headandneck 5000

# Follow-up Questionnaire

**Thank you for continuing to take part in this study.**

**You may remember some of the questions. Nevertheless, please take time to read the instructions for each set of questions. You do not have to spend too much time thinking about your responses as there are no right or wrong answers.**

**If you have any questions whilst completing the questionnaire, please contact the study team (details below).**

**We assure you that your responses will be kept strictly confidential.**

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

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**A1. Today's Date (day/month/year)** [ ][ ] / [ ][ ] / [ ][ ]

## About You

**A4. What is your current weight?** [ ][ ]1 Kg **OR** [ ][ ]2 Stone [ ][ ][ ]2 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

**a former user of tobacco** [ ]2

**or never used tobacco on a regular basis (1 tobacco product a day for a period of 1 year)?** [ ]3

*If you have never used tobacco, please go to question A12a.*

**A8a. Did you use tobacco during the time that you received treatment for your head and neck cancer?**

Yes [ ]1 No [ ]2 For some of the time [ ]3

**A8b. If you are a former user of tobacco, when did you stop using tobacco?**

a) Within the last month [ ]1 b) Within the last year [ ]2 c) Over a year ago [ ]3

**A8c. If you are a current user of tobacco, did you try to quit following your diagnosis with head and neck cancer?**

Yes [ ]1 No [ ]2 *If not, please tick "No" and go to question A11.*

**A8d. If you tried to quit, how long did you stop using tobacco for:**

Years [ ][ ]1 Months [ ][ ]2 Weeks [ ][ ]3

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

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

**b) Numbers of hand rolled cigarettes per day?** ☐☐ 2

**c) Numbers of pipes or cigars per day?** ☐☐ 3

**d) Number of smokeless tobacco per day?** ☐☐ 4

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

____________________________________________________________

**A12a. How many times (if at all) have you used marijuana or hashish (cannabis) in your life?** *If you have never used it, please tick "never" and go to question A13.*

| Never | Fewer than 10 times | Between 10 – 50 times | More than 50 times |
|---|---|---|---|
| ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 |

**A12b. How long ago did you last use marijuana or hashish (cannabis)?**

Days ☐☐ 1 Months ☐☐ 2 Years ☐☐ 3

**A12c. If you are a current user of marijuana or hashish (cannabis), do you use it for:**

Pain relief ☐ 1 Recreational reasons ☐ 2 OR Both ☐ 3

**A13. In a typical week how many days do you drink alcohol?** Please enter number of days in the box or tick "none" and go to question 17

☐☐ 1 Days OR None ☐ 1

**A15. About how many bottles of wine, spirits and pints of beer 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 |

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**A16. What brand of alcohol do you normally drink?**

________________________________________________________________ 1

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

*If you are not working, please tick "No" and continue to question A18 a.*

**A17a. If you are currently working, what is your occupation?** ______________________________

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

*Please answer and go to question A21.*

**A18a. Why do you no longer work?**

Because I am retired ☐ 1

Because of my head and neck cancer ☐ 2

Because of a health condition not related to my head and neck cancer ☐ 3

I am unemployed but available to work ☐ 4

Other ☐ 5 Please state ______________________________

**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 |

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

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

Very little ☐ 4 About a half ☐ 5 All ☐ 6

**A22a. If you have applied for welfare benefits did you have any support to do this?**

Yes ☐ 1 No ☐ 2

**A23. At present do you have any concerns about any of the following aspects of living with or after cancer? Please tick all that apply.**

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 ☐ 2

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 ☐ 3

d) Capable of only limited self care, confined to bed or chair more than 50% of waking hours ☐ 4

e) Completely disabled cannot carry out self care, totally confined to bed or chair ☐ 5

**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

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

**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 |

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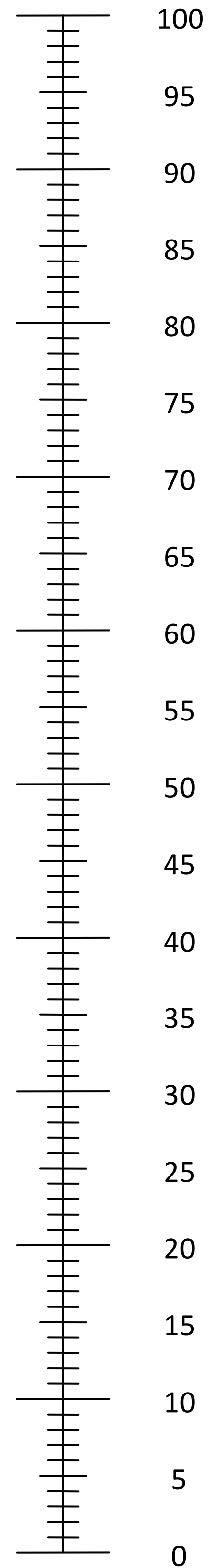
The best health you can imagine




The worst health you can imagine

**A26.**

- **We would like to know how good or bad your health is TODAY**
- **This scale is numbered from 0 – 100**
- **100 means the <u>best</u> health you can imagine**
  **0 means the <u>worst</u> 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

*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 responses 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 circle the number 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 |

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| 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 Medical History.

| Have you ever been diagnosed by a medical professional as having: | | | | |
|---|---|---|---|---|
| D36. | Heart Attack (myocardial infarction)? | ☐ 1 No | ☐ 2 Don't know | ☐ 3 Yes at ___ years old |
| D37. | Heart failure? | ☐ 1 No | ☐ 2 Don't know | ☐ 3 Yes at ___ years old |
| D38. | Peripheral vascular disease (blocked arteries in your legs/poor circulation causing purple feet or hands)? | ☐ 1 No | ☐ 2 Don't know | ☐ 3 Yes at ___ years old |
| D39. | Chronic obstructive lung disease (COPD), or chronic bronchitis? | ☐ 1 No | ☐ 2 Don't know | ☐ 3 Yes at ___ years old |
| D40. | Emphysema? | ☐ 1 No | ☐ 2 Don't know | ☐ 3 Yes at ___ years old |
| D41. | Stomach ulcers proven by a test? | ☐ 1 No | ☐ 2 Don't know | ☐ 3 Yes at ___ years old |
| D42. | Liver disease? Please specify: ____________________ | ☐ 1 No | ☐ 2 Don't know | ☐ 3 Yes at ___ years old |
| D43. | Hepatitis ? (A, B or C or other? Please specify______________________ ) | ☐ 1 No | ☐ 2 Don't know | ☐ 3 Yes at ___ years old |
| D44. | A stroke/mini-stroke? | ☐ 1 No | ☐ 2 Don't know | ☐ 3 Yes at ___ years old |
| D45. | Do you have hemiplegia (weakness/paralysis of arms/legs)? | ☐ 1 No | ☐ 2 Don't know | ☐ 3 Yes at ___ years old |
| D46. | Dementia (e.g. Alzheimer's)? | ☐ 1 No | ☐ 2 Don't know | ☐ 3 Yes at ___ years old |
| D47. | Rheumatoid arthritis (this is NOT osteoarthritis)? | ☐ 1 No | ☐ 2 Don't know | ☐ 3 Yes at ___ years old |
| D48. | Lupus (SLE), Scleroderma, Sjögren's, or connective tissue disease? | ☐ 1 No | ☐ 2 Don't know | ☐ 3 Yes at ___ years old |

| | | | | |
|---|---|---|---|---|
| **D49.** | **Other joint/bone problems?**<br>**If yes, please specify type:**<br>________________________________<br>________________________________ | ☐ [1] No | ☐ [2] Don't know | ☐ [3] Yes at ___ years old |
| **D50.** | **Serious kidney problems?**<br>**Please specify:**<br>________________________________<br>________________________________ | ☐ [1] No | ☐ [2] Don't know | ☐ [3] Yes at ___ years old |
| **D51.** | **Have you ever required dialysis?** | ☐ [1] No | ☐ [2] Don't know | ☐ [3] Yes at ___ years old |
| **D52.** | **Do you suffer from diabetes?** | ☐ [1] No | ☐ [2] Don't know | ☐ [3] Yes at ___ years old |
| | **If yes, have you ever had:** | | | |
| | **a) Eye problems due to your diabetes?** | ☐ [1] No | ☐ [2] Don't know | ☐ [3] Yes at ___ years old |
| | **b) Kidney problems due to your diabetes?** | ☐ [1] No | ☐ [2] Don't know | ☐ [3] Yes at ___ years old |
| **D53.** | **HIV/AIDS? (this will remain strictly confidential)** | ☐ [1] No | ☐ [2] Don't know | ☐ [3] Yes at ___ years old |

**D54.** **Past Cancer History:** Please fill in the table below if you have ever been **diagnosed with any type of cancer before the current diagnosis** (include leukaemia, lymphoma, and skin cancers like melanoma, basal cell or squamous cell skin cancer):

**Or tick None ☐ and go to question D55.**

| Type of Cancer (e.g. breast, lung, etc.) | Date of diagnosis | How were you treated? (surgery, chemo, radiation, etc) | Duration of treatment (months) |
|---|---|---|---|
| | | | |
| | | | |
| | | | |
| | | | |

**Have you ever had chemotherapy?** ☐ No ☐ Yes please specify when: ________________________________

________________________________________________________________

**D55. If you are a woman, have you ever been told by a doctor that you have cervical cancer?** (cancer of the womb)

Yes ☐1 No ☐2

**D56. If you are a man, has your current partner or a former partner ever been told by a doctor that they have cervical cancer?** (cancer of the womb)

Yes ☐1 No ☐2 Not sure ☐3

**D57. Have you ever had surgery to remove your tonsils** (a tonsillectomy)**?**

Yes ☐1 No ☐2 Not sure ☐3

*If you ticked "No" or "Not sure", please go to question D59.*

**D58. Were your tonsils removed before you developed head and neck cancer?**

Yes ☐1 No ☐1

*The following questions are about whether or not your head and neck cancer has come back and if you have received any treatment for this.*

**D59. Since you received your original head and neck cancer diagnosis, have you been told by your doctor that your head and neck tumour has come back?**

Yes ☐1 No ☐2 Not sure ☐3 OR My head and neck cancer never went away ☐4

*If you ticked "yes" please go to the next question, otherwise please go to question E1*

**D60. If your head and neck tumour has come back, when was this?**

Month ☐☐1 Year ☐☐☐☐2

**D61a. What type of treatment (if any) have you received for this?** Please tick all that apply.

None ☐1 Radiotherapy ☐2 Chemotherapy ☐3 Surgery ☐4 Other ☐5

**b. If you selected "Other", please specify what treatment you received:**

________________________________________

**D62. If you received treatment, has this finished?** Yes ☐1 No ☐2 Not sure ☐3

## 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 if 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

## Eating & 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 a 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

*We would like to ask you a few questions about your eating habits, now, and immediately after your treatment for head and neck cancer*

**F4. Do you feel that your eating habits have returned to how they were before your head and neck cancer?** By *eating habits* we mean the types and quantities of foods that you eat.

Yes ☐ 1 No ☐ 2

**F5. If you feel that your eating habits have returned to how they were before your diagnosis, about how long did this take?**

Years ☐☐ 2 Months ☐☐ 2

**F6. Since receiving treatment for head and neck cancer have you had any problems eating the following foods?** Please tick all that apply.

| Spicy foods | Black Pepper | Sweet foods | Sour foods | Salty foods | Hot foods | Cold foods |
|---|---|---|---|---|---|---|
| ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 | ☐ 5 | ☐ 6 | ☐ 7 |

**F7a. Have you experienced any changes to the smell of food?** Yes ☐ 1 No ☐ 2

**b. If so, what kind of changes did you experience?**

- Complete loss of smell ☐ 1
- Reduced sensitivity to smells ☐ 2
- Inability to discriminate between different smells ☐ 3
- Awareness of smells that weren't there ☐ 4
- A heightened sense of smell ☐ 5
- Other ☐ 1 Please describe: ______________________________

Study number: [ ][ ] / [ ][ ][ ][ ] Initials: [ ][ ]

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**F8. If you have experienced changes to your sense of smell, has this now returned to normal?**

Yes ☐ 1 No ☐ 2 Not sure ☐ 3

**F9. Have you experimented with new cooking approaches or food preparation techniques since your treatment for head and neck cancer?**

Yes ☐ 1 No ☐ 2

**F10. Are you throwing more food away since receiving your treatment?**

Yes ☐ 1 No ☐ 2

**F11. Do you take antacids regularly?**

Yes ☐ 1 No ☐ 2 *If you do not take regular antacids please go to question* *F15*

**F12. Are these antacids prescribed by your doctor?** Yes ☐ 1 No ☐ 2

**F13. Please give the name of the antacids that you take**

_______________________________________________________________________________

**F14. How often do you take antacids?**

Every day ☐ 1 4-6 days a week ☐ 2

1-3 days a week ☐ 3 Less than 4 days in a month ☐ 4

*The next set of questions are about feeding tubes. You may have had a feeding tube fitted in hospital. We would like to know whether you used a feeding tube* ***after you were discharged****. Therefore, when answering the following questions, please think about* ***the time after you left hospital following your initial treatment.***

**F15. After your initial treatment, did you have a feeding tube in place?**

Yes ☐ 1 No ☐ 2 *If you did not have a feeding tube please go to question G1*

**F16. If you did have a feeding tube in place, how long was it for?**

Weeks ☐☐ 1 OR Months ☐☐ 2 OR I still have my feeding tube ☐ 3

**F17. How long did you use your feeding tube for?**

Weeks ☐☐ 1 OR Months ☐☐ 2

**F18a. During the time that you used your feeding tube, did you also eat by mouth?**

Yes ☐ 1 No ☐ 2

**b. How often did you eat by mouth?**

Hardly ever ☐ 1 Sometimes ☐ 2 Quite often ☐ 1 Daily ☐ 1

**F19. What were your reasons for continuing to eat by mouth in addition to using your feeding tube? (please tick all that apply)**

For the taste ☐ 1

For the texture ☐ 2

For the nourishment ☐ 3

To feel more normal ☐ 4

Other ☐ 5 Please explain your reasons in the space below:

______________________________________________________________________________

______________________________________________________________________________

**F20. Did you avoid eating by mouth in front of others?**

Always ☐ 1 Most of the time ☐ 1 Sometimes ☐ 2 Never ☐ 3

## Thoughts around cancer recurrence

*The next set of questions touch on what it is like for you living after a cancer diagnosis. We would like to know how often, if at all, you think about your cancer returning.*

**G1. I am afraid that my cancer may recur.**

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

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

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

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

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

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

☐ 1 Not at all ☐ 2 A little ☐ 3 Sometimes ☐ 4 A lot ☐ 5 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 **in the last year** as a result of you being diagnosed with head and neck cancer.*

| Please think of **the last year** and answer each of the following questions in relation to yourself and/or any member of your immediate family. | *Please tick as appropriate NA = not applicable | | | If yes, please indicate |
|---|---|---|---|---|
| | Yes* | No* | NA* | |
| **H1.** Paid for any kind of **medication**? (e.g. conventional, alternative) | ☐ 1 | ☐ 2 | ☐ 3 | Type(s) of medication ____________ a<br>Approximate amount<br>£____________ b |
| **H2.** Paid for any kind of **treatment,** i.e. private health care? (e.g. conventional, alternative) | ☐ 1 | ☐ 2 | ☐ 3 | Type(s) of treatment ____________ a<br>Approximate amount<br>£____________ b |
| **H3.** Paid for **home help**? | ☐ 1 | ☐ 2 | ☐ 3 | Approximate amount<br>£____________ a |
| **H4.** Incurred any **travel expenses** for your hospital/clinic appointments? (e.g. train fares, bus fares, petrol, parking costs, overnight accommodation) | ☐ 1 | ☐ 2 | ☐ 3 | Approximate amount<br>£____________ a |
| **H5.** Incurred any **other out-of-pocket expenses**? (e.g. special dietary items, pain relief) | ☐ 1 | ☐ 2 | ☐ 3 | Type(s) of expenditure ____________ a<br>Approximate amount<br>£____________ b |

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| | *Please tick as appropriate. NA = not applicable | | | |
|---|---|---|---|---|
| | Yes* | No* | NA* | |
| **H6.** Have you taken **time off work** because of your illness? | For you | | | Number of weeks or months *(delete as appropriate)* |
| | ☐1 | ☐2 | ☐3 | ____________________a |
| **H7.** Has a member of your immediate family taken **time off work** because of your illness? | For your family | | | Number of weeks or months *(delete as appropriate)* |
| | ☐1 | ☐2 | ☐3 | ____________________a |
| **H8.** Have you suffered any **reduction of income** as a result of taking time off work because of your illness? | For you | | | Approximate amount of gross income that has been lost in total |
| | ☐1 | ☐2 | ☐3 | £____________________a |
| **H9.** Has any member of your immediate family suffered any **reduction of income** as a result of him/her taking time off work because of your illness? | For your family | | | Approximate amount of gross income that has been lost in total |
| | ☐1 | ☐2 | ☐3 | £____________________b |
| **H10.** Have you **given up work completely** because of your illness? | For you | | | Approximate amount of gross income that has been lost in total |
| | ☐1 | ☐2 | ☐3 | £____________________a |
| **H11.** Has any member of your immediate family **given up work completely** because of your illness? | For your family | | | Approximate amount of gross income that has been lost in total |
| | ☐1 | ☐2 | ☐3 | £____________________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 £____________________b |

Study number: | | | / | | | | | Initials: | | |

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## Your Dental Health

*The following questions ask about your teeth and your dental care*

**T1. Adults can have up to 32 natural teeth but over time people lose some of them. How many natural teeth, including crowns have you got?** ***(Please tick one box)***

- I have no natural teeth ☐ 1
- I have fewer than 10 natural teeth ☐ 2
- I have between 10 & 19 natural teeth ☐ 3
- I have 20 or more natural teeth ☐ 4

**T2. If you have some or all of your natural teeth, we would like you to answer the following questions (2a – 2d). If you do not have any natural teeth, please go to question T3.**

| | | |
|---|---|---|
| a) Are you happy with the appearance of your teeth at present? | Yes ☐ 1 | No ☐ 2 |
| b) Do you have any toothache or pain in your mouth? | Yes ☐ 1 | No ☐ 2 |
| c) Do you have any problems or difficulties biting or chewing food? | Yes ☐ 1 | No ☐ 2 |
| d) Do your gums bleed when you eat or brush your teeth | Yes ☐ 1 | No ☐ 2 |

**T3. About how long ago was your last visit to the "high street" dentist?** ***(Please tick one box)***

- Less than 1 year ago ☐ 1
- More than 1 year, up to 2 years ago ☐ 2
- More than 2 years, up to 5 years ago ☐ 3
- More than 5 years ago ☐ 4
- Never been to the dentist ☐ 5

**T4. Visiting the dentist – Do any of the following apply to you?** ***(Please tick all the boxes that apply)***

It is difficult to get time off work to go ☐ 1

It is difficult getting an appointment that suits me ☐ 2

I find dental treatment too expensive ☐ 3

It is a long way to go to the dentist ☐ 4

I have not found a dentist I like ☐ 5

I cannot get dental treatment under the NHS ☐ 6

I have difficulty in getting access, e.g. steps, wheelchair access ☐ 7

I don't think my dentist knows enough about managing the effects of my cancer and its treatment on my mouth and teeth ☐ 8

My dentist sends me back to the hospital because I have had cancer treatment ☐ 9

Other reason (please explain) ☐ 10

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

*The final section of the questionnaire is* ***only for people who have received Radiotherapy****. If this does not apply to you then you do not need to answer any further questions and we thank you for completing the questionnaire.*

***If you did receive radiotherapy****, please answer the following set of questions which relate to symptoms experienced following your treatment.*

**Your Symptoms**

Please answer the questions as to how you have been feeling over the last **2 WEEKS**

**The next few questions are about pain in your HEAD and NECK only:**

**L1. How severe is the pain?**

None ☐ 1

Mild ☐ 2

Moderate ☐ 3

Severe ☐ 4

**L2. Where is the pain? *(tick all that apply)***

Mouth ☐ 1
Throat ☐ 2
Jaw ☐ 3
Neck ☐ 4
Skin ☐ 5
Ear ☐ 6
Other ☐ 7 Please state: ____________________________________________

**L3. Are you taking any medication for this pain?**

No ☐ 1
Yes, occasionally ☐ 2
Yes, regularly ☐ 3

**L4. If Yes, please give name of medication and how often (please use an additional sheet if required)**

| Medication | How often |
|---|---|
| ___________________________ | ___________________________________________________________ |
| ___________________________ | ___________________________________________________________ |
| ___________________________ | ___________________________________________________________ |
| ___________________________ | ___________________________________________________________ |

**L5. Does the pain or painkillers interfere with daily self care activities** (Eg. bathing, getting about indoors, dressing, getting in / out of bed)

No ☐ 1
Yes ☐ 2

**The next few questions are about your mouth or eating:**

**L6. Have you lost your appetite'?**

No ☐ 1
Yes ☐ 2

**L7. Have you had difficulties in swallowing?**

No ☐ 1
Yes ☐ 2

**L8. Have you any difficulty opening your mouth?**

No ☐ 1
Yes ☐ 2

**L9. Do you have any alteration in your taste?**

No ☐1
Yes ☐2

**L10. If Yes, have you had any loss of taste and / or do you find taste unpleasant?**

No ☐1
Yes ☐2

**L11. Have you had a dry mouth?**

No ☐1
Yes ☐2

**L12. Have you had any changes to your saliva?**

None ☐1
Yes, it's slightly thickened ☐2
Yes, it's ropey, thick and sticky ☐3

**L13. If Yes, has it affected your taste?**

No ☐1
Yes, slightly ☐2
Yes, markedly ☐3

**L14. If you have saliva changes, how has it affected your daily self care activities?** (Eg bathing, getting about Indoors dressing, getting in / out of bed)

Not at all ☐1
Interferes with self care activities ☐2
Unable to self care ☐3

**L15. Has your diet been significantly affected?**

Normal regular diet ☐1
Yes, but can manage solid food ☐2
Yes, mostly soft or liquidised food ☐3
Cannot eat / swallow adequately or need fluid drip / tube feeding ☐4

**L16. If your diet has been significantly affected, what has caused it? *(tick all that apply)***

- Difficulty in swallowing ☐ 1
- Dry mouth ☐ 2
- Difficulty opening mouth ☐ 3
- Loss of appetite ☐ 4
- Altered taste ☐ 5
- Change in saliva ☐ 6
- Other ☐ 7 Please state: ______________________________

**L17. If you are on supplementary nutritional drinks, why are you requiring them? *(tick all that apply)***

- Not on supplementary drinks ☐ 1
- Difficulty in swallowing ☐ 2
- Weight loss ☐ 3
- Loss of appetite ☐ 4
- Altered taste ☐ 5
- Other ☐ 6 Please state: ______________________________

**The next few questions are about your skin <u>in the area treated with radiotherapy</u>:**

**L18. Have you any visible roughness or flaking of your skin**

- No ☐ 1
- Yes ☐ 2

**L19. If Yes, how obvious is it?**

- Only close-up ☐ 1
- Easily apparent ☐ 2

**L20. If Yes, does this affect your appearance?**

- No ☐ 1
- Yes ☐ 2
- Would like surgery if feasible ☐ 3

**L21. Have you any thickening or hardening of your skin (skin fibrosis)?**

- No ☐ 1
- Yes ☐ 2

**L22. If Yes, how severe is the skin thickening / hardening?**

- Mild ☐ 1
- Marked ☐ 2
- Interferes with self care activities ☐ 3

**L23. Have you any skin itchiness?**

- No ☐ 1
- Mild and localised ☐ 2
- Intense or widespread ☐ 3
- Interferes with self care activities ☐ 4

**L24. Do you have any puffiness in your head and neck?**

- No ☐ 1
- Yes ☐ 2

**L25. If Yes, has it interfered with any function (e.g. turning your head or opening mouth) compared with before radiotherapy?**

- No ☐ 1
- Yes ☐ 2

**The next few questions are about your voice:**

**L26. Are you getting any hoarseness / voice changes?**

- None ☐ 1
- Yes, intermittently ☐ 2
- Yes, persistently ☐ 3
- Voice box has been removed (laryngectomy) ☐ 4

**L27. If you have hoarseness / voice change, how severe is it?**

- Mild ☐ 1
- Moderate ☐ 2
- Severe and predominantly whispered speech ☐ 3
- Complete loss of voice ☐ 4

**L28. Can your voice be understood?**

- Fully understandable ☐ 1
- Needs occasional repetition but understandable on phone ☐ 2
- Needs frequent repetition or face to face contact to understand ☐ 3
- Non-understandable, requires voice aid machine or writing (>50% of time for communication) ☐ 4

**The next few questions are about your hearing:**

**L29.** Have you had any hearing loss?

No ☐ 1
Yes ☐ 2

**L30. If Yes, how severe has this been?**

Minor ☐ 1
Frequent difficulty with faint speech ☐ 2
Frequent difficulty with loud speech ☐ 3
Complete deafness ☐ 4

**L31. Do you require a hearing aid?**

No ☐ 1
Yes ☐ 2

**L32. Are you getting any noise or ringing in your ears?**

No ☐ 1
Yes, rarely ☐ 2
Yes, sometimes ☐ 3
Yes, often ☐ 4

**L33. If Yes, how has it affected your daily self care activities?** (Eg. bathing, getting about indoors, dressing, getting in / out of bed)

Not at all ☐ 1
Interferes with self care activities ☐ 2
Cannot self care ☐ 3

# Thank you very much for completing the questionnaire