HORIZONS

Understanding the impact of cancer diagnosis and treatment on everyday life

Third Questionnaire: 9 month follow-up

Study ID | | | / | | | / | N | | | |

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

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

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

This questionnaire is divided into 8 parts. It will ask for information about your health and symptoms and your experience of treatment. It will also ask about your thoughts and feelings about your cancer. It also covers topics such as how you are coping, 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.

How to fill in this questionnaire

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

Part 1 – Your General Health & Well-Being

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

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

MOBILITY

- ☐ I have no problems in walking about
- ☐ I have slight problems in walking about
- ☐ I have moderate problems in walking about
- ☐ I have severe problems in walking about
- ☐ I am unable to walk about

SELF-CARE

- ☐ I have no problems washing or dressing myself
- ☐ I have slight problems washing or dressing myself
- ☐ I have moderate problems washing or dressing myself
- ☐ I have severe problems washing or dressing myself
- ☐ I am unable to wash or dress myself

USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

- ☐ I have no problems doing my usual activities
- ☐ I have slight problems doing my usual activities
- ☐ I have moderate problems doing my usual activities
- ☐ I have severe problems doing my usual activities
- ☐ I am unable to do my usual activities

PAIN / DISCOMFORT

- ☐ I have no pain or discomfort
- ☐ I have slight pain or discomfort
- ☐ I have moderate pain or discomfort
- ☐ I have severe pain or discomfort
- ☐ I have extreme pain or discomfort

ANXIETY / DEPRESSION

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

We would like to know how good or bad your health is **TODAY**.

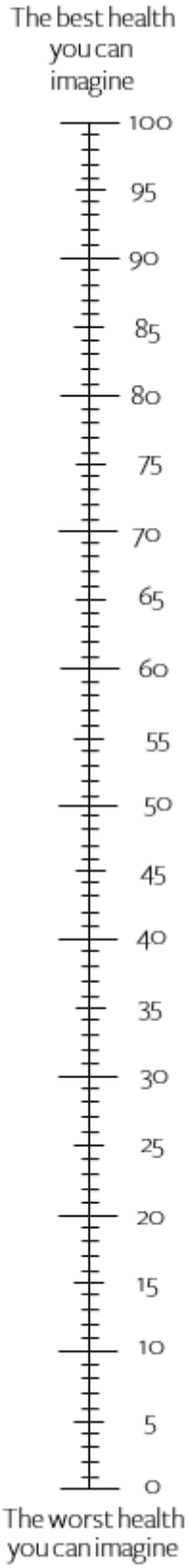
This scale is numbered from **0** to **100**.

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 =



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

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

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

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

Part 2 –Your Symptoms & How You Have Been Feeling

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

During the **past four weeks:**

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

During the **past four weeks:**

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

During the **past four weeks:**

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

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

	Not at all	A little	Quite a bit	Very much
67. Have you had pain during sexual intercourse or other sexual activity?	1	2	3	4
68. To what extent was sex enjoyable for you?	1	2	3	4
69. **For women only:** Has your vagina felt dry during sexual activity?	1	2	3	4
70. **For women only:** Has your vagina felt short and/or tight?	1	2	3	4
71. **For men only:** Did you have difficulty gaining or maintaining an erection?	1	2	3	4
72. **For men only:** Did you have ejaculation problems? (e.g. dry ejaculation)	1	2	3	4

Hospital Anxiety and Depression Scale (HADS)

Read each item below and tick the box beside the reply which 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 ☐
- A lot of the time ☐
- From time to time, occasionally ☐
- Not at all ☐

I still enjoy the things I used to enjoy:

- Definitely as much ☐
- Not quite so much ☐
- Only a little ☐
- Hardly at all ☐

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

- Very definitely and quite badly ☐
- Yes, but not too badly ☐
- A little, but it doesn't worry me ☐
- Not at all ☐

I can laugh and see the funny side of things:

- As much as I always could ☐
- Not quite so much now ☐
- Definitely not so much now ☐
- Not at all ☐

I feel as if I am slowed down:

- Nearly all the time ☐
- Very often ☐
- Sometimes ☐
- Not at all ☐

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

- Not at all ☐
- Occasionally ☐
- Quite often ☐
- Very often ☐

I have lost interest in my appearance:

- Definitely ☐
- I don't take as much care as I should ☐
- I may not take quite as much care ☐
- I take just as much care as ever ☐

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

- Very much indeed ☐
- Quite a lot ☐
- Not very much ☐
- Not at all ☐

Worrying thoughts go through my mind:

- A great deal of the time ☐
- A lot of the time ☐
- Not too often ☐
- Very little ☐

I look forward with enjoyment to things:

- As much as I ever did ☐
- Rather less than I used to ☐
- Definitely less than I used to ☐
- Hardly at all ☐

I feel cheerful:

- Never ☐
- 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 ☐

Part 3 – 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 1	2	3	4	5	6	7	8	9	Totally Confident 10
How confident are you that you can keep the fatigue caused by having had cancer and/or cancer treatment from interfering with the things you want to do?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
How confident are you that you can keep the physical discomfort or pain of having had cancer and/or cancer treatment from interfering with the things you want to do?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
How confident are you that you can keep the emotional distress caused by having had cancer and/or cancer treatment from interfering with the things you want to do?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
How confident are you that you can do the different tasks and activities needed to manage your cancer and/or cancer treatment so as to reduce your need to see a doctor?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
How confident are you that you can do things other than just taking medication to reduce how much having had cancer and/or cancer treatment affects your everyday life?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
How confident are you that you can access information about cancer and any effects of the diagnosis and treatment?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

	Not at all Confident 1	2	3	4	5	6	7	8	9	Totally Confident 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?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
How confident are you that you can deal by yourself with the problems cancer and/or cancer treatment has caused?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
How confident are you to contact your doctor about problems caused by cancer and/or cancer treatment?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
How confident are you that you can get support with problems caused by cancer/treatment from health and/or social care professionals?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Part 4 – Your Thoughts & Feelings About Your Cancer

We would now like to ask you about your feelings around having cancer and 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.	☐	☐	☐	☐	☐	☐	☐
You had financial problems because of the cost of cancer surgery or treatment.	☐	☐	☐	☐	☐	☐	☐
You worried that your family members were at risk of getting cancer.	☐	☐	☐	☐	☐	☐	☐
You realized that having had cancer helps you cope better with problems now.	☐	☐	☐	☐	☐	☐	☐
You were self-conscious about the way you look because of your cancer or its treatment.	☐	☐	☐	☐	☐	☐	☐
You worried about whether your family members might have cancer-causing genes.	☐	☐	☐	☐	☐	☐	☐
You felt unattractive because of your cancer or its treatment.	☐	☐	☐	☐	☐	☐	☐
You worried about dying from cancer.	☐	☐	☐	☐	☐	☐	☐
You had problems with insurance because of cancer.	☐	☐	☐	☐	☐	☐	☐
You were bothered by hair loss from cancer treatment.	☐	☐	☐	☐	☐	☐	☐
You worried about cancer coming back	☐	☐	☐	☐	☐	☐	☐
You felt that cancer helped you to recognize what is important in life.	☐	☐	☐	☐	☐	☐	☐
You felt better able to deal with stress because of having had cancer.	☐	☐	☐	☐	☐	☐	☐
You worried about whether your family members should have genetic tests for cancer.	☐	☐	☐	☐	☐	☐	☐

	Never	Seldom	Some times	About as often as not	Frequently	Very often	Always
You had money problems that arose because you had cancer.	☐	☐	☐	☐	☐	☐	☐
You felt people treated you differently because of changes to your appearance due to your cancer or its treatment.	☐	☐	☐	☐	☐	☐	☐
You had financial problems due to a loss of income as a result of cancer.	☐	☐	☐	☐	☐	☐	☐
Whenever you felt a pain, you worried that it might be cancer again.	☐	☐	☐	☐	☐	☐	☐
You were preoccupied with concerns about cancer.	☐	☐	☐	☐	☐	☐	☐

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

How much does your cancer 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 cancer will continue?

0	1	2	3	4	5	6	7	8	9	10
A very short time										Forever

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

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 cancer?

0	1	2	3	4	5	6	7	8	9	10
Not at all										Extremely helpful

How much do you experience symptoms from your cancer?

0	1	2	3	4	5	6	7	8	9	10
No symptoms at all										Many severe symptoms

How concerned are you about your cancer?

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 cancer?

0	1	2	3	4	5	6	7	8	9	10
Don't understand at all										Understand very clearly

How much does your cancer 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 cancer**:

The most important causes for me:

1. _____

2. _____

3. _____

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

Part 5 – Your Experiences of Treatment & Your Needs

We would now like to ask you about your experiences of your treatment and whether or not any needs which you may have faced as a result of your cancer and/or 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)?	☐	☐	☐	☐	☐	☐
...learn what foods you should eat to stay healthy?	☐	☐	☐	☐	☐	☐
...find information on the medications that you have to take?	☐	☐	☐	☐	☐	☐
...understand changes to your treatment plan?	☐	☐	☐	☐	☐	☐
...understand the reasons why you are taking some medicines?	☐	☐	☐	☐	☐	☐
...find sources of medical information that you trust?	☐	☐	☐	☐	☐	☐
...understand advice from different healthcare providers?	☐	☐	☐	☐	☐	☐

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?	☐	☐	☐	☐	☐
...schedule and keep track of your medical appointments?	☐	☐	☐	☐	☐
...make or keep appointments with **different** healthcare providers?	☐	☐	☐	☐	☐

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

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?	☐	☐	☐	☐	☐
...others reminding you to do things for your health like take your medicine, watch what you eat, or schedule medical appointments?	☐	☐	☐	☐	☐
...your healthcare needs creating tension in your relationships with others	☐	☐	☐	☐	☐
...others not understanding your health situation	☐	☐	☐	☐	☐

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

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

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

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

	Not at all	A little	Somewhat	Quite a bit	Very much
...work (include work at home)?	☐	☐	☐	☐	☐
...family responsibilities?	☐	☐	☐	☐	☐
...daily activities?	☐	☐	☐	☐	☐
...hobbies and leisure activities?	☐	☐	☐	☐	☐
...ability to spend time with family and friends?	☐	☐	☐	☐	☐
...ability to travel for work or vacation?	☐	☐	☐	☐	☐

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

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

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

☐ Yes ☐ No

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

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

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

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

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

	Not applicable	Satisfied	Low need	Moderate need	High need
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 6 – Your Interests & 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 engagement with interests, hobbies etc. can be a source of support to people 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	☐	☐	☐	☐	☐
Someone to give you information to help you understand a situation	☐	☐	☐	☐	☐
Someone to give you good advice about a crisis	☐	☐	☐	☐	☐
Someone to confide in or talk to about yourself or your problems	☐	☐	☐	☐	☐
Someone whose advice you really want	☐	☐	☐	☐	☐
Someone to share your most private worries and fears with	☐	☐	☐	☐	☐
Someone to turn to for suggestions about how to deal with a personal problem	☐	☐	☐	☐	☐
Someone who understands your problems	☐	☐	☐	☐	☐
Tangible Support:					
Someone to help you if you were confined to bed	☐	☐	☐	☐	☐
Someone to take you to the doctor if you needed it	☐	☐	☐	☐	☐
Someone to prepare your meals if you were unable to do it yourself	☐	☐	☐	☐	☐
Someone to help with daily chores if you were sick	☐	☐	☐	☐	☐

	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	☐	☐	☐	☐	☐
Someone to love and make you feel wanted	☐	☐	☐	☐	☐
Someone who hugs you	☐	☐	☐	☐	☐
Positive Social Interaction:					
Someone to have a good time with	☐	☐	☐	☐	☐
Someone to get together with for relaxation	☐	☐	☐	☐	☐
Someone to do something enjoyable with	☐	☐	☐	☐	☐
Additional Item:					
Someone to do things with to help you get your mind off things	☐	☐	☐	☐	☐

How many close friends do you have? ☐

How many close family members do you have? ☐

2. 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)	☐	☐	☐	☐
Voluntary work	☐	☐	☐	☐
Health or exercise groups, including taking part, coaching or going to watch	☐	☐	☐	☐
Cultural activities (e.g. sports, stately homes, concerts, museums/galleries, dance, opera)	☐	☐	☐	☐
Other groups or activities	☐	☐	☐	☐

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

☐ Practical help (e.g. gardening, pets, home maintenance, transport, running errands)

☐ Help with childcare or babysitting

☐ Teaching, coaching or giving practical advice

☐ Giving emotional support

☐ Other

Part 7 – Your Lifestyle

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 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:

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:

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
☐	☐	☐	☐	☐	☐

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
☐	☐	☐	☐	☐	☐

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 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?

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

Blank Page

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

Your participation is very helpful to us.

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

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

Please return this form in the FREEPOST envelope provided.

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

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