NPCA
National Prostate Cancer Audit

# Patient Survey

**Completing the questionnaire**
For each question please tick clearly inside the box that is closest to your views using a black or blue pen. Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box.

**IMPORTANT INFORMATION TO READ BEFORE COMPLETING THIS QUESTIONNAIRE**

By completing this questionnaire, you are giving your consent that the information that you give to us will be used for the purposes explained in the Patient Information Sheet.

You are agreeing that:

- Your response to the questionnaire can be held by the National Prostate Cancer Audit.
- The information that you provide can be combined with the information that is provided by your hospital and other NHS databases, such as the Hospital Episodes Statistics, and the National Cancer Registration and Analysis Service.

The National Prostate Cancer Audit will not release your personal details to other organisations, unless required by law or where there is a clear overriding public interest in disclosure.

Your participation is entirely voluntary. You are free to withdraw the information you have provided to the Audit at any time without giving any reason, without your medical care or legal rights being affected.

To protect your privacy, **please do not write your name or address anywhere on the questionnaire.**

If you have any queries about the questionnaire, please call the FREEPHONE helpline number **on 0800 783 1775**

## Patient details

**If you are helping to complete this questionnaire on behalf of the patient, please ensure that the information given below is that of the patient and not your own.**

**Q1. What is your date of birth?**

☐☐ / ☐☐ / ☐☐☐☐

D D M M Y Y Y Y

Please ensure this is your **date of birth NOT** today's date

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**Q2. Have you ever been told by a doctor that you have prostate cancer?**

| Yes | No |
|---|---|
| ☐ 1 | ☐ 2 |

If you have ticked **no** please accept our apologies, we have sent you this questionnaire by mistake. Please do not complete the questionnaire and send it back to us in the envelope provided.

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**The following questions are about how the prostate cancer was diagnosed and what treatment you have received.**

**Q3. How was the prostate cancer diagnosed?**

| | |
|---|---|
| I went to the GP with urinary symptoms, such as difficulty starting to urinate, weak flow of urine, urinating frequently | ☐ 1 |
| I attended my GP with other symptoms | ☐ 2 |
| I had no symptoms and my PSA (blood test) was part of a general health check | ☐ 3 |
| I had no symptoms and I asked my GP to measure my PSA | ☐ 4 |
| Other | ☐ 5 |

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**Q4. What treatment(s) have you received for your prostate cancer? Please tick all that apply**

| | |
|---|---|
| Surgery: this involves the removal of the prostate gland by a surgeon | ☐ 1 |
| Radiotherapy: this involves the use of X-ray beams or implanting radioactive material in the prostate | ☐ 2 |
| Hormone treatment | ☐ 3 |
| Active surveillance: close monitoring of the prostate cancer but no current treatment | ☐ 4 |
| High intensity focused ultrasound (HIFU): this treatment uses ultrasound waves to heat and destroy cancer tissue in the prostate | ☐ 5 |
| Cryotherapy: this treatment uses freezing and thawing to destroy cancer tissue in the prostate | ☐ 6 |
| Chemotherapy | ☐ 7 |
| Other treatment(s) | ☐ 8 |
| I am unsure what treatment I have had | ☐ 9 |

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**If you had "surgery", go to question 5. If not, skip this question**

**Q5. What type of surgery did you have?**

Open prostatectomy: this is the removal of the prostate through a cut in the abdominal wall (belly) or a cut in the perineum (area between the testicles and back passage) ☐ 1

Laparoscopic prostatectomy / Robotic-assisted prostatectomy: this is a keyhole operation to remove the prostate with only a small cut in the abdominal wall (belly) ☐ 2

I am unsure what type of surgery I had ☐ 3

**If you had "radiotherapy", go to question 6. If not, skip this question**

**Q6. What type of radiotherapy did you have? Please tick all that apply**

External beam radiotherapy: this is radiotherapy that uses equipment that produces high-energy X-rays ☐ 1

Permanent seed (low-dose) brachytherapy: this involves implanting radioactive material into the prostate **permanently** ☐ 2

Temporary (high-dose) brachytherapy: this involves placing a source of high-dose radiation into the prostate for **only a few minutes** ☐ 3

I am unsure what type of radiotherapy I have had ☐ 4

**If you have been on "active surveillance", go to question 7. If not, skip this question**

**Q7. What type of active surveillance did you have? Please tick all that apply**

A PSA test every three to six months ☐ 1

A digital rectal examination within a year ☐ 2

A prostate biopsy about a year after you were diagnosed ☐ 3

An MRI scan about a year after you were diagnosed ☐ 4

I did not have any of these investigations ☐ 5

I'm unsure what type of active surveillance I have had ☐ 6

**Q8. Have you been admitted to hospital <u>as an emergency</u> since you were diagnosed with prostate cancer? Please tick all that apply**

Yes, within the first three months after my prostate cancer was diagnosed ☐ 1

Yes, more than three months after my prostate cancer was diagnosed ☐ 2

No ☐ 3

**The next set of questions are about symptoms that men with prostate cancer sometimes experience. For each of the questions below please select the response that best applies to you.**

**The first three questions are about your symptoms immediately before your cancer was diagnosed.**

**Q9. Overall, how big a problem was your urinary function for you immediately before you were diagnosed with prostate cancer?**

- No problem ☐ 1
- Very small problem ☐ 2
- Small problem ☐ 3
- Moderate problem ☐ 4
- Big problem ☐ 5

**Q10. Overall, how big a problem were your bowel habits for you immediately before you were diagnosed with prostate cancer?**

- No problem ☐ 1
- Very small problem ☐ 2
- Small problem ☐ 3
- Moderate problem ☐ 4
- Big problem ☐ 5

**Q11. Overall, how big a problem was your sexual function or lack of sexual function for you immediately before you were diagnosed with prostate cancer?**

- No problem ☐ 1
- Very small problem ☐ 2
- Small problem ☐ 3
- Moderate problem ☐ 4
- Big problem ☐ 5

**The next set of questions are about your symptoms during the last 4 weeks.**

**Q12. Over the past 4 weeks, how often have you leaked urine?**

- More than once a day ☐ 1
- About once a day ☐ 2
- More than once a week ☐ 3
- About once a week ☐ 4
- Rarely or never ☐ 5

**Q13. Which of the following best describes your urinary control during the last 4 weeks?**

- No urinary control whatsoever ☐ 1
- Frequent dribbling ☐ 2
- Occasional dribbling ☐ 3
- Total control ☐ 4

**Q14. How many pads per day did you usually use to control leakage during the last 4 weeks?**

- None ☐ 1
- 1 pad per day ☐ 2
- 2 pads per day ☐ 3
- 3 or more pads per day ☐ 4

**Q15. How big a problem, if any, has each of the following been for you during the last 4 weeks?**
**Please tick one option on each line**

| | No problem | Very small problem | Small problem | Moderate problem | Big problem |
|---|---|---|---|---|---|
| Dripping or leaking urine | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 | ☐ 5 |
| Pain or burning on urination | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 | ☐ 5 |
| Bleeding with urination | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 | ☐ 5 |
| Weak urine stream or incomplete emptying | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 | ☐ 5 |
| Need to urinate frequently during the day | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 | ☐ 5 |

**Q16. Overall, how big a problem has your urinary function been for you during the last 4 weeks?**

- No problem ☐ 1
- Very small problem ☐ 2
- Small problem ☐ 3
- Moderate problem ☐ 4
- Big problem ☐ 5

**Q17. How big a problem, if any, has each of the following been for you during the last 4 weeks?**
**Please tick one option on each line**

| | No problem | Very small problem | Small problem | Moderate problem | Big problem |
|---|---|---|---|---|---|
| Urgency to have a bowel movement | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 | ☐ 5 |
| Increased frequency of bowel movements | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 | ☐ 5 |
| Losing control of your stools | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 | ☐ 5 |
| Bloody stools | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 | ☐ 5 |
| Abdominal / Pelvic / Rectal pain | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 | ☐ 5 |

**Q18. Overall, how big a problem have your bowel habits been for you during the last 4 weeks?**

- No problem ☐ 1
- Very small problem ☐ 2
- Small problem ☐ 3
- Moderate problem ☐ 4
- Big problem ☐ 5

**Q19. How would you rate each of the following during the last 4 weeks?**

| Please tick one option on each line | Very poor to none | Very poor | Fair | Good | Very good |
|---|---|---|---|---|---|
| Your ability to have an erection? | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 | ☐ 5 |
| Your ability to reach orgasm (climax)? | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 | ☐ 5 |

**Q20. How would you describe the usual quality of your erections during the last 4 weeks?**

- None at all ☐ 1
- Not firm enough for any sexual activity ☐ 2
- Firm enough for masturbation and foreplay only ☐ 3
- Firm enough for intercourse ☐ 4

**Q21. How would you describe the frequency of your erections during the last 4 weeks?**

- I **never** had an erection when I wanted one ☐ 1
- I had an erection **less than half** the time I wanted one ☐ 2
- I had an erection **about half** the time I wanted one ☐ 3
- I had an erection **more than half** the time I wanted one ☐ 4
- I had an erection **whenever** I wanted one ☐ 5

**Q22. Overall, how would you rate your ability to function sexually during the last 4 weeks?**

- Very poor ☐ 1
- Poor ☐ 2
- Fair ☐ 3
- Good ☐ 4
- Very good ☐ 5

**Q23. Overall, how big a problem has your sexual function or lack of sexual function been for you during the last 4 weeks?**

- No problem ☐ 1
- Very small problem ☐ 2
- Small problem ☐ 3
- Moderate problem ☐ 4
- Big problem ☐ 5

**Q24. How big a problem during the last 4 weeks, if any, has each of the following been for you?**

| Please tick one option on each line | No problem | Very small problem | Small problem | Moderate problem | Big problem |
|---|---|---|---|---|---|
| Hot flushes | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 | ☐ 5 |
| Breast tenderness / enlargement | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 | ☐ 5 |
| Feeling depressed | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 | ☐ 5 |
| Lack of energy | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 | ☐ 5 |
| Change in body weight | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 | ☐ 5 |

**Q25. If you were to spend the rest of your life with your symptoms, just the way they are now, how would you feel about that?**

- Delighted ☐ 1
- Pleased ☐ 2
- Mostly satisfied ☐ 3
- Mixed, about equally satisfied and dissatisfied ☐ 4
- Mostly dissatisfied ☐ 5
- Unhappy ☐ 6
- Terrible ☐ 7

**The following questions are about the care you received since you were diagnosed with prostate cancer.**

**Q26. When you were diagnosed with prostate cancer, how much information were you given about your condition and possible treatments?**

- Not enough ☐ 1
- The right amount ☐ 2
- Too much ☐ 3

**Q27. When you were diagnosed with prostate cancer, were you given a choice of different types of treatment?**

- Yes ☐ 1
- No, but I would have liked a choice ☐ 2
- I was not given a choice because only one type of treatment was suitable for me ☐ 3
- Not sure / can't remember ☐ 4

**Q28. Do you think your views were taken into account when the team of doctors and nurses caring for you were discussing which treatment(s) you should have?**

- Yes, definitely ☐ 1
- Yes, to some extent ☐ 2
- No, my views were not taken into account ☐ 3
- I didn't know my treatment was being discussed by a team of doctors / nurses ☐ 4
- Not sure / can't remember ☐ 5

**Q29. Were the possible side effects of treatment(s) explained in a way you could understand?**

- Yes, definitely ☐ 1
- Yes, to some extent ☐ 2
- No, side effects were not explained ☐ 3
- I did not need an explanation ☐ 4
- Not sure / can't remember ☐ 5

**Q30. Were you involved as much as you wanted to be in decisions about your care and treatment?**

- Yes, definitely ☐ 1
- Yes, to some extent ☐ 2
- No, but I would have liked to have been more involved ☐ 3
- Not sure / can't remember ☐ 4

**Q31. Were you given the name of a Clinical Nurse Specialist who would be in charge of your care?**

- Yes - **Go to Q32** ☐ 1
- No - **Go to Q33** ☐ 2
- Don't know / not sure - **Go to Q33** ☐ 3

**Q32. When you have important questions to ask your Clinical Nurse Specialist, how often do you get answers you could understand?**

- All or most of the time ☐ 1
- Some of the time ☐ 2
- Rarely or never ☐ 3
- I do not ask any questions ☐ 4

**Q33. Overall how would you rate your care? Please circle a number**

Very poor Very good

0 1 2 3 4 5 6 7 8 9 10

## The following questions are about your health overall

**Under each heading, please tick the ONE box that best describes your health TODAY**

**Q34. Mobility**

- I have no problems in walking about ☐ 1
- I have slight problems in walking about ☐ 2
- I have moderate problems in walking about ☐ 3
- I have severe problems in walking about ☐ 4
- I am unable to walk about ☐ 5

**Q35. Self-Care**

- I have no problems with washing or dressing myself ☐ 1
- I have slight problems washing or dressing myself ☐ 2
- I have moderate problems washing or dressing myself ☐ 3
- I have severe problems washing or dressing myself ☐ 4
- I am unable to wash or dress myself ☐ 5

**Q36. Usual Activities** *(e.g. work, study, housework, family or leisure activities)*

- I have no problems doing my usual activities ☐ 1
- I have slight problems doing my usual activities ☐ 2
- I have moderate problems doing my usual activities ☐ 3
- I have severe problems doing my usual activities ☐ 4
- I am unable to do my usual activities ☐ 5

**Q37. Pain / Discomfort**

- I have no pain or discomfort ☐ 1
- I have slight pain or discomfort ☐ 2
- I have moderate pain or discomfort ☐ 3
- I have severe pain or discomfort ☐ 4
- I have extreme pain or discomfort ☐ 5

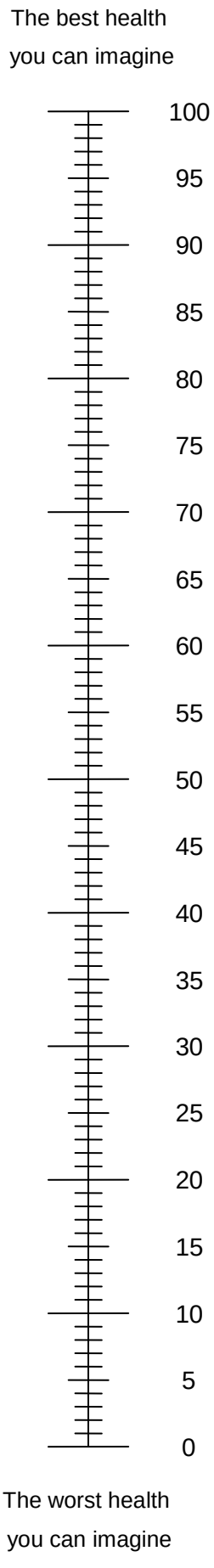
**Q38. Anxiety / Depression**

- I am not anxious or depressed ☐ 1
- I am slightly anxious or depressed ☐ 2
- I am moderately anxious or depressed ☐ 3
- I am severely anxious or depressed ☐ 4
- I am extremely anxious or depressed ☐ 5

**Q39.**

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine.
  0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY = ☐



**Q40. In general, how would you say your health is?**

| | |
|---|---|
| Excellent | ☐ 1 |
| Very good | ☐ 2 |
| Good | ☐ 3 |
| Fair | ☐ 4 |
| Poor | ☐ 5 |

**Q41. In general, how is your health now, compared to before your prostate cancer diagnosis?**

| | |
|---|---|
| Much better | ☐ 1 |
| A little better | ☐ 2 |
| About the same | ☐ 3 |
| A little worse | ☐ 4 |
| Much worse | ☐ 5 |

**Finally, we would like to ask a few questions about you, so that we may better understand your answers to the questionnaire.**

**Q42. Have you ever been told by a doctor that you have any of the following? Please tick all that apply**

| | |
|---|---|
| Heart disease, for example angina, heart attack or heart failure | ☐ 1 |
| High blood pressure | ☐ 2 |
| Problems caused by a stroke | ☐ 3 |
| Leg pain when walking due to poor circulation | ☐ 4 |
| Lung disease, for example asthma, chronic bronchitis or emphysema | ☐ 5 |
| Diabetes | ☐ 6 |
| Kidney disease | ☐ 7 |
| Diseases of the nervous system, for example Parkinson's disease or multiple sclerosis | ☐ 8 |
| Liver disease | ☐ 9 |
| Cancer other than prostate cancer, within the last 5 years | ☐ 10 |
| Depression | ☐ 11 |
| Arthritis | ☐ 12 |

**Q43. Which of the following best describes your current home circumstances?**

- Married or living with a partner ☐ 1
- In a significant relationship, but not living together ☐ 2
- Living alone / single ☐ 3
- Prefer not to say ☐ 4

**Q44. Could we send you a survey in the future to ask about your health and healthcare?**

- Yes, and I understand that this does **NOT** mean that I would have to take part in a future survey. ☐ 1
- No, I would prefer you not to contact me again. ☐ 2

**Q45. Today's date**

☐☐ / ☐☐ / 2 0 ☐☐

D D M M Y Y Y Y

Please ensure this **is today's date NOT** your date of birth

**Q46. What is your ethnic group? Choose one option that best describes your ethnic group or background**

**a. WHITE**

- 1 ☐ English
- 2 ☐ Welsh
- 3 ☐ Scottish
- 4 ☐ Northern Irish
- 5 ☐ Irish
- 6 ☐ Gypsy or Irish Traveller
- 7 ☐ Any other White background (please write in box)

**b. MIXED**

- 8 ☐ White and Black Caribbean
- 9 ☐ White and Black African
- 10 ☐ White and Asian
- 11 ☐ Any other Mixed/Multiple ethnic background (please write in box)

**c. ASIAN OR ASIAN BRITISH**

- 12 ☐ Indian
- 13 ☐ Pakistani
- 14 ☐ Bangladeshi
- 15 ☐ Chinese
- 16 ☐ Any other Asian background (please write in box)

**d. BLACK OR BLACK BRITISH**

- 17 ☐ Caribbean
- 18 ☐ African
- 19 ☐ Any other Black background (please write inbox)

**e. OTHER ETHNIC GROUP**

- 20 ☐ Arab
- 21 ☐ Any other ethnic group (please write in box)

**f.** 22 ☐ I do not want to answer this question

**Thank you very much for completing this questionnaire.**
**Please return the questionnaire in the FREEPOST envelope provided**