

# HORIZONS

Understanding the impact of cancer diagnosis and treatment on everyday life

## Fifth Questionnaire: 24 month follow-up

Study ID  /  /

### Thank you for your valuable and continued involvement in this study.

Your participation will help us to understand how a diagnosis of cancer and its treatment affects a person's everyday life and how this changes over time.

**Even if you have not experienced problems during your recovery, or you have moved on from cancer, we still want to know about your experiences.**

HORIZONS will be recruiting over 3,000 people across the UK and so are gathering a range of different experiences. These will help to inform support services in the future.

We understand that this questionnaire is long but we are asking a variety of questions to help us understand the impact of cancer and its treatment which other patients have said matter to them.

This questionnaire is divided into 7 parts. It will ask about your general health and wellbeing, managing your health, how you have been feeling, your experience of support and use of health services.

You will also notice that some questions are repeated from our last questionnaires but it's important to find out what has or has not changed since then. Some questions may also seem repetitive but each aims to measure slightly different things.

### How to fill in this questionnaire

- Please read the instructions and questions carefully.
- Please try to answer all of the questions but if you do not wish to, please leave these blank or cross through.
- You may wish to take breaks whilst completing the questionnaire.
- The information you provide will remain **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"/>

### **The General Health Survey Questionnaire, Short Form 12 Ver 2.0 (SF-12v2)**

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<https://campaign.optum.com/content/optum/en/optum-outcomes/what-we-do/health-surveys/sf-12v2-health-survey.html>

#### **Measure references:**

Ware, J.E., Kosinski, M. & Keller, S.D. (1996). A 12 Item Short Form Health Survey: Construction of Scales and Preliminary Tests of Reliability and Validity. *Medical Care*, 34(3), 220-233

Ware, J.E., Kosinski, M., Turner-Bowker, D.M., & Gandek, B. (2002). How to score Version 2 of the SF-12 Health Survey (with a supplement documenting Version 1). Lincoln RI: QualityMetric Incorporated

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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

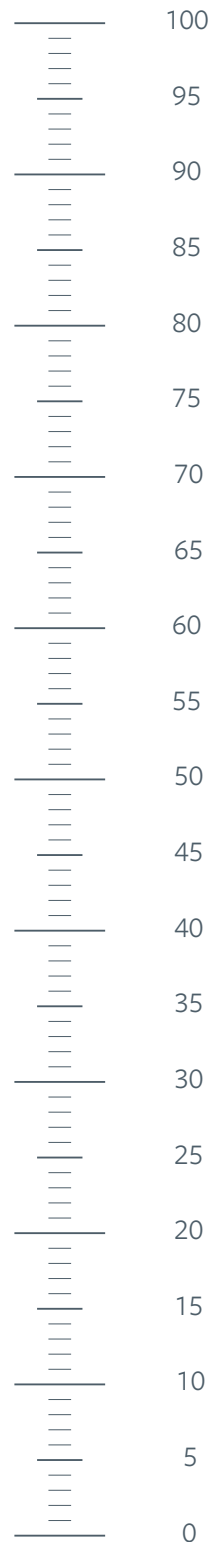
- Mark an **X** on the scale to indicate how your health is

**TODAY**

- Now, please write the number you marked on the scale in the box below.

**YOUR HEALTH TODAY =**

The best  
health you  
can imagine



The worst  
health you  
can imagine

please  
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## Part 2 -Your Experiences of Managing Your Health, Ongoing Care & Activities

We would now like to ask about how you cope and manage your health, as well as your experiences of any ongoing activities related to your 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"/>



### **Health Education Impact Questionnaire (heiQ)**


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#### **Measure reference:**

Osborne, R.H., Elsworth, G.R. & Whitfield, K. (2007). The Health Education Impact Questionnaire (heiQ): an outcomes and evaluation measure for patient education and self-management interventions for people with chronic conditions. *Patient education and counseling*, 66(2), 192-201.

The Health Education Impact Questionnaire (heiQ). © Copyright 2015 Deakin University.  
Authors: R.H. Osborne, K. Whitfield, G.R. Elsworth.



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**Connor-Davidson Resilience Scale 2-items (CD-RISC2)**

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**Measure reference:**

Vaishnavi, S., Connor, K. and Davidson, J.R., 2007. An abbreviated version of the Connor-Davidson Resilience Scale (CD-RISC), the CD-RISC2: Psychometric properties and applications in psychopharmacological trials. *Psychiatry research*, 152(2), 293-297.

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

**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"/>





	Strongly agree	Agree	Disagree	Strongly disagree	Not applicable
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"/>

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"/>

Have you used complementary and/or alternative medicines/therapies in the **last 3 months**? (e.g. meditation, mindfulness, homeopathy, acupuncture, osteopathy, herbal medicines, chiropractic, Traditional Chinese medicines, etc.)

Yes  No

If **'Yes'**, what complementary and/or alternative medicines/therapies have you used in the **last 3 months**?

please continue over

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:

# Part 3 -Your Experiences of Help and Support


In this section, we would like to find out more about the types of support and assistance you have available to you.

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"/>

How many close friends do you have?

How many close family members do you have?

please continue over 

## Your Social Network

Many people understand the term 'social network' to be social media. 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.

### On the next page:

1. 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, neighbours, colleagues, to pets and healthcare staff like GPs and nurses.
2. For each person, please let us know a couple of details about them:
  - (1) their relationship to you (e.g. friend, pet, GP, nurse, etc.)
  - (2) how often you see them in person, and
  - (3) approximately how far do they live from you
3. Then, 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)

Please use as many or as few of the lines provided.

Network Member Number	Network Member (name or initials)	Gender 1 = male 2 = female	Relationship (son, daughter, pet, friend, group, nurse, etc.)	How often do you see them? 1 = at least once a week, 2 = at least once a month, 3 = at least every couple of months, 4 = less often	How far do they live from you? (approx. in miles)	Rate the extent to which this member helps you with:		
						A. Information of your illness and illness management	B. Practical help with daily tasks	C. Emotional support
Example	A.Y.	① 2	Friend	1 2 ③ 4	10	1 2 ③	1 2 ③	1 2 ③
1		1 2		1 2 3 4		1 2 3	1 2 3	1 2 3
2		1 2		1 2 3 4		1 2 3	1 2 3	1 2 3
3		1 2		1 2 3 4		1 2 3	1 2 3	1 2 3
4		1 2		1 2 3 4		1 2 3	1 2 3	1 2 3
5		1 2		1 2 3 4		1 2 3	1 2 3	1 2 3
6		1 2		1 2 3 4		1 2 3	1 2 3	1 2 3
7		1 2		1 2 3 4		1 2 3	1 2 3	1 2 3
8		1 2		1 2 3 4		1 2 3	1 2 3	1 2 3
9		1 2		1 2 3 4		1 2 3	1 2 3	1 2 3
10		1 2		1 2 3 4		1 2 3	1 2 3	1 2 3
11		1 2		1 2 3 4		1 2 3	1 2 3	1 2 3
12		1 2		1 2 3 4		1 2 3	1 2 3	1 2 3
13		1 2		1 2 3 4		1 2 3	1 2 3	1 2 3
14		1 2		1 2 3 4		1 2 3	1 2 3	1 2 3
15		1 2		1 2 3 4		1 2 3	1 2 3	1 2 3
16		1 2		1 2 3 4		1 2 3	1 2 3	1 2 3
17		1 2		1 2 3 4		1 2 3	1 2 3	1 2 3
18		1 2		1 2 3 4		1 2 3	1 2 3	1 2 3
19		1 2		1 2 3 4		1 2 3	1 2 3	1 2 3
20		1 2		1 2 3 4		1 2 3	1 2 3	1 2 3

To help us plan better services for people diagnosed with cancer, we are interested in whether or not needs which you may have faced as a result of having cancer have been met.


For every item on the following pages, indicate whether you have needed help with this issue within the last month as a result of having cancer. **Put a circle around the number which best describes whether you have needed help with this in the last month.** There are 5 possible answers to choose from.

<b>No Need</b>	1	<b>Not applicable</b> – This was not a problem for me as a result of having cancer
	2	<b>Satisfied</b> – I did need help with this, but my need for help was satisfied at the time.
<b>Some Need</b>	3	<b>Low need</b> – This item caused me concern or discomfort. I had little need for additional help.
	4	<b>Moderate need</b> – This item caused me concern or discomfort. I had some need for additional help.
	5	<b>High need</b> – This item caused me concern or discomfort. I had a strong need for additional help.

In the <b>last month</b> , what was your level of need for help with:	No need		Some need		
	Not applicable	Satisfied	Low need	Moderate need	High need
Pain	1	2	3	4	5
Lack of energy/tiredness	1	2	3	4	5
Feeling unwell a lot of the time	1	2	3	4	5
Work around the home	1	2	3	4	5
Not being able to do the things you used to do	1	2	3	4	5
Anxiety	1	2	3	4	5
Feeling down or depressed	1	2	3	4	5
Feelings of sadness	1	2	3	4	5
Fears about the cancer spreading	1	2	3	4	5
Worry that the results of treatment are beyond your control	1	2	3	4	5
Uncertainty about the future	1	2	3	4	5
Learning to feel in control of your situation	1	2	3	4	5
Keeping a positive outlook	1	2	3	4	5
Feelings about death and dying	1	2	3	4	5
Changes in sexual feelings	1	2	3	4	5
Changes in your sexual relationships	1	2	3	4	5
Concerns about the worries of those close to you	1	2	3	4	5
More choice about which cancer specialists you see	1	2	3	4	5



In the <b>last month</b> , what was your level of need for help with:	No need		Some need		
	Not applicable	Satisfied	Low need	Moderate need	High need
More choice about which hospital you attend	1	2	3	4	5
Reassurance by medical staff that the way you feel is normal	1	2	3	4	5
Hospital staff attending promptly to your <b>physical</b> needs	1	2	3	4	5
Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs	1	2	3	4	5
Being given written information about the important aspects of your care	1	2	3	4	5
Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home	1	2	3	4	5
Being given explanations of those tests for which you would like explanations	1	2	3	4	5
Being adequately informed about the benefits and side-effects of treatments before you choose to have them	1	2	3	4	5
Being informed about your test results as soon as feasible	1	2	3	4	5
Being informed about cancer which is under control or diminishing (that is, remission)	1	2	3	4	5
Being informed about things you can do to help yourself to get well	1	2	3	4	5
Having access to professional counselling (e.g., psychologist, social worker, counsellor, nurse specialist) if you, family or friends need it	1	2	3	4	5
Being given information about sexual relationships	1	2	3	4	5
Being treated like a person not just another case	1	2	3	4	5
Being treated in a hospital or clinic that is as physically pleasant as possible	1	2	3	4	5
Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up	1	2	3	4	5

please  
continue  
over 

# Part 4 - Your Use of Health Services

We would now like to ask you about the health and support services you may have used.

## 1. Health service use

This section will ask you about the health services and support you may have used.

Please record the **number** of health and social care services you have used over the **last 3 months** including those due to any health problems, not just your cancer and its treatment.

### 1.1 Hospital visits and appointments

These refer to any contact you make with the hospital. This can include: overnight stays in hospital, outpatient visits, telephone calls and emails to hospital-based health professionals. Please do not include chemotherapy or radiotherapy treatment visits.

	Have you used this service in the last 3 months? (please tick if 'yes')	Approximate number of days
Hospital inpatient stay (at least 24 hours)	<input type="checkbox"/>	

Can you please describe the reasons for your overnight hospital stay?

	Have you used this service in the last 3 months? (please tick if 'yes')	Approximate number of visits	Approximate number of contacts by telephone and/or email
Accident and emergency department	<input type="checkbox"/>		
Cancer doctor	<input type="checkbox"/>		
Cancer nurse	<input type="checkbox"/>		
Cancer information and support service	<input type="checkbox"/>		
Day centre	<input type="checkbox"/>		
Dietician	<input type="checkbox"/>		
Hospital doctor	<input type="checkbox"/>		
Hospital nurse	<input type="checkbox"/>		
Occupational therapist	<input type="checkbox"/>		
Outpatient clinic	<input type="checkbox"/>		
Pharmacist	<input type="checkbox"/>		
Physiotherapist	<input type="checkbox"/>		
Psychiatrist or psychologist	<input type="checkbox"/>		
Radiographer	<input type="checkbox"/>		
Speech and language therapist	<input type="checkbox"/>		
Other specialist doctor, please specify: _____	<input type="checkbox"/>		

I have not used any of the services listed on this page



	Have you used this service in the last 3 months? (please tick if 'yes')	Approximate number of visits	Approximate number of contacts by telephone and/or email
Other specialist nurse, please specify: _____	<input type="checkbox"/>		
Other, please specify: _____	<input type="checkbox"/>		
	<input type="checkbox"/>		
	<input type="checkbox"/>		
	<input type="checkbox"/>		

Please specify any tests or scans performed in the hospital (e.g. X-ray, CT-scan but not blood tests).

	Have you had this test in the last 3 months? (please tick if 'yes')	Approximate number
Bone scan	<input type="checkbox"/>	
CT-Scan	<input type="checkbox"/>	
Internal vaginal examination	<input type="checkbox"/>	
Mammogram	<input type="checkbox"/>	
MRI Scan	<input type="checkbox"/>	
Papanicolaou test (Cervical smear test)	<input type="checkbox"/>	
Ultrasound	<input type="checkbox"/>	
X-ray	<input type="checkbox"/>	
Other, please specify: _____	<input type="checkbox"/>	
	<input type="checkbox"/>	
	<input type="checkbox"/>	
	<input type="checkbox"/>	

## 1.2 Other health and social care services

This refers to all health and social care that is **not** based in the hospital in the **last 3 months**.

	Have you used this service in the last 3 months? (please tick if 'yes')	Approximate number of <b>clinic</b> visits	Approximate number of <b>home</b> visits	Approximate number of contacts by telephone and/or email
Counsellor	<input type="checkbox"/>			
Dietician	<input type="checkbox"/>			
District nurse, health visitor or members of community team	<input type="checkbox"/>			
GP	<input type="checkbox"/>			
Mental health or emotional support services (e.g. mental health nurse)	<input type="checkbox"/>			

please continue over

I have not used any of the services listed on this page



	Have you used this service in the last 3 months? (please tick if 'yes')	Approximate number of <b>clinic</b> visits	Approximate number of <b>home</b> visits	Approximate number of contacts by telephone and/or email
Occupational therapist	<input type="checkbox"/>			
Pharmacist	<input type="checkbox"/>			
Physiotherapist	<input type="checkbox"/>			
Podiatrist	<input type="checkbox"/>			
Psychiatrist or psychologist	<input type="checkbox"/>			
Social worker	<input type="checkbox"/>			
Other, please specify: _____	<input type="checkbox"/>			
	<input type="checkbox"/>			
	<input type="checkbox"/>			
	<input type="checkbox"/>			

### 1.3 Other support services

This refers to all other support and care services that you may have used in the **last 3 months**.

	Have you used this service in the last 3 months? (please tick if 'yes')	Approximate number of visits/ contact
Cancer charity information and/or support services	<input type="checkbox"/>	
Cancer charity website and/or online forums	<input type="checkbox"/>	
Citizen's Advice Bureau	<input type="checkbox"/>	
Community transport services	<input type="checkbox"/>	
Day hospice	<input type="checkbox"/>	
Drug or alcohol rehabilitation services	<input type="checkbox"/>	
Employment advice service	<input type="checkbox"/>	
Family or patient support or self-help groups	<input type="checkbox"/>	
Financial or benefits advice service	<input type="checkbox"/>	
Food bank	<input type="checkbox"/>	
Food, medicine or laundry delivery service	<input type="checkbox"/>	
Home help or care worker	<input type="checkbox"/>	
Lifestyle advice services/workshops	<input type="checkbox"/>	
Lunch or social club	<input type="checkbox"/>	
Nursing/Residential home	<input type="checkbox"/>	
Other charity information and support service	<input type="checkbox"/>	

I have not used any of the services listed on this page





	Have you used this service in the last 3 months? (please tick if 'yes')	Approximate number of visits/ contact
Other charity website and/or online forums	<input type="checkbox"/>	
Telephone help lines	<input type="checkbox"/>	
Voluntary services/ assistance	<input type="checkbox"/>	
Walking group or physical activity service	<input type="checkbox"/>	
Other, please specify: _____	<input type="checkbox"/>	
	<input type="checkbox"/>	
	<input type="checkbox"/>	
	<input type="checkbox"/>	

I have not used any of the services listed on this page

## 2. Travel costs and additional expenses

### 2.1 Travel costs

This section refers to how much in the **last 3 months** you spent on travel to attend hospital or other health and social care appointments, including any unplanned visits.

Approximately, how many miles have you travelled by car?  miles

Approximately, how much have you spent on health-care related parking?

£

Approximately, how much have you spent on fares for public transport, taxis, etc.?

£

### 2.2 Other expenses

Please let us know if there have been any other costs or expenses due to your health or cancer treatment or follow up over **the last 3 months** (e.g. home adaptations, extra laundry, cleaning services, etc.):

Description	Approximate total cost (£)

please  
continue  
over

## Part 5 – How You Have Been Feeling

In this section, we would like to know more about how you have been feeling. Even if you have not experienced any problems, it is important for us to understand a range of experiences.

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
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





During the **past week**:

	Not at All	A Little	Quite a Bit	Very Much
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

please  
continue  
over

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 abdominal pain?	1	2	3	4
32. Did you have a bloated feeling in your abdomen/stomach?	1	2	3	4
33. Did you have problems with your clothes feeling too tight?	1	2	3	4
34. Did you experience change in bowel habit as a result of your disease or treatment?	1	2	3	4
35. Were you troubled by passing wind/gas/flatulence?	1	2	3	4
36. Have you felt full up too quickly after beginning to eat?	1	2	3	4
37. Have you had indigestion or heartburn?	1	2	3	4
38. Have you lost any hair?	1	2	3	4
39. Answer this question only if you had any hair loss: Were you upset by the loss of your hair?	1	2	3	4
40. Did food and drink taste different from usual?	1	2	3	4
41. Have you had tingling hands or feet?	1	2	3	4
42. Have you had numbness in your fingers or toes?	1	2	3	4
43. Have you felt weak in your arms or legs?	1	2	3	4
44. Did you have aches or pains in your muscles or joints?	1	2	3	4
45. Did you have problems with hearing?	1	2	3	4
46. Did you urinate frequently?	1	2	3	4
47. Have you had skin problems (e.g. itchy, dry)?	1	2	3	4
48. Did you have hot flushes?	1	2	3	4
49. Did you have night sweats?	1	2	3	4
50. Did you have headaches?	1	2	3	4
51. Have you felt physically less attractive as a result of your disease or treatment?	1	2	3	4
52. Have you been dissatisfied with your body?	1	2	3	4
53. How much has your disease been a burden to you?	1	2	3	4
54. How much has your treatment been a burden to you?	1	2	3	4
55. Were you worried about your future health?	1	2	3	4

During the past **four weeks**:

	Not at All	A Little	Quite a Bit	Very Much
56. To what extent were you interested in sex?	1	2	3	4
57. To what extent were you sexually active?	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
58.	To what extent was sex enjoyable for you?	1	2	3	4
59.	Has your vagina felt dry during sexual activity?	1	2	3	4
60.	Has your vagina felt short and/or tight?	1	2	3	4
61.	Have you had pain during sexual intercourse or other sexual activity?	1	2	3	4
62.	Have you been satisfied with your ability to reach an orgasm?	1	2	3	4

During the **past four weeks:**

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

During the **past week:**

			Not at All	A Little	Quite a Bit	Very Much
66.	Have you been feeling self-conscious about your appearance?		1	2	3	4
67.	Have you been <b>dissatisfied</b> with your appearance when dressed?		1	2	3	4
68.	Have you been feeling <b>less</b> feminine as a result of your disease or treatment?		1	2	3	4
69.	Did you find it difficult to look at yourself naked?		1	2	3	4
70.	Have you been feeling <b>less</b> sexually attractive as a result of your disease or treatment?		1	2	3	4
71.	Did you avoid people because of the way you felt about your appearance?		1	2	3	4
72.	Have you been feeling the treatment has left your body less whole?		1	2	3	4
73.	Have you been <b>dissatisfied</b> with the appearance of your scar?	N/A	1	2	3	4

please  
continue  
over 

**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.

Hospital Anxiety Depression Scale (HADS) copyright © R.P. Snaith and A.S. Zigmond, 1983, 1992, 1994. Record form items originally published in *Acta Psychiatrica Scandinavica*, 67, 361–70.

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**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

In this section, we would like you to think about “your illness” in relation to your experience of cancer and/or its effects on your health, well-being and day-to-day life.

**Please circle the number that best describes your views:**

How much does your illness affect your life?

0 1 2 3 4 5 6 7 8 9 10

---

No affect at all

Severely affects my life

How long do you think your illness will continue?

0 1 2 3 4 5 6 7 8 9 10

---

A very short time

Forever

How much control do you feel you have over your illness?

0 1 2 3 4 5 6 7 8 9 10

---

Absolutely no control

Extreme amount of control


How much do you think your treatment can help your illness?

0 1 2 3 4 5 6 7 8 9 10

---

Not at all

Extremely helpful

please  
continue  
over 

How much do you experience symptoms from your illness?

0      1      2      3      4      5      6      7      8      9      10

---

No symptoms at all

Many severe symptoms

How concerned are you about your illness?

0      1      2      3      4      5      6      7      8      9      10

---

Not at all concerned

Extremely concerned

How well do you feel you understand your illness?

0      1      2      3      4      5      6      7      8      9      10

---

Don't understand at all

Understand very clearly

How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)

0      1      2      3      4      5      6      7      8      9      10

---

Not at all affected emotionally

Extremely affected emotionally

Please list in rank-order the three most important factors that you believe caused your illness:

The most important causes for me:

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

# Part 6 – About You, Your Interests & Lifestyle

In this section, we would like to ask you if anything has changed about you and your lifestyle since the last questionnaires.

## 1. Other conditions or illnesses that you may have

**Since your diagnosis of cancer,** have you been told by a healthcare professional that you have another health condition?

Yes

No

If **'Yes'**, please work through both parts A & B in the table below and select the condition(s) you have been diagnosed with.

If **'No'**, please continue to **Page 31**.

**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 0, which is no limitation, to 7 which is severely limited.)

	<b>A.</b>  Has a health professional ever told you that you have this condition? (Please tick if 'Yes')	<b>B.</b> (If 'Yes' in A)  How severely does the condition limit the activities you do on a typical day?							
		No limitations				Severely limited			
		0	1	2	3	4	5	6	7
Anaemia	<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"/>
Arrhythmia/irregular heartbeat (e.g. AF or atrial fibrillation)	<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"/>
Rheumatoid Arthritis	<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"/>
Other Arthritis (e.g. osteoarthritis, psoriatic arthritis)	<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"/>
Asthma, chronic lung disease, bronchitis, emphysema, chronic obstructive pulmonary disease (COPD)	<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"/>
Cancer previous to your current diagnosis. Type of cancer, please state: <input type="text"/>	<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"/>
Chest pain or angina	<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"/>
Dementia	<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"/>



please continue over →



	<b>A.</b> <b>Has a health professional ever told you that you have this condition? (Please tick if 'Yes')</b>	<b>B.</b> <b>(If 'Yes' in A)</b> <b>How severely does the condition limit the activities you do on a typical day?</b>							
		No limitations				Severely limited			
		0	1	2	3	4	5	6	7
Depression or anxiety	<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"/>
Diabetes or high blood sugar (Type I)	<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"/>
Diabetes or high blood sugar (Type II)	<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"/>
Heart attack or myocardial infarction	<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"/>
Heart failure	<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"/>
High blood pressure or hypertension	<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"/>
HIV/AIDS	<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"/>
Inflammatory bowel disease, colitis or Crohn's disease	<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"/>
Kidney/renal disease	<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"/>
Liver disease or cirrhosis	<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"/>
Neurological condition (e.g. multiple sclerosis, Parkinson's disease)	<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"/>
Osteoporosis, osteopenia, or fragile/brittle bones	<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"/>
Over- or under- active thyroid	<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"/>
Pancreatitis	<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"/>
Stomach ulcers	<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"/>
Stroke/transient ischemic attack (TIA) or brain haemorrhage	<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"/>
Venous disease (DVT: deep vein thrombosis/PE: pulmonary embolism)	<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"/>
Other condition, please state: <input style="width: 100%; height: 20px;" type="text"/>	<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"/>

## 2. Body stats

What is your weight?

st   lbs

or    kg

## 3. Smoking habits

Have your smoking habits changed since the last questionnaire?

- Yes  No  
 I am unsure  I have never smoked/this does not apply to me

If '**Yes**' or '**I am unsure**', please complete the rest of this page.  
Otherwise please continue to the next page.

Which of the following currently best describes you?

- I am a **smoker**  
 I am an **ex-smoker**

Date you stopped smoking (month and year):

/


If you currently smoke or are an ex-smoker, how long have/did you smoke(d) for?

If you currently smoke or are an ex-smoker, how many cigarettes **a day** do/did you smoke?

Have you received, or been offered, help to stop smoking?

- Yes  No  Not applicable

Please tell us any other details about your smoking habits and changes since the last questionnaire:

please  
continue  
over 

#### 4. e-Cigarette use / Vaping habits

Has your use of e-Cigarettes changed since the last questionnaire?

Yes

No

I am unsure

I have never vaped/this does not apply to me

If **'Yes'** or **'I am unsure'**, please complete the rest of this page.  
Otherwise please continue to the next page.

Which of the following best describes you?

I **currently use** an e-Cigarette/vape

I have **previously used** an e-Cigarette/vaped

Are you using/have you used 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

4 to 8 mg/ml

9 to 12 mg/ml

13 to 16 mg/ml

17 to 20 mg/ml

More than 20 mg/ml

I don'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

I don't know

Please tell us any other details about your e-Cigarette use and changes since the last questionnaire:



## 5. Alcohol consumption

How often do you have a drink containing alcohol? (Please tick **one**)

- Never
- Monthly or less
- 2-3 times per month
- Once or twice a week
- 3-4 times a week
- 4 or more times a week

If you '**Never**' have a drink containing alcohol, please continue to the next section. Otherwise please complete the rest of this section.

Here is a guide to units of alcohol:


### Number of Units

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 of alcohol do you drink on a **typical day** when drinking?

- 1 or 2
- 3 or 4
- 5 or 6
- 7, 8, or 9
- 10 or more

Please tell us any other details about your alcohol intake and changes since the last questionnaire:

please  
continue  
over 

## 6. 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:	
<b>STRENUOUS EXERCISE (HEART BEATS RAPIDLY)</b> (e.g., running, jogging, hockey, football, squash, basketball, judo, roller skating, vigorous swimming, vigorous long distance cycling)	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> hours <input type="text"/> <input type="text"/> minutes
<b>MODERATE EXERCISE (NOT EXHAUSTING)</b> (e.g., fast walking, tennis, easy cycling, volleyball, badminton, easy swimming, dancing)	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> hours <input type="text"/> <input type="text"/> minutes
<b>MILD EXERCISE (MINIMAL EFFORT)</b> (e.g., yoga, archery, fishing, bowling, golf, easy walking)	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> hours <input type="text"/> <input type="text"/> minutes

During a typical **7-Day period** (a week), in your leisure time, how often do you engage in any regular activity long enough to work up a sweat (heart beats rapidly)?

- Often  
 Sometimes  
 Never/Rarely

Have you done any strength exercise(s) (such as weight lifting, sit-ups, and push-ups) 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:	
<b>STRENGTH EXERCISE</b> (e.g., weight lifting, sit-ups, and push-ups)	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> hours <input type="text"/> <input type="text"/> minutes

What type(s) of strength exercise(s) have you done?

Please tell us any other details about your exercise / physical activity habits and changes since the last questionnaire:

## 7. Diet

One portion of fruit is equal to...

1 Medium sized fresh fruit (e.g. apple, banana, pear, orange, etc.)

Half a Large sized fresh fruit (e.g. grapefruit, 1 slice of melon, 2 slices of mango)

1 heaped tablespoon of dried fruit (e.g. raisins)

Similar quantity of canned fruit as above (in natural juice not syrup)

150ml of unsweetened fruit juice drink or smoothies

(Do **not** count fruit punch, lemonade or fruit drinks such as squash or concentrated drinks)

**In a typical day**, how many **portions of fruit** do you eat? (Please tick the answer that best describes you)

None

1

2

3

4

5 or more

One portion of vegetables is equal to...

Green vegetables (e.g. 2 broccoli spears or 4 heaped tbs of cooked spinach or kale, etc.)

3 heaped tbs of cooked vegetables (e.g. carrots, peas, sweetcorn, etc.)

Salad vegetables (e.g. 3 sticks of celery, 1 medium tomato, a 5cm piece of cucumber)

Similar quantity of canned, tinned or frozen vegetables as above

3 heaped tablespoons of pulses and beans (e.g. baked beans, kidney beans, chickpeas, etc.)

150ml of unsweetened vegetable juice or smoothies

(Do **not** count potatoes, sweet potatoes, parsnips, turnips, swede, yams, cassava or plantain)

**In a typical day**, how many **portions of vegetables** do you eat? (Please tick the answer that best describes you)

None

1

2


3

4

5 or more

Please state if you currently follow any special/specific diet(s), for example: low fat, high fibre, vegetarian, vegan, lactose free, gluten free, diabetic, etc.:

Please tell us any other details about your diet and changes since the last questionnaire:

please  
continue  
over 

## 8. Receiving advice or information

Have you received any advice or information on any of the following issues? (Please tick **all that apply**)

- Alcohol consumption
- Quitting smoking
- Diet
- Physical activity/exercise
- Weight
- Financial help and benefits
- Free prescriptions
- Returning to or staying in work
- Information/advice for family/friends/carers
- The physical aspects of living with and after cancer (e.g. side effects or signs of recurrence)
- The psychological or emotional aspects of living with and after cancer
- How to access support groups
- I have all the information and advice I need
- I have **not** been offered **any of the above**

## 9. Your Hobbies, Interests and Supporting Others

Do you join in the activities of any of these organisations and if so, how often? (Please **tick as appropriate**)

	At least once a week	At least once a month	At least every three months	Less often
Community or neighbourhood groups (e.g. adult learning, religious, political, hobbies, lunch clubs, groups for children or older people)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Voluntary work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Health or exercise groups, including taking part, coaching or going to watch	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cultural activities (e.g. sports, stately homes, concerts, museums/galleries, dance, opera)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other groups or activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

In the **past month**, have you given any unpaid help in any of the ways shown below? Please do not count any help you gave through a group, club or organisation. (Please **tick as appropriate**)

- Practical help (e.g. gardening, pets, home maintenance, transport, running errands)
- Help with childcare or babysitting
- Teaching, coaching or giving practical advice
- Giving emotional support
- Other

## 10. About You

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 describe): \_\_\_\_\_

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

please  
continue  
over 

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 (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

## 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?

If you have any comments about the content of our questionnaires (e.g. any topics you feel should have been included) and/or any general comments about taking part in the HORIZONS study, please let us know here:

We offer the option to complete our follow-up questionnaires on paper or online.

For the **next** follow-up 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	Y
---	---	---	---	---	---	---	---	---	---

please  
continue  
over 

**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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