

HORIZONS

Understanding the impact of cancer diagnosis and treatment on everyday life

Second Questionnaire: 3 month follow-up

Study ID	/	/	/ N			
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Thank you for your valuable and continued involvement in this study.

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

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

This questionnaire is divided into 9 parts. It asks for information about your health and symptoms, how well you have been since you were diagnosed with cancer, as well as your experience of treatment and use of health services. It also covers topics such as how you are coping and managing your health, your lifestyle and the support you have available to you. Information and treatment details from your medical records will be gathered separately by a research nurse and included in our analyses.

We understand that the questionnaire is long but we need to ask a range of questions to help us understand the impact of cancer diagnosis and treatment. Some questions may seem repetitive but each aims to measure slightly different things.

How to fill in this questionnaire

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



Part 1 - Your General Health & Well-Being

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

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

MC	DBILITY
] 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
] Iam unable to walk about
SEI	LF-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
US	UAL 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
PA	IN/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
AN	IXIETY/DEPRESSION
	lam not anxious or depressed
Ļ] I am slightly anxious or depressed
Ļ	lam moderately anxious or depressed
L	lam severely anxious or depressed
	I am extremely anxious or depressed

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

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

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

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

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

Part 2 – About Your Symptoms

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

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

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

During the past week:

	Notat	A	Quite	Very
	all	little	abit	much
6. Were you limited in doing either your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4
11. Have you had trouble sleeping?	1	2	3	4
12. Have you felt weak?	1	2	3	4
13. Have you lacked appetite?	1	2	3	4
14. Have you felt nauseated?	1	2	3	4
15. Have you vomited?	1	2	3	4
16. Have you been constipated?	1	2	3	4
17. Have you had diarrhea?	1	2	3	4
18. Were you tired?	1	2	3	4
19. Did pain interfere with your daily activities?	1	2	3	4
20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4

During the past week:

	Notat	Α	Quite	Very
	all	little	abit	much
21. Did you feel tense?	1	2	3	4
22. Did you worry?	1	2	3	4
23. Did you feel irritable?	1	2	3	4
24. Did you feel depressed?	1	2	3	4
25. Have you had difficulty remembering things?	1	2	3	4
26. Has your physical condition or medical treatment interfered with your family life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your social activities?	1	2	3	4
28. Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you

29. How w	ould you rate	e your over	all health d	uring the pa	ast week?) `	
	1	2	3	4	5	6	7
	Very						Excellent
	Poor						
30. How w	ould you rate	e your over	all quality	of life duri	ng the past	week?	
	1	2	3	4	5	6	7
	Very						Excellent
	Door		,				

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:

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

During the past four weeks:

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

During the past four weeks:

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

During the past four weeks:

	Notat	А	Quite	Very
	all	little	a bit	much
65. To what extent were you interested in sex?	1	2	3	4
66. To what extent were you sexually active? (with or without	1	2	3	4
intercourse)				

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

	•	•		
	Notat	А	Quite	Very
	all	little	a bit	much
67. Have you had pain during sexual intercourse or other	1	2	3	4
sexual activity?		4		
68. To what extent was sex enjoyable for you?	1	2	3	4
69. For women only: Has your vagina felt dry during sexual	1	2	3	4
activity?				
70. For women only: Has your vagina felt short and/or	1	2	3	4
tight?				
71. For men only: Did you have difficulty gaining or	1	2	3	4
maintaining an erection?				
72. For men only: Did you have ejaculation problems? (e.g.	1	2	3	4
dry ejaculation)				

During the past week:

	Not at all	A little	Quite a bit	Very much
73. Have you been feeling self-conscious about your appearance?	1	2	3	4
74. Have you felt less physically attractive as a result of your disease or treatment?	1	2	3	4
75. Have you been dissatisfied with your appearance when dressed?	1	2	3	4
76. Have you been feeling less feminine/masculine as a result				
of your disease or treatment?	1	2	3	4
77. Did you find it difficult to look at yourself naked?	1	2	3	4
78. Have you been feeling less sexually attractive as a result of your disease or treatment?	1	2	3	4
79. Did you avoid people because of the way you felt about your appearance?	1	2	3	4
80. Have you been feeling the treatment has left your body less whole?	1	2	3	4
81. Have you felt dissatisfied with your body?	1	2	3	4

Part 3 – How You Are Feeling

This section will help us to understand how you are feeling and whether your ability to do certain day-to-day activities has been affected by your cancer and/or its treatment

Hospital Anxiety and Depression Scale (HADS)

Read each item below and tick the box beside the reply which comes closest to how you have been feeling in the **past week**. Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, thought-out response.

I feel tense or 'wound up':		I feel as if I am slowed down:	
Most of the time		Nearly all the time	
A lot of the time		Veryoften	
From time to time, occasionally		Sometimes	
Notatall		Notatall	
I still enjoy the things I used to enjoy:		I get a sort of frightened feeling like	
		'butterflies' in the stomach:	
Definitely as much		Notatall	
Not quite so much		Occasionally	
Only a little		Quite often	
Hardly at all		Veryoften	
, and the second		·	
I get a sort of frightened feeling as if	1	I have lost interest in my appearance:	
something awful is about to happen:			
Very definitely and quite badly		Definitely	
Yes, but not too badly		I don't take as much care as I should	
A little, but it doesn't worry me		I may not take quite as much care	
Notatall		Itake just as much care as ever	
		·	
I can laugh and see the funny side of		I feel restless as if I have to be on the	
things:		move:	
As much as I always could		Very much indeed	
Not quite so much now		Quite a lot	
Definitely not so much now		Not very much	
Notatall	$\bar{\Box}$	Notatall	

Worrying thoughts go through my mind:		I look forward with enjoyment to things:	
A great deal of the time A lot of the time Not too often Very little		As much as I ever did Rather less than I used to Definitely less than I used to Hardly at all	
I feel cheerful: Never Not often Sometimes Most of the time		I get sudden feelings of panic: Very often indeed Quite often Not very often Not at all	
I can sit at ease and feel relaxed:		I can enjoy a good book or radio or	
Definitely Usually Not often Not at all		television program: Often Sometimes Not often Very seldom	
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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. Work: Because of my cancer, my ability to work is impaired. If you are retired or choose not to have a job for reasons unrelated to your cancer, please tick 'N/A'. Slightly Definitely Markedly Not at Verv all Severely Home Management: Because of my cancer, my home management (cleaning, tidying, shopping, cooking, looking after home or children, paying bills, etc) is impaired 0 Slightly Definitely Markedly all Severely Social Leisure Activities: Because of my cancer, my social leisure activities (With other people, e.g. parties, pubs, outings, entertaining etc.) are impaired Very Not at all Severely Private Leisure Activities: Because of my cancer, my private leisure activities (Done alone, e.g. reading, gardening, sewing, hobbies, walking etc.) are impaired Definitely Markedly Very Not at all 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

O 1 2 3 4 5 6 7 8

Notat Slightly Definitely Markedly Very all Severely

Part 4 - How You Cope

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

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

	Not a Confi									Totally Infident
	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?] [

	Nota	tall								Totally
	Confi									nfident
	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 dea 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?							P			
For each item, please mark an "x" in th statements as they apply to you over the according to how you think you would ha	last m						-	_		
	lot true a	nt.	Rarely	S-0-2	metim	05		Т	cuo non	lyallof
1'	all (o)	at	true (1)	30	true (2)	(Oftentri (3)	ue	the ti	me
I am able to adapt when changes occur										
Itend to bounce back after illness, injury, or other hardships										

Part 5 - Your Experiences of Treatment & Managing Your Health

In this section, we would like to explore your experience of managing your health and the impact your cancer treatment may have had on you.

Please indicate how strongly you disagree or agree with the following statements by checking the response that best describes you \mathbf{now} .

	Strongly	Disagree	Agree	Strongly
	Disagree			Agree
Most days I am doing some of the things I really enjoy				
As well as seeing my doctor, I regularly monitor changes in my health				
Toften worry about my health				
Itry to make the most of my life				
I know what things can trigger my health problems and make them worse				
My health problems make me very dissatisfied with my life				
I am doing interesting things in my life	2			
I have plans to do enjoyable things for myself during the next few				
days				
Thave a very good understanding of when and why Lam				
supposed to take my medication				
I often feel angry when I think about my health				
I feel hopeless because of my health				
I feel like I am actively involved in life				
When I have health problems, I have a clear understanding of				
what I need to do to control them				
I carefully watch my health and do what is necessary to keep as				
healthy as possible				
I get upset when I think about my health				
With my health in mind, I have realistic expectations of what I can				
and cannot do				
If I think about my health, I get depressed				
If I need help, I have plenty of people I can rely on				
I have effective ways to prevent my symptoms (e.g., discomfort,				
pain and stress) from limiting what I can do in my life				
I have very positive relationships with my healthcare				
professionals				
I have a very good idea of how to manage my health problems				

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

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

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

, , , , , , , , , , , , , , , , , , , ,	Very easy	Easy	Neither easy nor difficult	Difficult	Very difficult	Not applicable
learn about your health problem(s)?						
learn what foods you should eat to stay healthy?						
find information on the medications that you have to take?						
understand changes to your treatment plan?						Ø
understand the reasons why you are taking some medicines?						
find sources of medical information that you trust?				P		
understand advice from different healthcare providers?						
In the past 4 weeks , how much of a prob		beenfory	ou to	0		
	Not at all	Alittle	Somewhat	Quite a bit	Verymuch	
make or keep your medical appointments?		0				
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 prob	olem has it	beenfory	ou to			
	Not at all	A little	Somewhat	Quite a bit	Verymuch	
monitor your health behaviors, e.g., tracking exercise, foods you eat, or medicines you take?						_
monitoryour health condition, e.g., weighing yourself, checking blood pressure, or checking blood sugar?						

In the past 4 weeks , how bothered have you been by								
	Not at all	A little	Somewhat	Quite a bit	Verymuch			
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					G.			
In general, how much do you agree/disa	ngree with the Strongly agree	he followi Agree	ng? Disagree	Strongly disagree	Not applicable			
I have problems with different healthcare providers not communicating with each other about my medical care			CP/					
I have to see too many different specialists for my health problem(s) or illness(es)								
I have problems filling out forms related to my healthcare								
I have problems getting appointments at times that are convenient for me								
I have problems getting appointments with a specialist								
I have to wait too long at my medical appointments								
I have to wait too long at the pharmacy for my medicine								

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

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

	Not at all	A little	Somewhat	Quite a bit	Verymuch
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 mast a weaks how often did your	aalf man		• maka yayıfad		
In the past 4 weeks , how often did your	Never	Rarely	Sometimes	Often	Always
anany		- Tarely	301110111103		7 tivvay3
angry?					
preoccupied?					
depressed?					
worn out?					
frustrated?					
Have you used complementary and/or alt mindfulness, homeopathy, acupuncture, medicines, etc.) Yes No If 'Yes', what complementary and/or alter	osteopath	ny, herbal r	medicines, chir	opractic, Tr	raditional Chinese

Part 6 - Your Use of Health Services

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

1. Health service use

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

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

1.1 Hospital visits and appointments

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

Have you used this service in the

	last 3 months? (please tick if 'yes'	''	of days
Hospital inpatient stay			
(at least 24 hours)			
Can you please describe the reasons for yo	ur overnight hospital stay	?	
)	
			1
	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			
Cancerdoctor			
Cancernurse			
Cancer information and support service			
Day centre Day centre			
Dietician			
Hospital doctor			
Hospital nurse			
Occupational therapist			
Outpatient clinic	Ц		
Pharmacist			
Physiotherapist	Ц		
Psychiatrist or psychologist			
Radiographer			
Speech and language therapist			

Other specialist nurse, pleas	se specify:			
Other, please specify:				
-				
Please specify any tests or sc	ans performed in the hos	spital (e.g. X-ray, C	T-scan but not blo	ood tests).
		Havey	ou had this test	Approximate
		in the	last 3 months?	number
		(ple	ase tick if 'yes')	Hamber
Bone scan				
CT-Scan				
Internal vaginal examination	า			
Mammogram				
MRIScan				
Papanicolaou test (Cervica	Ismeartest)			
Ultrasound				
X-ray				
Other, please specify:				
1.2 Other health a	and social care servic	es		
This refers to all health and so	ocial care that is not base	ed in the hospital i	n the last 3 mon	ths.
	Have you used this			Approximate
	service in the last 3	Approximate	Approximate	number of
	months?	number of	number of	contacts by
	(please tick if 'yes')	clinic visits	home visits	telephone
				and/oremail
Counsellor				
Dietician				
District nurse, health				
visitor or members of				
community team				1

GP

Mental health or emotional support services (e.g. mental

health nurse)

Other specialist doctor, please specify:

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 ${f last 3 months}$.

	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 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		
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

2.2 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 \mathfrak{t}	you spent on health-care related parking?
Approximately, how much have \pounds	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 (£)
Description	cost (£)

Part 7 – The Support You Have Available To You

We would now like to find out more about the types of support and assistance you have available to you. We would also like to look at how social relationships can be used by people to help support themselves at home and in their communities.

1. The Types of Support Available to You

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

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Emotional / informational Support:					
Someone you can count on to listen to you when you need to talk					
Someone to give you information to help you understand a situation					
Someone to give you good advice about a crisis					
Someone to confide in or talk to about yourself or your problems					
Someone whose advice you really want					
Someone to share your most private worries and fears with					
Someone to turn to for suggestions about how to deal with a personal problem					
Someone who understands your problems					
Tangible Support:					
Someone to help you if you were confined to bed					
Someone to take you to the doctor if you needed it					
Someone to prepare your meals if you were unable to do it yourself					
Someone to help with daily chores if you were sick					

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Affectionate Support:					
Someone who shows you love and affection					
Someone to love and make you feel wanted					
Someone who hugs you					
Positive Social Interaction:					
Someone to have a good time with					
Someone to get together with for relaxation					
Someone to do something enjoyable with					
Additional Item:					
Someone to do things with to help you get your mind off things					
How many close friends do you have?					
How many close family members do you have?					

2. Your Social Network

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

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

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

- their relationship to you (e.g. daughter, friend, GP)
- how often you see them in person (e.g. weekly, monthly, every couple of months)
- approximately how far do they live from you (approx. in miles)

Please use as many or as few of the lines provided.

Network	Network Member	Gender	Relationship	How often do you see them?	How far do they
Member	(name or initials)	1=male	(son, daughter,	1= at least once a week,	live from you?
Number		2=female	pet,friend,group, nurse,etc.)	2 = at least once a month, 3 = at least every couple of months,	(approx. in miles)
			nurse, etc.)	4=less often	
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	
21.		1 2		1 2 3 4	
22.		1 2		1 2 3 4	
23.		1 2		1 2 3 4	
24.		1 2		1 2 3 4	
25.		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	Rate the extent to which this member helps you with: 1 = No help at all, 2 = Some help, 3 = A lot of help				
numbered in the previous table)	A. Information about your illness and illness management	B. Practical help with daily tasks	C. 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		
21.	1 2 3	1 2 3	1 2 3		
22.	1 2 3	1 2 3	1 2 3		
23.	1 2 3	1 2 3	1 2 3		
24.	1 2 3	1 2 3	1 2 3		
25.	1 2 3	1 2 3	1 2 3		

Part 8 – Your Lifestyle

1. Body stats

We would now like to ask you some questions about your lifestyle and whether there have been any changes since the last questionnaire. We are collecting this information to try to build up a picture of who needs support in their cancer recovery and what this support might be.

What is your weight?
st lbs
or kg
2. Smoking habits
Have your smoking habits changed since the last questionnaire?
☐ Yes ☐ No
☐ I am unsure ☐ I have never smoked/this does not apply to me
If 'Yes' or 'I am unsure', please complete the rest of this page.
Otherwise please continue to the next page.
Which of the following currently best describes you?
□ lam a smoker
laman ex-smoker
- Date you stopped smoking (month and year):/
If you currently smoke or are an ex-smoker, how long have/did you smoke(d) for?
If you currently smoke or are an ex-smoker, how many cigarettes a day do/did you smoke?
If you currently smoke of all earrex-smoker, now mainy digarettes a day do/did you smoke:
Have you received, or been offered, help to stop smoking?
Yes No Not Applicable
Please tell us any other details about your smoking habits and changes since the last questionnaire:
riedse tell us any other details about your smoking habits and changes since the last question halfe.

3. e-Cigarette use / Vaping habits Has your use of e-Cigarettes changed since the last questionnaire? Yes No ☐ I am unsure I have never vaped/this does not apply to me If 'Yes' or 'I am unsure', please complete the rest of this page Otherwise please continue to the next page. Which of the following currently best describes you? Currently use an e-Cigarette/vape Thave **previously used** an e-Cigarette/vaped Are you using/have you used e-Cigarettes as a method of quitting or reducing your tobacco smoking? Yes No If you currently use or have used e-Cigarettes, what strength of nicotine do you mainly use? \square No nicotine (o mg/ml) □1to3mg/ml 4to8mg/ml ☐ 9 to 12 mg/ml ☐ 13 to 16 mg/ml ☐ 17 to 20mg/ml ☐ More than 20mg/ml Idon't know Approximately, what would you consider to be your **daily** e-Liquid use? Upto2ml More than 2 ml, up to 4 ml More than 4 ml, up to 6 ml

Please tell us any other details about your e-Cigarette use and changes since the last questionnaire:

HORIZONS; 3 month Questionnaire; NHL Version 2.0, 27/02/2017, IRAS Project ID: 202342, REC reference number 16/NW/0425

More than 6 ml, up to 8 mlMore than 8 ml, up to 10 ml

☐ More than 10 ml☐ I don't know

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
Otherwise please complete the rest of the page.
Here is a guide to units of alcohol: Number of Units 1.5 A small glass (125 ml) of red, white or rosé wine (ABV 12%) 2.1 A standard glass (175 ml) of red, white or rosé wine (ABV 12%) 3 A large glass (250 ml) of red, white or rosé wine (ABV 12%) 2 A pint of lower-strength (ABV 3.6%) lager, beer or cider 3 A pint of higher-strength (ABV 5.2%) lager, beer or cider 1.7 A bottle (330 ml) of lager, beer or cider (ABV 5%) 2 A can (440 ml) of lager, beer or cider (ABV 4.5%) 1.5 275 ml bottle of alcopop (ABV 5.5%) 1 25 ml single spirit and mixer (ABV 40%)
How many units of alcohol do you drink on a typical day when drinking? 1 or 2 3 or 4 5 or 6 7,8, or 9 10 or more Please tell us any other details about your alcohol intake and changes since the last questionnaire:

4. Alcohol consumption

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,		hoursminutes
judo, roller skating, vigorous swimming, vigorous long		
distance cycling)		
MODERATE EXERCISE (NOT EXHAUSTING)		
(e.g., fast walking, tennis, easy cycling, volleyball, badminton,		hoursminutes
easy swimming, dancing)		
MILD EXERCISE (MINIMAL EFFORT)		
(e.g., yoga, archery, fishing, bowling, golf, easy walking)		hoursminutes
During a typical 7-Day period (a week), in your leisure time, enough to work up a sweat (heart beats rapidly)? Often Sometimes Never/Rarely Have you done any strength exercise(s) (such as weight liftin Yes No	g, sit-ups, and push-ups)	in the last month ?
If 'Yes' , in a typical week, how many times and for how long h		xercise(s)?
	Times per week:	
STRENGTH EXERCISE (e.g., weight lifting, sit-ups, and push-ups)		hoursminutes
	I.	
What type(s) of strength exercise(s) have you done?		
25		
Please tell us any other details about your exercise/physical a	activity habits and chang	es 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	2 plums, satsumas or kiwi fruit, 3 apricots, 7 strawberries, 14 cherries
freshfruit	
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)
Driedfruit	1 heaped tablespoon of raisins or currants, 2 figs, 3 prunes
Canned fruit (in natural	Similar quantity of fruit as a fresh portion (e.g. 2 pear or peach halves)
juice not syrup)	
Fruit juice drink or	150ml of unsweetened fruit juice or smoothie
smoothies	
/S - ()	

(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 sweet corn, or 8 cauliflower florets			
Salad vegetables	3 sticks of celery, a 5 cm piece of cucumber, 1 medium tomato or 7			
	cherry tomatoes			
Tinned and frozen	Roughly the same quantity as you would eat for a fresh portion			
vegetables				
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 potatoes, sweet potatoes, parsnips, turnips, swede, yams, cassava or plantain)

In a typical day, how many portions of vegetables do you eat?

(Please tick the answer that best describes you)

None	1	2	3	4	5 or more

Please state if you currently follow any special/specific diet(s), for example: low fat, high fibre, vegetarian, vegan, constant and constan
lactose free, gluten free, diabetic, etc.:
Please tell us any other details about your diet and changes since the last questionnaire:
7. Receiving advice or information
Have you received any advice or information on any of the following issues? (Please tick all that apply).
Alcohol consumption
Quitting smoking
Diet
Physical activity/exercise
Weight
Financial help and benefits
Free prescriptions
Returning to or staying in work
☐ Information/advice for family/friends/carers ☐ The physical aspects of living with and after cancer (e.g. side effects or signs of recurrence)
The psychological or emotional aspects of living with and after cancer
How to access support groups
☐ I have all the information and advice I need
☐ I have not been offered any of the above

Part 9 – Your Comments

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

Is there anything else we have not asked about that you think we ought to know?	
We offer the option to complete our follow-up questionnaires on paper or online.	
For the next follow-up questionnaire, which of these methods would you prefer?	
Paper	
Online	
Today's Date	
<u> </u>	l
Please fill in the date you completed this D D M M M V Y Y Y Y	
questionnaire:	ļ

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.

