**Reference Number** 



## Men's Health & Wellbeing Survey

# Why are you being asked to do this survey?

We are asking a sample of men to complete this survey relating to everyday health issues which are quite common but often not talked about.

This survey is being run at the same time as another survey which is being sent out to men who have had a diagnosis of prostate cancer within the last three years.

Some of the problems that men with prostate cancer face are also quite often experienced by men who have not had prostate cancer, but we don't know just how common these problems are. To study this we need to compare the experiences of men without prostate cancer to those of men with prostate cancer. You have been randomly picked from the Northern Ireland population as one of the group **without** prostate cancer. If however, you have been recently diagnosed with prostate cancer, you do not need to complete the survey. Just return the pack in the envelope provided indicating when you were diagnosed with prostate cancer. We apologise for contacting you and you will not be contacted again.

By taking part in this survey you will provide important information on men's health which will help health services make decisions about how to improve the quality of care and support for men with and without prostate cancer.

This survey was originally designed to find out more about what life is like for men with prostate cancer. Many men with prostate cancer have problems with their bladder, bowels etc. and so some questions may seem a bit unusual and sensitive. This is because we need to be able to compare answers from this survey with those given by men with prostate cancer.

If you have any questions about this survey please call this FREEPHONE helpline number: 0808 801 06748.

We are very grateful for your time and effort in completing this survey. Your answers will be completely anonymous.

#### The survey

This survey is made up of six sections, and should take approximately 30 minutes to complete.

#### Who should complete the questionnaire?

The questions should be answered by the man named in the letter that came with this questionnaire. If that man needs help to answer the questions then the answers should be given from his point of view – not from the point of view of the person who is helping. The information you give us will be kept **securely and confidentially** and any personal details such as your name will not be available to our researchers. We will not publish any personal information that could allow anyone to identify you

#### Completing the questionnaire

Please use a black or blue pen and for each question tick clearly inside the box that best represents your views. 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.

Although there are a number of questions which may seem quite personal we would really appreciate you answering all questions frankly as it is so important to get a clear picture of what men's health issues are. **Your answers will be anonymous and no one will be able to identify you.** 

The more questions in this survey that you complete, the more information we will have to compare with those men who are living with and beyond prostate cancer. However, if you feel unable or uncomfortable about answering any of the questions, or if any question does not apply to you, please leave it blank and move on to the next one.

If reflecting on your situation has caused anxiety or uncertainty about your health, please contact your GP.

If you have any queries about the questionnaire, please call the FREEPHONE helpline number: 0808 801 06748.

# Section One: Your overall health today

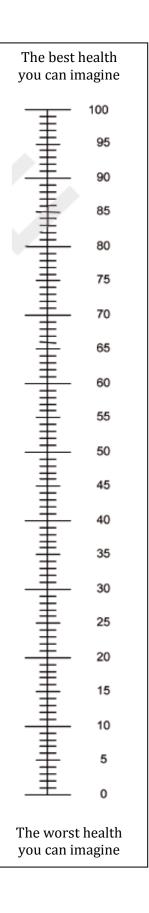
Under each heading, please tick ONE box that best describes your health TODAY

<b>1. MOBILITY</b> 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	
<b>3. USUAL ACTIVITIES</b> (e.g. work, study, housework, family or leisure active 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	ities)
<b>4. PAIN / DISCOMFORT</b> 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	
<b>5. ANXIETY / DEPRESSION</b> 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	

#### 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.





### Section Two: Men's Health Issues

1.	In the <b>last 3 years:</b> <i>Please tick all that apply</i> Have you attended your GP with urinary symptoms (e.g. urinating frequently, blood in urine)?
	Have you attended your GP with back pain or joint pain?
	Has your GP/Practice Nurse offered to test your PSA (blood test) as part of a general health check?
	If yes, Did you go ahead with the test?
$\square$	Have you asked your GP/Practice Nurse to measure your PSA? (blood test).
	Did your GP/ nurse test your PSA, when requested?
	Have you had a PSA test as part of a private health check?
	Have you had a biopsy of your prostate?

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.

2.	Over the <b>past 4 weeks</b> , how often have you leaked urine?
More than once a day	
About once a day	
More than once a week	
About once a week	
Rarely or never	

3.	Which of the following best describes your urinary control <b>during the last 4 weeks?</b>
No urinary control whatsoever	
Frequent dribbling	
Occasional dribbling	
Total control	

# Please answer only IF you leak urine

4.	IF you leak urine, How many pads <u>per day</u> did you usually use to control leakage <b>during the last 4 weeks?</b>
None	
1 pad per day	
2 pads per day	
3 or more pads per day	

5.	for you <b>du</b>	problem, if a r <b>ing the last</b> one box on e	t 4 weeks?	n of the follo	wing been
	No problem	Very small problem	Small problem	Moderate problem	Big problem
Dripping or leaking urine					
Pain or burning on urination					
Bleeding with urination					
Weak urine stream					
Incomplete emptying					
Need to urinate frequently during the day					

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

7.	How big a problem, if any, has each of the following been				
	for you?	Please tie	ck <b>one</b> box o	n each line.	
	No problem	Very small problem	Small problem	Moderate problem	Big problem
Urgency to have a bowel movement					
Increased frequency of bowel movements					
Losing control of your bowel movements					
Bloody stools					
Abdominal/ Pelvic/Rectal/ back passage pain					

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

The following questions are very personal and we appreciate your answers which will help us measure levels of problems that men have. All information provided is anonymous.

9.		l you rate eac <b>ks</b> ? <i>Please tic</i>			ng the
	Very poor to none	Poor	Fair	Good	Very good
Your ability to have an erection					
Your ability to reach orgasm (climax)					

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

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

12.	Overall, how would you rate your ability to function sexually <b>during the last 4 weeks</b> ?
Very poor	
Poor	
Fair	
Good	
Very good	

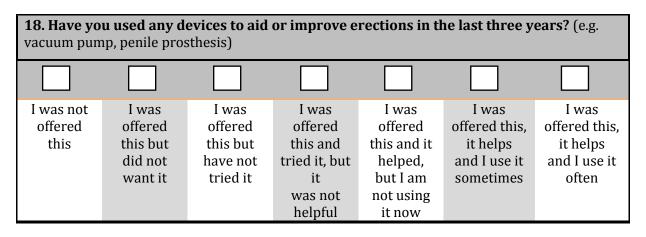
13.	Overall, how big a problem has your sexual function or lack of sexual function been for you <b>during the last 4</b> weeks?
No problem	
Very small problem	
Small problem	
Moderate problem	
Big problem	

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

During the last 4 weeks Please tick one box on each line.								
	Not	А	Quite a	Very				
	at all	little	bit	much				
<b>15.</b> To what extent were you interested in sex?								
<b>16</b> . To what extent were you sexually active (with or without intercourse)?								

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

17. Have you used any medications to aid or improve erections in the last three years? (e.g. tablets, penis injections, gels) *Please tick one box.* I was not I was I was I was I was I was I was offered offered offered offered offered offered this, offered this, this this but this but this and this and it it helps it helps did not have not tried it, but helped, and I use it and I use it want it tried it but I am sometimes often it was not not using helpful it now



<b>19. Have you used any specialist services to aid or improve erections in the last three years?</b> (e.g. counselling, psychosexual clinics, psychology)								
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		

During the past week: Please tick one box on each line.							
	Not at all	A little	Quite a bit	Very much			
<b>20.</b> Did you need to rest?							
<b>21</b> . Have you felt weak?							
<b>22.</b> Were you tired?							

## Section Three: Your everyday life

#### On each line please tick the box that best describes your answer. Please tick the <u>'no difficulty box'</u> if a question <u>does not apply to you</u>.

	During the past month:	No difficulty	A little difficulty	Quite a bit of difficulty	Very much difficulty
1.	Have you had any difficulty maintaining your independence?				
2.	Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)				
3.	Have you had any difficulty with managing your own personal care? (e.g. bathing, dressing washing)				
4.	Have you had any difficulty with looking after those who depend on you? (e.g. children, dependent adults, pets)				
5.	Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?				
6.	Have you had any difficulties with benefits? (e.g. Statutory Sick Pay, Personal Independence Payments, Attendance Allowance, Universal Credit)				
7.	Have you had any financial difficulties?				
8.	Have you had any difficulties with financial services? (e.g. loans, mortgages, pensions, insurance)				
9.	Have you had any difficulty concerning your work? (or education if you are a student)				
10	. Have you had any difficulty with planning for your own or your family's future? (e.g. care of dependents, legal issues, business affairs)				
11	. Have you had any difficulty with communicating with those closest to you? (e.g. partner, children ,parents)				

<b>12.</b> Have you had any difficulty with communicating with others? (e.g. friends, neighbours, colleagues, dates)		
<b>13.</b> Have you had any difficulty concerning plans to have a family?		
<b>14.</b> Have you had any difficulty concerning your appearance or body image?		
<b>15.</b> Have you felt isolated?		
16. Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)		
17. Have you had any difficulty in carrying out your recreational activities (e.g. hobbies, pastimes, social pursuits)		
<b>18.</b> Have you had any difficulty with your plans to travel or take a holiday?		

**19.** 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	I day	2 days	3 days	4 days	5 days	6 days	7 days

### Section Four: 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
<b>1.</b> I've been feeling optimistic about the future					
<b>2.</b> I've been feeling useful					
<b>3.</b> I've been feeling relaxed					
<b>4.</b> I've been dealing with problems well		H		H	
5. I've been thinking clearly				H	
6. I've been feeling close to other people					
<ol><li>I've been able to make up my own mind about things</li></ol>					

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
<b>8.</b> nervous?					
<b>9.</b> hopeless?					
<b>10</b> restless or fidgety?					
<b>11.</b> so depressed that nothing could cheer you up?					
<b>12.</b> that everything was an effort?					
<b>13.</b> worthless?					

<u>Section Five: Looking to the Future</u> 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
<b>1.</b> I am capable of handling my health				
<b>2.</b> I have all the information I need to manage my health				
<b>3.</b> I am capable of helping health professionals reach decisions related to my health				
<b>4.</b> My family are very supportive				
<b>5.</b> I need the support of my family and friends				
<b>6.</b> My family and friends still rely on me				
<b>7.</b> I can adapt to the changes in my lifestyle				
<b>8.</b> Health professionals are happy to include me in decisions related to my health				
<b>9.</b> I want my family and friends to continue to rely on me				
<b>10.</b> My friends are always supportive				
<b>11.</b> I still feel useful in my daily life				
<b>12.</b> My spiritual beliefs help me cope with my health				
<b>13.</b> I accept that I have to change my lifestyle				
<b>14.</b> Complementary therapies help me cope with my health				
<b>15.</b> I have a lot of confidence in my local GP				
	No	A little	Quite a	Very
<b>16.</b> How much of an impact have any health issues had on your life?	impact	impact	bit of impact	much impact

## Section Six: Questions about you

#### 1. How old are you?

2. 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		

#### 3. What was your employment status <u>3 years ago</u>? 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

# 4. What is your employment status <u>currently</u>? If on sick leave answer in relation to your usual <u>employment status</u>. 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

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

White				
	English/Welsh/Scottish			
	Northern Irish			
$\overline{\Box}$	British			
	Irish			
	Gypsy or Irish Traveller			
	Any other White background			
Mixed/M	Iultiple 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			
6. Do you	u consider yourself. Please tick one box.			
	Heterosexual / straight			
	Homosexual / gay			
	Bisexual			
	Don't know			
	Prefer not to answer			

7. Which, if any, of the following conditions do you have? Please tick all the boxes that apply.								
	A heart condition		Kidney disease					
	Angina		Diabetes					
	High blood pressure	Π	Stroke					
	Asthma or other chronic chest problem		Alzheimer's disease or dementia					
	Liver disease		Epilepsy					
	Problems with your stomach, bowels or gallbladder		Other long standing neurological problem					
	Problems with your pancreas		Received radiotherapy for any of the following cancers: kidney, bladder, bowel, testicular					
	Cancer (please indicate the type below)		A diagnosis of Arthritis					
8. How t	all are you?feetinches OR .	centim	etres Don't know					
9. How r	nuch do you weigh?stonepounds	ORkilo	ogramsgrams Don't know					
<ul> <li>Have you <u>ever in your lifetime</u> 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</li> <li>Yes</li> <li>No</li> </ul>								
<ul> <li>11. 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:</li> <li>Long term physical or mental health disability, or Problems relating to old age</li> <li>Yes</li> <li>No</li> </ul>								
12. If you were given the option would you complete this questionnaire online?								
	ı were given the option would you comple	te this que	estionnaire online?					

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

The person to whom this survey was sent

П

П

A representative of person to whom this survey was sent

(e.g. partner, family member, friend)

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

If you would like to know more about the overall study of which this is part then please visit our website at: <u>www.lifeafterprostatecancerdiagnosis.com</u>

If you have any questions about this survey please call this FREEPHONE helpline number: 0808 801 06748

If reflecting on your situation has caused anxiety or uncertainty about your health, please contact your GP.

*We very much appreciate the time and thought you have put into completing this survey.*