Study number:

		T				

headandneck
5000

Questionnaire Pack – 12 month Bristol

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.

Professor Andy Ness
The Head & Neck 5000 Study Team
Room T106b Chapter House
Bristol Dental School
Lower Maudlin Street
Bristol BS1 2LY
Telephone: 0117 342 2519
Email: headandneck5000@uhbristol.nhs.uk

Study number: | | | T | | | | |

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

Study number: | | | T | | | | |

headandneck 5000

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

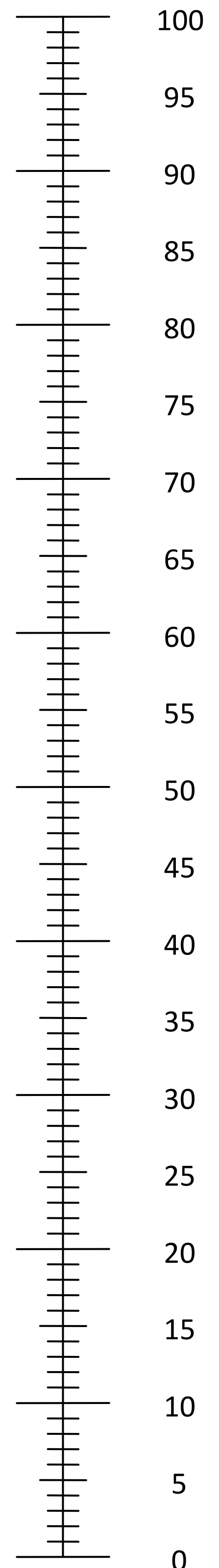
Study number: | | | T | | | | |

headandneck 5000

The best 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 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 = [ ]

The worst health you can imagine

UK (English) v.2 © 2009 EuroQol Group. EQ-5D™ is a trade mark of the EuroQol Group

Study number: | | | T | | | | |

headandneck 5000

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

Study number: | | | T | | | | |

headandneck 5000

		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

Study number: | | | T | | | | |

headandneck 5000

	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

Study number: | | | T | | | | |

headandneck 5000

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

Study number: | | | T | | | | |

headandneck 5000

During the past week:		Not at all	A little	Quite a	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

Study number: | | | T | | | | |

headandneck 5000

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

Study number: | | | T | | | | |

headandneck 5000

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

Study number: | | | T | | | | |

headandneck 5000

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

Study number: | | | T | | | | |

headandneck 5000

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*	No*	NA*	If yes, please indicate
	*Please tick as appropriate NA – not applicable			
H1. Paid for any kind of **medication**? (e.g. conventional, alternative)	☐ 1	☐ 2	☐ 3	Type(s) of medication ____________ a Approximate amount £____________ 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 Approximate amount £____________ b
H3. Paid for **home help**?	☐ 1	☐ 2	☐ 3	Approximate amount £____________ 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 £____________ a
H5. Incurred any **other out-of-pocket expenses**? (e.g. special dietary items, pain relief)	☐ 1	☐ 2	☐ 3	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

Study number: | | | T | | | | |

headandneck 5000

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* No* NA* *Please tick as appropriate NA – not applicable	If yes, please indicate
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

Your Quality of Life

This questionnaire asks about your views about your health and quality of life ***during the past seven days****. Please answer the following questions and statements as indicated.*

I1. Pain (Tick one box: ☑)

☐1 I have no pain.
☐2 There is mild pain not needing medication.
☐3 I have moderate pain - requires regular medication (e.g. paracetamol).
☐4 I have severe pain controlled only by prescription medicine (e.g. morphine).
☐5 I have severe pain, not controlled by medication.

Study number: [ ][ ][T][ ][ ][ ][ ]

headandneck 5000

I2. Appearance (Tick one box: ☑)

- [ ] 1 There is no change in my appearance.
- [ ] 2 The change in my appearance is minor.
- [ ] 3 My appearance bothers me but I remain active.
- [ ] 4 I feel significantly disfigured and limit my activities due to my appearance.
- [ ] 5 I cannot be with people due to my appearance.

I3. Activity (Tick one box: ☑)

- [ ] 1 I am as active as I have ever been.
- [ ] 2 There are times when I can’t keep up my old pace, but not often.
- [ ] 3 I am often tired and have slowed down my activities, although I still get out.
- [ ] 4 I don’t go out, because I don’t have the strength.
- [ ] 5 I am usually in bed or chair and don’t leave home.

I4. Recreation (Tick one box: ☑)

- [ ] 1 There are no limitations to recreation at home or away from home.
- [ ] 2 There are a few things I can’t do, but I still get out and enjoy life.
- [ ] 3 There are many times when I wish I could get out more, but I’m not up to it.
- [ ] 4 There are severe limitations to what I can do, mostly I stay at home and watch TV.
- [ ] 5 I can’t do anything enjoyable.

I5. Swallowing (Tick one box: ☑)

- [ ] 1 I can swallow as well as ever.
- [ ] 2 I cannot swallow certain solid foods.
- [ ] 3 I can only swallow liquid food.
- [ ] 4 I cannot swallow because it "goes down the wrong way" and chokes me.

I6. Chewing (Tick one box: ☑)

- [ ] 1 I can chew as well as ever.
- [ ] 2 I can eat soft solids but cannot chew some foods.
- [ ] 3 I cannot even chew soft solids.

I7 .Speech (Tick one box: ☑)

- [ ] 1 My speech is the same as always.
- [ ] 2 I have difficulty with saying some words, but I can be understood over the phone.
- [ ] 3 Only my family and friends can understand me.
- [ ] 4 I cannot be understood.

I8. Shoulder (Tick one box: ☑)

- [ ] 1 I have no problem with my shoulder.
- [ ] 2 My shoulder is stiff but it has not affected my activity or strength.
- [ ] 3 Pain or weakness in my shoulder has caused me to change my work / hobbies.
- [ ] 4 I cannot work or do my hobbies due to problems with my shoulder.

Study number: | | | T | | | | |

headandneck 5000

I9. Taste (Tick one box: ☑)

- ☐ 1 I can taste food normally.
- ☐ 2 I can taste most foods normally.
- ☐ 3 I can taste some foods.
- ☐ 4 I cannot taste any foods.

I10. Saliva (Tick one box: ☑)

- ☐ 1 My saliva is of normal consistency.
- ☐ 2 I have less saliva than normal, but it is enough.
- ☐ 3 I have too little saliva.
- ☐ 4 I have no saliva.

I11. Mood (Tick one box: ☑)

- ☐ 1 My mood is excellent and unaffected by my cancer.
- ☐ 2 My mood is generally good and only occasionally affected by my cancer.
- ☐ 3 I am neither in a good mood nor depressed about my cancer.
- ☐ 4 I am somewhat depressed about my cancer.
- ☐ 5 I am extremely depressed about my cancer.

I12. Anxiety (Tick one box: ☑)

- ☐ 1 I am not anxious about my cancer.
- ☐ 2 I am a little anxious about my cancer.
- ☐ 3 I am anxious about my cancer.
- ☐ 4 I am very anxious about my cancer.

I13. Which issues have been the most important to you during the past 7 days?

Tick ☑ up to 3 boxes.

☐ 1 Pain	☐ 5 Swallowing	☐ 9 Taste
☐ 2 Appearance	☐ 6 Chewing	☐ 10 Saliva
☐ 3 Activity	☐ 7 Speech	☐ 11 Mood
☐ 4 Recreation	☐ 8 Shoulder	☐ 12 Anxiety

GENERAL QUESTIONS

I14. Compared to the month before you developed cancer, how would you rate your health-related quality of life? (Tick one box: ☑)

- ☐ 1 Much better
- ☐ 2 Somewhat better
- ☐ 3 About the same
- ☐ 4 Somewhat worse
- ☐ 5 Much worse

Study number: | | | T | | | | |

headandneck 5000

I15. In general, would you say your *health-related quality of life* <u>during the past 7 days</u> has been: (Tick one box: ☑)

☐1 Outstanding
☐2 Very good
☐3 Good
☐4 Fair
☐5 Poor
☐6 Very poor

I16. Overall quality of life includes not only physical and mental health, but also many other factors, such as family, friends, spirituality, or personal leisure activities that are important to your enjoyment of life. Considering everything in your life that contributes to your personal well-being, rate your *overall quality of life* <u>during the past 7 days</u>. (Tick one box: ☑)

☐1 Outstanding
☐2 Very good
☐3 Good
☐4 Fair
☐5 Poor
☐6 Very poor

I17. Please indicate on the following lines any items (medical or nonmedical) that are important to your quality of life and have not been adequately addressed in the above questions and statements.

____

____

____

____

Difficulties in Your Life

Please read each question carefully and tick the response that best describes your answer.

- Please answer each question as honestly as possible.

- If you are not completely sure which response is the most accurate tick the box that you feel is the most appropriate.

- Please tick the 'no difficulty box' if a question does not apply to you.

- Do not spend long on each statement.

During the past month:		**No difficulty**	**A little**	**Quite a bit**	**Very much**
J1	Have you had any difficulty maintaining your independence?	☐1	☐2	☐3	☐4
J2	Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)	☐1	☐2	☐3	☐4

Study number: | | | T | | | | |

headandneck 5000

During the past month:		No difficulty	A little	Quite a bit	Very much
J3	Have you had any difficulty with managing your own personal care? (e.g. bathing, dressing, washing)	☐1	☐2	☐3	☐4
J4	Have you had any difficulty with looking after those who depend on you? (e.g. children, dependent adults, pets)	☐1	☐2	☐3	☐4
J5	Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?	☐1	☐2	☐3	☐4
J6	Have you had any difficulties with benefits? (e.g. statutory sick pay, attendance allowance, disability living allowance)	☐1	☐2	☐3	☐4
J7	Have you had any financial difficulties?	☐1	☐2	☐3	☐4
J8	Have you had any difficulties with financial services? (e.g. loans, mortgages, pensions, insurance)	☐1	☐2	☐3	☐4
J9	Have you had any difficulty concerning your work? (or education if you are a student)	☐1	☐2	☐3	☐4
J10	Have you had any difficulty with planning for your own or your family's future? (e.g. care of dependents, legal issues, business affairs)	☐1	☐2	☐3	☐4
J11	Have you had any difficulty communicating with those closest to you? (e.g. partner, children, parents)	☐1	☐2	☐3	☐4
J12	Have you had difficulty communicating with others? (e.g. friends, neighbours, colleagues, dates)	☐1	☐2	☐3	☐4
J13	Have you had any difficulty concerning sexual matters?	☐1	☐2	☐3	☐4
J14	Have you had any difficulty concerning plans to have a family?	☐1	☐2	☐3	☐4
J15	Have you had any difficulty concerning your appearance or body image?	☐1	☐2	☐3	☐4
J16	Have you felt isolated?	☐1	☐2	☐3	☐4
J17	Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)	☐1	☐2	☐3	☐4
J18	Have you had any difficulty with where you live? (e.g. space, access, damp, heating, neighbours, security)	☐1	☐2	☐3	☐4

Study number: | | | T | | | | |

headandneck 5000

During the past month:

		No difficulty	A little	Quite a bit	Very much
J19	Have you had any difficulty in carrying out your recreational activities? (e.g. hobbies, pastimes, social pursuits)	☐ 1	☐ 2	☐ 3	☐ 4
J20	Have you had any difficulty with your plans to travel or take a holiday?	☐ 1	☐ 2	☐ 3	☐ 4
J21	Have you had any difficulty with any other area of your everyday life?	☐ 1	☐ 2	☐ 3	☐ 4

Your Appearance

K1A Is there any aspect of the appearance of your head/neck (however small) that concerns you at all? **Yes** ☐ 1 **No** ☐ 2

If No, please go to section K1B
If Yes, please continue:

K2A The aspect of my head/neck about which I am most sensitive or self-conscious is

____

K3A The thing I don't like about the appearance of my head/neck is

____

K4A If you are sensitive or concerned about any other features of your body or your appearance, please say what they are

____

____

Instructions: The following questions are concerned with the way you feel or act. They are all simple. Please tick the answer that applies to you. If the item does not apply to you at all, tick the N/A (not applicable option). Don't spend long on any one question.

K1B How confident do you feel?

- Not at all ☐ 1
- Slightly ☐ 2
- Moderately ☐ 3
- Extremely ☐ 4

K2B How distressed do you get when you see yourself in the mirror/window?

- Extremely ☐ 1
- Moderately ☐ 2
- A little ☐ 3
- Not at all distressed ☐ 4

Study number: | | | T | | | | |

headandneck 5000

K3B My self-consciousness makes me irritable at home:

- N/A ☐ 1
- Never/almost never ☐ 2
- Sometimes ☐ 3
- Often ☐ 4
- Almost always ☐ 5

K4B How hurt do you feel?

- Extremely ☐ 1
- Moderately ☐ 2
- Slightly ☐ 3
- Not at all ☐ 4

K5B At present my self-consciousness has an adverse effect on my work:

- Almost always ☐ 1
- Often ☐ 2
- Sometimes ☐ 3
- Never/almost never ☐ 4
- N/A ☐ 5

K6B How distressed do you get when you go to the beach?

- N/A ☐ 1
- Not at all ☐ 2
- A little ☐ 3
- Moderately ☐ 4
- Extremely ☐ 5

K7B Other people mis-judge me because of the appearance of my head/neck:

- Almost always ☐ 1
- Often ☐ 2
- Sometimes ☐ 3
- Never/almost never ☐ 4
- N/A ☐ 5

K8B How feminine/masculine do you feel?

- Not at all ☐ 1
- Slightly ☐ 2
- Moderately ☐ 3
- Extremely ☐ 4

K19B How distressed do you get when going to social events?

- N/A ☐ 1
- Not at all ☐ 2
- Moderately ☐ 3
- A fair amount ☐ 4
- Extremely ☐ 5

K20B How normal do you feel?

- Not at all ☐ 1
- Slightly ☐ 2
- Moderately ☐ 3
- Extremely ☐ 4

K21B At present my self-consciousness has an adverse effect on my sex life:

- Almost always ☐ 1
- Often ☐ 2
- Sometimes ☐ 3
- Never/almost never ☐ 4
- N/A ☐ 5

K22B I avoid going out of the house:

- Almost always ☐ 1
- Often ☐ 2
- Sometimes ☐ 3
- Never/almost never ☐ 4

K23B How distressed do you get when other people make remarks about the appearance of your head/neck?

- N/A ☐ 1
- Not at all ☐ 2
- Moderately ☐ 3
- A fair amount ☐ 4
- Extremely ☐ 5

K24B I avoid going to pubs/restaurants:

- Almost always ☐ 1
- Often ☐ 2
- Sometimes ☐ 3
- Never/almost never ☐ 4
- N/A ☐ 5

Study number: | | | T | | | | |

headandneck 5000

K1C **My feature causes me physical pain/discomfort:**

- Never/almost never ☐ 1
- Sometimes ☐ 2
- Often ☐ 3
- Almost always ☐ 4

K2C **My feature limits my physical ability to do the things I want to do:**

- Almost always ☐ 1
- Often ☐ 2
- Sometimes ☐ 3
- Never/almost never ☐ 4

K3C **To what extent is any disfigurement or change to your appearance as a result of your cancer or its treatment noticeable to other people?**

Not at all noticeable			Moderately noticeable			Extremely noticeable
1	2	3	4	5	6	7
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7

K5C **How much has your treatment changed the way you look?**

Not at all				Very much
1	2	3	4	5
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

K6C **How much does this bother you?**

Not at all				Very much so
1	2	3	4	5
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Thank you for completing the questionnaire