

HORIZONS

Understanding the impact of cancer diagnosis and treatment on everyday life

Second Questionnaire: 3 month follow-up questionnaire

Study ID

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

~~This is the **3 month follow-up questionnaire** which will ask you about your health and how well you have been since your cancer diagnosis.~~

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

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

~~This questionnaire is divided into 9 parts. It asks for information about your health and symptoms, how well you have been since you were diagnosed with cancer, as well as your experience of treatment and use of health services. It also covers topics such as how you are coping and managing your health, your lifestyle and the support you have available to you. Information and treatment details from your medical records will be gathered separately by a research nurse and included in our analyses.~~

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

~~The study is supported by Macmillan Cancer Support and is carried out by teams all over the UK and led by researchers based at the University of Southampton.~~

~~We would like to know about your ongoing experiences, especially how they change during and following treatment.~~

~~We would be grateful if you would complete and return this questionnaire in the **FREEPOST** envelope provided.~~

How to fill in this questionnaire

- ~~— The questionnaire will take some time to complete - please take as much time as you need and you may wish complete this in several sittings. It is divided into nine parts which cover different aspects about you, your health, and your cancer experience.~~

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

**WE ARE
MACMILLAN.
CANCER SUPPORT**

Part 1 – Your General Health ~~and~~ & Well-Being

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

Under each heading, please tick the ~~one~~ **ONE** box that best describes your health ~~today~~ **TODAY**.

~~Mobility~~ **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~~ **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~~ **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~~ **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

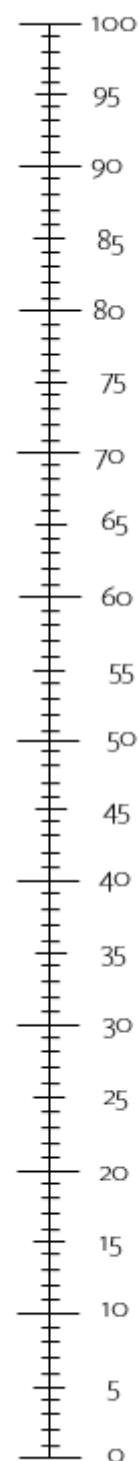
~~Anxiety / Depression~~ **ANXIETY / DEPRESSION**

- ☐ 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**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**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

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

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

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

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

The following questions ask about **how satisfied you feel**, on a scale from zero to 10. **Zero** means no satisfaction at all, **10** means you feel completely satisfied. (Please tick **one** answer for each question).

	No satisfaction at all	1	2	3	4	5	6	7	8	9	10	Completely satisfied
Thinking about your own life and personal circumstances, how satisfied are you with your life as a whole?	<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"/>	<input type="checkbox"/>	
How satisfied are you with your standard of living?	<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"/>	<input type="checkbox"/>	
How satisfied are you with your health?	<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"/>	<input type="checkbox"/>	
How satisfied are you with what you are achieving in 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"/>	<input type="checkbox"/>	
How satisfied are you with your personal relationships?	<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"/>	<input type="checkbox"/>	
How satisfied are you with how safe you feel?	<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"/>	<input type="checkbox"/>	
How satisfied are you with feeling part of your community?	<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"/>	<input type="checkbox"/>	
How satisfied are you with your future security?	<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"/>	<input type="checkbox"/>	
How satisfied are you with your spirituality or religion?	<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"/>	<input type="checkbox"/>	

Part 2 – About Your Symptoms

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

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

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

During the **past week:**

	Not at all	A little	Quite a Bit	Very much
6. Were you limited in doing either your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4
11. Have you had trouble sleeping?	1	2	3	4
12. Have you felt weak?	1	2	3	4
13. Have you lacked appetite?	1	2	3	4
14. Have you felt nauseated?	1	2	3	4
15. Have you vomited?	1	2	3	4
16. Have you been constipated?	1	2	3	4
17. Have you had diarrhea?	1	2	3	4
18. Were you tired?	1	2	3	4
19. Did pain interfere with your daily activities?	1	2	3	4

1 2 3 4

	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

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

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

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

Please indicate the extent to which you have experienced these symptoms or problems, please answer by circling the number that best applies to you. ~~during the past week. 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
<u>44. Have you had tingling or numbness in your hands or feet?</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>
<u>45. Did you have night sweats?</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>
<u>46. Have you had aches or pains in your muscles or joints?</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>

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
46. Answer this question only if you have been sexually active: To what extent was sex enjoyable for you?	1	2	3	4

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

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

During the **past week:**

	Not at all	A little	Quite a Bit	Very much
47 53. Did you have any pain in your arm or shoulder?	1	2	3	4
48 54. Did you have a swollen arm or hand?	1	2	3	4
49 55. Was it difficult to raise your arm or to move it sideways?	1	2	3	4
50 56. Have you had any pain in the area of your affected breast?	1	2	3	4
51 57. Was the area of your affected breast swollen?	1	2	3	4
52 58. Was the area of your affected breast oversensitive?	1	2	3	4
53 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
54 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?	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>
62 55. If applicable: Have you been concerned about your ability to have children?	1	2	3	4
63 56. If applicable: Have you had problems at your work or place of study due to the disease?	1	2	3	4
64 57. 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 58. Have you been feeling self-conscious about your appearance?	1	2	3	4	
66 59. Have you been dissatisfied with your appearance when dressed?	1	2	3	4	
67 60. Have you been feeling less sexually attractive as a result of your disease or treatment?	1	2	3	4	
68 61. Did you avoid people because of the way you felt about your appearance?	1	2	3	4	
69 62. Have you been feeling the treatment has left your body less whole?	1	2	3	4	
70 63. Have you been dissatisfied with the appearance of your scar?	1	2	3	4	N/A

Part 3 – How You Are Feeling

This section will help us to understand how you are feeling and whether your ability to do certain day-to-day activities has been affected by your cancer and/or its treatment

Hospital Anxiety and Depression Scale (HADS)

Read each item below and tick the box beside the reply comes closest to how you have been feeling in the **past week**. Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, thought-out response.

I feel tense or 'wound up':

- | | |
|---------------------------------|--------------------------|
| Most of the time | <input type="checkbox"/> |
| A lot of the time | <input type="checkbox"/> |
| From time to time, occasionally | <input type="checkbox"/> |
| Not at all | <input type="checkbox"/> |

I feel as if I am slowed down:

- | | |
|---------------------|--------------------------|
| Nearly all the time | <input type="checkbox"/> |
| Very often | <input type="checkbox"/> |
| Sometimes | <input type="checkbox"/> |
| Not at all | <input type="checkbox"/> |

I still enjoy the things I used to enjoy:

- | | |
|--------------------|--------------------------|
| Definitely as much | <input type="checkbox"/> |
| Not quite so much | <input type="checkbox"/> |
| Only a little | <input type="checkbox"/> |
| Hardly at all | <input type="checkbox"/> |

I get a sort of frightened feeling like 'butterflies' in the stomach:

- | | |
|--------------|--------------------------|
| Not at all | <input type="checkbox"/> |
| Occasionally | <input type="checkbox"/> |
| Quite often | <input type="checkbox"/> |
| Very often | <input type="checkbox"/> |

I get a sort of frightened feeling as if something awful is about to happen:

- | | |
|-----------------------------------|--------------------------|
| Very definitely and quite badly | <input type="checkbox"/> |
| Yes, but not too badly | <input type="checkbox"/> |
| A little, but it doesn't worry me | <input type="checkbox"/> |
| Not at all | <input type="checkbox"/> |

I have lost interest in my appearance:

- | | |
|---------------------------------------|--------------------------|
| Definitely | <input type="checkbox"/> |
| I don't take as much care as I should | <input type="checkbox"/> |
| I may not take quite as much care | <input type="checkbox"/> |
| I take just as much care as ever | <input type="checkbox"/> |

I can laugh and see the funny side of things:

- | | |
|----------------------------|--------------------------|
| As much as I always could | <input type="checkbox"/> |
| Not quite so much now | <input type="checkbox"/> |
| Definitely not so much now | <input type="checkbox"/> |
| Not at all | <input type="checkbox"/> |

I feel restless as I have to be on the move:

- | | |
|------------------|--------------------------|
| Very much indeed | <input type="checkbox"/> |
| Quite a lot | <input type="checkbox"/> |
| Not very much | <input type="checkbox"/> |
| Not at all | <input type="checkbox"/> |

Worrying thoughts go through my mind:

- | | |
|--------------------------|--------------------------|
| A great deal of the time | <input type="checkbox"/> |
| A lot of the time | <input type="checkbox"/> |
| Not too often | <input type="checkbox"/> |
| Very little | <input type="checkbox"/> |

I look forward with enjoyment to things:

- | | |
|--------------------------------|--------------------------|
| As much as I ever did | <input type="checkbox"/> |
| Rather less than I used to | <input type="checkbox"/> |
| Definitely less than I used to | <input type="checkbox"/> |
| Hardly at all | <input type="checkbox"/> |

I feel cheerful:

~~Not at all~~ Never

☐

~~Very often indeed~~ Not often

☐

Sometimes

☐

Most of the time

☐

I get sudden feelings of panic:

Very often indeed

☐

Quite often

☐

Not very often

☐

Not at all

☐

I can sit at ease and feel relaxed:

Definitely

☐

Usually

☐

Not often

☐

Not at all

☐

I can enjoy a good book or radio or television program:

Often

☐

Sometimes

☐

Not often

☐

Very seldom

☐

[Hospital Anxiety Depression Scale \(HADS\)](#) ~~HADS~~ copyright © R.P. Snaith and A.S. Zigmond, 1983, 1992, 1994.

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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 ~~problem~~ cancer, please tick ‘N/A’.

<input type="radio"/>	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

<input type="radio"/>	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

<input type="radio"/>	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

<input type="radio"/>	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

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

Part 4 – How You Cope

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

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"/>	<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"/>	<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"/>	<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"/>	<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"/>	<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"/>	<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"/>	<input type="checkbox"/>
How confident are you that you can access people to help and support you	<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"/>	<input type="checkbox"/>

when you have problems caused by cancer and/or cancer treatment?

	Not at all Confident								Totally Confident	
	1	2	3	4	5	6	7	8	9	10
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 5 – Your Experiences of Treatment and Managing Your Health

In this section, we would like to explore your experience of managing your health and the impact your cancer treatment may have had on you.

Please indicate how strongly you disagree or agree with the following statements by checking the response that best describes you **now**.

	Strongly disagree	Disagree	Agree	Strongly Agree
Most days I am doing some of the things I really enjoy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
As well as seeing my doctor, I regularly monitor changes in my health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I often worry about my health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I try to make the most of my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what things can trigger my health problems and make them worse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My health problems make me very dissatisfied with my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am doing interesting things in my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have plans to do enjoyable things for myself during the next few days	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a very good understanding of when and why I am supposed to take my medication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I often feel angry when I think about my health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel hopeless because of my health problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel like I am actively involved in life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When I have health problems, I have a clear understanding of what I need to do to control them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I carefully watch my health and do what is necessary to keep as healthy as possible	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get upset when I think about my health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
With my health in mind, I have realistic expectations of what I can and cannot do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If I think about my health, I get depressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If I need help, I have plenty of people I can rely on	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I have effective ways to prevent my symptoms (e.g., discomfort, pain and stress) from limiting what I can do in my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have very positive relationships with my healthcare professionals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Strongly disagree	Disagree	Agree	Strongly Agree
I have a very good idea of how to manage my health problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When I have symptoms, I have skills that help me cope	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I try not to let my health problems stop me from enjoying life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have enough friends who help me cope with my health problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I communicate very confidently with my doctor about my healthcare needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a good understanding of equipment that could make my life easier	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When I feel ill, my family and carers really understand what I am going through	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I confidently give healthcare professionals the information they need to help me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get my needs met from available healthcare resources (e.g., doctors, hospitals and community services)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My health problems do not ruin my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Overall, I feel well looked after by friends or family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel I have a very good life even when I have health problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get enough chances to talk about my health problems with people who understand me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I work in a team with my doctors and other healthcare professionals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I do not let my health problems control my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If others can cope with problems like mine, I can too	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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
...monitor your health behaviors, e.g., tracking exercise, foods you eat, or medicines you take?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...monitor your health condition, e.g., weighing yourself, checking blood pressure, or checking blood sugar?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

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

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

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

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

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

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

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**?

Part 6 - Your Use of Health Services

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

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. Hospital visits and appointments

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

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

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

--

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

Speech and language therapist	<input type="checkbox"/>		
Other specialist doctor, please specify: _____			
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. 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"/>			
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: _____				

2. 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		
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: _____		

Travel costs and additional expenses

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. 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 7 – The Support You Have Available To You

We would now 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 can be used by people to help support themselves at home and in their communities.

1. 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
Emotional/informational support:					
Someone you can count on to listen to you when you need to talk	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone to give you information to help you understand a situation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone to give you good advice about a crisis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone to confide in or talk to about yourself or your problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone whose advice you really want	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone to share your most private worries and fears with	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone to turn to for suggestions about how to deal with a personal problem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone who understands your problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tangible Support:					
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"/>

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Affectionate Support:					
Someone who shows you love and affection	<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"/>
Positive Social Interaction:					
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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How many close friends do you have?

How many close family members do you have?

2 Your Social Network

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

Your Social Network

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. In the boxes 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, pets to 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 ~~have contact with~~ them in person (e.g. weekly, monthly, every couple of months)
- approximately how far do they live from you (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? Distance (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	
21.		1 2		1 2 3 4	

<u>22.</u>		<u>1 2</u>		<u>1 2 3 4</u>	
<u>23.</u>		<u>1 2</u>		<u>1 2 3 4</u>	
<u>24.</u>		<u>1 2</u>		<u>1 2 3 4</u>	
<u>25.</u>		<u>1 2</u>		<u>1 2 3 4</u>	

For each person listed in the previous table, ~~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)

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
<u>1.</u>	<u>1 2 3</u>	<u>1 2 3</u>	<u>1 2 3</u>
<u>2.</u>	<u>1 2 3</u>	<u>1 2 3</u>	<u>1 2 3</u>
<u>3.</u>	<u>1 2 3</u>	<u>1 2 3</u>	<u>1 2 3</u>
<u>4.</u>	<u>1 2 3</u>	<u>1 2 3</u>	<u>1 2 3</u>
<u>5.</u>	<u>1 2 3</u>	<u>1 2 3</u>	<u>1 2 3</u>
<u>6.</u>	<u>1 2 3</u>	<u>1 2 3</u>	<u>1 2 3</u>
<u>7.</u>	<u>1 2 3</u>	<u>1 2 3</u>	<u>1 2 3</u>
<u>8.</u>	<u>1 2 3</u>	<u>1 2 3</u>	<u>1 2 3</u>
<u>9.</u>	<u>1 2 3</u>	<u>1 2 3</u>	<u>1 2 3</u>
<u>10.</u>	<u>1 2 3</u>	<u>1 2 3</u>	<u>1 2 3</u>
<u>11.</u>	<u>1 2 3</u>	<u>1 2 3</u>	<u>1 2 3</u>
<u>12.</u>	<u>1 2 3</u>	<u>1 2 3</u>	<u>1 2 3</u>
<u>13.</u>	<u>1 2 3</u>	<u>1 2 3</u>	<u>1 2 3</u>
<u>14.</u>	<u>1 2 3</u>	<u>1 2 3</u>	<u>1 2 3</u>
<u>15.</u>	<u>1 2 3</u>	<u>1 2 3</u>	<u>1 2 3</u>
<u>16.</u>	<u>1 2 3</u>	<u>1 2 3</u>	<u>1 2 3</u>
<u>17.</u>	<u>1 2 3</u>	<u>1 2 3</u>	<u>1 2 3</u>
<u>18.</u>	<u>1 2 3</u>	<u>1 2 3</u>	<u>1 2 3</u>
<u>19.</u>	<u>1 2 3</u>	<u>1 2 3</u>	<u>1 2 3</u>
<u>20.</u>	<u>1 2 3</u>	<u>1 2 3</u>	<u>1 2 3</u>
<u>21.</u>	<u>1 2 3</u>	<u>1 2 3</u>	<u>1 2 3</u>
<u>22.</u>	<u>1 2 3</u>	<u>1 2 3</u>	<u>1 2 3</u>
<u>23.</u>	<u>1 2 3</u>	<u>1 2 3</u>	<u>1 2 3</u>
<u>24.</u>	<u>1 2 3</u>	<u>1 2 3</u>	<u>1 2 3</u>
<u>25.</u>	<u>1 2 3</u>	<u>1 2 3</u>	<u>1 2 3</u>

[illegible]

Part ~~8~~ – Your Lifestyle

We would now like to ask you some questions about your lifestyle and whether there have been any changes since the last questionnaire. 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.

~~We would now like to ask you some questions about your lifestyle and if there have been any changes since the last questionnaire. 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 ~~remainder~~ rest of this page;
~~or~~ 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:



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 **y'Yes** or **'I am unsure'**, please complete the **remainder** 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 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:

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?

- ☒ ~~Not applicable, I do not drink alcohol~~
- ☐ 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:

--

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 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**

Part 10 – 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 also **welcome any comments** you may have **on this questionnaire** (for example its length, layout, ease of understanding and any topics you feel should have been included).~~
~~(Please write any comments in the box below)~~

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 immediately after we receive the questionnaire. Questionnaires and notes ~~and these~~ are not read by your health care team.

~~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 return this form in the **freepost** **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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