UNIVERSITY OF Southampton

HORIZONS

Understanding the impact of cancer diagnosis and treatment on everyday life

Second Questionnaire: 3 month follow-up

Study ID ☐☐/☐☐/V☐☐☐

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 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 are asking a range of questions which will help us to understand the impact of cancer diagnosis and treatment and which other patients have said matter to them. 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

WE ARE MACMILLAN. CANCER SUPPORT

Part 1 – Your General Health & 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** 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

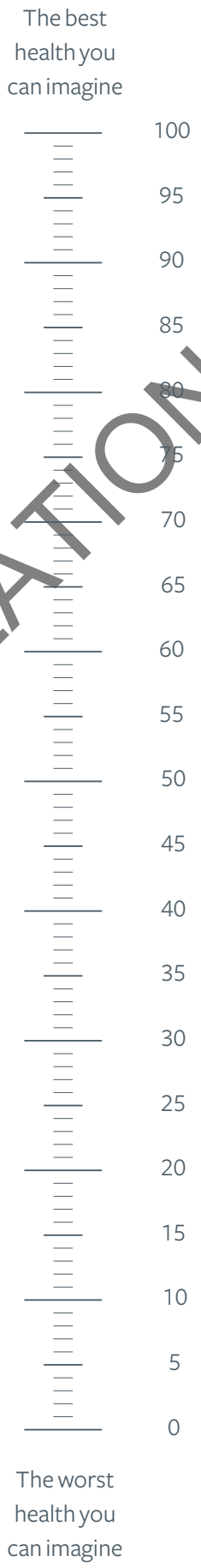
PAIN / DISCOMFORT

- ☐ 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 = ☐

please continue over

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 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.	☐	☐	☐	☐	☐	☐	☐
You avoided your friends.	☐	☐	☐	☐	☐	☐	☐
You had aches or pains.	☐	☐	☐	☐	☐	☐	☐

	Never	Seldom	Some times	About as often as not	Frequently	Very often	Always
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.	☐	☐	☐	☐	☐	☐	☐

please continue over

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
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?

Very Poor						Excellent
1	2	3	4	5	6	7

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

Very Poor						Excellent
1	2	3	4	5	6	7

please continue over

Patients sometimes report that they have the following **symptoms or problems**. Some of these relate to the genital area. Whether or not you have had surgery in your genital area, please indicate the extent to which you have experienced these symptoms or problems.

During the **past week**:

		Not at All	A Little	Quite a Bit	Very Much
31.	Have you had pain in your genital area?	1	2	3	4
32.	Have you had itchy or irritated skin in your genital area?	1	2	3	4
33.	Have you had sore skin in your genital area?	1	2	3	4
34.	Have you had tearing or splitting of the skin in your genital area?	1	2	3	4
35.	Have you had narrowing/tightness of your vaginal entrance?	1	2	3	4
36.	Has scarring in your genital area caused you problems?	1	2	3	4
37.	Have you had difficulties sitting due to problems in your genital area?	1	2	3	4
38.	Have you had unpleasant discharge from your vagina or genital area?	1	2	3	4
39.	Have you had swelling in the genital area?	1	2	3	4
40.	Has the skin felt tight in your genital area?	1	2	3	4
41.	Have you had swelling in your groin?	1	2	3	4
42.	Have you had sore skin in your groin?	1	2	3	4
43.	Have you had pain in your groin?	1	2	3	4
44.	Have you had swelling in one or both legs?	1	2	3	4
45.	Have you felt heaviness in one or both legs?	1	2	3	4
46.	Has the skin felt tight in your leg(s)?	1	2	3	4
47.	Have you had pain in your leg(s)?	1	2	3	4
48.	Have you felt physically less attractive as a result of your disease or treatment?	1	2	3	4
49.	Have you felt less feminine as a result of your disease or treatment?	1	2	3	4
50.	Have you been dissatisfied with your body?	1	2	3	4
51.	Did you have night sweats?	1	2	3	4
52.	Have you had hot flushes?	1	2	3	4
53.	Did you have headaches?	1	2	3	4
54.	Have you had aches or pains in your muscles or joints?	1	2	3	4
55.	Have you had tingling or numbness in your hands or feet?	1	2	3	4
56.	Have you had skin problems (e.g. itchy, dry)?	1	2	3	4

During the **past week**:

57.	Do you have a urine catheter or a urine stoma bag (artificial bladder)?	No	Yes

Please answer these questions only if you do NOT have a urine catheter or a urine stoma bag

During the **past week:**

		Not at All	A Little	Quite a Bit	Very Much
58.	Have you passed urine frequently?	1	2	3	4
59.	Have you had pain or a burning feeling when passing urine?	1	2	3	4
60.	Have you had leaking of urine?	1	2	3	4
61.	When you felt the urge to pass urine, did you have to hurry to get to the toilet?	1	2	3	4

62.	Do you have a bowel stoma bag?	No	Yes

Please answer these questions only if you do NOT have a bowel stoma bag

During the **past week:**

		Not at All	A Little	Quite a Bit	Very Much
63.	Have you had leaking of stools?	1	2	3	4
64.	When you felt the urge to move your bowels, did you have to hurry to get to the toilet?	1	2	3	4

During the **past 4 weeks**:

65.	Have you been sexually active?	No	Yes

Please answer these questions only if you have been SEXUALLY ACTIVE DURING THE PAST 4 WEEKS

During the **past 4 weeks:**

		Not at All	A Little	Quite a Bit	Very Much
66.	Have you worried that sex would be painful?	1	2	3	4
67.	Have you had pain during sexual intercourse or other sexual activity?	1	2	3	4
68.	Has your vagina felt narrow and/or tight during sexual intercourse or other sexual activity?	1	2	3	4
69.	Has your vagina felt dry during sexual intercourse or other sexual activity?	1	2	3	4
70.	Has sexual activity been enjoyable for you?	1	2	3	4
71.	To what extent were you interested in sex?	1	2	3	4
72.	Have you been satisfied with your ability to reach an orgasm?	1	2	3	4

please continue over

During the **past 4 weeks:**

		Not at All	A Little	Quite a Bit	Very Much
73.	Have you worried about your health in the future?	1	2	3	4
74.	How much has your disease been a burden to you?	1	2	3	4
75.	How much has your treatment been a burden to you?	1	2	3	4
76.	**If applicable:** Have you had problems at your work or place of study due to the disease?	1	2	3	4
77.	**If applicable:** Have you worried about not being able to continue working or your education?	1	2	3	4
78.	**If applicable:** Have you been concerned about your ability to have children?	1	2	3	4

During the **past week:**

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

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 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

Worrying thoughts go through my mind:

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

I feel cheerful:

- ☐ Never
- ☐ Not often
- ☐ Sometimes
- ☐ Most of the time

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 if I have to be on the move:

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

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 get sudden feelings of panic:

- ☐ Very often indeed
- ☐ Quite often
- ☐ Not very often
- ☐ Not at all

please continue over

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

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

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

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

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

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

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

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

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

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

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

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

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?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
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?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

please continue over

	Not at all Confident									Totally Confident
	1	2	3	4	5	6	7	8	9	10
How confident are you that you can access people to help and support you when you have problems caused by cancer and/or cancer treatment?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
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?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

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	Rarely true	Sometimes true	Often true	True nearly all of the time
	(0)	(1)	(2)	(3)	(4)
I am able to adapt when changes occur	☐	☐	☐	☐	☐
I tend to bounce back after illness, injury, or other hardships	☐	☐	☐	☐	☐

Part 5 – Your Experiences of Treatment & 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	☐	☐	☐	☐
As well as seeing my doctor, I regularly monitor changes in my health	☐	☐	☐	☐
I often worry about my health	☐	☐	☐	☐
I try to make the most of my life	☐	☐	☐	☐
I know what things can trigger my health problems and make them worse	☐	☐	☐	☐
My health problems make me very dissatisfied with my life	☐	☐	☐	☐
I am doing interesting things in my life	☐	☐	☐	☐
I have plans to do enjoyable things for myself during the next few days	☐	☐	☐	☐
I have a very good understanding of when and why I am supposed to take my medication	☐	☐	☐	☐
I often feel angry when I think about my health	☐	☐	☐	☐
I feel hopeless because of my health problems	☐	☐	☐	☐
I feel like I am actively involved in life	☐	☐	☐	☐
When I have health problems, I have a clear understanding of what I need to do to control them	☐	☐	☐	☐
I carefully watch my health and do what is necessary to keep as healthy as possible	☐	☐	☐	☐
I get upset when I think about my health	☐	☐	☐	☐
With my health in mind, I have realistic expectations of what I can and cannot do	☐	☐	☐	☐
If I think about my health, I get depressed	☐	☐	☐	☐
If I need help, I have plenty of people I can rely on	☐	☐	☐	☐
I have effective ways to prevent my symptoms (e.g., discomfort, pain and stress) from limiting what I can do in my life	☐	☐	☐	☐

please continue over

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

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?	☐	☐	☐	☐	☐

please continue over

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**?

please continue over

Part 6 – Your Use of Health Services

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

1. Health service use

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

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

1.1 Hospital visits and appointments

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

	Have you used this service in the last 3 months? (please tick if 'yes')	Approximate number of days
Hospital inpatient stay (at least 24 hours)	☐	

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

	Have you used this service in the last 3 months? (please tick if 'yes')	Approximate number of visits	Approximate number of contacts by telephone and/or email
Accident and emergency department	☐		
Cancer doctor	☐		
Cancer nurse	☐		
Cancer information and support service	☐		
Day centre	☐		
Dietician	☐		
Hospital doctor	☐		
Hospital nurse	☐		
Occupational therapist	☐		

	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
Outpatient clinic	☐		
Pharmacist	☐		
Physiotherapist	☐		
Psychiatrist or psychologist	☐		
Radiographer	☐		
Speech and language therapist	☐		
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	☐	
CT-Scan	☐	
Internal vaginal examination	☐	
Mammogram	☐	
MRI Scan	☐	
Papanicolaou test (Cervical smear test)	☐	
Ultrasound	☐	
X-ray	☐	
Other, please specify: _____	☐	
_____	☐	
_____	☐	
_____	☐	

please continue over

1.2 Other health and social care services

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

	Have you used this service in the last 3 months? (please tick if 'yes')	Approximate number of **clinic** visits	Approximate number of **home** visits	Approximate number of contacts by telephone and/ or email
Counsellor	☐			
Dietician	☐			
District nurse, health visitor or members of community team	☐			
GP	☐			
Mental health or emotional support services (e.g. mental health nurse)	☐			
Occupational therapist	☐			
Pharmacist	☐			
Physiotherapist	☐			
Podiatrist	☐			
Psychiatrist or psychologist	☐			
Social worker	☐			
Other, please specify: _____	☐			
_____	☐			
_____	☐			
_____	☐			

1.3 Other support services

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

	Have you used this service in the last 3 months? (please tick if 'yes')	Approximate number of visits / contact
Cancer charity information and/or support services	☐	
Cancer charity website and/or online forums	☐	
Citizen's Advice Bureau	☐	
Community transport services	☐	
Day hospice	☐	
Drug or alcohol rehabilitation services	☐	
Employment advice service	☐	
Family or patient support or self-help groups	☐	
Financial or benefits advice service	☐	
Food bank	☐	

	Have you used this service in the last 3 months? (please tick if 'yes')	Approximate number of visits / contact
Food, medicine or laundry delivery service	☐	
Home help or care worker	☐	
Lifestyle advice services / workshops	☐	
Lunch or social club	☐	
Nursing / Residential home	☐	
Other charity information and support service	☐	
Other charity website and/or online forums	☐	
Telephone help lines	☐	
Voluntary services / assistance	☐	
Walking group or physical activity service	☐	
Other, please specify: _____	☐	
_____	☐	
_____	☐	
_____	☐	

2. Travel costs and additional expenses

2.1 Travel costs

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

Approximately, how many miles have you travelled by car?	
Approximately, how much have you spent on health-care related parking?	£
Approximately, how much have you spent on fares for public transport, taxis, etc.?	£

2.2 Other expenses

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

Description	Approximate total cost (£)

please continue over

Part 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	☐	☐	☐	☐	☐
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?

☐☐

please continue over

2. Your Social Network

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

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

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

– their relationship to you (e.g. daughter, friend, GP)

– how often you see them in person (e.g. weekly, monthly, every couple of months)

– approximately how far do they live from you (approx. in miles)

Please use as many or as few of the lines provided

Network Member Number	**Network Member** (name or initials)	**Gender** 1 = male 2 = female	**Relationship** (son, daughter, pet, friend, group, nurse, etc.)	**How often do you see them?** 1= at least once a week, 2 = at least once a month, 3 = at least every couple of months, 4 = less often	**How far do they live from you?** (approx. in miles)
Example	Alistair	(1) 2	Friend	1 2 (3) 4	10 miles
1		1 2		1 2 3 4	
2		1 2		1 2 3 4	
3		1 2		1 2 3 4	
4		1 2		1 2 3 4	
5		1 2		1 2 3 4	
6		1 2		1 2 3 4	
7		1 2		1 2 3 4	
8		1 2		1 2 3 4	
9		1 2		1 2 3 4	
10		1 2		1 2 3 4	
11		1 2		1 2 3 4	
12		1 2		1 2 3 4	
13		1 2		1 2 3 4	
14		1 2		1 2 3 4	
15		1 2		1 2 3 4	
16		1 2		1 2 3 4	
17		1 2		1 2 3 4	
18		1 2		1 2 3 4	
19		1 2		1 2 3 4	
20		1 2		1 2 3 4	

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

A. Information of your illness and illness management – things to do with your long-term condition (e.g. helping you to understand health information, diet, medicines, etc)

B. Practical help with daily tasks (e.g. running your household, etc)

C. Emotional support (your wellbeing, helping you feel good, comforting you when you are worried, etc)

Network Member Number (as numbered in the previous table)	**Rate the extent to which this member helps you with:** **1** = No help at all, **2** = Some help, **3** = A lot of help								
	Information of your illness and illness management			**Practical help with daily tasks**			**Emotional support**		
Example	1	2	(3)	1	2	(3)	1	2	(3)
1	1	2	3	1	2	3	1	2	3
2	1	2	3	1	2	3	1	2	3
3	1	2	3	1	2	3	1	2	3
4	1	2	3	1	2	3	1	2	3
5	1	2	3	1	2	3	1	2	3
6	1	2	3	1	2	3	1	2	3
7	1	2	3	1	2	3	1	2	3
8	1	2	3	1	2	3	1	2	3
9	1	2	3	1	2	3	1	2	3
10	1	2	3	1	2	3	1	2	3
11	1	2	3	1	2	3	1	2	3
12	1	2	3	1	2	3	1	2	3
13	1	2	3	1	2	3	1	2	3
14	1	2	3	1	2	3	1	2	3
15	1	2	3	1	2	3	1	2	3
16	1	2	3	1	2	3	1	2	3
17	1	2	3	1	2	3	1	2	3
18	1	2	3	1	2	3	1	2	3
19	1	2	3	1	2	3	1	2	3
20	1	2	3	1	2	3	1	2	3

please continue over

Part 8 – 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):

M M / Y Y Y Y

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

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

☐☐☐

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

☐ Yes ☐ No ☐ Not applicable

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

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 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:

please continue over

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 this page.

Here is a guide to units of alcohol:

Number of Units	
1.5	A small glass (125 ml) of red, white or rosé wine (ABV 12%)
2.1	A standard glass (175 ml) of red, white or rosé wine (ABV 12%)
3	A large glass (250 ml) of red, white or rosé wine (ABV 12%)
2	A pint of lower-strength (ABV 3.6%) lager, beer or cider
3	A pint of higher-strength (ABV 5.2%) lager, beer or cider
1.7	A bottle (330 ml) of lager, beer or cider (ABV 5%)
2	A can (440 ml) of lager, beer or cider (ABV 4.5%)
1.5	275 ml bottle of alcopop (ABV 5.5%)
1	25 ml single spirit and mixer (ABV 40%)

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

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

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

5. Exercise & Physical activity

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

	Times per week:	
STRENUOUS EXERCISE (HEART BEATS RAPIDLY) (e.g., running, jogging, hockey, football, squash, basketball, judo, roller skating, vigorous swimming, vigorous long distance cycling)	☐☐	☐☐ hours ☐☐ minutes
MODERATE EXERCISE (NOT EXHAUSTING) (e.g., fast walking, tennis, easy cycling, volleyball, badminton, easy swimming, dancing)	☐☐	☐☐ hours ☐☐ minutes
MILD EXERCISE (MINIMAL EFFORT) (e.g., yoga, archery, fishing, bowling, golf, easy walking)	☐☐	☐☐ hours ☐☐ minutes

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

- ☐ Often
- ☐ Sometimes
- ☐ Never/Rarely

Have you done any strength exercise(s) (such as weight lifting, sit-ups, and push-ups) in the **last month**?

☐ Yes ☐ No

If **yes**, in a typical week, how many times and for how long have you done strength exercise(s)?

	Times per week:	
STRENGTH EXERCISE (e.g., weight lifting, sit-ups, and push-ups)	☐☐	☐☐ hours ☐☐ minutes

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

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

please continue over

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, 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**

please continue over

Part 9 – Your Comments

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

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

We offer the option to complete our follow-up questionnaires on paper or online.
For the **next** follow-up questionnaire, which of these methods would you prefer? (Please tick **one**)

☐ Paper ☐ Online

Today's Date

Please fill in the date you completed this questionnaire:

D D / M M / Y Y Y Y

Thank you very much for your participation

please continue over

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

Your participation is very helpful to us.

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

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

Please return this form in the FREEPOST envelope provided.

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