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Questionnaire Pack – 12 month

Thank you for continuing to take part in this study.

This questionnaire pack contains several sets of questions that we would like you to complete.

You will be familiar with all the questions, but please take time to read the instructions for each set of questions, but do not waste too much time thinking about your responses, as there are no right or wrong answers.

If you have any questions whilst completing the questionnaire, do not hesitate to contact the study team (details below).

In the unlikely event that you may find some of the questions intrusive or upsetting, please contact the study team and we will respond to your concerns.

Thank you once again for taking the time to answer these questions.

We assure you that your responses will be kept confidential.

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headandneck 5000

About You

A1. Date (day/month/year) ☐☐/☐☐/☐☐ 1

A2. What is your date of birth? (day/month/year) ☐☐/☐☐/☐☐ 1

A4. What is your current weight? ☐☐☐ 1 **Kg** **OR** ☐☐ 2 **Stone** ☐☐☐ 3 **lbs**

A5. Are you currently?

Single	☐ 1	**Widowed**	☐ 2	**Separated**	☐ 3
Married	☐ 4	**Divorced**	☐ 5	**Living with a partner**	☐ 6

A8. Are you a current user of tobacco ☐ 1 **Or, have you recently quit using tobacco or never used tobacco?** ☐ 2

If you have you recently quit using tobacco or never used tobacco please skip to question A13

A11. About how much do you use tobacco on average each day?

☐☐ 1 **a) Numbers of cigarettes per day?**

☐☐ 1 **b) Numbers of hand rolled cigarettes per day?**

☐☐ 1 **c) Numbers of pipes or cigars per day?**

☐☐ 1 **d) Number of smokeless tobacco per day?**

A12. What brand of cigarettes/tobacco do you normally smoke?

_____ 1

A13. In a typical week how many days do you drink alcohol? Please enter number of days in the box ☐ 1

If none, tick the box and go to question A17 ☐ 2

A15. About how many bottles of wine, spirits and pints of beers do you drink on average each week?

	a) Bottles of wine	b) Bottles of Spirits	c) Pints of beer/lager/cider	
None	☐ 1	☐ 1	**None**	☐ 1
Less than 1	☐ 2	☐ 2	**Less than 7**	☐ 2
1	☐ 3	☐ 3	**7-14**	☐ 3
2-3	☐ 4	☐ 4	**15-21**	☐ 4
4-6	☐ 5	☐ 5	**22-28**	☐ 5
7-10	☐ 6	☐ 6	**28-35**	☐ 6
11 or more	☐ 7	☐ 7	**36 or more**	☐ 7

A16. What brand of alcohol do you normally drink?

_____ 1

A17. Are you currently working? Yes ☐ 1 No ☐ 2

A18. If you are currently working, how many hours per week do you work? ☐☐ 1

A21. What is your total household income from all sources before tax & other deductions?

Weekly income before tax		Annual income before tax	
Less than £77	☐ 1	Less than £3999	☐ 9
£77 - £154	☐ 2	£4000 - £7999	☐ 10
£155 - £230	☐ 3	£8000 - £11999	☐ 11
£231 - £346	☐ 4	£12000 - £17999	☐ 12
£347 - £442	☐ 5	£18000 - £22999	☐ 13
£443 - £558	☐ 6	£23000 - £28999	☐ 14
£559 - £673	☐ 7	£29000 - £34999	☐ 15
£674 or more	☐ 8	£35000 or more	☐ 16

A22. What proportion of your household income (including your own) would you say comes from benefits?

None ☐ 1 About a quarter ☐ 2 About three quarters ☐ 3

Very little ☐ 4 About half ☐ 5 All ☐ 6

A23. At present do you have any concerns about any of the following aspects of living with or after cancer?

No	☐ 1	Financial concerns	☐ 2	Staying in work/college	☐ 3
Cost of attending appointments	☐ 4	Taking time off work/college	☐ 5	Returning to work/college	☐ 6

A24. Please tick the box that describes best what you can do:

a) Able to carry out all normal activities without restriction	☐ 1
b) Restricted in physically strenuous activity but able to walk and do light work	☐ 1
c) Able to walk and carry out all self care but unable to carry out any work, up and about more than 50% of waking hours	☐ 1
d) Capable of only limited self care, confined to bed or chair more than 50% of waking hours	☐ 1
e) Completely disabled cannot carry out self care, totally confined to bed or chair	☐ 1

A25. Under each heading, please tick the ONE box that best describes your health today

a) Mobility

- **I have no problems in walking about** ☐ 1
- **I have slight problems in walking about** ☐ 2
- **I have moderate problems in walking about** ☐ 3
- **I have severe problems in walking about** ☐ 4
- **I am unable to walk about** ☐ 5

b) Self care

- **I have no problems washing or dressing myself** ☐ 1
- **I have slight problems washing or dressing myself** ☐ 2
- **I have moderate problems washing or dressing myself** ☐ 3
- **I have severe problems washing or dressing myself** ☐ 4
- **I am unable to wash or dress myself** ☐ 5

c) Usual activities (e.g. work, study, house work, family or leisure activities)

- **I have no problems doing my usual activities** ☐ 1
- **I have slight problems doing my usual activities** ☐ 2
- **I have moderate problems doing my usual activities** ☐ 3
- **I have severe problems doing my usual activities** ☐ 4
- **I am unable to do my usual activities** ☐ 5

d) Pain discomfort

- **I have no pain or discomfort** ☐ 1
- **I have slight pain or discomfort** ☐ 2
- **I have moderate pain or discomfort** ☐ 3
- **I have severe pain or discomfort** ☐ 4
- **I have extreme pain or discomfort** ☐ 5

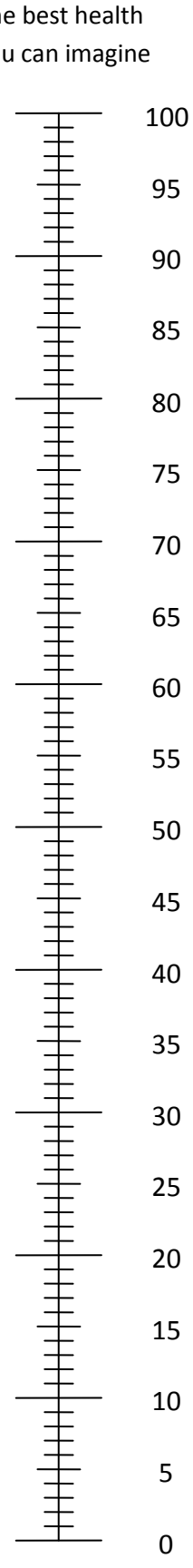
e) Anxiety/depression

- **I am not anxious or depressed** ☐ 1
- **I am slightly anxious or depressed** ☐ 2
- **I am moderately anxious or depressed** ☐ 3
- **I am severely anxious or depressed** ☐ 4
- **I am extremely anxious or depressed** ☐ 5

A26.

- **We would like to know how good or bad your health is TODAY**
- **This scale is numbered from 0 – 100**
- **100 means the best health you can imagine**
- **0 means the worst health you can imagine**
- **Mark an X on the scale to indicate how your health is TODAY**
- **Now, please write the number you marked on the scale in the box below**

YOUR HEALTH TODAY = ☐



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Your Outlook

Instructions:
Please answer the following questions about yourself by indicating the extent of your agreement using the following scale.
Be as honest as you can throughout, and try not to let your responses to one statement influence your response to other statements. There are no right or wrong answers. Answer according to your own feelings rather than how you think 'most people' would answer.

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
B1. In uncertain times, I usually expect the best.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
B2. It's easy for me to relax.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
B3. If something can go wrong for me, it will.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
B4. I'm always optimistic about my future.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
B5. I enjoy my friends a lot.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
B6. It's important for me to keep busy.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
B7. I hardly ever expect things to go my way.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
B8. I don't get upset too easily.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
B9. I rarely count on good things happening to me.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
B10. Overall, I expect more good things to happen to me than bad.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Your General Health

We are interested in some things about you and your health. Please answer all of the questions yourself by ticking the box that best applies to you. There are no "right" or "wrong" answers.

		Not at all	A little	Quite a bit	Very much
C1	Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	☐ 1	☐ 2	☐ 3	☐ 4
C2	Do you have any trouble taking a long walk?	☐ 1	☐ 2	☐ 3	☐ 4

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		Not at all	A little	Quite a bit	Very much
C3	Do you have any trouble taking a short walk outside of the house?	☐ 1	☐ 2	☐ 3	☐ 4
C4	Do you need to stay in bed or a chair during the day?	☐ 1	☐ 2	☐ 3	☐ 4
C5	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
C6	Were you limited in doing either your work or other daily activities?	☐ 1	☐ 2	☐ 3	☐ 4
C7	Were you limited in pursuing your hobbies or other leisure time activities?	☐ 1	☐ 2	☐ 3	☐ 4
C8	Were you short of breath?	☐ 1	☐ 2	☐ 3	☐ 4
C9	Have you had pain?	☐ 1	☐ 2	☐ 3	☐ 4
C10	Did you need to rest?	☐ 1	☐ 2	☐ 3	☐ 4
C11	Have you had trouble sleeping?	☐ 1	☐ 2	☐ 3	☐ 4
C12	Have you felt weak?	☐ 1	☐ 2	☐ 3	☐ 4
C13	Have you lacked appetite?	☐ 1	☐ 2	☐ 3	☐ 4
C14	Have you felt nauseated?	☐ 1	☐ 2	☐ 3	☐ 4
C15	Have you vomited?	☐ 1	☐ 2	☐ 3	☐ 4
C16	Have you been constipated?	☐ 1	☐ 2	☐ 3	☐ 4
C17	Have you had diarrhoea?	☐ 1	☐ 2	☐ 3	☐ 4
C18	Were you tired?	☐ 1	☐ 2	☐ 3	☐ 4

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	During the past week:	Not at all	A little	Quite a bit	Very much
C19	Did pain interfere with your daily activities?	☐ 1	☐ 2	☐ 3	☐ 4
C20	Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	☐ 1	☐ 2	☐ 3	☐ 4
C21	Did you feel tense?	☐ 1	☐ 2	☐ 3	☐ 4
C22	Did you worry?	☐ 1	☐ 2	☐ 3	☐ 4
C23	Did you feel irritable?	☐ 1	☐ 2	☐ 3	☐ 4
C24	Did you feel depressed?	☐ 1	☐ 2	☐ 3	☐ 4
C25	Have you had difficulty remembering things?	☐ 1	☐ 2	☐ 3	☐ 4
C26	Has your physical condition or medical treatment interfered with your family life?	☐ 1	☐ 2	☐ 3	☐ 4
C27	Has your physical condition or medical treatment interfered with your social activities?	☐ 1	☐ 2	☐ 3	☐ 4
C28	Has your physical condition or medical treatment caused you financial difficulties?	☐ 1	☐ 2	☐ 3	☐ 4

For the following questions please tick the box between 1 and 7 that best applies to you

C29 How would you rate your overall health during the past week?

Very poor ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 Excellent

C30 How would you rate your overall quality of life during the past week?

Very poor ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 Excellent

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Specific Aspects of Your Health

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week. Please answer all of the questions yourself by ticking the box that best applies to you. There are no "right" or "wrong" answers.

	During the past week:	**Not at all**	**A little**	**Quite a bit**	**Very much**
D1	Have you had pain in your mouth?	☐ 1	☐ 2	☐ 3	☐ 4
D2	Have you had pain in your jaw?	☐ 1	☐ 2	☐ 3	☐ 4
D3	Have you had soreness in your mouth?	☐ 1	☐ 2	☐ 3	☐ 4
D4	Have you had a painful throat?	☐ 1	☐ 2	☐ 3	☐ 4
D5	Have you had problems swallowing liquids?	☐ 1	☐ 2	☐ 3	☐ 4
D6	Have you had problems swallowing pureed food?	☐ 1	☐ 2	☐ 3	☐ 4
D7	Have you had problems swallowing solid food?	☐ 1	☐ 2	☐ 3	☐ 4
D8	Have you choked when swallowing?	☐ 1	☐ 2	☐ 3	☐ 4
D9	Have you had problems with your teeth?	☐ 1	☐ 2	☐ 3	☐ 4
D10	Have you had problems opening your mouth wide?	☐ 1	☐ 2	☐ 3	☐ 4
D11	Have you had a dry mouth?	☐ 1	☐ 2	☐ 3	☐ 4
D12	Have you had sticky saliva?	☐ 1	☐ 2	☐ 3	☐ 4
D13	Have you had problems with your sense of smell?	☐ 1	☐ 2	☐ 3	☐ 4
D14	Have you had problems with your sense of taste?	☐ 1	☐ 2	☐ 3	☐ 4

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During the past week:		Not at all	A little	Quite a bit	Very much
D15	Have you coughed?	☐ 1	☐ 2	☐ 3	☐ 4
D16	Have you been hoarse?	☐ 1	☐ 2	☐ 3	☐ 4
D17	Have you felt ill?	☐ 1	☐ 2	☐ 3	☐ 4
D18	Has your appearance bothered you?	☐ 1	☐ 2	☐ 3	☐ 4
D19	Have you had trouble eating?	☐ 1	☐ 2	☐ 3	☐ 4
D20	Have you had trouble eating in front of your family?	☐ 1	☐ 2	☐ 3	☐ 4
D21	Have you had trouble eating in front of other people?	☐ 1	☐ 2	☐ 3	☐ 4
D22	Have you had trouble enjoying your meals?	☐ 1	☐ 2	☐ 3	☐ 4
D23	Have you had trouble talking to other people?	☐ 1	☐ 2	☐ 3	☐ 4
D24	Have you had trouble talking on the telephone?	☐ 1	☐ 2	☐ 3	☐ 4
D25	Have you had trouble having social contact with your family?	☐ 1	☐ 2	☐ 3	☐ 4
D26	Have you had trouble having social contact with friends?	☐ 1	☐ 2	☐ 3	☐ 4
D27	Have you had trouble going out in public?	☐ 1	☐ 2	☐ 3	☐ 4
D28	Have you had trouble having physical contact with family or friends?	☐ 1	☐ 2	☐ 3	☐ 4
D29	Have you felt less interest in sex?	☐ 1	☐ 2	☐ 3	☐ 4
D30	Have you felt less sexual enjoyment?	☐ 1	☐ 2	☐ 3	☐ 4

During the past week:		Yes	No
D31	Have you used pain-killers?	☐ 1	☐ 2
D32	Have you taken any nutritional supplements (excluding vitamins)?	☐ 1	☐ 2
D33	Have you used a feeding tube?	☐ 1	☐ 2
D34	Have you lost weight?	☐ 1	☐ 2
D35	Have you gained weight?	☐ 1	☐ 2

Your Feelings

Please choose one response from the four given for each question. Please give your immediate response and don't think too long about your answer.

E1 I feel tense or 'wound up':

☐ 1 Most of the time
☐ 2 A lot of the time
☐ 3 From time to time, occasionally
☐ 4 Not at all

E2 I still enjoy the things I used to enjoy:

☐ 1 Definitely as much
☐ 2 Not quite so much
☐ 3 Only a little
☐ 4 Hardly at all

E3 I get a sort of frightened feeling as if something awful is about to happen:

☐ 1 Very definitely and quite badly
☐ 2 Yes, but not too badly
☐ 3 A little, but it doesn't worry me
☐ 4 Not at all

E4 I can laugh and see the funny side of things:

☐ 1 As much as I always could
☐ 2 Not quite so much now
☐ 3 Definitely not so much now
☐ 4 Not at all

E5 Worrying thoughts go through my mind:

- ☐ 1 A great deal of the time
- ☐ 2 A lot of the time
- ☐ 3 From time to time, but not too often
- ☐ 4 Only occasionally

E6 I feel cheerful:

- ☐ 1 Not at all
- ☐ 2 Not often
- ☐ 3 Sometimes
- ☐ 4 Most of the time

E7 I can sit at ease and feel relaxed:

- ☐ 1 Definitely
- ☐ 2 Usually
- ☐ 3 Not often
- ☐ 4 Not at all

E8 I feel as if I am slowed down:

- ☐ 1 Nearly all the time
- ☐ 2 Very often
- ☐ 3 Sometimes
- ☐ 4 Not at all

E9 I get a sort of frightened feeling like 'butterflies' in the stomach:

- ☐ 1 Not at all
- ☐ 2 Occasionally
- ☐ 3 Quite often
- ☐ 4 Very often

E10 I have lost interest in my appearance:

- ☐ 1 Definitely
- ☐ 2 I don't take as much care as I should
- ☐ 3 I may not take quite as much care
- ☐ 4 I take just as much care as ever

E11 I feel restless as I have to be on the move:

- ☐ 1 Very much indeed
- ☐ 2 Quite a lot
- ☐ 3 Not very much
- ☐ 4 Not at all

E12 I look forward with enjoyment to things:

- ☐ 1 As much as I ever did
- ☐ 2 Rather less than I used to
- ☐ 3 Definitely less than I used to
- ☐ 4 Hardly at all

E13 I get sudden feelings of panic:

- ☐ 1 Very often indeed
- ☐ 2 Quite often
- ☐ 3 Not very often
- ☐ 4 Not at all

E14 I can enjoy a good book or radio or TV program:

- ☐ 1 Often
- ☐ 2 Sometimes
- ☐ 3 Not often
- ☐ 4 Very seldom

Your Diet

We would now like to ask you a few questions about your diet over the past year.

F1 In summary, how many servings of fruit do you usually eat, not counting juices?

- ☐ 1 None
- ☐ 2 Less than one per month
- ☐ 3 1 – 3 per month
- ☐ 4 1 per week
- ☐ 5 2 – 4 per week
- ☐ 6 5 – 6 per week
- ☐ 7 1 per day
- ☐ 8 2 – 3 per day
- ☐ 9 4 – 5 per day
- ☐ 10 6 or more per day

F2 In summary, how many servings of vegetables do you usually eat, not counting salad or potatoes?

- ☐ 1 None
- ☐ 2 Less than one per month
- ☐ 3 1 – 3 per month
- ☐ 4 1 per week
- ☐ 5 2 – 4 per week
- ☐ 6 5 – 6 per week
- ☐ 7 1 per day
- ☐ 8 2 – 3 per day
- ☐ 9 4 – 5 per day
- ☐ 10 6 or more per day

F3 In summary, how often do you eat deep fried food (e.g. French fries, fried chicken, fried fish, fried clams, fried shrimp etc.)?

- ☐ 1 Never
- ☐ 2 Less than once per week
- ☐ 3 Once per week
- ☐ 4 2 – 4 times per week
- ☐ 5 5 – 6 times per week
- ☐ 6 Daily

You and Cancer

G1. I am afraid that my cancer may recur.

☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Not at all	A little	Sometimes	A lot	All the time

G2. I am worried about the possibility of cancer recurrence.

☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Not at all	A little	Sometimes	A lot	All the time

G3. How often have you worried about the possibility of getting cancer again?

☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
None of the time	Rarely	Occasionally	Often	All the time

G4. I get waves of strong feelings about the cancer coming back.

☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Not at all	A little	Sometimes	A lot	All the time

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Your personal costs

*We'd like to ask you about any **expenses** you or your immediate family members have incurred as a result of you being diagnosed with head and neck cancer.*

Please think of the time since you were diagnosed with cancer, and answer each of the following questions in relation to yourself and/or any member of your immediate family.	Yes* ☐1	No* ☐2	NA* ☐3	If yes, please indicate
	*Please tick as appropriate NA – not applicable			
H1. Paid for any kind of **medication**? (e.g. conventional, alternative)				Type(s) of medication _____a Approximate amount £_____b
H2. Paid for any kind of **treatment,** i.e. private health care? (e.g. conventional, alternative)				Type(s) of treatment _____a Approximate amount £_____b
H3. Paid for **home help**?				Approximate amount £_____a
H4. Incurred any **travel expenses** for your hospital/clinic appointments? (.e.g. train fares, bus fares, petrol, parking costs, overnight accommodation)				Approximate amount £_____a
H5. Incurred any **other out-of-pocket expenses**? (e.g. special dietary items, pain relief)				Type(s) of expenditure _____a Approximate amount £_____b
H6. Have you taken **time off work** because of your illness?	For you ☐1	☐2	☐3	Number of weeks or months (delete as appropriate) _____a
H7. Has a member of your immediate family taken **time off work** because of your illness?	For your family ☐1	☐2	☐3	Number of weeks or months (delete as appropriate) _____a

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H8. Have you suffered any **reduction of income** as a result of taking time off work because of your illness?

For you

☐1 ☐2 ☐3

Approximate amount of gross income that has been lost in total

£_____a

H9. Has any member of your immediate family suffered any **reduction of income** as a result of he/she taking time off work because of your illness?

For your family

☐1 ☐2 ☐3

Approximate amount of gross income that has been lost in total

£_____b

H10. Have you **given up work completely** because of your illness?

For you

☐1 ☐2 ☐3

Approximate amount of gross income that has been lost in total

£_____a

H11. Has any member of your immediate family **given up work completely** because of your illness?

For your family

☐1 ☐2 ☐3

Approximate amount of gross income that has been lost in total

£_____a

H12 Have you run into difficulties with paying the **mortgage or rent** for the property where you live?

☐1 ☐2 ☐3

Number of months having this difficulty

£_____a

Approximate amount of mortgage or rent per month

£_____a

Thank you for completing the questionnaire