UNIVERSITY OF Southampton

HORIZONS

Understanding the impact of cancer diagnosis and treatment on everyday life

First Questionnaire

Study ID ☐☐/☐☐/V☐☐☐

Thank you for taking part 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 7 parts. It asks for information about you, your health, and how well you have been since you were diagnosed with cancer. It also covers topics such as how you are coping and managing your health, your lifestyle and interests, as well as 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 – About You

Firstly, we would like to know a little about you. This information helps us to build a picture of your background, the health services you may have accessed and other conditions and illnesses you may have had.

How old are you?

☐☐☐ years old

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

- ☐ Male
- ☐ Female
- ☐ Other, please specify:

How would you describe yourself? (Please tick **one**)

White:

- ☐ English / Welsh / Scottish / Northern Irish / British
- ☐ Irish
- ☐ Gypsy or Irish Traveller
- ☐ Any other White background, please specify:

Mixed / multiple ethnic groups:

- ☐ White and Black Caribbean
- ☐ White and Black African
- ☐ White and Asian
- ☐ Any other Mixed / multiple ethnic background, please specify:

Asian / Asian British:

- ☐ Indian
- ☐ Pakistani
- ☐ Bangladeshi
- ☐ Chinese
- ☐ Any other Asian background, please specify:

Black / African / Caribbean / Black British:

- ☐ African
- ☐ Caribbean
- ☐ Any other Black / African / Caribbean background, please specify:

Other ethnic background:

- ☐ Arab
- ☐ Any other ethnic background, please specify:

Which of the following options best describes how you think of yourself? (Please tick **one**)

- ☐ Heterosexual or Straight
- ☐ Gay or Lesbian
- ☐ Bisexual
- ☐ Other, please specify: _____
- ☐ I prefer not to say

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
- ☐ Child(ren)
- ☐ Parent(s)
- ☐ Friend(s)
- ☐ Other, please specify: _____
- ☐ None of the above, I live alone

Which of the following best describes your current household accommodation (home)?
(Please tick **one**)

- ☐ Owner-occupied (home is owned outright or is being bought through a mortgage/loan)
- ☐ Rented from a Council or Housing Association
- ☐ Rented from a private landlord
- ☐ Temporary accommodation
- ☐ Other, please specify: _____

Do you, or does anyone in your household, own or have regular use of a car or van?

☐ Yes ☐ No

Do you use the internet, for example to check emails or shop online? (Please tick **one**)

☐ Yes, regularly ☐ Yes, occasionally ☐ No

please continue over

Which of the following best describes your highest level of education completed?
(Please tick **one**)

- ☐ Still in compulsory school education
- ☐ Less than compulsory school education
- ☐ Compulsory school education
- ☐ Apprenticeship
- ☐ Further education (e.g. sixth form college or equivalent)
- ☐ Higher education - undergraduate degree
- ☐ Higher education - postgraduate degree
- ☐ Professional qualification (e.g. accountancy, nursing)
- ☐ Other vocational / work-related qualifications
- ☐ None of the above
- ☐ Other, please specify: _____

Which of the following best describes your current employment? (Please tick **all that apply**)

- ☐ Employed, full-time
- ☐ Employed, part-time
- ☐ Self-employed
- ☐ On sick-leave
- ☐ Looking after home or family
- ☐ Voluntary work
- ☐ Disabled or long-term sick
- ☐ Unemployed
- ☐ Retired
- ☐ In full-time education / training
- ☐ In part-time education / training
- ☐ Other, please specify: _____

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

_____ hours ☐ Not applicable

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

_____ days

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

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

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

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

Do you (yourself or jointly) receive any of the following types of payments? (Please tick **all that apply**)

- ☐ Unemployment-related benefits, or National Insurance Credits
- ☐ Income Support
- ☐ Sickness, disability or incapacity benefits (including Employment and Support Allowance)
- ☐ Child Benefit
- ☐ Tax credits, such as the Working Tax Credit or Child Tax Credit
- ☐ Any other family related benefits or payment
- ☐ Housing or Council Tax Benefit other than the single-person council tax discount
- ☐ Income from any other state benefit
- ☐ None of the above
- ☐ I prefer not to say

Are you currently receiving a pension? (Please tick **all that apply**)

- ☐ Yes, through a private pension (e.g. an employer's pension scheme or a personal pension scheme)
- ☐ Yes, through a government state pension
- ☐ No
- ☐ I prefer not to say

please continue over

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

Have you had contact with a GP in the **last 3 months**?

☐ Yes ☐ No

If '**Yes**', how did you contact the GP? (Please tick **all that apply**)

☐ GP practice

If **yes**, how many times in the last 3 months? ☐☐☐

☐ At home

If **yes**, how many times in the last 3 months? ☐☐☐

☐ Over the telephone

If **yes**, how many times in the last 3 months? ☐☐☐

Have you attended A&E or an emergency department in the **last 3 months**?

☐ Yes, for myself ☐ Yes, accompanying family, friends or other ☐ No

Have you ever used mental health and/or emotional support services?

☐ Yes ☐ No

The following table/grid refers to other conditions or illnesses that you may have.

Please work through both parts A & B:

A. From the following list of conditions in the table below, please select those which a health professional has told you that you have.

B. From the conditions you have indicated you have, please let us know how severely the condition has limited the activities you do on a typical day. For example, but not limited to: work, working around the house or garden, bathing or dressing yourself, social activities.

(Please choose a number from **0**, which is no limitation, to **7** which is severely limited.)

	A. **Has a health professional ever told you that you have this condition?** (Please tick if '**Yes**')	**B.** (If '**Yes**' in **A**) **How severely does the condition limit the activities you do on a typical day?** No limitations 0 1 2 3 4 5 6 7 Severely limited
Anaemia	☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
Arrhythmia/irregular heartbeat (e.g. AF or atrial fibrillation)	☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
Rheumatoid Arthritis	☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
Other Arthritis (e.g. osteoarthritis, psoriatic arthritis)	☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
Asthma, chronic lung disease, bronchitis, emphysema, chronic obstructive pulmonary disease (COPD)	☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
Cancer previous to your current diagnosis. Type of cancer, please state:	☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
Chest pain or angina	☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
Dementia	☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
Depression or anxiety	☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
Diabetes or high blood sugar (Type I)	☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
Diabetes or high blood sugar (Type II)	☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
Heart attack or myocardial infarction	☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
Heart failure	☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
High blood pressure or hypertension	☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
HIV/AIDS	☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
Inflammatory bowel disease, colitis or Crohn's disease	☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

please continue over

	A. **Has a health professional ever told you that you have this condition?** (Please tick if '**Yes**')	**B.** (If '**Yes**' in **A**) **How severely does the condition limit the activities you do on a typical day?** No limitations 0 1 2 3 4 5 6 7 Severely limited
Kidney / renal disease	☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
Liver disease or cirrhosis	☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
Neurological condition (e.g. multiple sclerosis, Parkinson's disease)	☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
Osteoporosis, osteopenia, or fragile/brittle bones	☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
Over- or under- active thyroid	☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
Pancreatitis	☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
Stomach ulcers	☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
Stroke / transient ischemic attack (TIA) or brain haemorrhage	☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
Venous disease (DVT: deep vein thrombosis / PE: pulmonary embolism)	☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
Other condition, please state:	☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

Part 2 – Your General Health & Well-Being

We would now 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

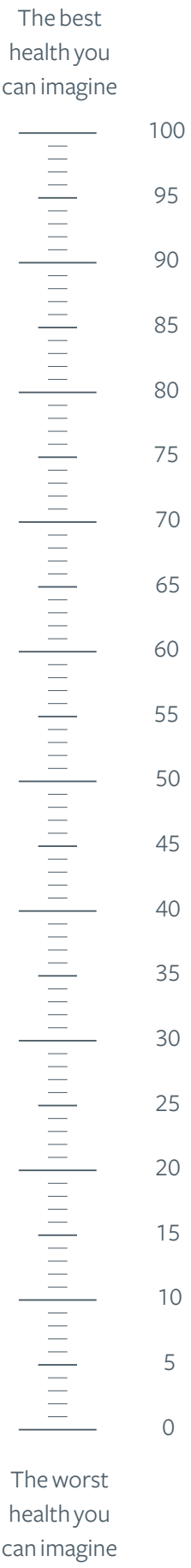
ANXIETY / DEPRESSION

- ☐ 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

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 = ☐



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.	☐	☐	☐	☐	☐	☐	☐

please continue over

	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.	☐	☐	☐	☐	☐	☐	☐

Part 3 – Your Symptoms & How You Are 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
21.	Did you feel tense?	1	2	3	4

please continue over

During the **past week**:

		Not at All	A Little	Quite a Bit	Very Much
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

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

please continue over

During the **past week**:

56.	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
57.	Have you passed urine frequently?	1	2	3	4
58.	Have you had pain or a burning feeling when passing urine?	1	2	3	4
59.	Have you had leaking of urine?	1	2	3	4
60.	When you felt the urge to pass urine, did you have to hurry to get to the toilet?	1	2	3	4

During the **past week:**

61.	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
62.	Have you had leaking of stools?	1	2	3	4
63.	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**:

64.	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
65.	Have you worried that sex would be painful?	1	2	3	4
66.	Have you had pain during sexual intercourse or other sexual activity?	1	2	3	4
67.	Has your vagina felt narrow and/or tight during sexual intercourse or other sexual activity?	1	2	3	4
68.	Has your vagina felt dry during sexual intercourse or other sexual activity?	1	2	3	4
69.	Has sexual activity been enjoyable for you?	1	2	3	4
70.	To what extent were you interested in sex?	1	2	3	4
71.	Have you been satisfied with your ability to reach an orgasm?	1	2	3	4

During the **past 4 weeks:**

		Not at All	A Little	Quite a Bit	Very Much
72.	Have you worried about your health in the future?	1	2	3	4
73.	How much has your disease been a burden to you?	1	2	3	4
74.	**If applicable:** Have you had problems at your work or place of study due to the disease?	1	2	3	4
75.	**If applicable:** Have you worried about not being able to continue working or your education?	1	2	3	4
76.	**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
77.	Have you been feeling self-conscious about your appearance?		1	2	3	4
78.	Have you been dissatisfied with your appearance when dressed?		1	2	3	4
79.	Did you find it difficult to look at yourself naked?		1	2	3	4
80.	Have you been feeling less sexually attractive as a result of your disease or treatment?		1	2	3	4
81.	Did you avoid people because of the way you felt about your appearance?		1	2	3	4
82.	Have you been feeling the treatment has left your body less whole?		1	2	3	4
83.	Have you been dissatisfied with the appearance of your scar?	N/A	1	2	3	4

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.

Part 4 – How You Cope & Manage Your Health

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

How confident are you filling out forms by yourself?

Extremely	Quite a bit	Somewhat	A little bit	Not at all
☐	☐	☐	☐	☐

How often do you have someone help you read hospital materials?

Never	Occasionally	Sometimes	Often	Always
☐	☐	☐	☐	☐

How often do you have problems learning about your medical condition because of difficulty reading hospital materials?

Never	Occasionally	Sometimes	Often	Always
☐	☐	☐	☐	☐

Health Education Impact Questionnaire (heiQ)
As per our licence, the heiQ measure cannot be shared without agreement from the copyright holders.

The heiQ is available through licence, please see: https://eprovide.mapi-trust.org/instruments/health-education-impact-questionnaire

Measure reference:
Osborne, R.H., Elsworth, G.R. & Whitfield, K. (2007). The Health Education Impact Questionnaire (heiQ): an outcomes and evaluation measure for patient education and self-management interventions for people with chronic conditions. *Patient education and counseling, 66(2)*, 192-201.

please continue over

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?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

please continue over

Connor-Davidson Resilience Scale 2-items (CD-RISC2)
As per our licence, the CD-RISC2 measure cannot be shared without agreement from the copyright holders. The CD-RISC2 is available through licence, for more information please see: http://www.connordavidson-resiliencescale.com/

Measure reference:
Vaishnavi, S., Connor, K. and Davidson, J.R., 2007. An abbreviated version of the Connor-Davidson Resilience Scale (CD-RISC), the CD-RISC2: Psychometric properties and applications in psychopharmacological trials. *Psychiatry research, 152(2),* 293-297.

Spirituality can be explained in many different ways and can mean something different to everyone. For some, it can be about participating in organised religious practices (e.g. going to a church, synagogue, mosque, etc.). For others, it could include other practices such as private prayer, yoga, meditation, quiet reflection, or even long walks. So it is not always associated with a religious belief. Many people without a religious belief still have 'spiritual feelings'.

Please respond to all of the statements yourself by circling the number that best applies to you.

More generally:

	Not at All	A Little	Quite a Bit	Very Much
I believe in God or in someone or something greater than myself	1	2	3	4
I have spiritual wellbeing	1	2	3	4

How would you rate your overall spiritual wellbeing? (Please circle **one** number below)

Don't know/ Can't answer	Very Poor						Excellent
0	1	2	3	4	5	6	7

Part 5 – 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 social relationships and engagement with interests 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	☐	☐	☐	☐	☐

please continue over

	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

please continue over

3. 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 6 – Your Lifestyle & Health

In this section, we would like to ask you some questions about your lifestyle. 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

What is your height?

☐☐ feet ☐☐ inches

or ☐☐☐ cms

2. Smoking habits

Which of the following best describes you?

☐ I have **never smoked**

☐ I **currently smoke**

☐ 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**, please complete the rest of this page.
Otherwise, please continue to the next page.

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 your smoking habits changed since your diagnosis of cancer?

☐ Yes ☐ No ☐ Not applicable

If '**Yes**', please tell us more details...

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

☐ Yes ☐ No ☐ Not applicable

HORIZONS; Baseline Questionnaire; Vulval Version 1.0, 18/10/2017, IRAS Project ID: 202342, REC reference number 16/NW/0425

3. e-Cigarette use / Vaping habits

Which of the following best describes you?

- ☐ I have **never used** an electronic cigarette (e-Cigarette)/vaped
- ☐ I **currently use** an e-Cigarette/vape
- ☐ I have **previously used** an e-Cigarette/vaped

If you **currently use** e-Cigarettes or have **previously used** e-Cigarettes, please complete the rest of this page. Otherwise, please continue to the next page.

Are you using/did you use 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

Has your use of e-Cigarettes changed since your diagnosis of cancer?

- ☐ Yes
- ☐ No
- ☐ Not applicable

If '**Yes**', please tell us more details...

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 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

Has your alcohol intake changed since your diagnosis of cancer?

☐ Yes ☐ No

If '**Yes**', please tell us more details...

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, baseball, 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?

Have your exercise / physical activity habits changed since your diagnosis of cancer?

☐ Yes ☐ No

If '**Yes**', please tell us more details...

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, 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) (e.g. low fat, high fibre, vegetarian, vegan, lactose free, gluten free, diabetic, etc.):

Has your diet changed since your diagnosis of cancer?

☐ Yes ☐ No

If '**Yes**', please tell us more details...

7. Your Menstrual Cycle

We would like to know whether or not you have gone through the menopause. The menopause is a normal 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 7 – 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 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.