

# HORIZONS

Understanding the impact of cancer diagnosis and treatment on everyday life

Third Questionnaire: 12 month follow-up

Study ID   /   / B

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**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 9 parts
- It will ask about your general health and wellbeing, your experiences of treatment and ongoing care. It will also ask about your thoughts and feelings about cancer as well as how you have been coping, your lifestyle and the support you have available to you
- 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](mailto: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, or feel you have moved on with your life since your diagnosis or treatment, 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 some 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 our last questionnaires, this is important for us find out what has or has not changed since then.

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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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We would now 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	Sometimes	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"/>
	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	Always
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"/>
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.

You were content with your  
life.

PLEASE DO NOT CIRCULATE

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

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### 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

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.

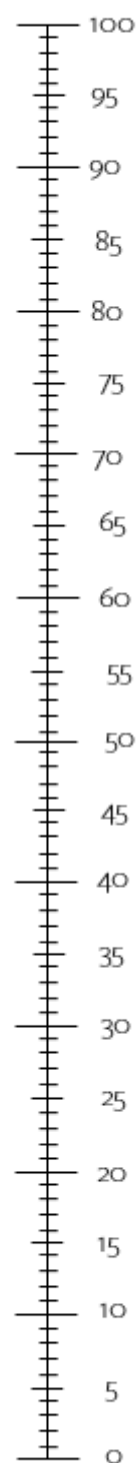
**0** means the worst health you can imagine.

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

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## Part 2 –How You Have Been Feeling

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

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

	Not at all	A little	Quite a bit	Very much
1. Do you have any trouble doing strenuous activities like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2. Do you have any trouble taking a 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
--	---	---	---	---

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?

1	2	3	4	5	6	7
Very Poor						Excellent

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

1	2	3	4	5	6	7
Very Poor						Excellent

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

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

During the past week:

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

During the past four weeks:

	Not at all	A little	Quite a bit	Very much
47. To what extent were you interested in sex?	1	2	3	4
48. To what extent were you sexually active? (with or without intercourse)	1	2	3	4

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

	Not at all	A little	Quite a bit	Very much
49. Has your vagina felt dry during sexual activity?	1	2	3	4
50. Has your vagina felt short and / or tight?	1	2	3	4

51. Have you had pain during sexual intercourse or other sexual activity?	1	2	3	4
52. To what extent was sex enjoyable for you?	1	2	3	4

PLEASE DO NOT CIRCULATE

During the **past week**:

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

During the past **four weeks**:

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

During the **past week**:

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

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

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#### Measure reference:

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

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

**Work:** Because of my cancer, my **ability to work** is impaired.

If you are retired or choose not to have a job for reasons unrelated to your cancer, please tick 'N/A'.

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

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

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

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

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

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

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



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

0      1      2      3      4      5      6      7      8

---

Not at  
all

Slightly

Definitely

Markedly

Very  
Severely

PLEASE DO NOT CIRCULATE

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"/>

	Not at all Confident								Totally Confident	
	1	2	3	4	5	6	7	8	9	10
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"/>

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

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

### Part 3 – Your Thoughts & Feelings About Your Cancer

We understand that it has been over a year since your diagnosis. We would now like to ask you about some of your thoughts and feelings about your cancer diagnosis, its treatment and any effects.

The next set of questions asks specifically about the effect of your cancer or its treatment. 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 checked="" 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"/>
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.

You worried about whether your family members should have genetic tests for cancer.

You had money problems that arose because you had cancer.

	Never	Seldom	Some times	About as often as not	Frequently	Very often	Always
--	-------	--------	------------	-----------------------	------------	------------	--------

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.

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

PLEASE DO NOT CIRCULATE

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 DO NOT CIRCULATE



## Part 4 – Your Experiences of Ongoing Care & Your Needs

We would now like to ask you about your experiences of your treatment and ongoing care. We would also like to ask about whether or not any needs which you may have faced as a result of your cancer and/or its treatment have been met.

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

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

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

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

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

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

	Not at all	A little	Somewhat	Quite a bit	Very much
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

...monitor your health behaviors, e.g., tracking exercise, foods you eat, or medicines you take?

---

...monitor your health condition, e.g., weighing yourself, checking blood pressure, or checking blood sugar?

PLEASE DO NOT CIRCULATE

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

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

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

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

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

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

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

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?

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>	<b>1</b>	<b>Not applicable</b> – This was not a problem for me as a result of having cancer.
	<b>2</b>	<b>Satisfied</b> – I did need help with this, but my need for help was satisfied at the time.
<b>SOME NEED</b>	<b>3</b>	<b>Low need</b> – This item caused me concern or discomfort. I had little need for additional help.
	<b>4</b>	<b>Moderate need</b> – This item caused me concern or discomfort. I had some need for additional help.
	<b>5</b>	<b>High need</b> – 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
	Not applicable	Satisfied	Low need	Moderate need	High need
More choice about which cancer specialists you see	1	2	3	4	5
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 5 - 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"/>		
	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 doctor, please specify: _____			
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	<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: _____		

### 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	<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"/>			
	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	<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: _____				

### 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"/>	
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: _____		

PLEASE DO NOT CHECK LATE

## 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 6 – The Support You Have Available To You

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

### 1. Your Hobbies & Interests

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

## 2. Your Social Network

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

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

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

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

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

Network Member Number	Network Member (name or initials)	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)
Example	Alistair	1 2	Friend	1 2 3 4	10 miles
1.		1 2		1 2 3 4	
2.		1 2		1 2 3 4	
3.		1 2		1 2 3 4	
4.		1 2		1 2 3 4	
5.		1 2		1 2 3 4	
6.		1 2		1 2 3 4	
7.		1 2		1 2 3 4	
8.		1 2		1 2 3 4	
9.		1 2		1 2 3 4	
10.		1 2		1 2 3 4	
11.		1 2		1 2 3 4	
12.		1 2		1 2 3 4	
13.		1 2		1 2 3 4	
14.		1 2		1 2 3 4	
15.		1 2		1 2 3 4	
16.		1 2		1 2 3 4	
17.		1 2		1 2 3 4	
18.		1 2		1 2 3 4	
19.		1 2		1 2 3 4	
20.		1 2		1 2 3 4	

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

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

Network Member Number (as numbered in the previous table)	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 about your illness and illness management	B. Practical help with daily tasks	C. Emotional support
Example	1 2 <input checked="" type="radio"/> 3	1 2 <input checked="" type="radio"/> 3	1 2 <input checked="" type="radio"/> 3
1.	1 2 3	1 2 3	1 2 3
2.	1 2 3	1 2 3	1 2 3
3.	1 2 3	1 2 3	1 2 3
4.	1 2 3	1 2 3	1 2 3
5.	1 2 3	1 2 3	1 2 3
6.	1 2 3	1 2 3	1 2 3
7.	1 2 3	1 2 3	1 2 3
8.	1 2 3	1 2 3	1 2 3
9.	1 2 3	1 2 3	1 2 3
10.	1 2 3	1 2 3	1 2 3
11.	1 2 3	1 2 3	1 2 3
12.	1 2 3	1 2 3	1 2 3
13.	1 2 3	1 2 3	1 2 3
14.	1 2 3	1 2 3	1 2 3
15.	1 2 3	1 2 3	1 2 3
16.	1 2 3	1 2 3	1 2 3
17.	1 2 3	1 2 3	1 2 3
18.	1 2 3	1 2 3	1 2 3
19.	1 2 3	1 2 3	1 2 3
20.	1 2 3	1 2 3	1 2 3

### 3. The Types of Support 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 checked="" type="checkbox"/>	<input checked="" 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"/>

**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?

## Part 7 – About You & Your Lifestyle

In this section, we would like to ask you if anything has changed about you and your lifestyle since the last questionnaires. We are collecting this information to try to build up a picture of who needs support in their cancer recovery and what this support might be.

### 1. Body stats

What is your weight?

st

lbs

or

kg

### 2. 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 DO NOT CIRCULATE

### 3. 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 currently 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 20mg/ml  
 More than 20mg/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:

#### 4. 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 page.  
Otherwise please complete the rest of the page.

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:

## 5. Exercise & Physical activity

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

	Times per week:	
STRENUOUS EXERCISE (HEART BEATS RAPIDLY) (e.g., running, jogging, hockey, football, squash, basketball, judo, roller skating, vigorous swimming, vigorous long distance cycling)		___ hours ___ 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:

PLEASE DO NOT CIRCULATE

## 6. Diet

Here is a guide to portions of fruit:

One portion of fruit is equal to...

2 or more small pieces of fresh fruit	2 plums, satsumas or kiwi fruit, 3 apricots, 7 strawberries, 14 cherries
Medium sized fresh fruit	1 apple, banana, pear, or orange
Large sized fresh fruit	Half a grapefruit, 1 slice of papaya or melon, 2 slices of mango (please note: 1 slice = approx. 5 cm thick)
Dried fruit	1 heaped tablespoon of raisins or currants, 2 figs, 3 prunes
Canned fruit (in natural juice not syrup)	Similar quantity of fruit as a fresh portion (e.g. 2 pear or peach halves)
Fruit juice drink or smoothies	150ml of unsweetened fruit juice or smoothie

(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
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Here is a guide to portion sizes of vegetables:

One portion of vegetables is equal to...

Green vegetables	2 broccoli spears or 4 heaped tablespoons of cooked kale, spinach, spring greens or green beans
Cooked vegetables	3 heaped tablespoons of cooked vegetables, such as carrots, peas or sweetcorn, or 8 cauliflower florets
Salad vegetables	3 sticks of celery, a 5cm piece of cucumber, 1 medium tomato or 7 cherry tomatoes
Tinned and frozen vegetables	Roughly the same quantity as you would eat for a fresh portion
Pulses and beans	3 heaped tablespoons of baked beans, haricot beans, kidney beans, cannellini beans, butter beans or chickpeas
Vegetable juice drinks or smoothies	150ml of unsweetened vegetable juice or smoothie

(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
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



PLEASE DO NOT CIRCULATE

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:

### 7. 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

### 8. About You

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

HORIZONS; 12 month Questionnaire; Breast

Version 2.1, 29/06/2020, IRAS Project ID: 202342, REC reference number 16/NW/0425



- In part-time education / training  
 Other, please specify: \_\_\_\_\_

How many hours per week do you currently work in your job/business? Please exclude breaks

hours  Not applicable

In the last 3 months, approximately how many days have you taken off work due to your health?

days

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

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

Approximately what is your current total yearly gross/pre-tax salary or income? (Please tick **one**)

- Less than £5,199  
 £5,200 and up to £10,399  
 £10,400 and up to £15,599  
 £15,600 and up to £20,799  
 £20,800 and up to £25,999  
 £26,000 and up to £31,199  
 £31,200 and up to £36,399  
 £36,400 and up to £51,999  
 £52,000 and above  
 I prefer not to say

Do you (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 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

PLEASE DO NOT CIRCULATE

## Part 8 – Your Comments

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:

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?

HORIZONS; 12 month Questionnaire; Breast

Version 2.1, 29/06/2020, IRAS Project ID: 202342, REC reference number 16/NW/0425

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?

- Paper       Online

### Today's Date

Please fill in the date you completed this questionnaire:

D	D	/	M	M	/	Y	Y	Y	Y
---	---	---	---	---	---	---	---	---	---

**Thank you very much for your participation**

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

Your participation is very helpful to us.

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

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

Please return this form in the FREEPOST envelope provided.

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

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