UNIVERSITY OF Southampton

# HORIZONS

**Understanding the impact of cancer diagnosis and treatment on everyday life**

## Fourth Questionnaire: 18 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. Even if you have not experienced problems during recovery, or you have moved on from cancer, it is important that you complete this questionnaire so that we can compare your experience with others. This information will help inform support services in the future.

This questionnaire is divided into 5 parts. It will ask for information about your general health and wellbeing, how you have been feeling, and your experiences of support, ongoing care and activities related to your health. 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 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

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

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

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

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

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

The next set of questions asks specifically about the effects of your cancer or its treatment. Again, for each statement, indicate how often each of these statements has been true for you in the **past four weeks.** (Please tick **one** answer for each question)

| | Never | Seldom | Some times | About as often as not | Frequently | Very often | Always |
|---|---|---|---|---|---|---|---|
| You appreciated life more because of having had cancer. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| You had financial problems because of the cost of cancer surgery or treatment. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| You worried that your family members were at risk of getting cancer. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| You realized that having had cancer helps you cope better with problems now. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| You were self-conscious about the way you look because of your cancer or its treatment. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| You worried about whether your family members might have cancer-causing genes. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

please continue over

| | Never | Seldom | Some times | About as often as not | Frequently | Very often | Always |
|---|---|---|---|---|---|---|---|
| You felt unattractive because of your cancer or its treatment. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| You worried about dying from cancer. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| You had problems with insurance because of cancer. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| You were bothered by hair loss from cancer treatment. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| You worried about cancer coming back. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| You felt that cancer helped you to recognize what is important in life. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| You felt better able to deal with stress because of having had cancer. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| You worried about whether your family members should have genetic tests for cancer. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| You had money problems that arose because you had cancer. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| You felt people treated you differently because of changes to your appearance due to your cancer or its treatment. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| You had financial problems due to a loss of income as a result of cancer. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Whenever you felt a pain, you worried that it might be cancer again. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| You were preoccupied with concerns about cancer. | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

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

**MOBILITY**

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

**SELF-CARE**

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

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

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

**PAIN / DISCOMFORT**

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

**ANXIETY / DEPRESSION**

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



please continue over

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

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

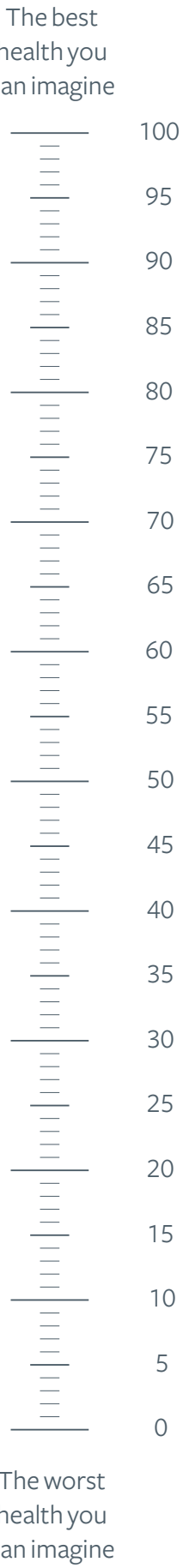
– **100** means the **best** health you can imagine

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

– Mark an **X** on the scale to indicate how your health is **TODAY**

– Now, please write the number you marked on the scale in the box below.

**YOUR HEALTH TODAY =** ☐



# Part 2 – Your Experiences of Support, Ongoing Care and Activities

We would like to find out more about the types of support and assistance you have available to you. We would also like to ask you about your experiences of your treatment and any ongoing activities related to your health and also about how people cope and manage their health.

For each of the following questions, please tick the box that corresponds to your confidence that you can do the tasks regularly **at the present time**.

| | Not at all Confident | | | | | | | | | 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? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| How confident are you that you can access people to help and support you when you have problems caused by cancer and/or cancer treatment? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| How confident are you that you can deal by yourself with the problems cancer and/or cancer treatment has caused? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| How confident are you to contact your doctor about problems caused by cancer and/or cancer treatment? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| How confident are you that you can get support with problems caused by cancer/treatment from health and/or social care professionals? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

please continue over

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 |

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it? (Please **tick one box on each line**)

| | None of the time | A little of the time | Some of the time | Most of the time | All of the time |
|---|---|---|---|---|---|
| **Emotional / informational Support:** | | | | | |
| Someone you can count on to listen to you when you need to talk | ☐ | ☐ | ☐ | ☐ | ☐ |
| Someone to give you information to help you understand a situation | ☐ | ☐ | ☐ | ☐ | ☐ |
| Someone to give you good advice about a crisis | ☐ | ☐ | ☐ | ☐ | ☐ |
| Someone to confide in or talk to about yourself or your problems | ☐ | ☐ | ☐ | ☐ | ☐ |
| Someone whose advice you really want | ☐ | ☐ | ☐ | ☐ | ☐ |
| Someone to share your most private worries and fears with | ☐ | ☐ | ☐ | ☐ | ☐ |
| Someone to turn to for suggestions about how to deal with a personal problem | ☐ | ☐ | ☐ | ☐ | ☐ |
| Someone who understands your problems | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Tangible Support:** | | | | | |
| Someone to help you if you were confined to bed | ☐ | ☐ | ☐ | ☐ | ☐ |
| Someone to take you to the doctor if you needed it | ☐ | ☐ | ☐ | ☐ | ☐ |
| Someone to prepare your meals if you were unable to do it yourself | ☐ | ☐ | ☐ | ☐ | ☐ |
| Someone to help with daily chores if you were sick | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Affectionate Support:** | | | | | |
| Someone who shows you love and affection | ☐ | ☐ | ☐ | ☐ | ☐ |
| Someone to love and make you feel wanted | ☐ | ☐ | ☐ | ☐ | ☐ |
| Someone who hugs you | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Positive Social Interaction:** | | | | | |
| Someone to have a good time with | ☐ | ☐ | ☐ | ☐ | ☐ |
| Someone to get together with for relaxation | ☐ | ☐ | ☐ | ☐ | ☐ |
| Someone to do something enjoyable with | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Additional Item:** | | | | | |
| Someone to do things with to help you get your mind off things | ☐ | ☐ | ☐ | ☐ | ☐ |

please continue over

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? | ☐ | ☐ | ☐ | ☐ | ☐ |

please continue over

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? | ☐ | ☐ | ☐ | ☐ | ☐ |

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:

Do you have caring responsibilities for children aged under 18 years?

☐ Yes ☐ No

If **'Yes'**, how many children (aged under 18 years) do you care for?

☐ children

Do you look after, or give any help or support to family, friends, neighbours or others? This may be because of either long-term physical or mental health disability, or problems relating to old age.

☐ Yes ☐ No

Does anyone look after, or give you help or support? This may be because of either a long-term physical or mental health disability, or problems relating to old age.

☐ Yes ☐ No

If **'Yes'**: Is this formal paid care? (e.g. nurse, home-help etc.):

☐ Yes ☐ No

Is this informal unpaid care? (e.g. relative, neighbour, friend etc.):

☐ Yes ☐ No

please continue over

# Part 3 – How You Have Been Feeling

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

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

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

During the **past week:**

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

During the **past week:**

| | | Not at All | A Little | Quite a Bit | Very Much |
|---|---|---|---|---|---|
| 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 |
| 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 |

During the **past week:**

| | | Not at All | A Little | Quite a Bit | Very Much |
|---|---|---|---|---|---|
| 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 |

| | | | |
|---|---|---|---|
| 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 four 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 four 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 four 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 been concerned about your ability to have children? | 1 | 2 | 3 | 4 |
| 77. | **If applicable:** Have you had problems at your work or place of study due to the disease? | 1 | 2 | 3 | 4 |
| 78. | **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 |
|---|---|---|---|---|---|
| 79. | Have you suffered from pain and tingling in your feet/ toes? | 0 | 1 | 2 | 3 |
| 80. | Have you suffered from pain and tingling in your hands/fingers? | 0 | 1 | 2 | 3 |
| 81. | Have you suffered from numb or cold feet or toes? | 0 | 1 | 2 | 3 |
| 82. | Have you suffered from numb or cold hands or fingers? | 0 | 1 | 2 | 3 |
| 83. | Have you suffered from ringing in your ears? | 0 | 1 | 2 | 3 |
| 84. | Have you suffered from reduced hearing? | 0 | 1 | 2 | 3 |
| 85. | **If applicable:** Was the ringing present before your cancer treatment? | No | | Yes | |
| 86. | **If applicable:** Was the hearing loss present before your cancer treatment? | No | | Yes | |

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

To what extent does worry about your cancer spill over or intrude into your other thoughts and activities?

| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---|---|---|---|---|---|---|---|---|---|---|
| Not at all | | | | | | | | | | A great deal |

How often have you worried about the possibility that your cancer might come back after treatment?

| 0 | 1 | 2 | 3 | 4 |
|---|---|---|---|---|
| None of the time | Rarely | Occasionally | Often | All the time |

please continue over

**Hospital Anxiety and Depression Scale (HADS)**
As per our licence, the HADS instrument cannot be shared without agreement from the copyright holders. HADS is available through licence from GL Assessment, please see: http://www.gl-assessment.co.uk/products/hospital-anxiety-and-depression-scale/hospital-anxiety-and-depression-scale-faqs

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

**Please answer the following questions about your general health:**

| | Yes | No |
|---|---|---|
| In general, do you have any health problems that require you to limit your activities? | ☐ | ☐ |
| Do you need someone to help you on a regular basis? | ☐ | ☐ |
| In general, do you have any health problems that require you to stay at home? | ☐ | ☐ |
| In case of need, can you count on someone close to you? | ☐ | ☐ |
| Do you regularly use a stick, walker or wheelchair to get about? | ☐ | ☐ |

## Your Menstrual Cycle

We would like to know whether or not you have gone through the menopause. The menopause is an event in a woman's life marked by the end of menstrual periods. By providing this information you will help us understand your answers to other questions we ask in this questionnaire. If you do not wish to answer, please leave this question blank.

How would you describe your current menstrual cycle (periods) status? (Please tick **one**)

- ☐ Pre-menopause (regular periods in the last 3 months and no change in the frequency of periods)
- ☐ Early menopause transition (have had periods in the last 3 months but noticed a change in the frequency of these periods)
- ☐ Late menopausal transition (at least 3 months in a row without a period but for less than 12 months)
- ☐ Post-menopause (at least 12 months in a row without a period)

If **'Post-menopause'**, was your menopause: (Please tick **one**)

- ☐ Spontaneous ("natural")
- ☐ Surgical (removal of both ovaries)
- ☐ Due to chemotherapy or radiation therapy; reason for therapy: _____ _____
- ☐ Other (please explain): _____ _____

please continue over

# Part 4 – About You

In this section, we would like to know a little about yourself and if anything has changed since the first questionnaire.

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

- ☐ Single
- ☐ In a relationship

What is your **current** domestic status? (Please tick **one**)

- ☐ Never married and/or never in a registered same-sex civil partnership
- ☐ Married
- ☐ Separated, but still legally married
- ☐ Divorced
- ☐ Widowed
- ☐ In a registered same-sex civil partnership
- ☐ Separated, but still legally in a same-sex civil partnership
- ☐ Formerly in a same-sex civil partnership which is now legally dissolved
- ☐ Surviving partner from a same-sex civil partnership

Which of the following people usually live in your household with you? (Please tick **all that apply**)

- ☐ Wife/husband/partner/civil partner/cohabitee
- ☐ Child(ren)
- ☐ Parent(s)
- ☐ Friend(s)
- ☐ Other (please specify): _____
- ☐ None of the above, I live alone

Have any first degree relative(s) of yours (parent, brother/sister or child) ever been diagnosed with cardiac health problems (e.g. heart attack or myocardial infarction, heart failure, high blood pressure)?

☐ Yes ☐ No ☐ Unknown

# Part 5 – 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** questionnaire, which of the following 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**

**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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