Life and Bladder Cancer Survey





This survey is for people who have been diagnosed with bladder cancer in the last 10 years.

IMPORTANT INFORMATION TO READ BEFORE FILLING IN THIS QUESTIONNAIRE

The survey

This survey is made up of nine 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 bladder 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 questionnaire.

- If you have had a diagnosis of bladder cancer in the last 10 years you are eligible to take part in this study.
- Please make sure you have read the information sheet.
- If there are any things you have questions about please ring the FREEPHONE helpline on 0800 917 1163.

You do not have to take part if you don't want to.

If you are happy to take part in this study please tick the box below and put a date in the box beside it. These mean you are **consenting** to take part in this study. Please follow the instructions below about how to fill in the questions.

I understand that the information I provide will be stored securely for use in research. I am happy to take part in this study and give my consent.

Tick here if you consent:

Date:

D D / M M / Y Y Y

If you do not want to take part in this study do not fill in any of the questions. Please return the survey pack in the envelope provided.







REC reference: 17/YH/0095, CAG reference 17/CAG/054

IRAS 219200: Life and Bladder Cancer patient reported outcomes survey

SECTION 1: Your Overall Health Under each heading, please tick the ONE box that best describes your health TODAY.

Q1	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
Q2	SELF-CARE		
	I have no problems with washing or dressing myself	П	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
Q3	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
Q4	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
Q5	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

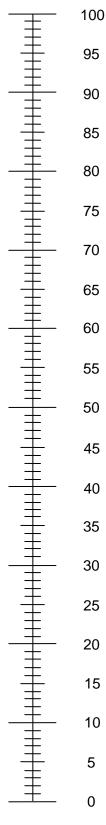
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The best health you can imagine

Q6

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the <u>best</u> health you can imagine.
 0 means the <u>worst</u> 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 =	



The worst health you can imagine

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SECTION 2: Your Treatment

Please tell us which treatment you have had following your diagnosis of bladder cancer.

Q7	Have you had surgery?				
	(this includes TURBT – transurethral resection of bladder tumour)				
	Yes \square 1 \rightarrow Go to Question 8 No \square 2 \rightarrow Go to Question 9				
Q8	What type of surgery have you had? (Please tick all that apply)				
	Radical Cystectomy (Removal of the bladder)				
	Telescopic/endoscopic surgery to remove cancer cells (TURBT)				
	(Surgery is carried out using an endoscope and leaves the bladder intact)				
	I don't know / can't remember				
Q9	Have you had radiotherapy?				
	Yes				
Q10	Have you had treatments directly into your bladder?				
	Yes ☐ 1 → Go to Question 11 No ☐ 2 → Go to Question 12				
Q11	If you had treatments directly into your bladder, what were they?				
	(Tick all that apply)				
	Chemotherapy or mitomycin				
	BCG instilled directly into your bladder (Bacillus Calmette-Guerin)				
	I don't know / can't remember 3				
Q12	Have you had any sort of chemotherapy into a vein?				
	Yes				

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SECTION 3: 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 the box that best describes your answ	er:			
		Not at all	A little	Quite a bit	Very much
Q13	Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	□ 1	□ 2	П з	<u> </u>
Q14	Do you have any trouble taking a long walk?	□ 1	□ 2	□ 3	□ 4
Q15	Do you have any trouble taking a short walk outside of the house?	□ 1	□ 2	П з	□ 4
Q16	Do you need to stay in bed or a chair during the day?	□ 1	□ 2	3	□ 4
Q17	Do you need help with eating, dressing, washing yourself or using the toilet?	□ 1	□ 2	3	□ 4
During	the <u>past week</u> :				
Q18	Were you limited in doing either your work or other daily activities?	□ 1	□ 2	□ 3	□ 4
Q19	Were you limited in pursuing your hobbies or other leisure time activities?	□ 1	□ 2	П з	□ 4
Q20	Were you short of breath?	□ 1	□ 2	□ 3	□ 4
Q21	Have you had pain?	□ 1	□ 2	П з	□ 4
Q22	Did you need to rest?	□ 1	□ 2	П з	□ 4
Q23	Have you had trouble sleeping?	□ 1	□ 2	П з	□ 4
Q24	Have you felt weak?	□ 1	□ 2	П з	□ 4
Q25	Have you lacked appetite?	□ 1	□ 2	П з	□ 4
Q26	Have you felt nauseated?	□ 1	□ 2	П з	□ 4
Q27	Have you vomited?	□ 1	□ 2	П з	□ 4
Q28	Have you been constipated?	□ 1			

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During	g the <u>past week</u> :			Not at a	II A littl	e Quite a	a bit	Very much
Q29	Have you had d	liarrhoea?			1 🗆	2	3	□ 4
Q30	Were you tired?)			1 🗆	2] 3	□ 4
Q31	Did pain interfer	d pain interfere with your daily activities?			1 🗆	2	3	□ 4
Q32	Have you had d things like readi television?	•	, 🗆	1 🗆	2	3	□ 4	
Q33	Did you feel ten	se?			1 🗆	2] 3	□ 4
Q34	Did you worry?				1	2	3	□ 4
Q35	Did you feel irrit	able?			1 🗆	2] 3	□ 4
Q36	Did you feel dep	oressed?			1 🗆	2	3	□ 4
Q37	Have you had difficulty remembering things?				1 🗆	2	3	□ 4
Q38	Has your physical condition or medical treatment interfered with your family life?				1 🗆	2] 3	□ 4
Q39	Has your physical condition or medical treatment interfered with your social activities?				1 🔲	2	3	□ 4
Q40	Has your physical condition or medical treatment caused you financial difficulties?				1 🗆	2	3	□ 4
For the f	ollowing question	ns please ci	rcle the number	between 1	and 7 tha	at best appli	es to	you.
Q41	How would you	ı rate your o	verall health dui	ring the pa	st week?			
	Very poor							Excellent
	1	2	3	4	5	6		7
Q42	How would you	ı rate your o	verall quality of	life during	the past	week?		
	Very poor							Excellent
	1	2	3	4	5	6		7

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Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems **during the** <u>past week</u>.

Please tick the box that best describes your answer.

Please answer questions 43 – 49 only if you **do not** have a urostomy.

During	g the past week:	Not at all	A little	Quite a bit	Very much
Q43	Have you had to urinate frequently during the day?	□ 1	□ 2	П з	□ 4
Q44	Have you had to urinate frequently at night?	□ 1	□ 2	П з	□ 4
Q45	When you felt the urge to pass urine, did you have to hurry to get to the toilet?	□ 1	□ 2	П з	□ 4
Q46	Was it difficult for you to get enough sleep, because you needed to get up frequently at night to urinate?	□ 1	□ 2	□ 3	□ 4
Q47	Have you had difficulty going out of the house, because you needed to be close to a toilet?	□ 1	□ 2	П з	□ 4
Q48	Have you had any unintentional release (leakage) of urine?	□ 1	□ 2	П з	□ 4
Q49	Have you had pain or a burning feeling when urinating?	□ 1	□ 2	П з	□ 4
Please	e answer questions 50 – 55 only if you have a uro	stomy.			
During	g the <u>past week</u> :	Not at all	A little	Quite a bit	Very much
Q50	Has urine leaked from your urostomy bag?	□ 1	□ 2	□ 3	□ 4
Q51	Did you have problems with caring for your urostomy?	□ 1	□ 2	П з	□ 4
Q52	Was your skin around the urostomy irritated?	□ 1		□ 3	□ 4
Q53	Have you felt embarrassed because of your urostomy?	□ 1	□ 2	П з	□ 4
Q54	Have you been dependent on others for caring for your urostomy?	□ 1	□ 2	П з	□ 4
Q55	Did you frequently have to change the urostomy bag?	□ 1	□ 2	□ 3	□ 4

Please answer question 56 only if you **have used a catheter** during the **past week**, otherwise go to Q57.

		Not at all	A little	Quite a bit	Very much
Q56	Have you had problems with self- catheterisation (inserting a tube in the bladder to pass urine)?	□ 1	□ 2	П 3	□ 4
During	g the <u>past week</u> :	Not at all	A little	Quite a bit	Very much
Q57	Did you have a fever?	□ 1	□ 2	П 3	□ 4
Q58	Did you feel ill or unwell?	□ 1	□ 2	□ 3	□ 4
Q59	Did you have trouble arranging your life around the repeated bladder treatment appointments (cystoscopies or instillations)?	□ 1	□ 2	П з	□ 4
Q60	Did you worry about having repeated bladder treatments (cystoscopies or instillations)?	□ 1	□ 2	П з	□ 4
Q61	Were you worried about your health in the future?	□ 1		□ 3	□ 4
Q62	Did you worry about the results of examinations and tests?	□ 1	□ 2	□ 3	□ 4
Q63	Did you worry about possible future treatments?	□ 1	□ 2	□ 3	□ 4
Q64	Did you have a bloated feeling in your abdomen?	□ 1	□ 2	□ 3	□ 4
Q65	Have you had flatulence or gas?	□ 1	□ 2	□ 3	□ 4
Q66	Have you felt physically less attractive as a result of your illness or treatment?	□ 1	□ 2	П з	□ 4
Q67	Have you been dissatisfied with your body?	□ 1	□ 2	П з	□ 4
Q68	Have you felt less feminine/masculine as a result of your illness or treatment?	□ 1	□ 2	П 3	□ 4

During	the past <u>4 weeks</u> :	Not at all	A little	Quite a bit	Very much
Q69	To what extent were you interested in sex?	□ 1	□ 2	□ 3	□ 4
Q70	To what extent were you sexually active (with or without sexual intercourse)?	□ 1	□ 2	□ 3	□ 4
Q71	For men only: Did you have difficulty gaining or maintaining an erection?	□ 1	□ 2	□ 3	□ 4
Q72	For men only: Did you have ejaculation problems (e.g. dry ejaculation)?	□ 1	□ 2	П 3	□ 4
	answer the following 4 questions only if you ha		·		
		ve been sex Not at all	ually active A little	Quite a bit	Very much
During	the past <u>4 weeks</u> : Have you felt uncomfortable about being	Not at all	A little	Quite a bit	Very much
During Q73	Have you felt uncomfortable about being sexually intimate? Have you worried that you may contaminate your partner during sexual contact with the	Not at all	A little	Quite a bit	Very much

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SECTION 4: 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.

During	g the <u>past month</u> :	No difficulty	A little difficulty	Quite a bit of difficulty	Very much difficulty
Q77	Have you had any difficulty in maintaining your independence?	□ 1	□ 2	П з	 4
Q78	Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)	□ 1	□ 2	□ 3	<u> </u>
Q79	Have you had any difficulty with managing your own personal care? (e.g. bathing, dressing, washing)	□ 1	□ 2	□ 3	□ 4
Q80	Have you had any difficulty with looking after those who depend on you? (e.g. children, dependant adults, pets)	□ 1	□ 2	□ 3	□ 4
Q81	Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?	□ 1	□ 2	□ 3	□ 4
Q82	Have you had any difficulties with benefits? (e.g. Statutory Sick Pay, Personal Independence Payments, Attendance Allowance, Universal Credit)	□ 1	□ 2	□ ₃	□ 4
Q83	Have you had any financial difficulties?	□ 1	□ 2	П з	□ 4
Q84	Have you had any difficulties with financial services? (e.g. loans, mortgages, pensions, insurance)	□ 1	□ 2	□ 3	□ 4
Q85	Have you had any difficulty concerning your work (or education if you are a student)?	□ 1	□ 2	П 3	□ 4
Q86	Have you had any difficulty with planning for your own or your family's future? (e.g. care of dependants, legal issues, business affairs)	□ 1	□ 2	П з	□ 4
Q87	Have you had any difficulty with communicating with those closest to you? (e.g. partner, children, parents)	□ 1	□ 2	П з	□ 4

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During	the <u>past month</u> :	No difficulty	A little difficulty	Quite a l	,
Q88	Have you had any difficulty with communicating with others? (e.g. friends, neighbours, colleagues, dates)	□ 1	□ 2		3
Q89	Have you had any difficulty concerning plans to have a family?	□ 1	□ 2		3 4
Q90	Have you had any difficulty concerning your appearance or body image?	□ 1	<u> </u>		3 4
Q91	Have you felt isolated?	□ 1	□ 2		3
Q92	Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)	□ 1	□ 2		3
Q93	Have you had any difficulty in carrying out your recreational activities? (e.g. hobbies, pastimes, social pursuits)	□ 1	□ 2		3
Q94	Have you had any difficulty with your plans to travel or take a holiday?	□ 1	□ 2		3 🔲 4
	Social Difficulties Inventory Copyright (c) 2	2005 Univers	ity of Leeds.	(Funded by	y Cancer Research UK)
SECTIO	N 5: Your Emotional Wellbeing				
	re some statements about feelings and though erience of each over the <u>last 2 weeks</u> .	ts. Please t	ick the box	on each li	ne that best describes
		None of the time	,	ome of e time	Often All of the time
Q95	I've been feeling optimistic about the future	□ 1	□ 2	П з	☐ 4 ☐ 5
Q96	I've been feeling useful	□ 1	□ 2	П з	☐ 4 ☐ 5
Q97	I've been feeling relaxed	□ 1	□ 2	П 3	□ 4 □ 5
Q98	I've been dealing with problems well	□ 1	□ 2	□ 3	□ 4 □ 5
Q99	I've been thinking clearly	□ 1	□ 2	П 3	□ 4 □ 5
Q100	I've been feeling close to other people	□ 1	2	П з	4 5
Q101	I've been able to make up my own mind about things	□ 1		П 3	4 5

"Short Warwick Edinburgh Mental Well-Being Scale (SWEMWBS) © NHS Health Scotland, University of Warwick and University of Edinburgh, 2008, all rights reserved."

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SECTION 6: Exercise

During a **typical 7 day period (a week)**, how many times on average did you do the following kinds of exercise for more than 15 minutes during your free time (write on each line the appropriate number)?

Q102	Times per week:
STRENUOUS EXERCISE (HEART BEATS RAPIDLY)	
(e.g. running, jogging, hockey, football, rugby, squash, basketball, judo, roller skating, vigorous swimming, vigorous long distance bicycling)	
MODERATE EXERCISE (NOT EXHAUSTING)	
(e.g. fast walking, tennis, easy bicycling, volleyball, badminton, easy swimming, popular and folk dancing)	
MILD EXERCISE (MINIMAL EFFORT)	
(e.g. yoga, archery, fishing from river bank, bowling, golf, easy walking)	

Q103	• • • • • • • • • • • • • • • • • • • •	(a week), in your leisure time, how often do you engage ingh to work up a sweat (heart beats rapidly)?
	Often	1
	Sometimes	2
	Rarely or never	3

Adapted from Godin and Shephard (1985). A Simple Method to Assess Exercise Behaviour in the Community. Canadian Journal of Applied Sport Sciences. 10(3)141-146.

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SECTION 7: Smoking

Q104	This question is about smoking tobacco (e.g. cigarettes, cigars, pipes that best describes your answer.	ipes). Please tick the box						
	I smoke more than 20 cigarettes a day, or more than 8 pipe bowls of tobacco, or more than 10 cigars a day		1					
	I smoke between 10 and 20 cigarettes a day, or between 4 and 8 pipe bowls of tobacco, or between 5 and 10 cigars a day		2					
	I smoke less than 10 cigarettes a day, or less than 4 pipe bowls of tobacco, or less than 5 cigars a day		3					
	I used to smoke and gave up in the last year		4					
	I used to smoke and gave up more than a year ago		5					
	I have never smoked tobacco		6					
Q105	This question is about using e-cigarettes (e.g. electronic cigarettes, electronic vaporis vaping). Please tick the box that best describes your answer.							
	I currently use e-cigarettes and I used them before my diagnosis		1					
	I currently use e-cigarettes and I have used them since my diagnosis		2					
	I used to use e-cigarettes but no longer do so		3					
	I have never used e-cigarettes		4					
Q106	This question is about passive smoking (e.g. breathing in other peopl hand smoke). Thinking about all the people you have lived with, pleas best describes your answer.							
	I have never breathed in the second hand smoke of someone I live or lived with		1					
	I have breathed in the second hand smoke of someone I live or lived with for less than 1 year		2					
	I have breathed in the second hand smoke of someone I live or lived with for between 1 and 5 years		3					
	I have breathed in the second hand smoke of someone I live or lived with for between 5 and 10 years		4					
	I have breathed in the second hand smoke of someone I live or lived with for over 10 years		5					

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SECTION 8: About You		(Q110	What is	your ethnic group?		
0407	What is very data of hinth?				(Tick o	ne only)	
Q107	What is your date of birth?				WHITE		
					1	English / Welsh / Scottish / Northern Irish / British Irish	
	D D M M Y Y Y Y				3 🔲	Gypsy or Irish traveller	
Q108	What is your legal marital state Please tick <u>one</u> box.	us?			4 🔲	Any other White background (Please write in box)	
	Marviad						
	Married	Ш	1		MIXED	/ MULTIPLE ETHNIC GROUPS	
	In a civil partnership		2		5	White and Black Caribbean	
					6	White and Black African	
	Separated	Ш	3		7	White and Asian	
	Divorced / dissolved civil partnership		4		8 🔲	Any other Mixed / multiple ethnic background (Please write in box)	
	Widowed / surviving partner		5		ASIAN OR ASIAN BRITISH		
	Single (never married / never in civil partnership)		6		9	Indian Pakistani	
	Other		7		11 🔲	Bangladeshi	
	Other		,		12	Chinese	
Q109 Which of the following options best describes how you think of		t		13	Any other Asian background (Please write in box)		
	yourself?						
	Heterosexual or Straight		1			/ AFRICAN / CARIBBEAN / BRITISH	
	Gay or Lesbian		2		14	African	
	Bisexual		3		15	Caribbean	
	Other		4		16	Any other Black / African / Caribbean background (Please	
	Prefer not to say		5			write in box)	
				OTHER	ETHNIC GROUP		
					17	Arab	
					18	Any other ethnic group (Please write in box)	

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Q111	Which, if any, of the following conditions do you have? Please tick all the boxes that apply.			Q114	How tall are you? Feet Inches			
	A heart condition		1	OR	reet Inches			
	Angina		2		Centimetres			
	High blood pressure		3		Don't know			
	Asthma or other chronic chest problem		4	Q115	How much do you weigh?			
	Liver disease		5		Stones Pounds			
	Problems with your stomach, bowels or gallbladder		6	OR				
	Problems with your pancreas		7		Kilos Grams			
	Kidney disease		8		Don't know 1			
	Diabetes		9	SECTION	N 9: Your Employment Status			
	Stroke		10	Q116	Please tick one box for the catego			
	Alzheimer's disease or dementia		11		that best describes your employm before your diagnosis of bladder cancer.	ent		
	Epilepsy		12		Not in paid work:			
	Other long standing neurological problem		13		Retired			
	A diagnosis of arthritis		14		Unemployed, seeking work			
Q112	Have you ever in your lifetime seen a health care professional (such as a GP, psychiatrist, psychologist,				Unable to work due to disability (cancer related)	□ 3 —		
	social worker, counsellor, psychotherapist, mental health nurse, or any other such			Unable to work due to disability (other than cancer)	<u> </u>			
	professional) for problems with your emotions or nerves or your use of alcohol or drugs?				At home and not looking for paid employment (e.g. looking after your home, family or other dependants)			
	Yes				Student	□ 6		
Q113	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 phsyical or mental health disability, or • Problems relating to old age				Paid work, full time (30 hours or more/week)	□ 7		
					Paid work, part time (less than 30 hours/week)	□ 8		
					Self employed			
	Yes							

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Q117	Please tick one box for the category that best describes your employment now after your diagnosis of bladder			Q118	Please answer the following question only if you are in <u>paid</u> work.			
	cancer.				Did you need to take any sick leave in the last 6	Yes	□ 1	
	Not in paid work:				weeks because of the	No		
	Retired		1		cancer?			
	Unemployed, seeking work		2		If yes, how many days off have you taken in the last 6 weeks?			
	Unable to work due to disability (cancer related)		3		If you needed to take sick le	eave:		
	Unable to work due to disability (other than cancer)		4		Did you receive sick pay from your employer?	Yes	□ 1	
	At home and not looking for paid employment (e.g. looking after		5			No	□ 2	
	your home, family or other dependants)				Did the sick pay cover your full wages?	Yes	□ 1	
	Student		6		raii wagoo .	No	□ 2	
	Paid work, full time (30 hours or more/week)		7		Approximately what percentage of your wages			
	Paid work, part time (less than 30 hours/week)		8		have you received for the time you have been off work?			
	Self employed		9					

Thank you for your help

Please post this questionnaire back in the FREEPOST envelope provided or via **Freepost, QUALITY HEALTH.**No stamp is needed.

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