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Version: Supplemental Material

Article:

Downing, A orcid.org/0000-0002-0335-7801, Wright, P orcid.org/0000-0001-6129-4143, Hounsome, L et al. (23 more authors) (2019) Quality of life in men living with advanced and localised prostate cancer in the UK: a population-based study. *Lancet Oncology*, 20 (3). pp. 436-447. ISSN 1470-2045

[https://doi.org/10.1016/s1470-2045\(18\)30780-0](https://doi.org/10.1016/s1470-2045(18)30780-0)

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Web extra material

Supplementary file 1: Copy of the LAPCD survey

Life After Prostate Cancer Diagnosis: Patient Reported Outcomes Survey

More men are now living longer after a diagnosis of prostate cancer. We want to find out what life is really like for this group of men. Your answers will benefit other men with prostate cancer in the future by providing information to help clinical teams, service providers and policy makers make decisions about how to improve the quality of services for prostate cancer patients. We would be grateful if you would complete this survey, which asks for information about your health and quality of life.

If you have **not** had a diagnosis of prostate cancer this questionnaire is not relevant to you. Please tick the “no” box below and please accept our apologies for contacting you. Please return the blank questionnaire in the envelope provided and we will correct our records. If you have any questions about this survey please contact the FREEPHONE helpline number: **0808 801 0678**.

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

Yes

No

If you have ticked yes to the first question please complete the rest of the survey.

If you have ticked no, please accept our apologies and send the questionnaire back to us in the envelope provided.

The survey

This survey is made up of eight sections and will take approximately 30 minutes to complete.

Who should complete the questionnaire?

The questions should be answered by the person named in the letter that came with this questionnaire. If that person needs help to answer the questions then the answers should be given from their point of view – not from the point of view of the person who is helping.

Completing the questionnaire

For each question please tick clearly inside the box of the response that best represents your views, using a black or blue pen. Do not worry if you make a mistake. Just cross out the mistake and put a tick in the correct box. Do not write your name or address anywhere on the questionnaire. The more questions in this survey that you complete, the more we can understand what life is like for those living with and beyond prostate cancer. However, if you feel unable or uncomfortable about answering any of the questions, leave it blank and move on to the next one.

The information you give us will be kept **securely** and treated in **confidence**. We will not publish any personal information that could allow anyone to identify you. We are very grateful for your time and effort in completing this survey.

If you have any queries about the questionnaire, please call the FREEPHONE helpline number: **0808 801 0678**

You can find more information about the study at:
<http://www.lifeafterprostatecancerdiagnosis.com/>

Section One: Your overall health

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

1. MOBILITY

- I have no problems in walking about
- I have slight problems in walking about
- I have moderate problems in walking about
- I have severe problems in walking about
- I am unable to walk about

2. SELF-CARE

- I have no problems washing or dressing myself
- I have slight problems washing or dressing myself
- I have moderate problems washing or dressing myself
- I have severe problems washing or dressing myself
- I am unable to wash or dress myself

3. USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

- I have no problems doing my usual activities
- I have slight problems doing my usual activities
- I have moderate problems doing my usual activities
- I have severe problems doing my usual activities
- I am unable to do my usual activities

4. PAIN / DISCOMFORT

- I have no pain or discomfort
- I have slight pain or discomfort
- I have moderate pain or discomfort
- I have severe pain or discomfort
- I have extreme pain or discomfort

5. ANXIETY / DEPRESSION

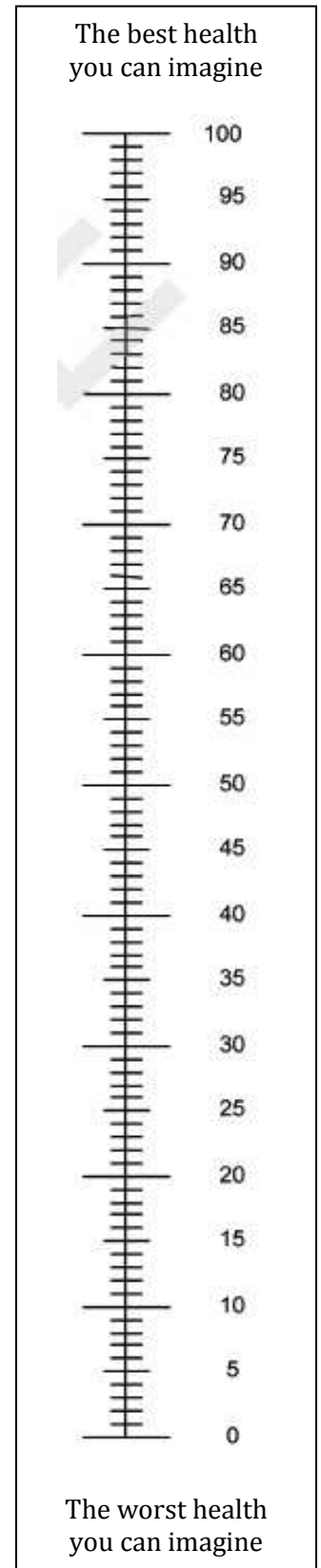
- I am not anxious or depressed
- I am slightly anxious or depressed
- I am moderately anxious or depressed
- I am severely anxious or depressed
- I am extremely anxious or depressed

Are there any additional HEALTH issues that are of concern to you?

6. 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 mark on the scale in the box below.

YOUR HEALTH TODAY =



Section Two: Your diagnosis and treatment

7. How were you diagnosed? Please tick **all that apply**

- I attended my GP with urinary symptoms (e.g. urinating frequently, blood in urine)
- I attended my GP with other symptoms (e.g. back pain, joint pain)
- I had no symptoms and my GP offered to test my PSA (blood test) as part of a general health check
- I had no symptoms and I asked my GP to measure my PSA (blood test)
- I had symptoms and I asked my GP to measure my PSA (blood test)
- I had a PSA test as part of a private health check
- Other

8. Please tell us which treatments you have had following your diagnosis of prostate cancer
Please tick **all** the options that apply.

A. Have you had surgery (prostatectomy)?

No Yes

If **no**, go to **B**

If **yes**, what type of surgery? Please tick one box

Open prostatectomy

Operation performed through a cut in the abdomen above the pubic bone area (retropubic prostatectomy) or a cut in the area between the testicles and back passage (perineal prostatectomy).

Laparoscopic (keyhole) prostatectomy

Operation performed through small incisions in the abdominal wall.

Robotic prostatectomy

Operation performed with the assistance of a surgical robot (Da Vinci prostatectomy).

I don't know what kind of operation I had

B. Have you had radiotherapy?

No Yes

If **no**, go to **C**

If **yes**, what type of radiotherapy? Please tick all that apply

External beam radiotherapy (with or without hormone treatment)

Radiotherapy uses high-energy X-ray beams to treat the whole prostate. This form of treatments includes both 3-dimensional conformal radiotherapy (3D-CRT) and intensity modulated radiotherapy (IMRT).

Permanent seed (low-dose) brachytherapy

This involves implanting radioactive seeds into the prostate gland.

Temporary (high-dose) brachytherapy (with or without external beam radiotherapy or hormone treatment)

This involves inserting a source of high-dose radiation into the prostate gland for a few minutes.

I don't know what type of radiotherapy or brachytherapy I had

C. Have you had any of the following treatments?

Please tick all that apply.

High intensity focused ultrasound (HIFU)

This treatment uses ultrasound waves to heat and destroy cancer cells in the prostate.

Cryotherapy

This treatment uses freezing and thawing to kill the cancer cells in the prostate.

Chemotherapy (not including hormones)

Hormone treatment (either continuous or on/off treatment)

Abiraterone and/or Enzalutamide

D. Are doctors and nurses currently monitoring your prostate cancer?

If **no**, go to question 9

No

Yes

If **yes**, what type of monitoring? Please tick one box.

Active Surveillance

*Surveillance is monitoring of low risk, slow growing **localised prostate cancer** with the aim of avoiding or delaying **curative treatment** (e.g. surgery, radiotherapy). This involves having regular tests.*

Watchful waiting

Watchful waiting is a way of monitoring prostate cancer that isn't causing any symptoms or problems. The aim is to keep an eye on the cancer over the long term and only having treatment if the cancer deteriorates or the patient gets symptoms. This involves fewer tests than in active surveillance.

Clinical follow-up during or after one of the treatments mentioned above in 8A, B or C

I am unsure about the type of monitoring I am currently having

9a. Do you think your views were taken into account when the team of doctors and nurses caring for you were discussing which treatment you should have? Please tick one of the following boxes:

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

9b. Please answer the following questions whether or not you were actively involved in the decisions made about your treatment.

Please think about the decisions you made about your treatment for prostate cancer after talking to your doctor, surgeon, nurse, health care professional etc.

Please show how you feel about these statements by ticking **one** box on each row.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
a. It was the right decision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. I regret the choice that was made	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I would go for the same choice if I had to do it over again	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. The choice did me a lot of harm	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. The decision was a wise one	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please add anything else you would like to tell us about your diagnosis, treatment, and the decision making process.

Section Three: How things are for you now

We understand that some of the following questions are very sensitive, but we would really appreciate you answering them if possible. As with the rest of the questionnaire, your answers will be kept confidential and no one will be able to identify you.

Please tick **one** box for each question.

10. Over the past 4 weeks , how often have you leaked urine?	
More than once a day	<input type="checkbox"/>
About once a day	<input type="checkbox"/>
More than once a week	<input type="checkbox"/>
About once a week	<input type="checkbox"/>
Rarely or never	<input type="checkbox"/>

11. Which of the following best describes your urinary control during the last 4 weeks?	
No urinary control whatsoever	<input type="checkbox"/>
Frequent dribbling	<input type="checkbox"/>
Occasional dribbling	<input type="checkbox"/>
Total control	<input type="checkbox"/>

12. How many pads <u>per day</u> did you usually use to control leakage during the last 4 weeks?	
None	<input type="checkbox"/>
1 pad per day	<input type="checkbox"/>
2 pads per day	<input type="checkbox"/>
3 or more pads per day	<input type="checkbox"/>

13. How big a problem, if any, has each of the following been for you during the last 4 weeks? <i>Please tick one box on each line.</i>					
	No problem	Very small problem	Small problem	Moderate problem	Big problem
a. Dripping or leaking urine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Pain or burning on urination	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Bleeding with urination	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Weak urine stream or incomplete emptying	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Need to urinate frequently during the day	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

14. Overall, how big a problem has your urinary function been for you during the last 4 weeks? <i>Please tick one box.</i>	
No problem	<input type="checkbox"/>
Very small problem	<input type="checkbox"/>
Small problem	<input type="checkbox"/>
Moderate problem	<input type="checkbox"/>
Big problem	<input type="checkbox"/>

15. How big a problem, if any, has each of the following been for you during the last 4 weeks? <i>Please tick one box on each line.</i>					
	No problem	Very small problem	Small problem	Moderate problem	Big problem
a. Urgency to have a bowel movement	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Increased frequency of bowel movements	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Losing control of your stools	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Bloody stools	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Abdominal/ Pelvic/Rectal pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

16.	Overall, how big a problem have your bowel habits been for you during the last 4 weeks ? <i>Please tick one box.</i>
No problem	<input type="checkbox"/>
Very small problem	<input type="checkbox"/>
Small problem	<input type="checkbox"/>
Moderate problem	<input type="checkbox"/>
Big problem	<input type="checkbox"/>

17.	How would you rate each of the following during the last 4 weeks ? <i>Please tick one box on each line.</i>				
	Very poor to none	Poor	Fair	Good	Very good
a. Your ability to have an erection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Your ability to reach orgasm (climax)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

18.	How would you describe the usual QUALITY of your erections during the last 4 weeks ? <i>Please tick one box.</i>
None at all	<input type="checkbox"/>
Not firm enough for any sexual activity	<input type="checkbox"/>
Firm enough for masturbation and foreplay only	<input type="checkbox"/>
Firm enough for intercourse	<input type="checkbox"/>

Please tick **one** box for each question.

19.		How would you describe the FREQUENCY of your erections during the last 4 weeks?
I NEVER had an erection when I wanted one		<input type="checkbox"/>
I had an erection LESS THAN HALF the time I wanted one		<input type="checkbox"/>
I had an erection ABOUT HALF the time I wanted one		<input type="checkbox"/>
I had an erection MORE THAN HALF the time I wanted one		<input type="checkbox"/>
I had an erection WHENEVER I wanted one		<input type="checkbox"/>

20.		Overall, how would you rate your ability to function sexually during the last 4 weeks?
Very poor		<input type="checkbox"/>
Poor		<input type="checkbox"/>
Fair		<input type="checkbox"/>
Good		<input type="checkbox"/>
Very good		<input type="checkbox"/>

21.		Overall, how big a problem has your sexual function or lack of sexual function been for you during the last 4 weeks?
No problem		<input type="checkbox"/>
Very small problem		<input type="checkbox"/>
Small problem		<input type="checkbox"/>
Moderate problem		<input type="checkbox"/>
Big problem		<input type="checkbox"/>

22. How big a problem during the last 4 weeks , if any, has each of the following been for you? <i>Please tick one box on each line.</i>					
	No problem	Very small problem	Small problem	Moderate problem	Big problem
Hot flushes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Breast tenderness/enlargement	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling depressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of energy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Change in body weight	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

During the last 4 weeks <i>Please tick one box on each line.</i>					
	Not at all	A little	Quite a bit	Very much	
23. To what extent were you interested in sex?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
24. To what extent were you sexually active (with or without intercourse)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

25. Have you used any medications to aid or improve erections since your prostate cancer diagnosis? (e.g. tablets, penis injections, gels) <i>Please tick one box.</i>							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
I was not offered this	I was offered this but did not want it	I was offered this but have not tried it	I was offered this and tried it, but it was not helpful	I was offered this and it helped, but I am not using it now	I was offered this, it helps and I use it sometimes	I was offered this, it helps and I use it often	

26. Have you used any devices to aid or improve erections since your prostate cancer diagnosis? (e.g. vacuum pump, penile prosthesis) <i>Please tick one box.</i>							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
I was not offered this	I was offered this but did not want it	I was offered this but have not tried it	I was offered this and tried it, but it was not helpful	I was offered this and it helped, but I am not using it now	I was offered this, it helps and I use it sometimes	I was offered this, it helps and I use it often	

27. Have you used any specialist services to help with your sex life following your diagnosis of prostate cancer? (e.g. counselling, psychosexual clinics, psychology)

*Please tick **one** box.*

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was not offered this	I was offered this but did not want it	I was offered this but have not tried it	I was offered this and tried it, but it was not helpful	I was offered this and it helped, but I am not using it now	I was offered this, it helps and I am still using the service

During the past week: *Please tick **one** box on each line.*

	Not at all	A little	Quite a bit	Very much
28. Did you need to rest?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Have you felt weak?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. Were you tired?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please add anything else you would like to tell us about your symptoms or the side effects of your treatment.

Section Four: Your everyday life

On each line please tick the box that best describes your answer.

Please tick the '**no difficulty box**' if a question **does not apply to you**.

<i><u>During the past month:</u></i>	No difficulty	A little difficulty	Quite a bit of difficulty	Very much difficulty
31. Have you had any difficulty maintaining your independence?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. Have you had any difficulty with managing your own personal care? (e.g. bathing, dressing, washing)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. Have you had any difficulty with looking after those who depend on you? (e.g. children, dependent adults, pets)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. Have you had any difficulties with benefits? (e.g. Statutory Sick Pay, Personal Independence Payments, Attendance Allowance, Universal Credit)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. Have you had any financial difficulties?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. Have you had any difficulties with financial services? (e.g. loans, mortgages, pensions, insurance)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. Have you had any difficulty concerning your work? (or education if you are a student)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. Have you had any difficulty with planning for your own or your family's future? (e.g. care of dependents, legal issues, business affairs)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. Have you had any difficulty with communicating with those closest to you? (e.g. partner, children, parents)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<i>During the past month:</i>	No difficulty	A little difficulty	Quite a bit of difficulty	Very much difficulty
42. Have you had any difficulty with communicating with others? (e.g. friends, neighbours, colleagues, dates)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. Have you had any difficulty concerning plans to have a family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. Have you had any difficulty concerning your appearance or body image?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45. Have you felt isolated?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
46. Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
47. Have you had any difficulty in carrying out your recreational activities (e.g. hobbies, pastimes, social pursuits)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
48. Have you had any difficulty with your plans to travel or take a holiday?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

49. In the **past week**, on how many days have you done a total of 30 minutes or more of physical activity, which was enough to raise your heart rate?
(This may include sport, exercise and brisk walking or cycling for recreation or to get to and from places, but should not include housework or physical activity that is part of your job.)

Please tick **one** box.

- None
 1 day
 2 days
 3 days
 4 days
 5 days
 6 days
 7 days

Please add anything else you would like to tell us about how your prostate cancer has had an impact on your everyday life.

Section Five: Your emotional wellbeing

Below are some statements about feelings and thoughts. Please tick the box on each line that best describes your experience of each over **the last 2 weeks**.

STATEMENTS	None of the time	Rarely	Some of the time	Often	All of the time
50. I've been feeling optimistic about the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
51. I've been feeling useful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
52. I've been feeling relaxed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
53. I've been dealing with problems well	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
54. I've been thinking clearly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
55. I've been feeling close to other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
56. I've been able to make up my own mind about things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The following questions ask about how you have been feeling during the **past 30 days**. For each question, please tick the box on each line that best describes how often you had this feeling.

During the past 30 days, about how often did you feel...

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
57. ...nervous?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
58. ...hopeless?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
59. ...restless or fidgety?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
60. ...so depressed that nothing could cheer you up?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
61. ...that everything was an effort?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
62. ...worthless?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please add anything else you would like to tell us about how your prostate cancer has had an impact on your emotional well-being.

Section Six: Looking to the future

Even if you are now free from prostate cancer please complete this section.

Please read the statements carefully and tick your responses to them. *Please tick **one** box on each line. If a question does not apply to you please leave it blank.*

	Strongly agree	Agree	Disagree	Strongly disagree
62. I am capable of coping with my prostate cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
63. I have all the information I need to manage my prostate cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
64. I am capable of helping health professionals reach decisions related to my prostate cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
65. My family are very supportive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
66. I need the support of my family and friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
67. My family and friends still rely on me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
68. I can adapt to the changes in my lifestyle	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
69. Health professionals are happy to include me in decisions related to my prostate cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
70. I want my family and friends to continue to rely on me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
71. My friends are always supportive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
72. I still feel useful in my daily life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
73. My spiritual beliefs help me cope with my prostate cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
74. I accept that I have to change my lifestyle	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
75. Complementary therapies help me cope with my prostate cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
76. I have a lot of confidence in my local GP	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
77. How much of an impact has prostate cancer had on your life?	No impact <input type="checkbox"/>	A little impact <input type="checkbox"/>	Quite a bit of impact <input type="checkbox"/>	Very much impact <input type="checkbox"/>

What have been the most important issues that you have faced since your prostate cancer diagnosis?

Section Seven: Questions about you

78. How old are you (in years)?

79. What is your **legal** marital status? *Please tick **one** box.*

- Married
- In civil partnership
- Separated
- Divorced/dissolved civil partnership
- Widowed/surviving partner from civil partnership
- Single (never married/never in civil partnership)
- Other

80. What was your employment status before your diagnosis of prostate cancer? *Please tick **one** box.*

- Full time employment
- Part time employment
- Self employed
- Looking after family/home
- Retired
- Unemployed, seeking work
- Unemployed, unable to work for health reasons
- Other

81. What is your employment status currently? *If on sick leave answer in relation to your usual employment status. Please tick **one** box.*

- Full time employment
- Part time employment
- Self employed
- Looking after family/home
- Retired
- Unemployed, seeking work
- Unemployed, unable to work for health reasons
- Other

82. To which of these ethnic groups would you say you belong? *Please tick **one** box.*

White

- English/Welsh/Scottish/Northern Irish/British
- Irish
- Gypsy or Irish Traveller
- Any other White background

Mixed/Multiple ethnic groups

- White and Black Caribbean
- White and Black African
- White and Asian
- Any other Mixed/multiple ethnic background

Asian / British Asian

- Indian
- Pakistani
- Bangladeshi
- Chinese
- Any other Asian background

Black/African/Caribbean/Black British

- Black African
- Black Caribbean
- Any other Black / African / Caribbean background

Other ethnic group

- Arab
- Any other ethnic group

83. Do you consider yourself... *Please tick **one** box.*

- Heterosexual / straight
- Homosexual / gay
- Bisexual
- Don't know
- Prefer not to answer

84. Which, if any, of the following conditions do you have? *Please tick **all** the boxes that apply.*

- A heart condition
- Angina
- High blood pressure
- Asthma or other chronic chest problem
- Liver disease
- Problems with your stomach, bowels or gallbladder
- Problems with your pancreas
- Kidney disease
- Diabetes
- Stroke
- Alzheimer's disease or dementia
- Epilepsy
- Other long standing neurological problem
- A diagnosis of arthritis

85. How tall are you?feet.....inches ORcentimetres Don't know

86. How much do you weigh?stone.....pounds ORkilograms... grams Don't know

87. Have you ever in your lifetime seen a health care professional (such as a GP, psychiatrist, psychologist, social worker, counsellor, psychotherapist, mental health nurse, or any other such professional) for problems with your emotions or nerves or your use of alcohol or drugs?

- Yes No

88. Do you look after, or give any help or support (not part of your paid employment) to family members, friends, neighbours or others because of either:

- Long term physical or mental health disability, or
- Problems relating to old age

- Yes No

Is there anything else you would like to tell us about what life has been like for you following your prostate cancer diagnosis?

Please would you tell us who filled in this survey? *Please tick **one** box.*

- The person to whom this survey was sent
- A representative of the person to whom this survey was sent
(e.g. partner, family member, friend)

Follow-up survey

Thank you for completing this survey. We will be **contacting you again in a years time** for the follow-up survey. If you decide at that time you would rather not complete the survey again there is no obligation to do so.

Follow-up interview

As part of this work we are going to be interviewing a small number of men and some partners /spouses to gain a better understanding of their experience. This will only involve men and their partners / spouses who indicate they are interested in being interviewed. We would normally only be able to interview either the participant or their partner/spouse. We will not be interviewing couples together.

If you or your partner/spouse is interested in being involved in the interview, please tick the relevant boxes below.

- I am interested in being interviewed for this work
- My partner / spouse is interested in being interviewed for this work

We are sorry we will not be able to contact all those who would like to participate in the interview, but we will make sure that we get the views of a varied group. If you are one of the group we would like to interview we will write to you explaining how to get in touch with us to find out more about the interview. If you are still interested, we would arrange a time for the interview. If you think your partner/spouse would like to be interviewed, we would follow a similar process by making the initial contact with you by letter.

If you would like to know more about this study then please visit our website:
<http://www.lifeafterprostatecancerdiagnosis.com/>

We very much appreciate the time and thought you have put into completing this survey. If reflecting on your situation has caused anxiety or uncertainty in any way, please do not hesitate to contact your specialist cancer nurse or call one of the specialist nurses on Prostate Cancer UK's Confidential Help Line.

*Prostate Cancer UK's Specialist Nurse Telephone Line: **0800 074 8383***

(Free from UK landlines)

(Monday – Friday 9-6pm, Wednesday 10-9pm).

They are there to listen to your concerns, and offer support and helpful information

You have completed the survey. Thank you for your time.

Supplementary file 2: Treatment data

Self-reported treatments (question 8) were categorised into single therapies or combination therapies. Many different treatment combinations were reported; some of these combinations were too small to report separately. The ten single and combination treatment groups with the largest numbers of men and highest clinical relevance were included in treatment-specific analyses.

A much higher than expected proportion (3.4%) reporting having High Intensity Focused Ultrasound (HIFU), indicating some confusion with this terminology. This group was excluded from analyses by treatment type, as were men reporting having radiotherapy who did not know which type (4.6%) and those who were unsure which type of follow-up they were receiving (2.1%).

Treatment categories

	n	%
Single treatments:		
Surgery	7,054	19.7
Androgen deprivation therapy (ADT)	3,116	8.7
Active surveillance	2,928	8.2
External beam radiotherapy (EBRT)	2,536	7.1
Watchful waiting	2,292	6.4
Included in treatment-specific analyses	1,208	3.4
Combinations:		
EBRT + ADT	7,488	20.9
Surgery + EBRT/ADT	2,349	6.6
Systemic therapy + ADT	630	1.8
Systemic therapy + EBRT (+/- ADT)	513	1.4
Other:		
Excluded from treatment-specific analyses	1,664	4.6
RT unknown type (alone or in combination)	1,231	3.4
HIFU (alone or in combination)	746	2.1
Follow-up only (unknown type)	294	0.8
No options ticked		
Unassigned combination	1,774	5.0
	35,823	100

Systemic therapy: Chemotherapy/Abiraterone/Enzalutamide; RT: Radiotherapy; HIFU: High intensity focused ultrasound

Supplementary table 1: Comparison of responders and non-responders

Characteristic		Non-responder	Responder	Total	Response rate
Age at diagnosis*	<55 years	1,293	1,392	2,685	51.8%
	55-64 years	5,013	8,529	13,542	63.0%
	65-74 years	8,886	16,992	25,878	65.7%
	75-84 years	6,407	8,094	14,501	55.8%
	85+ years	1,385	810	2,195	36.9%
	Unknown	123	6	129	
	Total	23,107	35,823	58,930	60.8%
Ethnic group*†	White	17,493	28,705	46,198	62.1%
	Mixed	121	78	199	39.2%
	Asian	536	333	869	38.3%
	Black	1,040	586	1,626	36.0%
	Other	210	173	383	45.2%
	Unknown	481	590	1,071	55.1%
	Total	19,881	30,465	50,346	60.5%
Stage of disease at diagnosis	1	7,606	10,880	18,486	58.9%
	2	4,776	8,719	13,495	64.6%
	3	3,761	7,209	10,970	65.7%
	4	2,825	3,925	6,750	58.1%
	Unknown	4,139	5,090	9,229	55.2%
	Total	23,107	35,823	58,930	60.8%
Deprivation quintile	1 - least deprived	4,446	9,408	13,854	67.9%
	2	4,978	9,289	14,267	65.1%
	3	4,782	7,381	12,163	60.7%
	4	4,401	5,266	9,667	54.5%
	5 - most deprived	3,881	3,620	7,501	48.3%
	Unknown	619	859	1,478	58.1%
	Total	23,107	35,823	58,930	60.8%

*This table shows registry-collected age at diagnosis and ethnic group for comparison with the non-responders. The figures here differ to those in Tables 1-3 which use self-reported age and ethnic group.

†Registry-collected ethnic group data only available for England.

Supplementary table 2: Missing data

	N	%
EQ-5D dimensions		
Mobility	412	1.2
Self-care	353	1.0
Usual activities	407	1.1
Pain/discomfort	474	1.3
Anxiety depression	513	1.4
All 5 dimensions	1,054	2.9
Self-assessed health*	820	2.3
EPIC-26 domains**		
Urinary incontinence	3,996	11.2
Urinary irritation/obstruction	6,549	18.3
Bowel function	4,962	13.9
Sexual function	3,298	9.2
Vitality/hormone	4,077	11.4
Individual EPIC items		
Leaking >1 time/day	593	1.7
Frequent dribbling	634	1.8
Any pad use**	853	2.4
Leaking/dripping	3,287	9.2
Pain or burning	5,471	15.3
Haematuria	5,755	16.1
Weak stream	5,002	14.0
Frequency	3,573	10.0
Overall urinary problem	516	1.4
Urgency	1,598	4.5
Frequency	4,424	12.3
Incontinence	4,807	13.4
Bloody stools	4,782	13.3
Rectal pain	4,621	12.9
Overall bowel problem	376	1.0
Poor erections	1,783	5.0
Orgasm difficulty	3,781	10.6
Erections not firm	2,319	6.5
Erections not reliable	3,096	8.6
Poor sexual function	2,951	8.2
Overall sexual problem	2,883	8.0
Hot flushes	2,729	7.6
Breast tenderness	4,651	13.0
Depression	3,560	9.9
Lack of energy	2,626	7.3
Weight gain	3,198	8.9
Sexual intervention items		
Medications	2,046	5.7
Devices	2,086	5.8
Specialist services	2,170	6.1
Total in sample	35,823	

*Missing from both the box and the scale (see question 6 of the questionnaire).

**Following substitution of missing values as per EPIC-26 guidance

Supplementary table 3: Outcomes for EPIC-26 individual items in men diagnosed with prostate cancer 18-42 months previously

		Adjusted % (95% CI) reporting moderate or big problem (where *) or problem as indicated under 'Item'													
Domain	Item	Overall	Stage at diagnosis			Treatment group									
			I/II	III	IV	AS	WW	Brachy alone	Surg alone	Surg + EBRT/ADT	EBRT alone	EBRT + ADT	ADT alone	Syst + ADT	Syst + EBRT
Urinary incontinence	Leaking >1 time/day	12.7 (12.3-13.0)	12.4 (11.9-12.8)	13.8 (12.9-14.6)	13.1 (12.0-14.2)	6.9 (5.9-7.8)	8.5 (7.4-9.5)	5.6 (4.3-6.9)	23.4 (22.3-24.5)	22.8 (21.1-24.6)	8.5 (7.4-9.5)	7.7 (7.1-8.3)	8.8 (7.8-9.8)	11.1 (8.7-13.6)	10.0 (7.4-12.6)
	Frequent dribbling	7.3 (7.1-7.6)	6.8 (6.5-7.2)	7.9 (7.3-8.6)	8.7 (7.8-9.6)	3.9 (3.2-4.6)	5.0 (4.2-5.9)	3.6 (2.6-4.7)	11.4 (10.6-12.3)	12.5 (11.1-13.9)	4.6 (3.8-5.4)	4.6 (4.1-5.0)	6.1 (5.2-6.9)	7.5 (5.5-9.6)	7.6 (5.3-9.9)
	Any pad use	12.6 (12.3-13.0)	12.0 (11.6-12.5)	15.2 (14.3-16.0)	11.7 (10.7-12.7)	2.9 (2.3-3.5)	5.0 (4.1-5.8)	4.5 (3.3-5.7)	31.4 (30.2-32.6)	26.4 (24.6-28.2)	5.9 (5.0-6.8)	6.5 (5.9-7.0)	6.5 (5.7-7.4)	8.6 (6.4-10.8)	9.7 (7.1-12.2)
	Dripping/leaking*	7.5 (7.2-7.8)	7.0 (6.6-7.4)	8.3 (7.7-9.0)	7.5 (6.6-8.4)	4.5 (3.7-5.2)	4.5 (3.7-5.4)	2.9 (1.9-3.8)	12.5 (11.6-13.3)	14.5 (13.0-16.0)	5.1 (4.2-6.0)	4.9 (4.4-5.4)	5.4 (4.6-6.3)	6.6 (4.6-8.6)	5.6 (3.6-7.6)
	Pain or burning*	2.6 (2.4-2.8)	2.6 (2.4-2.9)	2.6 (2.2-3.0)	2.6 (2.0-3.1)	1.8 (1.3-2.3)	1.5 (1.0-2.1)	5.8 (4.4-7.2)	1.4 (1.2-1.7)	3.2 (2.5-3.6)	2.9 (2.2-3.6)	2.3 (2.0-2.7)	2.0 (1.4-2.5)	2.4 (1.2-3.7)	3.1 (1.6-4.6)
Urinary irritation/obstruction	Haematuria*	0.8 (0.7-0.9)	0.7 (0.6-0.9)	0.7 (0.5-0.9)	0.9 (0.6-1.3)	0.6 (0.3-0.9)	0.6 (0.2-0.9)	0.5 (0.1-0.9)	0.5 (0.3-0.7)	1.1 (0.7-1.6)	1.2 (0.7-1.6)	0.9 (0.7-1.1)	0.6 (0.3-0.9)	1.1 (0.2-1.9)	1.6 (0.5-2.8)
	Weak stream*	11.6 (11.3-12.0)	11.3 (10.9-11.8)	11.1 (10.3-11.9)	13.6 (12.4-14.8)	16.9 (15.4-18.4)	13.2 (11.7-14.7)	10.7 (9.9-12.6)	7.2 (6.6-7.9)	11.4 (10.0-12.7)	11.1 (9.8-12.4)	11.1 (10.4-11.9)	14.0 (12.6-15.4)	14.1 (11.2-17.0)	15.0 (11.7-18.3)
	Frequency*	18.6 (18.1-19.0)	17.8 (17.2-18.3)	19.1 (18.1-20.0)	21.5 (20.1-22.9)	22.5 (20.9-24.1)	18.4 (16.7-20.0)	15.9 (13.7-18.1)	13.2 (12.3-14.0)	20.0 (18.3-21.7)	17.9 (16.3-19.5)	18.6 (17.7-19.5)	21.1 (19.5-22.7)	21.4 (18.0-24.9)	22.1 (18.3-25.9)
	Overall urinary problem*	12.5 (12.1-12.8)	11.8 (11.4-12.3)	13.2 (12.5-14.0)	14.2 (13.1-15.3)	11.6 (10.4-12.8)	10.6 (9.4-11.8)	10.3 (8.5-12.1)	12.2 (11.4-13.1)	16.3 (14.8-17.8)	11.3 (10.1-12.5)	10.9 (10.2-11.6)	13.6 (12.4-14.9)	12.8 (10.2-15.4)	14.1 (11.1-17.2)
Bowel function	Urgency*	8.8 (8.5-9.2)	8.1 (7.7-8.5)	10.4 (9.7-11.1)	10.1 (9.1-11.0)	4.6 (3.8-5.3)	4.9 (4.0-5.7)	8.0 (6.4-9.6)	4.4 (3.9-4.9)	11.8 (10.5-13.1)	11.4 (10.2-12.7)	13.2 (12.4-14.0)	7.2 (6.3-8.1)	5.9 (4.1-7.8)	12.2 (9.3-15.1)
	Frequency*	6.8 (6.5-7.1)	6.4 (6.0-6.8)	8.0 (7.4-8.7)	6.7 (5.9-7.6)	3.5 (2.8-4.1)	3.7 (2.9-4.5)	7.0 (5.5-8.5)	3.3 (2.8-3.7)	9.2 (8.0-10.4)	9.1 (7.9-10.3)	10.0 (9.3-10.8)	4.9 (4.1-5.7)	5.4 (3.5-7.2)	8.2 (5.7-10.7)
	Incontinence*	3.7 (3.5-3.9)	3.4 (3.1-3.6)	4.5 (4.0-5.1)	4.2 (3.6-4.9)	1.4 (1.0-1.9)	1.8 (1.3-2.4)	3.2 (2.1-4.2)	1.7 (1.4-2.1)	4.8 (3.9-5.7)	5.2 (4.3-6.1)	5.8 (5.2-6.3)	3.0 (2.4-3.6)	3.5 (2.1-5.0)	5.4 (3.4-7.5)
	Bloody stools*	2.5 (2.3-2.7)	2.5 (2.2-2.7)	3.2 (2.8-3.7)	1.9 (1.4-2.3)	0.4 (0.1-0.6)	0.5 (0.2-0.8)	3.4 (2.3-4.5)	0.7 (0.5-0.9)	3.1 (2.4-3.8)	4.7 (3.8-5.6)	5.0 (4.4-5.5)	0.6 (0.3-0.8)	0.0 (0.0-0.0)	3.9 (2.2-5.7)
	Rectal pain*	3.7 (3.5-4.0)	3.5 (3.2-3.8)	3.8 (3.4-4.3)	5.1 (4.4-5.9)	2.5 (1.9-3.0)	2.0 (1.4-2.6)	2.8 (1.9-3.7)	2.7 (2.4-3.1)	4.9 (4.1-5.8)	3.1 (2.4-3.8)	4.5 (4.0-5.0)	4.4 (3.6-5.2)	4.0 (2.5-5.6)	7.9 (5.5-10.3)

	Overall bowel problem*	7.9 (7.6-8.2)	7.4 (7.0-7.7)	8.8 (8.1-9.4)	9.4 (8.5-10.3)	3.9 (3.2-4.6)	4.7 (4.0-5.5)	8.1 (6.5-9.8)	4.9 (4.4-5.4)	10.9 (9.7-12.2)	8.3 (7.3-9.4)	10.2 (9.5-10.9)	7.6 (6.7-8.5)	8.1 (6.0-10.2)	12.2 (9.3-15.0)
Vitality/ hormonal function	Hot flushes*	17.0 (16.6-17.4)	11.0 (10.5-11.4)	24.9 (23.9-25.9)	35.6 (34.0-37.2)	2.6 (2.0-3.2)	4.6 (3.7-5.4)	3.3 (2.2-4.3)	2.5 (2.2-2.9)	20.7 (19.0-22.4)	16.1 (14.6-17.7)	29.6 (28.6-30.7)	34.3 (32.4-36.2)	34.5 (30.7-38.3)	37.4 (33.1-41.7)
	Breast tenderness*	5.2 (4.9-5.4)	3.6 (3.3-3.9)	7.9 (7.2-8.6)	9.0 (8.0-10.0)	0.8 (0.5-1.1)	1.1 (0.7-1.6)	1.4 (0.7-2.0)	0.8 (0.6-1.0)	7.1 (6.0-8.2)	5.4 (4.4-6.4)	9.2 (8.5-9.9)	11.0 (9.6-12.4)	6.7 (4.6-8.8)	7.3 (5.0-9.6)
	Depression*	9.1 (8.8-9.4)	7.9 (7.5-8.3)	10.1 (9.4-10.9)	13.1 (11.9-14.2)	5.5 (4.6-6.3)	5.6 (4.6-6.6)	4.4 (3.2-5.5)	7.2 (6.6-7.8)	10.8 (9.5-12.1)	7.6 (6.5-8.7)	10.5 (9.8-11.3)	12.8 (11.5-14.2)	12.2 (9.6-14.9)	11.0 (8.3-13.8)
	Lack of energy*	21.9 (21.5-22.4)	18.5 (17.9-19.0)	25.2 (24.1-26.2)	34.7 (33.0-36.3)	11.9 (10.7-13.1)	14.9 (13.5-16.4)	13.0 (11.0-15.0)	12.6 (11.8-13.4)	24.9 (23.1-26.8)	21.3 (19.7-23.0)	27.3 (26.2-28.4)	31.4 (29.5-33.3)	40.3 (36.1-44.6)	45.8 (41.2-50.3)
	Weight gain*	14.2 (13.8-14.5)	10.8 (10.4-11.3)	18.7 (17.7-19.6)	24.1 (22.7-25.5)	4.2 (3.4-4.9)	5.5 (4.6-6.5)	5.9 (4.6-7.2)	5.6 (5.0-6.1)	15.7 (14.2-17.3)	14.9 (13.4-16.4)	22.6 (21.6-23.6)	23.5 (21.7-25.3)	24.5 (21.0-28.0)	22.0 (18.3-25.7)
		Poor erections	81.5 (81.1-82.0)	75.5 (74.8-76.1)	91.0 (90.4-91.7)	95.6 (94.9-96.3)	50.8 (48.9-52.8)	57.9 (55.7-60.0)	62.4 (59.5-65.3)	86.0 (85.2-86.8)	93.5 (92.5-94.4)	78.9 (77.1-80.6)	87.5 (86.7-88.2)	92.9 (91.7-94.0)	97.8 (96.6-98.9)
Sexual function	Orgasm difficulty	76.6 (76.1-77.1)	69.7 (68.9-70.4)	86.4 (85.5-87.2)	95.5 (94.8-96.2)	46.1 (44.1-48.2)	54.1 (51.8-56.4)	58.4 (55.4-61.5)	72.6 (71.5-73.8)	84.7 (83.2-86.1)	75.6 (73.7-77.5)	86.5 (85.7-87.4)	93.3 (92.1-94.5)	98.0 (96.9-99.1)	95.3 (93.6-97.1)
	Erections not firm	89.5 (89.2-89.9)	85.8 (85.3-86.3)	95.4 (94.9-95.8)	98.2 (97.8-98.6)	68.5 (66.6-70.3)	73.8 (71.8-75.8)	77.6 (75.3-80.0)	92.7 (92.2-93.3)	96.3 (95.6-97.0)	88.6 (87.3-90.0)	93.0 (92.4-93.6)	97.1 (96.4-97.9)	98.6 (97.7-99.5)	97.5 (96.3-98.7)
	Erections not reliable	86.2 (85.8-86.6)	81.8 (81.2-82.4)	93.7 (93.1-94.2)	97.2 (96.7-97.8)	60.6 (58.6-62.5)	66.1 (63.9-68.3)	72.0 (69.4-74.6)	89.7 (89.0-90.4)	94.7 (93.9-95.6)	85.2 (83.6-86.7)	91.1 (90.4-91.8)	95.8 (94.9-96.7)	97.9 (96.7-99.0)	96.3 (94.7-97.9)
	Poor sexual function	81.0 (80.6-81.5)	75.0 (74.3-75.6)	90.4 (89.7-91.1)	96.0 (95.3-96.6)	51.1 (49.1-53.1)	57.9 (55.7-60.1)	62.8 (60.0-65.6)	83.7 (82.8-84.6)	91.9 (90.8-93.0)	78.8 (77.0-80.5)	88.2 (87.4-89.0)	93.6 (92.4-94.7)	97.8 (96.6-98.9)	95.2 (93.4-97.1)
	Overall sexual problem*	45.2 (44.5-45.8)	43.5 (42.8-44.2)	50.5 (49.2-51.7)	46.1 (44.4-47.8)	28.9 (27.1-30.7)	35.3 (33.2-37.4)	38.6 (35.7-41.5)	51.9 (50.6-53.1)	52.0 (50.0-54.1)	45.6 (43.6-47.7)	46.2 (45.0-47.4)	41.6 (39.6-43.5)	41.3 (37.2-45.5)	41.3 (36.8-45.9)

Adjusted for age at survey, socio-economic deprivation and number of other long-term conditions. AS: Active surveillance; WW: Watchful waiting; Brachy: Brachytherapy; Surg: Surgery; EBRT: External beam radiotherapy; ADT: Androgen deprivation therapy; Syst: Systemic therapy (Chemotherapy/Abiraterone/Enzalutamide).

Supplementary table 4: Outcomes for EPIC-26 vitality/hormonal domain items in men treated with and without androgen deprivation therapy (ADT)

Item	Treated with ADT	No ADT
Hot flushes	30.7 (29.8-31.6)	5.4 (5.0-5.8)
Breast tenderness	9.5 (8.9-10.0)	1.6 (1.4-1.8)
Depression	11.4 (10.8-12.0)	6.6 (6.2-7.0)
Lack of energy	29.4 (28.6-30.3)	14.7 (14.2-15.3)
Weight gain	22.5 (21.7-23.3)	6.9 (6.5-7.3)

Supplementary Table 5: Access to and use of interventions to improve sexual function in men diagnosed with prostate cancer 18-42 months previously

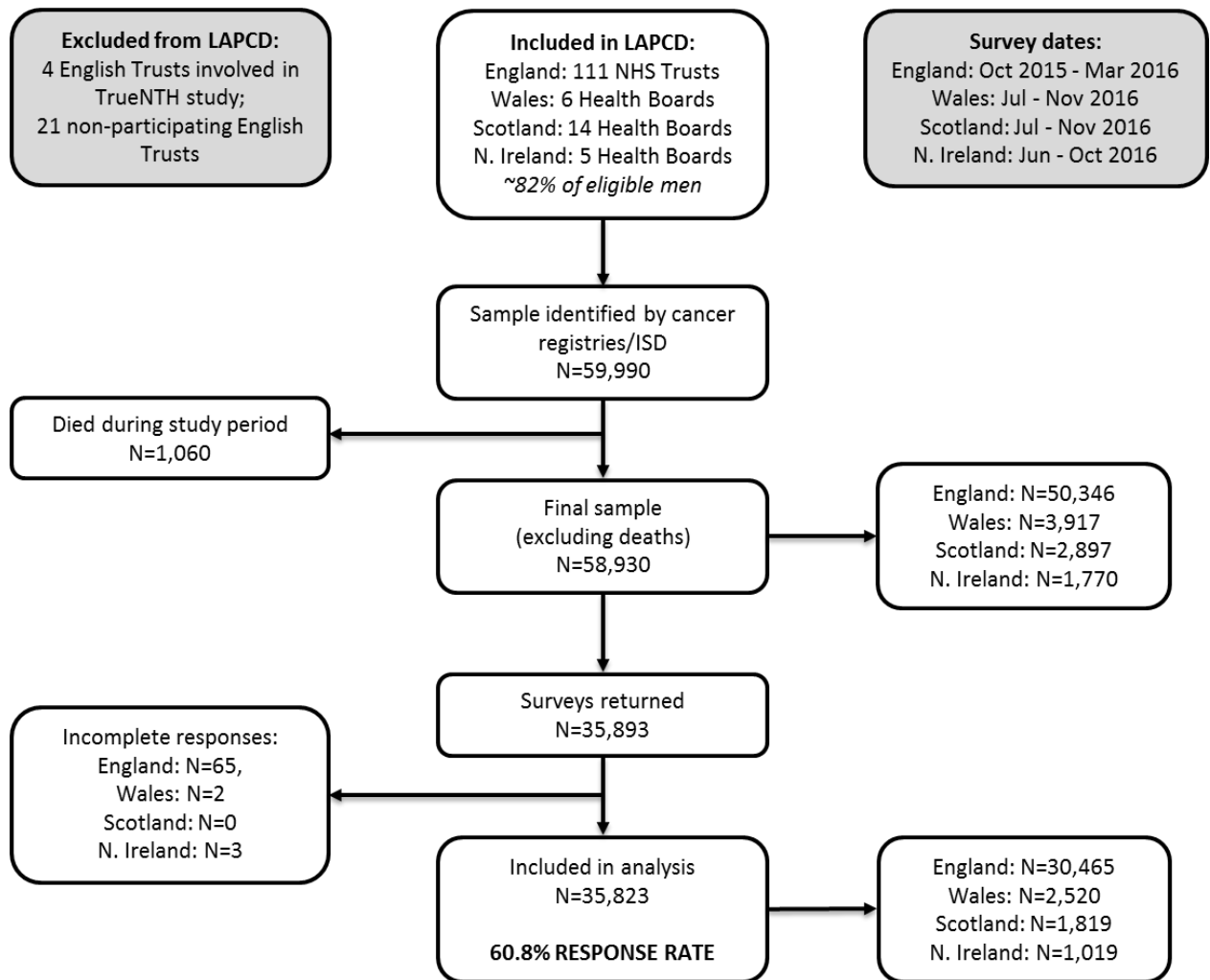
a) Any intervention: Medications, devices or services					
	All men with PCa			Men offered intervention	
	No.	%		No.	%
Not offered	18,782	55.8			
Offered but did not want/try it	5,534	16.4	Offered but did not want/try it	5,534	37.2
Offered but did not help	3,546	10.5	Offered but did not help	3,546	23.8
Offered and it helped	5,812	17.3	Offered and it helped	5,812	39.0
Total	33,674	100.0	Total	14,892	100.0
Total offered any intervention	14,892	44.2			

b) Medications to aid or improve erections					
	All men with PCa			Men offered intervention	
	No.	%		No.	%
Not offered	19,805	58.6			
Offered but did not want/try it	5287	15.7	Offered but did not want/try it	5287	37.8
Offered but did not help	3911	11.6	Offered but did not help	3911	28.0
Offered and it helped	4774	14.1	Offered and it helped	4774	34.2
Total	33,777	100.0	Total	13,972	100.0
Total offered medications	13,972	41.4			

c) Devices to aid or improve erections					
	All men with PCa			Men offered intervention	
	No.	%		No.	%
Not offered	26,116	77.4			
Offered but did not want/try it	4017	11.9	Offered but did not want/try it	4017	52.7
Offered but did not help	1450	4.3	Offered but did not help	1450	19.0
Offered and it helped	2154	6.4	Offered and it helped	2154	28.3
Total	33,737	100.0	Total	7,621	100.0
Total offered devices	7,621	22.6			

d) Specialist services to improve sex life					
	All men with PCa			Men offered intervention	
	No.	%		No.	%
Not offered	28,669	85.2			
Offered but did not want/try it	3445	10.2	Offered but did not want/try it	3445	69.1
Offered but did not help	596	1.8	Offered but did not help	596	12.0
Offered and it helped	943	2.8	Offered and it helped	943	18.9
Total	33,653	100.0	Total	4,984	100.0
Total offered specialist services	4,984	14.8			

Supplementary figure 1: Study inclusions, exclusions and response rates



N. Ireland: Northern Ireland; ISD: Information Services Division (Scotland)

The samples from England, Wales and NI were identified through cancer registration data. The Scottish sample was identified through hospital data and verified via cancer registration data. This resulted in a higher proportion of men who had undergone surgery. The final sample was adjusted to match the profile of the full population of men with PCa in Scotland.