UNIVERSITY OF Southampton

HORIZONS

Understanding the impact of cancer diagnosis and treatment on everyday life

Sixth Questionnaire: 36 month follow-up

Study ID ☐☐/☐☐/N☐☐☐

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

Over 3,300 people across the UK are taking part in HORIZONS.

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

About this questionnaire

- 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
- The information you give will remain confidential and will not be seen by your clinical team
- Please return your completed questionnaire in the FREEPOST envelope provided

You can also complete this questionnaire online

- It's easy to use and is laid out like the paper version
- Saves your progress as you go
- Based on your answers, it will show or hide follow-on questions if relevant
- You create your own secure log-in details

To do this or to find out more, please contact us: HORIZONS@soton.ac.uk or 023 8059 6885

Why is this questionnaire so long?

- HORIZONS covers a wide range of topics that people affected by cancer have said matter to them and want to know more about
- Please try to answer all the questions but feel free to skip questions if you don't think they apply to you
- You may also want to take breaks

Are my answers still useful for the study?

- Yes, 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
- You may also feel that you have other health conditions that may influence your answers, we consider all aspects of your health and so these answers are still very useful for us to understand your experiences

Why do some questions repeat?

- The questionnaire includes different sets of questions which measure different topics. Sometimes questions will seem similar but unfortunately, we cannot change them as this will affect how we can interpret the results
- You will also notice that some questions are repeated from the last questionnaires, this is important for us to find out what has or has not changed since then

Funded by MACMILLAN CANCER SUPPORT

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

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

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.	☐	☐	☐	☐	☐	☐	☐
You had financial problems because of the cost of cancer surgery or treatment.	☐	☐	☐	☐	☐	☐	☐
You worried that your family members were at risk of getting cancer.	☐	☐	☐	☐	☐	☐	☐
You realized that having had cancer helps you cope better with problems now.	☐	☐	☐	☐	☐	☐	☐
You were self-conscious about the way you look because of your cancer or its treatment.	☐	☐	☐	☐	☐	☐	☐
You worried about whether your family members might have cancer-causing genes.	☐	☐	☐	☐	☐	☐	☐

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.	☐	☐	☐	☐	☐	☐	☐
You worried about dying from cancer.	☐	☐	☐	☐	☐	☐	☐
You had problems with insurance because of cancer.	☐	☐	☐	☐	☐	☐	☐
You were bothered by hair loss from cancer treatment.	☐	☐	☐	☐	☐	☐	☐
You worried about cancer coming back.	☐	☐	☐	☐	☐	☐	☐
You felt that cancer helped you to recognize what is important in life.	☐	☐	☐	☐	☐	☐	☐
You felt better able to deal with stress because of having had cancer.	☐	☐	☐	☐	☐	☐	☐
You worried about whether your family members should have genetic tests for cancer.	☐	☐	☐	☐	☐	☐	☐
You had money problems that arose because you had cancer.	☐	☐	☐	☐	☐	☐	☐
You felt people treated you differently because of changes to your appearance due to your cancer or its treatment.	☐	☐	☐	☐	☐	☐	☐
You had financial problems due to a loss of income as a result of cancer.	☐	☐	☐	☐	☐	☐	☐
Whenever you felt a pain, you worried that it might be cancer again.	☐	☐	☐	☐	☐	☐	☐
You were preoccupied with concerns about cancer.	☐	☐	☐	☐	☐	☐	☐

Please indicate for each of the statements below the degree to which this change occurred in your life as a result of the cancer diagnosis and/or treatment using the 0 to 5 scale:

	I did not experience this change	I experienced this change to a very small degree	I experienced this change to a small degree	I experienced this change to a moderate degree	I experienced this change to a great degree	I experienced this change to a very great degree
I changed my priorities about what is important in life.	0	1	2	3	4	5
I have a greater appreciation for the value of my own life.	0	1	2	3	4	5
I am able to do better things with my life.	0	1	2	3	4	5
I have a better understanding of spiritual matters.	0	1	2	3	4	5
I have a greater sense of closeness with others.	0	1	2	3	4	5
I established a new path for my life.	0	1	2	3	4	5
I know better that I can handle difficulties.	0	1	2	3	4	5
I have a stronger religious faith.	0	1	2	3	4	5
I discovered that I'm stronger than I thought I was.	0	1	2	3	4	5
I learned a great deal about how wonderful people are.	0	1	2	3	4	5

The General Health Survey Questionnaire, Short Form 12 Ver 2.0 (SF-12v2)
As per our licence, the SF-12v2 measure cannot be shared without agreement from the copyright holders.

The SF-12v2 is available through licence, please see:
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

please continue over

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

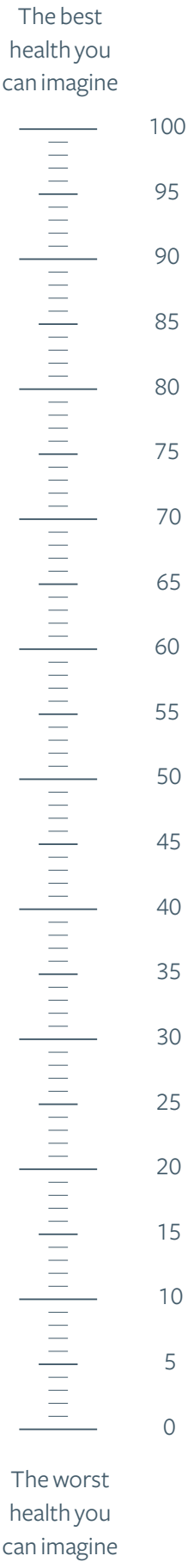
ANXIETY / DEPRESSION

- ☐ 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

please continue over ➡

- 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 = ☐



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 1	2	3	4	5	6	7	8	9	Totally Confident 10
How confident are you that you can keep the fatigue caused by having had cancer and/or cancer treatment from interfering with the things you want to do?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
How confident are you that you can keep the physical discomfort or pain of having had cancer and/or cancer treatment from interfering with the things you want to do?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
How confident are you that you can keep the emotional distress caused by having had cancer and/or cancer treatment from interfering with the things you want to do?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
How confident are you that you can do the different tasks and activities needed to manage your cancer and/or cancer treatment so as to reduce your need to see a doctor?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
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?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
How confident are you that you can access information about cancer and any effects of the diagnosis and treatment?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
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?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
How confident are you that you can deal by yourself with the problems cancer and/or cancer treatment has caused?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
How confident are you to contact your doctor about problems caused by cancer and/or cancer treatment?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
How confident are you that you can get support with problems caused by cancer/treatment from health and/or social care professionals?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

please continue over ➡

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

As per our licence, the CD-RISC2 measure cannot be shared without agreement from the copyright holders. The CD-RISC2 is available through licence, for more information please see:
http://www.connordavidson-resiliencescale.com/

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.

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	☐	☐	☐	☐	☐
I have to see too many different specialists for my health problem(s) or illness(es)	☐	☐	☐	☐	☐
I have problems filling out forms related to my healthcare	☐	☐	☐	☐	☐
I have problems getting appointments at times that are convenient for me	☐	☐	☐	☐	☐
I have problems getting appointments with a specialist	☐	☐	☐	☐	☐
I have to wait too long at my medical appointments	☐	☐	☐	☐	☐
I have to wait too long at the pharmacy for my medicine	☐	☐	☐	☐	☐

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)?	☐	☐	☐	☐	☐
...family responsibilities?	☐	☐	☐	☐	☐
...daily activities?	☐	☐	☐	☐	☐
...hobbies and leisure activities?	☐	☐	☐	☐	☐
...ability to spend time with family and friends?	☐	☐	☐	☐	☐
...ability to travel for work or vacation?	☐	☐	☐	☐	☐

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

	Never	Rarely	Sometimes	Often	Always
...angry?	☐	☐	☐	☐	☐
...preoccupied?	☐	☐	☐	☐	☐
...depressed?	☐	☐	☐	☐	☐
...worn out?	☐	☐	☐	☐	☐
...frustrated?	☐	☐	☐	☐	☐

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**?

Patient Activation Measure (PAM)

As per our licence, the PAM cannot be shared without agreement from the copyright holders. The PAM is available through licence, for more information please see:
https://www.insigniahealth.com/products/pam-survey

Measure reference:
Hibbard, J. H., Stockard, J., Mahoney, E. R., & Tusler, M. (2004). Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. Health services research, 39(4p1), 1005-1026.

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:

please continue over

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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
Emotional / Informational Support:					
Someone you can count on to listen to you when you need to talk	☐	☐	☐	☐	☐
Someone to give you information to help you understand a situation	☐	☐	☐	☐	☐
Someone to give you good advice about a crisis	☐	☐	☐	☐	☐
Someone to confide in or talk to about yourself or your problems	☐	☐	☐	☐	☐
Someone whose advice you really want	☐	☐	☐	☐	☐
Someone to share your most private worries and fears with	☐	☐	☐	☐	☐
Someone to turn to for suggestions about how to deal with a personal problem	☐	☐	☐	☐	☐
Someone who understands your problems	☐	☐	☐	☐	☐
Tangible Support:					
Someone to help you if you were confined to bed	☐	☐	☐	☐	☐
Someone to take you to the doctor if you needed it	☐	☐	☐	☐	☐
Someone to prepare your meals if you were unable to do it yourself	☐	☐	☐	☐	☐
Someone to help with daily chores if you were sick	☐	☐	☐	☐	☐
Affectionate Support:					
Someone who shows you love and affection	☐	☐	☐	☐	☐
Someone to love and make you feel wanted	☐	☐	☐	☐	☐
Someone who hugs you	☐	☐	☐	☐	☐
Positive Social Interaction:					
Someone to have a good time with	☐	☐	☐	☐	☐
Someone to get together with for relaxation	☐	☐	☐	☐	☐
Someone to do something enjoyable with	☐	☐	☐	☐	☐
Additional Item:					
Someone to do things with to help you get your mind off things	☐	☐	☐	☐	☐

How many close friends do you have? ☐ How many close family members do you have? ☐

please continue over

We would like you to think about the people around you that are important in helping you manage your everyday needs while living with your condition. This could include relationships with: family members, friends, neighbours, colleagues, members of hobby and interest groups, health professionals, acquaintances.

People who are important to you can be different in many ways. You may be in contact with them every day, monthly or less often. You may have very close relationships with them or may not know them very well. Some relationships may be important to you because of the help and advice they offer to people you care about.

Please answer each question by circling the answer (1 – 5) which you think is closest to your experiences over the last year. Don't spend too long thinking about each question; your first reaction to each item will probably be most accurate. If there is anything unclear or you would like to comment on a particular question, please feel free to make a note in the space below this table.

		Strongly disagree				Strongly agree
1.	With my health in mind, there are people around me who know how to support me	1	2	3	4	5
2.	I do not ask for practical help from the people around me even when I need it	1	2	3	4	5
3.	There are people around me who fully understand what I can and cannot do	1	2	3	4	5
4.	Most of the people around me are able to see when I need help	1	2	3	4	5
5.	I find it difficult to accept that I may need help from others	1	2	3	4	5
6.	People around me help me to maintain a healthy lifestyle	1	2	3	4	5
7.	In critical situations, I can rely on the people around me for help	1	2	3	4	5
8.	People around me try to find solutions to the problems I am facing	1	2	3	4	5
9.	People around me will work together if they think that I need help	1	2	3	4	5
10.	I don't expect support from people around me because they have problems of their own	1	2	3	4	5
11	I do not ask for emotional help from people around me even when I need it	1	2	3	4	5
12.	People around me are able to adapt when my needs change	1	2	3	4	5

Please add any comments about the questions above here:

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 continue over

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:** **1** = No help at all, **2** = Some help, **3** = A lot of help		
						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.

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

In the **last month**, 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

please continue over

In the **last month**, 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 **physical** 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

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)	☐	

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	☐		
Cancer doctor	☐		
Cancer nurse	☐		
Cancer information and support service	☐		
Day centre	☐		
Dietician	☐		
Hospital doctor	☐		
Hospital nurse	☐		
Occupational therapist	☐		
Outpatient clinic	☐		
Pharmacist	☐		
Physiotherapist	☐		
Psychiatrist or psychologist	☐		
Radiographer	☐		
Speech and language therapist	☐		
Other specialist doctor, please specify: _____	☐		

☐ **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: _____	☐		
Other, please specify: _____	☐		
	☐		
	☐		
	☐		

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	☐	
CT-Scan	☐	
Internal vaginal examination	☐	
Mammogram	☐	
MRI Scan	☐	
Papanicolaou test (Cervical smear test)	☐	
Ultrasound	☐	
X-ray	☐	
Other, please specify: _____	☐	
	☐	
	☐	
	☐	

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 **clinic** visits	Approximate number of **home** visits	Approximate number of contacts by telephone and/or email
Counsellor	☐			
Dietician	☐			
District nurse, health visitor or members of community team	☐			
GP	☐			
Mental health or emotional support services (e.g. mental health nurse)	☐			

☐ **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 **clinic** visits	Approximate number of **home** visits	Approximate number of contacts by telephone and/ or email
Occupational therapist	☐			
Pharmacist	☐			
Physiotherapist	☐			
Podiatrist	☐			
Psychiatrist or psychologist	☐			
Social worker	☐			
Other, please specify: _____	☐			
	☐			
	☐			
	☐			

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	☐	
Cancer charity website and/or online forums	☐	
Citizen's Advice Bureau	☐	
Community transport services	☐	
Day hospice	☐	
Drug or alcohol rehabilitation services	☐	
Employment advice service	☐	
Family or patient support or self-help groups	☐	
Financial or benefits advice service	☐	
Food bank	☐	
Food, medicine or laundry delivery service	☐	
Home help or care worker	☐	
Lifestyle advice services / workshops	☐	
Lunch or social club	☐	
Nursing / Residential home	☐	
Other charity information and support service	☐	

☐ **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	☐	
Telephone help lines	☐	
Voluntary services / assistance	☐	
Walking group or physical activity service	☐	
Other, please specify: _____	☐	
	☐	
	☐	
	☐	

☐ **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 (£)

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 **long** walk?	1	2	3	4
3.	Do you have any trouble taking a **short** walk outside of the house?	1	2	3	4
4.	Do you need to stay in bed or a chair during the day?	1	2	3	4
5.	Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4

During the **past week**:

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

please continue over

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 **family** life?	1	2	3	4
27.	Has your physical condition or medical treatment interfered with your **social** activities?	1	2	3	4
28.	Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

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

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

		Not at All	A Little	Quite a Bit	Very Much
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.	Have you passed urine frequently?	1	2	3	4
62.	When you felt the urge to pass urine, did you have to hurry to get to the toilet?	1	2	3	4
63.	Did you experience change in bowel habit as a result of your disease or treatment?	1	2	3	4
64.	**If applicable:** Have you had problems at your work or place of study due to the disease?	1	2	3	4
65.	**If applicable:** Have you worried about not being able to continue working or your education?	1	2	3	4
66.	**If applicable:** Have you been concerned about your ability to have children?	1	2	3	4
67.	To what extent were you interested in sex?	1	2	3	4
68.	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
69.	Have you had pain during sexual intercourse or other sexual activity?	1	2	3	4
70.	To what extent was sex enjoyable for you?	1	2	3	4
71.	**For women only:** Has your vagina felt dry during sexual activity?	1	2	3	4
72.	**For women only:** Has your vagina felt short and/or tight?	1	2	3	4
73.	**For men only:** Did you have difficulty gaining or maintaining an erection?	1	2	3	4
74.	**For men only:** Did you have ejaculation problems? (e.g. dry ejaculation)	1	2	3	4
75.	Have you been satisfied with your ability to reach an orgasm?	1	2	3	4

During the **past week:**

		Not at All	A Little	Quite a Bit	Very Much
76.	Have you been feeling self-conscious about your appearance?	1	2	3	4
77.	Have you felt **less** physically attractive as a result of your disease or treatment?	1	2	3	4
78.	Have you been **dissatisfied** with your appearance when dressed?	1	2	3	4
79.	Have you been feeling **less** feminine/masculine as a result of your disease or treatment?	1	2	3	4
80.	Did you find it difficult to look at yourself naked?	1	2	3	4
81.	Have you been feeling **less** sexually attractive as a result of your disease or treatment?	1	2	3	4
82.	Did you avoid people because of the way you felt about your appearance?	1	2	3	4
83.	Have you been feeling the treatment has left your body **less** whole?	1	2	3	4
84.	Have you felt **dissatisfied** with your body	1	2	3	4

During the **past week:**

		Not at All	A Little	Quite a Bit	Very Much
85.	Have you suffered from pain and tingling in your feet/toes?	0	1	2	3
86.	Have you suffered from pain and tingling in your hands/fingers?	0	1	2	3
87.	Have you suffered from numb or cold feet or toes?	0	1	2	3
88.	Have you suffered from numb or cold hands or fingers?	0	1	2	3
89.	Have you suffered from ringing in your ears?	0	1	2	3
90.	Have you suffered from reduced hearing?	0	1	2	3

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.

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

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. _____

please continue over

In the following questions, we would like you to think about "illness" in relation to your experience of cancer and/or its effects on your health, well-being and day-to-day life.

Please circle or mark one number per line to indicate your response as it applies to the past 7 days. Where the word 'family' is used, please consider this to also include your partner and/or children if applicable.

Responsibilities and Social Life

	Not at all	A little bit	Some-what	Quite a bit	Very much
My illness interferes with performing my responsibilities at home (e.g. cooking, cleaning, gardening, DIY)	0	1	2	3	4
I am less able to fulfil my caregiving responsibilities (e.g. looking after children, grandchildren, another adult, pets)	0	1	2	3	4
I have less patience for my caregiving responsibilities (e.g. looking after children, grandchildren, another adult, pets)	0	1	2	3	4
I feel sad that my illness forces me to miss out on doing things with my children and/or other family members	0	1	2	3	4
I socialise less because of my illness	0	1	2	3	4

Family Wellbeing

	Not at all	A little bit	Some-what	Quite a bit	Very much
I worry about the impact of my illness on my partner (or the person who is my main support)	0	1	2	3	4
I worry about the impact of my illness on my children and/or other family members	0	1	2	3	4
I worry about the impact of my illness on people that I normally provide support to (e.g. friends, neighbours, parents and/or grandchildren)	0	1	2	3	4
The way I see myself within the family has changed because of my illness	0	1	2	3	4
I worry how my family will cope in the future	0	1	2	3	4

Financial Wellbeing

	Not at all	A little bit	Some-what	Quite a bit	Very much
I feel in control of my financial situation	0	1	2	3	4
I worry about the financial problems I will have in the future as a result of my illness or treatment	0	1	2	3	4
My family and/or friends have to help me financially	0	1	2	3	4
My family gives up things because of the financial impact of my illness	0	1	2	3	4
The additional costs of my illness are more than I thought they would be (e.g. travel and parking, heating, healthy eating, supplements, non-prescription medication, paying for help at home)	0	1	2	3	4
I have difficulty meeting the additional costs of my illness	0	1	2	3	4

Jobs and Career

I have stopped paid employment altogether because of my illness	Yes	No	N/A
I intend to return to paid employment	Yes	No	N/A

PLEASE ONLY ANSWER THE FOLLOWING QUESTIONS IF YOU ARE CURRENTLY EMPLOYED

	Not at all	A little bit	Some-what	Quite a bit	Very much
I have reduced my working hours because of my illness	0	1	2	3	4
My working hours are flexible to accommodate my treatment and appointments	0	1	2	3	4
I feel I am able to do my job as well as I would like	0	1	2	3	4
I worry that my illness will impact my employment in the future (including return to work)	0	1	2	3	4
I am concerned about keeping my job and income	0	1	2	3	4
I feel that my illness has limited my career opportunities	0	1	2	3	4
I feel supported by my employer	0	1	2	3	4

Please tell us any other details about changes related to your job and career:

please continue over

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 cancer my **ability to work** is impaired.
If you are retired or choose not to have a job for reasons unrelated to your problem, please tick 'N/A'

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

Home Management

Because of 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 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 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 cancer my ability to form and maintain **close relationships** with others, including those I live with, is impaired.

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

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 37**.

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.)

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

please continue over

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

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):

M M / Y Y Y Y

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:	
STRENUOUS EXERCISE (HEART BEATS RAPIDLY) (e.g., running, jogging, hockey, football, squash, basketball, judo, roller skating, vigorous swimming, vigorous long distance cycling)	☐☐	☐☐ hours ☐☐ minutes
MODERATE EXERCISE (NOT EXHAUSTING) (e.g., fast walking, tennis, easy cycling, volleyball, badminton, easy swimming, dancing)	☐☐	☐☐ hours ☐☐ minutes
MILD EXERCISE (MINIMAL EFFORT) (e.g., yoga, archery, fishing, bowling, golf, easy walking)	☐☐	☐☐ hours ☐☐ 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:	
STRENGTH EXERCISE (e.g., weight lifting, sit-ups, and push-ups)	☐☐	☐☐ hours ☐☐ 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 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. For example, the use of food supplements (e.g. fish oils, vitamins, minerals, etc.):

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)	☐	☐	☐	☐
Voluntary work	☐	☐	☐	☐
Health or exercise groups, including taking part, coaching or going to watch	☐	☐	☐	☐
Cultural activities (e.g. sports, stately homes, concerts, museums/galleries, dance, opera)	☐	☐	☐	☐
Other groups or activities	☐	☐	☐	☐

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

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

☐ Single ☐ In a relationship

What is you 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 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
- ☐ Universal Credit
- ☐ 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 7 – Your Comments

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

Is there anything else we have not asked about that you think we ought to know?

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

For the **next** 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

Thank you very much for your participation

please continue over

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.

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Funded by

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