

HORIZONS

Understanding the impact of cancer diagnosis and treatment on everyday life

First Questionnaire

StudyID		/	В		

Thank you for taking part in this study.

This UK-wide study is supported by Macmillan Cancer Support and led by researchers based at the University of Southampton.

Your participation will help us to understand the impact of cancer diagnosis and treatment on everyday life and how this changes over time. This information will help inform support services in the future.

This questionnaire is divided into 7 parts. It asks for information about you, your health, and how well you have been since you were diagnosed with cancer, It also covers topics such as how you are coping and managing your health, your lifestyle and interests, as well as the support you have available to you. Information and treatment details from your medical records will be gathered separately by a research nurse and included in our analyses.

We understand that the questionnaire is long but we need to ask a range of questions to help us understand the impact of cancer diagnosis and treatment. Some questions may seem repetitive but each aims to measure slightly different things.

How to fill in this questionnaire

- Please read the instructions and questions carefully.
- Fill in the answer which best describes how you feel most questions will ask you to tick a box, circle a number or write a comment.
- Please try to answer all the questions. If you do not wish to answer the question, please leave this blank.
- Do not spend too long on each question the first answer which comes to you is probably the best one.
- There are no right or wrong answers. If you are unsure about how to answer a question please put the best answer you can.
- You may wish to take breaks whilst completing the questionnaire.
- The information you provide will remain **strictly confidential** and will not be seen by your clinical team.
- Please return your completed questionnaire in the **FREEPOST** envelope provided.



Part 1 – About You

Firstly, we would like to know a little about you. This information helps us to build a picture of your background, the health services you may have accessed and other conditions and illnesses you may have had.

How old are you?	
years old	
Are you (Please tick one):	
☐ Male	
☐ Female	
Other, please specify:	
How would you describe yourself? (Please tick one)	
White:	Mixed / multiple ethnic groups:
☐ English/Welsh/Scottish/Northern Irish/British	☐ White and Black Caribbean
☐ Irish	☐ White and Black African
☐ Gypsy or Irish Traveller	☐ White and Asian
☐ Any other White background, please specify:	Any other Mixed/multiple ethnic background,
	please specify:
Asian / Asian British:	Black/African/Caribbean/Black British:
☐ Indian	☐ African
☐ Pakistani	☐ Caribbean
☐ Bangladeshi	☐ Any other Black/African/Caribbean
Chinese	background, please specify:
☐ Any other Asian background, please specify:	
	Other ethnic background:
	☐ Arab
	Any other ethnic background, please specify:

Which of the following options best describes how you think of yourself? (Please tick one)	
☐ Heterosexual or Straight	
☐ Gay or Lesbian	
☐ Bisexual	
☐ Other, please specify:	
☐ I prefer not to say	
What is your current domestic status? (Please tick one)	
☐ Never married and/or never in a registered same-sex civil partnership	
☐ Married	
☐ Separated, but still legally married	
☐ Divorced	
☐ Widowed	
☐ In a registered same-sex civil partnership	
☐ Separated, but still legally in a same-sex civil partnership	
☐ Formerly in a same-sex civil partnership which is now legally dissolved	
☐ Surviving partner from a same-sex civil partnership	
Which of the following people usually live in your household with you? (Please tick all that apply)	
☐ Wife/husband/partner/civil partner	
☐ Child(ren)	
☐ Parent(s)	
☐ Friend(s)	
☐ Other, please specify:	
☐ None of the above, I live alone	
Which of the following best describes your current household accommodation (home)?	
(Please tick one)	
☐ Owner-occupied (home is owned outright or is being bought through a mortgage/loan)	
☐ Rented from a Council or Housing Association	
☐ Rented from a private landlord	
☐ Temporary accommodation	
☐ Other, please specify:	
Do you, or does anyone in your household, own or have regular use of a car or van?	
☐ Yes ☐ No	
Do you use the internet, for example to check emails or shop online? (Please tick one)	
Yes, regularly Yes, occasionally No	please

Which of the following best describes your highest level of education completed? (Please tick one)
☐ Still in compulsory school education
☐ Less than compulsory school education
☐ Compulsory school education
☐ Apprenticeship
☐ Further education (e.g. sixth form college or equivalent)
☐ Higher education - undergraduate degree
☐ Higher education - postgraduate degree
☐ Professional qualification (e.g. accountancy, nursing)
☐ Other vocational / work-related qualifications
☐ None of the above
☐ Other, please specify:
Which of the following best describes your current employment? (Please tick all that apply)
Employed, full-time
☐ Employed, part-time
☐ Self-employed
☐ On sick-leave
☐ Looking after home or family
☐ Voluntary work
☐ Disabled or long-term sick
☐ Unemployed
Retired
☐ In full-time education/training
☐ In part-time education/training
☐ Other, please specify:
How many hours per week do you currently work in your job/business? Please exclude breaks:
hours Not applicable
In the last 3 months , approximately how many days have you taken off work due to your health?
days

We would now like to ask you some questions related to finances. Please remember that all of the information we collect is **entirely confidential** and we do not share your details with anyone.

We are collecting this information to try to explore the financial impact of cancer and cancer treatment. You do not need to answer any of these questions if you do not wish to – please select the option 'I prefer not to say' and continue to the next page.

Approximately what is your current total yearly gross/pre-tax salary or income? (Please tick one)
Less than £5,199
☐ £5,200 and up to £10,399
☐ £10,400 and up to £15,599
☐ £15,600 and up to £20,799
☐ £20,800 and up to £25,999
☐ £26,000 and up to £31,199
☐ £31,200 and up to £36,399
☐ £36,400 and up to £51,999
☐ £52,000 and above
☐ I prefer not to say
Do you (vourself or jointly) receive any of the following types of payments (Planetiste Wheet and b)
Do you (yourself or jointly) receive any of the following types of payments? (Please tick all that apply)
☐ Unemployment-related benefits, or National Insurance Credits
☐ Income Support
☐ Sickness, disability or incapacity benefits (including Employment and Support Allowance)
☐ Child Benefit
☐ Tax credits, such as the Working Tax Credit or Child Tax Credit
☐ Any other family related benefits or payment
☐ Housing or Council Tax Benefit other than the single-person council tax discount
☐ Income from any other state benefit
☐ None of the above
☐ I prefer not to say
Are you currently receiving a pension? (Please tick all that apply)
Yes, through a private pension (e.g. an employer's pension scheme or a personal pension scheme)
☐ Yes, through a government state pension
□ No
☐ I prefer not to say

Do you have caring responsibilities for children aged under 18 years?
☐ Yes ☐ No
If ' Yes ', how many children (aged under 18 years) do you care for?
children
Do you look after, or give any help or support to family, friends, neighbours or others? This may be because of either long-term physical or mental health disability, or problems relating to old age.
☐ Yes ☐ No
Does anyone look after, or give you help or support? This may be because of either a long-term physical or mental health disability, or problems relating to old age.
☐ Yes ☐ No
If 'Yes':
Is this formal paid care? (e.g. nurse, home-help etc):
☐ Yes ☐ No
Is this informal unpaid care? (e.g. relative, neighbour, friend etc):
☐ Yes ☐ No
Have you had contact with a GP in the last 3 months ?
☐ Yes ☐ No
If ' Yes ', how did you contact the GP? (Please tick all that apply)
☐ GP practice
If yes , how many times in the last 3 months?
☐ At home
If yes , how many times in the last 3 months?
☐ Over the telephone
If yes , how many times in the last 3 months?
Have you attended A&E or an emergency department in the last 3 months ?
Yes, for myself Yes, accompanying family, friends or other No
Have you ever used mental health and/or emotional support services?
☐ Yes ☐ No

The following table/grid refers to other conditions or illnesses that you may have.

Please work through both parts A & B:

- **A.** From the following list of conditions in the table below, please select those which a health professional has told you that you have.
- **B.** From the conditions you have indicated you have, please let us know how severely the condition has limited the activities you do on a typical day. For example, but not limited to: work, working around the house or garden, bathing or dressing yourself, social activities.

(Please choose a number from ${\bf 0},$ which is no limitation, to ${\bf 7}$ which is severely limited.)

	A. Has a health professional ever told you that you have	B. (If 'Yes' in A) How severely does the condition limit the activities you do on a typical day?							
	this condition? (Please tick if 'Yes')	No limitations 0 1 2 3			Severel 4 5		ly limi 6	ited 7	
Anaemia				U					
Arrhythmia/irregular heartbeat (e.g. AF or atrial fibrillation)									
Rheumatoid Arthritis									
Other Arthritis (e.g. osteoarthritis, psoriatic arthritis)									
Asthma, chronic lung disease, bronchitis, emphysema, chronic obstructive pulmonary disease (COPD)									
Cancer previous to your current diagnosis. Type of cancer, please state:									
Chest pain or angina									
Dementia									
Depression or anxiety									
Diabetes or high blood sugar (Type I)									
Diabetes or high blood sugar (Type II)									
Heart attack or myocardial infarction									
Heart failure									
High blood pressure or hypertension									
HIV/AIDS									
Inflammatory bowel disease, colitis or Crohn's disease									





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	A. Has a health professional ever told you that you have this condition? (Please tick if 'Yes')	B. (If 'Yes' in A) How severely does the conditi limit the activities you do on typical day? No limitations Severely lir 0 1 2 3 4 5 6						on a	1
Kidney/renal disease									
Liver disease or cirrhosis									
Neurological condition (e.g. multiple sclerosis, Parkinson's disease)			9	D					
Osteoporosis, osteopenia, or fragile/brittle bones									
Over- or under- active thyroid									
Pancreatitis									
Stomach ulcers									
Stroke/transient ischemic attack (TIA) or brain haemorrhage									
Venous disease (DVT: deep vein thrombosis / PE: pulmonary embolism)									
Other condition, please state:									

Part 2 – Your General Health & Well-Being

We would now like to ask some questions about your current health and quality of life.

Under each heading, please tick the ONE box that best describes your health TODAY .
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
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
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
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
ANXIETY / DEPRESSION
☐ Iam not anxious or depressed
☐ I am slightly anxious or depressed
☐ Iam moderately anxious or depressed
☐ I am severely anxious or depressed
☐ I am extremely anxious or depressed

We would like to know how good or bad your health is TODAY .	
	The best
This scale is numbered from 0 to 100 .	health you can imagine
100 means the best health you can imagine	——— 100
0 means the worst health you can imagine	
Mark an X on the scale to indicate how your health is TODAY	<u>=</u> 95
Now, please write the number you marked on the scale in the box below.	95
	<u>=</u> 85
	80
	75
	65
YOUR HEALTH TODAY =	50
2	
	<u>=</u> = =
	30
	0
	The worst health you

We would like to ask you about some things that can affect the **quality of people's lives**. Some of these questions may sound similar, but please be sure to answer each one.

Below is a scale rating from **'never'** to **'always'**. Please indicate how often each of these statements has been true for you in the **past four weeks**. (Please tick **one** answer for each question)

	Never	Seldom	Some times	About as often as not	Frequently	Very often	Always
You had the energy to do the things you wanted to do.							
You had difficulty doing activities that require concentrating.							
You were bothered by having a short attention span.							
You had trouble remembering things.							
You felt fatigued.					19		
You felt happy.							
You felt blue or depressed.							
You enjoyed life.							
You worried about little things.							
You were bothered by being unable to function sexually.							
You didn't have energy to do the things you wanted to do.	<u></u>						
You were dissatisfied with your sex life.							
You were bothered by pain that kept you from doing the things you wanted to do.							
You felt tired a lot.							
You were reluctant to start new relationships.							
You lacked interest in sex.							
Your mood was disrupted by pain or its treatment.							
You avoided social gatherings.							
You were bothered by mood swings.							
You avoided your friends.							
You had aches or pains.							



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	Never	Seldom	Some times	About as often as not	Frequently	Very often	Always
You had a positive outlook on life.							
You were bothered by forgetting what you started to do.							
You felt anxious.							
You were reluctant to meet new people.							
You avoided sexual activity.							
Pain or its treatment interfered with your social activities.							
You were content with your life.							

Part 3 – Your Symptoms & How You Are Feeling

In this section, we would like to know more about any symptoms you might be experiencing and how you have been feeling.

Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

		Not at All	A Little	Quite a Bit	Very Much
1.	Do you have any trouble doing strenuous activities like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2.	Do you have any trouble taking a long walk?	1	2	3	4
3.	Do you have any trouble taking a short walk outside of the house?	1	2	3	4
4.	Do you need to stay in bed or a chair during the day?	1	2	3	4
5.	Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4

During the **past week**:

		Not at All	A Little	Quite a Bit	Very Much
6.	Were you limited in doing either your work or other daily activities?	1	2	3	4
7.	Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8.	Were you short of breath?	1	2	3	4
9.	Have you had pain?	1	2	3	4
10.	Did you need to rest?	1	2	3	4
11.	Have you had trouble sleeping?	1	2	3	4
12.	Have you felt weak?	1	2	3	4
13.	Have you lacked appetite?	1	2	3	4
14.	Have you felt nauseated?	1	2	3	4
15.	Have you vomited?	1	2	3	4
16.	Have you been constipated?	1	2	3	4
17.	Have you had diarrhea?	1	2	3	4
18.	Were you tired?	1	2	3	4
19.	Did pain interfere with your daily activities?	1	2	3	4
20.	Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21.	Did you feel tense?	1	2	3	4





During the **past week**:

		Not at All	A Little	Quite a Bit	Very Much
22.	Did you worry?	1	2	3	4
23.	Did you feel irritable?	1	2	3	4
24.	Did you feel depressed?	1	2	3	4
25.	Have you had difficulty remembering things?	1	2	3	4
26.	Has your physical condition or medical treatment interfered with your family life?	1	2	3	4
27.	Has your physical condition or medical treatment interfered with your social activities?	1	2	3	4
28.	Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

29. How would you rate your overall **health** during the past week?

Very Poor Excellent
1 2 3 4 5 6 7

30. How would you rate your overall **quality of life** during the past week?

 Very Poor
 Excellent

 1
 2
 3
 4
 5
 6
 7

Patients sometimes report that they have the following **symptoms or problems**.

Please indicate the extent to which you have experienced these symptoms or problems, please answer by circling the number that best applies to you.

During the **past week**:

		Not at All	A Little	Quite a Bit	Very Much
31.	Did you have a dry mouth?	1	2	3	4
32.	Did food and drink taste different than usual?	1	2	3	4
33.	Were your eyes painful, irritated or watery?	1	2	3	4
34.	Have you lost any hair?	1	2	3	4
35.	Answer this question only if you had any hair loss: Were you upset by the loss of your hair?	1	2	3	4
36.	Did you feel ill or unwell?	1	2	3	4
37.	Did you have hot flushes?	1	2	3	4
38.	Did you have headaches?	1	2	3	4
39.	Have you felt physically less attractive as a result of your disease or treatment?	1	2	3	4
40.	Have you been feeling less feminine as a result of your disease or treatment?	1	2	3	4
41.	Did you find it difficult to look at yourself naked?	1	2	3	4
42.	Have you been dissatisfied with your body?	1	2	3	4
43.	Were you worried about your health in the future?	1	2	3	4
44.	Have you had tingling or numbness in your hands or feet?	1	2	3	4
45.	Did you have night sweats?	1	2	3	4
46.	Have you had aches or pains in your muscles or joints?	1	2	3	4

During the **past four weeks**:

		Not at All	A Little	Quite a Bit	Very Much
47.	To what extent were you interested in sex?	1	2	3	4
48.	To what extent were you sexually active? (with or without intercourse)	1	2	3	4

Answer these questions only if you have been sexually active during the past four weeks:

		Not at All	A Little	Quite a Bit	Very Much
49.	Has your vagina felt dry during sexual activity?	1	2	3	4
50.	Has your vagina felt short and / or tight?	1	2	3	4
51.	Have you had pain during sexual intercourse or other sexual activity?	1	2	3	4
52.	To what extent was sex enjoyable for you?	1	2	3	4

During the **past week**:

		Not at All	A Little	Quite a Bit	Very Much
53.	Did you have any pain in your arm or shoulder?	1	2	3	4
54.	Did you have a swollen arm or hand?	1	2	3	4
55.	Was it difficult to raise your arm or to move it sideways?	1	2	3	4
56.	Have you had any pain in the area of your affected breast?	1	2	3	4
57.	Was the area of your affected breast swollen?	1	2	3	4
58.	Was the area of your affected breast oversensitive?	1	2	3	4
59.	Have you had skin problems on or in the area of your affected breast (e.g., itchy, dry, flaky)?	1	2	3	4

During the **past four weeks**:

		Notat	A Little	Quite	Very
		All		a Bit	Much
60.	How much has your disease been a burden to you?	1	2	3	4
61.	If applicable: Have you been concerned about your ability to have children?	1	2	3	4
62.	If applicable: Have you had problems at your work or place of study due to the disease?	1	2	3	4
63.	If applicable: Have you worried about not being able to continue working or your education?	1	2	3	4

During the **past week**:

			Not at	A Little	Ouito	Von
			All	ALILLIE	Quite a Bit	Very Much
64.	Have you been feeling self-conscious about your appearance?		1	2	3	4
65.	Have you been dissatisfied with your appearance when dressed?		1	2	3	4
66.	Have you been feeling less sexually attractive as a result of your disease or treatment?		1	2	3	4
67.	Did you avoid people because of the way you felt about your appearance?		1	2	3	4
68.	Have you been feeling the treatment has left your body less whole?		1	2	3	4
69.	Have you been dissatisfied with the appearance of your scar?	N/A	1	2	3	4

Hospital Anxiety and Depression Scale (HADS)	
Read each item below and tick the box beside the reply we the past week . Don't take too long over your replies, you more accurate than a long, thought-out response.	ŷ G
I feel tense or 'wound up':	I feel as if I am slowed down:
☐ Most of the time	☐ Nearly all the time
☐ Alot of the time	☐ Very often
☐ From time to time, occasionally	Sometimes
☐ Not at all	☐ Notatall
I still enjoy the things I used to enjoy:	I get a sort of frightened feeling like 'butterflies' in the stomach:
☐ Definitely as much	□ Notatall
☐ Not quite so much	☐ Occasionally
☐ Only a little	☐ Quite often
☐ Hardly at all	☐ Very often
I get a sort of frightened feeling as if something awful is about to happen:	I have lost interest in my appearance:
☐ Very definitely and quite badly	☐ Definitely
Yes, but not too badly	I don't take as much care as I should
☐ A little, but it doesn't worry me	I may not take quite as much care
☐ Not at all	☐ I take just as much care as ever
I can laugh and see the funny side of things:	I feel restless as if I have to be on the move:
☐ As much as I always could	☐ Very much indeed
☐ Not quite so much now	☐ Quite a lot
☐ Definitely not so much now	☐ Not very much
☐ Not at all	☐ Notatall
Worrying thoughts go through my mind:	I look forward with enjoyment to things:
☐ A great deal of the time	☐ As much as I ever did
☐ A lot of the time	☐ Rather less than I used to
☐ Not too often	☐ Definitely less than I used to
☐ Very little	☐ Hardly at all

I feel cheerful:	I get sudden feelings of panic:
☐ Never	☐ Very often indeed
☐ Not often	☐ Quite often
☐ Sometimes	☐ Not very often
☐ Most of the time	☐ Not at all
I can sit at ease and feel relaxed:	I can enjoy a good book or radio or television program:
☐ Definitely	☐ Often
☐ Usually	☐ Sometimes
☐ Not often	☐ Not often
☐ Not at all	☐ Very seldom

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Part 4 – How You Cope & Manage Your Health

These questions will help us to understand how people cope and manage their health – it will help us to explore how patients may be supported in future.

How confident are	you filling out forms by y	ourself?				
Extremely	Quite a bit	Somewhat	A little b	it	Nota	at all
How often do you	have someone help you r	road hospital materials?				
Never	Occasionally	Sometimes	Often		Alw	221/5
Nevel		Sometimes			AIW	ays
Ш						
How often do you materials?	have problems learning a	about your medical condition	on because	of difficult	yreading	hospital
Never	Occasionally	Sometimes	Often		Alw	ays
Please indicate how that best describes	0,,	or agree with the followings	statements	by checkin	ng the res	ponse
			Strongly Disagree	Disagree	Agree	Strongly Agree
Most days I am d	oing some of the things I	really enjoy				
As well as seeing health	my doctor, I regularly mo	onitor changes in my				
I often worry abo	out my health					
I try to make the	most of my life					
I know what thing worse	gs can trigger my health p	oroblems and make them				
My health proble	ems make me very dissati	sfied with my life				
I am doing intere	sting things in my life					
I have plans to do	enjoyable things for my	self during the next few				
I have a very good to take my medic	d understanding of wher	and why I am supposed				
I often feel angry	when I think about my h	ealth				
I feel hopeless be	ecause of my health					
I feel like I am act	ively involved in life					
When I have heal	•	ar understanding of what				



	Strongly Disagree	Disagree	Agree	Strongly Agree
I carefully watch my health and do what is necessary to keep as healthy as possible				
I get upset when I think about my health				
With my health in mind, I have realistic expectations of what I can and cannot do				
If I think about my health, I get depressed				
If I need help, I have plenty of people I can rely on				
I have effective ways to prevent my symptoms (e.g., discomfort, pain and stress) from limiting what I can do in my life				
I have very positive relationships with my healthcare professionals				
I have a very good idea of how to manage my health problems				
When I have symptoms, I have skills that help me cope				
I try not to let my health problems stop me from enjoying life				
I have enough friends who help me cope with my health problems				
I communicate very confidently with my doctor about my healthcare needs				
I have a good understanding of equipment that could make my life easier				
When I feel ill, my family and carers really understand what I am going through				
I confidently give healthcare professionals the information they need to help me				
I get my needs met from available healthcare resources (e.g., doctors, hospitals and community services)				
My health problems do not ruin my life				
Overall, I feel well looked after by friends or family				
I feel I have a very good life even when I have health problems				
I get enough chances to talk about my health problems with people who understand me				
I work in a team with my doctors and other healthcare professionals				
I do not let my health problems control my life				
If others can cope with problems like mine, I can too				

the tasks regularly at the present time .										
Not at all Confident								Tot	ally Cor	ifident
	1	2	3	4	5	6	7	8	9	10
How confident are you that you can keep the fatigue caused by having had cancer and/or cancer treatment from interfering with the things you want to do?										
How confident are you that you can keep the physical discomfort or pain of having had cancer and/or cancer treatment from interfering with the things you want to do?										
How confident are you that you can keep the emotional distress caused by having had cancer and/or cancer treatment from interfering with the things you want to do?							2	-	7	
How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?										
How confident are you that you can do the different tasks and activities needed to manage your cancer and/or cancer treatment so as to reduce your need to see a doctor?		Q	2							
How confident are you that you can do things other than just taking medication to reduce how much having had cancer and/ or cancer treatment affects your everyday life?										

For each item, please mark an "x" in the box below that best indicates how much you agree with the following statements as they apply to you over the **last month**. If a particular situation has not occurred recently, answer according to how you think you would have felt.

	Not true at all	Rarely true	Sometimes true	Often true	True nearly all of the time
	(0)	(1)	(2)	(3)	(4)
I am able to adapt when changes occur					
I tend to bounce back after illness, injury, or other hardships					

Spirituality can be explained in many different ways and can mean something different to everyone. For some, it can be about participating in organised religious practices (e.g. going to a church, synagogue, mosque, etc.). For others, it could include other practices such as private prayer, yoga, meditation, quiet reflection, or even long walks. So it is not always associated with a religious belief. Many people without a religious belief still have 'spiritual feelings'.

Please respond to all of the statements yourself by circling the number that best applies to you.

More generally:

	Not at All	A Little	Quite a Bit	Very Much
I believe in God or in someone or something greater than myself	1	2	3	4
I have spiritual wellbeing	1	2	3	4

How would you rate your overall spiritual wellbeing? (Please circle **one** number below)

Don't know/
Can't answer

0 1 2 3 4 5 6 7

Part 5 – Your Interests & the Support You Have Available To You

In this section, we would like to find out more about the types of support and assistance you have available to you. We would also like to look at how social relationships and engagement with interests can be used by people to help support themselves at home and in their communities.

1. The Types of Support Available to You

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Emotional / Informational Support:					
Someone you can count on to listen to you when you need to talk					
Someone to give you information to help you understand a situation					
Someone to give you good advice about a crisis					
Someone to confide in or talk to about yourself or your problems					
Someone whose advice you really want					
Someone to share your most private worries and fears with					
Someone to turn to for suggestions about how to deal with a personal problem					
Someone who understands your problems					
Tangible Support:					
Someone to help you if you were confined to bed					
Someone to take you to the doctor if you needed it					
Someone to prepare your meals if you were unable to do it yourself					
Someone to help with daily chores if you were sick					

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Affectionate Support:					
Someone who shows you love and affection					
Someone to love and make you feel wanted					
Someone who hugs you					
Positive Social Interaction:					
Someone to have a good time with					
Someone to get together with for relaxation					
Someone to do something enjoyable with					
Additional Item:					
Someone to do things with to help you get your mind off things					
How many close friends do you have?					
How many close family members do you have?					

2. Your Hobbies & Interests

Do you join in the activities of any of these organisations and if so, h	how often? (Please tick a	s appropriate)
	At least once a	At least once a	At least every three	Less
	week	month	months	orten
Community or neighbourhood groups (e.g. adult learning, religious, political, hobbies, lunch clubs, groups for children or older people)				
Voluntary work				
Health or exercise groups, including taking part, coaching or going to watch				4
Cultural activities (e.g. sports, stately homes, concerts, museums/galleries, dance, opera)				
Other groups or activities		B		
In the past month , have you given any unpaid help in any of the wa help you gave through a group, club or organisation. (Please tick as a)	3	elow? Plea	se do not cou	intany
Practical help (e.g. gardening, pets, home maintenance, transp	ort, running	errands)		
☐ Help with childcare or babysitting				
☐ Teaching, coaching or giving practical advice				
☐ Giving emotional support				
Other				

3. Your Social Network

Many people understand the term 'social network' to be social media, like Facebook. Whilst social media can play an important role in the lives of people with cancer, we are particularly interested in looking at the social relationships that people use to support themselves in their communities.

In the table below, please list all the people who have played an important role in helping and supporting you to deal with your diagnosis and/or treatment of cancer. They can be anyone from family members, friends, neighbours, colleagues, to pets and healthcare staff like GPs and nurses.

For each person, please let us know a couple of details about them:

- their relationship to you (e.g. daughter, friend, GP)
- how often you see them in person (e.g. weekly, monthly, every couple of months)
- approximately how far do they live from you (approx. in miles)

Please use as many or as few of the lines provided

Network Member Number	Network Member (name or initials)	1=	nder male emale	Relationship (son, daughter, pet, friend, group, nurse, etc.)	1= at 2 = at	the least o least o t least e	do you em? once a w nce a m every co onths, s often	reek, onth,	How far do they live from you? (approx. in miles)
Example	Alistair	1	2	Frienc	1	2	3	4	10 miles
1		1	2		1	2	3	4	
2		1	2		1	2	3	4	
3		1	2		1	2	3	4	
4		1	2		1	2	3	4	
5		1	2		1	2	3	4	
6		1	2		1	2	3	4	
7		1	2		1	2	3	4	
8		1	2		1	2	3	4	
9		1	2		1	2	3	4	
10		1	2		1	2	3	4	
11		1	2		1	2	3	4	
12		1	2		1	2	3	4	
13		1	2		1	2	3	4	
14		1	2		1	2	3	4	
15		1	2		1	2	3	4	
16		1	2		1	2	3	4	
17		1	2		1	2	3	4	
18		1	2		1	2	3	4	
19		1	2		1	2	3	4	
20		1	2		1	2	3	4	

For each person listed in the previous table, please circle a number between 1 and 3 to indicate the extent they help you with:

- **A.** Information of your illness and illness management things to do with your long-term condition (e.g. helping you to understand health information, diet, medicines, etc)
- **B. Practical help with daily tasks** (e.g. running your household, etc)
- **C. Emotional support** (your wellbeing, helping you feel good, comforting you when you are worried, etc)

Network Member Number (as numbered in the previous table)	Info	rmation dess and illianagem	1= of your Iness	member hel help, 3 = A lot with	of help	onal su	upport		
Example	1	2	3	1			1	2	3
1	1	2	3	1	2	3	1	2	3
2	1	2	3	1	2	3	1	2	3
3	1	2	3		2	3	1	2	3
4	1	2	3	1	2	3	1	2	3
5	1	2	3	1	2	3	1	2	3
6	1	2	3	1	2	3	1	2	3
7	1	2	3	1	2	3	1	2	3
8	1	2	3	1	2	3	1	2	3
9	1	2	3	1	2	3	1	2	3
10	1	2	3	1	2	3	1	2	3
11	1	2	3	1	2	3	1	2	3
12	1	2	3	1	2	3	1	2	3
13	1	2	3	1	2	3	1	2	3
14	1	2	3	1	2	3	1	2	3
15	1	2	3	1	2	3	1	2	3
16	1	2	3	1	2	3	1	2	3
17	1	2	3	1	2	3	1	2	3
18	1	2	3	1	2	3	1	2	3
19	1	2	3	1	2	3	1	2	3
20	1	2	3	1	2	3	1	2	3

Part 6 – Your Lifestyle & Health

In this section, we would like to ask you some questions about your lifestyle. We are collecting this information to try to build up a picture of who needs support in their cancer recovery and what this support might be.

1. Body stats	
What is your weight?	What is your height?
st Ibs	feet inches
or kg	or cms
2. Smoking habits	
Which of the following best describes you?	
☐ I have never smoked	
☐ currently smoke	
☐ Iaman ex-smoker	
Date you stopped smoking (month and year):	
M M / Y Y Y	
If you currently smoke or are an ex-smoker , ple	ease complete the rest of this page.
Otherwise, please continue to the next page.	
If you currently smoke or are an ex-smoker, how lo	ang have/did you smoke/d) for?
If you currently smoke of are arrex smoker, now to	ng nave/ala you smoke(a) for :
If you currently smoke or are an ex-smoker, how m	nany cigarettes a day do/did you smoke?
Have your smoking habits changed since your diag	gnosis of cancer?
☐ Yes ☐ No	☐ Not applicable
If 'Yes', please tell us more details	
Have you received, or been offered, help to stop si	moking?

☐ No

Yes

☐ Not applicable

3. e-Cigarette use / Vaping habits

Which of the following best describes you?
☐ I have never used an electronic cigarette (e-Cigarette)/vaped
☐ I currently use an e-Cigarette/vape
☐ I have previously used an e-Cigarette/vaped
If you currently use e-Cigarettes or have previously used e-Cigarettes, please complete the rest of this page. Otherwise, please continue to the next page.
Are you using/did you use e-Cigarettes as a method of quitting or reducing your tobacco smoking?
☐ Yes ☐ No
If you currently use or have used e-Cigarettes, what strength of nicotine do you mainly use?
☐ No nicotine (0 mg/ml)
☐ 1 to 3 mg/ml
☐ 4to8mg/ml
□ 9 to 12 mg/ml
☐ 13 to 16 mg/ml
☐ 17 to 20 mg/ml
☐ More than 20 mg/ml
☐ Idon't know
Approximately, what would you consider to be your daily e-Liquid use?
□ Up to 2 ml
☐ More than 2 ml, up to 4 ml
☐ More than 4 ml, up to 6 ml
☐ More than 6 ml, up to 8 ml
☐ More than 8 ml, up to 10 ml
☐ More than 10 ml
☐ Idon't know
Has your use of e-Cigarettes changed since your diagnosis of cancer?
Yes No Not applicable
If ' Yes ', please tell us more details

4. Alcohol consumption

How often do yo	ou have a drink containing alcohol? (Please tick one)
☐ Never	
☐ Monthly or	less
2-3 times pe	er month
☐ Once or twi	ce a week
☐ 3-4 times a v	week
 ☐ 4 or more ti	
	ave a drink containing alcohol, please continue to the next page.
Otherwise pleas	se complete the rest of the page.
Here is a guide t	o units of alcohol:
Number of Uni	ts
1.5	A small glass (125 ml) of red, white or rosé wine (ABV 12%)
2.1	A standard glass (175 ml) of red, white or rosé wine (ABV 12%)
3	A large glass (250 ml) of red, white or rosé wine (ABV 12%)
2	A pint of lower-strength (ABV 3.6%) lager, beer or cider
3	A pint of higher-strength (ABV 5.2%) lager, beer or cider
1.7	A bottle (330 ml) of lager, beer or cider (ABV 5%)
2	A can (440 ml) of lager, beer or cider (ABV 4.5%)
1.5	275 ml bottle of alcopop (ABV 5.5%)
1	25 ml single spirit and mixer (ABV 40%)
How many units	s of alcohol do you drink on a typical day when drinking?
☐ 1 or 2	
□ 3 or 4	
□ 5 or 6	
7,8,or9	
☐ 10 or more	
Has your alcoho	l intake changed since your diagnosis of cancer?
☐ Yes	□ No
If ' Yes ', please to	ell us more details

5. Exercise & Physical activity

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

	Times per week:	
STRENUOUS EXERCISE (HEART BEATS RAPIDLY)		
(e.g., running, jogging, hockey, football, squash, basketball, judo, roller skating, vigorous swimming, vigorous long distance cycling)		hours
MODERATE EXERCISE (NOT EXHAUSTING)		hours
(e.g., fast walking, baseball, tennis, easy cycling, volleyball, badminton, easy swimming, dancing)		minutes
MILD EXERCISE (MINIMAL EFFORT)		hours
(e.g., yoga, archery, fishing, bowling, golf, easy walking)		minutes
	c. 1	
During a typical 7-Day period (a week), in your leisure time, how long enough to work up a sweat (heart beats rapidly)?	w orten do you eng	age in any regular activity
Often	~\) \	7
Sometimes		
☐ Never/Rarely		
Have you done any strength exercise(s) (such as weight lifting, s	it-ups, and push-up	os) in the last month ?
☐ Yes ☐ No		
If 'Yes', in a typical week, how many times and for how long have	you done strength	exercise(s)?
	Times per week:	
STRENGTH EXERCISE		hours
(e.g., weight lifting, sit-ups, and push-ups)		minutes
What type(s) of strength exercise(s) have you done?		
	diagnosis of cancer	?
Have your exercise/physical activity habits changed since your		
Yes No		
☐ Yes ☐ No		
☐ Yes ☐ No		
☐ Yes ☐ No		

continue over

6. Diet

Ononortica		Here is a guide to portions of fruit:			
One portion of fri	uit is equal to				
2 or more small pi of fresh fruit	eces	2 plums, satsumas or 3 apricots 7 strawberries 14 cherries	kiwi fruit		
Medium sized fres	sh fruit	1 apple, banana, pear,	or orange		
Large sized fresh f	fruit	Half a grapefruit 1 slice of papaya or m 2 slices of mango (please note: 1 slice = a	elon	k)	
Dried fruit		1 heaped tablespoon 2 figs 3 prunes		•	
Canned fruit		Similar quantity of fru	it as a fresh port	ion	
(in natural juice no	ot syrup)	(e.g. 2 pear or peach h	alves)		
Fruit juice drink o	rsmoothies	150ml of unsweetene	d fruit juice or sr	moothie	
(Do not count frui	t punch, lemoi	nade or fruit drinks suc	h as squash or co	oncentrated drinks)	
In a typical day,	now many por	tions of fruit do you e	at? (Please tick the	answer that best describe	es you)
None	1	2	3	4	5 or more
Here is a guide to p	ortion sizes of	vegetables:			
One portion of ve					
Green vegetables	0.1	proccoli spears or 4 hea		s of cooked kala spin	ach caring
		eens or green beans	iped tablespoon	s of cooked kale, spir	iacii, spriiig
Cooked vegetable	groes 3 h	•		·	. 0
Cooked vegetables Salad vegetables	groes 3 h or 3 s	eens or green beans neaped tablespoons of	cooked vegetabl	les, such as carrots, p	eas or sweetcorn,
	groes 3 h or 3 s to	eens or green beans neaped tablespoons of 8 cauliflower florets ticks of celery, a 5cm p	cooked vegetabl	les, such as carrots, p	eas or sweetcorn, or 7 cherry
Salad vegetables Tinned and frozer	groes 3h or 3s to Ro	eens or green beans neaped tablespoons of 8 cauliflower florets ticks of celery, a 5cm p matoes hughly the same quantit	cooked vegetable iece of cucumbe by as you would e	les, such as carrots, p r, 1 medium tomato at for a fresh portion	eas or sweetcorn, or 7 cherry
Salad vegetables Tinned and frozer vegetables	groes 3 h or 3 s to n Ro	eens or green beans neaped tablespoons of 8 cauliflower florets iticks of celery, a 5cm p matoes oughly the same quantit	cooked vegetable lece of cucumbe by as you would e baked beans, har ickpeas	les, such as carrots, p r, 1 medium tomato at for a fresh portion ricot beans, kidney be	eas or sweetcorn, or 7 cherry
Salad vegetables Tinned and frozer vegetables Pulses and beans Vegetable juice dr smoothies	groes 3h or 3s to n Ro 3h be rinks or 15	eens or green beans heaped tablespoons of 8 cauliflower florets hicks of celery, a 5cm p matoes hughly the same quantit heaped tablespoons of ans, butter beans or ch	cooked vegetable iece of cucumbe by as you would e baked beans, har ickpeas egetable juice or	les, such as carrots, p r, 1 medium tomato at for a fresh portion ricot beans, kidney be smoothie	eas or sweetcorn, or 7 cherry eans, cannellini
Salad vegetables Tinned and frozer vegetables Pulses and beans Vegetable juice dr smoothies (Do not count pot	groes 3 h or 3 s to n Ro 3 h be rinks or 15	eens or green beans neaped tablespoons of 8 cauliflower florets nticks of celery, a 5cm p matoes nughly the same quantit neaped tablespoons of ans, butter beans or ch Oml of unsweetened ver notatoes, parsnips, turn tions of vegetables of	cooked vegetable iece of cucumbe by as you would ebaked beans, har ickpeas egetable juice or ips, swede, yams	les, such as carrots, p r, 1 medium tomato at for a fresh portion ricot beans, kidney be smoothie	eas or sweetcorn, or 7 cherry eans, cannellini
Salad vegetables Tinned and frozer vegetables Pulses and beans Vegetable juice dr smoothies (Do not count pot In a typical day, h (Please tick the answer	groes 3 h or 3 s to n Ro 3 h be rinks or 15	eens or green beans neaped tablespoons of 8 cauliflower florets nticks of celery, a 5cm p matoes nughly the same quantif neaped tablespoons of ans, butter beans or ch Oml of unsweetened ver notatoes, parsnips, turn tions of vegetables of nesyou)	cooked vegetable iece of cucumbers as you would estable beans, having the ickpeas regetable juice or ips, swede, yams lo you eat?	les, such as carrots, p r, 1 medium tomato at for a fresh portion ricot beans, kidney be smoothie	eas or sweetcorn, or 7 cherry eans, cannellini
Salad vegetables Tinned and frozer vegetables Pulses and beans Vegetable juice dr smoothies (Do not count pot	groes 3 h or 3 s to n Ro 3 h be rinks or 15	eens or green beans neaped tablespoons of 8 cauliflower florets nticks of celery, a 5cm p matoes nughly the same quantit neaped tablespoons of ans, butter beans or ch Oml of unsweetened ver notatoes, parsnips, turn tions of vegetables of	cooked vegetable iece of cucumbe by as you would ebaked beans, har ickpeas egetable juice or ips, swede, yams	les, such as carrots, p r, 1 medium tomato at for a fresh portion ricot beans, kidney be smoothie	eas or sweetcorn, or 7 cherry eans, cannellini

	ase state if you currently follow any special/specific diet(s) (e.g. low fat, high fibre, vegetarian, vegan, lactose e, gluten free, diabetic, etc.):
Has	your diet changed since your diagnosis of cancer?
	Yes No
If 'Y	es', please tell us more details
7. You	ur Menstrual Cycle
	would like to know whether or not you have gone through the menopause. The menopause is a normal
unde	t in a woman's life marked by the end of menstrual periods. By providing this information you will help us erstand your answers to other questions we ask in this questionnaire. If you do not wish to answer, please this question blank.
unde	erstand your answers to other questions we ask in this questionnaire. If you do not wish to answer, please
unde	erstand your answers to other questions we ask in this questionnaire. If you do not wish to answer, please
unde	erstand your answers to other questions we ask in this questionnaire. If you do not wish to answer, please this question blank.
Hov	erstand your answers to other questions we ask in this questionnaire. If you do not wish to answer, please this question blank. www.wwould.you.describe.your.current.menstrual.cycle.(periods).status?(Please tick.one)
Hov	erstand your answers to other questions we ask in this questionnaire. If you do not wish to answer, please this question blank. wwould you describe your current menstrual cycle (periods) status? (Please tick one) Pre-menopause (regular periods in the last 3 months and no change in the frequency of periods) Early menopause transition (have had periods in the last 3 months but noticed a change in the frequency of
Hov	erstand your answers to other questions we ask in this questionnaire. If you do not wish to answer, please this question blank. wwould you describe your current menstrual cycle (periods) status? (Please tick one) Pre-menopause (regular periods in the last 3 months and no change in the frequency of periods) Early menopause transition (have had periods in the last 3 months but noticed a change in the frequency of these periods)
Hov	erstand your answers to other questions we ask in this questionnaire. If you do not wish to answer, please this question blank. We would you describe your current menstrual cycle (periods) status? (Please tick one) Pre-menopause (regular periods in the last 3 months and no change in the frequency of periods) Early menopause transition (have had periods in the last 3 months but noticed a change in the frequency of these periods) Late menopausal transition (at least 3 months in a row without a period but for less than 12 months)
Hov	erstand your answers to other questions we ask in this questionnaire. If you do not wish to answer, please this question blank. Would you describe your current menstrual cycle (periods) status? (Please tick one) Pre-menopause (regular periods in the last 3 months and no change in the frequency of periods) Early menopause transition (have had periods in the last 3 months but noticed a change in the frequency of these periods) Late menopausal transition (at least 3 months in a row without a period but for less than 12 months) Post-menopause (at least 12 months in a row without a period)
Hov	erstand your answers to other questions we ask in this questionnaire. If you do not wish to answer, please this question blank. Wwould you describe your current menstrual cycle (periods) status? (Please tick one) Pre-menopause (regular periods in the last 3 months and no change in the frequency of periods) Early menopause transition (have had periods in the last 3 months but noticed a change in the frequency of these periods) Late menopausal transition (at least 3 months in a row without a period but for less than 12 months) Post-menopause (at least 12 months in a row without a period) ost-menopause', was your menopause: (Please tick one)
Hov	erstand your answers to other questions we ask in this questionnaire. If you do not wish to answer, please ethis question blank. Wwould you describe your current menstrual cycle (periods) status? (Please tick one) Pre-menopause (regular periods in the last 3 months and no change in the frequency of periods) Early menopause transition (have had periods in the last 3 months but noticed a change in the frequency of these periods) Late menopausal transition (at least 3 months in a row without a period but for less than 12 months) Post-menopause (at least 12 months in a row without a period) ost-menopause', was your menopause: (Please tick one) Spontaneous ("natural")
Hov	erstand your answers to other questions we ask in this questionnaire. If you do not wish to answer, please ethis question blank. wwould you describe your current menstrual cycle (periods) status? (Please tick one) Pre-menopause (regular periods in the last 3 months and no change in the frequency of periods) Early menopause transition (have had periods in the last 3 months but noticed a change in the frequency of these periods) Late menopausal transition (at least 3 months in a row without a period but for less than 12 months) Post-menopause (at least 12 months in a row without a period) ost-menopause', was your menopause: (Please tick one) Spontaneous ("natural") Surgical (removal of both ovaries)
Hov	erstand your answers to other questions we ask in this questionnaire. If you do not wish to answer, please ethis question blank. wwould you describe your current menstrual cycle (periods) status? (Please tick one) Pre-menopause (regular periods in the last 3 months and no change in the frequency of periods) Early menopause transition (have had periods in the last 3 months but noticed a change in the frequency of these periods) Late menopausal transition (at least 3 months in a row without a period but for less than 12 months) Post-menopause (at least 12 months in a row without a period) ost-menopause', was your menopause: (Please tick one) Spontaneous ("natural") Surgical (removal of both ovaries)

Part 7 – Your Comments

Is there anything else that has happened in your life (other than your cancer and its treatment) that you think we should know about which may have affected your health and wellbeing?

Is there anything else we have not asked about that you think we ought to know?
We offer the option to complete our follow-up questionnaires on paper or online. For the next questionnaire,
which of these methods would you prefer? (Please tick one)
☐ Paper ☐ Online
Today's Date
Please fill in the date you completed this questionnaire:
D D / M M / Y Y Y

Thank you very much for your participation

Thank you very much for your help. We really value the time you have taken to complete this questionnaire.

Your participation is very helpful to us.

It is possible that you may have found some of these questions have raised issues for you which may be upsetting. If you have any concerns following the completion of this questionnaire we recommend that you seek support from your health care providers, such as your GP or specialist nurse, or through the helpline provided by Macmillan Cancer Support, who can be contacted on 0808 808 0000.

Please be aware that what you have written is not always read and analysed until some time after we receive the questionnaire. Questionnaires and notes are not read by your health care team.

Please return this form in the FREEPOST envelope provided.

If you would like further information or have any queries about this study, please contact the HORIZONS Research Team on 023 8059 6885 or email HORIZONS@soton.ac.uk.

