

Men's views on quality care in prostate cancer

What does good quality care mean for men with prostate cancer?

Executive summary

From October 2011 to January 2012 we circulated a survey to men with prostate cancer and a separate survey to partners/relatives/friends of men with prostate cancer, throughout the UK. The aim of this survey was to help to build a picture of what good quality care looks like for men with prostate cancer.

The results from our survey suggest that most men have had a positive experience of prostate cancer treatment and care. Three quarters of men told us that they received 'the best possible care' either 'most of the time' or 'every time'.

However, a significant proportion of men told us that they were not given good quality information about the diagnosis and treatment of prostate cancer, or about life during and after treatment. For example, over 1 in 4 men said they received 'too little' information from the NHS when they were diagnosed.

Additionally, many men told us that they weren't given enough emotional and practical support to help them cope during and after their diagnosis and treatment. We were also told by many men that their partners did not receive the help and support they needed. For example, over 1 in 5 men (22%) said they thought the support their partner received was 'bad' or 'very bad.'

The data from the survey was used to develop draft standards of quality prostate cancer care. We are continuing to consult with people affected by prostate cancer as well as healthcare professionals about these draft standards. The results from this consultation will be used to produce a final set of standards which the charity will be launching in autumn 2012.

Overview of methodology

In order to explore in depth the different areas related to prostate cancer care, we designed a questionnaire which sought to allow each man with prostate cancer to describe his experiences and to express what he believed was key to ensuring quality care. Areas which the survey covered were:

- Diagnosis
- Treatment
- Side effects
- Support for partners
- End of life



**PROSTATE
CANCER UK**

Helping more men survive prostate cancer and enjoy a better quality of life

The survey was promoted among the charity's networks of supporters, volunteers and people affected by prostate cancer between October 2011 and January 2012. It was also promoted in 25 regional local newspapers across the UK and via Local Involvement Networks (LINks) and prostate cancer support groups. Online and paper versions were made available to respondents.

In total, the charity received 610 completed responses from men with prostate cancer. A further 89 questionnaires were returned incomplete and therefore not included in the analysis. Although the results of this survey provide an insight across the whole patient pathway, they are not able to give detailed analyses on each prostate cancer stage on possible treatment choice, location or service provider. Also, we did not ask respondents for their socioeconomic status, and we only received a few responses from Black Minority Ethnic (BME) backgrounds.

The data from the survey was used to develop a set of draft standards of quality prostate cancer care. Between March and April 2012 we have further consulted with people affected by prostate cancer about their experiences and what constitutes good quality care. We are also conducting a survey of healthcare professionals to better understand their views on delivering good quality care for those affected by prostate cancer. The results from these consultations will be used to produce a final set of standards which the charity will be launching in autumn 2012.

2. The experiences of men with prostate cancer

In order to fully inform our quality care work, the questionnaire covered the whole of the prostate cancer pathway from diagnosis, through treatment, to support for living with and beyond prostate cancer.

Outlined below are some of the key findings across prostate cancer care settings.

2.1 Overall

The results from our survey overall suggest that men have had a positive experience of prostate cancer treatment and care. Men told us that they received 'the best possible care' either 'most of the time' (36%) or 'every time' (48%).

2.2 Diagnosis

Overall just over half (51%) of UK men reported that their experience of care around diagnosis was 'very good' with a further third (33%) describing it as 'good'. Only a small percentage of men (6%) described their care around diagnosis as 'very bad' or 'bad'.

Although most men told us that they had been given a full and clear explanation during their diagnosis, some men did not feel their diagnosis was delivered in a sensitive way. Over 1 in 4 men (27%) said they had received too little information, care and support when they were diagnosed.

The survey also revealed that men value early access to a Prostate Cancer Specialist Nurse at the point of diagnosis. Over three quarters of men (76%) told us that being given the name and contact details of a Specialist Nurse at an early stage was 'very important' to them.



**PROSTATE
CANCER UK**

Helping more men survive prostate cancer and enjoy a better quality of life

A respondent commented:

“On the day of diagnosis I was assigned a nurse specialist. She is very special and a superb source of information and more importantly a very caring person.”

When men were asked to describe (in their own words) what was good about their diagnosis, almost 1 in 4 men (24%) said they were pleased at the speed of their diagnosis. Additionally, 16% of men who had had a good experience stated the support of the clinical nurse specialist made the diagnosis process positive. However, when asked about negative experiences over one in 10 men (12%) said (in their own words) they had experienced delays in getting a diagnosis.

A respondent commented:

I was diagnosed with prostate cancer in Dec 2010 with a PSA of 29 and a rectal examination showing prostate growth. The biopsy was eventually done in Aug 2011 and it confirmed this diagnosis. I started Hormone Treatment in October 2011 and Radiotherapy will start in Feb 2012. I thought that there was a code (timescale) for the treatment of cancers?

2.3 Treatment

At the treatment stage, many men reported that they had a good experience with healthcare professionals. They frequently praised clinicians for their friendliness, reassurance and professionalism. However, a quarter of men (27%) told us that they had not received enough information in order to make an informed choice about what treatment to have or what side effects they might experience after treatment. The 2010 National Cancer Patient Experience Survey (NCPES) also found that prostate cancer patients were less likely than patients from other common tumour groups to receive information about the side effects of cancer treatment.² Over 1 in 4 men (26%) in our survey said they received too little information about their treatment options.

Respondent comments included:

“Treatment options were discussed and my preferences were respected and acknowledged. I was made to feel an active partner in the decision about treatment.”

“Consultants and surgeon may be very clever but some forget that they are treating a PERSON not just a PROSTATE.”

“I wish consultants had been more explanatory and sensitive. This was quite traumatic at the time. Cancer is something we all dread and we are all different.”

The men who responded to our survey had undergone a wide range of treatments. The most common treatment reported was radiotherapy which over two in 5 (43%) respondents said they had been given. Over 1 in 3 men (35%) said they had surgery. A quarter (26%) of the respondents said they had hormone therapy. From these results it is likely that men who responded to our survey will have had several treatments. One in 5 (20%) of respondents reported that they were placed under watchful waiting or active surveillance.



**PROSTATE
CANCER UK**

Helping more men survive prostate cancer and enjoy a better quality of life

2.4 Living with and beyond prostate cancer

An overwhelming majority of men reported experiences of treatment side effects. Over 4 out of 5 (85%) told us that they had experienced side effects as a result of their treatment. However, some men reported that they haven't received the necessary care and support to deal with them. One in 5 men (19%) said the care and support they received for the side effects they experienced were 'bad' or 'very bad'. After completing treatment, 1 in 3 men (31%) said that they received 'too little' aftercare for the treatment of side effects.

Respondent comments included:

"There should be more support services in place for side effects and the consultant should check at each follow-up visit on the status of any side effects and whether further help is required."

"The support I am receiving for erectile dysfunction is abysmal. I really believe the urology specialists do not fully understand either the emotional or physical difficulties endured. They give what treatment they think will pacify you but do not really listen to what's needed."

"Six words sum up my experiences - 'Absolutely amazing treatments, absolutely awful side effects'. I know that no two people have the same side effects but I should have been able to get more information on how my side effects were likely to develop."

2.5 End of life

When we asked men what they believed to be the most important factors at the end of life, well over 8 in 10 (85%) men said information about how to manage pain and other symptoms would be very important. Just under 8 in 10 men (79%) said having the contact details of a clinical nurse specialist would be 'very important'. This again demonstrates the importance of information and support across the patient pathway.

A respondent commented:

"It's vital that men receive first class nursing care and support with the final stage of their lives"

3. Support for partners

A significant number of men feel that the support that their partner received through their experiences was not good enough. One in 5 men (22%) thought the support their partner received was 'very bad' or 'bad'. The men reported that their partners had not been offered any support or given information about prostate cancer. Some men (36%) said the support their partner received was 'very good' or 'good'. They reported that they valued the fact that their partners were able to attend consultations with them and were able to ask questions. Additionally, some men said that their partners also received support from the clinical nurse specialist.



**PROSTATE
CANCER UK**

Helping more men survive prostate cancer and enjoy a better quality of life

Respondent comments included:

“Care for Carers is not always as considerate as it should be. Carers sometimes take a greater impact of the problem than the patient.”

“My wife could have benefitted from conversation with a professional regarding my loss of libido and sexual drive.”

4. Co-ordination of care

Throughout the survey, men described how important it was for services to be joined up and allow a smooth transition between primary and secondary care. Over three quarters of men (77%) said that good communication between their specialists and GP was ‘very important’. A similar number of men (76%) said that being given the name and contact details of a prostate cancer nurse specialist was ‘very important’ throughout their journey.

Respondent comments included:

“Specialist said that treatments for prostate cancer needed to be integrated with treatments for my other conditions – but no one could provide such integration. My GP leaves integration to the specialists; specialists leave it to the GP.”

“The co operation between Urologist, Oncologist and Surgeon was seamless - it was as if I was dealing with one medical team.”

5. Summary of key findings

The results from our survey overall suggest that men have had a positive experience of prostate cancer treatment and care. However, a significant proportion of men told us that they were not given good quality information about the diagnosis and treatment of prostate cancer or life during and after treatment. These results indicate that, while most men have had a positive experience of treatment for prostate cancer, their information and support needs are not always being met.

It is clear from the survey that men believe that improving their access to information has to be made a priority. Men have told us that access to good quality information about each step of their treatment and care, and the support of a specialist nurse, are key to having a good experience as a patient, as is good coordination of care.

6. Recommendations

1. More must be done to ensure that all men with prostate cancer have access to information and support across their prostate cancer journey. The results from this survey show that when information and support are provided they enable a man to manage very difficult aspects of prostate cancer, such as severe side effects. All men should receive this.
2. Evidence from this survey identifies services for men with prostate cancer are not always based around the individuals’ needs and wishes. To ensure men get high quality primary,



**PROSTATE
CANCER UK**

Helping more men survive prostate cancer and enjoy a better quality of life

secondary and social care services, these services must be integrated and centred on the man with prostate cancer.

3. GPs must be informed about their patients' care by specialists, so that they are able to coordinate a care package. The importance of a GP around diagnosis and after treatment must not be underestimated.
4. The results from this survey clearly demonstrate the important and vital role clinical nurse specialists (CNS) have to ensuring men across the UK receive good quality care across their journey. The charity's findings confirm what the National Cancer Patient Experience Survey found in 2010 that patients with a CNS are 'significantly more likely to be positive about their care treatment'. All men should have access to a CNS following a diagnosis.

7. Next steps

The data from the survey has been used to develop a set of draft standards of quality prostate cancer care. We are currently consulting people affected by prostate cancer as well as healthcare professionals about these draft standards. The results from this consultation will be used to produce a final set of standards which the charity will be launching in autumn 2012.



**PROSTATE
CANCER UK**

Helping more men survive prostate cancer and enjoy a better quality of life

5. Profile of respondents

5.1 Age: the vast majority of respondents were aged between 65 and 84

UK Age	Number of respondents	Percentage of respondents (to the nearest 1%)
Under 55	19	3
55-64	127	21
65-74	282	46
75-84	116	19
85 and over	19	3
Unknown	47	8

5.2 Stage: most men had localised disease

Prostate cancer stage	Number of respondents	Percentage of respondents (to the nearest 1%)
Localised	239	39
Locally advanced	89	14
Advanced	58	10
Not sure	61	10
Not recorded	163	27

5.3 Country: overwhelming majority of responses were from England, but responses from Scotland and Wales disproportionately high

Country	Number of respondents	Percentage of respondents (to nearest 0.1%)	Population percentage of UK as whole (ONS data, to nearest 0.1%)
UK	610		
England	395	64.7	83.8
Scotland	98	16.1	8.4
Wales	72	11.8	4.8
Northern Ireland	4	0.7	3.0
Unknown / not given	41	6.7	



**PROSTATE
CANCER UK**

Helping more men survive prostate cancer and enjoy a better quality of life

Prostate Cancer UK is a registered charity in England and Wales (1005541) and in Scotland (SC039332). A company limited by guarantee registered number 2653887 (England and Wales).

5.4. Treatments: breakdown of treatments received:

Treatment	Number of respondents	Percentage of respondents to the question (to the nearest 1%)
Active surveillance	59	10
Brachytherapy	147	24
Chemotherapy	129	21
Cryotherapy	9	1
HIFU	23	4
Hormone therapy	156	26
Other	25	4
Radiotherapy	265	43
Surgery	214	35
Watchful waiting	64	10

5.5 Side effects: number of men who experienced a side effect and type after treatment

Experience of any side effects from any treatments for prostate cancer	Number	Percentage respondents to the question (to the nearest 1 %)
Yes	459	85
No	59	11
Unsure	20	4

Side effect	Number of men experiencing side effects (percentage of respondents to the nearest 1%)	Percentage respondents rating this side effect as bad or very bad (to the nearest 1 %)
Anxiety	281 (52%)	60
Erectile dysfunction	410 (76%)	79
Fatigue	358 (67%)	59
Loss of libido	371 (69%)	72
Problems passing urine	306 (57%)	33
Urinary incontinence	367 (68%)	54

² Department of Health (2010) National Cancer Patient Experience Survey Programme. 2010 National Survey Report.

