Study number:			В				
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Questionnaire Pack - Baseline (Bristol)

Thank you for agreeing to take part in this study.

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

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

Questionnaire Pack - Baseline Bristol

Version 4.2 13/05/13

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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
	. In uncertain times, I usually expect e best.	1	2	3	4	5
В2	. It's easy for me to relax.	ı	2	3	4	5
B3 wi	I. If something can go wrong for me, it	1	2	3	4	5
	. I'm always optimistic about my ture.	ı	2	3	4	5
В5	. I enjoy my friends a lot.	1	2	3	4	5
В6	i. It's important for me to keep busy.	1	2	3	4	5
B7 wa	. I hardly ever expect things to go my ay.	1	2	3	4	5
В8	8. I don't get upset too easily.	1	2	3	4	5
	. I rarely count on good things ppening to me.	1	2	3	4	5
	0. Overall, I expect more good things happen to me than bad.	ı	2	3	4	5
	Yo /e are interested in some things about yo y ticking the box that best applies to you.	•	health. Pleas no "right" or '	"wrong" ans	wers.	
C	1 Do you have any trouble doing stre	nuous	Not at all	A little	Quite a bit	Very much
	activities, like carrying a heavy shop or a suitcase?	ping bag	1	2	3	4
C	2 Do vou have any trouble taking a lo	ng walk?	П.			

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		Not at all	A little	Quite a bit	Very much
C3	Do you have any trouble taking a <u>short</u> 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
Durir	ng 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?	ı	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
C 9	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?	ı	2	3	4

Study number:			В				
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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?	ı		3	4
C21	Did you feel tense?	1	2	3	4
C22	Did you worry?	ı	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		3	4
C26	Has your physical condition or medical treatment interfered with your <u>family</u> life?	1	2	3	4
C27	Has your physical condition or medical treatment interfered with your <u>social</u> 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 bo	ox between 1	and 7 that	best applies t	o you
C29	How would you rate your overall <u>health</u> duri	ng the past w	eek?		
	Very poor	4	5	6 7	Excellent
C30	How would you rate your overall <u>quality of li</u>	<u>fe</u> during the	past week?		
	Very poor	4	5	6 7	Excellent

Study number:		В					
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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?	ı	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?	i	2	3	4
D9	Have you had problems with your teeth?	1	2	3	4
D10	Have you had problems opening your mouth wide?	i	2	3	4
D11	Have you had a dry mouth?	1	2	3	4
D12	Have you had sticky saliva?	ı	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?	ı		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		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?	ı	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	
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?	i	2	3	,
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	
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	g the past week:	Yes	No
D31	Have you used pain-killers?	1	
D32	Have you taken any nutritional supplements (excluding vitamins)?	1	
D33	Have you used a feeding tube?	1	
D34	Have you lost weight?	1	2
D35	Have you gained weight?	1	
	Your Feelin	ıgs	
Please	choose one response from the four given for each		Please give your immediate
	nse and don't think too long about your answer.	•	5 ,
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 a	awful is ab	out 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:			В					
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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:
E8	I feel as if I am slowed down: Nearly all the time
E8	
E812	Nearly all the time
E8	Nearly all the time Very often
E8	Nearly all the time Very often Sometimes
1 2 3 4	Nearly all the time Very often Sometimes Not at all
1 2 3 4	Nearly all the time Very often Sometimes Not at all I get a sort of frightened feeling like 'butterflies' in the stomach:
1 2 3 4	Nearly all the time Very often Sometimes Not at all I get a sort of frightened feeling like 'butterflies' in the stomach: Not at all
1 2 3 4	Nearly all the time Very often Sometimes Not at all I get a sort of frightened feeling like 'butterflies' in the stomach: Not at all Occasionally
1 2 3 4	Nearly all the time Very often Sometimes Not at all I get a sort of frightened feeling like 'butterflies' in the stomach: Not at all Occasionally Quite often
1	Nearly all the time Very often Sometimes Not at all I get a sort of frightened feeling like 'butterflies' in the stomach: Not at all Occasionally Quite often Very often
1	Nearly all the time Very often Sometimes Not at all I get a sort of frightened feeling like 'butterflies' in the stomach: Not at all Occasionally Quite often Very often I have lost interest in my appearance:
1	Nearly all the time Very often Sometimes Not at all I get a sort of frightened feeling like 'butterflies' in the stomach: Not at all Occasionally Quite often Very often I have lost interest in my appearance: Definitely

Study number:			В				
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E11	I feel restless as I have to be on the move:
	Very much indeed
	Quite a lot
2	Not very much
3	Not at all
⁴ E12	I look forward with enjoyment to things:
	As much as I ever did
1 	Rather less than I used to
2	
] 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 wo	ould 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 1 per week
4	2 – 4 per week
5	5 – 6 per week
7	1 per day
8	2 – 3 per day
9	4 – 5 per day
10	6 or more per day

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In summary, how many servings of vegetables do you usually eat, not counting salad or potatoes? None Less than one per month 1 - 3 per month 1 per week 5 - 6 per week 5 - 6 per week 1 per day 2 - 3 per day 6 or more per day
In summary, how often do you eat deep fried food (e.g. French fries, fried chicken, fried fish, fried clams, fried shrimp etc.)? Never Less than once per week Once per week 2 - 4 times per week 5 - 6 times per week Daily
Your Quality of Life This questionnaire asks about your views about your health and quality of life during the nast seven

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. Pai	n (Tick one box: ☑)
	I have no pain.
	There is mild pain not needing medication.
	I have moderate pain - requires regular medication (e.g. paracetamol).
	I have severe pain controlled only by prescription medicine (e.g. morphine).
	I have severe pain, not controlled by medication.

Study number:		В		
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I2. App	pearance (Tick one box:) There is no change in my appearance.
	The change in my appearance is minor.
3	My appearance bothers me but I remain active.
	I feel significantly disfigured and limit my activities due to my appearance.
5	I cannot be with people due to my appearance.
I3. Act	ivity (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. Rec	reation (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.
15. Sw	rallowing (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. Che	ewing (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.
17 .Spe	eech (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.
18. Sh	oulder (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:		В		



I10. Saliva (Tick one box: ☑) ☐ My saliva is of normal consistency.
I have less saliva than normal, but it is enough. I have too little saliva. 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.
Tick ☑ up to 3 boxes. ☐ Pain ☐ Swallowing ☐ Papearance ☐ Chewing ☐ Nood ☐ Recreation ☐ Shoulder ☐ Anxiety ☐ Anxiety ☐ 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

Study number:		В		



115. lr	n general, would you say your <i>health-related qu</i> (Tick one box: 図)	uality of life <u>d</u>	uring the pa	st 7 days has	been:
	Outstanding				
	Very good				
	Good				
	Fair				
⁴	Poor				
H	Very poor				
6	, ·				•
such a enjoyr	overall quality of life includes not only physical and selections of life includes not only physical and selections of life. Considering everything in your life our overall quality of life during the past 7 days	e activities the	at are impo utes to your	rtant to your	
	Outstanding				
	Very good				
	Good				
	Fair				
	Poor				
	Very poor				
	Please indicate on the following lines any items uality of life and have not been adequately add	•		•	
	Difficulties in read each question carefully and tick the response answer each question as honestly as possible.		lescribes you	ur answer.	
- If you	i are not completely sure which response is the n t appropriate.	nost accurate	tick the box	that you feel	is the
	se tick the 'no difficulty box' if a question does no ot spend long on each statement.	t apply to you	ı.		
During	g 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

Study number:			В				
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	During the past month:	No difficulty	A little	Quite a bit	Very much
J2	Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)	ı	2	3	4
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		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)	_,		3	4
J7	Have you had any financial difficulties?	1	2	3	4
18	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 with communicating with those closest to you? (e.g. partner, children, parents)	1	2	3	4
J12	Have you had any difficulty communicating with others? (e.g. friends, neighbours, colleagues, dates)	1		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

Study number:			В				
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	During the past month:	No difficulty	A little	Quite a bit	Very much	
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	
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?	ı	2	3	4	
J21	Have you had any difficulty with any other area of your everyday life?	1	2	3	4	
	Your Appe	arance				
K1A	Is there any aspect of the appearance of your he (however small) that concerns you at all?	ead/neck	Yes	1	No 2	
	If No, please go to section K1B If Yes, please continue:					
К2А	The aspect of my head/neck about which I am m	ost sensitive	or self-consc	ious is		
КЗА	The thing I don't like about the appearance of my head/neck is					
К4А	If you are sensitive or concerned about any other please say what they are	r features of	your body or	your appe	arance,	

Study number:			В				
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<u>Instructions</u>: 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	
	Moderately	3
	Extremely	4
K2B	How distressed do you	get when you see yourself in the mirror/window?
	Extremely	1
	Moderately	
	A little	3
	Not at all distressed	4
КЗВ	My self-consciousness	makes me irritable at home:
	N/A	
	Never/almost never	
	Sometimes	3
	Often	4
	Almost always	
K4B	How hurt do you feel?	
	Extremely	1
	Moderately	
	Slightly	3
	Not at all	4
K5B	At present my self-con	sciousness has an adverse effect on my work:
	Almost always	1
	Often	
	Sometimes	
	Never/almost never	4
	N/A	5

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K6B	How distressed do you	get when you go to the beach?
	N/A	
	Not at all	
	A little	3
	Moderately	4
	Extremely	5
К7В	Other people mis-judg	ge me because of the appearance of my head/neck:
	Almost always	
	Often	
	Sometimes	3
	Never/almost never	
	N/A	
K8B	How feminine/mascul	ine do vou feel?
	Not at all	
	Slightly	
	Moderately	
	Extremely	3
	Extremely	4
K19B	How distressed do you	u get when going to social events?
	N/A	
	Not at all	
	Moderately	3
	A fair amount	4
	Extremely	5
K20B	How normal do you fe	el?
	Not at all	
	Slightly	
	Moderately	3
	Extremely	4

Study number:			В					
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K21B	At present my self-cor	nsciousness has an adverse effect on my sex life:
	Almost always	
	Often	
	Sometimes	3
	Never/almost never	4
	N/A	s
K22B	I avoid going out of th	e house:
	Almost always	1
	Often	
	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	
	Not at all	
	Moderately	3
	A fair amount	4
	Extremely	s
K24B	I avoid going to pubs/	restaurants:
	Almost always	
	Often	
	Sometimes	3
	Never/almost never	4
	N/A	5
K1C	My feature causes me	physical pain/discomfort:
	Never/almost never	1
	Sometimes	
	Often	3
	Almost always	4

Study number:		В			
		_			



K2C	My feature limit	ts my <u>physical</u> abilit	y to do the things I	want to do:							
	Almost always	1									
	Often										
	Sometimes										
	Never/almost ne	ever \square									
	,	4									
КЗС	To what extent	is any disfiguremen	it or change to you	r appearance as	a result of	your cancer or					
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		Moderately			Extremely					
Not at all Moderately noticeable						noticeable					
1	L 2	3	4	5	6	7					
Г	1										
		23	4	5	6	7					
K4C How much will your treatment change the way you look?											
Ν	ot at all	ot at all Very much									
	1	2	3	4		5					
	1	2	3	4		5					
K6C How much does this bother you?											
N	ot at all				\	Very much so					
	1	2	3	4		5					

Thank you for completing the questionnaire