

# HORIZONS

Understanding the impact of cancer diagnosis and treatment on everyday life

## Fourth Questionnaire: 18 month follow-up

Study ID  /  / N

### Thank you for your valuable and continued involvement 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. Even if you have not experienced problems during recovery, or you have moved on from cancer, it is important that you complete this questionnaire so that we can compare your experience with others. This information will help inform support services in the future.

This questionnaire is divided into 5 parts. It will ask for information about your general health and wellbeing, how you have been feeling, and your experiences of support, ongoing care and activities related to your health. 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 are asking a range of questions which will help us to understand the impact of cancer diagnosis and treatment which other patients have said matter to them. 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 – Your General Health & Well-Being

First, we would like to ask some questions about your current health and quality of life.

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 ranging 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.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You had difficulty doing activities that require concentrating.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You were bothered by having a short attention span.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You had trouble remembering things.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You felt fatigued.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You felt happy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You felt blue or depressed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You enjoyed life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You worried about little things.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You were bothered by being unable to function sexually.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You didn’t have energy to do the things you wanted to do.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You were dissatisfied with your sex life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You were bothered by pain that kept you from doing the things you wanted to do.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You felt tired a lot.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You were reluctant to start new relationships.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You lacked interest in sex.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your mood was disrupted by pain or its treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You avoided social gatherings.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>





	Never	Seldom	Some times	About as often as not	Frequently	Very often	Always
You were bothered by mood swings.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You avoided your friends.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You had aches or pains.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You had a positive outlook on life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You were bothered by forgetting what you started to do.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You felt anxious.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You were reluctant to meet new people.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You avoided sexual activity.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain or its treatment interfered with your social activities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You were content with your life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The next set of questions asks specifically about the effects of your cancer or its treatment. Again, for each statement, 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 appreciated life more because of having had cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You had financial problems because of the cost of cancer surgery or treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You worried that your family members were at risk of getting cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You realized that having had cancer helps you cope better with problems now.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You were self-conscious about the way you look because of your cancer or its treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You worried about whether your family members might have cancer-causing genes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

please continue over





	Never	Seldom	Some times	About as often as not	Frequently	Very often	Always
You felt unattractive because of your cancer or its treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You worried about dying from cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You had problems with insurance because of cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You were bothered by hair loss from cancer treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You worried about cancer coming back.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You felt that cancer helped you to recognize what is important in life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You felt better able to deal with stress because of having had cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You worried about whether your family members should have genetic tests for cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You had money problems that arose because you had cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You felt people treated you differently because of changes to your appearance due to your cancer or its treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You had financial problems due to a loss of income as a result of cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Whenever you felt a pain, you worried that it might be cancer again.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You were preoccupied with concerns about cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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**

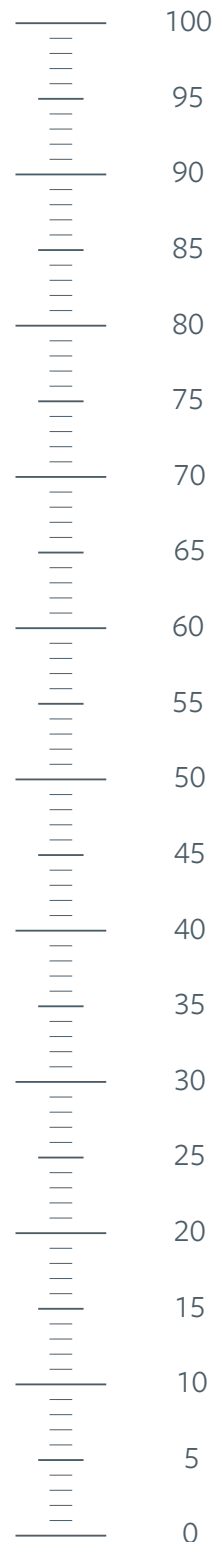
- I am not anxious or depressed
- I am slightly anxious or depressed
- I am moderately anxious or depressed
- I am severely anxious or depressed
- I am extremely anxious or depressed

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

The best health you can imagine



**YOUR HEALTH TODAY =**


The worst health you can imagine

## Part 2 – Your Experiences of Support, Ongoing Care and Activities

We would like to find out more about the types of support and assistance you have available to you. We would also like to ask you about your experiences of your treatment and any ongoing activities related to your health and also about how people cope and manage their health.

For each of the following questions, please tick the box that corresponds to your confidence that you can do the tasks regularly **at the present time**.

	Not at all Confident					Totally Confident				
	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?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How confident are you that you can access information about cancer and any effects of the diagnosis and treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How confident are you that you can access people to help and support you when you have problems caused by cancer and/or cancer treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How confident are you that you can deal by yourself with the problems cancer and/or cancer treatment has caused?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How confident are you to contact your doctor about problems caused by cancer and/or cancer treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How confident are you that you can get support with problems caused by cancer/treatment from health and/or social care professionals?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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People’s problems sometimes affect their ability to do certain day-to-day tasks in their lives. To rate your problems look at each section and determine on the scale provided how much your problem impairs your ability to carry out the activity.

**Work:** Because of my cancer, my **ability to work** is impaired. If you are retired or choose not to have a job for reasons unrelated to your cancer, please tick ‘N/A’.

0	1	2	3	4	5	6	7	8	<input type="checkbox"/>
Not at all		Slightly		Definitely		Markedly		Very Severely	N/A

**Home Management:** Because of my cancer, my **home management** (cleaning, tidying, shopping, cooking, looking after home or children, paying bills, etc) is impaired

0	1	2	3	4	5	6	7	8
Not at all		Slightly		Definitely		Markedly		Very Severely

**Social Leisure Activities:** Because of my cancer, my **social leisure activities** (with other people, e.g. parties, pubs, outings, entertaining etc.) are impaired

0	1	2	3	4	5	6	7	8
Not at all		Slightly		Definitely		Markedly		Very Severely

**Private Leisure Activities:** Because of my cancer, my **private leisure activities** (done alone, e.g. reading, gardening, sewing, hobbies, walking etc.) are impaired

0	1	2	3	4	5	6	7	8
Not at all		Slightly		Definitely		Markedly		Very Severely


**Family and Relationships:** Because of my cancer, my ability to form and maintain **close relationships** with others, including the people that I live with, is impaired

0	1	2	3	4	5	6	7	8
Not at all		Slightly		Definitely		Markedly		Very Severely



People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it? (Please **tick one box on each line**)

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
<b>Emotional / informational Support:</b>					
Someone you can count on to listen to you when you need to talk	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone to give you information to help you understand a situation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone to give you good advice about a crisis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone to confide in or talk to about yourself or your problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone whose advice you really want	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone to share your most private worries and fears with	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone to turn to for suggestions about how to deal with a personal problem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone who understands your problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Tangible Support:</b>					
Someone to help you if you were confined to bed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone to take you to the doctor if you needed it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone to prepare your meals if you were unable to do it yourself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone to help with daily chores if you were sick	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Affectionate Support:</b>					
Someone who shows you love and affection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone to love and make you feel wanted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone who hugs you	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Positive Social Interaction:</b>					
Someone to have a good time with	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone to get together with for relaxation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone to do something enjoyable with	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Additional Item:</b>					
Someone to do things with to help you get your mind off things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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For each of the questions, please indicate which response on the scale you most agree with.

In the **past 4 weeks**, how easy/ difficult has it been to...

	Very easy	Easy	Neither easy nor difficult	Difficult	Very difficult	Not applicable
...learn about your health problem(s)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...learn what foods you should eat to stay healthy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...find information on the medications that you have to take?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...understand changes to your treatment plan?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...understand the reasons why you are taking some medicines?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...find sources of medical information that you trust?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...understand advice from different healthcare providers?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

In the **past 4 weeks**, how much of a problem has it been for you to...

	Not at all	A little	Somewhat	Quite a bit	Very much
...make or keep your medical appointments?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...schedule and keep track of your medical appointments?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...make or keep appointments with <b>different</b> healthcare providers?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

In the **past 4 weeks**, how much of a problem has it been for you to...

	Not at all	A little	Somewhat	Quite a bit	Very much
...monitor your health behaviors, e.g., tracking exercise, foods you eat, or medicines you take?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...monitor your health condition, e.g., weighing yourself, checking blood pressure, or checking blood sugar?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

In the **past 4 weeks**, how bothered have you been by...

	Not at all	A little	Somewhat	Quite a bit	Very much
...feeling dependent on others for your healthcare needs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...others reminding you to do things for your health like take your medicine, watch what you eat, or schedule medical appointments?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...your healthcare needs creating tension in your relationships with others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...others not understanding your health situation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**In general**, how much do you agree/disagree with the following?

	Strongly agree	Agree	Disagree	Strongly disagree	Not applicable
I have problems with different healthcare providers not communicating with each other about my medical care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have to see too many different specialists for my health problem(s) or illness(es)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have problems filling out forms related to my healthcare	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have problems getting appointments at times that are convenient for me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have problems getting appointments with a specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have to wait too long at my medical appointments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have to wait too long at the pharmacy for my medicine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

In the following questions, **self-management** refers to all of those tasks and activities that you have to do specifically for your health problem(s) or illness(es) in order to stay healthy. This can include taking medicine, going to medical appointments, monitoring your health, diet, and exercise.

In the **past 4 weeks**, how much has your **self-management** interfered with your...

	Not at all	A little	Somewhat	Quite a bit	Very much
...work (include work at home)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...family responsibilities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...daily activities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...hobbies and leisure activities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...ability to spend time with family and friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...ability to travel for work or vacation?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

please  
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In the **past 4 weeks**, how often did your **self-management** make you feel...

	Never	Rarely	Sometimes	Often	Always
...angry?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...preoccupied?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...depressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...worn out?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...frustrated?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Are you experiencing any particular problems relating to your cancer and/or its treatment?

If **yes**, please can you describe them here:

If you are experiencing problems, have you found ways to manage them?

If **yes**, please can you describe them here:

Have you received any support in managing problems following your treatment?

If **yes**, please can you describe it here:

Do you think additional support would be helpful?

If **yes**, please can you describe here:

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

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## Part 3 – How You Have Been Feeling

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

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 <b>long</b> walk?	1	2	3	4
3. Do you have any trouble taking a <b>short</b> 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





During the **past week**:

	Not at All	A Little	Quite a Bit	Very Much
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
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 <b>family</b> life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your <b>social</b> activities?	1	2	3	4
28. Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

**For the following questions please circle the number between 1 and 7 that best applies to you**

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

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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, 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. Have you had muscle weakness?	1	2	3	4
32. Have you had aches or pains in your muscles or joints?	1	2	3	4
33. Have you had aches or pain in your bones?	1	2	3	4
34. Have you had a dry cough?	1	2	3	4
35. Have you had a dry mouth?	1	2	3	4
36. Have you had problems with your sense of taste?	1	2	3	4
37. Have you felt ill or unwell?	1	2	3	4
38. Have you had tingling hands or feet?	1	2	3	4
39. Have you had numbness in your fingers or toes?	1	2	3	4
40. Have you had shortness of breath on exertion?	1	2	3	4
41. Have you felt you had setbacks in your physical condition?	1	2	3	4
42. Have you had a lack of energy?	1	2	3	4
43. Have you felt drowsy?	1	2	3	4
44. Have you had sudden tiredness?	1	2	3	4
45. Have you had mood changes?	1	2	3	4
46. Have you felt a lack of confidence in your body?	1	2	3	4
47. Have you been dissatisfied with how your body functions?	1	2	3	4
48. Have you had difficulty accepting limitations due to the disease?	1	2	3	4
49. Have you had hot flushes?	1	2	3	4
50. Did you have night sweats?	1	2	3	4
51. Did you have headaches?	1	2	3	4




During the **past four weeks:**

	Not at All	A Little	Quite a Bit	Very Much
52. Have you worried about picking up an infection?	1	2	3	4
53. Have you worried about your health in the future?	1	2	3	4
54. Have you worried about recurrence of your disease?	1	2	3	4
55. Have you worried about becoming chronically ill?	1	2	3	4
56. Have you worried about becoming dependent on others?	1	2	3	4
57. Have you worried about getting another type of cancer?	1	2	3	4
58. Have you worried about your treatment causing future health problems?	1	2	3	4
59. Have you worried about damage to your heart and blood vessels?	1	2	3	4
60. How much has your disease been a burden to you?	1	2	3	4
61. How much has your treatment been a burden to you?	1	2	3	4

During the **past four weeks:**

	Not at All	A Little	Quite a Bit	Very Much
62. <b>If applicable:</b> Have you had problems at your work or place of study due to the disease?	1	2	3	4
63. <b>If applicable:</b> Have you worried about not being able to continue working or your education?	1	2	3	4
64. <b>If applicable:</b> Have you been concerned about your ability to have children?	1	2	3	4

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During the **past four weeks:**

	Not at All	A Little	Quite a Bit	Very Much
65. To what extent were you interested in sex?	1	2	3	4
66. 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 in the past four weeks:**

	Not at All	A Little	Quite a Bit	Very Much
67. Have you had pain during sexual intercourse or other sexual activity?	1	2	3	4
68. To what extent was sex enjoyable for you?	1	2	3	4
69. <b>For women only:</b> Has your vagina felt dry during sexual activity?	1	2	3	4
70. <b>For women only:</b> Has your vagina felt short and/or tight?	1	2	3	4
71. <b>For men only:</b> Did you have difficulty gaining or maintaining an erection?	1	2	3	4
72. <b>For men only:</b> Did you have ejaculation problems? (e.g. dry ejaculation)	1	2	3	4
73. Have you been satisfied with your ability to reach an orgasm?	1	2	3	4
74. <b>If applicable:</b> Have you had a change in the ability to reach an orgasm since you received treatment for cancer?	No		Yes	

During the **past week:**

	Not at All	A Little	Quite a Bit	Very Much
75. Have you suffered from pain and tingling in your feet/toes?	0	1	2	3
76. Have you suffered from pain and tingling in your hands/fingers?	0	1	2	3
77. Have you suffered from numb or cold feet or toes?	0	1	2	3
78. Have you suffered from numb or cold hands or fingers?	0	1	2	3
79. Have you suffered from ringing in your ears?	0	1	2	3
80. Have you suffered from reduced hearing?	0	1	2	3
81. <b>If applicable:</b> Was the ringing present before your cancer treatment?	No		Yes	
82. <b>If applicable:</b> Was the hearing loss present before your cancer treatment?	No		Yes	

**For the following questions, please circle the number that best corresponds to your views:**

To what extent does worry about your cancer spill over or intrude into your other thoughts and activities?

0      1      2      3      4      5      6      7      8      9      10

---

Not at all

A great deal

How often have you worried about the possibility that your cancer might come back after treatment?

0                      1                      2                      3                      4

---


None of the time

Rarely

Occasionally

Often

All the time

please  
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### **Hospital Anxiety and Depression Scale (HADS)**

As per our licence, the HADS instrument cannot be shared without agreement from the copyright holders. HADS is available through licence from GL Assessment, please see: <http://www.gl-assessment.co.uk/products/hospital-anxiety-and-depression-scale/hospital-anxiety-and-depression-scale-faqs>

#### **Measure reference:**

Zigmond, A.S. & Snaith, R.P. (1983). The hospital anxiety and depression scale. *Acta psychiatrica scandinavica*, 67(6), 361-370.

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**Please answer the following questions about your general health:**

	Yes	No
In general, do you have any health problems that require you to limit your activities?	<input type="checkbox"/>	<input type="checkbox"/>
Do you need someone to help you on a regular basis?	<input type="checkbox"/>	<input type="checkbox"/>
In general, do you have any health problems that require you to stay at home?	<input type="checkbox"/>	<input type="checkbox"/>
In case of need, can you count on someone close to you?	<input type="checkbox"/>	<input type="checkbox"/>
Do you regularly use a stick, walker or wheelchair to get about?	<input type="checkbox"/>	<input type="checkbox"/>

**FOR WOMEN ONLY: Your Menstrual Cycle**

We would like to know whether or not you have gone through the menopause. The menopause is an event in a woman’s life marked by the end of menstrual periods. By providing this information you will help us understand your answers to other questions we ask in this questionnaire. If you do not wish to answer, please leave this question blank.

How 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)

If **‘Post-menopause’**, was your menopause: (Please tick **one**)

- Spontaneous (“natural”)
- Surgical (removal of both ovaries)
- Due to chemotherapy or radiation therapy; reason for therapy: \_\_\_\_\_
- Other (please explain): \_\_\_\_\_

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## Part 4 – About You

In this section, we would like to know a little about yourself and if anything has changed since the first questionnaire.

Are you **currently**: (Please tick **one**)

- Single
- In a relationship

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/cohabitee
- Child(ren)
- Parent(s)
- Friend(s)
- Other (please specify): \_\_\_\_\_
- None of the above, I live alone

Have any first degree relative(s) of yours (parent, brother/sister or child) ever been diagnosed with cardiac health problems (e.g. heart attack or myocardial infarction, heart failure, high blood pressure)?

- Yes
- No
- Unknown

## Part 5 – 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 the following 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	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](mailto:HORIZONS@soton.ac.uk).**

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