Southampton



Third Questionnaire: 12 month questionnaire



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

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

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

This questionnaire is divided into 8 parts. It will ask for information about your general health, symptoms and your experiences of treatment and ongoing care. It will also ask about your thoughts and feelings about your cancer. It also covers topics such as how you are coping, your lifestyle and the support you have available to you. Information and treatment details from your medical records will be gathered separately by a research nurse and included in our analyses.

We understand that the questionnaire is long but we 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



HORIZONS; 12 month Questionnaire; Cervical Version 1.0, 12/06/2017, IRAS Project ID: 202342, REC reference number 16/NW/0425

Part 1 – Your General Health & Well-Being

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

The General Health Survey Questionnaire, Short Form 12 Ver 2.0 (SF-12v2)

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The SF-12v2 is available through licence, please see: https://campaign.optum.com/content/optum/en/optum-outcomes/what-we-do/health-surveys/sf-12v2-health-survey.html

Measure references:

Ware, J.E., Kosinski, M. & Keller, S.D. (1996). A 12 Item Short Form Health Survey: Construction of Scales and Preliminary Tests of Reliability and Validity. Medical Care, 34(3), 220-233

Ware, J.E., Kosinski, M., Turner-Bowker, D.M., & Gandek, B. (2002). How to score Version 2 of the SF-12 Health Survey (with a supplement documenting Version 1). Lincoln RI: QualityMetric Incorporated

SF-12v2[™] Health Survey 1992-2002 by Health Assessment Lab, Medical Outcomes Trust and QualityMetric Incorporated. All rights reserved. SF-12[®] is a registered trademark of Medical Outcomes Trust.

We would now 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.							

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

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

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 We would like to know how good or bad your health is TODAY. 	T I I .	
- This scale is numbered from 0 to 100 .	The best health you	
 – 100 means the best health you can imagine 	can imagine	
 – O means the worst health you can imagine 		100
 Mark an X on the scale to indicate how your health is 		95
TODAY		
 Now, please write the number you marked on the scale in the box below. 		90
	 	85
		80
	 	75
		70
		65
		60
		55
YOUR HEALTH TODAY =		50
		45 40
		35
		30
		25
		20
		15
		10
		5
		0
	The worst health you can imagine	

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Part 2 – 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 Po	or					Excellent
1	2	3	4	5	6	7

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

Very Poo	or					Excellent
1	2	3	4	5	6	7

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

Please indicate the extent to which you have experienced these symptoms or problems, please answer by circling the number that best applies to you.

During the **past week**:

Not at All	A Little	Quite a Bit	Very Much
1	2	3	4
1	2	3	4
1	2	3	4
1	2	3	4
1	2	3	4
1	2	3	4
1	2	3	4
1	2	3	4
1	2	3	4
1	2	3	4
1	2	3	4
1	2	3	4
1	2	3	4
1	2	3	4
1	2	3	4
1	2	3	4
1	2	3	4
1	2	3	4
1	2	3	4
1	2	3	4
	1	1 2	1 2 3

During	gune past rour weeks:				
		Not at All	A Little	Quite a Bit	Very Much
51.	Have you worried that sex would be painful?	1	2	3	4
52.	Have you been sexually active?	1	2	3	4

Answer these questions only if you have been sexually active during the past four weeks:							
		Not at All	A Little	Quite a Bit	Very Much		
53.	Has your vagina felt dry during sexual activity?	1	2	3	4		
54.	Has your vagina felt short?	1	2	3	4		
55.	Has your vagina felt tight?	1	2	3	4		
56.	Have you had pain during sexual intercourse or other sexual activity?	1	2	3	4		
57.	Was sexual activity enjoyable for you?	1	2	3	4		

During the **past four weeks**:

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

During the **past week**:

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

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.

Hospital Anxiety Depression Scale (HADS) copyright © R.P. Snaith and A.S. Zigmond, 1983, 1992, 1994. Record form items originally published in Acta Psychiatrica Scandinavica, 67, 361–70.

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

		5	· ·	to work is i er, please tick	•	d. If you are re	etired or	choose not t	o have			
0	1	2	3	4	5	6	7	8				
Not at all												

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

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?										

	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?												

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.

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Part 3 – Your Thoughts & Feelings About Your Cancer

We understand that it has been over a year since your diagnosis. We would now like to ask you about some of your thoughts and feelings about your cancer diagnosis, its treatment and any effects.

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

	Never	Seldom	Some times	About as often as not	Frequently	Very often	Always
You appreciated life more because of having had cancer.							
You had financial problems because of the cost of cancer surgery or treatment.							
You worried that your family members were at risk of getting cancer.							
You realized that having had cancer helps you cope better with problems now.							
You were self-conscious about the way you look because of your cancer or its treatment.							
You worried about whether your family members might have cancer-causing genes.							
You felt unattractive because of your cancer or its treatment.							
You worried about dying from cancer.							
You had problems with insurance because of cancer.							
You were bothered by hair loss from cancer treatment.							
You worried about cancer coming back							
You felt that cancer helped you to recognize what is important in life.							
You felt better able to deal with stress because of having had cancer.							
You worried about whether your family members should have genetic tests for cancer.							

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

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

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
Notatall									A	great deal
How ofter	n have yo	u worrie	d about th	ie possibi	lity that yo	urcance	er might c	ome bac	k after tro	eatment?
(C		1		2		3		4	4
None of	thetime		Rarely	0	ccasionally	,	Often		Allth	etime

In this section, we would like you to think about "your illness" in relation to your experience of cancer and/or its effects on your health, well-being and day-to-day life.

Please circle the number that best describes your views:

How much does your illness affect your life?

0	1	2	3	4	5	6	7	8	9	10
Noaffec	t at all							Seve	rely affe	cts my life
Howlong	g do you t	hink your	illness wi	ll continu	ie;					
0	1	2	3	4	5	6	7	8	9	10
Averysh	norttime									Forever

How mue	ch contro	l do you f	eel you ha	aveovery	ourillnes	ss?				
0	1	2	3	4	5	6	7	8	9	10
Absolut	ely no cor	ntrol						Extremea	amount o	fcontrol
How mue	ch do you	think you	ir treatm	ent can h	elpyouri	lness?				
0	1	2	3	4	5	6	7	8	9	10
Notata									Extreme	ly helpful
Howmu	ch do you	experien	ce sympt	omsfron	n your illn	ess?				
0	1	2	3	4	5	6	7	8	9	10
No symp	otoms at a	all						Many	severe sy	mptoms
Howcon	cerned ar	re you abo	outyouri	llness?						
0	1	2	3	4	5	6	7	8	9	10
Notata	ll concerr	ned						Extr	emely co	ncerned
How well	l do you fe	eel you un	derstand	your illne	ess?					
0	1	2	3	4	5	6	7	8	9	10
Don't ur	nderstand	l at all						Under	stand ve	ry clearly
How muc depresse	-	ourcance	r affect y	ou emoti	onally? (e	.g. does it	: make yo	ou angry, s	cared, up	oset or
0	1	2	3	4	5	6	7	8	9	10
Notatal	llaffectec	lemotion	ally				Extre	emely affe	ected em	otionally
		order the auses for 1		stimport	tant facto	ors that yo	ou believe	e caused y	our can	cer . The
1										
2										
3										

Part 4 – Your Experiences of Ongoing Care & Your Needs

We would now like to ask you about your experiences of your treatment and ongoing care. We would also like to ask about whether or not any needs which you may have faced as a result of your cancer and/or its treatment have been met.

For each of the questions, please indicate which response on the scale you most agree with.

In the **past 4 weeks**, how easy/difficult has it been to...

	Very easy	Easy	Neither easy nor difficult	Difficult	Very difficult	Not applicable
learn about your health problem(s)?						
learn what foods you should eat to stay healthy?						
find information on the medications that you have to take?						
understand changes to your treatment plan?						
understand the reasons why you are taking some medicines?						
find sources of medical information that you trust?						
understand advice from different healthcare providers?						

In the past 4 weeks , how much of a problem has it been for you to								
	Not at all	A little	Somewhat	Quite a bit	Very much			
make or keep your medical appointments?								
schedule and keep track of your medical appointments?								
make or keep appointments with different healthcare providers?								

In the past 4 weeks , how much of a problem has it been for you to									
	Not at all	A little	Somewhat	Quite a bit	Very much				
monitor your health behaviors, e.g., tracking exercise, foods you eat, or medicines you take?									
monitor your health condition, e.g., weighing yourself, checking blood pressure, or checking blood sugar?									

In the past 4 weeks , how bothered have you been by					
	Notatall	Alittle	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? Disagree Strongly Agree Strongly Not disagree applicable agree 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 \square \square health problem(s) or illness(es) I have problems filling out forms related to my healthcare I have problems getting appointments at times that \Box \square are convenient for me I have problems getting appointments with a \square \square 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...

	Notatall	Alittle	Somewhat	Quite a bit	Very much
work (include work at home)?					
family responsibilities?					
daily activities?					
hobbies and leisure activities?					
ability to spend time with family and friends?					
ability to travel for work or vacation?					

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

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

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

□ Yes

🗌 No

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

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

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

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

In the last month , what was your level of	Nor	need		Some need	
need for help with:	Not applicable	Satisfied	Low need	Moderate need	High need
Pain	1	2	3	4	5
Lack of energy/tiredness	1	2	3	4	5
Feeling unwell a lot of the time	1	2	3	4	5
Work around the home	1	2	3	4	5
Not being able to do the things you used to do	1	2	3	4	5
Anxiety	1	2	3	4	5
Feeling down or depressed	1	2	3	4	5
Feelings of sadness	1	2	3	4	5
Fears about the cancer spreading	1	2	3	4	5
Worry that the results of treatment are beyond your control	1	2	3	4	5
Uncertainty about the future	1	2	3	4	5
Learning to feel in control of your situation	1	2	3	4	5
Keeping a positive outlook	1	2	3	4	5
Feelings about death and dying	1	2	3	4	5
Changes in sexual feelings	1	2	3	4	5
Changes in your sexual relationships	1	2	3	4	5
Concerns about the worries of those close to you	1	2	3	4	5
More choice about which cancer specialists you see	1	2	3	4	5

In the last month , what was your level of	Nor	leed		Someneed	
need for help with:	Not applicable	Satisfied	Low need	Moderate need	High need
More choice about which hospital you attend	1	2	3	4	5
Reassurance by medical staff that the way you feel is normal	1	2	3	4	5
Hospital staff attending promptly to your physical needs	1	2	3	4	5
Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs	1	2	3	4	5
Being given written information about the important aspects of your care	1	2	3	4	5
Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home	1	2	3	4	5
Being given explanations of those tests for which you would like explanations	1	2	3	4	5
Being adequately informed about the benefits and side-effects of treatments before you choose to have them	1	2	3	4	5
Being informed about your test results as soon as feasible	1	2	3	4	5
Being informed about cancer which is under control or diminishing (that is, remission)	1	2	3	4	5
Being informed about things you can do to help yourself to get well	1	2	3	4	5
Having access to professional counselling (e.g., psychologist, social worker, counsellor, nurse specialist) if you, family or friends need it	1	2	3	4	5
Being given information about sexual relationships	1	2	3	4	5
Being treated like a person not just another case	1	2	3	4	5
Being treated in a hospital or clinic that is as physically pleasant as possible	1	2	3	4	5
Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up	1	2	3	4	5

Part 5 – 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			

please continue over

	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
Bonescan		
CT-Scan		
Internal vaginal examination		
Mammogram		
MRI Scan		
Papanicolaou test (Cervical smear test)		
Ultrasound		
X-ray		
Other, please specify:		
· · · · · · · · · · · · · · · · · · ·		

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

2.2 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 (\pounds)

Part 6 – The Support You Have Available To You

In this section, we would like to find out more about the types of support and assistance you have available to you. We would also like to look at how engagement with interests, hobbies etc. can be a source of support to people at home and in their communities.

1. 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

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)

Network Member Number	Network Member (name or initials)	1 = M	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								
	illno	mation (ess and i anagem	llness		Practical help with daily tasks		Emoti	ıpport	
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

3. 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					
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?

Part 7 – About You & Your Lifestyle

In this section, we would like to ask you if anything has changed about you and your lifestyle since the last questionnaires. 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 Ibs				
2. Smoking habits				
Have your smoking habits changed since the last q				
☐ Yes	□ No			
□ Iam unsure	□ I have never smoked/this does not apply to me			
If ' Yes ' or ' I am unsure ', please complete the rest Otherwise please continue to the next page.	of this page.			
Which of the following currently best describes yo	u?			
🗆 Iama smoker				
Iaman ex-smoker				
Date you stopped smoking (month and year):				
M M / 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 m	any cigarattas a day da/did you smaka?			
	any cigarettes a day dojdid you smoke:			
Have you received, or been offered, help to stop sr	noking?			
□ Yes □ No	□ Not applicable			
Please tell us any other details about your smoking	habits and changes since the last questionnaire:			
L				

continue over

please

3. e-Cigarette use / Vaping habits

Has your use of e-Cigarettes changed since the las	t questionnaire?
🗆 Yes	□ No
□ Iam unsure	\Box I have never vaped/this does not apply to me
If ' Yes ' or ' I am unsure ', please complete the rest Otherwise please continue to the next page.	of this 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 met	hod of quitting or reducing your tobacco smoking?
If you currently use or have used e-Cigarettes, what 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	It strength of nicotine do you mainly use?
Approximately, what would you consider to be you 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-Cigare	

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 continue to the next 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,or9
- □ 10 or more

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

5. Exercise & Physical activity

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

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

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

□ Often

Sometimes

□ Never/Rarely

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

🗌 Yes

🗌 No

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

	Times per week:	
STRENGTH EXERCISE (e.g., weight lifting, sit-ups, and push-ups)		hours minutes
What type(s) of strength exercise(s) have you done?		

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

6. Diet

Here is a guide to portions of fruit:				
One portion of fruit is equal	to			
2 or more small pieces of fresh fruit	2 plums, satsumas or kiwi fruit 3 apricots 7 strawberries 14 cherries			
Medium sized fresh fruit	1 apple, banana, pe	ear, orange		
Large sized fresh fruit	half a grapefruit 1 slice of papaya or 2 slices of mango (please note: 1 slice		iick)	
Driedfruit	1 heaped tablespoon of raisins or currants 2 figs 3 prunes			
Canned fruit	Similar quantity of fruit as a fresh portion			
(in natural juice not syrup)	(e.g. 2 pear or peach halves)			
Fruit juice drink or smoothies	150ml of unsweetened fruit juice or smoothie			
(Do not count fruit punch, le	monade or fruit drin	ks such as squash	or concentrated	drinks)
In a typical day, how many	portions of fruit do	you eat? (Please tic	k 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 vege	tables is e	qual to			
Green vegetables		2 broccoli spears or 4 heaped tablespoons of cooked kale, spinach, spring greens or green beans			
Cooked vegetables		eaped tablespoons eetcorn, or 8 caulifle	0	ables, such as car	rots, peas or
Salad vegetables		icks of celery, a 5cm natoes	n piece of cucum	nber, 1 medium to	omato or 7 cherry
Tinned and frozen vegetables	Rou	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 150ml of unsweetened vegetable juice or smoothie smoothies					
(Do not count potate	pes, sweet	potatoes, parsnips,	turnips, swede,	yams, cassava or	plantain)
In a typical day, how	w many po	rtions of vegetab	les do you eat?	(Please tick the answer	that best describes you)
None	1	2	3	4	5 or more

HORIZONS; 12 month Questionnaire; Cervical Version 1.0, 12/06/2017, IRAS Project ID: 202342, REC reference number 16/NW/0425

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**

8. About You

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

HORIZONS; 12 month Questionnaire; Cervical Version 1.0, 12/06/2017, IRAS Project ID: 202342, REC reference number 16/NW/0425

- □ 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 pe	er week do y	/ou currentl	work in	vour job	b/business?	Please exclude b	reaks:
					/)			

hours

days

□ Not applicable

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

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
- □ 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

Part 8 - Your Comments

Are you experiencing any particular problems relating to your cancer and/or its treatment? If yes, please can you describe them here:

If you are experiencing problems, have you found ways to manage them? If yes, please can you describe them here:

Have you received any support in managing problems following your treatment? If yes, please can you describe it here:

Do you think additional support would be helpful? If yes, please can you describe here: Is there anything else that has happened in your life (other than your cancer and its treatment) that you think we should know about which may have affected your health and wellbeing?

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

We offer the option to complete our follow-up questionnaires on paper or online. For the next
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:

DD/MM/	ΥΥΥΥΥ
--------	-------

please continue over

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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