monthly stats Apr 11 - Mar 2012

## Appendix E – Service user typology

### Typology 1: Active information seeker

All quotes are from service user interviews (including follow up interviews). Unless otherwise specified, the quotes are from diagnosed men.

#### Description of the type (including demographic information)

Common, high-level characteristics of an active information seeker often include:

- Mixed levels of health knowledge
- Well educated; possibly a professional/managerial background
- Web savvy
- Accustomed to seeking health information
- Likely to go beyond medical professionals for health information
- May have a partner or family member supporting them

“All of the publications that I got were very helpful...there is a balance between detail and the general picture. Where I wanted details, I went to the website”.

“[Prostate Cancer UK] Helped to broach conversations with my wife – she read all [of the information].”

#### What are their needs?

Active information seekers are keen to gain a **full understanding** of their condition and in particular their **treatment options**. They may be seeking information to gain **reassurance** about their condition and/or to be able to engage with health professionals.

“[Prostate Cancer UK] helped put my mind at rest: not something to panic about, options available.”

“In early stages I spoke to one of the volunteers...who told me his experiences. This was helpful... his treatment was similar to what I was going to go through – told me how he felt on hormone treatment, about radiotherapy.”

A concerned user said “I wanted to discuss symptoms, get a medical opinion, bounce the symptoms with someone who understood prostate cancer – to see if my symptoms gave cause for concern.”

#### What services do they currently get from Prostate Cancer UK?

This group uses a range of services from Prostate Cancer UK (the website, helpline, Tool Kit, and Online Community) and will also consult their **health professionals**, and possibly other services as well.

“I do occasionally look up the website to see if there is anything new there. Not in a structured way, just randomly.”



“Initially, when I was dealing with the issues I thought it [the Online Community] was a really great help. As soon as I raised any queries there I got 5 or 6 responses.”

“Together with six monthly checks with the oncologist, I’ve managed to piece things together through using the literature [Prostate Cancer UK information].”

### What is their general health information seeking behaviour?

Active information seekers:

- **Proactively seek** health information
- This user is not necessarily diagnosed; they may be seeking information in response to a publicity campaign. If not diagnosed, they use the information to educate themselves about the condition and their level of risk, and make decisions about medical help
- If diagnosed, they use the information to enhance their knowledge (about the condition and treatment options); to clarify information from health professionals; and to gain reassurance
- They may read beyond the specifics of their own situation to understand the condition more widely
- Are more likely to visit the doctor when they are concerned or if they exhibit symptoms
- Go beyond medical professionals – would use helpline, visit charity websites etc.

“When I have needed more info, I have been able to get it from the sources, GP, oncologist, the information I have received from Prostate Cancer UK...I could phone the Macmillan nurse, but I haven’t had the need to do that.”

“Generally speaking, I was more than satisfied with the information that I got, but when you are looking for information you tend to look around to get a different perspective on things.”

“In the main I called the helpline to get more information...When I used it [the helpline] on the last occasion, I felt they were keen that I get all of the information that I needed, which was good.”

### What do they think of the services they get from Prostate Cancer UK?

Active information seekers are generally **very satisfied** with Prostate Cancer UK’s services. Feedback suggests they appreciate the level of detail offered.

“[The Tool Kit gives a] more rounded picture. At the hospital, doctors – they’re telling me things, but it’s down to you to find out about these things. I was able to do that with the Tool Kit.”

“I was very impressed by the information I received – I have nothing but praise.”

### What else can Prostate Cancer UK provide to support this type of user?

In general these users are likely to be very satisfied with the services they have received from Prostate Cancer UK. However, they may be less aware that the charity can continue to

**offer support beyond treatment.** Post-treatment support is an area that could benefit this group.

“Hopefully I’ve been cured – but until someone says you’re in total remission [you don’t know]... that’s the only thing in the future”

“What would be helpful to me, may be asking for the moon, to be able to phone Prostate Cancer UK one year down the line...to ask is there anything you, Prostate Cancer UK, can offer.”

“A year on, is there any targeted publication?”

#### **What else could Prostate Cancer UK do to engage and communicate this type?**

Given this group’s willingness to engage with Prostate Cancer UK’s services, ensuring that **potential users are aware** of the charity is crucial.

Prostate Cancer UK should continue to promote the charity, including on **television and radio**.

“...more awareness in media, TV adverts, books, campaign to make people aware has got a lot better - Bill Bailey ads. There seems to be a greater awareness. I had no inkling you could have a PSA test on demand from 50 from your doctor – I would have had that because my father died at 60 from prostate cancer.”

Although this group may be seeking reasonably advanced information, the focus groups revealed that also more educated people appreciate having the **Easy Read material as one option**.

## Typology 2: Active information user

All quotes are from service user interviews (including follow up interviews). Unless otherwise specified, the quotes are from diagnosed men.

### Description of the type (including demographic information)

Common, high-level characteristics of an active user often include:

- High levels of health knowledge
- Well educated; possibly a professional/managerial background
- Web savvy
- Accustomed to seeking health information
- Likely to go beyond medical professionals for health information
- May have a partner or family member supporting them
- **Go beyond active information seekers** and use the information to help **make a decision**

“The [Prostate Cancer UK information] firmed up my views. Having had the details – on for example potential side effects/radical prostatectomy - it has given me the information to make a decision.”

“I use the internet a lot. Seeking information about prostate cancer, it came up in the search listings.”

“It seemed a respected charity (trustworthy) – partly because it is endorsed by health professionals and also because as a brand it looks very professional.”

### What are their needs?

Active users are keen to gain a full understanding of their condition and in particular their treatment options. They may not get enough information from their health professionals.

They go **beyond information seekers** in that they want to play a part in their **treatment decision**.

“I was looking for general information. I had been diagnosed but was totally ignorant to the situation: ‘Looking for answers’”.

“[I’ve contacted Prostate Cancer UK] Quite a few times, whenever I have had any queries or needed any information. I prefer to talk to somebody - I mainly use the helpline.”

“I had one or two problems with the hospital, with the information I got from Prostate Cancer UK I was able to make more decisions.”

### What services do they currently get from Prostate Cancer UK?

This group uses a range of services from Prostate Cancer UK and will also consult their health professionals, and possibly other services.

“[I went] from the brochure to the website and then ordering Tool Kit. I also looked at testimonial videos.”

“Firstly through the website...used the helpline”. After speaking on the helpline, he was sent all of the information leaflets.

“I also used a local support group. The contact with other people was very helpful.”

### What is their general health information seeking behaviour?

Active information users:

- **Proactively seek** health information
- They may read beyond the specifics of their own situation to understand the condition more widely
- Are more likely to visit the doctor when are concerned or if they exhibit symptoms
- Go beyond medical professionals – would use helpline, visit charity websites etc
- Use the information to **ask better questions of health professionals**; ask better-informed questions; and **challenge / change treatment decisions** as a result.
- Are generally highly satisfied with Prostate Cancer UK, but may still use other sources of information.

“If it was a medical thing, I would go to my GP. If it was something I wanted to find out, I would call the Prostate Cancer UK site. I might just do a Google search by topic. Invariably that takes you to the NHS site, Prostate Cancer UK, Cancer Research UK or other charities.”

“I resisted their recommendation to have my prostate removed because it is progressing slowly. You’re able to ask questions not just listen.”

“Obviously looked around and had information from other websites, but [Prostate Cancer UK] is what I found most easy to understand”.

### What do they think of the services they get from Prostate Cancer?

Active information users are generally **very satisfied** with Prostate Cancer UK’s services. In particular, they appreciate the level of **detail** of the information and the fact that it is **easy to understand**.

However, some may be relatively **critical of health information** in general and there is some specialist information they may not feel they can get from Prostate Cancer UK.

“What it did for me was very carefully described each point. From the Tool Kit I could read through the pros and cons of each treatment – the consequences, side effects. It very carefully explained what I would go through.”

“I think it’s given me an in depth understanding of what I’ve got. Probably more so than what the health professionals were able to tell me.”

“Found a lot of the information to be at a basic level [has a strong medical background]. It’s aimed at a layman level”. (After determining that, he went back to the Macmillan information because it gives him more of the detailed, medically-oriented information.)

#### What else can Prostate Cancer UK provide to support this type of user?

They may want more information to help them decide their treatment (see the above quotes for examples). This group may want relatively **advanced information**, for instance they may be interested in recent research into prostate cancer. Prostate Cancer UK can help this group by providing links to any important developments and also by providing data, where possible, which can help support decisions.

On the other hand, it may prove beneficial to encourage active information users to have a **discussion with another person**, either through the helpline or another route. This might help to make sense of the information they collect.

“One of the things that comes out is how imprecise the knowledge of prostate cancer is [general knowledge, not specifically Prostate Cancer UK]...A lot more research is needed – much more data is needed.”

“One of the deciding factors in not having surgery is the side effects. The Tool Kit is very frank, and is honest about the numbers.”

“I’m quite often on websites. Where my health is concerned, I find you find 5,000 things are wrong with you, so I wanted to speak to a human first.”

Similar to active information seekers, this group may be most aware that Prostate Cancer UK can help with a treatment decision and with side effects, but **may not** view the charity as a source of **longer term support** post-treatment.

#### What else could Prostate Cancer UK do to engage and communicate this type?

Given this group’s willingness to engage with Prostate Cancer UK’s services, ensuring that potential users are aware of the charity is important.

This group is more likely to engage in an internet search than other groups. Ensuring that the **website appears prominently** in answer to prostate cancer related web searches is important.

“I googled what ‘PSA should I expect after removed’, Prostate Cancer UK didn’t come up, but other charities did. Would have used it had it come up.”

Although this group may be seeking more in depth information, the focus groups revealed that also more educated people appreciate having the **Easy Read material as one option**.

Active information users go further in terms of the information they want. They may appreciate more information on the **detail of treatments** and the options in the local area.

“Also looking at DVDs, films on YouTube on which procedure I would prefer to go ahead with.”

### Typology 3: Conduit user

All quotes are from service user interviews (including follow up interviews). Unless otherwise specified, the quotes are from family/partners/friends of men diagnosed with prostate cancer.

#### Description of the type (including demographic information)

Common, high-level characteristics of a conduit user often include:

- Partner/ family member/ friend of a man diagnosed with/concerned about prostate cancer
- Seeking information to support a man who may be elderly or is unlikely to access health information
- May also be supporting a man who has other barriers to accessing information (disability)
- Uses the information needs to fill often basic information needs
- May help the man to seek a medical opinion, ask the right questions, or to ensure that the treatment option is the right one
- Also benefits personally from the information in terms of support and reassurance.

“Just wanted to get info for father – he’s 87, slightly cognitive impaired – finds computer use difficult now. I could get information and order booklets and give him relevant ones he could digest at his own pace, tell him things he could expect as treatment progressed.”

“Initially trying to understand concepts and ideas such as what a PSA test mean - general information.”

“He [the husband] doesn’t ask enough questions, I like to push to see he gets the right treatment.”

“First time I phoned was the evening he was diagnosed. It’s awful, you go straight to the internet. I have a certain amount of experience with cancer, so I wanted to see if my concerns were...what do I need to brace myself for?”

#### What are their needs?

Conduit users are keen to gain an understanding of their partner/family member’s condition. By getting this information, conduit users may be hoping that the person with cancer can take more control over their treatment. They may also be looking for information to reassure themselves.

Some conduit users will be looking for information to support a man who is not health information literate and would therefore benefit from simple information.

“Information – Dad had recently been diagnosed, trying to find out as much as we could.”

“By him having more information, it means he has more control and independence over his treatment and his care.”

“Little info coming from medical people; and questions I wanted to know, but I didn’t want to ask in front of my partner. The day we found out I went and looked on the site [Prostate Cancer UK], FAQs, I wanted to find out more info and be more reassured.”

### What services do they currently get from Prostate Cancer UK?

This group uses a range of services from Prostate Cancer UK and will also consult their health professionals. They benefit from talking to others, either by phone or through the Online Community.

“Spoke to helpline once. Then got brochures, read and sent to him....We went on the website a couple of times to check side effects.”

“Actually speaking to someone is so valuable. Can get reams of information from Mac [Macmillan], website – but having someone help you make sense of that and talk to you – invaluable.”

“[The forum is] very helpful. It is like community, a band of brothers...When you are feeling down, you are frightened, you can find out from other people. You get reassurance from them.”

### What is their general health information seeking behaviour?

Conduit users:

- Seek health information on behalf of partner/family member who may be unlikely to seek information themselves
- May also be seeking information for a man who has other barriers to accessing information (e.g. disability)
- May be seeking basic information to understand the condition better
- May also be in need of reassurance themselves
- Are generally highly satisfied with Prostate Cancer UK.

“Googled prostate cancer after my father was diagnosed...browsed through various sites, found this by far the best.”

“I saw the advert and told him I’m going to go online. I got the leaflet, and passed it on. We had a discussion about it. Then he spoke to the doctor. He was re-assured after reading the leaflet.” (Partner of concerned man)

“You can scare yourself on the internet. With the Tool Kit you know it is reliable and correct.”

“It was really reassuring that it [the helpline] was manned by specialist nurses.”

### What do they think of the services they get from Prostate Cancer?

Conduit information seekers are generally **very satisfied** with Prostate Cancer UK’s services. They appreciate the **detail of the information**, particularly when it allows them to ensure the man gets the best treatment possible.

This group also benefits from the **support** they have been able to receive through the service and they value the **compassionate** tone of the staff and the wider support available through the Online Community.

“[The Online Community] is immensely helpful...My husband opted for robotic surgery...he got ideas from people’s experience of it.”

“Probably the helpline [was most useful] – I was really emotionally upset, she was so helpful and so reassuring. All of it has been useful but that one-to-one contact and being able to ask questions and talk about an individual case was incredibly useful.”

“Absolutely brilliant [Prostate Cancer UK]. We weren’t sure if my husband needed to have a PSA test before going back to see consultant. We checked and the Tool Kit told us the answer. We always check the Tool Kit and the answer’s there. It’s the way the Tool Kit is laid out in little sections, makes it easy to find out what you want very quickly.”

“We know what questions to ask, check the helpline to know whether what they [health professionals] are providing is state of art. Want to know he is getting first rate treatment. That empowers me. Knowing what is good and knowing what should work.”

#### What else can Prostate Cancer UK provide to support this type of user?

In general these users are likely to be very satisfied with the services they have received from Prostate Cancer UK.

However, they may want more support **for carers specifically**. Some conduit users have identified this support as existing already through Prostate Cancer UK, but it was less obvious to others. **Prostate Cancer UK could consider having a dedicated section of the website for partners/family.**

“Only thing I haven’t looked at, so don’t know [if it is available], is whether there’s a forum for family members – difficulties in supporting someone through it – there are times when I feel fraught or upset. If there isn’t one it would be worth having.”

“If I look on the website, prostate cancer affects those close to them...There’s not so much around for people who are supporting people with cancer. On the forum, you get people talking about the individual with cancer – not so much support for people who support them. Not much around anywhere.”

These users would also like more information on **side effects**: in particular some of the **worst cases**, to help them understand how it will affect the lifestyle of the man affected by prostate cancer. Also, conduit users could benefit from more information down the line (post treatment), to help them to **continue to support those with cancer**.

“There could be more literature, for example on recurring/secondary cancer. More information later on [her father has had it five years].”

“More information on incontinence – exactly how bad things could be. They [Prostate Cancer UK information] went for the best options, the easy scenario – explain the bad scenarios too, examples of worst incontinence. Those that are opting for radiotherapy still don’t realise what could happen.”



“In retrospect, we would like more info on long term side effects.”

**What else could Prostate Cancer UK do to engage and communicate this type?**

Conduit users may want to offer ongoing support to others. **Continuing to engage these users**, by letting them know ways they can help and giving them the support to do so, could be an effective way to raise awareness.

“Still will be going on the forum – we can help people embarking on the journey. [For example, there was] a young man on it last week who is scared of the operation, speed of recovery – we were able to reassure him. We would like to be able to do that because people did it for us.”

“I’m very passionate about men going to get checked. [Husband’s name], at first, didn’t want to talk about it, but now he is worse than me – have you had your prostate checked?”

“Awareness raising. I know a lot of men with prostate cancer. No way I could have discussed it with some of the men – not easy for a woman to approach a man...It’s got to come from medical sources. Gents lavatories, urology clinics that kind of thing.”

## Typology 4: Older user

All quotes are from service user interviews (including follow up interviews). Unless otherwise specified, the quotes are from diagnosed men.

### Description of the type (including demographic information)

Common, high-level characteristics of an older user often include:

- Older man (over 70)
- Seeking information to fill often basic information needs
- Often takes a 'matter of fact' approach and wants practical advice
- Mixed use of internet/helplines: some are internet savvy, confident about health information; others will not be.

"It's there, has to be dealt with"

"At the hospital, doctors – they're telling me things, but it's down to you to find out about these things. I was able to do that with the Tool Kit."

"In the first stages, you are in a bit of a shock. Very useful to have something which explains things."

### What are their needs?

Older users are keen to gain an **understanding** of their condition. They often want **practical support** in terms of treatment options and side effects. They also want **advice on lifestyle changes**, such as diet and exercise.

"Some people panic and don't want baffling information."

"Got the information from my consultant, told me I was diagnosed. He told me some results and some of the possible treatments. Not much time with the consultant. They [Prostate Cancer UK] helped clear the fog."

"Specifically researched information to help decide on appropriate treatment. I was offered more than one course of treatment and wanted information to decide."

"Main thing I was worried about at the start was diet, getting the diet right for radiotherapy – we started doing menus from the info in Tool Kit. Diet, exercise and prostate cancer section tells you how to improve health, help with side effects."

### What services do they currently get from Prostate Cancer UK?

This group uses a range of services from Prostate Cancer UK and will also consult their health professionals.

They may want physical information rather than reading on the website. We know from our research with older men that there is a mixed level of use of the internet for health information.

Some older men may be reluctant to use a helpline or other support (e.g. the Online Community or attend other support groups).

“[Tool Kit] it’s easier to read than the website – you read a bit, then think a bit then do something else – you can pick it up easier on paper than screen. I printed some stuff off from website”.

“On the website it says if you want to ask a question you can insert it there – did that – and then got called by the helpline.”

### What is their general health information seeking behaviour?

Older users may be seeking basic information. As a group they have different preferred source of information: some use the internet, while others rely on more traditional sources of information, especially health professionals.

As a group, older users are more likely than others to also rely on conduits for information. They may be getting some information themselves, while also getting help from their wife, child or friend.

They are generally highly satisfied with Prostate Cancer UK.

“I searched the website. [Prostate Cancer UK was] one of many web searches.”

“Some leaflets at the hospital, about what it [prostate cancer] was.”

“Aware of it through both TV advertising and press advertising.”

“I was told about the website and the services by a friend of mine who had been diagnosed – the friend was very positive about the service.”

“I would talk to the wife about it. My daughter, she sent away for different things for me.”

### What do they think of the services they get from Prostate Cancer UK?

Older information seekers are generally satisfied with Prostate Cancer UK. They appreciate that the information is something that can be useful with family as well as themselves and it helps when dealing with health professionals.

“I was very impressed with everything I got, very thorough.”

“Reassuring - that you don’t get time to talk to your doctor about.”

“Helped me immensely, put my mind at rest – with regard to the side effects especially. Helped explain the treatments, alternatives to the one I was getting.”

“Wife and daughter were able to read as well, it was good for the whole family, not just myself.”

### What else can Prostate Cancer UK provide to support this type of user?

While appreciating practical support around diet and exercise, this group may also be less able to put this into practice and may find it **difficult to act on the advice** they are receiving.

This group may require further support to assist in that, for example through support groups.

“It’s fatigue mainly at the moment. That doesn’t give you any enthusiasm to do anything.”

“Helped tremendously, can’t put everything into practice that’s the problem.”

“Then the sexual side, which you lost, which can make you very irritable, a psychological thing.”

#### What else could Prostate Cancer UK do to engage and communicate this type?

This kind of user may rely on receiving information from **traditional sources** (i.e. not the internet). They may also be heavily reliant on their health professionals for information - we know this in particular from the focus groups carried out for this research – and also families e.g. wives and children.

Prostate Cancer UK could do more to **encourage health professionals** to raise the issue of prostate cancer with men, in particular by ensuring they have information they can confidently hand out. The **Easy Read material** was well received by older users in the focus groups.

“I was tending to look through it [Tool Kit] and reading too much. I wanted to be informed, sometimes you can delve into too much and know a little too much.”

## Typology 5: Unaware non-user

All quotes are from focus group participants.

### Description of the type (including demographic information)

The unaware non-user type covers a very wide range of people. Common, high-level characteristics often include:

- Low levels of health knowledge
- Low levels of literacy or other barriers to accessing information e.g. poor English skills
- Unlikely to seek health information proactively – seeks health information only when very concerned
- Does not go beyond medical professionals for health information i.e. they don't use helplines or visit websites etc, despite unsatisfactory experiences with health professionals
- No partner or family member who finds information on his behalf / a partner or family member who are equally unlikely to seek information

We know from wider research that men who are less likely to seek health information are often poorer and have lower levels of education. They may have 'old fashioned' views on health e.g. that illness is weakness and men should just 'get on with things.'

Although Tom is on medication for his enlarged prostate, which keeps him "up and down in the night going to toilet," he has not sought any advice other than from his GP.

Tom would trust anything he got from the GP. Sometimes the surgery sent out leaflets about health. He also trusted health information on TV which was "there for a reason – to guide you".

Ian, a BME person, revealed that he was recovering from prostate cancer. Despite this, he had not used the services of Prostate Cancer UK. He felt strongly that word of mouth was the best way to learn about health.

### What are their needs?

Linked to the above, non-users have complex and over-lapping needs, including **barriers to accessing information** that could be:

- personal e.g. preferring to 'not know' about health problems;
- socio-economic e.g. low levels of literacy, little or no access to the internet;
- or cultural.

Ian, the BME man who had prostate cancer, admits that a lot of his peer group "don't like the idea of going to the doctor for the check, but I have been and I tell other people to go."

Bob, who had prostate cancer, was happy with the doctor as a source of information. Asked whether he'd use a helpline, he said he would "ask a nurse and if she doesn't know she can phone the helpline."

Tom, who has an enlarged prostate, had never called a telephone helpline about his health and wasn't keen on the idea of doing this. "If I wanted to know anything, the surgery would be the first place".

Tom revealed that he often goes online, for banking and emails, but not for health information.

The focus group and site visit research also highlighted the existence of **socially isolated groups** of people facing **extreme barriers** to accessing information and services, such as **D/deaf people, Gypsies and Travellers, homeless people** and people with **learning disabilities**.

#### What services do they currently get from Prostate Cancer UK?

This group receive no services from Prostate Cancer UK and the vast majority are not aware of the charity.

Mary stated "my husband died of prostate cancer. If I had known about Prostate Cancer UK and the helpline and all the support they could have given me...well."

#### What is their general health information seeking behaviour?

Unaware non-users:

- Do not proactively seek health information
- Only visit a doctor when they are very concerned and / or serious symptoms cannot be ignored
- Do not go beyond medical professionals – doesn't use helpline, visit charity websites etc
- Are more likely to describe unsatisfactory experiences when dealing with a health professional.

Bob, a prostate cancer patient, does not search for information pro-actively, instead he thinks the "GP should get you in [ie to the doctor] without you having to go to him".

Bob received Macmillan information. However, he didn't find it himself, instead he thinks the "GP must have told them".

Tom, who has an enlarged prostate, revealed that he had not gone beyond his doctor for information about his enlarged prostate, "I've never actually gone into detail, only what the doctors said".

#### What do they think of the services they get from Prostate Cancer UK?

By definition, non-users have not experienced using Prostate Cancer UK's services. Based on feedback at focus groups, where non-users were shown examples of information resources, this type:

- Appreciate simple and accessible information e.g. Easy-Read and other highly visual materials

Presented with the Easy Read material, Tom, who has an enlarged prostate, said he found it "very easy to follow", "straightforward", and "enough to make you understand without

going into medical detail". Asked about the images, he said "for someone who's got the problems, yes – you aren't going to learn if there's no diagrams."

Tom also thought the 'Know your Prostate' booklet was "very good". He contrasted it with the Easy Read material – "you have to settle down and have a read". Asked what was good about it, he said it had "more information".

Despite seeing his doctor on a number of occasions, Tom said it was the first time he had been given any information relating to his condition and symptoms. He said "It's nice to see something in print that actually affects you".

Ian, the Black British man, was shown the 'What do you know about your prostate? Information for African and African Caribbean men' booklet, along with the 'Z card' and 'A Guide for Newly Diagnosed Men'. He stated, "The colour is doom and gloom. Cancer is a negative thing anyway, even though we can live with it now". Regarding the content, Ian said "we can all read, but when we calculate this information in our heads we lose it."

#### What else can Prostate Cancer UK provide to support this type of user?

Unaware non-users are only likely to seek medical advice when they are very concerned and / or serious symptoms cannot be ignored. Prostate Cancer UK could tailor a message to this group that **it is "okay" for a man to seek medical advice** at an earlier stage.

Produce more information in **simple and easily understandable formats**.

Tom, a man with an enlarged prostate, was asked to imagine that he was talking to the head of Prostate Cancer UK and had to advise him about ways to improve access to information for men like himself. He said that they had already done that, by developing the Easy Read material. "I'm not saying to do away with the detailed leaflets. Both could be useful for me. I would read both".

Tom felt that a lot of the Prostate Cancer UK material shown to him does affect him and agreed that the information made him feel less alone.

Ian, a Black British man, said that information that used jargon was not good because not everyone could understand. Instead of jargon filled booklets, he restated the importance of community support. He said: "we can all help each other".

#### What else could Prostate Cancer UK do to engage and communicate this type?

Promote the charity's services through more **non-clinical / health-related routes**: betting shops; sports venues (building on the recent work with football clubs); working men's clubs; care homes and hospices.

Continue to promote the charity on **television and radio**, including BME and non English-speaking media.

Ian, the Black British man, felt that adverts in the newspaper had to strike a balance between being attention grabbing and scary. He suggested adverts with a subtle message that would spark people's attention and interest, for example a series of adverts asking "have you checked?" would be better than something more alarming and in your face.

Bob, a prostate cancer patient, said “I don’t like junk mail, but I don’t mind getting health information.”



## Typology 6: Health professionals

All quotes are from health professional interviews.

### Description of the type (including demographic information)

Common, high-level characteristics of a health professional often include:

- Seeking information to inform others
- Or to keep themselves up to date or other staff
- Want to know about what is available (events/services)
- But acts under time pressure
- Appreciates Prostate Cancer UK information (free, quality info)
- Have their own views on how to make the information more health professional-friendly.

“People [patients] like to be given something to take away...They might remember some of the things I’ve said, but they feel good if they get a booklet.”

“Information is excellent. It’s just getting the information out there. Health professionals are often very busy and don’t always have time to find information.”

“Good quality, looks professional, factual, all of the information. Everything is there that I would want a patient to have.”

### What are their needs?

Health professionals want information that they can give to those affected by prostate cancer to support them and further their understanding. **Simple information** can help health professionals when the education level of patients is not high. Information on possible treatments and side effects can help **patients’ decision making**.

The information can also help health professionals and aid their own understanding.

“Education levels may not be very high [patients’ knowledge of cancer]”.

“Patients tend to expect health professionals to have the answer, but it is difficult, you cannot say one treatment versus another.”

“Time in the clinic is a factor, may only have 30 minutes. So the information gives them something to take away with them to use in their own time”.

“I read all of the information from cover to cover, for me personally they are useful. For patients, we can have consultations; we are looking to educate our patients so they can make informed decisions on treatment options. Information they can dip in and out of when they need to.”

### What services do they currently get from Prostate Cancer UK?

This group distributes the physical information from Prostate Cancer UK (mainly booklets). They may also refer the **website** and occasionally the **helpline** as well. Most say they do not

refer the **Tool Kit to patients** as it has too much information, but this may be used for educating staff.

“[The Tool Kit] includes every treatment option, but not every treatment option is going to be appropriate, even from the start it might be obvious some are not. Very good for educating staff, nurses in general ward, but would tailor the information more for patients.”

“I go on the Prostate Cancer UK website, when I have specific questions e.g. new treatments, specific drugs. You can print off what it is relevant without having to print off reams and reams.”

“I also recommend the site and the helpline to newly diagnosed patients. They often have lots of questions when they have first been diagnosed so the site is a good resource...The forum is also helpful for men to hear other people’s experiences.”

### What is their general health information seeking behaviour?

Health professionals often have a **long-standing relationship** with Prostate Cancer UK and most that we spoke to had been using the information for a long time. However, they may also find the information if **reviewing their current provision**. Often, health professionals can find Prostate Cancer UK online if they are considering what other prostate cancer information to provide.

They mostly contact the charity to order information. One issue that arose is that this process can be cumbersome (for instance, the website doesn’t remember details). Some also mentioned that it was frustrating to be asked to donate each time they order information.

“It was just out there – can’t remember how I first heard of them.”

“We needed additional information from other charities...It was a case of going on online and finding what information is available and what is free. You come up in Google.”

“I saw the booklets and leaflets at a conference – thought it was really good.”

“The website is fine but could be improved. Why can’t it store my details so I don’t have to keep giving my details?...There are limits to how much you can order...for example, you can only order 20 in one go.”

A health professional interviewed during a site visit emphasised the importance of free material being made available given budget cuts to NHS budgets.

### What do they think of the services they get from Prostate Cancer UK?

Health professionals that use Prostate Cancer UK’s services are generally very satisfied. In particular, the information provided is considered of a high quality and importantly it is seen as **complementing what they say**.

Health professionals appreciate being able to give patients something to **take away** and also, importantly, **that it is free**.

One potential issue is that ultimately Prostate Cancer UK **cannot make a decision for patients**. Similarly, health professionals sometimes worry (with specific regard to the **Tool Kit**) that patients get **too much information**.

“Simple and easy to read; doesn’t contradict, in fact it complements what we say.”

“Invaluable. I can talk and go over things, but they [patients] may not understand at first. If they can go back and read information, they can then come back with questions.”

“Very useful. Brilliant that it is free, absolutely excellent. A couple of charities try to charge and we just don’t stock it.”

“The nurses on the helpline cannot decide for them either, so sometimes they feel it hasn’t moved them forward.”

#### What else can Prostate Cancer UK provide to support this type of user?

Health professionals, **frequently time pressed**, would benefit from advice on what information and services are available. **Local support groups** could help to complement the information available and provide further support to patients.

Health professionals also want the information to be suitable for **all user groups**, including where there are **potential barriers**, such as those who do not speak English as their first language.

“When treatment finishes, patients feel a bit lost...Support groups are popular. This is not necessarily for patients; carers may want support groups, even if the men affected don’t always.”

“Prostate Cancer UK has just brought a booklet out about supporting partners of prostate cancer. But this seemed to be more for female partners – in terms of the images used. The use of more images that are supportive of gay partners could be useful.”

“I don’t know how much of your information is produced in different languages, health literacy is always a problem we encounter. Especially in London Boroughs where there is a lot of ethnic diversity, English is not a lot of people’s first language.”

#### What else could Prostate Cancer UK do to engage and communicate this type?

Prostate Cancer UK should seek to raise awareness within the health professional community of their information and also the services available in different areas.

Some health professional also felt strongly that Prostate Cancer UK should develop more of a **local presence**.

“Nurses are happy to receive information, but may not have time to seek it out.”

“In future, get out into the actual clinics, work with the clinical nurse specialists to see how we actually need the material. Might change their focus on how they design it.”

“Get more people out of London – that will increase their credibility. Macmillan get a lot of donations because they have a strong local presence, for example the local benefits office is run by Macmillan.”

## Appendix F – Organisational case studies

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### Velindre Cancer Centre

#### Introduction

Velindre Cancer Centre in Cardiff is a tertiary centre which provides specialist cancer services to over 1.5 million people in South East Wales and beyond. It is one of the largest cancer centres in the UK. Each year over 5,000 new referrals and around 50,000 new outpatient appointments are seen. It employs over 640 staff with an annual budget of £49 million.

The researcher spoke to the Patient and Carer Information and Support Manager; a Clinical Nurse Specialist; a Registrar and Consultant (together); and two Clinic Co-ordinators (together).

#### Velindre's work

The majority of prostate patients are **referred** to Velindre by DGH urology surgeons and prostate multi-disciplinary teams across South East Wales for radiotherapy treatment. All patients will have already been seen for diagnosis and many will have seen a surgeon. Some will and others will not have already had scans. For example Gwent patients are mainly seen for scan results and to discuss radiotherapy treatment; and, if metastatic, to discuss clinical trials or if unsuitable for that, hormone therapy. If metastatic and just having hormone treatment, or if having surgery, the patient remains with the DGH surgeons, but gets referred to Velindre for radiotherapy or if they have relapsed post hormone treatment.

The researcher was informed that Cancer Research Wales, Tenovus (a Cardiff based cancer charity) and Macmillan all have rooms in the hospital staffed by volunteers.

The **Information Manager** is responsible for signposting carers and patients or giving them information e.g. about support groups in the local area which she reported to be the most popular query. She has expanded her role from initially providing only bespoke chemotherapy leaflets, to now bringing in groups to support patients and carers and liaising with support groups in the area. In relation to prostate cancer she is supported by a highly knowledgeable patient with metastatic prostate cancer, who comes to the weekly outpatients prostate cancer clinic waiting room to chat and answer patients' questions. As the Information Centre is situated away from the waiting area, patients need to come down the corridor to visit it, meaning that she only sees those referred by clinicians or those walking past. She mainly only gets visited by the younger prostate patients: *"I rarely get the elderly (70+) – they just sit there and wait for their appointment. It's the younger ones who want everything."*

She reported that the Clinical Nurse Specialist (CNS) interacts with patients and answers more questions than she does, having the *"in-depth chat"* with patients. She reflected that it is the CNS who *"gets to know what they [patients] need"* and refers them on e.g. to one

of the two benefits advisors, or three psychologists, on site. She stressed that only the clinicians discussed medical issues with patients e.g. issues about clinical trials.

The **Clinic Co-ordinators** are responsible for booking patients in and out of appointment. They noted that if a patient asks to speak to someone, they refer them to a nurse or doctor, not the Patient Information Manager, unless they ask for a specific piece of information in which case they would send them down to the information room. They are regularly asked questions by the patients but felt that they did not discuss issues with the patients, especially as they were working in a busy public area, other than making a quick call to the secretary or the Consultant for them.

The **CNS** has various roles including explaining diagnosis and treatment options, working through and discussing options, highlighting side effects and *“hopefully helping them come to rational decisions for themselves about the direction to go in”*. The majority of the work is following up patients e.g. monitoring PSA post-treatment, preparing people for future secondary treatments needed and running through ‘what if’ options, or discussing what lies ahead before referring people to palliative care. The CNS is also there to answer patients’ telephone queries between appointments, e.g. re anxiety about symptoms or discussing what the patient wishes to raise with a GP. As well as clinics at Velindre, the centre runs clinics in local district general hospitals (DGH) in South East Wales.

The **Consultant and Registrar** work as a team. For prostate patients they do a follow up urology treatment clinic and also see new patient referrals, as well as chemotherapy and radiotherapy clinics. They also see lung, kidney and bladder cancer patients, prostate constituting about half of the workload. The Consultant noted that 70% had localised disease and were having curative treatment, with the remaining 30% metastatic. The consultant reported the average age on diagnosis of his patients to be 70 with most of his patients aged 65-75.

The Consultant reported being very treatment oriented and having little interaction with **friends and families**. In contrast the CNS has a lot of contact with patients’ wives, reporting that most patients came with them and they usually stay in the room, which can be useful: *“sometimes you don’t always get the full story from the men – they say ‘I’m fine/ok, the wife shakes her head, which prompts you to dig deeper”*. The Clinic Co-ordinators also noted that all the prostate patients, most of whom were retired, came with their wives who seem very involved e.g. doing the appointment booking. One compared the wives to a *“little secretary”* who knows everything that is going on, comes to appointments and writes down the next appointment. The Information Manager noted that while she only got visited by the younger prostate patients, the wives of the older men did visit her.

Most interviewees felt that Velindre did not serve as many **Black and minority ethnic** (BME) patients as would be expected from the demography of the area it served. Some reflected on specific populations in South Wales which they would expect to see at the hospital but did not: these included the big Somali community in Cardiff, the BME groups in Gwent and the large African Caribbean community in Newport, especially given the higher rates of prostate cancer within the African Caribbean population group. This was seen as owing to a lack of engagement with GPs and not an issue specific to prostate cancer, but a general lack of information, engagement and education. Another interviewee reported that a local

hospice had found the same so had contacted a local community group and found the community to be caring for people at home. The Patient Information Manager is planning to ask a local BME community group to come and look round Velindre and show them the range of information available in other languages. However the Clinic Co-ordinators, whose responsibilities included liaising with the secretaries to book interpreters when needed, felt that there were small numbers of minority ethnic groups represented, citing Chinese, Indian, Somalians, Polish, Czech, Middle Eastern and Asian patients. They noted that while some needed an interpreter to be booked, some brought a son or a friend. They also liaised with the secretaries to book signers for deaf patients when needed.

### Information

The researcher observed that the **outpatients' clinic waiting area** has various information on display, mainly Macmillan booklets and leaflets, although there is also a Cancer Research Wales display, and a few Tenovus and carers' charities leaflets. The outpatients area also contains information carrier bags for new patients which contain English and Welsh language information from Velindre itself, Tenovus leaflets, two Macmillan booklets (the Cancer Guide and Help with the Cost of Cancer) and leaflets for local support groups. The new patient bags are also available in the **Patient Information Centre** which is a walk further down the corridor away from the main waiting area and consulting rooms. This is an information room with a computer and many leaflets and booklets. The Centre is dominated by a wide range of Macmillan brochures and leaflets, including two on prostate cancer. There is also a Cancer Research UK display of several leaflets, several Tenovus leaflets and some Breast Cancer Care leaflets, plus a bookcase with carer information such as local carer centre leaflets. There were some un-branded patient information packs, and some Welsh charities' leaflets on cancer and other health issues such as drugs, alcohol and mental health. Around the corner is the **Patient and Carer Information Manager's office**, in which more Macmillan leaflets are on display, Breast Cancer Care leaflets and several shelves filing other information. No Prostate Cancer UK information was on display in any of the areas observed.

The Clinic Co-ordinators reported that although the new patient information carrier bags were hanging up by the desk for patients to help themselves, they themselves did not make patients aware of them. Sometimes nurses took the bags and gave them to patients. They reported being sometimes asked for information, often about benefits, in which case they refer people to the benefits advisor. They had noticed from reading patient notes, which they prepared for appointments, that many patients had looked online at treatments in other countries, and that some brought clippings from newspapers to the clinic. They had found that a news item on a particular cancer drug would lead to people coming in or phoning asking for information.

The Patient and Carer Information and Support Manager reported that the main information she is asked for is when nurses and CNSs ask her for information on prostate support groups in the local area. She provides a display of Macmillan booklets in the Information Centre, including the early and advanced prostate cancer booklets, which go quickly, along with many Macmillan leaflets in the outpatient waiting area on a variety of topics. In addition she provides Velindre's bespoke in-house leaflets on chemotherapy, contacts, and side effects, and when needed e.g. by a patient's wife orders social services' carers' information

packs from each of the local areas in Velindre's large catchment area. In addition Velindre's website has a patient information page, which includes information on prostate support groups, which had a lot of hits. Funding has been provided which will enable the Manager to provide simple touchscreens in the outpatient department with comprehensive patient information, leaflets and support group details. It will have links to organisations such as Breast Cancer Care and Prostate Cancer UK. The Information Manager has found patients to become more active information seekers as they go through the patient journey. She cited a patient who had tried every trial and had been constantly looking for information, and another who had travelled internationally looking for information.

The Consultant saw the provision of information to patients as the responsibility of the nursing team, either at the local DGH or at Velindre, again emphasising that he had only time to focus on treatment issues such as options, risks, benefits and plans. He also highlighted that the role of the CNSs in Velindre was different to CNSs in other sites – he saw the Velindre CNSs as having a more clinical, *"treatment driven"* role than CNSs in local hospitals who would have a broader role in supporting patients and had the time to go through non-clinical support issues with them. He noted that Velindre patients were given the Macmillan booklets on prostate cancer but did not know if they found them useful or what they did with them.

The CNS reported that as Velindre patients have been referred from their local hospital, they already have had various bits of information, for example Gwent area patients have had the Macmillan leaflet from their DGH. Velindre provides its own bespoke leaflet on radiotherapy treatment and are keen to give information pre-treatment so they know the side effects. Information about treatment and diagnosis is a mix of oral information, bespoke Velindre leaflets and Macmillan leaflets. They also run radiotherapy open evenings so patients can look at the machines etc, along with chemotherapy education clinics. The CNS felt that many patients do not read the information leaflet they had been given, or say that their wife had read it. However he reported it to be very beneficial when patients had read them: *"You know the ones who do in terms of how they interact with you, they are more aware of the side effects, that helps ... it's more of a clarification process – and they may have some questions they're ready to ask you about which is very helpful."*

The CNS highlighted that those who are isolated face **barriers to accessing information and support**, having found that clinic patients have often gone for a PSA test on the suggestion of a friend – *"people who are more insular don't have that extra impetus to find and get information, or have others' experiences to work on."* The Consultant noted that men, and particularly older men, engage less with health professionals and resources. He also emphasised that in the area he served many people do not have IT or use the internet, making *"web based support for patients ... irrelevant for a good chunk of my population"*. The Information Manager had found that older patients preferred booklets while younger patients preferred online information. She felt however that the CNS would pick up in consultation any patient information needs.

None of the interviewees had accessed a **telephone helpline** for advice and only the CNS was able to report that a couple of his patients had rung one. He cited the local Tenovus Helpline, whose nurses had contacted him occasionally asking him to ring someone.



## The Northern Ireland Cancer Centre at Belfast City Hospital

### Introduction

The Cancer Centre was opened at Belfast City Hospital in 2006. The Centre provides a range of cancer treatments, including surgery, radiotherapy and chemotherapy, as well as an outpatient and inpatient service. It also specialises in the treatment of rare or less common cancers. The Centre is home to a clinical trial led practice in prostate cancer and in this capacity, has institutional links with Queen's University, Belfast.

The researchers interviewed a consultant clinical oncologist, a non-specialist cancer nurse, the lead clinical research radiographer, the information and support radiographer, and a uro-oncology project nurse.

### Work of the Cancer Centre

The consultant clinical oncologist oversees a research based oncology service. Part of this role includes working with a regional multidisciplinary team on prostate cancer. The team meet to discuss individual cases and how best to treat them. The consultant's main focus is on clinical research, specifically understanding prostate cancer and how to treat it. The consultant interacts with men who have all stages of prostate cancer from the very early stages to the incurable, fatal stages. However, there is a skew toward the more advanced cases as the consultant's trials are aimed at more aggressive cancers.

The non-specialist cancer nurse works in the outpatient clinic. She sees people from their initial diagnosis, through their reviews and scans, as well as post-treatment. The nurse acts as a conduit between the patient and the doctor. The nurse also provides support for the patient and guides them through hospital processes.

The lead clinical research radiographer heads a team of two clinical research radiographers as well as full time support staff that work on the hospital's clinic trials. Many of the trials include people who have prostate cancer (breast cancer is also a common subject of clinical trials). In the past, the Centre has been one of the largest recruiters for prostate cancer studies. The lead clinical research radiographer sees patients from diagnosis through to treatment and during this time builds a relationship with the patient in terms of treatment schedules and care. Many patients are seen in a palliative setting.

### Information

The reception/waiting room at the cancer centre is well stocked with information about cancer treatment options and other support. The vast majority of information is from Macmillan Cancer Support. Macmillan's booklets are presented on the reception desk and are easily accessible for anyone who wants to pick one up. Other information about local support services are available on a single pin board, also in the waiting area. This information includes details about local support groups and services such as wig shops.

The uro-oncology project nurse is a Macmillan funded post in the urology department of the hospital. In the main, the role is in developing information to meet the needs and to support patients – mainly those with prostate cancer, but also those with testicular cancer. The project nurse is developing a range of information: pre-PSA reading information, a PSA



record card, patient information packs and new-patient information packs. The project nurse is also developing a decisions support sheet, to aid decision making among new patients. Prostate Cancer UK information is used as part of the information packs that are being developed.

The information and support radiographer is funded by 'Friends of the Cancer Centre', a leading local charity, and provides additional information and support. This is available downstairs from the radiography department at the entrance of the hospital. There is physical information available here, although according to the staff, *"a lot of the time, I might just sit for 10-15 minutes [with the patient]"*. Prostate Cancer UK information is available at a stand here and the information and support radiographer hands out information (including Prostate Cancer UK). However, she wanted a larger dedicated information zone: *"We have an information stand outside of my office. Not a lot there. I would like to get more information out into the department."*

As part of this role, the information and support radiographer disseminates information to patients before, during and after treatment. They see patients mainly on referral – typically a patient would be referred if it was thought they could benefit from additional information and support. Once a patient is referred, the information and support radiographer examines their notes to see what information they need. The information is then collected and given to the patient during a face to face meeting. The service is flagged - a leaflet about the information and support service goes with the first planning letter - so that patients can also request information. Information needs may focus on radiotherapy treatment, side effects, financial support or general anxiety. She also mentioned that having the information stationed in her "area" (this is near the entrance to the hospital but behind a set of doors) helps, since it is more "private": *"People might be a bit nervous about hovering around information."*

Aside from literature, the information and support radiographer provides a limited audio information service. For example, information on fatigue can be provided in audio format. She said that *"I think they do find the audio information useful. The people that are actually the voice in those always seem to be quite relaxed. Anyone who I have given them to has found it useful."*

The information and support radiographer noted the importance of her role, in particular, her ability to provide relevant information on demand: *"Knowing that I'm here is important. They know that they can call in on me anytime. That link is there after treatment. They know they can just ring through...but some people think that because there is just one of me I am too busy."*

The lead clinical research radiographer provides the patient with technical information about their treatments. The hospital has specific leaflets that they produce on site to assist with explaining the complexities of each trial.

The non-specialist cancer nurse explained that it is the doctors who decide what leaflets to give to the patients. According to the nurse, these were mostly Macmillan cancer leaflets.

The clinic is also in the process of developing their own toolkit clinic for prostate cancer patients in Northern Ireland. This process is being led by the specialist nurse. The toolkit will

contain a card to record the PSA score after a consultation. It will also contain a decision making guide that presents all options available to patients.

In demographic terms, the interviewees suggested that men in Northern Ireland are a relatively homogenous group. For instance, the Consultant Clinical Oncologist said *"Altogether though, men in Northern Ireland are not very ethnically diverse"*. He contrasted this with working in his former practice in London.

According to the consultant, from a clinical point of view, there are three things men want to know at an initial consultation. Firstly, and most immediately, men want to know if their cancer is life or death. Many will ask *"how long have I got left to live?"* Second, they want to understand the implications of the cancer for their health. They want to know what damage has already been done and how much is fixable. For example, many men want to know if they will ever pass urine normally again. Third, they want to know what their treatment options are and how quickly it can be done.

Beyond this, exactly what information a patient may want was thought to be dependent on personality. For example, the consultant stated that *"It is personality types that rule which men need more support and guidance. The main difference between the different types of men that come in here is personality."*

Similarly, the lead clinical research radiographer commented that there is a *"broad spectrum of needs"*. Whereas *"some people have written everything down"* and *"have all their questions"*, others *"can't process too much information"* and *"all they want to know is what happens next, their car park pass, when do I come back"*.

Overall, it was thought that the typical married Northern Irish man would be able to make an easy decision about their treatment. An anxious man would be less likely to do so. Differences in decision making processes were also evident between men facing different treatment options. This was explained by the consultant: *"The men that need the most support with decision making are those who are thinking about active surveillance versus surgery. There are some very indecisive men out there. And some men are influenced by old wives tales and personal experience"*.

The non-specialist clinical nurse also described a wide range of needs in terms information men required. For example, some men asked about personal issues such as sexual function, but as the nurse explained *"it depends on personality. Some can deal with loss of sexual function and don't need to know much about it, but some cannot deal with it."*

The impact of a loss of sexual function was also discussed by the consultant who stated that *"some patients won't be as concerned about this. I need to tailor my advice to the individual's circumstances."*

The information and support radiographer, whose role is to respond to patients' information requests, suggested that one of the most common (specific) information requests was about travel insurance, but that *"most often it seems to be information to do with how to look after themselves: diet and exercise, coping with fatigue"*. Similarly, she commented that patients seem to *"want to be more in control, themselves...to know the services that are available. How do they access the services?"*

It was acknowledged that the health professional's primary relationship is with the men, but often relatives attend the clinic too. According to the consultant, who had previously run a clinical practice in London, it is much more common than elsewhere for NI men to attend the clinic with their friends or family. Relatives come for two main reasons. Firstly, they want to support their family member. Secondly, they are there to be *"a second pair of ears"*. In their support role, the family member often hears information that the man with cancer does not hear. When family members are older children (e.g. around 40 or 50 years old) the consultant suggest they explore the Prostate Cancer UK website. The importance of children in the decision making process was also discussed by the non-specialist cancer nurse: *"The patient is usually shocked and they don't have any immediate questions. The older children are most useful and they know what to ask."*

However, a potential drawback to having family there was highlighted by the lead clinical research radiographer. She mentioned that *"A lot of side effects are very uncomfortable, such as erectile dysfunction, urine, continence problems - and their wives are there"*. She mentioned sometimes asking men on their own, in case something is going unsaid, although this was not common.

## Maggie's Centre Glasgow

### Introduction

Maggie's provides free practical, emotional and social support to people with cancer and their family and friends, following the ideas about cancer care originally laid out by Maggie Keswick Jencks. Built in the grounds of NHS cancer hospitals, Maggie's Centres are places with professional staff on hand to offer the support people need.

Maggie's Glasgow is based on the grounds of Gartnavel General Hospital. It is very close to Scotland's leading oncology facility, the Beatson West of Scotland Cancer Centre, which serves a population of 2.8 million people (60 per cent of Scotland's population).

The researcher spoke to two Cancer Support Specialists, a Counselling Psychologist and a volunteer receptionist.

### Maggie's work

An important tenet of the Maggie's centres is that people self-refer: they come to the centre because they choose to. However, with the close proximity to the hospital and oncology centre, a number of patients may be signposted to the centre by their oncologist or someone else from the hospital.

Despite being close to the hospital, the centre is distinct in that it is not a clinical environment. Rather it is a place where *"people can make their own cup of tea"*. Anyone affected by cancer can visit a Maggie's centre and the staff reported seeing a number of partners or family and friends.

There are a number of classes and services held at the centre, some of which are drop in and for which it is not necessary to book, including:

- Welfare rights

- Relaxation group
- Prostate support group
- Living with less stress
- Nutrition workshop.

Further to this, staff such as Cancer Supports Specialists, Benefits Advisers or a Counselling Psychologist are available for one-to-one discussions. There are also two support groups for men with prostate cancer each week (run in conjunction with Prostate Cancer UK).

- Tuesday Morning - Newly diagnosed mostly. (6 Men on average)
- Wednesday Morning - Established support group. (16 Men on average)
- Also a friends and carers group which meets once a month.

The centre sees a mix of people. It exists for all cancers. In terms of the people with prostate cancer, there is no standardized point in their cancer journey for people to visit Maggie's, but most patients that are seen will already have been diagnosed or will be at the point of diagnosis. They will tend to visit the centre either at diagnosis or where there is a shift in treatment – it is uncommon to see people at pre-diagnosis.

In general, it is considered that *“choice comes at an early stage for prostate cancer”*, relative to, for instance, breast cancer. Staff feel that there are recently more people coming at the point of diagnosis, reflecting a growing awareness of the centre.

The centre sees many families and it is thought that there might be a roughly 50/50 split between family/partners and men affected by prostate cancer. One Cancer Support Specialist suggests that sometimes women access the centre first. This may be because men may not be able to talk at first about treatment choices, with some element of a *“stiff upper lip”* at play. However, it was thought that over time men come to the centre and it was useful that they can see other men there.

The centre also sees men from a range of backgrounds. It was suggested that the welfare/benefits service is important in securing this – *“Without that, not sure we would see the range of men that we see. Welfare services are a route in for men from a poorer background. They come in to get their finances sorted”*.

The **Cancer Support Specialist** is a role that exists in all Maggie's centres. They would normally be one of the first people that anyone entering a Maggie's centre would speak to and act to help identify user needs and provide support, signposting services or classes available or simply engaging with users to provide support (depending on what is most suitable).

The role normally requires some experience of cancer therapies and tends to be carried out by former nurses. Staff might come from quite specialist backgrounds into this role at Maggie's. The role is broad. In the first place, it is about greeting people who come to the centre and *“hearing their story”*. In building a relationship with users, sometimes over a long time period, they help to create a *“safe space”*. This allows people to *“vocalize fears, without thinking that they are having a terrible effect on others”* (such as family or friends).

The process of identifying particular needs happens in a very informal manner and there is not a list of protocols. One of the particular aims of the centre is to empower those who come - ensuring that they are “*active parties*”. This takes place by having a two-way dialogue, in which the Cancer Support Specialists are asking people what they need.

As highlighted above, the Cancer Support Specialist can refer users to any of the wide range of classes or services available, from yoga to benefits advice, or continue with private conversations if that is most appropriate. This decision should reflect the needs of the individual. Cancer Support Specialists can suggest any particular support they feel might be beneficial, but again this is something that is up to a particular person.

One of the Cancer Support Specialists also facilitates the prostate cancer groups. The prostate cancer support groups are considered “*a very light touch facility*”, with the groups having met for years and “*running themselves to some extent*”. The website explains that:

*“Group support is available for people with any type of cancer and their friends and families: before, during or after treatment. Every group provides an opportunity to talk to other people who are in a similar situation to you, and to share experiences. Groups offer a safe space to express emotions you might not want to share with your friends and family. You might learn from those a little way ahead of you in their journey and develop your own strategies for coping.”<sup>18</sup>*

The **Counselling Psychologist** provides psychological support where an individual has “more than just a general need”. The role of the Counselling Psychologist is to give “*the tools and techniques*” to deal with the needs of people with or affected by cancer. The psychological needs for prostate cancer are the same as would be for any other cancer: in particular, anxiety, or more existential needs i.e. fear of mortality.

The Counselling Psychologist works with people at different stages of the cancer journey. It can be that this need only emerges post-treatment: “*during treatment people may not need support, but afterwards they want to know... why am I only feeling this now?*”

People can approach the Counselling Psychologist directly, but more often they are referred by one of the nurses. Most often this involves seeing individuals alone. Normally, it would begin with a psychological assessment to see if they need psychological help. Beyond that it is about “*building a working alliance*” and “*establishing goals for the therapy*” based on what an individual wants to get from the treatment. Sometimes it is just a place to talk.

The Counselling Psychologist also takes part in stress relief classes in the centre.

**Volunteers** play a major role at Maggie’s. According to a volunteer, this is mainly a “*meet and greet role*”, but this is particularly significant given the importance of an open and welcoming atmosphere at the Maggie’s Centre.

The volunteers are there to “*make people feel as well as possible*”. In keeping with the culture and approach of the centre, volunteers will “*get their first cup of tea or coffee, but*

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<sup>18</sup> <https://www.maggiescentres.org/our-centres/maggies-glasgow/whats-on/>

*after that we encourage them to do it". They show people around the centre and highlight the classes and support available. They also put them in touch, particularly if they have any medical questions, with the Cancer Support Specialists.*

*As a volunteer said, "people are often under the impression that it is a sad place, that people here are miserable. But we show them that it is not".*

### Information

The researcher observed that there is a large information display at the entrance of the centre. This has leaflets and information from a range of charities, such as Macmillan. For prostate cancer, there are a broad range of Prostate Cancer UK leaflets. The information starts from the treatment specific booklets rather than diagnostics or screening / warning signs. As the partner hospital is a tertiary referral centre, it is uncommon to see men pre-diagnosis. Aside from specific information about particular cancers, there is also a range of literature, including books, on topics such as dealing with stress or other emotional support.

The Cancer Support Specialists reported that information needs often start within the context of a huge shock at the start. Although people may have been given information already, owing to the initial shock, they may not have absorbed anything. For instance, most people display little or no knowledge of the PSA test or Gleason score. Even if they have already been told, there may be issues with people *"saying 'yes' and 'we understand'" – "but nobody asks if they really get it, nobody pushes it"*. In this environment, *"people are more willing to say 'I don't get this'"*.

Some of the most frequent questions are around treatment choices; comparing potential side effects; how it will impact on their daily lives. Younger men are reported to often wonder how they can fit treatment around work, dwelling less on the side effects.

Again, people differ and some people are comfortable to *"just get it done"*, they don't need to know all the treatment options. They can just put their *"foot on the conveyor belt and go forward"*.

There are a range of ways to access information, for instance there are computers for people to use in the centre. They can search for information online – this can be either a guided or non-guided search. One staff member mentioned that the internet *"is a problem in that people can go on and scare themselves witless"*. As such, the staff do suggest some core sites, such as Macmillan, Prostate Cancer UK, Cancer Research UK. The information may be enough or people may need to talk it through. However, it is thought that *"some people may prefer to read"*.

As mentioned above, there are also a number of leaflets available. In terms of people's needs, the Cancer Support Specialists highlighted the emotional effects. It is reported that the booklets that get taken are those that are about *"how to talk about cancer"* rather than the *"more scientific or clinical leaflets"*. A Cancer Support Specialist suggested that what they do at Maggie's is less about the actual cancer, but more about the person and their relationships. Families reportedly take more leaflets compared to men.

However, one Cancer Support Specialist says *“we don’t use leaflets a great deal”*; instead, Cancer Support Specialists report giving a lot more information orally. They would also, if they saw someone looking at the leaflets, engage with them to support their choice of material, where they thought that would be helpful (i.e. if someone looked uncertain over the best material).

Maggie’s is also a signposting service. The staff try to make sure people leave with the information that they need. An example of this is Prostate Cancer UK’s helpline number. They don’t want people to be dependent on the Maggie’s Centre, although people are always welcome to come back and ask something.

The Counselling Psychologist reported giving some information to men about *“anxiety, phobias, depression”*. More specifically, this information may be information about *“what happens under depression or anxiety”*. People are thought to value practical advice to help them understand the way they feel and how they can act to change it. The information given is normally a couple of A4 sheets. They take it away to read and can come back if it is helpful.

The staff discussed possible barriers to people accessing information. Barriers included issues such as low literacy, although it was noted that a lot of the interaction that takes place is oral, or other people who do not have English as a first language.

Anxiety was mentioned as being the *“biggest barrier”*, but *“This whole place exists to remove that”*. Likewise, another barrier identified is the *“exposing and depersonalising experience of the clinical environment”*. This again is something the centre seeks to alleviate.

When seeing families, there is often a problem of *‘...he’s not talking to me’*. It is hard for people to understand that there is a *“fundamental shift when they have cancer”*. Another barrier identified is that Maggie’s operates as a *“9-5 service”*, although some of the support groups are in the evening.

Among other resources, the staff do refer people to helplines, including Prostate Cancer UK. One person mentioned that they are *“more confident [referring people to the helpline] knowing that Prostate Cancer UK helpline has specialist nurses”*.

## Nottinghamshire Healthcare NHS Trust Local Services Division

### Introduction

Nottinghamshire Healthcare NHS Trust’s Local Services Division provides services to older people, adults, children and adolescents, people with learning disabilities, and people who misuse substances in a range of settings across the county including community and acute settings. The current Business Plan (2010-11 – 2014-15) states that the Division employs 3,067 staff and operates with an income of £137m. The services delivered by the Division include Adult Mental Health Services, Mental Health Services for Older People (covering over 65s and both organic and functional mental health), Learning Disabilities, Substance



Misuse Services and Child and Adolescent Mental Health Services. The Business Plan notes that in the previous year the Division provided 617 inpatient beds; registered over 13,000 new patients; saw over 12,000 outpatients in over 40,000 appointments; and that the 1,617 community staff had 344,108 face-to-face contacts with 26,405 patients.

The researcher spoke to:

- one staff member from **Older People's Mental Health Services** - a Junior Matron working over all inpatient areas
- four members of staff from the **Learning Disabilities (LD) Directorate**:
  - a Health Facilitator, based in a health centre, who supports people aged over 18 with learning disabilities to navigate primary health care and offers advice and training to GP practices to ensure people with learning disabilities get equal access to services
  - a Community Nurse and Community Nurse Manager, who work with a caseload of people with learning disabilities in the local community aged 18 and over around health issues, who have been referred to them from various health and social care professionals e.g.GPs and social workers. They also refer patients onto other professionals e.g.psychologists, social workers and therapists.
  - a Senior Acute Liaison Learning Disabilities Nurse, who works within a local hospital to work with individual patients and raise staff/organisational awareness around LD.

#### The Division's work re cancer

##### Older People's Mental Health

The Junior Matron works within older people's inpatient mental health services which he reported to have roughly 50/50 men and women patients. The interviewee noted that while individuals might come through the ward with a prostate cancer diagnosis, as they were primarily on the ward for mental health *"we wouldn't pay a great deal of attention to it"*. However he noted that over recent years the service had increased its awareness and skills around physical health and was trying to treat and assess both physical and mental health. While problems such as diabetes, blood clots and infections would be treated on the ward, more specialist issues would be treated elsewhere. He felt that if a patient was going to the toilet too often *"our staff's first thought would be UTI, an anxiety related problem, or a side effect of medication – prostate cancer wouldn't be high on their mind"*. He later concluded that the interview had given him something to think about – *"physical healthcare is something we're really pushing and trying to improve – we perhaps need to think a bit wider – we mainly do diabetes, things like that"*.

##### Learning Disabilities

All the interviewees had had little experience of prostate cancer within their caseload. The acute nurse commented that statistics four years ago had shown people with learning disabilities to be 55 times more likely to die before age 50 than the general population. He explained that the age difference between the general population and males with learning disabilities is slightly less than 20 years, with the average age of death of a person with Down's Syndrome having risen from 25 thirty years ago, to over 55 at present. In the



previous year there had been a greater proportion of older people amongst the patients with learning disabilities he was seeing at the hospital. He felt that more cases of prostate cancer were likely to be found in the future with the rising life expectancy of people with learning disabilities. The health facilitator also put the low instance of prostate cancer among her patients as possibly being down to the lower life expectancy of people with learning disabilities and agreed that with people with learning disabilities living longer, *“I think there will be more with prostate cancer in the future”*.

The community nurse had worked with a patient in the community who was reporting going to the toilet more often at night, so the nurse identified prostate issues and discussed this as a possibility with him and that *“we needed to go to the GP”*. The GP offered an examination *“but he declined a check – he has [mental] capacity so we can’t force him.”* The health facilitator reported having been rung by his social worker as a residential care resident in his late 60s had an enlarged prostate. The residential home staff were very anxious that he might have prostate cancer, as they had recently lost another resident to cancer. The health facilitator reassured them that he had an enlarged prostate, not cancer.

The acute nurse reported having had a few cancer patients with learning disabilities in the hospital in which he worked (but no prostate patients). He explained that his role was to ensure reasonable adjustments were made for patients with learning disabilities and to promote that concept within the hospital - e.g. re times of appointments, booking double appointments, allowing the patient to wait in a quiet area or to use a bay on a ward, pre-booking parking spaces.

The health facilitator and community nurses explained their work re cancer by giving specific examples of people they had supported, including:

- Working with individuals re what to expect from cancer screening, using books and models. The health facilitator highlighted a low uptake in cervical screening among this patient group. She cited a lady who she had been referred to in a residential home to explain the breast screening process, who had died of breast cancer by the next time she was due to see her. *“There was no time for input – late in diagnosis”*.
- Staff had contacted the health facilitator as they were trying to get a lady in residential care into the GP practice, as she had been *“in and out of hospital”*. Eventually it was found that she had inoperable ovarian cancer. The interviewee observed that there had been a lot of delay in getting the lady any support and she was at an advanced stage by the time of diagnosis. The delay was caused because the lady had no means of verbal communication, and so was not able to tell people that she was in pain – the first sign had been that she was not eating and drinking.
- A recent male Downs syndrome patient of the health facilitator had testicular cancer. He lives in supported living and has a very supportive family who take care of his health appointments. The health facilitator explained that *“we promote people having control of their own health, each patient has a Health Action Plan (HAP), all about every area of health.”* This particular patient uses his HAP as a diary of his illness and keeps a record of

treatments, and *“would be able to tell you all about his treatments - a very positive story”*. The GP practice and the supported living staff were reported to be *“on top of it from the start”*. The health facilitator’s role was supportive, e.g. helping develop the HAP.

- The community nurse cited a patient who had recently died at home, from cancer of the esophagus. The community nurse played a big role in supporting the carer, and co-ordinating the care with other professionals. The patient was cared for by his 86 year old mother at home, with whom the community nurse worked closely as she was very distressed. He also liaised with district nurses to make sure the patient was as comfortable as possible. The community nurse played the role of intermediary between the mother and different professionals who found Mother *“difficult ... most of the issues were around Mum and her understanding. We knew one false move and she’d stop all of us going in.”* The patient himself did not have an understanding of his condition and did not understand he was dying. *“The hardest thing for us was it was the last days of his life and Mum just didn’t see it.”* The community nurse reported that the patient had been losing weight rapidly before getting his diagnosis and there was *“possibly a delay in getting the diagnosis. Looking back I would question why there was no further offer of treatment when he was diagnosed. If it happened again I would question ‘has treatment been offered?’”*

The community nurse explained that while most of their work is focused on a caseload of patients who have been referred to them, they have also started doing health promotion work with the wider population of people with learning disabilities, e.g. baseline health checks, blood pressure, BMI. For example the nurse went to a local community centre for people with learning disabilities where people drop in to use the gym equipment, and would come to see the nurse beforehand to have checks done. The nurse had just done a session on sexuality and also worked with a stop smoking group.

Both the community nurse and the health facilitator highlighted the problem of ‘diagnostic overshadowing’ with this patient group. The health facilitator observed that *“it’s not uncommon for diagnostic overshadowing to happen where symptoms are seen as related to their [people with learning disabilities] disability – so it can be too late. This can be a problem in GP practices.”* The community nurse observed that for *“our service users it [ie symptoms] would be seen as a behavioural thing not physical, so we need to raise staff awareness, as this can delay diagnosis by months.”*

## Information

### Older People’s Mental Health

The interviewee reported that leaflets around issues such as cancer were *“not a priority”* and would not be something the wards would normally stock, although the ward staff could signpost patients to information if needed. However on reflection the interviewee felt that *“a poster to signpost people to ask”* might be useful. When asked about telephone helplines as a source of information he felt that these would be good to publicise as they *“would be really useful for either the patient or the carers”*.

The interviewee pointed out that patients with functional mental health issues were cognitively intact and so their information needs would not be much different from that of

the general population, although there was a need to be person centred and sensitive in giving information to patients (e.g. taking into account if they were obsessive about physical illness). He reported that about two-thirds of the Service's patients were cognitively impaired to varying degrees and would need Easy Read material. However he emphasised the importance of maintaining patients' dignity and self esteem – it would be insensitive to present people who were only mildly cognitively impaired with overly simple information and they might take offence. A range of material was needed as *“people with dementia with capacity to understand illness would probably still have the capacity to read and absorb complexity”*. However, for some patients it would not be in their best interests to give them any information at all e.g. if they didn't have the capacity to understand their illness or a terminal diagnosis. The best interests of the patient would always be at the centre of staff's approach to information giving.

### Learning Disabilities

The health facilitator runs a health and wellbeing group with patients which looks at all different subjects. People are given information orally and visually, e.g. by showing DVDs. Examples included:

- A DVD on bowel screening test specifically developed for people with LDs, with accompanying Easy Read leaflet, had been shown to the group.
- The East Midlands Ambulance Service struggled with understanding calls from people with learning disabilities, so developed a CD Rom and Workbook - 'The Ambulance and Me' - about when to call the ambulance, which used people with learning disabilities in the video (which the interviewee considered to be good practice). *“We use it as a group session.”*
- Sessions on breast screening, cervical screening and testicular awareness.

The health facilitator observed that *“we use DVDs all the time – we can look at it as a group, or with the individual, or the carer can look at it with them at home.”* When asked about the internet, she observed that *“not many of the people with learning disabilities I work with use the internet – only a few. Some of them are more clued up than me – but they are few and far between.”* She had found that using models, DVDs and Easy Read material were the best means of transmitting information to people with learning disabilities. The community nurse also used DVDs a lot, for example the DVDs on breast and testicles checking. *“DVDs help understanding and take the pressure off people – not being directly spoken to”*. The community nurse used resources such as fake testicles and breasts to teach people how to check themselves – *“proactive stuff”* - explaining that this would mainly be done in group work. Resources provided by other organisations e.g. from the NHS Resources Centre were used, along with the community nurse team making their own resources using the Somerset communication tool. They used 'social stories' a lot e.g. if patients were going to die. The team did not have any resources on prostate cancer *“but I'm sure something would be in the NHS Resource Centre if needed”*.

The acute nurse used Easy Read material and the 'My Health Vision' DVD which the hospital had developed with the local MENCAP. The hospital both produced its own Easy Read

material and stored that of others. They used the Access Easy Health national database of material ([www.easyhealth.org.uk](http://www.easyhealth.org.uk)) and also praised 'A Picture of Health'. The acute nurse noted that Macmillan and Easy Health had done a series of Easy Read books on cancer – three for carers and three for service users, on identification, diagnosis and treatment, and palliative. He commented that these had been *"very generic"* rather than on specific cancers. The acute nurse could not think of any information around prostate cancer for people with learning disabilities. When asked if the Easy Read material on prostate cancer being developed would be of interest he commented *"without a shadow of doubt, absolutely"*. He stressed that staff working within the hospital setting needed different information from staff working in the community. While the latter needed *"information on how to identify prostate cancer, signs and symptoms"* the hospital based staff *"would want information on treatment options, how to explain diagnosis – Easy Read material on that would be critical"*.

However, information for staff was vital, not just information for patients. The acute nurse noted that the *"main thing we try and do is share information about the patient with the hospital"* using a 'Traffic Light Assessment' which tells wards how to support the person and what their interests are, so staff can initiate conversations with them. They also used a 'Hospital Passport' using different versions for patients with learning disabilities and patients with dementia, customized for different areas' needs. It was important to *"provide a snapshot of information about the patient that nurses have time to read"*.

The community nurse stressed that people with learning disabilities would not be reached by strategies such as radio adverts or information at football matches. Of the service users he worked with, only one goes to football matches, people with learning disabilities being *"quite socially isolated"*. Going to places like the community centre for people with learning disabilities was the most effective means of reaching them. The community nurse emphasized the importance of staff such as themselves being *"a lot more proactive"* with this client group, observing: *"I might pick up on a radio or TV advert but our client group would not. Any leaflets have to be Easy Read, don't rely on words."* However TV soaps were highlighted as an information source which did impact on people with learning disabilities – e.g. the recent storyline re Hayley's suicide on Coronation St had caused much discussion.

The health facilitator observed that the group she ran had not had a session on prostate cancer as she had *"very little experience of seeing it"*. She would be interested to know if there was any data on people with learning disabilities and prostate cancer. She would be willing to run a session in the future with her group on prostate cancer and promote awareness of the symptoms. The acute nurse also reported that he had never worked with any patients with learning disabilities who had prostate cancer. The community nurse also had found prostate cancer to be *"fairly rare"* among his patients, with only one case remembered, and considered raising the awareness of staff, including support staff, and families about prostate cancer to be important as it was *"more hidden than breast cancer, what signs to look out for"*. The nurse felt it would be good to go out and talk to staff teams for example at residential homes – it was important not to aim education only at the people with learning disabilities themselves, but rather also *"give staff the tools to notice"*.

The health facilitator felt that telephone helplines would not be accessed by people with learning disabilities but *“would be useful for carers and staff”* as it would be *“someone you could run things by”*.

## HMP Whatton

### Introduction

HMP Whatton is a national treatment centre for male sex offenders, whose offences range widely from e.g. online access to violent murder with a sexual element. It is a Category C prison with 841 beds, and runs at full capacity. The average length of stay for prisoners is 3-4 years making it a relatively stable prison population. The largest age group in HMP Whatton is aged 50+, many (but not all) of whom are housed in the Older People's Wing which has 40-60 prisoners. There is an Older Prisoners' social group to try and get people who are retired from prison work off the wing; this starts at age 55 (or younger for people who are medically retired).

All prisoners have to admit to having committed their crime to be eligible to come to HMP Whatton. It is estimated that nearly a quarter of HMP Whatton prisoners have learning difficulties or disabilities, within whom a significant number also have Aspergers or ADHD. The Healthcare Unit is planning with the Psychology Department to set up a Learning Disabilities service in the prison, to identify people who need additional support to undertake the behavioural therapy programmes which are an important component of securing release. (Half the prisoners are on indeterminate sentences.) Nearly a quarter of prisoners have a personality disorder, making HMP Whatton the second biggest population of such prisoners in the country. The Psychology Department also runs the National Adapted Deaf Sex Offender Programme.

The Healthcare Unit is run by the Healthcare team which is part of Notts Healthcare NHS Trust. The Trust provides secondary mental health inreach in 11 prisons across the region, and in 8 (including HMP Whatton) provides all healthcare. The Trust's Offender Health Directorate has been established for three years as a stand alone Directorate and provides primary and secondary mental health, substance misuse services and physical healthcare services.

The current Head of Healthcare at HMP Whatton has been in post since April 2012. At that time mental health and physical health services worked separately side by side. In 2013 the Trust started providing substance misuse services in the prison. Now the Head of Healthcare manages all three services as one integrated service, with a core team of nurses and substance misuse workers who are directly employed. Services are sub-contracted out as required - to e.g. GPs (1 session delivered each day), dental cover, optician cover, rehab OT and physio (key to this older age group of prisoners). Muscular skeletal physio is provided once a week, and specialist services (e.g. diabetes, retinopathy screening) visit on an ad hoc basis. The Unit tries to ensure as much is provided in house as possible given the cost and public safety implications of sending prisoners for treatment outside the prison.

The Unit works along the lines of a health centre. Prisoners put in requests for appointments. All are triaged by a nurse, who decides who they are best seen by. If warranted, the prisoner sees the in-reach GP who does any diagnostics. The health centre is

a daytime service – 7.30-6.30 (8-12.30 weekends), with no access to nursing care out of those hours, when an out of hours agency provides vetted healthcare assistants as needed. They can be contacted for help with overnight patients.

The researcher spoke to the HMP Whatton Head of Healthcare; a Senior Practice Nurse who specialises in End of Life Cancer Care; one of the in-reach GPs; two Disability Awareness Co-ordinators (prisoners - together); a prison officer leading work on prisoners with personality disorder; and two Mental Health Assistant Practitioners (together). The researcher was also given a tour of the Healthcare Unit and of the palliative care facilities.

### HMP Whatton's work re cancer

At the time of the researcher's visit, 14 prisoners in HMP Whatton had a cancer diagnosis. 3 were undergoing chemotherapy and radiotherapy treatment at the local hospital. 2 of the 14 were prostate cancer patients. 1 had had a radical prostatectomy and was transferred to HMP Whatton post-surgery (i.e. was a prisoner in a different prison at the time of the surgery). HMP Whatton has 6-8 deaths per annum (the average for prisons is 1-2), most of which are cancer-related.

The main role of the in-reach GP (both within HMP Whatton and in her general practice) regarding cancer is at the time of diagnosis. *"On a daily basis I assess people's symptoms of people worried about symptoms, or worrying about getting it. Or referring people with abnormal results"*. Once diagnosed the GP's main role is at end life - *"communication, liaising with secondary care, co-ordinating a more Multi Disciplinary Team approach to end life care"*. She also might discuss treatment plans with patients. Nurses have the main contact with people on 'watchful waiting' e.g. giving injections or administering PSA tests.

Patients at HMP Whatton who are diagnosed by the GP as suspected cancer cases get referred to the local acute trust as a '2 week wait' (i.e. to meet the national requirement that those with a suspected cancer diagnosis have to be seen by a specialist within 2 weeks). There are a *"high proportion of referrals"* per week. *"We liaise with the prison re anyone suspected of having cancer, with the patient's consent – a complex process, there are security issues re them going out. We have good relations with the prison team, Governors come down and discuss the plans re patients."*

Anybody diagnosed with cancer comes under the Senior Practice Nurse (End of Life Cancer Care Lead)'s caseload. She is made aware of all 2 week wait patients. The nurse meets the patient and explains that she is their named nurse, and offers support: *"picking them up at the very beginning of their journey and I support them all the way through treatment through to end of life care"*. The nurse leads cancer review clinics where she sees cancer patients for an hour and talks to them about issues such as what to expect in treatment and Advance Directives. Cancer patients have a standing open appointment with the nurse, *"all they have to do is get the officer to ring and I will see them the same day if I'm in"*.

When patients go out to hospital appointments they are escorted by and handcuffed to prison officers, for security reasons. There are 6 medical escorts per day plus medical emergencies (e.g. a bowel cancer patient who had a huge tumour so had to be got to the hospital that day). If a patient is going for an appointment and is going to get 'bad news', one of the Unit's nurses will also accompany them to the appointment. The Head of



Healthcare is planning to look at doing the 'Chemo at Home' Programme within the prison to avoid patients having to be escorted out to the hospital. *"The impact of cancer on our resources is massive for us especially where there's a palliative diagnosis – even though fairly low numbers of people. At the moment we have 3 people all going out for daily chemo and radiotherapy – which requires 6 prison officers and a driver. Has potentially a knock on effect on resources for other patients being able to go out for treatment and diagnostics."*

Cancer patients are managed as long as possible on the prison wings. There are multi-disciplinary team meetings about patients as needed which meet regularly. For palliative patients the team can involve officials such as the catering staff and chaplain; *"prison staff are very responsive in attending meetings"*. Cancer patients are supported by prisoners – Disability Awareness Co-ordinators (DACs) - who have been trained by the prison's Equality and Diversity Unit and the healthcare staff to support individuals going through major surgery, multiple long term conditions and particular needs. The DACs give support such as doing their laundry, taking them to appointments in a wheelchair, keeping the cell tidy, getting their meals or just popping in for a chat. (However given the nature of their offence, the DACs are not allowed to do any personal care such as help in washing, which is provided by the nursing staff.) The DACs *"view it as taking a lot of the pressure off them ... we try and make them as comfortable as can be ... I have had a couple of guys who have been disowned by their family, so have no outside contact, so a friendly face popping in is important. They're very grateful, keep saying 'you're such a good friend'"*. The DACs also observed that as they see the patient regularly throughout the day they can notice changes and raise them with staff.

A trained team of prison staff act as family liaison officers for people with cancer. *"Many prisoners, owing to the nature of their offence, don't have links with the family. If they have an end of life diagnosis and they want to contact their family e.g. to get closure, the prison pick that up. Other prisons have the family liaison officer but we have it well honed. The individual goes out to hospital, have diagnostics done, go through any appropriate treatment (if any) – supported by the nursing team here and the prison team here. All prisoners have personal officers, these are good relationships as they are long stay prisoners. The personal officers are key to helping support individuals as they become unwell."*

Once HMP Whatton prisoners have been diagnosed with cancer they would not be moved on to another prison. *"If they are terminal, we give the patient the option of hospital, hospice or care here in the prison. We have three or four specialist areas for people with more complex needs. They go in an ensuite large cell [funded by the King's Fund] with a hospital bed. All the palliative patients choose to stay here – where they know people and have friends."*

The Unit follows the Liverpool Care Pathway. When the patient is starting to get onto the LCP, and needs more round the clock care, they are moved into a unit (also funded by the King's Fund) called The Retreat where they are nursed until they die. No prison officer is present. *"In other prisons patients go to a hospice or a hospital at that point – we have facilities in house for prisoners who want to stay."* One interviewee explained that the origin of The Retreat was the request made by a prisoner with a terminal illness to die in prison, as he felt that the prison was where his friends and family were. However there was

then no facility for him to be cared in so he had to go to a hospice for his end life care, accompanied by prison officers.

Agency staff stay with the patient in The Retreat 24 hours a day and stay with them until they die. The agency staff do not have keys. The prison rules state that the prisoner has to be locked in a cell, but this rule is waived for palliative patients after going through a risk assessment process. *"We have been doing this enhanced care for 5 years – 100% of patients have chosen to die here rather than go to a hospital or a hospice. We're a national prison – prisoners may be from far away – they can't manage the journey. Most hospices are not set up to be a secure environment for people who might prove a threat such as sex offenders – the nurses/visitors might be at risk – we have to take this into consideration. A lot of guys don't have contact with their families, and feel vulnerable to the assumptions of others. All when going to hospital have to be [hand]cuffed to at least one prison officer. Prisoners find it very distressing. The palliative care suite here allows them not to endure that, gives them privacy and dignity. And if relatives choose, they can come and visit. It's important for families as well as patients to get closure, this offers the opportunity."*

The palliative care at HMP Whatton has been praised as exemplary by the Prisons Ombudsman and by external clinical reviewers and coroners (who investigate all deaths in custody). *"Cancer is complicated, needs planning, but I think we do it very well. ... it is part and parcel of the routine workload – not unusual."* Some interviewees contrasted the cancer care, and particularly end life care, at HMP Whatton favourably with that provided in the community, e.g. where some patients are not given access to a named nurse. *"Out in the community their workloads are massive, the resources aren't there. I'm confident our patients are receiving a good quality level of care."*

The Unit also undertakes health promotion work around nationally flagged health issues. It runs 1 or 2 big open day health promotion events per year where external people come in and have stands (having been vetted by the prison security team first as appropriate). The events are attended by both prisoners and staff, with promotional leaflets and information distributed.

In terms of screening, the current focus is on screening for specific groups rather than undertaking an annual healthcheck, but the Unit is now looking at doing annual healthchecks for non-specific areas. The Unit is covered by both the national commissioning and prison indicators, which are *"slightly different"*, so to meet these the Unit's focus is *"generalized, not on specific groups in the population"*. The Unit is currently doing a lot of work on asthma, diabetes and COPD which have a very high prevalence in the HMP Whatton population. While cancer is also high prevalence it *"does not have long waits"* and access to services is seen as good so these other areas are seen as higher priority for screening at present. *"We've looked at things we could do in-house e.g. re early detection. But the volume doesn't make it cost-effective. We looked at urology services coming in – potentially an argument for it being a visiting session – but if we had surgeries/sessions here, we would only run it once a month to be cost-effective – so we wouldn't be able to follow the 2 week wait rule."*



## Information

Every prisoner when admitted goes onto an induction wing and has an induction programme. This includes an information session from the Healthcare Team about its services.

At the time of the researcher's visit there was no cancer information on display anywhere in the prison. An interviewee who had worked at HMP Whatton for several years said when asked, *"I can't remember ever seeing a poster on the wall with the symptoms of prostate cancer in the prison"*.

The researcher observed various notice board information displays in the Healthcare Unit, e.g. in the corridors and in waiting and consultation rooms. The topics covered included weight loss, dementia *"one of our big things at the moment"*, healthy eating, smoking cessation, diabetes, oral health, sexual health and mental health. The Unit does not have a budget for publications and journals so cannot pay for information materials. *"We need to get sent the materials to put up [or] we can print stuff out off the internet."* There are also healthcare notice boards on each of the wings which were seen by the Disability Awareness Co-ordinators as a more effective means of communicating information as prisoners pass by them every day.

The Healthcare Unit waiting room had an unused TV on which the team are hoping to put health information. It also contained posters with general information about what's going on in the prison re health/wellbeing. A prisoner in the Waiting Room confirmed that he reads the health promotion posters. One of the posters advertised prison radio which is a national service which prisoners listen to through their TV and has 24/7 availability ([www.nationalprisonradio.com](http://www.nationalprisonradio.com)). The Head of Healthcare saw this as a particularly good way of getting information across to some people. Healthcare articles are also regularly included in the prison magazine which comes out every 2/3 months.

The GP reported that she sees general practice patients post-investigation and diagnosis to support the information given by secondary care, as hospital consultations *"can be short, they can be quite shocked, disbelief"*. As they often will come out already having been given a lot of printed information on their treatment plan from secondary care, the GP mainly gives oral information *"from what I have read"*. The GP was not aware of having any specific information in the general practice surgery to give patients: *"GPs use ourselves as resources"*.

The Senior Practice Nurse reported that for HMP Whatton cancer patients, often information given out at hospital appointments is given to the accompanying prison officer and *"sometimes it doesn't reach the patient"*. The nursing team either go back to the hospital and asks them to send it in - *"I don't like any of the patients not to have information to refer to, they would get that in the community, I don't want our patients disadvantaged"* and/or accesses information for the patient, usually from either Cancer Research UK or Macmillan - *"I have a drawer of Macmillan information"*. Prostate patients are offered either Prostate Cancer UK or Macmillan information. Online resources are searched *"if they want more in-depth information"*.

The Unit frequently uses CDs and DVDs as a source of health information – *“anything we get given by a specialist team we will bring into Healthcare [Unit] and allow individuals to watch on TV, alone or accompanied ... We try and use information from national resources rather than develop any ourselves – we can’t keep up with best practice”*. The Mental Health Assistant Practitioner reported using a Loss and Bereavement DVD with patients but commented on how difficult it had been to find something that was usable in a prison setting. This interviewee responded *“Hell, no!”* to a query about the appropriateness of the internet as a source of information for prisoners. CDs and DVDs are the preferred format of information given the restrictions placed upon information seeking in the prison. *“It’s easier for us to manage – prisoners have very restricted access to the internet, they would be blocked from accessing a lot. So any visual material is better on DVD. DVDs work well. If necessary, security will watch DVDs first to make sure they are appropriate and are risk assessed before utilizing with the patient.”*

One interviewee observed that it’s hard to get information that can be retained across to people with Learning Disabilities, Aspergers and personality disorder. The Unit has devised a general health passport for prisoners with Learning Disabilities, with lots of pictorials e.g. to help them with medication, which also helps meet the needs of the deaf group of prisoners. It is modelled on the ‘diabetes passport’ given by GP to all patients with diabetes (Diabetes UK initiative). Another interviewee reported being unable to meet the information needs of a Pakistani origin lymphoma patient who had been given a booklet and found the medical terms hard to understand and so asked for it in his own language. Neither the lymphoma support group nor Macmillan when contacted were able to provide this. *“I rang the hospital and asked for them to arrange an interpreter to be there at his next clinic appointment so he would fully understand his treatment plan.”*

Another interviewee pointed to low literacy rates as an information issue, as well as learning disabilities. The prison Equality and Diversity Unit has produced a pictorial version of prisoner information – e.g. the facilities list – to cater for the non-literate and people with learning disabilities. Anything new to communicate should be provided in alternative formats – pictorial / radio / TV station / the prison magazine. *“Simplified written information can sometimes be okay, with smaller words or fewer words”*. Pictorial formats were also helpful for the non-English speaking prisoners and second language speakers. The interviewee stressed however that given the nature of the offence the prison also had a higher proportion than most prisons of prisoners at the higher educational end of the spectrum. This meant that *“alternative formats are good here to cover the range”*.

Information is also provided to the family members of some patients. Families are not allowed to go to hospital appointments with patients because of the security implications, so *“it’s often quite scary for them”*. When cancer patients receive ‘the news’ at hospital appointments they *“don’t take it all in”*; and as their families cannot be with them the families only get the information that the patient recalls. The Senior Practice Nurse offers all cancer patients the opportunity that she meets with their family if the patient is still in touch with them (given the nature of the offence some prisoners have been disowned by their family, which is in some cases the setting of the offence). If families come in the nurse arranges to meet them in a private room: *“I try and do as much as I can for them, e.g. signposting”*. For example, the wife of a bowel cancer patient who was concerned about

treatment options was given access by the nursing team to a DVD and ongoing support. This lack of access to family support at appointments is perceived as making prisoners “disadvantaged” compared to patients in the community and makes the support of the nursing team even more important. *“Support is critical for them in this environment as they don’t have family – they need a point of contact to support them through their journey.”*

Similarly, it was highlighted that unlike patients in the community, prisoners would not be able to access telephone helplines from the wing by themselves. However, the nurse observed that if a prisoner wanted to do this *“I’d be happy for them to use it but I would have to stay in the room for security reasons. I would actively promote that if the patient required that.”* However there is an in-house ‘listening’ scheme whereby prisoners can talk 24/7 to a ‘listener’ prisoner trained by the Samaritans, on a confidential basis, or alternatively can have the Samaritans phone brought to their cell at any time.

While the Senior Practice Nurse had never referred a patient to a telephone helpline she had rung the Macmillan Helpline (to try and get the information for the Pakistani origin patient) and had found it helpful. The GP highlighted the Nottingham Cancer BACUP helpline which patients in her general practice use which *“can be very useful, especially when people have read about a new treatment in the paper”*. She also mentioned the local Maggie’s Centre as a source of information for the general practice patients.

## Working with marginalised groups

### Introduction

Two interviews were held with organisations that aim to support marginalised groups, who do not access mainstream health care. In both studies, the marginalised groups were described as ‘hidden from’ or ‘not willing to engage with’ mainstream healthcare services.

The first interview took place over the phone with a representative from GypsyLife, an organisation that aims to support Gypsy/Romany and Traveller (GRT) populations across the UK. The second interview took place during a site visit to interview the NHS Westminster team providing outreach healthcare services to homeless people at The Passage, a charity based in Victoria, London, which aims to help homeless people in London transform their lives.

### GypsyLife’s work

GypsyLife is a non-funded community organisation that represents the GRT community. The organisation’s primary focus is on improving outcomes in health and education. This is particularly significant given that the GRT community has the lowest life expectancy of any ethnic population in the UK. According to the interviewee, very few members of the community have a GP; one quarter of women die in childbirth; one quarter of children do not live beyond five years old; and women find it difficult to access ante-natal care. To overcome some of these issues, GypsyLife’s Health Ambassador Project was commissioned in 2011 by Newark and Sherwood Clinical Commissioning Group (CCG). The project aims to empower and engage the GRT community by breaking down the barriers to health care. Successes to date include a reduction in the reliance on accident and emergency services and increases in GP registrations (1,500 people in one CCG are now registered with GPs) and MMR immunisations.

The interviewee at GypsyLife was one of the organisation founders.

### The Passage's NHS Outreach Service's work

The Passage is the largest voluntary sector homeless organisation in London. Although the organisation offers some limited residential care, the charity's primary focus is to provide a day service. On first admission to The Passage, a service user is provided with breakfast, lunch, laundry, showers and activity groups. During this time they are assessed for possible referral on to specialist services. A key part of the assessment service is to establish what benefits and support service-users are entitled to. Service users are also encouraged to visit the Primary Health Care Service, which have permanent dedicated medical rooms. The health team confirmed that the majority of their patients arrived for a health assessment following their benefits/housing assessment. Very few individuals will go to The Passage specifically to see a health professional.

The Primary Health Care service is an outreach service that is offered via the NHS. It was established in 2002. The service is staffed by a nurse five days a week, and a sessional GP who attends for an hour three times a week. The nurses operate out of two fully equipped medical rooms. For each patient, the nurses complete a holistic health assessment, which includes a physical, social and mental health assessment and also blood tests/vaccinations etc. If patients require further treatment the nurse's aim is to support and guide the patient through the referral and treatment process.

Given the difficulties that homeless people face in accessing mainstream healthcare, the outreach service aims to: reduce inequalities in healthcare; catch disease early so people do not develop chronic conditions; and prevent inappropriate use of accident and emergency departments.

The researcher interviewed two Nurse Practitioners who are based at The Passage five days a week.

### Information

In understanding how marginalised groups interact with health information, including specific needs of marginalised communities, two broad themes emerged. These are low levels of literacy, and isolation. Furthermore, there were two issues specific to each marginalised group. For the GRT groups, cultural norms around illness create a barrier to accessing information. For the homeless group, the capacity to engage in decision relating to health care was an issue.

According to the representative from GypsyLife, 97% of the GRT community are illiterate. Furthermore, the interviewee described how the 3% who are literate have reading skills equivalent to a 7-11 year old. In the words of the interviewee: *"It is difficult for people to have healthcare if they don't understand the treatment and if they are uncertain."*

Although they would like to produce DVDs, a lack of funding was highlighted as a barrier.

Similarly, at The Passage over half the service users are not British and do not have English as a first language. For example, over a period of 10 clinic days over Christmas 2013 the health centre saw 61 people: 53 men, and 8 women, two of whom were transgender. Of that 61, 28 were from the UK (this is less than half of all service users – 45.9%), and three were from Ireland. The remaining service users originated from France (3 people); Poland (3); Latvia (3); Colombia (3); Bulgaria (3); Uganda (2); Nigeria (2); Romania (1); Ecuador (1);

Portugal (1); Kuwait (1); Somalia (1); Jamaica (1); Russia (1); Burundi (1); Macedonia (1); Iran (1); Egypt (1); and the Czech Republic (1). The nurses use the Language Line service to help translate.

Partly because of literacy issues, and partly because of a limited capacity to engage in personal-decision making (see below), the nurses at The Passage explained that all the information they gave out was clear and not too technical. To this end, the nurses print out information from the NHS website. Additionally, the NHS website is on a list of trusted websites. Other trusted websites include charities whose main aim is to address health issues.

The nurses at The Passage described how the isolation experienced by homeless people creates barriers to accessing health information from health professionals. There were two aspects to this isolation. Firstly, most homeless people are alone, especially those who sleep rough. This means that the homeless population are often unable to discuss health issues with friends and family. Secondly, homeless people who do not have a permanent address are often unable to access mainstream healthcare through a GP. During the interview, the nurses explained the importance of outreach for homeless people who struggle to register with a GP: *“If you don’t have a passport or a driving licence, or proof of address you are not going to be able to get registered. This shouldn’t be the case as doctors are meant to register you anyway, but it often is the case.”*

This also means that if diagnosed with a condition, health professionals are unable to post out details of medical appointments, as well as general health care information, unless they use daycentres etc. as their postal address.

The interviewee at GypsyLife described how the RGT community’s isolation resulted in significant barriers to accessing health professionals and health information from outside the community. According to the interviewee, the RGT fear the settled community and, as such, are reluctant to integrate. One reason for this is the prominence that the Holocaust still has within the community; over 3 million Gypsy and Travellers died in the Holocaust and many people fear this may happen again. Furthermore, the interviewee described how negative perceptions of GRT groups affect integration: *“The way the press portray the Gypsy-Traveller community demonises us. An establishment such as MacDonald’s and Frankie and Benny’s will ask us to leave. So, as a family we would struggle to go for a meal, never mind go for healthcare.”*

The interviewee also reported barriers to health information that exist between members of the GRT community. Stigma around illness prevents open discussions within the community. Importantly, men and women do not discuss health with each other, except in the case of a husband and wife. However, even when married the status of women within the community mean that men are unlikely to listen to their partner’s advice. The interviewee explained that *“a man becomes a man at the age of eleven”*; however, *“a woman is a girl until she is a married”*. As a girl, she is her father’s property. As a married woman, she is her husband’s property and the word of the husband is the final word.

Cultural barriers to accessing health information emerged as a particular concern for those in the GRT community. The interviewee pointed out that health was a difficult topic for the community to discuss because of traditional views of the human body. The interviewee

explained: *“Imagine you have been told that half of your body is good and the other half is evil.”*

More specifically, a code of cleanliness, known as *mochadi*, dictates which parts of the body are seen as good or evil. For example, blood is viewed as tainted and cancer is considered an evil curse. A terminal illness is seen as a punishment. The interviewee explained that *“you would only consider going for a cancer test or screening if you thought you had been evil in your life.”* The status of a person with a condition such as cancer creates an overall reluctance to engage with health information.

For the men at the homeless centre, the capacity to engage in any aspect of the health screening or treatment process was a barrier. One nurse described how *“health is absolutely the last thing on their mind when they come to the centre. Health is an extremely low priority for most of the people who come here.”*

The nurses further explained that for someone who is sleeping rough on the street, the first priority is to get warm, seek shelter and find food. Even when men were diagnosed with an illness, they generally do not want information about their condition. Instead, the men were happy to be told exactly what to do next. For example, men generally do not want to make decisions about what tests to have; when to receive treatment; or, what treatment is most appropriate. Due to the complexity of their daily struggles, making decisions about health care was not on the radar of most men. In the words of one of the nurses: *“They have so many pressures in every aspect of their life that they are happy to have their hand held and be guided through the process of getting health care. They look to us nurses for guidance. Mostly, people will not want to know the results of their blood tests or what those results mean; they will just want us to hold their hand, guide them through and tell them what to do next.”*

In relation to prostate cancer, each of the marginalised groups faced a specific barrier in accessing information and support. First, for the homeless group, the social issues that accompany chronic homelessness (e.g. alcohol misuse) mask the symptoms of prostate cancer. Second, for the GRT group, the stigma around the prostate investigation makes prostate cancer a taboo illness.

The nurses at The Passage described how the men who visit the health centre may well have symptoms of prostate cancer but they often attribute these problems to drinking. This is particularly true of men who are over-50 (the group who are most at risk of prostate cancer). The nurse described this group: *“they are the entrenched, chronic rough sleepers who will not pick up on the symptoms for years. They attribute any problems they are having to alcohol.”*

All men to the clinic are asked if they have issues with their bladder and bowels regardless of the reason for their visit. Where men do describe urine issues, they are referred to the GP or to a urology department.

The interviewee at Gypsylife described how the organisation aims to raise awareness of prostate cancer with GRT families at the annual Appleby Horse Fair. Importantly, the organisation aims to raise awareness that prostate cancer is not a death sentence, especially with an early diagnosis. The organisation has spoken to 150 men about prostate cancer – the

men were left with the message that a simple (but intrusive) test “can ease your mind”. Of the 150 men, 120 refused to be tested. In the words of the interviewee, *“they all walked away”*. However, 30 men agreed to be tested. Of those men, one was found to have prostate cancer and was successfully treated. The interviewee described how people were very shocked about the screening process, more so than the potentially fatal consequence of unmonitored prostate cancer: *“People are very shocked about how you get screened for it; obviously it is a very intrusive examination. That is the main thing to get round the community. Learning that you can die from prostate cancer is actually less shocking than learning what the test involves.”*

The interviewee also stated that *“if I was to learn today that I had Prostate Cancer, my community would see it more respectable to end a life rather than seek treatment.”*

To deal with cultural barriers, the interviewee described an effort should be made to normalise the test. This would involve recasting the test as positive rather than negative. Efforts would also need to be made to deal with pervasive myths, such as the idea that the test can cause homosexuality, or that prostate cancer is caused by infidelity.

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